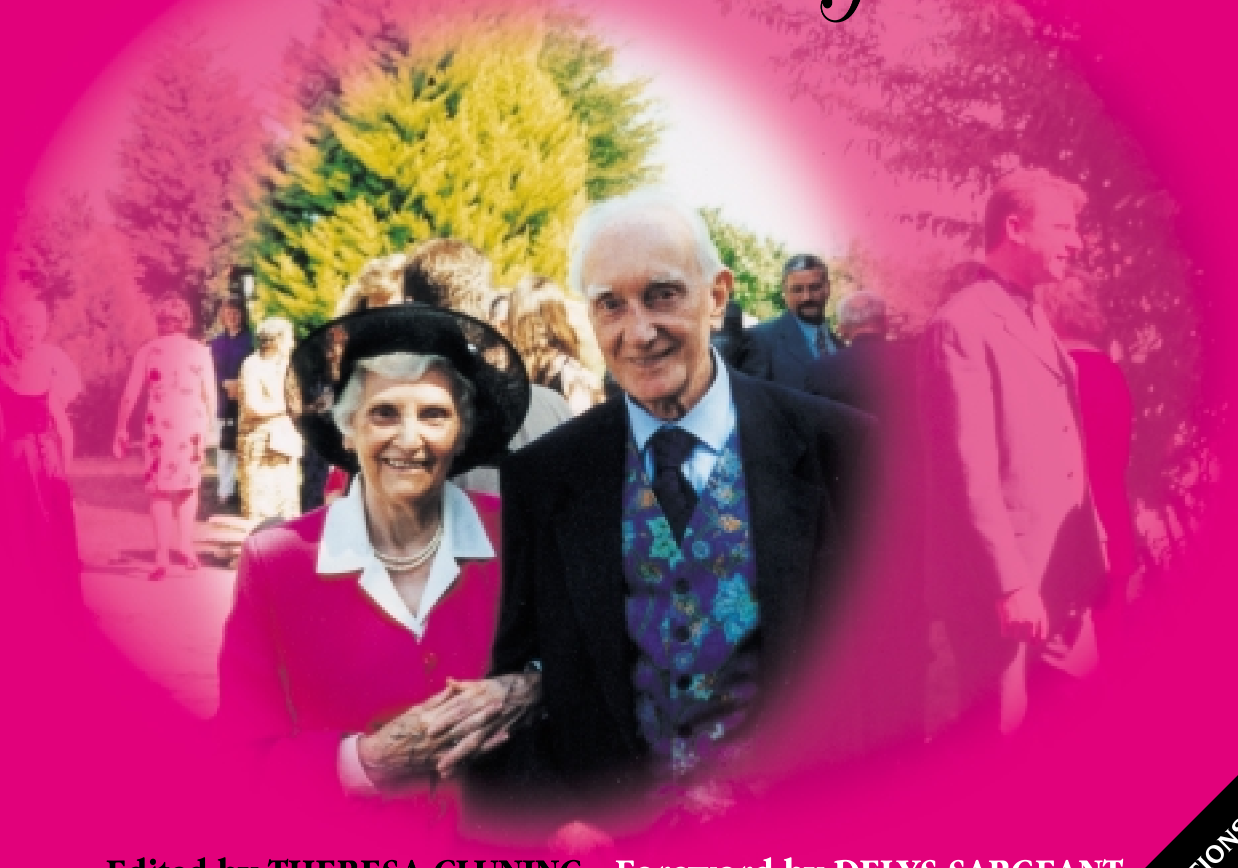
Ageing at Home

Practical Approaches to Community Care



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Cover: With thanks to Mr and Mrs Alan Kent who are enjoying healthy old age.

Foreword

All of us age . . . and an increasing number of us do, or will, live into really ripe old age, some of us living still when our ripeness needs to be specially valued and even protected.

When young, many look forward to being older . . . to gaining from the options and lack of restrictions of adulthood; but on the whole, relatively few people eagerly anticipate becoming ‘older/elderly/aged/senior/old’.

Pessimism towards increasing age is based on a whole range of reasons to which are attached negative stereotypes which in turn result in prejudice towards people grouped on the grounds of their age. It is common that old people themselves also carry ageist attitudes and may well collude with those who are discriminating against them because of their age. Consequently, any publication which sets out to explain services that care for older people with concerns needs to be assessed as to whether the same principles, ways of working and conclusions would be drawn if age were not, of itself, a primary issue. There is no doubt that the attitudes and life experience of each worker will differ, but an essential prerequisite for working with older people is for every worker to be alert to the negative consequences of ageism, and to review his or her own attitudes and behaviours towards those older people.

The United Nations logo designed for the 1999 International Year of Older Persons symbolised, by three concentric open circles, the need to promote

- **vitality** of mind, spirit and body
- **recognition and respect** for diversity
- **support** for independence and interdependence.

The assumptions and styles of practice carried by the worker into community care with, of and for older people will necessarily be different, and likely to be more effective, in supporting the principles of IYOP than when working in institutional care. I think this difference is evident in many of the contributions to this book.

‘Ageing in place’ has become a term commonly in use to highlight the need for an understanding by those in the ‘caring’ services which are to ‘protect our ripeness’ in old age. Most of us as older people have life experiences which we like best to be valued and we want to continue to ‘ripen’ in our own familiar social territory while having our special care needs addressed.

'Ageing at home' usually directly implies that we are focusing on how community rather than institutional services may be planned, accessed and relevant to the special needs of amazingly diverse individuals living in THEIR space, order and contexts as CITIZENS in their communities.

The ageisms that have been present and still persist in much of the organised care of older people with special needs are increasingly being challenged by both activist older people themselves and by publications such as this.

This book is an ambitious, and I think largely successful, attempt to bring together information about the many different types of services currently available and acessible to people in their own home, and what can be expected of them. A perpetual dilemma faced by the service provider in whatever skill area is the need to recognise the opportunities open to encourage the further 'ripening' of the older person . . . in the face of what may be judged as decreasing abilities.

The reading of the contributions by people outside the direct areas of service with which the provider may be familiar can only benefit the understanding of how our 'old wholes' are much more fascinating, diverse and worthy of attention than the sum of 'our old parts'!

And **we intererested older people** can well benefit from being better informed by reading and discussing this book as if it had been produced specifically for us.

Delys Sargeant

Delys Sargeant, AM
Bachelor of Science with Honours, Master of Education
Vice-President, Council on the Ageing (Aust.)

Dedication

This book is dedicated to my family and to all families and groups of people who continue to love and support each other, thus forming special communities.

I have been loved and supported by my husband, Brian, and our children, John and Rosemary. They have been interested in, shown enthusiastic patience for and always offered moral support for my interests, studies, work and projects.

I would also like to acknowledge my large extended family, especially my mother, Agnes, who was widowed at a young age and continues to be an inspirational ageing person as she was an inspirational younger and middle-aged person. My sisters, Rosemary, Denise and Barbara, as well as my brothers, Tony, Stephen, Shaun and Brendan, and their families have all shown, by example, what community living means. My father John must not be forgotten. He left us all two invaluable gifts: our sense of humour, and each other.

I hope this book will assist all members of the professional and nonprofessional community to respect and care for ageing people as they would like their loved ones to be respected and cared for by others.

Acknowledgment

I would like to thank the Managing Editor of Ausmed Publications, Robyn Whiteley, for her generosity of spirit, her willingness to share her professional knowledge, her continuous support and her ability to give a direct answer to a direct query; all of which have been given with a great sense of humour, which I have found to be the essential part of writing and editing. Robyn's husband, John Collins, must also be acknowledged for his support and generous hospitality.

Contents

Appendixes

ILLUSTRATIONS

Figures

Tables

ELIZABETH OZANNE

Bachelor of Arts, Diploma of Social Studies (Melbourne), Master of Arts — Sociology, Master of Social Work, Doctor of Philosophy (University of Michigan)

Senior Lecturer and Coordinator of Ageing and Long Term Care Research Unit, School of Social Work, The University of Melbourne

Dr Elizabeth Ozanne coordinates the Ageing and Long Term Care Research Unit in the School of Social Work at The University of Melbourne. She has published numerous books, monographs, chapters and articles on aged social policy and various aspects of community care in Australia, including:

- assessment and case management practice
- the psychiatry of late life
- the financing of aged care
- ethical and legal issues in work with the aged
- support networks in later life
- older men's access to community mental health services
- ageing futures.

Recently Elizabeth completed three substantial research projects on disability in late life. At present she is completing a monograph comparing the long-term care systems of five countries, drawing out implications for Australia.

CHAPTER ONE

Aged Care in the New Millenium—Retrospect and Prospect

Elizabeth Ozanne

INTRODUCTION

The past decade in aged care has been one of considerable ferment and challenge in relation to:

- the growing demand on health and social services from an increasingly ageing Australian population
- the gradually rising profile of ageing as a national and international social policy issue
- the increasingly proactive stance of the aged as a political constituency in their own right.

After more than a decade of reform from the mid 1980s, by the Australian Labour Party (which shifted the focus of aged care from the elaboration of largely residential options to a more diversified range of community and home care support services), the Liberal Coalition government came to power in 1996 determined to curb expenditure in aged care and pursue a policy of greater individual responsibility in relation to both the financing and the provision of care. Thus, in a period of increasing demand, Australia made a major philosophical shift in how care was to be provided and who would be primarily responsible for providing that care.

This chapter will elaborate on basic demographic trends in terms of:

- growing demand and increasing dependency
- how the pattern of services has evolved to respond to this demand
- how programs have been affected by recent policy changes.

As Australia seeks to elaborate its aged services into the new millenium, several key issues remain to be resolved:

1. Who should get community care and how should eligibility be assessed?
2. Who should pay for community care and by what means?
3. How should community care be organised — in what combination/ packages and via what arrangements?
4. How can the quality of community care be assured?
5. How can consumers participate actively in the process of community care?
6 What is the role and what are the limits of family care?

AUSTRALIA'S AGEING IN COMPARATIVE PERSPECTIVE

As at 30 June 1998, the Australian Bureau of Statistics estimated that there were 2.3 million people aged 65 years and over in Australia, representing 12.2 per cent of the total population. Of these, 30 per cent were aged 65–69 years, 48 per cent were aged 70–79, and 23 per cent were aged 80 and over.

In terms of future projections, the Australian Bureau of Statistics projects that the Australian population aged 65 and over will reach 4 million by the year 2021, and 5.8 million by 2041. The number of people aged 80 and over is projected to grow from an estimated 0.5 million in 1998 to 0.9 million in 2021 and to 1.9 million in 2041.

Australia has, however, been ageing very gradually and still has a relatively young population profile compared with some European nations. The OECD ranks Australia as the third youngest of its 23 member countries, with only 12 per cent aged 65+ in the year 2000. Even with 18 per cent aged 65+ in 2020, Australia will be younger than many contemporary European countries. Sweden and the UK, for instance, reached around 12 per cent aged 65+ in 1960 and now approach 16 per cent aged 65+. Among Australia's neighbouring countries Japan is ageing the most rapidly, reaching 12 per cent of population aged 65+ in 1990, 17 per cent in 2000 and 25 per cent by 2020, a level that Australia will not reach even by 2040 (Howe, 1999b).

As a proportion of the total population of Australia, those aged 85 and over are projected to increase from 1.2 per cent in 1997 to 4.6 per cent in 2051. Although the absolute numbers of the population are relatively small, the implied rates of growth of this age cohort are significant. The average annual rate of growth of those 85 and over is 3.5 per cent. The rate of growth will increase steadily to 2031 when the front end of the post World War II baby, supplemented by the large influx of adult migrants during the 1940s and

1950s, will reach the age of 85. The rate of growth will increase from 2021 and peak in 2036 (AIHW, 1999a:169).

ESTIMATING THE NEED FOR SERVICES

The total population potentially in need of services is taken as those identified in surveys of ageing and disability (conducted by the Australian Bureau of Statistics) as having a moderate, severe or profound restriction in communication and in activities of daily living such that they require assistance from another person. Just over one-third of the total population aged 70 years and over come within this definition of the handicapped or frail-aged population. These two populations are the basis for planning community care and residential care.

The proportion of people aged 65 and over with any specific activity restriction ('handicap' in the l993 survey) increased slightly between 1993 (44.6 per cent) and 1998 (45.5 per cent) but is similar to that reported in 1988 (45.1 per cent). The proportion of the population reporting a profound or severe core activity restriction (age-standardised) dropped marginally from 17.9 per cent in 1988 to 17.1 per cent in 1993, increasing to 19.6 per cent in 1998. Over the three surveys, while the changes have been modest, the trend is for a drop from 1988 to 1993, and an increase from 1993 to 1998 (AIHW, 1999a:168).

The number of people aged 65 and over who require at least some assistance with the basic activities of daily living will increase from slightly more than 0.25 million in 1981 to a projected 0.5 million by 2001, and more than 1 million by 2031 (AIHW, 1999a:208).

Of all those in need of assistance it has been estimated by Howe (1996) that:
- 18 per cent live in residential care facilities (mainly in Commonwealth-funded nursing homes and hostels, but a small number are in non-subsidised supported accommodation)
- 13 per cent live in the community with support from services only
- 33 per cent live in the community with a mix of support from services and informal carers
- 33 per cent live in the community with support only from informal carers
- 3 per cent live in the community without any support.

Dependency levels continued to increase in hostels and nursing homes between 1994 and 1998, although the Australian Institute of Health and Welfare reports that the discontinuities in the data as a result of the 1997 structural reforms make accurate assessment of more recent trends difficult (AIHW, 1999a:166).

Another critical issue in predicting need for services is changes in the supply of unpaid care from families, relatives and friends. High rates of female workforce participation, high rates of divorce, and an increasing number of single-person households are expected to affect both the structure and functioning of informal support networks, and the availability of volunteer labour in the welfare services industry in the future.

MANAGEABILITY OF AUSTRALIA'S POPULATION AGEING

The two factors that most commonly give rise to concerns about funding aged care are rapid population ageing and escalating health care costs. The way in which both these factors were presented by the National Commission of Audit (1996) generated alarm over the sustainability of existing arrangements and provided justification for the radical changes that incoming governments have sought to make. The position taken by the Commission of Audit was markedly at odds with the many commentators who had for some time argued that Australia did not face a demographic doomsday, and that health expenditures had been well controlled by concerted policy effort (Goss et al., 1997).

In 1997–98, expenditure on aged care services totalled $3849.8 million, an increase of 33 per cent in real terms from 1994. The services this expenditure covered included:

- assessment
- HACC (the Home and Community Care program)
- Community Aged Care Packages
- the Domiciliary Nursing Care Benefit
- hostels
- nursing homes.

However, aged care accounts for only a very small share of GDP (Gross Domestic Product), around 1 per cent at present, compared with 3 per cent for the Age Pension and around 8 per cent for health care costs.

Between 1980–81 and 1995–96 total government expenditure on older persons from all sources (income support, medical services, hospital services, pharmaceutical services and aged care) remained relatively unchanged as a proportion of GDP, approximately 5 per cent (AIHW, 1999a).

While demographic trends underlie the growth of interest in ageing-related policy areas over the last two decades, the scale and pace of population ageing in Australia is modest and the view that Australia will experience ageing at an unprecedented rate in the future is not supported by the data.

EVOLUTION OF AUSTRALIA'S AGED CARE SYSTEM

The goal of the Australian aged care service delivery system as stated in government documents is the

> provision of a cohesive framework of high quality and cost-effective
> care services for frail older people and their carers.
> (DHFS, 1996a:117)

Over the last couple of decades Australia has developed a relatively modern aged care system with a diversified range of both residential and community care services incorporating a number of quite innovative components (e.g. Aged Care Assessment Teams, National Dementia Strategy) that have been emulated by such other countries as Japan, Israel and Canada. One of the achievements of the mid 1980s to mid 1990s was the shift in the 'balance of care' from predominantly institutional to a much more diversified range of community care options. This is clearly evident when budget allocations for 1985–86 are compared with those of 1996–97 (Howe, l996).

Table 1.1 Shifts in configuration of aged care services 1985–86 to 1996–97

	1985–86	**1996–97**
Community care (including Community Care Packages)	8%	23%
Hostels	6%	13%
Nursing homes	83%	61%
Other (including assessment)	3%	3%

Historically, in Australia, the nongovernment sector has been the major provider of residential aged care services with a number of private-for-profit organisations providing high-intensity residential aged care and a number of religious and charitable organisations providing low-intensity residential aged care. In 1995–96 total recurrent expenditure on high-intensity residential care (nursing homes) was $2902m — 60 per cent ($2002m) provided by the Commonwealth government, 8 per cent ($223m) sourced from state and local governments and 23 per cent being provided by individuals through resident charges. In the same period, total recurrent expenditure on low-intensity residential care (hostels) was $1018m, with 41 per cent ($417m) being provided by the Commonwealth government, 2.5 per cent ($25m) sourced from state and local governments, and 57 per cent ($576m) being provided both by individuals through resident charges ($360m) and by nongovernment organisations ($216m). Total expenditure on the HACC Program in the same period was $697m: 50 per cent ($423m) being provided by the Commonwealth, 40 per cent ($274m) being provided by state and territory governments and 10 per cent coming from a mix of local government and community agencies.

Under the original Labour Government Aged Care Reform Strategy, produced by the Department of Health, Housing and Community Services in 1991, the planned level of residential aged care provision was 40 high-intensity places and 50 low-intensity places per 1000 persons over 70 years, to be available by 2011. These residential care places were supplemented by the availability of 10 Community Care Packages per 1000 persons aged 70+.

The policies of the Labour years were articulated under a Social Justice Strategy which emphasised access and equity considerations and recognised the priority needs of particular groups. The major outline of the policies of the Labour years has been detailed elsewhere (Howe, 1999b).

MAJOR CHANGES TO THE AGED CARE SYSTEM SINCE 1997

In 1996 the Liberal Coalition government came to power with a new, more market-oriented philosophy and a strong preoccupation with the fiscal bottom line. The new government commissioned a National Commission of Audit (1996) which projected a relatively negative scenario in relation to the impact of population ageing and then proceeded to introduce a major restructuring and cost-shifting program in residential care.

The key elements of the National Aged Care Strategy announced in 1996 and implemented during 1997–98 were as follows:

- Nursing homes and hostels were amalgamated into one single system of residential care.
- The eight-category Resident Classification Scale was introduced to determine the level of payment to which facilities were entitled for each resident (based on residents' level of dependency).
- Income- and asset-tested fees were introduced.
- A pre-existing system of contributions to the capital cost of some aged care facilities (means tested) was modified and expanded to include all residential aged care facilities.

- A new system of accreditation for residential aged care facilities was developed.

The new government continued to expand coordinated forms of home-based care and respite services. Community Aged Care Packages expanded quite dramatically from 4441 places in 1996 to 10 046 places in 1998. In relation to the size of the aged population, this represented a doubling of supply, from three places per 1000 people aged 70 and over in 1996 to six places in 1998 (AIHW, 1999a:208). Despite this expansion however, general HACC programs remain by far the major supplier of home-based care services for older Australians.

The Commonwealth government also announced a range of new carer initiatives to assist states and families in supporting frail older persons to continue to live at home, for example the National Agenda for Carers (DHFS, 1966b).

The number of residential care places continued to increase, up from 131 351 in 1994 to 139 058 in 1997 and 139 917 in 1998. The ratio of residential care places to people aged 70 and over decreased, from 93 places per 1000 people aged 70 and over in 1994 to 87 places in 1998. This trend was counterbalanced by the increasing availability of Community Aged Care Packages — the combined residential care and care packages ratio was relatively stable during the period, at 94 places and packages per 1000 people aged 70 and over (AIHW, 1999a:209).

The new quality appraisal system for the accreditation of residential aged care facilities was implemented in 2000, replacing the Outcome Standards monitoring system of the previous government (Gibson, 1998).

THE NATIONAL STRATEGY FOR AN AGEING AUSTRALIA

In 1999, the International Year of Older Persons (IYOP), the Commonwealth government announced that its key policy response would be the development of a National Strategy for an Ageing Australia. The Prime Minister appointed a Ministerial Reference Group to develop the strategy focusing on four themes:

> Firstly, helping Australians to be independent and to provide for their later years through employment, life long learning, and financial security. Secondly, delivering quality health care through new approaches to service delivery, co-ordinated-care and independent living. Thirdly improving attitudes to older people and ageing, lifestyle issues such as personal safety, housing, transport, recreation and

> community support. And fourthly, encouraging healthy ageing and the role of general practitioners in maintaining wellbeing of older people
>
> (John Howard, quoted in Bishop, 1999:vi)

The National Strategy essentially appears a broad-brush approach to projecting Australia's ageing into the 21st century along the lines recommended by a series of recent OECD and World Bank Reports (OECD, 1994, 1996a, 1996b, 1998; World Bank, 1994). It articulates a more self-reliant philosophy, in line with Liberal Party policy and the earlier policy directions set out in the National Commission of Audit (1996).

HOW CAN AUSTRALIA DEVELOP AND MAINTAIN AN APPROPRIATE COMMUNITY CARE SYSTEM FOR THE AGED IN THE NEW MILLENIUM?

Looking to the future, several issues remain problematic in Australia's elaboration of a comprehensive service system for the aged. These are explored briefly below.

1. Who should get community care and how should eligibility be assessed?

With increasing demand from a diversity of groups with an interest in home and community care services, the question of how to allocate the HACC dollar across high-need and low-need clients has become an increasingly critical issue. Though HACC began as a universally available service, its resources have been increasingly targeted to intensive home support programs. A 1995 Review of the Efficiency and Effectiveness of HACC (DHSH, 1995) and a later study of targeting (Howe and Gray, 1999) have highlighted the need for more systematic data collection, assessment and identification of the best ways to prioritise client need and resource allocation relative to that need. The relative efficiency of providing a little or a lot of service to differently situated clients has been the continuing subject of research in a number of countries (Challis et al., 1998; Howe, 1994) in an attempt to better refine both clinical and economic criteria for more effective resource allocation in this area.

2. Who should pay for community care and by what means?

Under the current Commonwealth government, questions of financing and who should pay for aged care have been much to the fore, particularly in relation to residential care, where much greater responsibility has been put onto individual consumers. In relation to health and social security initially, but now increasingly in relation to long-term care services, most countries are looking to contain costs by greater efficiencies and downward substitution to less expensive service types, as well as by diversifying their funding base to reduce their too-heavy reliance on general revenue (World Bank, 1994; Morris et al., 1998; McCallum et al., 1998; Howe and Sargeant, 1999). A number of countries are exploring the viability of public and private long-term care insurance schemes in attempts to diversify their funding base (Wiener et al., 1994). In Australia, at present, user charges for community care are fairly minimal and public attitudes are such that individuals still expect governments to be the major provider of such services. Both recent government initiatives and the increasing privatisation and marketisation of health and home care services might see a gradual shift in these attitudes.

3. How should community care be organised — in what combination/ packages and via what arrangements?

In the 1980s and early 1990s there was a major expansion of the service types and mix in Australian aged care, particularly in the range of home care options. This period also witnessed increased attention to the interface between:
- acute and long-term care
- housing and community care services
- formal services and the informal/family/carer system.

The modern geriatric care system also evolved over this period with
- the setting up of specialist geriatric units
- the refinement of assessment and treatment modalities in relation to the aged
- the differentiation of fast- and slow-stream rehabilitation facilities.

Present initiatives in relation to the consolidation of hostels and nursing homes suggest that new and more innovative housing options might develop in the future, much as, in the United States of America, 'assisted living' has emerged as an increasingly popular housing option offering independent living which also can incorporate various levels of supportive service. We have seen considerable innovation in the past in the expansion of care options, so there is every reason to assume that this will continue into the future (Kane et al., 1999). It is possible that the shape of services in the future might be quite different from what it has been in the past as more efficient and effective models continue to evolve. Present evaluations of the Community Options/Linkages Program and the various other package programs now available (Gibson and Mathur, 1999) will no doubt feed into this process as will findings from the Australian Co-ordinated Care Trial Evaluations (Commonwealth of Australia, 1999).

The two-year review of the Aged Care Reform Policy being carried out by Professor Len Gray, which was commissioned by the Commonwealth government in 1998 for report in 2000, had the mandate to evaluate the impact of the government's reforms in relation to:

- access
- affordability
- quality
- choice
- appropriateness
- industry viability.

No doubt this review will present a further opportunity for innovation and reform.

4. How can the quality of community care be assured?

Over the past couple of decades, there has been considerable attention to quality in the reform of the aged care system, from the initiation of service standards in most areas of community and residential care to the implementation (initially) of the Standards Monitoring procedures in residential care (Gibson, 1998) and now the new Accreditation arrangements.

A major emphasis given to clients' rights in the 1980s put in place national advocacy services and complaints units which continue to play an important role in representing consumers' interests and assuring quality. State and Commonwealth governments have also been increasingly preoccupied with the implementation of appropriate outcome measures to enable more effective program management and regulation.

However, as even regulators themselves suggest (Braithwaite, 1998), assuring quality in community care requires adequate resourcing and incentives being given to agencies and workforces to voluntarily upgrade their practices. With rising demand and consequent cost-cutting pressures created by competition policy, both the residential and home care workforce look increasingly vulnerable in this regard. In relation to home care many countries are now having major problems in the recruitment of home care workers because of the low pay and poor conditions for what is acknowledged to be a very difficult job. Issues related to training, adequate supervision and accreditation of workers are some of the core labour market concerns of the sector (Leutz et al., 1992; Morris et al., 1998; Kane et al., 1999).

5. How can consumers participate actively in the process of community care?

One of the major aims of the IYOP in 1999 was to assure greater participation of older persons in their communities and in the planning and implementation of social policies that affect their lives. Successive governments have set up both advisory councils and consumer forums in which peak organisations (concerned with the aged) and individuals can participate either directly or as representatives, and it is an increasing requirement for service providers, as a condition of funding, to carry out regular consumer satisfaction surveys and demonstrate consumer involvement in service delivery.

The acknowledgement and validation of the consumer voice in decision making around major care options is still, however, variably recognised and affirmed in much agency practice, despite the above initiatives, suggesting the need for aged individuals and organisations to be continually vigilant in articulating their preferences and interests.

6. What is the role and what are the limits of family care?

The current direction of policy is to increasingly involve the family in long-term care either through implicit or explicit co-option (Baldock and Evers 1991). The various carers' initiatives implemented by successive Australian governments highlight recognition of carers as both co-clients and co-providers of services. Although the family remains at the heart of any long-term care system, it is also important to recognise that some family members cannot and should not be caregivers. Though efforts need to be directed to supporting informal care where it is feasible and desirable, such care should not be mandated. Many countries are currently grappling with equity considerations for family caregivers, attempting to determine whether and under what circumstances family caregivers should receive financial compensation for their services.

In a recent book on long-term care Kane et al. (1999:303) suggest that the primary goals of a country's long-term care system should be:

1. to make long-term care services available in the community so that people of all ages can, as much as possible, lead normal and dignified lives, pursuing age-appropriate pursuits, experiencing personal relationships, and enjoying privacy
2. to introduce more user choice and control into long-term care
3. to curb the growth of long-term care costs
4. to ensure that long-term care services meet acceptable quality standards

5. to coordinate and integrate long-term care with acute care
6. to provide support and encouragement to family members who are giving long-term care to their relatives, usually without direct payment.

Australia has in fact been moving on most of these fronts and has in some periods been a leader rather than follower in reform. It remains to be seen how our progress will be evaluated in the new millenium.

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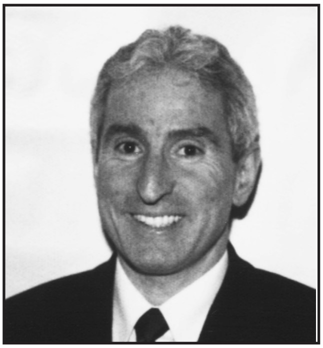

David Fonda

Walter Gee

DAVID FONDA

Bachelor of Medicine, Bachelor of Surgery, Bachelor of Medical Science, Fellow of the Royal Australian College of Physicians, Fellow of the Australian Faculty of Rehabilitation Medicine

Director of Aged Care Services, Caulfield General Medical Centre, Melbourne

David is an Associate Professor of Medicine at Monash University. He has a special clinical and research interest in bladder and bowel dysfunction. He was the Foundation President of the Continence Foundation of Australia and chairs various national and international committees. He is co-author, with four fellow geriatricians, of another Ausmed Publications book *Geriatric Medicine* (2^{nd} edn) and was also co-author, with Cynthea Wellings, of Ausmed's very first book, *Urinary Incontinence.*

WALTER GEE

Bachelor of Medicine and Bachelor of Surgery, both with Honours

Walter was born in Hong Kong but, at a young age, immigrated to Australia with his family. His childhood was spent in the Victorian provincial city of Bendigo. He attended medical school at Monash University in Melbourne, graduating in 1990. After gaining experience in a number of Victorian hospitals he is now undertaking his advanced training in geriatrics at Caulfield General Medical Centre.

CHAPTER TWO

Normal Ageing

David Fonda
Walter Gee

INTRODUCTION

Although everybody ages, different people do it in different ways. Some people live longer and are able to maintain a better quality of life than others. The health of an elderly person is the result of:

- the interaction of the effects of ageing
- any superimposed disease processes
- any harmful exposures the person may have experienced during life such as tobacco smoke or alcohol

One can view ageing as the result of two distinct phenomena — physiological ageing and pathological ageing. The former process involves the changes that the human body undergoes inexorably as time progresses, free of any influences from disease or environmental hazards. The latter process is what occurs when these detrimental influences supervene. At any moment in time, how well an individual is ageing is determined by the relative contributions of each of these processes. This chapter does not deal with pathological ageing, but rather provides an overview of some aspects of physiological ageing.

Since the mid-19th century life expectancy at birth in most developed countries has nearly doubled. In the first part of the 20th century advances in such areas as vaccination and the treatment of various infections brought about gains in life expectancy by reducing maternal, infant and neonatal mortality. In the last decades of the 20th century increases in life expectancy were due to improvements in death rates from chronic degenerative diseases following medical and surgical advances.

A great deal of what had been previously attributed to the ageing process has now been identified as being caused by disease processes instead. Potentially modifiable risk factors for these diseases have been recognised, such as:
- alcohol excess
- tobacco smoking
- dietary influences
- environmental exposures.

Primary prevention programs aimed at these risk factors have the potential to further reduce the morbidity and mortality associated with a number of illnesses.

Few people actually die of old age. The pure ageing process does not result in major disability but rather reduces the body's physiological reserve. Altered homeostatic mechanisms mean, for example, that an elderly person may not mount a febrile or white cell response even when faced with a significant infection. The body of the older person loses its capacity to withstand stresses placed upon it from illnesses and other influences. Thus an older person is more susceptible to death when faced with overwhelming stressors.

THEORIES OF AGEING

Throughout history people have been trying to understand the process of ageing and its cause. A number of theories currently exist.

Genetic theories

Genetic theories propose that the whole phenomenon of ageing is under genetic control. Leonard Hayflick in 1977 introduced one of the best-known genetic theories. What is now called the 'Hayflick limit' proposes that the number of times that a cell will undergo division and replication is predetermined by its genetic make-up. Once a cell has reached its limit it will stop replicating and so, when it dies, it will not be replaced. Thus, ageing is the result of a gradual decline in the total number of cells in the body with progressive functional loss (Hayflick, 1977).

Damage theories

The basis of damage theories is the concept that irreversible defects in molecules gradually accumulate over time as the result of naturally occurring chemical reactions. Repeated micro-insults from a variety of exposures — such as heat, ultraviolet radiation, infectious agents etc. — lead eventually to damage which, if not repaired, will result ultimately in loss of function. The repair processes that normally prevent this may be overwhelmed by the amount of injury or may become slowly less effective with ageing. The loss of function is therefore, gradual, but because of the considerable reserve in physiological systems, a significant amount of function has to be lost before a system failure occurs.

One of the best-known types of damage theories involves 'free radicals'. Free radicals are products of oxygen metabolism and, because of their chemical structure, are able to link to other molecules, causing damage. Cellular components are attacked and oxidised, which may result eventually in cell death (Johnson, 1985).

THERMOREGULATION

Elderly people are at increased risk of injury when exposed to extremes of temperature. This is because of impaired thermoregulation — the ability to heat or cool the body sufficiently when there is a change, or a potential change, in core body temperature.

When a person is exposed to extreme cold, shivering is a means of metabolic heat gain. Because elderly people have reduced lean muscle mass, not only do they have reduced basal metabolic heat production, they also have a limited capability to generate more heat by means of shivering. With age there is thinning of the superficial layer of the skin (the epidermis) and there is loss of subcutaneous fat in such areas as the limbs, reducing the body's natural heat insulation.

An older person is also at a disadvantage when exposed to extreme heat. Sweating is the body's most effective means of cooling itself down. As the skin ages there is a considerable reduction in the density of sweat glands. In addition the blood flow through the skin declines, thus limiting the capacity of the body to dissipate excess heat through increasing body surface temperatures. When an elderly person is exposed to extreme heat there is a delayed sweating response and once sweating is established it needs to continue for a longer period of time, as the rate of sweating (and thus heat loss) is lower than in a younger person.

THE IMMUNE SYSTEM

As we age, various changes occur to our immune system. The thymus is a gland located in the anterior mediastinum behind the upper sternum. It is involved in T lymphocyte production and it starts to involute after puberty. By the time we reach old age it is nothing but connective tissue. As the thymus shrinks there is progressive impairment in T cell mediated immunity. There is a decrease in the total number of T cells overall and a change in the T cell ratio. There is a reduced proportion of T-helper cells and an increased proportion of T-suppressor cells. On the other hand, B cell function and immunoglobulin levels remain relatively unaffected by ageing.

The elderly have an increased susceptibility to infections and these have the propensity to become more severe and fulminant. There is an increased incidence of neoplasms and this may be partially explained by the fact that the immune system is involved in the surveillance and destruction of abnormal cells that have the potential to develop into cancers. Previously latent diseases held in check by the immune system, such as tuberculosis, may reactivate in old age as immunity wanes. Paradoxically, the incidence of autoimmune diseases is increased in the elderly and this may reflect aberrations in the control of various immune processes.

THE CARDIOVASCULAR SYSTEM

One of the most notable changes that occurs in the cardiovascular system with ageing is that both the systolic and the diastolic blood pressure rises. This is due to the reduced compliance of the blood vessels and the increased peripheral resistance to blood flow. Most of these changes are thought to be due to disease processes and not to be part of normal ageing.

Baroreceptors are pressure receptors located in the arch of the aorta and a part of the carotid arteries called the carotid sinus. These baroreceptors detect changes in systemic blood pressure and instigate appropriate cardiovascular responses to return the blood pressure to its homeostatic level. When blood pressure suddenly drops, these baroreceptor reflexes are important in maintaining the blood flow through vital organs such as the brain. Unfortunately, as we age, these reflexes start to fail. When an elderly person suddenly rises from a lying to a standing position there can be a substantial drop in their systolic blood pressure. When the drop is greater than 20mmHg this is regarded as being significant and is called postural hypotension. The underperfusion of the central nervous system that occurs can result in symptoms of faintness, dizziness or weakness. Elderly people may fall or collapse. It is estimated that up to 30 per cent of people aged 65–75 years suffer this condition and that up to 50 per cent of people aged 75 years and older are troubled with this complaint.

Resting cardiac output declines at about 1 per cent per year beginning in the third decade. The maximum heart rate that can be achieved during strenuous exercise is reduced by 5–10 beats each decade and, unfortunately, no amount of training seems to be able to halt this progressive decline. Stroke volume also falls as a result of reduced cardiac contractility. Thus cardiac reserve is diminished, as this is dependent on maximal achievable heart rate and stroke volume. The reduced cardiac output, both at rest and during exercise, results in reduced perfusion to all body systems as we age. These changes are most evident in renal perfusion at rest and in the blood supply to skeletal muscle during times of exertion.

THE RESPIRATORY SYSTEM

In the absence of any diseases or harmful exposures (such as cigarette smoking) the respiratory system of healthy elderly people functions very well under conditions of rest or moderate exercise. The pulmonary system is usually not the limiting factor in reaching maximal work capacity, but rather the maximal cardiac output, which is reduced for the reasons described above.

On lung function testing most of the pulmonary volumes change little with ageing. However forced vital capacity (the total volume of air that can be voluntarily moved from maximum inspiration to maximum expiration) does decline with age. It decreases linearly by approximately 5 per cent each decade after about 30 years of age. However, this is of no real clinical significance except at times of stress.

THE LIVER

This vital organ is responsible for the metabolism of many substances which may be endogenous (such as bilirubin) or exogenous (such as pharmaceutical preparations). The liver also produces many vital products needed by the body (such as albumin).

As we age, the liver decreases in size. At age 50 it constitutes about 2.5 per cent of total body weight. By age 90 this figure declines to 1.6 per cent. Along with this there is a gradual reduction in hepatic blood flow. The capacity of the ageing liver to regenerate itself is diminished.

There is a decline in the activity of the microsomal enzymes, which are involved in a large part of drug metabolism. Thus, in the elderly, drugs that undergo biotransformation in the liver show increased plasma half-life or decreased rates of plasma clearance. With advancing age, there is an increased incidence of adverse drug reactions, probably related to the longer exposure time that elderly people have to the drugs or their byproducts. Certain drugs, such as some benzodiazepines, can have remarkably long half-lives in the elderly, causing protracted unwanted effects.

THE GASTROINTESTINAL SYSTEM

Constipation is a common complaint of the elderly. This problem is often multifactorial in origin, but may be partially due to the fact that transit time through the colon is reduced as we age. Other factors, especially diet and medications, probably have a more significant contribution in many cases.

There are age-related changes in oesophageal motility referred to as presbyoesophagus. During peristalsis the amplitude of the contractions down the oesophagus are reduced. Normally this poses no clinical problems; it is only when disease processes supervene that oesophageal motility is significantly affected.

With age, the number of parietal cells in the stomach drops. These cells are responsible for gastric acid production. Thus maximal gastric acid output is impaired but in non-disease situations this has little clinical significance.

THE UROGENITAL SYSTEM

A steady decline in renal function occurs as we age. The kidney undergoes a decline in mass, blood flow and glomerular filtration rate. The microscopic filtration units of the kidney (called the nephrons) reduce in number and there is fibrosis (termed sclerosis) of the remaining units. The filtration membrane of the nephrons (called the basement membrane) thickens with age. The reduction in glomerular filtration rate (the rate at which the nephrons filter the blood) means that certain drugs which are predominantly renally excreted will have a longer half-life in the elderly. As mentioned previously this longer half-life can result in adverse events or prolonged effects.

The loss of nephrons appears to particularly affect those involved in the concentration of urine. Paradoxically, because of other changes, the maximal diluting capacity of the kidney is also diminished. It becomes increasingly difficult for the ageing kidney to retain sodium when required and to excrete free water when fluid overloaded. This is particularly evident at times of illness or other stress. Because of their limited capacity to regulate body water, elderly people are more susceptible to dehydration, fluid overload and electrolyte disturbances such as hyponatraemia.

Changes occur in the bladder with age. Bladder capacity gradually declines so it can hold less maximal volumes and it is more prone to unstable contractions (a condition called detrusor instability). If these contractions are strong enough they may result in urinary incontinence.

THE MUSCULOSKELETAL SYSTEM

Maximal muscular strength is reached in the second and third decades of life and then slowly declines. Most of this age-related decline in muscle strength can be attributed to reduced muscle mass, which drops substantially with ageing. It has been reported that the maximal cross-sectional area of the quadriceps muscle (a major thigh muscle) may be 25 per cent larger in a 20-year old compared with a 70-year old (Young et al., 1985). Connective tissue replaces most of the lost muscle mass.

Although muscle mass declines with ageing this decline can be significantly modified by a regime of good nutrition and regular weight-bearing exercise. The nutritional status of many elderly people is suboptimal for a number of reasons (such as economic limitations or lack of interest in food) and this, combined with physical inactivity, can result in a downward spiral of muscle loss. People whose jobs require strength above the levels involved in a sedentary lifestyle usually maintain muscle mass well into middle age.

The losses in muscular strength are gradual until about age 60, after which a more marked decline begins. This loss can be slowed down to a great degree by resistance strength training. It allows people to maintain high levels of strength for many years and it provides an opportunity for previously sedentary people to prevent or even reverse some of the age-related deterioration in muscles. Indeed older people who have embarked on a regime of regular resistance strength exercises have commonly reported increased vigour and vitality.

As we age, our body composition changes. The percentage of body weight contributed to by adipose tissue rises while that contributed to by lean body tissue and bone drops. This new adipose tissue is distributed in a typical pattern around the body. It accumulates in predominantly central sites such as in the omentum, around the kidneys and in central organs such as the liver. There is weight gain around the trunk and loss of subcutaneous fat from the limbs. In the male this weight gain is most noticeable around the abdominal region, while in the female the weight gain is first noticed around the hips.

Stature also changes with ageing. After it reaches a peak in the early 40s height declines at a rate of about 1cm per decade on average, although losses can be more marked in some individuals. The loss of stature is attributed to flattening of the foot arches, an increase in spinal curvature and true shortening of the vertebral column as the intervertebral discs dry out, losing height. Vertebral bodies also lose height secondary to osteoporotic crush fractures.

Osteoporosis is a condition which afflicts many postmenopausal women and some elderly men. In women the onset of menopause signals significant reduction in a number of hormones, including oestrogen. This lack of oestrogen results in bone loss, which is most marked in the first five years after the onset of menopause. There is actual loss of bone content and thus bones become more porous and weaker. They are prone to break when subjected to less force than required previously. Thus fractures may occur at crucial sites — such as vertebral bodies, wrists and necks of femurs — when exposed to seemingly usual forces.

Women are more affected by osteoporosis than men for several reasons. Their peak bone mass, which is achieved in early adulthood, is less than men, but they live longer in general and thus have the chance to develop weaker bones. In Western societies one of the main sources of dietary calcium is from milk products. Because these are often perceived as being fattening women are more likely than men to avoid consuming them.

THE NERVOUS SYSTEM

It is estimated that we lose 50 000 to 100 000 nerve cells per day. As we age, macroscopic changes occur to the brain, which reflects this loss of neurons. The brain appears to shrink, with deepening of the corrugations on the surface of the brain (called sulci). The interconnecting central spaces within the brain, known as the ventricles, become larger as they compensate for the reduced amounts of brain tissue. These age-related changes in the brain are detectable with a number of radiological investigations such as computerised tomography (CT) or magnetic resonance imaging (MRI). In addition blood flow through the brain reduces by approximately 20 per cent between the ages of 20 and 70 years.

The result of these changes is that the central nervous system of elderly people seems to process information at a slower rate than in younger people. Older people are slower at handling simple cognitive tasks and are considerably slower when these tasks become more complex and novel. They display more rigidity in their thought processes; they have less capacity to form new concepts and reduced capabilities for abstraction. Thus they are less able to assimilate to new environments or cognitive challenges than the young. However, despite all this, some elderly people can be quite surprising in their capabilities.

With normal ageing there are some minor losses in memory, but certainly nothing that should affect day-to-day functioning. People can maintain their mental faculties well into old age. It is only when diseases such as Alzheimer's disease or cerebrovascular disease (strokes) supervene that significant cognitive impairment develops.

THE SENSES

Eyesight

Eyesight changes with ageing. As people approach middle age they become what is known as 'far-sighted'. They have difficulty focusing on nearby objects and this can become especially obvious when they attempt such tasks as reading or needlework. This is because, as we age, the lens in the eye becomes less elastic and the muscles that normally change the lens conformation (the ciliary muscles) weaken and atrophy. As a result most elderly people require 'reading' glasses.

Cataract formation is associated with advancing age, although cataracts may develop at younger ages for a number of reasons. Approximately 40 per cent of people over the age of 75 suffer from cataracts. A significant risk factor in the development of cataracts is exposure to ultraviolet radiation. Thus it is important to wear sunglasses with good ultraviolet protection when outdoors, especially in summer. Surgery is indicated when the cataract affects vision and in this procedure the diseased lens is replaced by an artificial intraocular lens.

Hearing

Hearing problems are especially common in the elderly. Up to 50 per cent of people 75 years and older suffer from hearing loss caused by a condition called presbyacusis. It results in the gradual onset of bilateral high-frequency neural hearing loss. There is decreased hearing at the higher frequencies and for pure tones. People have difficulty differentiating the various loudness of sounds and this is especially notable when they try to understand somebody speaking in a noisy environment. Even with the use of a hearing aid this may still be a problem. It is estimated that 30–35 per cent of people over the age of 65 have sufficient hearing loss to warrant the use of a hearing aid.

THE SKIN

One of the most obvious changes that occurs with ageing involves the skin. With age, the skin shows increased laxity and wrinkling. Although chronic sun exposure may cause a large proportion of the wrinkling it is evident even in protected skin.

Human skin is divided into two major layers. The epidermis is the superficial part, composed of layers of skin cells which gradually migrate towards the surface where they are eventually sloughed off. With advancing age the ability of the epidermis to replace itself diminishes and so too does its capacity to repair itself. The surface of the epidermis becomes rough and scaly, imparting the dry appearance associated with elderly skin.

The deeper layer of the skin is called the dermis and this contains the support structure of the skin, composed of a network of collagen and elastin fibres. Ageing is associated with a breakdown of these fibres and results in thinning and reduced pliability and elasticity of the dermis. With age, the circulation to the dermis decreases and becomes less efficient. Elderly skin

- does not heal as quickly
- is more susceptible to sun damage
- is less efficient at thermoregulation
- has a reduced capacity to mount an inflammatory response when compared with younger skin.

Undoubtedly chronic sun exposure is responsible for most of the skin changes that are regarded as an inevitable part of ageing. In 1991 Warren and his coworkers used high-resolution facial photography and instrumentation measuring elasticity to compare the faces of younger (aged 25–31 years) and older (aged 45–51 years) women who had either had more than 12 hours of sun exposure per week for the previous year or less than 2 hours of sun exposure per week for the previous year. The high sun exposure did not result in a significant difference in the elasticity, skin colour or wrinkles in the two groups of younger women. The results in the older age group were quite different, however. Significantly more wrinkles and much less elasticity were evident in the skin of the older women with the high sun exposure (Warren et al., 1991).

As we age, progressive hair loss occurs. The number of scalp hair follicles decreases inexorably throughout life from approximately 1100 hair follicles per square centimetre at adolescence to 600 hair follicles per square centimetre in the third decade but only 450 hair follicles per square centimetre in the ninth decade. Of course, in some men, superimposed male pattern baldness intervenes, with much more rapid and complete hair loss occurring.

SEXUAL FUNCTION

Sexual activity declines with old age, but it is unclear how much of this is due to normal ageing and how much is due to disease. Menopause results in atrophy of the vaginal mucosa and in reduced vaginal lubrication. This can make sexual intercourse less comfortable and sometimes even painful. Artificial lubricants can overcome this problem.

Testosterone levels gradually fall with age. Whether this has a significant impact upon sexual ability or desire is not known. Impotence increases in frequency with advancing years, reflecting the higher incidence of vascular and neurological disease in this age group. However it is well known that elderly men can father children and that many couples enjoy an active and satisfying sex life well into old age.

CONCLUSION

As we can see, the process of physiological ageing is a fairly benign process. There are certainly changes in body habitus and physical appearance that distinguish an elderly person from a younger person. Despite these external appearances, at rest, the body of an elderly person who has undergone purely physiological ageing functions in similar fashion to the body of a younger person. It is only when the older person is stressed physiologically (such as by disease process or exertion) that the differences become evident.

Ageing diminishes the physiological reserve on many body systems. If, however, pathological ageing intervenes, the health of an elderly person can be significantly impaired. As more and more gains in life expectancy are achieved, let us hope that, through public health measures, prevention programs and advances in medicine, an increasing number of people are able to reach old age free of disease and morbidity.

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THERESA CLUNING

Registered Nurse, Registered Midwife, Diploma of Applied Science (Community Health and Maternal and Child Health), Bachelor of Applied Science (Advanced Nursing), Master of Educational Studies, Fellow of the College of Nursing Australia

Theresa has worked in many roles within acute hospitals, residential care, community health, community case management, academia and management.

Her colleagues have become her friends, and as she believes she never stops learning from others, she acknowledges the support and the sharing of knowledge she has received in every area she has worked.

CHAPTER THREE

Holistic Care: Why and How

Theresa Cluning

INTRODUCTION

Health care professionals working with ageing people in a community setting deal primarily with the impact of the consequences of a disease or impairment. We assist the person — and their family and support people — by helping them regain the overall balance in their life. But unless professionals have both the interest and skills to elicit what the impact and consequences mean to the person and their family, so that trust and an effective team approach will develop between the ageing person and the professional, a mutually satisfying outcome will not be achieved.

In my opinion holistic care can be achieved only when we are mindful that each ageing person, whether they live in a comfortable home or are homeless, requires us, as health care professionals working in the community, to be aware of their uniqueness — their particular physical, psychological, emotional, social, cultural and spiritual being; their strengths and challenges and their subsequent needs. To enable us to become aware of what value the person places upon all facets of their being, we need to engage with them as two people coming together to talk about:

- what their priorities are
- what is required
- how this is going to be achieved (by whom, using what strategies).

Once this rather simplistic notion is truly accepted and practised, holistic care is possible. Through focusing on the purpose of the interaction and the needs of the ageing person, holistic care should become inevitable, effective and professionally satisfying. Professionals from all health disciplines are involved in the community setting and each discipline has its own focus and level of involvement with the person, whether short term or long term, minimal or intensive. The aim of this chapter is to encourage you, the health care professional working with the aged in the community, whether your involvement is for one visit or for the long term, to clarify your professional involvement with each ageing person and to develop strategies that will assist your reflection and practice.

I continue to be humbled by what people of any age can manage to achieve, with grace and good humour, when confronted with challenging situations, and I believe most community workers consider it a privilege to be a part of the lives of the people with whom they work, even those ageing people whose values and ways of communicating and interacting vary from their own. Ageing people are exactly that, people; some you enjoy working with more than others. Remember though that if working with the ‘others’ becomes a problem, you should seek supervision and debriefing before the professional, supportive relationship you are trying to build is affected.

HOW MUCH INVOLVEMENT DO YOU REALLY HAVE?

The assumption made in this chapter is that the ageing person has come into the community support system because they have needs which they cannot meet alone as they have exhausted their resources. These needs may be physical, social, emotional, psychological, spiritual, environmental or any combination of these, which is the most common situation.

I believe that we, as professionals, can provide support that will be of enormous benefit to the ageing person, their family and the community. I’m also aware we are a very small cog in the wheel of their life, but we are important. As an example of what I mean I would like you to meet Agnes.

VIGNETTE

Agnes is 80 years old. Bert died 10 years ago so Agnes lives alone, with a loving, supportive but physically distant family. Agnes’s diabetes has resulted in Agnes visiting her GP regularly and requiring daily visits from the nursing service for medication, occasional dressings and monitoring. She visits a podiatrist every six weeks, she accesses some meals via the community service and she has two hours of home help assistance every week from an agency. Despite this level of service, which may average out at only about an hour per day, it is clear that Agnes is still very much her

> *own person and in control of her wellbeing. For 23 hours of each day she continues as she has for 80 years being Agnes, an independent and interdependent woman; problem solving, decision making and leading a full social life.*

Professionals need to be proactive in monitoring Agnes's health and support system whilst at the same time taking a balanced approach in their interactions with her. Agnes's need for assistance may increase in time but it is only if her situation becomes more complex that she may require further community support. She may then benefit from having a community case manager.

In reality Agnes is conducting her life as she wishes and we, the health professionals in the community, are supporting her to maintain her health and live safely. With this in mind we must then have sufficient professional understanding and personal humility to respect her wishes when, of sound mind, she makes decisions that could cause her health to deteriorate. Just as we would not attempt to manipulate a younger person, so must we respect Agnes's decision making; but we must also exercise our professional responsibility to inform her of any possible consequences of her decision making. I think by grounding ourselves in the reality of the ageing person in the community, we show respect, but we can also expect respect for doing our jobs correctly.

MAKING A DIFFERENCE

How can we, as community workers, be effective and make a difference to the quality of life of people like Agnes?

- by analysing our own perceptions about ageing
- by learning about the normal ageing process
- by learning continuously about diseases, conditions, current treatments and medication regimes
- by utilising the best practice methods of our professional disciplines
- by honing our assessment, goal-setting, reviewing and problem-solving skills
- by networking with colleagues in the community
- by being an advocate for the client
- by encouraging mutual respect between our ageing clients and ourselves
- by developing our interpersonal skills to a very high level
- by acknowledging our place in the scheme of each ageing person's life

- by acknowledging and accepting the uniqueness of each person
- by respecting each ageing person's right to make decisions
- by being personally committed to our roles
- by using both our professionally objective and our intuitive skills to predict the possible consequences of any situation for our ageing clients
- by being willing to influence the formulation and implementation of policy affecting the aged
- by saying to funding bodies that we are not prepared to give poor service just because there is a lack of finance and resources
- by developing ways to ensure we are involved with discharge planning if an ageing client is admitted to the acute sector
- by giving of ourselves and to ourselves. (This means taking time to acknowledge and nurture our own needs, which will allow us to give of our best to our ageing clients without 'losing' ourselves to the professional role. This realisation and practice will hopefully prevent personal and professional burnout. The community needs committed, caring, experienced professionals not jaded people staying bitterly in the system or shell-like wrecks leaving it prematurely.)

All that I have said so far is a challenge. Where does the care of ageing people come in, you may be asking yourself? That is exactly my point. None of us can expect to be effective and give holistic care if we do not know:

- ourselves
- our professional role
- what is available for the client in the community who has X disease or impairment
- what is X
- what are X's possible physical consequences
- what are the possible social, emotional, psychological, spiritual and environmental consequences of X for this unique ageing person?

Holistic care in the community is the care of the whole — the ageing person, that person's particular support network, and ourselves. This requires us as practitioners to:

- develop excellent communication skills
- hone our assessment and problem-solving skills
- develop realistic goals with the client and family/carer
- develop our own professional goals (which may be additional to and vary from the client's goals)
- be prepared to regularly review the goals
- be prepared to adapt to changing circumstances and respond quickly to crisis situations
- be prepared to facilitate a multidisciplinary approach to care that will prevent duplication of services, confusion for the ageing person and —

dare I say it — professional rivalry due to misunderstanding between practitioners
- be prepared to be involved in an ongoing relationship with the ageing person.

ELEMENTS OF HOLISTIC CARE

Mutual respect is essential in any healthy relationship. This is particularly pertinent when there is a possibility that the power of one person could be diminished because of the interaction. Therefore, when you enter a prospective new client's home, you, as the professional, need to remind yourself and acknowledge to the ageing person by your behaviour that you are there as a guest and will act accordingly, now and in the future.

Professionals can give lip service to this premise if they make the false assumption that the ageing person has the same amount of knowledge as they do about health, disease, community services and the options available. The balance of power very quickly alters towards the health professional if they assume either knowledge or ignorance. I believe it is the duty of the professional to assess what the ageing person wants and needs and also what the person knows is possible. Assumptions made by any community professional or support worker can impact negatively on the self-determination of the ageing person.

How does a professional community worker assess the level of knowledge of an ageing person? By attaining highly developed interpersonal communication skills and information-gathering strategies and using them effectively. These skills must be the primary prerequisites of any professional, but any community-based professional will sink without them, or more poignantly, the ageing person may agree to a course of action or treatment which they don't want because of ignorance about their options.

An effective professional does not go into a home with a 'clipboard, pen and list of questions' approach. This will not result in anything like a good picture of the ageing person. It will elicit the basic data, but it will not lead to any shared understanding or reach a point where the person wants to divulge any further personal information.

The following points about home visiting, assessment, goal setting and reviews may appear simplistic to many readers. I do not apologise for the simplicity. I believe that to become proficient at anything, we must break the process down to 'bit-size' chunks, reflect upon these and then rebuild them to make the complex appear simple.

IMPLEMENTING HOLISTIC CARE: ASSESSMENT, INITIAL HOME VISIT, SOCIAL ASSESSMENT AND GOAL SETTING

The moment an ageing person is referred to an agency or individual professional the journey together has begun. Every piece of data collected from then should assist the journey or not be collected. The tools and the process — the referral, the agency screening for suitability, the assessment, the review and the closure — should be integrated with minimal (but preferably no) repetition of data.

Much informal information professionals carry in their heads. Often it is some time before such information can be defined enough to be documented. The experienced professional puts the jigsaw together over time, using subjective as well as objective information.

Supervision of your practice

This informal aspect of community work highlights the need for:

- regular peer discussions about practice
- regular individual supervision within the agency
- access to external supervision if required.

If supervision of your practice is either not available or is ineffective within your agency, seek external supervision. Be prepared to pay for good professional supervision, because it will serve well yourself, your practice and your clients.

Assessment

Assessment depends on:

- who is doing the assessment
- what is their professional discipline
- what is the purpose and level of their involvement with the ageing person.

Anecdotal evidence suggests that people do not want to be continually 'assessed'. To have different people repeating basic questions (e.g. name, address, age etc.) can be annoying. Basic personal information can be shared within the boundaries of professional confidentiality but no professional can practise effectively using only generic information, in my opinion.

A major part of interaction with a client is not just information gathering, it is relationship building. Speaking personally, I am not going to trust anyone with knowledge about my physical wellbeing, personal needs, values, desires and aspirations if I do not have an opportunity to gauge their worthiness to receive this information. Why should an ageing person feel any different about assessment which is designed to lead to their future care?

What should be included in an assessment?

The answer can be found in the following questions:

- What is the purpose of the interaction?
- Will the relationship be short term or long term?
- What is the role of the professional?
- What are the expectations of the ageing person?
- What are the expectations of the family, carers or friends?
- What are the expectations of the professional?
- What can realistically be funded by the community for this person?

Unless and until all parties are clear about these issues, the ageing person is not in a position to decide if they wish to be involved and the health professional is not in a position to know if they can meet the expectations of the ageing person or their carer(s).

Comprehensive assessment regarding an ageing person's situation may take several weeks or months to complete, as trust needs to be established. If the person has reduced cognitive ability, initial information is often scant, especially when the person is socially isolated and you are unable to 'fill in the gaps' without extensive detective work. This is where community networking is essential. I know many experienced community professionals who have thought they had all the pertinent information, gleaned over time, only to find, several weeks later, another service is also involved with the person or an unknown relative pops out of the woodwork.

If you visit any academic library you will find many texts about the various elements of data collection and assessment of someone who is ageing, and/or their carer(s). Although adequate data collection and assessment are essential for the provision of good care by any community-based worker, there are other important elements of good practice, for example:

- using comprehensive and appropriate referral
- screening for agency suitability
- review
- closure processes
- professional networking
- informal information gathering.

Working from this multi-faceted base will lead you, the community professional, towards the development of realistic aims with your ageing client and your client's carer(s), and then to appropriate short- and long-term goals that will facilitate the development and implementation of effective creative and flexible strategies to assist the ageing person to stay at home.

Initial home visit: a checklist

Whilst many of the following points should be considered during any visit, it is essential to establish a rapport with your client during your initial interaction so you should consider these basic elements as a way of keeping your first visit focused.

- Ask yourself why you are making the visit and what you hope to achieve. You are starting down the information-gathering road, you are trying to begin to get a picture of the person in their environment and what may be able to be provided by the community to assist them to stay at home — if this is what they want.

- Make a mutually suitable appointment time. Ask the person who they would like to be present, perhaps a nonresident family member or friend.

- Never take anyone with you unless you have asked permission prior to the visit. Do not allow students to tag along unannounced. It is inappropriate and unfair to both the client and the student.

- Allow at least an hour to visit, plus time to travel. Plan your visit so that you are not rushing from one appointment to the next — your new client must get the impression that you are interested in them and will allow them time. When I hear an ageing person say 'Oh they are so busy with all the people they have to visit, I did not want to bother them' I sometimes wonder who is supporting whom and how effective is that community professional. (I am not ignoring how much work is currently being asked of so few. What I am saying is, let us think about what we are asked to do with limited resources. We must make our visits effective, we must influence policy, and we must lobby governments and funding bodies to increase funding and resources.)

- Arrive prepared for the meeting. Make sure you have reread the referral data, and keep in mind any informal knowledge you have about the client.

- If possible be introduced by the person making the referral to your service, particularly if you expect the person to be tentative about accepting any community service, for example, someone who appears to lack insight into their current level of functioning. (If someone is dementing it is essential to be introduced. Only go alone if there is absolutely no-one to pave the way for you.)

- Whilst you are attempting to develop a relationship, it must be a professional relationship. Much can be learned over an informal cup of tea but remember, this is not social visiting.

- From the moment you pull up outside the house, start observing. For example, an obviously well-planned and formerly cared-for garden which is now in need of tender loving care can start to give you a picture of the challenges facing the person living in the home.

- Does the house look welcoming? Is it locked up like a fortress? If it is, this could indicate that the person is fearful of contact with the outside world. You need to assess whether this is a new way of living or whether the person has always lived this way. If it's the latter, this may indicate ongoing social isolation and therefore little support by family, neighbours and friends. If this person does require assistance it will probably need to come from community-based funded services. But locked doors might just mean the person lives in a high-crime area and is very careful to keep a safe environment.

- Has the person remembered your appointment? Are they ready for you? If not why not? Did you make a mistake or is this an indication of their memory loss? Are they under stress due to a personal crisis, e.g. pain, sudden exacerbation of ill health, recent illness or death of a loved one? The way you handle the situation is crucial to building an ongoing relationship. The situation requires respect and good communication skills. If the person is clearly not expecting you it may be better to say, 'OK, can we make another time?' but I would advise trying to allow the visit to go ahead if possible as this may be the perfect opportunity to show the person how you work — calmly, with respect and patience. Ask whether they wish to proceed or not. Say you have plenty of time, so you are happy to stay now or come back later. If the person has memory loss you will be able to assess how they respond to an unexpected situation and what level of social skills they are able to use. I believe a community worker who develops and values his or her intuitive side and gut responses will respond appropriately to most situations.

- What is important is to give the person a clear understanding of what your role is but without overwhelming them. You can leave pamphlets about your agency but be especially clear about how your agency links with other community agencies.

- Do not be surprised when someone occasionally asks you 'Is there a fee for your service?' before you have even had time to explain your role and your agency's fee structure. Remember this is a valid question and is usually due to concern about their ability to pay for the service. The referral information should indicate whether these people are eligible to receive a subsidised service. Do not make assumptions about anyone's financial security. Remember, ageing people are sometimes asset rich and cash poor. These people invariably live in quite reduced circumstances and, from my experience, they will often sit in cold draughty houses existing on tea and toast to maintain their homes.

- When you leave, the person needs to understand that he or she can agree or decline to be involved with you. Do not make the assumption they either need or want your assistance or that you or your agency are the most appropriate to give assistance.

- When you have finished your visit, make sure you have the skills to complete the visit with clarity. To do this effectively you need to confirm with the person
    1. what you have spoken about
    2. what you have agreed to do
    3. what they have agreed to think about and do
    4. what they have given their approval for you to do
    5. when you will speak to them again
    6. how they can contact you if they need to before the next scheduled appointment.

- Knowing what data your particular agency requires is imperative; this will be based upon the focus of your service. Transcribe all your mental notes to hard copy, or key them into your portable computer, as soon as possible — I would advise always allocating some additional time to enable you to do this in the car or as soon as you return to your office.

If the relationship is to be ongoing, it is important for you to develop strategies to enable you to build up a picture of:

- where this person sees him or herself in the world
- who are their support people
- where are their strengths and current challenges.

To complete the picture you must place importance on the social aspects of this person's life as well as on the physical and environmental aspects. Your own professional and agency forms and tools should assist with information gathering about the person's physical and environmental needs. Which tools you use to develop a picture of the life and needs of a person will depend on:

- your specific discipline
- your role
- the agency you work for
- the focus of your agency.

How to do a social assessment

You need to use all your professional knowledge, experience, senses, and communication and analytical skills, as well as appropriate tools, to develop knowledge about the person's social strengths and needs. Remember any tools used should assist and streamline your professional practice.

I believe all assessments, particularly when you have long-term involvement, should incorporate genograms and ecomaps (see Appendix 3.1 at the end of this chapter.) These provide a pictorial method of seeing the quality and extent of the ageing person's relationships with family, friends and the broader community as well as any changes over time.

I have developed a community and professional participation prompt sheet to assist community workers to gain a clearer picture about who has links with the ageing person and their family and support people. The aim of the prompt sheet is to allow you to see quickly:

- who is involved
- the intensity and length of the involvement
- to whom or what agency the person or carer has been or should be referred
- (over time) who is no longer involved.

This prompt sheet is designed to quickly give community-based professionals a visual overview of who is or should be involved with the person who is their client and/or that person's carer(s). This prompt sheet can be used

Figure 3.1 Community and professional participation prompt sheet

Possible relationships of your client and carer (Attach a separate sheet to note relationship and contact details.)	**Who has a current or past relationship with your client and/or carer?**		**Would a relationship be beneficial?**		**Action, comments or referral** **• who to?** **• by whom?** **• when?**
	Yes or maybe	*No*	*Yes or maybe*	*No*	
Family members					
Friends					
Neighbours					
Community groups, e.g. cultural, religious					
Local doctor					
Medical specialist(s)/geriatrician					
Community case manager					
Allied health professionals, e.g. occupational therapist, physiotherapist, social worker					
Community nursing service/clinical nurse specialists, e.g. continence adviser/aged care specialist					
Aged Care/Psychogeriatric Assessment Service					
Personal carers					
Home help and home maintenance providers					
Respite provider (both in home and out of home)					
Meals provider					
Day centre					
Community rehabilitation centre and or community health centre					
Guardian and/or administrator					
Carers group					
Other					
Other					

- during the process of assessment
- on occasions when problems need to be solved
- when reviewing care.

The idea is to ask yourself 'Where are the support strengths and gaps in this person's life?' This requires other questions to be asked such as:

- Who is involved at present?
- Who has been involved in the past?
- Who must be involved?
- Who should be involved?
- Who could be involved?
- What strategies could you use to seek others' involvement?
- What are the possible time lines for arranging this involvement?

Often the most important question will be, is it your role to initiate involvement or is it someone else's?

You can use ticks, crosses, questions marks and symbols such as flags to assist the process. The list is not meant to be definitive. You can add or subtract any other possible relationships.

Why use social assessment tools?

By gaining an insight into the relationships and the quality of those relationships, you may be able to ascertain what is important in the ageing person's life. This insight will then lead you to what you need to do to assist them to maintain their overall wellbeing and quality of life, and will help you clarify and then work around issues such as:

- Do they have supportive family, friends and neighbours?

- Is the person's primary carer finding the role sustainable or unsustainable? (See chapter 6, 'Ageing people giving and receiving care'.) How can you support them?

- Do they have supportive health professionals or community group members?

- Are they isolated by choice?

- Are they grieving for people who have died recently or a long time ago, or for broken or lost relationships, lost opportunities, or current losses?

- Do they insist on staying at home when 'at risk' because this is where they 'feel' their dead partner?

- Is their home no longer feeling like a safe haven?

- Are they happy?

- Are they sad?

- Are they depressed?

- Are they telling you about their spiritual beliefs easily and will these beliefs affect their decision making?

- Why do they feel they have to manage alone at all costs, and where did this belief come from?

- Can you assist them to accept help in a way which will not make them feel uncomfortable?

I believe that tools like the genograms, the ecomaps and the prompt sheet add a pictorial element to situations which can initially appear to be like a bowl of tangled spaghetti. The tools are designed to assist you to see the issues more clearly and to help you and your client prioritise them. I think the tools are particularly helpful for community-based case managers and care coordinators but if you don't find them helpful, don't use them.

Goal setting: some ideas about establishing realistic, client-centred goals

Goals can be short term or long term or a combination of both. The essential point is that they be:

- realistic and achievable
- measurable and specific
- time limited
- expressed simply
- reviewed cyclically.

When goals are reviewed it is possible to assess whether interventions are working or if they need to be revised or discarded. Of course you will be monitoring the situation frequently and altering the functional aspects of the care plan according to need.

Developing strategies to achieve the aims and goals often sounds so linear that the aims give rise to the goals and the strategies almost suggest themselves. This is not always so.

- It is possible to be unclear about the goals but be quite clear about the basic strategies which could be used to assist the client.

- The goals may be clear but the strategies to achieve them may not be clear.

- Sometimes you may start with a strategy and work backwards towards the aim and goals.

I believe there is an assumption that establishing the aim, the goals and the strategies is an easy process within a community setting. It is not. It takes time and a commitment to not taking a simplistic, 'one size fits all' approach to community aged care.

Start by asking the person what they want

From my experience a community professional will know the person's overall basic aim is 'to stay at home'. And sometimes some of the basic strategies, such as more physical and environmental assistance, will also be quite clear. But unless you sit down, listen and talk to the person about anything and everything, you will not be able to gain an insight into their life. This approach, I believe, will inevitably lead to developing creative and flexible strategies to assist the ageing person.

If you ask anyone 'What are your aims and goals?' about anything in life, I'm sure you will often be greeted with a rather bemused expression. Instead ask:
- 'What would make your life easier?'
- 'What is really frustrating you around the house?'
- 'What did you do in the past which you really enjoyed?'
- 'Is there anything you would really like to do?'
- 'If you had a magic wand what would you do?'

What is essential is to have a commitment to having an issues-based, empathetic, problem-solving approach to working with your ageing client. Setting aims and goals and developing strategies will take quite some time, but the process should be able to be documented and then analysed logically. If you don't use this process, I believe you risk not applying an effective professional approach to both the specific and broader needs of this unique ageing person.

Working in the community requires collaboration

You and your ageing client have now worked together setting realistic goals that are client centred. To achieve successful outcomes will require working in collaboration with other community health professionals, workers and services. Collaboration may mean simply referring your client to another practitioner or it may mean several of you working more closely together as practitioners.

In order to provide truly effective support for your aged client, you must also work with your client's family at the agreed level and intensity of involvement. If the person has cognitive problems you will have negotiated what this level should be with a family carer or other support person. You may also have some contact with formal support people such as:
- personal care attendants
- day care centre staff
- home care and home maintenance workers
- meal providers.

It is also important to be aware of your ageing client's informal support networks within the community, such as:
- ethnic support groups
- senior citizens clubs
- social and church groups
- neighbours.

You may be required to apply for funding for additional services or to arrange for in-home and out-of-home respite. You should also know about and assist the ageing person and/or their carer(s) to apply for additional government funding for direct care and for physical aids and appliances.

Transition to residential care

According to Fine et al. (1998) statistics show that most ageing people:
- stay at home
- do not require residential care
- are cared for by female relatives.

Although this is an accurate reflection of the whole population, often community health professionals play an integral role during the transition process from home to residential care of the ageing people who cannot stay at home. You need to develop as much knowledge as possible about:

- your regional services
- how the process works
- when to refer to aged care assessment services
- which facilities may be more suitable than others for this person's unique needs
- what financial issues are involved when someone enters and lives in an aged care residential facility (you should be able to give broad-based but accurate information).

It is also important to use your knowledge and skills to advise families when to start looking. Aged care facilities have committed and caring staff who make as homely an environment as possible but, from my experience, most people entering an aged care facility for the first time are shocked by even the most pleasant environment. This is where and when the enormity of the decision they are about to make becomes a reality. Be ready for their response and prepare them well.

Whilst the decision to leave home is the responsibility of the person, their family and their carer(s), as community-based professionals you will be asked for guidance and information. It is your role to assist all those concerned through this time and process, a time which is often fraught with anxiety, frustration, guilt, exhaustion, relief, grief and just plain sadness. It is important that you are able to acknowledge the stress this process places upon all concerned, including yourself.

Personally, I am always distressed when someone has to leave their home suddenly and is not prepared in any way emotionally, psychologically or spiritually. This situation sometimes occurs when the primary carer is unexpectedly very ill or dies. It can also happen when people 'don't want to think about it just yet'. As an experienced community professional you will usually be able to use your knowledge about disease and impairment processes, as well as your crystal ball, to predict that, eventually, either the person or their support system will not be able to sustain them at home.

The way the community and the residential support systems are structured at present, and because of the limited time available to professionals in both systems, there is little opportunity for anything more than the briefest discussion to take place before and after admission to permanent care. Therefore, it is important for the ageing person to take with them as much as they can of themselves when they enter a residential facility. To do this effectively the ageing person, carers and professionals should, over time, develop documents describing:

- the ageing person's likes and dislikes
- what they are interested in

- what they enjoy doing
- what they do not like doing, reading and listening to.

Historical and anecdotal scrapbooks and photo albums are a part of what makes the ageing person and their life experience unique.

When residential care becomes a reality for your ageing client and your client's family, carers and friends, you must be just as gentle, caring and honest as you have aspired to be at every stage of your relationship throughout the previous weeks, months or years.

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APPENDIX 3.1 GENOGRAMS AND ECOMAPS

This material (slightly adapted here to fit the pattern of this current book) appeared first as part of chapter 2, 'Social Assessment Documentation: Genograms and Ecomaps' by Theresa Cluning in Nursing Documentation: writing what we do, *published by Ausmed Publications in 1997. This material is used here with the permission of the author and the publisher.*

What follows is a brief overview of how to incorporate genograms and ecomaps into nursing practice, as described by Wright and Lahey (1994), Friedman (1992) and Hanson and Boyd (1996). The tools are derived from their work on assessment and intervention models useful when working with families.

DEFINITION OF FAMILY

To begin with, it is important to define *family*. According to the traditionally held view, a family is comprised of two or more people who are related through marriage, birth or adoption. However, when working in the community, I held a similar viewpoint to such writers as Gilliss et al. (1989) and Friedman (1992) who defined the family in a broader manner. Friedman (1992) suggests a family is composed of two or more people who are emotionally involved and in close geographic proximity. However, I feel that to qualify as family members in today's very mobile society, close proximity is not an essential prerequisite for family membership. Therefore, I'd like to suggest broadening the definition of family to include people, other than those connected by blood and marriage, whose importance in the life of the client could be summarised as being connected to the client by 'emotional bonds'. By adopting this broad view of family, those people who are important to the client, although not biologically or legally related, will not be overlooked.

WHAT ARE GENOGRAMS AND ECOMAPS?

Once the broad family is identified, we need tools to help establish what structure and internal mechanisms — including methods of functioning and interaction — influence the health of that particular family.

- **Genograms** show the *individual* in relation to others in the family.
- **Ecomaps** show the *family* in relation to the wider community.

According to Wright and Lahey (1994:49):

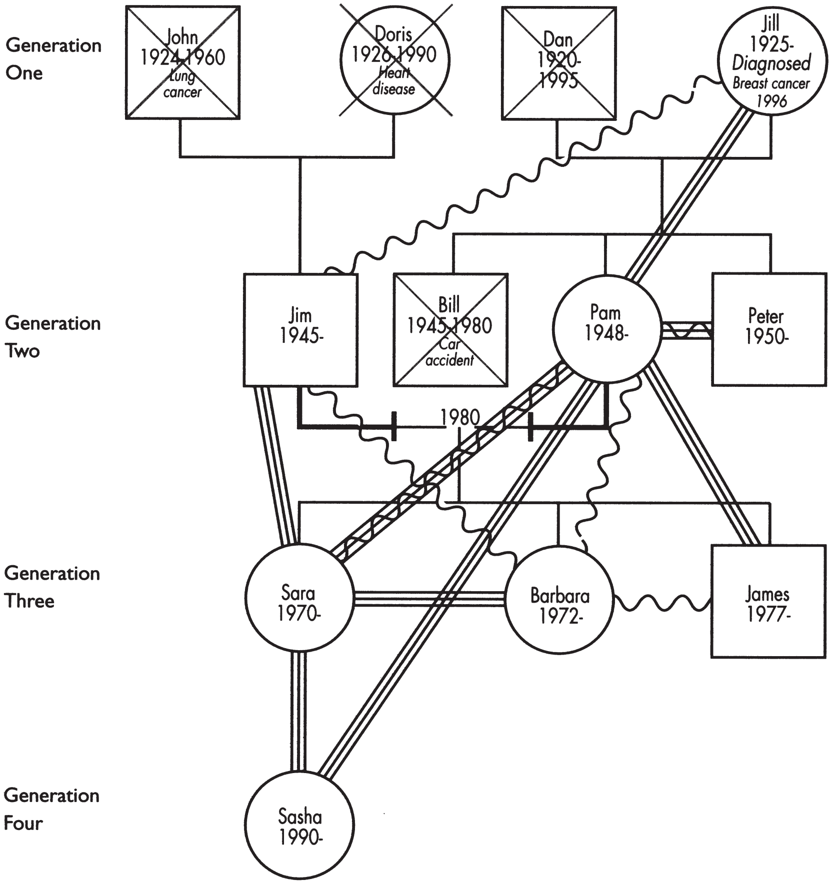
> The genogram and ecomap are two tools that are particularly helpful for the nurse to use in outlining the family's internal and external structures.

Hanson and Boyd (1996:155) suggest:

> A genogram is a format for drawing a family tree that records information about family members and their relationships over at least three generations . . . [It is a] . . . diagram, a skeleton, a constellation showing the structure of intergenerational relationships.

Figure 3.2 A genogram of the Williams family
(see Figure 3.3 for a key to the symbols used)

Family name: Williams
Address: 99 Ausmed Street, Melbourne
Nurse: T. Cluning
Date: 18.03.97



The **genogram** (see Figure 3.2), as described by Wright and Leahey (1994) and Hanson and Boyd (1996), graphically illustrates such aspects of family life as:

- family structure, including household composition, sibling constellation and any unusual family configurations
- pattern repetition across generations, such as patterns of individual functioning, and family relationships and interaction
- life events and the impact of life changes, transitions and traumas
- family health history, such as illness, morbidity and mortality
- relational triangular patterns, such as parent-child triangles, divorce and remarriage triangles and multigenerational triangles;
- family balance and imbalance, in family structure, roles, level and style of functioning, resources; and
- family members' religious and ethical background.

On the other hand, an **ecomap** (see Figure 3.4) shows how a particular family relates to the wider community. An ecomap also gives an estimation of both the nature and quality of that relationship, assisting the nurse [community professional] to organise a large amount of information in a user-friendly, visual format.

As suggested by Hanson and Boyd (1996:158):

> Ecomaps not only can portray the present but can also be used to set goals, for example to increase connections and exchanges with individuals and agencies in the community.

How to do a genogram

Equipment

You only need a pen and piece of paper initially (to assist memory), and a copy of the genogram and ecomap symbols.

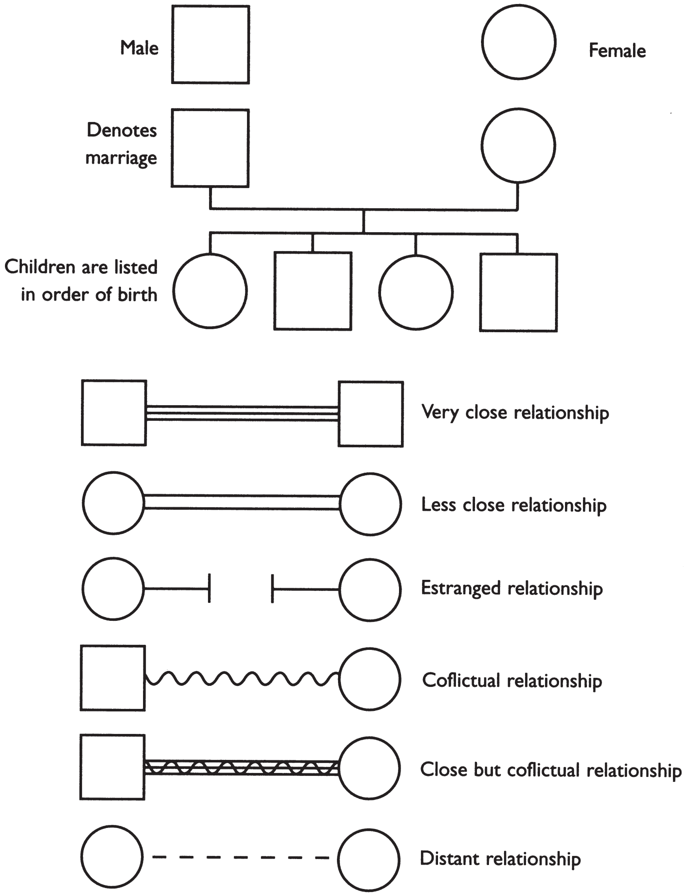
Symbols

(See Figure 3.3)

- All family members are represented.
- A square is used for each male and a circle for each female.

- The person's name and age are written inside the square or circle.
- Inside the square or circle, details such as year of birth, death and marriage are recorded. Other details such as work and living arrangements can also be noted.
- Related individuals are joined to others in the same generation by horizontal lines.
- The person's children are denoted by vertical lines and rank ordered left to right, beginning with the oldest child.
- Close relationships are denoted by joining symbols with three unbroken lines, while distant relationships are indicated by one broken line.
- Conflicted relationships can be denoted by a jagged line, while estranged or cut-off relationships are indicated by single lines which have been broken. Dates of marital separations are recorded at the break in the line. Close but conflicted relationships can also be denoted by joined and jagged lines.

Figure 3.3 Symbols used in genograms and ecomaps

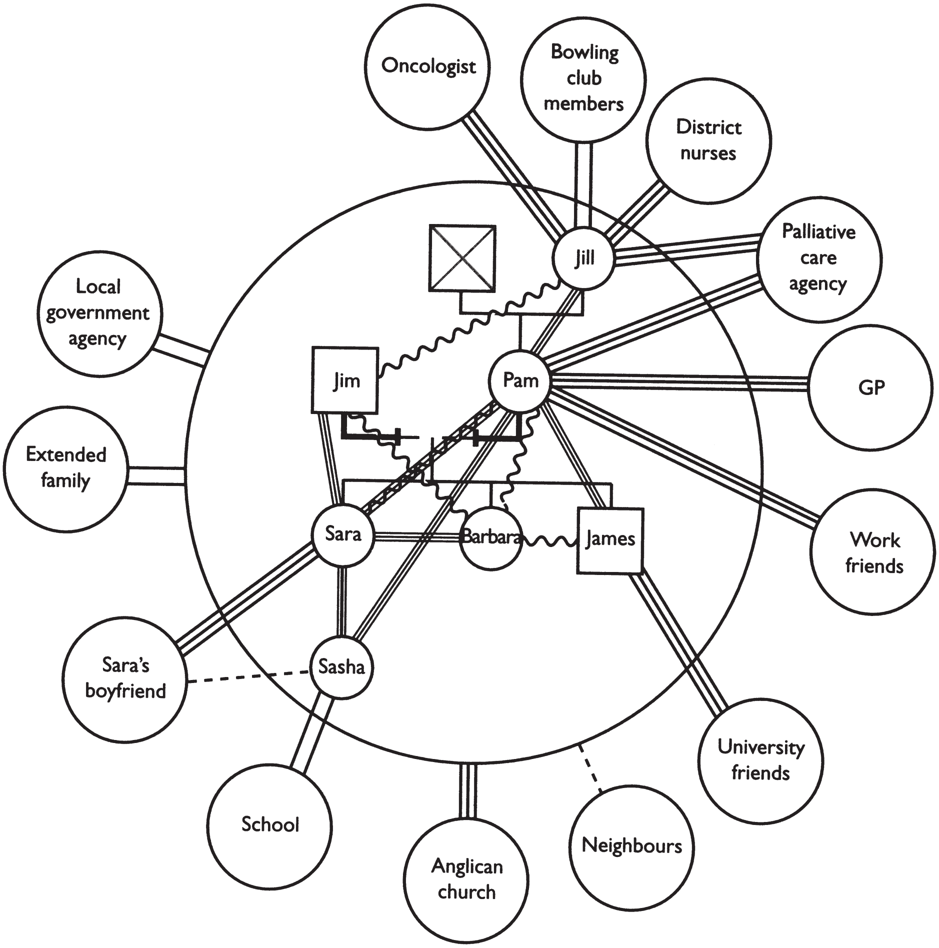


How to do an ecomap

The information we are seeking by making an ecomap relates to the interactions of the person within the family, and with the outside world. Therefore, although the information is usually of a less intimate nature than the genogram, the same symbols can be used. In the example in Figure 3.4 the various relationships existing between the person, family members and the outside world are clearly demonstrated.

By taking a few minutes to prepare a genogram and an ecomap, the nurse [community professional] can provide a powerful tool, enabling any team member to see at a glance how the new resident, client or patient fits and interacts with other family members — and the wider world.

Figure 3.4 An ecomap of the Williams family



Genograms and **ecomaps** can provide nurses [community professionals] with invaluable information, for instance during a person's transition from home to nursing home (Figure 3.4). Whilst the aged care assessment teams (ACATs) may have provided all the relevant social information, some details not essential to admission, but important to the resident's ongoing care, may not be included. Such important but frequently omitted information may be, for example, the name of the regular home help worker who cared for the client or resident for 10 years, or the neighbour who was a substitute daughter. It has been my experience that sometimes such people, who were central to the resident managing at home, fail to be officially recognised and just 'disappear'. Even if they have been the resident's only active family they fade away, not wanting to intrude. In this way an important emotional support is lost to the resident, increasing potential feelings of loss and difficulty in adjustment.

ELIZABETH BROPHY

Bachelor of Laws, Diploma of Social Studies, Master of Social Work (with Honours)

Barrister and Solicitor of the Supreme Court of Victoria, Barrister and Accredited Mediator, The Victorian Bar

Elizabeth is a lawyer and social worker by qualification. She worked for seven years as the Senior Advocate and Consultant in Dispute Resolution at Residential Care Rights, a Commonwealth-funded aged care advocacy program in Victoria where she provided advice to consumers of residential and community services. She also represented consumers in mediations and hearings under the Complaints Resolution Scheme and at hearings at the Guardianship and Administration Board. Elizabeth has conducted many seminars for health practitioners, service providers, lawyers and students in aged care and health law, and has contributed to publications in the area.

At present Elizabeth is practising as a barrister at the Victorian Bar and has a particular interest in elder, health, medical and family law. She is a also candidate for the degree of Doctor of Juridical Science at the University of Melbourne.

CHAPTER FOUR

Legal and Ethical Issues and Their Impact on the Care of the Older Person in the Community

Elizabeth Brophy

INTRODUCTION

The law and ethics have a critical impact on how you as a psychologist, nurse, physiotherapist, occupational therapist, social worker, podiatrist, or dietitian provide community care to older people. Legal and ethical obligations provide a framework which you must consider when making decisions in community care. Health professionals generally have a good knowledge of such obligations and many will routinely take these into account in decision making. However, there is often a need in more complex cases to be able to focus on the specifics of legal and ethical obligations and to articulate the dilemmas and conflicts in a more conscious way to ensure that the best decision is made.

Issues that you face in your work may be affected by legal and/or ethical rules.[1] While this chapter looks primarily at legal obligations affecting health professionals, you will also need to consider ethical obligations, including your professional code of ethics or code of conduct.[2] If you do not belong to a particular profession any code of conduct put in place by your employer will be relevant.

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[1] For a discussion of legal and ethical decision making in an allied health context see Wallace M (1995): *Health Care and the Law: A Guide for Nurses*, 2nd edn. Sydney: The Law Book Company, Chapter 19, p. 433. For an introduction to ethics in the health context see Beauchamp TL and Childress JF (1994): *Principles of Biomedical Ethics,* 4th edn. Oxford: Oxford University Press.

[2] For example, the Australian Association of Occupational Therapists Code of Ethics, 1996; and Speech Pathology Australia Code of Ethics, 1996.

The chapter discusses some important legal obligations but is not comprehensive and does not provide answers to specific problems. The information is fairly general as it is not possible to provide detail about specific obligations at a state level in a short chapter in a national publication. It is also important to note that the facts of each case are unique and it is your task as a health professional to learn to apply the general principles to each unique situation. The chapter will give you some pointers and it will be necessary for you to do some additional training[3] and research to clarify the obligations that are relevant to the state and context in which you work. Of course, where necessary, it is important that legal advice is accessed.

Legal obligations stem from two sources — the common law (the law made by judges) and statute law (the law made by Parliaments). Two specific areas of the common law that you need to be aware of are the law of negligence and the law of contract. There may also be a number of statutes with which you need to be familiar, depending on the context in which you work. This chapter focuses on statutes directly relevant to the provision of aged care services and guardianship and administration legislation.[4]

COMMON LAW OBLIGATIONS

The law of negligence

The law of negligence is about our duty of care. Everybody, according to the law, has a duty to take reasonable care to avoid acts and omissions which a reasonable person would, in the circumstances, foresee as likely to cause harm or injury to another. Someone is negligent when he or she fails to take that care. A negligent person can only be successfully sued, however, if his or her negligence actually caused the reasonably foreseen harm or injury to another.

In your work as a health professional you must take reasonable care to avoid acts or omissions which a health professional in similar circumstances could reasonably foresee as likely to cause damage to another.[5] You would

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[3] A health professional should attend seminar(s) covering legal obligations that particularly address issues relevant to his or her profession.

[4] You also need to be aware of mental health, disability, anti-discrimination, state fair trading and Commonwealth trade practices legislation and other common law obligations such as the intentional torts of defamation and false imprisonment.

[5] Sam Blay (1999): *Torts* (4th edn) Butterworths, p 31.

be negligent if you breached your duty of care through the failure or omission to do something which a reasonable health professional would do or by doing something which a reasonable health professional would not do.[6] The omission to do something may involve a failure to even be aware that you needed to take any action or may be a conscious decision not to act, a practice that is not uncommon in community care. When you make a decision to act or not to act it is important that you make notes at the time about your problem-solving process, your decision and the reasons for your decision. Such documentation will be critical if there is a complaint or if legal action is taken.

The law of negligence is a most important area of the law to understand as it permeates every area of practice including diagnosis or assessment, treatment or intervention as well as advice and information sharing. Very importantly, it also provides the greatest potential for legal action.[7]

Health professionals are generally aware that they owe a duty of care to their clients but what does this actually mean in day-to-day practice? When discussing the law of negligence a helpful framework to consider is: what would have to be proved if you were sued in negligence by a client?[8] There are three basic things that would need to be proved:

1. you owed a duty of care to that person;
2. you breached that duty of care; and
3. your breach caused harm or injury to the person.

The first question to consider then is 'Do I owe the person a duty of care?' Where you have a client relationship with an ageing person the answer will inevitably be. 'Yes'. However, in aged care, health professionals often work with 'client systems' in which a number of people have a role in the ageing person's life. Your obligations to the ageing person's family and friends and to members of the public, such as your client's neighbours, may not be as clear as your obligation to the ageing person. To assist in clarifying whether you owe a duty of care to a person, such as a family member or neighbour, consider whether they are persons who are so closely and directly affected by your acts that you ought reasonably to have them in your consideration

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[6] *Blyth v Birmingham Waterworks Co* (1856) 11 Exch 781; [1843-60] All ER Rep 470 at 479–480.

[7] Wallace M (1995): *Health Care and the Law: A Guide for Nurses,* 2nd edn. Sydney: The Law Book Company, p. 118; Swain P (1996): Social workers and professional competence: A last goodbye to the Clapham omnibus? *Torts Law Journal* (4):52.

[8] There are a number of packages available that have been developed to educate health practitioners in duty of care.

when acting or deciding not to act in relation to your client.[9] This is known as the principle of proximity (closeness or nearness). Whether a person is sufficiently 'proximate' to you in this sense depends on the facts in each case. Where family members are concerned, the fact that you are a professional with skill and expertise who assumes responsibility for a 'client system' and the fact that there is reliance on you by the family are both relevant factors.[10]

You also need to consider if it is reasonably foreseeable (not far-fetched or fanciful) that the person (family member, friend or neighbour) will suffer harm through your action or your failure to act.[11] The question to ask is: would a reasonable person in your position foresee that the situation involves a real risk of injury to the person or to a limited class of persons (family or neighbours generally) of which the person is a member?[12]

When you are clear that you owe a duty of care to someone, you have an obligation to take steps to prevent foreseeable harm to the person. You are not an insurer of the person and are not required to prevent all harm at all times, but you are required to take reasonable steps to prevent the harm that is reasonably foreseeable in the circumstances. Consider what the reasonable podiatrist, dietitian, social worker or physiotherapist etc. would do in response to the foreseeable risk. To assist in establishing what the reasonable health professional would do, consider the magnitude of the risk and the degree of probability of its occurrence as well as the expense, the difficulty and inconvenience of taking preventive action and any other conflicting responsibilities of your organisation.[13]

The next step is to establish if you breached that duty of care. This involves identifying the facts of the case — what you actually did and comparing this with what you should have done. What you should have done is the legal standard of care required for the duty of care to be fulfilled. If your conduct fell below that legal standard of care, then you breached your duty of care.

What though is the legal standard of care required to meet your duty of care?

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[9] *Donoghue v Stevenson* (1932) AC 562 at 580. This is the test laid down by Lord Atkin.

[10] Law Book Company, *Laws of Australia,* vol 33 (as at 1/2/99) Torts '33.2 Negligence' [8] [5] and [12].

[11] Public policy is also a consideration that can negate duty of care or limit damages in some circumstances: Law Book Company, *Laws of Australia*, vol 33 (as at 1/2/99) Torts '33.2 Negligence' [19] and [20].

[12] Law Book Company, *Laws of Australia*, vol 33 (as at 1/2/99) Torts '33.2 Negligence' [8] and [5].

[13] *The Council of the Shire of Wyong v Shirt* [1979–1980] 146 CLR 40, 47–48.

> In Australia, it has been accepted that the standard of care to be observed by a person with some special skill or competence is that **of the ordinary skilled person exercising and professing to have that special skill.**[14]

A health professional who holds him or herself out to be a physiotherapist or a social worker or a nurse will be expected to provide the standard of the ordinary skilled physiotherapist, social worker or nurse. The practice of other members of the profession is relevant but is only one aspect that the court will take into account. Policy, procedure and practice manuals, employer directives, expert evidence of peers and statutory obligations relevant to your work context will all be relevant and assist the court to establish the legal standard of care required in the circumstances.[15]

Unfortunately, you will only know what a real court finds to be the standard of care in your situation if you get sued. What you must do to avoid that is to try to predict what a court would say is your standard of care.

Thirdly, to be successful in a negligence action against you, a plaintiff (the person who institutes civil legal proceedings) also needs to show that he or she has suffered harm because of your breach of duty. The harm may be physical injury, nervous shock and/or property damage and must stem from something that you did or failed or omitted to do. If you have breached the standard of care required but the client suffers no harm then there is no legal case of negligence. However, not measuring up to the standard of care required may still lead to a complaint by the client, or disciplinary action by your organisation or a professional body.

A plaintiff must be also able to show a causal connection between the harm suffered and your breach of the standard of care. A client may suffer harm and you may have breached your standard of care but there may not be a sufficient connection between these two occurrences to establish negligence. There are different ways that the court will look at the issue of causation, such as applying common sense and the 'but for' test.[16] To apply that test is to ask 'Would the harm not have occurred but for the breach of the health professional?'

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[14] *Rogers v Whitaker* (1992) 175 CLR 479 at 487; *Naxakis v Western General Hospital* (1999) 162 ALR 540 at 545 and 562 (emphasis is added).

[15] Wallace M (1995): *Health Care and the Law: A Guide for Nurses,* 2nd edn. Sydney: Law Book Company, pp. 135–136.

[16] This test is important as an exclusionary mechanism in causation but is not an exclusive test: *March v E & H Stramare Pty Ltd* (1991) 171 CLR 506 at 516: Law Book Company, *Laws of Australia,* vol 33 (as at 12/8/96) '33.10 Damages' [85].

Two defences that may be relevant in a claim for negligence are voluntary assumption of risk and contributory negligence. Voluntary assumption of risk may arise where the client is fully informed and understands the risks of a course of action and he or she voluntarily chooses to take that path despite the risks.[17] Of course, the client needs to have the competence to understand and accept the risks and potential consequences involved (see 'Substitute decision making and Guardianship and Administration legislation' later in this chapter). In practice, this defence is rarely accepted by the courts. Contributory negligence on the other hand may arise where a client fails to meet the standard of care to which he or she is reasonably required to conform for his or her own safety.[18] While voluntary assumption of risk may be a complete defence to negligence, contributory negligence, if found, would only reduce the liability of the health professional.[19]

You may be sued as an individual. If you are an employee or agent at the time that the harm occurred your employer is also vicariously liable, provided that you were acting in the course and scope of your employment.[20] If you are not sued as an individual your employer may still claim from you a proportionate contribution to the damages,[21] i.e. the compensation paid by the negligent party to the plaintiff.

To avoid being negligent in assessment, intervention and advice giving, it is important to ensure that you are delivering care and services at the necessary standard. This involves being familiar with the policy, procedure and practice manuals of your organisation, identifying gaps in your professional knowledge and experience, undertaking programs that will help build the necessary level of skill and seeking supervision when necessary. It is particularly important to alert supervisors if you are faced with decisions or tasks that are outside your level of competence. You also need to be familiar with statutory obligations that are relevant to the context in which you work (see 'Statutory obligations' later in this chapter) as such obligations will also assist in establishing the standard of care that you are required to meet.

Many employees of home care services are personal care assistants who have had minimal training. They are required to meet the same legal obligations as

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[17] Law Book Company, *Laws of Australia*, vol 33 (as at 1/8/98) Torts '33.9 Defences' [62].

[18] Fleming JG (1998): *The Law of Torts,* 9th edn. Sydney: Law Book Company, p. 318.

[19] Law Book Company, *Laws of Australia*, vol 33 (as at 1/8/98) Torts '33.9 Defences' [60] and [50].

[20] Wallace M (1995): *Health Care and the Law: A Guide for Nurses,* 2nd edn. Sydney: Law Book Company, p. 157.

[21] Wallace M (1995): *Health Care and the Law: A Guide for Nurses,* 2nd edn. Sydney: Law Book Company, p. 160.

qualified health professionals but the standard of care to be observed by personal care assistants under the law of negligence is that of the ordinary skilled person exercising or professing to have that skill.[22] As with qualified health practitioners, the practice of other personal care assistants, policy, procedure and practice manuals, employer directives and statutory obligations will all assist the court to establish the standard of care required in the circumstances.[23] Training of personal care assistants must include information about duty of care and statutory obligations, and the policy and procedure manuals made available to personal care assistants should also reflect such obligations. It is essential that personal care assistants receive an appropriate level of supervision and support from qualified health practitioners.

Consent

Two areas of law are relevant to the issue of consent: the law of trespass and the law of negligence.

Before providing treatment to a client you need to have his or her valid consent. The client's consent (1) must be given voluntarily, without duress or misrepresentation; (2) the client must have information about the procedure; and (3) the client must have the necessary level of competence to make the decision.[24] (See 'Substitute decision making and Guardianship and Administration legislation' later in this chapter.)

The law of trespass makes it unlawful to directly and intentionally or negligently make contact with a client without his or her consent.[25] Such contact without consent also constitutes the criminal offence of assault.[26] Setting aside contact arising from the conduct of daily life, such as brushing against someone in a crowded hospital lift, any contact that has not been consented to, including contact via an instrument such as a stethoscope, will meet this definition.[27] To avoid an action under the law of trespass,

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[22] *Rogers v Whitaker* (1992) 175 CLR 479 at 487; *Naxakis v Western General Hospital* (1999) 162 ALR 540 at 545 and 562.

[23] Wallace M (1995): *Health Care and the Law: A Guide for Nurses,* 2nd edn. Sydney: Law Book Company, p. 135–136.

[24] Devereux Dr J (1997): *Medical Law: Texts, Cases and Materials.* Sydney: Cavendish Publishing, p. 51.

[25] Luntz H, Hambly D (1995): *Torts: Cases and Commentary,* 4th edn. Sydney: Butterworths, p. 649.

[26] Law Book Company, *Laws of Australia,* vol 27 (as at 30/6/99) '27.2 Medical Practitioners' [5].

[27] Law Book Company, *Laws of Australia,* vol 33 (as at November 1998) 33 Torts '33.8 Intentional Torts' [15]; Higgins PFP: (1970): *Elements of Torts in Australia.* Sydney: Butterworths, p. 74.

which unlike negligence is actionable without proof of harm,[28] it is necessary to have the client's consent where contact is involved. In addition to the first and third elements of a valid consent, what is required is consent to the broad nature of the procedure.[29] The consent may be actual or implied.[30] Routine minor treatments are usually the subject of implied consent.[31] The extended arm to facilitate the taking of blood pressure implies consent. At the commencement of service provision and for more invasive procedures, express consent, whether verbal or written, is necessary.[32] Verbal consents should be documented in your progress notes.

A touching without consent may be justified where it is reasonably believed that it is necessary to act to avert an imminent danger to a person or property and the force used is not excessive in the circumstances.[33] For example, one may be justified in restraining a client at a day care centre when it is apparent that he or she is about to strike another person.

The law of negligence is also relevant to consent. While consent to the broad nature of the procedure will justify the touching of a client and avoid an action in trespass (provided the other elements of a valid consent are present), to avoid an action in negligence you must go beyond providing this minimal information. Informed consent requires that the client also be informed about the material risks of treatment prior to consenting.[34] A risk is considered to be material if a reasonable person in the client's position would be likely to consider it significant or if the practitioner is or should be aware that the particular client would be likely to consider it significant.[35] The amount of information will vary with each procedure, depending on whether it is a significant or a minor or routine matter, but generally you should provide information about what is to occur in assessment and intervention, the material risks and benefits of the procedure, alternative assessment or intervention options and the outcome of accepting or declining services. It is important that you answer all the client's questions as fully as possible.

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[28] Jones MA (1996): *Medical Negligence,* 2nd edn. London: Sweet and Maxwell, p. 284

[29] *Chatterton v Gerson* [1981] 1 QB 432, 443; *Rogers v Whitaker* (1992) 175 CLR 479 at 490.

[30] Butterworths, *Halsbury's Laws of Australia,* vol 26 (as at 1/8/1997) 415 Tort, '2 Torts Derived from Trespass' [415-360].

[31] Law Book Company, *Laws of Australia,* vol 20 (as at 1/11/ 1996) 20 Health and Guardianship '20.6 Consent' [17].

[32] Law Book Company, *Laws of Australia,* vol 20 (as at 1/11/ 1996) 20 Health and Guardianship '20.6 Consent' [17].

[33] Law Book Company, *Laws of Australia*, vol 33 (as at 31/12/97) Torts '33.8 Intentional Torts' [22].

[34] *Rogers v Whitaker* (1992) 175 CLR 479 at 490.

[35] *Rogers v Whitaker* (1992) 175 CLR 479 at 490.

To succeed in an action of negligence for failure to provide information about a material risk the plaintiff must prove all the elements of a negligence claim as set out in 'The law of negligence' (earlier in this chapter).

Duty of care and the rights of the older person

Depending on the context, the older person may have statutory rights (the second sort of legally enforceable rights) and/or moral rights (which if not turned into legal rights are not legally enforceable). In some respects we can think about the law of negligence as the 'right' of the older person to safety — to a safe environment free from reasonably foreseeable harm. It is the 'right to safety' that may conflict with the older person's other rights, such as the right to autonomy and to take risks. Inevitably, dilemmas you face will involve some conflict of these or other rights of the older person or the rights of others. A framework for balancing rights — a checklist which can be used to assist in working through duty of care and rights dilemmas — is a valuable aid.[36]

VIGNETTE

Mary is 84 years old. She has mild dementia and lives in her home in a country town with her son, Bill, who is away at work from 7 a.m. to 5 p.m. each day. Bill is devoted to his mother and says that he promised her that he would never place her in residential care. Your agency provides domestic assistance twice per week and personal care each day. Mary also attends a day care centre three days per week and receives meals on wheels. Mary manages quite well when alone but she sometimes forgets to turn off the gas stove. This has already led to a small fire in the kitchen, which was put out by a neighbour when Mary called for help.

To whom do you owe a duty of care? Is there a risk of foreseeable harm? What type of harm is foreseeable? What would the reasonable nurse, social worker etc. do in response to this foreseeable risk? What rights does Mary have? Are there any other rights at stake? Will you take these rights into account in your decision making? If so, how will you take such rights into account?

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[36] A useful checklist 'A framework for balancing rights' is included in *Rights in Practice: Working in a Hostel* or *Rights in Practice: Working in a Nursing Home,* available from Residential Care Rights, Suite 4B, 343 Little Collins Street, Melbourne 3000, phone (03) 9602 3066, fax (03) 9602 3102. Although the checklist was developed for the residential context it can be adapted for the community setting.

Law of contract

A contract is a legally enforceable agreement negotiated between two or more persons or parties under which the parties are obliged to do certain things. Such an agreement or contract may be oral or in writing. Service providers of Community Aged Care Packages are required to enter into a contract with care recipients prior to the provision of service. The *Aged Care Act 1997* (Cth) and the Aged Care Principles 1997 set out clauses that must be included in the contract between the care recipient and the service provider.[37]

For a contract to exist, four elements are necessary:

- an intention to create legal relations
- an offer by one party
- acceptance by the other
- consideration.[38]

Consideration is effectively what one party 'pays' in exchange for the other party becoming obliged to do what they offered to do. For example, you will be obliged to make good your offer to provide health care services if your offer is accepted and promised to be paid for by the client. Looked at another way, the client is obliged to pay you money because of your consideration in the form of the provision of your services. If a promise is not thus exchanged for consideration, it will not usually be legally enforceable. Each party also needs to have the necessary level of competence to understand the nature and consequences of entering a contract. This is an important consideration in aged care where many clients suffer from dementia and may lack the necessary competence.

A contract sets out the legal relationship between the parties and clarifies the boundaries of that relationship — what services are to be provided, how often, for how much and for how long. The contract is a key document (when in writing) to assist in clarifying rights and obligations, particularly when problems arise.

Where required by statute, contracts must be entered into and you will need to be aware of the terms of the agreements that you have or your organisation has with clients. There are usually terms, for example, that set

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[37] See s 61-1 of the *Aged Care Act 1997* (Cth) and s 23.95 of the *User Rights Principles* 1997 made by the Minister under the Act. The provisions do not specify that the contract be in writing but this is implied.

[38] Law Book Company, *Laws of Australia*, vol 7 (as at 31/3/93) Contract '7.1 Formation' [1].

out how the contract can be terminated by either party. If service provision is terminated contrary to the provisions of the contract a client may have a remedy for breach of contract, such as damages (compensation) for any harm or loss suffered.

The termination of services is often a complex and ambiguous area of practice in community settings. The needs of clients invariably change over time as the clients become increasingly frail or disabled. Sometimes a client's needs can absorb increasing levels of the service provider's resources. The needs of the client may be beyond the capacity of the community organisation but the client may refuse to move to residential care. Are you, the health professional, required to provide the necessary level of service to meet your duty of care? Pressure can also come from other organisations, such as a hospital eager to discharge a patient. Does your organisation have to resume the provision of services after an episode of acute care, even though the client's needs have increased significantly?

The primary goal of community care is to help people with ill health and disabilities to stay in the community. The focus is on providing supports and services to compensate for the losses of the client to enable him or her to function at an effective level. There may come a time, however, when the resources available cannot provide the level of compensation needed and it is at this point that services may need to be terminated. Hospitals owe a duty of care to patients to discharge them to a situation where their needs can be met. If you consent to the discharge of the ageing person to your care, you are accepting any risks involved and you need to put in place what is reasonably necessary to avoid foreseeable harm. If your agency does not have the resources to provide the necessary level of care, then you need to let the hospital know (in writing) that you are not able to accept responsibility for the discharge. However, you need to be mindful of any contractual and statutory obligations you have to your clients and the implications these have for the way you, in turn, discharge a client from your services. Being clear with clients about the limits of service provision from the outset is essential. A written contract with the client that establishes boundaries around the level of care that will be provided and a clear process for termination of the arrangement will help to clarify the organisation's responsibilities in difficult cases.

For Community Aged Care Packages, the agreement must be in place prior to service provision. For other services where a contract is not required, it is a good idea to have one in writing. Even with existing clients, you may consider putting oral agreements into writing.

One of the hallmarks of community care in recent times has been the focus on flexible and cooperative arrangements with other community organisations. Purchasing services from other community organisations (subcontracting) or sharing resources, such as funds and staff, to maximise the services that can be provided, benefits clients, but such arrangements can also become complex. It is important that community organisations have written contracts in place about such arrangements to ensure clarity about their respective obligations, in relation to one another, and to the clients they are serving.

VIGNETTE

Florence has mild to moderate dementia. Her social skills are intact so she presents very well but she lacks insight into the extent of her problems. She has been living at home with a variety of community supports. Florence has a fall, is hospitalised and later receives some slow-stream rehabilitation. You are concerned about Florence returning home and believe that there are a number of risks (the house has lots of hazards including boxes of possessions stored in hallways and there are significant questions about her level of competence) but there is pressure for her to be discharged from the hospital and Florence is adamant she will not go to residential care. Her family also believe that she deserves an opportunity to have a trial at home.

What statutory and common law obligations do you have? What additional steps need to be taken to clarify the situation? What options are available? Who should be involved in the decision making? What avenues of advice are available to you to assist you? What will you document about your decision making?

Confidentiality

It is unlawful to disclose information about a client without their consent. Where information is unlawfully disclosed, a client may have a common law action for breach of contract or negligence and possibly an equitable remedy for breach of confidence.[39] A breach of confidentiality is also professionally unethical behaviour and may be the subject of disciplinary

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[39] Skene L (1998): *Law and Medical Practice: Rights, Duties, Claims and Defence.* Sydney: Butterworths, p. 192.

action by a professional body.[40] There are also statutory obligations to maintain confidentiality. The *Aged Care Act 1997* (Cth) has provisions for the protection of client information given to service providers under the Act and there are penalties for those who breach this statutory obligation.[41] Provisions for confidentiality are also outlined in the Home and Community Care Statement of Rights and Responsibilities and in the objectives in the Guidelines for the Home and Community Care National Service Standards.

Maintaining confidentiality when working in a multidisciplinary health team is a challenge as there is a certain amount of information that needs to be shared for effective service provision.[42] Clients should be informed of the limits to confidentiality and the practices for information sharing within your organisation. Health professionals should also ensure that only information that is needed to provide effective care is shared.[43]

There are certain situations where confidential information can be disclosed:

1. **If the client consents.** Where there is a need to disclose confidential information, the client's consent should always be sought. Where this is not forthcoming, there are two other circumstances where the information can be disclosed.

2. **Disclosure is compelled by law.** For example, some statutes require notifiable diseases to be reported. Also, if a court so orders, health professionals must produce records and answer questions in court even if this involves disclosing confidential information.[44]

3. **There is a duty to the public to disclose.** Information may be disclosed in the public interest where, for example, you suspect that a client's serious injuries have resulted from an assault. The suspected criminal activity should be reported to the police.[45]

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[40] See your professional code of ethics and organisational requirements in relation to confidentiality.

[41] Part 6.2 *Aged Care Act 1997* (Cth).

[42] Wallace M (1995): *Health Care and the Law: A Guide for Nurses,* 2nd edn. Sydney: Law Book Company, p. 187.

[43] For a discussion of 'absolute' and relative' confidentiality see Swain P (1995): Confidentiality. In: Swain P (ed.): *In the Shadow of the Law: the Legal Context of Social Work Practice.* Sydney: The Federation Press, p. 226.

[44] Skene L (1998): *Law and Medical Practice: Rights, Duties, Claims and Defence.* Sydney: Butterworths, p. 203–204.

[45] Wallace M (1995): *Health Care and the Law: A Guide for Nurses,* 2nd ed. Sydney: Law Book Company, p. 181; Office of the Public Advocate (1990): *No Innocent Bystanders: A Study of Abuse of Older People in Our Community.* Melbourne: Office of the Public Advocate, p. 137.

STATUTORY OBLIGATIONS

Health and aged care legislation

There are two Commonwealth statutes that affect the provision of community care in all States: the *Aged Care Act 1997* (Cth) and the *Home and Community Care Act 1985* (Cth).The Aged Care Principles 1997, made by the Minister under the *Aged Care Act 1997* (Cth), set out the rights of care recipients [46] and the standards of care — the Community Care Standards[47] — required in the provision of Community Aged Care Packages.[48] The Community Care Standards are very broad and do not give much detail about what is actually required.An accountability framework, incorporating quality assessment, service provision and financial accountability components, is being developed by the Department of Health and Aged Care and should implemented during 2001.[49]

The *Home and Community Care Act 1985* is the legislation relevant to Home and Community Care (HACC) services.This Act sets out the original agreement, the 'Principal Agreement' between the Commonwealth of Australia and the Australian states and territories. All states and territories have now entered an 'Amending Agreement'.[50] Each state and territory enters a funding and service agreement with each service provider within the state or territory. Where service providers enter into subcontracting arrangements, agreements, although not required, ensure that obligations arising under the *Home and Community Care Act 1985* and under funding and service agreements fall upon those who actually provide the services.

HACC includes a wide range of services such as home help, allied health services, home maintenance, transport, meals on wheels and day care services.[51] Two documents developed as part of a consumer strategy in 1989 are the HACC Statement of Rights and Responsibilities and the Guidelines for

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[46] See s 23.25 of the *User Rights Principles* 1997.

[47] See *Quality of Care Principles* 1997, Schedule 4.

[48] As at 30/6/99 there were 13,750 Community Aged Care Packages available: Personal communication, Department of Health and Aged Care.

[49] Personal communication, Department of Health and Aged Care, 19/7/00.

[50] Western Australia was the last to sign in December 2000. Included in the changes in the amending agreement is the possibility for private organisations to tender for HACC services. There are minor variations in agreements between the Commonwealth and each state and territory: Personal communication, Department of Health and Aged Care 18/1/00 and 22/12/00.

[51] As at 30/6/99 575,000 people had received assistance from HACC during the previous financial year: Personal communication, Department of Health and Aged Care.

the HACC National Service Standards.[52] The former sets out the rights and responsibilities of both consumers and service providers and the standards set out seven objectives, covering areas such as access to services, confidentiality, complaints and disputes. The standards are designed to assist with quality control, monitoring and evaluation of services[53] and should be used by health professionals to achieve these goals. During 2000, a Standards Instrument was developed by the Commonwealth and the states and territories for the monitoring of standards, and implementation is now occurring in each state and territory.[54]

Private home care services fall into two groups: those providing HACC services and those providing services that are not government subsidised. Private agencies providing HACC services have the same statutory obligations as other HACC providers. Non-subsidised private home care services, used as an alternative or in addition to HACC and Community Aged Care Packages, are not subject to any specific aged care legislation or regulations. However, such services are still subject to common law obligations such as the law of negligence and contract law and relevant statutes such as fair trading and trade practices legislation.

SUBSTITUTE DECISION MAKING AND GUARDIANSHIP AND ADMINISTRATION LEGISLATION[55]

Working with older people involves assessing whether the client is capable of making decisions, and this can be a difficult task. Whether a person has

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[52] Policy and Guidelines manuals setting out requirements for service providers are available in each state and territory.

[53] Phillips R (1996): *Older Residents and the Law.* Melbourne: Residential Care Rights, Older Persons Action Centre, Office of the Public Advocate, 300.

[54] The HACC National Standards Instrument and Guidelines is available at www.health.gov.au/acc/hacc/index.htm For information about training and implementation in your state or territory contact the state or territory department with responsibility for HACC.

[55] It is not possible to cover the detail relating to each state and territory in this chapter. For information about powers of attorney and guardianship and administration legislation contact: Victoria — Office of the Public Advocate, 5th Floor, 436 Lonsdale Street, Melbourne, phone (03) 9603 9500, Guardianship List, Victorian Civil and Administrative Tribunal, 55 King Street, Melbourne, phone (03) 9628 9700; New South Wales — Office of the Public Guardian, 133 Castlereagh Street, Piccadilly Tower Sydney, phone (02) 9265 1443, website www.gt.nsw.gov.au ; Guardianship Board, 2A Rowntree Street, Balmain, phone (02) 9555 8500, toll free 1800 463 928; Australian Capital Territory — Guardianship and Management of Property Tribunal, ACT Magistrates Court Building, Knowles Place, Canberra City, phone (02) 6217 4280, Office of the Community

decision-making capacity is ultimately a legal question[56] and one that can be decided only by a court and/or by guardianship and administration boards or tribunals in each state and territory. In practice, it is those providing community care who are often required to assess if the client has the capacity to consent to treatment and service provision. Health professionals like yourself make such decisions on a daily basis.[57] Where the ageing person's cognitive capacity is unclear it is appropriate to have a geriatrician or a neuropsychologist make a formal assessment. In some cases a functional assessment is also needed to get a picture of overall competence for particular decision-making capacity. For example, in assessing whether a client has the capacity to use an electric wheelchair outside the home, it may be necessary to have an occupational therapist assess the client's ability to manoeuvre the chair safely in addition to assessing the cognitive capacity of the client to weigh up the risks and consequences of such an activity.

Because of the progressive nature of dementia, a person does not become globally incompetent overnight but moves along a continuum from global competence to global incompetence in the terminal states of the disease. Each person will be affected by the disease in a unique way. He or she may be competent to make some decisions but not others[58] or may be competent to make decisions on some days but not on others. There is no fixed test as a prerequisite to all decisions,[59] but generally a person needs

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Advocate, Level 3, GIO House, City Walk, Canberra, phone (02) 62070707, website www.oca.act.gov.au ; Northern Territory — Office of Adult Guardianship, 4th Floor, Health House, 87 Mitchell Street, Darwin, phone (08) 89992896, Office of the Public Guardian, 1st Floor, Casuarina Plaza, 258 Trower Road, Casuarina, phone (08) 8922 7116 and Flynn Drive, Alice Springs, phone (08) 8941 6739; Queensland — Office of the Adult Guardian, Level 14, 15 Adelaide Street, Brisbane, phone (07) 3239 6296, toll free 1300 653 187, web site www.justice.qld.gov.au ; South Australia — Office of the Public Advocate, 8th Floor, ABC Building, 85 North East Road, Collingwood, phone (08) 8269 7575, toll free 1800 066969, website www.opa.sa.gov.au ; Tasmania — Guardianship Board, 99 Bathurst Street, Hobart, phone (03) 6233 3085, website www.justice.tas.gov.au Office of the Public Guardian, 15 Murray Street, Hobart, phone (03) 62 337 608; Western Australia — Office of the Public Advocate, Level 1, Hyatt Centre, Terrace Road, East Perth, phone (08) 9278 7300, toll free 1800 807 437, Guardianship and Administration Board, Level 1 Hyatt Centre, Terrace Road, East Perth, phone (08) 9278 7350, toll free 1800 191 009, web site www.justice.wa.gov.au

[56] British Medical Association (1997): *Assessment of Mental Capacity: Guidance for Doctors and Lawyers.* London: The Law Society, p. 11.

[57] British Medical Association (1997): *Assessment of Mental Capacity: Guidance for Doctors and Lawyers.* London: The Law Society, p. 11.

[58] Law Book Company, *Laws of Australia,* vol 20 (as at November 1996) 20 Health and Guardianship '20.6 Consent' [6].

[59] *Gibbons v Wright* (1954) 91 CLR 423 at 437.

to be able to understand the general nature and consequences of his or her decision.[60]

When the ageing person is no longer capable of making decisions about his or her life there is a need for someone else to make those decisions on the person's behalf.[61] It is first necessary to establish whether the client has executed one or more enduring[62] powers of attorney while still competent. Enduring powers of attorney giving the attorney the power to make financial decisions are available in every Australian state and territory.[63] At December 2000 enduring powers of attorney or advance directives giving the substitute decision maker the power to refuse medical treatment were available in South Australia, Victoria, Australian Capital Territory, Tasmania, Queensland and Northern Territory, and enduring powers of attorney giving the attorney power to make lifestyle decisions and health care decisions were available in Victoria, South Australia, New South Wales, Tasmania, Queensland and Australian Capital Territory. The number of enduring powers of attorney needed to cover the different types of decisions varies across the states and territories. For example, in Victoria an attorney holding an enduring power of attorney (financial) could make financial decisions, while one holding an enduring power of attorney (medical treatment) could consent to or refuse medical treatment, and an enduring guardian could make health care and lifestyle decisions.

Many of your clients will still be competent and if they have not yet executed enduring powers of attorney it can be a good idea to do so. Executing an enduring power of attorney gives the ageing person the opportunity to choose someone he or she trusts to act in their best interests to make decisions for them. This can be done through a solicitor or by using a power of attorney kit.

An attorney appointed under a power of attorney has duties such as acting in the best interests of the person and where these duties are

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[60] *Gibbons v Wright* (1954) 91 CLR 423 at 437.

[61] Although it is now a little out of date, a comprehensive reference covering all aspects of substitute decision making for all Australian states and territories is Creyke R (1995): *Who Can Decide? Legal Decision-Making For Others.* Canberra: Department of Human Services and Health.

[62] The nature of an enduring power of attorney is that it endures beyond the incapacity of the donor.

[63] *Powers of Attorney Act* 1956 (ACT); *Conveyancing Act* 1919 (NSW); *Powers of Attorney Act* 1980 (NT); *Property Law Act* 1974 (Qld); *Powers of Attorney and Agency Act* 1984 (SA); *Powers of Attorney Act* 1934 (Tas); *Instruments Act* 1958 (Vic); *Guardianship and Administration Act* 1990 (WA).

breached there are penalties, such as revocation of the power of attorney, that can apply.[64]

At December 2000 New South Wales, South Australia, Queensland, South Australia, Victoria and Tasmania have legislation that provides for a hierarchy of persons, including primary carers and family members who have not necessarily been legally appointed under an enduring power of attorney or guardianship legislation to make certain medical and dental decisions.[65] These provisions are referred to as 'person responsible' or 'statutory health attorney' laws. When such provisions are available there is usually no need for an application to be made for a guardian to be appointed to make medical decisions for particular types of medical and dental treatment. The types of medical and dental decisions that are covered varies across the Australian states. In Victoria, for example, medical treatment includes 'any medical or surgical procedure, operation or examination and any prophylactic, palliative or rehabilitative care, normally carried out by, or under the supervision of a registered practitioner'.[66]

Where there is no legally appointed decision maker already in place and for decisions not covered by person responsible or statutory health attorney laws, informal methods of decision making are mostly used. This involves health professionals working with next of kin, usually the spouse or an adult child who has the role of primary carer. In many cases decisions are made in this way without complications.

Where there is family conflict, consider convening a conference involving all family members as this may achieve consensus about the health care and service provision for the ageing person and resolve any difficulties. If this is unsuccessful or there is some controversy, it may be necessary to make an application for the appointment of a guardian.[67]

Where the management of finances is concerned, not all financial dealings require a legally appointed decision maker. For example, a joint bank account holder can usually manage banking without being appointed an

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[64] Creyke R (1995): *Who Can Decide? Legal Decision-Making For Others.* Canberra: Department of Human Services and Health, pp. 116–122.

[65] For a discussion of such laws and for a discussion of health care decision making generally see Creyke R (1995): *Who Can Decide? Legal Decision-Making For Others.* Canberra: Department of Human Services and Health, chapter 8.

[66] Section 3 *Guardianship and Administration Act* 1986 (Vic).

[67] If you are unsure about what is appropriate in a given situation, seek advice. For a list of relevant organisations see footnote 55 above.

administrator or manager. However, transactions such as the sale of property will need a legally appointed administrator or manager.[68]

All Australian states and territories have legislation providing for the appointment of guardians and administrators or managers.[69] The purpose of the legislation is to provide for the appointment of substitute decision makers when someone is no longer competent to make decisions for themselves and a legally appointed decision maker is needed. The emphasis of the guardianship legislation around Australia is on appointment being the least restrictive alternative available in the circumstances. For this reason, person responsible laws or informal decision making should be used wherever appropriate.

VIGNETTE

Bill is 79 and lives on his own. He has dementia and lacks insight into his health and personal needs. He receives services from your organisation and daily support and assistance from his daughter who works with staff and makes all significant decisions for Bill.

Bill has recently been diagnosed with a tumour. Doctors consider that it is in his best interests that he have surgery and that his prognosis is reasonable. The daughter has stated that she will not consent to any surgery as she knows that her father would not want to go through this treatment. Bill's son says that he would like to see his father have the treatment but that, as he lives in the country, he does not want to interfere with his sister's care of Bill. The daughter holds an enduring power of attorney (financial).

What is the status of the daughter's decision? Is the daughter's decision binding on the doctor? Are person responsible laws or statutory health attorney laws relevant? What action could/should the doctor take? Is an application under guardianship legislation necessary?

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[68] See Creyke R (1995): *Who Can Decide? Legal Decision-Making For Others.* Canberra: Department of Human Services and Health, chapters 4 and 7, for a discussion of informal financial decision making and the appointment of administrators and managers.

[69] *Guardianship and Management of Property Act 1991* (ACT); *Guardianship Act 1987* (NSW); *Adult Guardianship Act 1988* (NT); *Guardianship and Administration Act 1993* (SA); *Guardianship and Administration Board Act 1986* (Vic); *Guardianship and Administration Act 1990* (WA); *Guardianship and Administration Act 1995* (Tas); *Guardianship and Administration Act 2000* (Qld).

ELDER ABUSE[70]

There is no statute in Australia requiring mandatory reporting of elder abuse. However, health professionals need to be aware of other relevant laws that may be applicable to dealing with abuse experienced by ageing people, such as criminal law and laws relating to powers of attorney and guardianship and administration.

Elder abuse can take many forms — physical, mental, emotional and financial as well as neglect. In this respect, elder abuse is similar to abuse perpetrated against other members of the community. Where elder abuse differs is that it is often an adult child that is the perpetrator. Sometimes, moreover, that abusive adult child is actually dependent on the older person.[71] Of course, abuse may also be perpetrated by staff and strangers. Professional malpractice is also a possibility.[72]

The causes of abuse are complex, but isolation, physical and cognitive dependence, the psychopathology of the abuser (including mental illness, personality and substance abuse problems), physical illness, carer stress, family violence and societal factors such as ageism, all contribute to older people being more vulnerable to abuse. Physical abuse has been particularly associated with carer burnout and poor mental health, while psychological abuse is more commonly associated with a history of poor relationships.

Where family members are involved, emotional ties, feelings of obligations and complex, lifelong interrelationships can limit the choices that an ageing person can make to deal with any abuse. It is the experience of the Aged Rights Advocacy Service Abuse Prevention Program in Adelaide that the ageing person will want strategies designed to overcome the abuse to have consideration for the impact on the abuser. The ageing person and the abuser may both need a range of community supports, such as counselling, drug and alcohol and care services.

Once abuse is identified, it is essential that the response to the abuse is well thought out to minimise the creation of new problems. You should maintain contact with the ageing person to build trust, provide support, clarify the

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[70] The author gratefully acknowledges the contribution of the staff at the Aged Rights Advocacy Service Abuse Prevention Program in Adelaide to this section on Elder Abuse.

[71] A study by the Aged Rights Advocacy Service Abuse Prevention Program, Adelaide, found that 50 per cent of abusers were adult children. Personal communication 4/2/00.

[72] See Brophy E, McDermott J, Ozanne E (1995): Decision Making in Socio-Legal Practice with the Elderly. In: Swain P (ed.): *In the Shadow of the Law — The Legal Context of Social Work Practice.* Sydney: The Federation Press, p. 159.

facts about what is actually happening, explain the options for action and any possible consequences (such as disruption or damage to relationships) and gain his or her consent before implementing the plan.

Elder abuse can remain hidden because of a lack of awareness amongst professionals, as well as the general community, and because of a reluctance or inability of the ageing person to report the abuse. Ageing people may, for example, fear institutionalisation as an outcome of the investigation of the abuse. The signs and symptoms of abuse can also be confused with age-related health problems such as dementia.

South Australia and Queensland have specifically funded elder abuse services[73] and referrals can be made or advice sought from these services for those working in these states. Other states, such as Victoria, have elected to develop protocols on a regional basis and to educate practitioners to utilise existing community services to address elder abuse. For example, where a crime has been committed, such as assault, it may be appropriate that the matter be referred to the police. Police can also assist with steps that need to be taken to obtain restraining or intervention orders. Where a power of attorney is being misused there are remedies, such as in Victoria, where an application can be made to the Guardianship List within the Victorian Civil and Administrative Tribunal to have the power of attorney revoked and a guardian and/or administrator appointed.[74]

There are a number of valuable resources available to assist in the identification of abuse and the development of organisational policies, procedures and practices.[75]

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[73] Aged Rights Advocacy Service Abuse Prevention Program, 45 Flinders Street, Adelaide, SA 5000, phone (08) 8232 5377; Elder Abuse Prevention Unit, Brisbane Lifeline, PO Box 108 Fortitude Valley, Q. 4006, phone 1300 651 192. The Elder Abuse Prevention Unit is the national contact of the Australian Network of Elder Abuse. If you want to know where to access advice in your state or territory contact 1300 651 192. Aged Care Assessment Services are also a valuable resource. Where the older person has dementia, the Alzheimers Association is an important contact. For carers, the Carers Association is a key organisation for assistance and referral.

[74] See Creyke R (1995): *Who Can Decide? Legal Decision-Making For Others.* Canberra: Department of Human Services and Health, p. 118–122.

[75] See, for example, (Vic) Department of Health and Community Services (undated): *With Respect to Age: A Guide for Health Services and Community Agencies Dealing with Elder Abuse.* Melbourne: Department of Health and Community Services; Office of the Public Advocate (1990): *No Innocent Bystanders: A Study of Abuse of Older People In Our Community.* Melbourne: Office of the Public Advocate. In Victoria protocols were developed on a regional basis during 1999–2000. (Qld) Taskforce on the Prevention of Intimidation and Abuse of the Elderly (1992): *Dignity and Security — the right of older*

VIGNETTE

Fred is 75 years old and lives at home with his grandson. The grandson, Jason, has lived with Fred for a number of years and provides considerable personal care to Fred. Jason is unemployed and has a dependence on alcohol. He can become verbally abusive and threatening when he is under the influence of alcohol. Fred fell out with his son, Jason's father, some time ago but says that Jason has always been a favourite. Your agency provides care and domestic services to Fred and there is a problem with unpaid utility and chemist bills. You suspect that Jason is using Fred's pension and savings for his own needs.

How will you deal with this situation? Work out a plan of action, including a list of agencies you may involve or use for advice. If the grandson has been using Fred's funds, should the police be involved?

CONCLUSION

It is important that you be thoroughly familiar with your legal and ethical obligations. This knowledge should not form the basis of defensive practice but provide an important part of the foundation and framework for competent practice. It is also a tool to assist you in resolving difficult issues that arise in your work. If you lack particular knowledge, supervisors are always an important first call for assistance, and professional organisations

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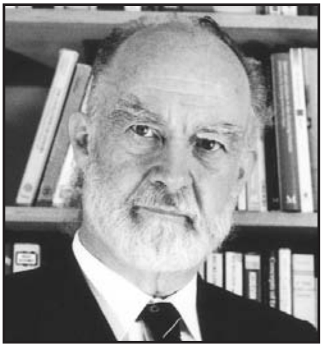
persons. Brisbane: Taskforce on the Prevention of Intimidation and Abuse of the Elderly. (WA) Council on the Ageing (1993): *Responding to Elder Abuse: A protocol for non-government agencies*. Perth: Council on the Ageing. (NSW) Department of Ageing and Disability (1996): *Dealing with Abuse of Clients and Their Carers: A Training Kit.* Sydney: Department of Ageing and Disability. (SA) Aged Rights Advocacy Service (1999): *Rights Focussed Advocacy and Abuse Prevention*. Adelaide: Aged Rights Advocacy Service. (General) Kurrle SE, Sadler PM, Lockwood K, Cameron ID (1997): Elder Abuse: prevalence intervention and outcomes in patients referred to four Aged Care Assessment Teams. *Medical Journal of Australia* 166:119–122; Kinnear P, Graycar A (1999): *Abuse of Older People: Crime or Family Dynamics?* Australian Institute of Criminology; McCallum J, Matiasz S, Graycar A (1990): *Abuse of the Elderly at Home: The Range of the Problem*. Canberra: National Centre of Epidemiology and Population Health; Colney C, Mortimer A (1995): Elder abuse and dementia: a pilot study, *International Journal of Social Psychiatry* 41(4):276–283; Paveza GJ, Cohen D, Eisdorfer C, Freels S et al. (1992): Severe family violence and Alzheimer's disease: prevalence and risk factors. *The Gerontologist* 32(4):493–497.

and unions can also provide advice in some circumstances. Where legal issues are involved it is important to get legal advice. While this may involve extra cost, a consultation with a lawyer who is familiar with the obligations of health professionals can be short and help to clarify the issues at stake and minimise any potential future difficulties.



ELERY HAMILTON-SMITH, AM

Professor and Honorary Research Fellow, Lincoln Gerontology Centre, La Trobe University, Melbourne, Australia

Elery Hamilton-Smith is a sociologist with more than 50 years' experience in social research and social planning, having worked at the community level, then as a social planning consultant across some 25 countries and, eventually, as an academic at Preston (later Phillip) Institute of Technology, now part of RMIT University in Melbourne.

Elery has wide-ranging interests in social policy and social development and has been a visiting professor at many universities in North America and Europe. His long-standing interest in ageing people led to his involvement in a research program on improving the lot of people with a dementing illness. That research culminated in the development of the ELTOS (Enhanced Living Through Optimal Stimulus) theory and the book *Rethinking Dementia — an Australian approach* (of which he was joint Editor) with its companion kit *Teaching About Dementia,* both published by Ausmed Publications and both of which have sold widely in Australia and are now beginning to penetrate overseas.

Elery is now exploring the application of the ELTOS guidelines to better home care for people with dementia.

CHAPTER FIVE

Cultural Issues: Their Impact on the Health and Care of the Ageing Person

Elery Hamilton-Smith

WHAT IS CULTURE?

Culture is one of the most complicated words in the English language — it has a number of very different meanings, many of them contested. For instance, think of the debates over whether a specific piece of music belongs to folk culture, pop culture or even high culture.

When we use the word in relation to the ageing population, all too often we get it wrong and think only of those who come from a non-English-speaking background (NESB). Many publications about cultural difference tell us how we might communicate better with, or provide more adequately for, the care of our NESB population.

But culture, in this kind of sociological usage, is the basic learning about ourselves and our society which every person carries with them throughout life. Even in this one sense, it has many facets. It is:

- the 'social heritage' of the community in which we live
- the capabilities and habits which we acquire as members of society
- maps of meaning through which our world is made intelligible
- a set of norms and expectations which support and maintain order and predictability in society
- a set of preferences which distinguish one culture from another
- a set of signs or symbols which serve to regulate social behaviour.

So, culture is expressed in everyday life through:

- shared ideas, values and beliefs
- shared moral, religious and spiritual values

- preferences for particular food, drink, clothing, and other everyday life activities
- tools and artefacts which support our everyday life
- the web of communication within which we constantly gather information
- patterns of personal and social behaviour which are accepted as 'normal' or 'proper'.

Culture can be contrasted with nature. We often assume that it is natural, or part of nature, to behave in specific ways. We may even argue that we are born to hold specific kinds of values and to behave in specific ways. A whole range of possibilities, tendencies, opportunities and constraints are almost certainly built into our genetic code and hence are part of our birthright. But in fact our specific values and behaviours are learned, commencing virtually from the day we are born. Despite the current debate about how far gender differences are innate, there is indisputable evidence that these and many other personal differences are in fact learned and hence cultural in nature.

CULTURE, COMMUNITY AND SELF

Culture is one of the major determinants of our personal sense of self. We know who we are in terms of the ways in which our own experience of being acts as a mirror. It reflects back to us the value and belief system within which we live and function as people. At the same time, it develops and continually reinforces our sense of belonging within a community with other people.

But our society and our community are not static. They are constantly subject to change and so place a demand upon us to change as individuals. As we grow and change in the course of our own development and our new learning, we become torn between, on the one hand, clinging to our past and what is familiar and, on the other hand, embracing new opportunities or challenges that face us.

- If we move from growing up in a country town to living in a metropolitan suburb, we face a major cultural shift. Some people enthusiastically enjoy the new and wider opportunities, while others strive to maintain the shared community of their past.

- In the world at present, many people are torn between the cooperative social values and visions that developed during the 1960s and 1970s, and the highly competitive individualistic culture of globalisation in which we are now immersed.

- The concept of a progressive work career (crowned by a gold watch for years of service) around which many built their life and sense of self is no longer realistic — most people have to deal with a succession of fragmented, uncertain and unsatisfying jobs.

Many ageing people are, of course, disengaged from this struggle. A large number own their home, have an income which is adequate to their needs and live a generally good life (though reflecting upon their children's lives with some confusion). But all too many find themselves regretting the way in which their working life ended and struggling to cope with less income than they anticipated. Many feel out of touch with younger people, including their own children, and often blame the younger generation for being unemployed, not getting into the right kind of job, not coping with drugs, and the like; all issues of which the ageing person has little experience or understanding.

Not everyone changes at the same rate, of course. We commonly see, for instance, a family who originated from a small rural village in Southern Europe, who came to Australia 40 years ago; today, one partner may be well assimilated to the Australian language, lifestyle and behaviour while the other still has a very limited command of the English language and still lives mainly within the traditions of the past, socialising largely with others of the same character. The children may well reject the lifestyle of either parent, possibly because they live in the past or perhaps because they have not held true to their own traditions.

So, although culture is a centrally important element in shaping all of us, and in determining the kind of person we become, it is both dynamic and diversified in its effects. One of the worst mistakes in understanding culture is to say, 'Of course, all Australians are . . . ', or 'All Greeks are . . . ', or any other statement which stereotypes people from a specific cultural background. We certainly can make some generalisations, and these are often valuable in helping us to understand patterns of behaviour, but we must always remember that they are not true of all people, and that any one person may well change from day to day in the extent to which they fit with any generalisations.

BROAD PRINCIPLES IN INTERCULTURAL UNDERSTANDING

Given that we all have our own cultural background, many of the principles which must apply to intercultural situations are exactly the same as those which apply in caring for people from our own culture. We must remember, however, that we should never make assumptions about the uniformity of any culture, including our own Anglo-Celtic traditions — people who have lived all their life in a remote rural community may be just as much culturally removed from many city-dwellers as people from another country. So, to some broad principles.

- Recognise and respect every person as an individual who is different from other individuals. In fact, the longer we live, the more we accumulate individuality and difference.

- This means there should be no recipes about names. I recall meeting and talking with one gentle old lady whose long-time professional carers had, with the best of intentions and no doubt as instructed by their agency, commenced calling her Mrs Brown. She started crying as she explained to me that the staff no longer called her 'Betty' — she felt she had done something wrong! Then of course, the Australian terms of 'Mr' and 'Mrs' are simply offensive to those who prefer to be called 'Inche' or 'Sri' or some other culturally appropriate form of address, or to those who simply use their given name without any other form of address. Find out what is most appropriate for each individual.

- Understand and accept differences in people without making judgements. For instance, individuals have different levels of tolerance to pain, and low tolerance may be more likely in some cultures than in others. Do not make judgements about or blame people who make a lot of noise when in pain, or who become demanding of attention. This is just an expression of themselves.

- Learn how to indicate respect for each individual. It may be in terms of the name by which we call them, but it may also demand specific patterns in the general use of language, body language, patterns of touching or not touching, patterns of moving about their house or other personal space and the like.

- Food is important to all of us but it is more than just nourishment; it also provides opportunities for socialising and opportunities for celebration of special days, festivals or events, whether these are personal (e.g. birthdays or namedays) or cultural (e.g. Christmas, Easter, Passover, Nowruz and a multitude of others). People should always be offered choices in food, and as far as possible, their preferences should be observed. The choice should be not just a matter of menu, but extend to the situation within which people eat, for example, issues of where and with whom they sit. Many older people suffer a degree of malnutrition, and hence weight loss and decline in health, simply because they do not enjoy the food which is provided and their mode of eating is often disregarded. This is not a matter of people being fussy, it is a matter of carers being insensitive and lacking in respect or love.

- Religion and/or a personal sense of spirituality may well be a central element of a person's sense of self. A colleague encountered a women who was in intense pain, but fought against the attempts of nursing staff to relieve that pain because her Taoist faith led her to believe that the pain had been sent by God, and that, at the end, God would judge her in terms of her response to the challenge of pain. While this poses an obvious professional dilemma, it certainly cannot be resolved without understanding of and due respect for the religious belief of the person concerned.

- Each culture has its own norms and standards about gendered social contact and relationships. Thus many people find physical examination or simple routines of daily care by a person of the opposite gender to be totally unacceptable, while others may find it acceptable, or even desirable. Sensitive and responsible care must again be based upon respecting the values and preferences of each person.

CULTURE AND THE MEANING OF AGEING

The very meaning of ageing, and the ways in which both the ageing person and their family respond to it, is largely shaped by culture. Anglo-Celtic Australians generally see ageing in somewhat negative terms, as a time of failing capacity, health problems, or even redundancy. Alternatively, older people may be patronised as somebody to whom one should be nice. But many traditional Aboriginal societies saw the ageing people as tribal elders who were to be respected for their wisdom and judgement and who were the source of traditional knowledge and understanding. Most people see death as a mysterious or even frightening phenomenon, and may wish or fantasise that it might be postponed for as long as possible or even eliminated. Others see it as inevitable, acceptable, and often as the transition to an ultimate peace.

We must accept and come to grips with understanding a wide range of individual positions about ageing and death, even though these are shaped by the general tendencies in any one culture. Similarly, the place of family relationships will vary from one culture to another, and of course are especially important in thinking about care practices. Many cultures believe it is the responsibility of the family to provide whatever care the ageing person needs, and so may resist both acceptance of community support services and placement in residential care, even when they cannot themselves provide what health workers might see as appropriate care.

If placement in residential care occurs without support to help the family deal with the sense of trauma and guilt which they feel, the results may be disastrous. The family may feel so much guilt that they cannot visit, or they may believe that removal from the family circle is the same as the physical event of death. The result, of course, is to exacerbate the isolation of the ageing person and this has massive impacts upon both their happiness and health. So, community support workers, who often see this transition occurring, should ensure that families are given the opportunity to talk about their feelings, and emotional support to help them cope with the trauma of placement in residential care.

There is a great deal of difference in community attitudes to the care of the aged. Some communities show a great willingness to share responsibility and care for other people in need while others may be much more inclined to delegate responsibility or to avoid it under the rubric of 'minding our own business'. In some cultures, nursing or other personal care jobs are not highly regarded and this creates additional problems in providing quality care for ageing people.

A significant proportion of ageing people move into dementia. Cultural factors may well assume an even greater importance for these people. Although dementia is dealt with in more detail elsewhere in this volume (see chapter 15, 'Responding to dementia'), we should note here that the very form of dementia is shaped in part by the person's cultural background. People with dementia become confused and often relive some of the most important aspects of their past lives, often exhibiting aspects of their being which have not been previously recognised or known by their children and family. At the present time, and for at least some time into the future, many Australians will have grown up in a very different culture from that in which they are living now. When they enter dementia, they often relive their former lifestyle, speak their former language, prefer their former food, and the like. In the case of those from a NESB culture, this may create special problems in communication. Many will forget any second language even though they may have used it for years.

There is no question that these people are best provided for by residential or community support services that are based in their own culture. In residential care, this leads to the so-called ethnospecific establishments (which can only truly claim that status if they use the language and daily life traditions of the original culture from which the residents came). In community support services, it may mean arranging to subcontract services for a specific household to the appropriate local community association or even to a nearby family from the same culture.

THE ABORIGINAL CULTURE

There are special responsibilities and special issues attached to the care of Aboriginal people and so they will be dealt with here in more detail than most others. First, there is probably greater diversity amongst Aboriginal people than amongst all other Australians. Before the arrival of white man, the Aboriginal people comprised more than 600 different linguistic and tribal groupings. Since 1788, they have further differentiated into a spectrum from those who have embraced and virtually become part of the mainstream Anglo-Celtic culture to those who are living on their own lands and according to their own ancient traditions. Meanwhile, new cultural groupings have emerged, and most Aboriginal people prefer to be recognised according to the names of their current cultural identity, e.g. Koori, Murri, Nyungar, Anangu. Most have been subject to the adverse impacts of colonialism, and so continue to suffer poor living conditions, bad health, poor levels of education, problems of alcohol abuse and other problems.

Within many Aboriginal cultural groups, there are special patterns of avoidance. Social contact, even at a superficial level, may be prohibited between specific people. This avoidance, sometimes to the point of not making any eye contact, is seen as respectful and appropriate behaviour and must not be interpreted as rudeness. Similar rules also govern contact with specific persons or groups of people of the opposite gender.These behavioural norms mean that even arranging for Aboriginal people to staff aged services may infringe these rules.As with other NESB cultures, the best care will be that provided within the context of the relevant Aboriginal culture. With the relatively recent renaissance of pride in Aboriginality, this is coming to be demanded and developed by the Aboriginal people themselves. Traditional medicine survives in some cultural groups, or is being revived in others, and can very appropriately coexist with Western medical understandings.

Special issues arise during the dying and grieving process. Special ceremonies are often demanded to release the spirit of the dead person from the room or space in which they have died. Funeral ceremonies are of special importance, both in terms similar to our own concept of respect for the dead and in reaffirming identity with one’s land and one’s people. Special taboos or constraints may apply to relatives, including abstaining from certain foods, not seeing images of the dead person or even destroying their personal possessions.

But all these are generalisations that have varying degrees of validity from one cultural group to another and from one family to another. We must always ascertain, as far as possible, the values and norms of the family for whom we are providing services.

DEVELOPING UNDERSTANDING

Obviously space does not permit any detail being given about specific cultural groups, but there are a range of ways in which you can develop your own understanding of any one cultural group with whom you must work.

- At the broad level, most state agencies dealing with aged care offer resource kits that include various details of specific cultures, for example, *Nursing Home and Hostel Care: A Multicultural Resource Kit* produced by the Multicultural Access Unit and Quality Management Section of the Health Department of Western Australia in 1995. These kits are valuable in providing a general orientation, and in alerting you to issues that should be clarified with any person with whom you may be working.

- In thinking about any one cultural identity, you will generally find there is a local community association, and that they are very willing to help you become informed about and understand their culture. In many cases, you may well find books or videos that will further deepen your understanding.

- But essentially, talk with the person you are caring for about their values and preferences. This is the most vital source of all. Talk also with their family and friends who may provide other insights that the ageing person assumes to be known but which you do not know.

Theresa Cluning

Christine Bigby

THERESA CLUNING

Registered Nurse, Registered Midwife, Diploma of Applied Science (Community Health and Maternal and Child Health), Bachelor of Applied Science (Advanced Nursing), Master of Educational Studies, Fellow of the College of Nursing Australia

Theresa has worked in many roles in various areas of health care including acute hospitals, residential care, community health, academia and community case management.

She has worked with many people who have cared for others and is always humbled by the experience. Having also been a carer herself, she is aware not only of the sadness and the pleasure that caring for another person can bring, but also of the physically, emotionally and psychologically demanding nature of the carer's role.

CHRISTINE BIGBY

Bachelor of Arts with Honours, Master of Social Work, Doctor of Philosophy

Senior Lecturer in the Department of Social Work and Social Policy, La Trobe University, Bundoora Campus, Melbourne

Dr Christine Bigby works in the Department of Social Work and Social Policy at La Trobe University. She has extensive experience as a social work practitioner in both direct service and policy development. Her primary research and practice interest for the last 10 years has been older carers and ageing people with intellectual disability. Her doctoral research examined the informal and formal sources of support for middle-aged and older people with intellectual disability and the nature of their transition from parental care in mid-life.

CHAPTER SIX

Ageing People Giving and Receiving Care

Theresa Cluning

INTRODUCTION

Ageing people both give and receive care and support within their homes and the community. The first section of this chapter takes a global overview of the various challenges people face when they take on the primary caring role of ageing people. It covers such issues as the effect caring has on the emotional, psychological, and physical wellbeing of carers. The second part of the chapter looks specifically at ageing people who are carers of middle-aged or younger people with life-long disabilities, primarily those people with an intellectual disability. Advice is shared with community-based health professionals about how to assist carers to access support for day-to-day caring responsibilities. The chapter also discusses the challenges facing all carers when they are thinking about relinquishing full-time care, and the difficulties this transition may present.

When reading this chapter reference should be made to other chapters within this book.

- Elder abuse and administration and guardianship issues are covered in chapter 4, 'Legal and ethical issues and their impact on the care of the ageing person in the community'.

- Issues experienced specifically by carers of people with dementia are covered in chapter 15 'Responding to dementia'.

- Suggestions about supporting both the ageing person and the carer are highlighted in chapter 3 'Holistic care: why and how'.

PART ONE:
CARERS OF AGEING PEOPLE LIVING AT HOME

By the nature of the work, we, as community-based health professionals working with ageing people with complex needs, have regular contact with people who provide support to the ageing person. For the purposes of this chapter the word 'carer' means a nonprofessional person supporting the ageing person in the community without any formal arrangement.

The dilemma we, as health professionals, face when we use the word 'carer' is captured by Schultz and Schultz (1998:1):

> A carer? Who? Me? Does this mean I am no longer a wife, mother, husband, father, partner, son, daughter, or close companion, because of the extraordinary level of care I am now providing? Or have I become something else, now that I wear more than one hat? What is a carer anyway, and is that what I want to be called?

Our dilemma is how to use the word 'carer' without negating the relationship which pre-existed (and currently exists) between the caring person and the ageing person whilst at the same time maintaining an awareness that the quality and intensity of the relationship is altered by the change in roles. Experience tells us that many relationships are harmonious and strengthened by the caring role and others are stretched to breaking point. Although people usually become carers because they love the ageing person and want to care, the responsibility is often carried alone and for long periods of time. Therefore, the caring role impacts on the physical, emotional, psychological, spiritual and financial wellbeing of the primary carer.

WHO ARE THE CARERS OF PEOPLE AGEING IN THE COMMUNITY?

Carers may live with the ageing person (co-resident) or live separately (nonresident). They may provide all or most of the hands-on care or they may manage the care giving; often it is a combination of both. Whilst carers come from every group in society, Australian research by Pierce and Nankervis (1998) shows that:

> overall 3 in 4 primary carers are women (78 per cent) although the proportion of males is slightly greater among spouse carers.

Most of the care recipients are over 74 years of age and the carer is usually a close relative. Half of all spouse carers are 65 years or over; 39 per cent of carers are adult children caring for a parent, and these carers are usually between 35 and 64 years of age. Whilst the majority of carers are within the work force age group, only 39 per cent are in paid employment (Pierce and Nankervis 1998:58), a clear indication that women carry most of the caring responsibility.

WHAT ARE THE NEEDS OF SOMEONE IN A CARING ROLE?

Although many carers have developed their own informal support system consisting of family members, friends and community groups, often either carers are reluctant to ask for help or they believe their supporters are already doing enough. Professionals may gain a clearer understanding about how we can help through looking at when and why carers reach crisis point. Research by Schofield et al. (1998) showed several clearly defined occasions when carers sought professional help. These occasions were directly related to events or changes associated with the care recipient's disease or impairment:

- at diagnosis
- upon admission to an institutional setting
- at discharge
- when there was deterioration in the person's condition or behaviour.

The reasons why carers sought help fell into five areas:

1. a need for information and formal supports, such as knowledge about and assistance with practical matters and service provision
2. issues surrounding their ability to choose to be a carer or not, the responsibility for caring, and changes to former roles
3. issues involving the carer's adjustment to the caring situation, i.e. coping with the ageing person's behaviour without damaging their own health and wellbeing
4. emotional issues such as grief and loss, guilt, anxiety and anger
5. concerns about relationships, including family-related issues, social relationships of the carer and care recipient and wider social and cultural issues

As community health professionals we should be developing our professional expertise, understanding and knowledge about these issues. We may then be able to work effectively with the carer by helping to clarify situations and provide support and by advising about strategies that will aid them in their caring role.

It is also apparent from our experience that many carers gain emotional and psychological support by being able just to talk to someone. We should encourage carers to reflect upon and talk about their lives and current experience. Often carers have not been asked 'How are *you*?' They need the opportunity to express how they are feeling emotionally, psychologically and physically to a supportive, nonjudgmental, caring health professional.

Need for information and formal supports

The Commonwealth, state and local governments of Australia have developed a range of support services for ageing people and their carers living in the community. However, the community care system can appear to be like a maze. Finding out how it links with acute care and the residential sector, or who can provide what and when, how often and at what cost, is a challenging task for anyone. There are often changes in government department names, personnel, procedures and processes. In recent times, additional providers have entered the aged care field. With the gradual phasing out of direct government service provision, private companies have joined the not-for-profit church and charitable organisations in the provision of direct service and support.

For a new carer or a carer who has previously shunned outside support, it can be a confusing and time-consuming experience just trying to find basic assistance. In addition, the need to seek information and outside help usually comes at a time when the carer's emotional and psychological reserves are depleted because of physical exhaustion, anxiety, grief, guilt or depression, or any combination of these.

We health professionals working in the community need to keep abreast of what support is available for carers. Our professional role is as adviser to and advocate for the carer, to search for them and/or to support their search through the maze. Unless we are well informed, neither the ageing person nor the carer will be well served. This means reading every new journal or bulletin, networking, and sharing information with individual colleagues and such agencies as:

- government departments
- district nursing organisations
- aged care assessment services
- community health centres
- other community support groups.

Carers can also receive information from local and regional carers networks. In Australia the Carer Resource Centres and Carer Respite Centres, which are funded under the National Respite for Carers Program, both have 1800 help line telephone numbers and Internet sites.

Practical assistance to carers may involve:

- arranging help with the activities of daily living — this can be purchased from various community-based agencies for personal care, home care, home maintenance, gardening, shopping and transport
- referral to allied health professionals, for example physiotherapists and

occupational therapists, who will advise about such issues as home modifications, home safety advice and safe manual-handling techniques
- accessing in-home and out-of-home care which can allow the carer regular planned respite
- advising about carer support agencies that may provide counselling and involvement with peer support groups
- accessing up-to-date information about various diseases or impairments from relevant organisations — this may assist the carer to increase their knowledge and understanding
- assisting carers to access support and services from such organisations as
    - ➢ aged care assessment services
    - ➢ community nursing services
    - ➢ continence services
    - ➢ personal alarm providers
    - ➢ case management and brokerage services
    - ➢ allied health professionals such as podiatrists and speech pathologists
    - ➢ funding bodies that may provide financial support for physical aids and appliances
- advising about available financial support such as the Carer Payment and the Carer Allowance.

The emotional and psychological aspect of caring

Carers often experience confusing emotional responses to the person they are caring for and the caring role. As Mace and Rabins suggest (1981:155):

> One might both love and dislike the same person, or want to keep a family member at home and put her in a nursing home, all at the same time. Having mixed feelings might not seem logical but it is common. Often people do not realise that they have mixed feelings.

Whilst these writers were talking about carers of people with a dementing illness, this description could easily apply to anyone in a caring role. In the community setting health professionals work frequently with carers who experience these thoughts and emotions. The carer may be able to resolve these by acknowledging them and by being encouraged to know theirs is not an abnormal response to caring. But they may also be reaching the point where they can longer continue to care in such an intensive manner. It is essential to reassess regularly:
- how the carer is managing
- whether they want to continue caring
- what thoughts they may have about gradually relinquishing full-time care.

The time may come when there is an increase in the ageing person's level of dependency without an increase in the level of support the carer is receiving. The carer may benefit from:

- extra in-home respite
- extra out-of-home respite
- extra support with the direct physical care of the ageing person
- more frequent assistance with activities of daily living — shopping, cooking, housework, and gardening.

It is our responsibility to anticipate carers' needs, to assist them to understand what it is they are experiencing and to reassure them that they are not alone.

Caring changes a carer's relationships not only with the care recipient but also with family and friends. As well as having less time available to maintain outside relationships, carers often experience chronic physical tiredness and increasing emotional and psychological stress. They can suffer:

- social isolation
- loneliness
- depression.

It is important for carers to be able to maintain their sense of self, to not immerse themselves completely in the role of carer. As professionals we need to be aware that our role is to support the carer to continue to lead a balanced lifestyle of their choice. This can be challenging for the carer, considering the stressors inherent in the caring role. Therefore, it is important that we encourage and support the carer to continue with and enjoy their outside interests and activities.

Sometimes carers' psychological stress may be reduced if they are able to remain in paid employment. Although after-work hours will usually be consumed by the various responsibilities of living plus the caring role, carers may be able to maintain their work friendships and other external relationships. If carers need or wish to be in paid employment, it is our responsibility to support them with flexible and creative service provision.

Financial issues

The financial cost of caring should not be underestimated. Anyone with a chronic illness, deteriorating condition or impairment will incur additional medical, hospital and home care expenses such as

- utilities for heating, cooling and washing
- transport

- special aids and equipment beyond those funded by government subsidy
- extra in-home respite and/or appropriate personal and home care services which are expensive but may need to be used because government-subsidised services are unable to meet specific demands or may not be available or at a time that suits the ageing person or the carer.

The carer may feel obliged to leave paid employment to give full-time care and thus often becomes dependent on a reduced fixed income or a social security pension.

ANTICIPATION AND PREVENTION ARE BETTER THAN MANAGEMENT

Experienced community health professionals have usually been involved with many people in caring circumstances similar to those outlined above. On the other hand it is usually a carer's first experience with the provision of intensive, ongoing care. It is our role to support the needs of both the ageing person and their carer through:

- education
- anticipation
- facilitation
- monitoring
- advocacy.

Whilst many carers continue to care unsupported by professionals for many years, others can sometimes reach a crisis point relatively quickly. This may be because of changes in the needs of the person they are caring for, or external stressors or an alteration in their own wellbeing. By definition a crisis is not planned. Therefore, as services to support carers are not designed around crisis situations, an ageing person may be admitted to care inappropriately to facilitate urgent respite for their carer. The carer may be so overwhelmed and exhausted as to not be able to care effectively again. This development can compound the grief, loss and guilt experienced by carers during the transition of the ageing person from care at home to care within a residential environment.

It is important to be aware that just as there are novice and expert community health professionals there are novice and expert carers. Assumptions should not be made about a carer's knowledge base or level of experience; each situation is unique and should be approached accordingly.

CLIENT AND CARER: INDIVIDUAL AND DUAL ASSESSMENT

It is essential to take a holistic approach to community care if we are going to be effective. Therefore, whilst the ageing person may be the designated client of a community agency we professionals consider the ageing person plus their carer as our client. This can present problems, as it is possible for the needs of the ageing person to usurp the needs of the carer, or vice versa. Therefore, the carer and client should be assessed and cared for both separately and as a unit.

TRANSITIONS AND DECISION MAKING

The caring role is a complex one and whilst some people gladly take on the responsibility, others do so reluctantly. Some carers find they adapt easily to being a carer but others find the challenges too demanding. Their particular life circumstance, family and work responsibilities, and life stage will affect anyone's ability to take on and maintain the (often escalating) level of care required. People who love and want to care often are not in a position to do so at all or they are not able to continue to be a carer indefinitely.

Carers need to be supported during all the transitional challenges caring presents and the subsequent decision making that must be confronted. The possible challenges include:

- the transition from non-carer to carer
- the changes to and dynamics within relationships
- the adaptation required because of the changing level or intensity of care
- the transition from being a full-time home-based carer to caring for someone who has entered permanent residential care — the hardest challenge of all.

As community-based health professionals it is our responsibility to assist both people on their journey. Although many carers have cared expertly for someone for a long time, their experience is usually confined to caring for one person. Often they have not had much exposure to other people in similar caring situations. We professionals can use our knowledge and understanding to share information and caring strategies, and provide advocacy and support in a gentle, nonjudgmental, well-informed manner.

PART TWO:
THE UNIQUE CHALLENGES OF SUPPORTING OLDER CARERS OF YOUNGER AND MIDDLE-AGED ADULTS WITH DISABILITIES

INTRODUCTION

Older carers of young and middle-aged adults with lifelong disabilities are a relatively new group of carers who have emerged in recent years as the life expectancy of people with lifelong disabilities has increased significantly. In Australia it is estimated that 7700 people with a disability live with a parent aged 65 years or more (Australian Institute of Health and Welfare, 1997). Although older carers are primarily parents, they may be grandparents, siblings or more distant relatives who care for adults with a lifelong physical, intellectual or psychiatric disability. The common age differential between older carers and their offspring is 30 years, thus offspring will range upwards from 25 years of age and they are likely to have been born between the 1930s and 1970s (Stehlick, 1997; Todd et al., 1993). The largest group, about whom most knowledge exists, are older parental carers of adults with intellectual disability.

Because of their age, and because of the nature and duration of the caring relationship, older carers face a unique set of challenges. Their situation raises dual issues for service providers — provision of ongoing support for carers to continue in their role for as long as they wish, and laying the foundations for a smooth transition from parental care for middle-aged adults with disabilities when their parents are no longer able to care. These are new issues which require a complex and multifaceted response from community-based service providers. This part of the chapter discusses how the challenges confronting older carers of younger and middle-aged adults with lifelong disabilities are different from those faced by other carers. A range of strategies to support this group to both continue caring and begin the process of letting go are suggested.

DIFFERENT CHALLENGES

Although Todd and his colleagues suggest that 'parenting an offspring with a disability can be considered an active career for up to five decades' (1993:137), caregiving relationships are dynamic and affected by age-related changes as well as historic and cohort effects. Thus, caring in later life for a middle-aged adult child with a disability is very different from the experience of being the parent of a young child. According to Smith et al. (1994) and Janicki (1996), older carers, as a group, are more likely than their younger counterparts to be sole carers, to live in smaller households and to have smaller informal support networks, but are less likely to be in touch with formal services. The offspring of older carers, though more able, are less likely to have a full-time occupation and more likely to have unoccupied days than those people with intellectual disability who are younger and live with a younger generation of carers. Older parents are less optimistic about the progress of their offspring than younger parents although the dependency levels of their offspring have an inverse relationship to carer age (Todd et al., 1993).

The family lifespan of older carers is likely to be 'off cycle', with a postponed launching stage and the rare occurrence of an 'empty nest'. Many express a strong desire to continue caring as long as they are able. This may be due to positive elements such as choice, satisfaction with caring, and commitment, or more negative reasons such as a lack of acceptable alternatives or growing interdependence between carer and care recipient. Only half to a third of ageing carers make any concrete plans for the future care of their offspring and even those who do plan do not wish to implement plans until absolutely necessary (Bigby, 1996). Accordingly, it is their own death or incapacity that often marks the cessation of caring, whereas for other carer groups the situation is reversed — the end of caring is often marked by the death or entry into a nursing home of the care recipient (Seltzer and Krauss, 1989).

For older carers, adaptation to age-related changes such as reduced physical capacity and mobility, which impact on their caring ability, occurs in the context of ongoing parental responsibilities (Seltzer and Krauss, 1994). Some carers may also confront age-related decrements of their offspring, especially if they suffer from early onset Alzheimer's disease, which is common among middle-aged adults with Down syndrome (Hawkins et al., 1993). These factors suggest that, as carers age, their internal and external caregiving resources are reduced, which may increase the stresses and burdens of care giving. According to Smith (1996) possible stresses of later-life caring are perceived as unending dependency, chronic sorrow, age-associated decrements, lack of formal services, social isolation and financial pressures.

However, the most common stress mentioned in relation to older carers is anxiety about the future care of their offspring. One manifestation of this is that, compared with other ageing parents, these carers are less accepting of the ageing process and death, and their fear of death increases with age (Smith and Tobin, 1993a). Of all age groups, carers of adults aged over 40 years are seen as the most vulnerable (McGrath and Grant, 1993). O'Malley suggests (1996:108) that as parents age it is 'harder and increasingly frustrating to provide care'.

Recognition that the rewards and stresses of care giving are quite separate dimensions is particularly salient for older carers. Despite the factors indicative of greater stress, ageing carers of adults with intellectual disability are consistently found to experience greater satisfaction with caring and less stress than their younger counterparts (Hayden and Heller, 1997; Seltzer and Krauss, 1989; Smith and Tobin, 1993a). Older female carers are also found to have a greater subjective wellbeing than other women of their own age. For example (Seltzer and Krauss, 1994:7),

> despite the long duration of their caretaking roles, many of the mothers seemed resilient, optimistic, and able to function well in multiple roles. Specifically the women were healthier than other non caregiving women their age, they had better morale than caregivers of elderly persons and reported no more burden than family caregivers of elderly residents and less stress than parents of young children with retardation.

WHAT THE LITERATURE SAYS

Older carers have received considerable attention from the media and advocacy groups focused primarily on who or what services will replace parental care (Star, 1995; Tippet, 1994). In addition, a growing body of research, has investigated their characteristics and needs (Heller et al., 1997; Seltzer et al., 1996; Walker and Walker, 1998). A much smaller body of research (Grant, 1986; Kahana et al., 1995; Morris, 1993; Walmsley, 1996) refers to:

- the possible costs of being a care recipient
- the importance of achieving a balance between the interests of carer and care recipients
- the potential tensions and conflicts between the respective needs of carers and care recipients.

Reciprocity and the relationship between the carer and care recipient are suggested as central to an understanding of the giving and receiving of support (Finch and Mason, 1993; Grant and Nolan, 1993). Nevertheless, in regard to ageing carers, the focus of investigation has been on the caregiver; perspectives of care recipients have not been extensively considered.

The foregoing review suggests that ageing carers do not express a high demand for services and may be less stressed than other carer groups. From this perspective, their needs may not appear as complex or urgent, implying that no particular attention from community service agencies is warranted. However, a unique dimension of their caregiving relationship is its vulnerability to breakdown as a result of the carer's own death or incapacity. The transfer of care and use of formal services is inevitable, although uncertainty surrounds the timing (Walker and Walker, 1998).

Thus, attention to these issues must be added to the more usual tasks of the community health professional which are:

- sustaining the caring relationship
- providing complementary support
- balancing the needs of the carer with those of the care recipient.

The distrust of and disconnection from formal services characteristic of the current cohort of ageing carers, and their disinclination to engage in concrete planning for the future, add to the complexity and challenges of addressing their needs (Prosser, 1997; Todd et al., 1993).

Both researchers and advocacy groups make a strong case for the utility of proactive, preventive intervention which will avoid future crises and reduce both financial and emotional costs (Grant, 1986; Harris, 1998; Magrill et al., 1997; Smith and Tobin, 1993a; Walker and Walker, 1998). For example (Janicki, 1996:110),

> . . . we strongly believe that when you assist an aging carer, everyone benefits. The help provided can avert crises and keep the family intact. It can also help adults with a lifelong disability plan their own future and make a planful transition from their family home, if they choose to do so. . . . Contact now with families will permit timely consideration of more independent and therefore less costly options for services in the future.

The literature indicates considerable agreement on the broad aims of service interventions with ageing carers (Heller and Factor, 1993; Janicki, 1996; Kelly and Kropf, 1995; Smith et al., 1994). These include:

- identification of 'hidden' carers and their transformation into clients
- avoidance of crises of unplanned transition by facilitating parental planning
- creation of linkages to formal services systems
- prediction of future needs
- preparation of adult children with intellectual disability for transition and greater independence
- support to maintain existing caregiving situations for as long as possible
- counselling parents to assist the resolution of conflicting demands and psychological issues and renegotiation of their caring role.

Ageing carers confront many tensions and conflicting demands, which require particular skills from community health professionals working with them. Personal conflicts include (Grant, 1993):

- carer's rights versus the rights of the care recipient
- maintenance of interdependence and reciprocity versus the rights of the care recipient to independence

- continued nurturance versus letting go
- known costs and benefits of informal care versus the unknown world of future services.

Ageing carers have not experienced many of the rituals associated with 'letting go' and renegotiating their parental relationship from that of adult–child to adult–adult (Kropf and Greene, 1993; Richardson and Ritchie, 1986). Parents face considerable guilt and anxiety in confronting decisions about the future (Smith and Tobin, 1993b). Working with older carers is much different from working with younger carers and community health professionals need to develop expertise in working with the older group (McCallion and Tobin, 1995). Continuity, longevity, and the development of acceptance and trust in our relationship are vital components (Kropf and Green, 1993). McCallion and Tobin (1995) point out that time is required to develop trust; it is slow work and there are no quick tangible outcomes. Kropf and Greene (1993) consider that, in contrast to younger parents, older carers have greater needs for nurturance and support as well as other more diverse needs. And Smith and Tobin say (1993b:72):

> . . . case managers are aware of the emphasis on empowerment and also how the system's focus on quick outcomes hinders the necessary pacing in approaching and then addressing planning for the future. It is, however essential to go slowly and gingerly. Whereas pacing is always important in counselling, it is especially important to this group who resist planning. It takes time and clinical acumen to develop the trust necessary to overcome resistance.

STRATEGIES FOR WORKING WITH OLDER CARERS

Specialist workers and dedicated caseloads are suggested as the ideal means of case management for this group (Lehman and Roberto, 1993; McCallion and Tobin, 1995). In support of this position, Smith and Tobin (1993a) suggest that few workers within the disability system have any knowledge of gerontology or the aged care network and their practice may be distorted by inaccurate stereotypes. A central component of service provision for older carers is collaboration between the aged care and disability networks (Janicki et al., 1998). Older carers, like some older people with lifelong disabilities, may fall between service systems as neither takes responsibility for them (Wood, 1993). Developing the knowledge and capacity of direct care workers, administrative staff and both service networks to respond to the needs of older carers is also crucial if their needs are to be met (Smith and Tobin, 1993a).

Case management with older carers must be oriented to both maintenance and change. Maintenance of the current caring situation involves reducing the demands of the older carers' psychosocial environment and partial replacement of roles previously undertaken by parents with formal or other informal supports. To achieve this, change is often required on the part of older carers in terms of their acceptance, trust and willingness to use external supports or services. Partially replacing previous parental roles with other supports may simultaneously increase or maintain the environmental demands for the adult with intellectual disability, thus effecting change in their lives and providing vital ingredients for preparation for the future.

Change may also involve confronting issues of planning and separation, working on their problem-solving capacity, and beginning to let go of their adult child with intellectual disability.

Core elements of the case management practice required with older carers are:

- a dual focus on the carer and the adult with intellectual disability
- multiple modes of intervention including direct casework, groupwork, resource development and systemic advocacy
- the use of the relationship between case managers and older carers to effect change
- sustained and long-term interventions with varying intensity and degrees of assertiveness
- extensive use of supervised, focused support workers as frontline change agents to demonstrate and rehearse possibilities
- working through carers' existing supportive networks
- outreach strategies to locate older carers not in touch with service systems.

A diversity of family and client characteristics, needs and risks are found amongst older carers, and some will present with higher, more urgent needs than others. However, all must tackle the task of preparation for the future transition of care of their adult offspring and the cessation of their own caring.

RESOURCES

- The Carers Association of Victoria has produced various booklets, documents and tools which are available for both carers and professionals.

- Many carers support groups have been established at local and regional level. They are often disease or impairment specific, although general carers groups are available.

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GEOFF SUSSMAN

Graduate of the Victorian College of Pharmacy, Member of the Pharmaceutical Society of Australia, Member of the Society of Hospital Pharmacists, Member Sports Medicine Australia, Associate Fellow of the Australian Institute of Pharmacy Management, Member of the Australian Pharmaceutical Science Association, Justice of the Peace

Senior Associate and Director of Wound Education and Research in the Department of Pharmacy Practice, Monash University, Melbourne

Having been involved in pharmacy practice for more than 25 years Geoff Sussman has vast experience in clinical pharmacy and has published widely on the topic. For 15 years he was the Director of Pharmacy Services at the Repatriation General Hospital in the Melbourne suburb of Heidelberg. He has lectured extensively on drugs and pharmacology for many years. He is an Associate of Australia's National Ageing Research Institute, which is based in Melbourne.

Geoff was awarded the 1998 Pharmacy Practice Foundation of Australia Medal of Excellence for his work in wound management.

CHAPTER SEVEN

Medication and the Ageing Person

Geoff Sussman

INTRODUCTION

The ageing of the population brings with it many apparent and also many unforeseen outcomes and a number of these relate to medications and their use. It is important to recognise that by the year 2031 20 per cent of the Australian population will be older than 65 and that the greatest increase will be for people over the age of 75 years. A number of studies have shown that 12 per cent of all admissions to medical wards and 15–22 per cent of all emergency admissions among the elderly in Australian hospitals are drug related (Ioannides-Demos and Christophidis, 1993).

FACTORS INFLUENCING MEDICATION USE

There are a number of factors which influence the problems experienced by people as they age in relation to the use of medication:

- the ageing process (and the resulting altered body physiology)
- changes in the pharmacokinetics/pharmacology of drugs
- increased risk of adverse drug reactions
- polypharmacy
- compliance.

The ageing process (and the resulting altered body physiology)

The body is finely tuned and maintained in balance by a process called homeostasis, which allows the body to adjust (or compensate) and repair itself. However there is a point, as we age, when the body is no longer able to compensate itself. This leads to system breakdown and ultimate failure. The major changes resulting from the process of ageing are:

- physical changes
- body composition changes
- changes in organ function.

The physical changes with ageing include weight, contour, posture and hair. The changes of body composition are lean body mass, water, bone and fat. Organ systems change significantly with ageing. Most organs and systems in the body lose function, including the heart, lungs, blood vessels, nerves, digestive system, muscles, endocrine system, brain, taste buds and metabolism. Shock (1962) indicated that when compared with a 30-year-old male a 75-year-old male has only 56 per cent brain weight, 70 per cent cardiac output at rest, 69 per cent Glomeruli Filtration Rate (kidney function), 35 per cent taste buds and 40 per cent maximum oxygen uptake (during exercise). (See also chapter 2, 'Normal ageing'.)

Pharmacokinetics/Pharmacology

Drugs enter the body orally, by injection, by inhalation, by infusion or by being applied topically. The body then absorbs and distributes the drug — either as free drug or bound to plasma proteins — to the organs and the tissues. Drugs are then either metabolised into inert compounds which have no pharmacological activity or are metabolised as active fractions where the metabolites exert an action on the body and are then excreted, mainly by the kidneys, the liver, the lungs and the skin. Some drugs are excreted unchanged from the body through the kidneys, liver, lungs and skin. The process is altered as we age because of changes in absorption, distribution, metabolism and excretion.

The ability of the gut to absorb drugs alters, as does the process of the breaking down of individual medication, because of:

- changes in the pH of the stomach
- delay in gastric emptying time
- gut motility.

There are some drugs that require the acid pH of the stomach to begin the process of decomposition and if this is reduced the distribution of that drug may be affected. On the other hand, some drugs are coated to prevent breakdown by the acid pH of the stomach and are broken down by the more alkaline pH of the small intestine. However, if the normal motility of the gut is reduced and there is a delay in the gastric emptying time these drugs remain in the acidic stomach and will be broken down, therefore not reaching the small intestine in time to be effective. A further complication is that, with ageing, the acid levels and thus the pH of the stomach are reduced and this may also alter drug absorption.

The other influencing factor in relation to distribution of drugs is the level of the plasma proteins in the blood that bind drugs for transport and distribution throughout the body. Malnutrition or a poor diet will reduce the level of albumin (plasma protein) in the blood. The consequence of a reduction in albumin is that more free drug is transported, leading to a more pronounced effect of the drug and a diminution of length of action of that drug. It may be necessary, when a lower albumin level is known, to reduce the doses of those drugs highly protein bound to lower the risk of an adverse reaction.

Another factor which affects the activity of drugs as we age is the ability of the liver to metabolise (detoxify) drugs prior to excretion. Low rates of metabolisation may be related to a reduction in hepatic blood flow, enzyme activity and liver mass. With ageing there is also a reduction in kidney function, which affects the capacity of the kidneys to eliminate free drugs or their metabolites. Hypotension and heart failure will also impact on kidney function. This reduction in the ability of the kidneys to excrete drugs and their by-products from the body may require dose reductions. Digoxin (Lanoxin®) and aminoglycoside antibiotics (e.g. gentamicin) are two examples. The dose effect can be modified either by a reduction in dose of the drug or by increasing the time between doses.

Adverse drug reactions

In Australia 11 per cent of the population receive pensions — aged, veterans or invalid — but they consume 22 per cent of all prescribed medication. People aged more than 60 years and living in the community average three prescription drugs at any time. The problem associated with multiple drug administration is the increased risk of:

- drug interactions
- side effects
- adverse drug reactions.

There is clear evidence of an increase in adverse drug reactions in elderly patients. The reasons for this increase relate to the problems of altered pharmacokinetics of absorption, distribution, metabolism and excretion. Drugs act by attaching to receptors in various parts of the body. The response to these receptors may decrease or increase resulting in a change in the activity and action of the drug. The major contributing factors for adverse drug reactions relate to the number of medications taken. The greater the number of drugs used the greater the risk of adverse drug reaction. The presence of chronic diseases will impact on the activity and actions of drugs. Atypical disease presentation, misdiagnosis, inappropriate prescribing and use of non-prescribed medication may also contribute to the problem.

Because the population is ageing people have more chronic conditions and need more drugs to manage them. The management of these chronic diseases may not always be satisfactory and may prompt patients to seek advice and treatment from a number of practitioners, including non-traditional and alternative therapists, each of whom may prescribe another medication. Part of the reason for the increase in medication usage relates to the side-effect profile of many drugs. It is not uncommon for patients to experience symptoms such as nausea, changes in bowel function, sedation, indigestion and cardiac or respiratory changes. These signs, often directly related to medication, are perceived as symptoms of other diseases so new drugs are added to the ones already being administered. This is called polypharmacy or multiple drug therapy.

Polypharmacy

Polypharmacy is the administration of a number of drugs to a patient for the ongoing treatment and management of their conditions. There are a number of factors that contribute to the high level of polypharmacy.

- **There is a misbelief that all diseases require medical treatment with drugs.** Most patients believe that they need a DRUG to be prescribed or they are not receiving the best treatment.

- **Patients often have the false impression that there is limited availability of alternative measures.** Some patients think that medication is the only way to treat most diseases and symptoms.

- **There is a misconception that drug therapy should be continued indefinitely**. Patients who are prescribed night sedation while in hospital may continue to use the drug indefinitely.

- **Patients will visit a number of different doctors and alternative therapists and a number of pharmacies to obtain their medication.**

- **There is increased use of over-the-counter proprietary medicines and herbal products.** There appears to be a large increase in the use of herbal, non-traditional and alternative therapies as some patients become disillusioned with traditional medical treatment. These products are believed to be natural and thus safe and once patients commence using the products they are reluctant to discontinue usage. However there are now reports of adverse reactions to a number of herbal products, including dermatitis, bronchospasm, anaphylactic shock, haemolytic anaemia, diarrhoea, nephropathy and colitis.

An additional aspect of multiple drug use is the risk of drug interactions. Many drugs, when given together, will interact.

- These interactions may increase or decrease the activity of either or both drugs.

- The absorption of the drugs may be affected or one of the drugs may become inactive.

- Drug combinations may result in chemical interactions between drugs or pharmacological interactions affecting action or resulting in unwanted side effects.

- Drug interactions may also affect the metabolism and excretion of the free drug or its by-products.

- Some drugs may also block or enhance the receptors of other drugs resulting in an increased or decreased effect.

- Substances such as alcohol can have a marked effect on the action of a number of drugs. Alcohol can increase a patient's sensitivity to a drug, and some drugs may increase the effects of the alcohol. A number of drugs will be affected by co-administration with alcohol. Alcohol can either stimulate or inhibit the metabolism of a number of drugs, as shown in Table 7.1.

Compliance

One of the essential aspects of the use of any medication is strict adherence to the directions for use of the drug or drugs. A patient's ability to ensure that the medication prescribed is taken according to the instructions is called compliance. Incorrect or inaccurate administration of drugs is known

Table 7.1 Drugs that are affected by being taken with alcohol

Generic name	**Trade name**
Warfarin	Coumadin®, Marevan®
Methotrexate	Ledertrexate®, Methoblastin®
Diazepam	Valium, Ducene®
Salicylates	Aspirin, Disprin®
Phenytoin	Dilantin®
Sulphonureas	Daonil®, Minidiab®, Rastinon®
Nitrates	Anginine®, Isordil®
Antidepressants	Prozac®, Zoloft®, Tryptanol®

as non-compliance. Most patients are not compliant. Table 7.2 shows the most common ways that patients are not compliant.

Reasons given by patients for non-compliance fall into a number of categories.

1. **They forget to take the medication** because they slept in, were busy, were going out etc.

Table 7.2 How patients in general are non-compliant

Non-compliant action	Examples
They do not take the drugs at the specific times ordered.	A medication may be required to be taken before food, to ensure its absorption, but patients take it after food. A drug prescribed four times a day may be taken only twice a day.
They interrupt the treatment.	Antibiotics should be taken until the course is completed, however some patients will discontinue the doses if the symptoms have stopped.
They do not adhere to the dose to be administered.	If the dose stated is 'two tablets for pain', some patients take four tablets to increase the analgesia
They add other drugs not prescribed.	It is not uncommon for a friend to give unused portions of a medication to someone who is describing similar symptoms to those for which the drug was prescribed.

2. **Their symptoms have disappeared so they no longer need to take the medicine.** This is a serious problem if the medication is being taken to control the symptoms of a chronic illness. The fact that the patient is symptom free only indicates that the medication is in fact performing the role for which it was prescribed.

3. **They neglect to have the prescription re-dispensed.** Some patients run out of prescriptions but wait for their next appointment to see their doctor rather than making a special trip. Or they may just forget to have the repeat prescription filled.

4. **The medicine is expensive.** This is an increasing reason for non-compliance, as the cost of medicines increases, especially for self-funded retirees not covered by a pension or unable to obtain their drugs at a reduced cost or if the drug or medical device is not available on the national health schedule.

5. **They experience side effects from taking the medicine**. Instead of speaking to their doctor or pharmacist, patients may just stop taking medication essential to their treatment.

Why is it that some patients are more likely to be non-compliant than others? Table 7.3 sets out some of the reasons.

Another problem is hoarding of drugs. Ageing patients seem to do this for two main reasons:

- a reluctance to dispose of out-of-date or no-longer-required drugs because it is seen as wastage
- the belief that they need to be seen to be 'sick' or they will lose their pension.

DRUG USE IN THE ELDERLY

A number of commonly prescribed drugs will cause unpleasant and sometimes debilitating side effects (see Table 7.4).

The World Health Organisation (1981) recommends that ageing people should avoid a number of drugs completely. These are shown in Table 7.5 together with the unwanted side effects that they cause.

Table 7.3 Why some patients are non-compliant

Reason	Example
Increased age	As discussed above, as we age, there are many changes in the body systems.
Living alone	This increases the potential for error and non-compliance.
Dementia, forgetfulness	Anyone may forget to take the occasional dose of medication, but a patient suffering from a reduction in cognitive skills is particularly at risk.
Confusion with drug names	There are so many drugs available on the market — many with very similar names — that it is very easy to become confused.
Complicated administration of drugs	Many patients need to take large numbers of drugs with complex multi-times-a-day doses and different numbers of tablets at different times of the day, e.g. two tablets in the morning, one at lunchtime, one at teatime and two at bedtime.
Size, colour, taste	Most tablets have a marked code on their surface, but it is not easy to see. A patient required to take a number of white tablets during the day may mix up the different drugs. Some patients have difficulty recognising differences in colour among several medications.
Packaging	Medications presented in 'blister packs' can be difficult to open. Medications containers required by law to be 'child-proof' may also be 'adult proof', especially for older patients with arthritis or reduced strength in their hands.
Visual impairment	Patients with a visual impairment will find difficulty in reading the directions on the label of prescription medication or even proprietary medicines or herbal products, increasing the risk of error.
Lack of understanding and poor patient education	If a doctor or pharmacist does not have time to make sure the patient understands why and how the medication must be taken there is increased potential for non-compliance.
Cultural or idiosyncratic factors	Some patients just won't do what they are told.

Multiple drug treatment (polypharmacy)	See page 116-7.
The use of a single container for many of the patient's drugs	Patients often put all their drugs into one container, especially if they are out and about during the day, because they believe this will simplify the number of containers to be carried. However, the patient may become confused as to which medicine to take when and there is a risk that drugs stored in an unsuitable container may become unstable, e.g. glyceryl trinitrate (Anginine®) should not be exposed to heat or air.

Table 7.4 Side effects of drugs

Drug	Side effects	Cause
Digoxin e.g. Lanoxin®	Nausea, vomiting, cardiac arrhythmias, confusion, weakness, visual disturbances	Reduced excretion
Diuretics e.g. Lasix® Chlotride®	Electrolyte disturbances (e.g. lower potassium, sodium and magnesium), higher urea and glucose, altered calcium excretion	Increased kidney function
Antiemetics e.g. Stemitil® Maxolon®	Ataxia, extrapyramidal side effects causing a high risk of falling, dizziness	Central nervous system actions
Non-steroidal anti-inflammatory drugs e.g. Voltaren® Nurofen® Feldene®	Gastrointestinal upset, fluid retention, oedema, heart failure, renal impairment, confusion, anti-platelet action	Gastric irritant in patients with cardiac dysfunction, hypertension and renal damage; similar to aspirin in causing cardiac dysfunction, hypertension and renal damage
Hypnotics and sedatives e.g. Euhypnos® Mogadon® Normison®	Dependency, excessive sedation, confusion, ataxia, increased risk of fracture of neck of femur	Central nervous system action
Codeine-containing analgesics e.g. Codral Forte® Panadeine Forte®	Constipation	Reduced intestinal and gut motility

Table 7.5 Drugs which should be avoided by the elderly

Drug	Unwanted effect
Barbiturates	Confusion
Bethanidine	Severe postural hypotension
Chlorthalidone	Prolonged diuresis, incontinence
Nitrofurantoin	Peripheral neuropathy
Phenylbutazone	Aplastic anaemia, hypotension, toxic hepatitis

GENERAL RECOMMENDATIONS ON MEDICATION USE IN THE ELDERLY

The are a number of ways that community health professionals can assist their ageing clients to prevent damage from medication or at least reduce the risks.

1. Regularly review all medication being used to ensure that it is still needed.

2. Reduce any medication if possible and stop any medication that is unnecessary.

3. Check patients' knowledge of the dose and dosage schedule of their drugs to ensure that they are compliant.

4. Ask the patient about any non-prescription medication also being taken and check to see if there is any risk of interactions with any of the prescribed drugs.

5. In conjunction with the client's carer, doctor and pharmacist, modify the dose of any drug to allow for the pharmacokinetic changes in the ageing patient.

6. Simplify the dosage schedule — ask the doctor and pharmacist to use, if possible, a medication that can be administered by a once-daily dose.

7. Ensure that patients speak regularly about their medication to their doctor and pharmacist, especially if there have been changes made to the drugs being used or to the dosage schedule.

8. Consider using specially loaded tablet devices for patients who have difficulty with their containers or are confused by the number of medications being taken.

9. Make sure your client's diagnosis is reviewed regularly to ensure that any symptoms that may have been masked are identified.

10. Consider the use of non-drug treatments to improve your client's health, e.g. diet, exercise, relaxation methods.

11. Encourage your clients to become responsible for their own drug use.

12. When you visit your clients ask to see their supply of medications. Check for hoarding. Ask to see any containers used to carry small quantities of the medications to ensure that they are suitable.

13. If a client experiences side effects or adverse reactions ensure that the cause is identified to differentiate symptoms of some new condition from side effects of medication.

Remember drugs can be a friend or an enemy. What is essential is that, in the ageing patient, they are used with caution, understanding and knowledge so as to be safe as well as effective.

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KEITH DAVID HILL

Bachelor of Applied Science (Physiotherapy), Graduate Diploma of Physiotherapy, Doctor of Philosophy

Physiotherapist and Senior Research Fellow, National Ageing Research Institute, Parkville, Victoria, Australia

Keith has 20 years' experience as a physiotherapist involved in rehabilitation and aged care. He developed the physiotherapy assessment process for the specialist Falls and Balance Clinic which was established jointly between the National Ageing Research Institute and Melbourne Extended Care and Rehabilitation Service in 1988. At present Keith is co-director of the Falls and Balance Clinic.

Keith completed a PhD entitled 'Balance studies in older people' in 1998. He has been involved in the development of a new clinical measure of balance (the Step Test) and an expanded measure of fear of falling (the Modified Falls Efficacy Scale). He coordinates several falls-related projects and research initiatives and has published 12 papers in the areas of balance and mobility assessment and management.

JENNIFER ANNE SCHWARZ

Bachelor of Medicine, Bachelor of Surgery, Graduate Diploma of Education, Fellow of the Royal Australasian College of Physicians

Senior Consultant Physician in Geriatric Medicine, Melbourne Extended Care and Rehabilitation Service, Parkville

Jenny has been a geriatrician since 1987. She has been working in the area of falls and balance problems in older people since 1990. She is co-director of the Falls and Balance Clinic based at the Melbourne Extended Care and Rehabilitation Service, the first such clinic in Australia. She also works at the recently established Falls and Balance Service at Bundoora Extended Care Centre. She was a member of the Department of Human Services (Vic.) working party that developed guidelines for the development of Falls and Mobility Clinic services for Victoria.

Jenny's other interests are in the fields of medical education and ethical issues in aged care.

ROBYN SMITH

Bachelor of Applied Science (Occupational Therapy), Graduate Diploma in Gerontology, Master of Public Health

Director, Public Health Division, National Ageing Research Institute

About five years ago Robyn moved from work as a clinical occupational therapist specialising in adult rehabilitation and acute geriatrics to full-time research. She has held a number of positions with the Occupational Therapy Association at both state and national level. At present she is Chair of the National Advisory Group — Aged Care for OT Australia — National. She is also a member of the Australian Association of Gerontology and of the Public Health Association of Australia.

Robyn's research has included work on:
- community rehabilitation centres
- community support services
- home-based rehabilitation services
- hospital readmissions
- in-patient respite services
- health promotion.

Her main interests are health service systems, the measurement of health outcomes, evidence-based clinical practice and health promotion.

BELINDA GILSENAN

Registered Nurse, Bachelor of Arts, Postgraduate Diploma of Arts

Project Officer, National Ageing Research Institute

As a nurse Belinda worked for a number of years in geriatric rehabilitation and at the same time completed a Bachelor of Arts. Her Honours thesis explored the involvement of older adult organisations in the policy-making process in Australia.

Her work in the area of falls prevention has included the development of a national database of community-based falls prevention programs which incorporates a critical appraisal of each program. More recently she has been working with staff and residents in aged care facilities to promote an awareness of falls risk factors, and to institute a falls risk screening process for all new residents.

KAREN BULL

Bachelor of Applied Science (Occupational Therapy)

Occupational Therapist, Peninsula Falls Prevention Service, Mount Eliza Aged Care and Rehabilitation Service, Peninsula Health Care Network, Mount Eliza, Victoria

Karen is a team member of the Peninsula Falls Prevention Service and the Peninsula Falls and Balance Clinic. Her primary role is as Coordinator for the 'Foothold on Safety' Program throughout the Peninsula Health Care Network. Through collaborative planning and interventions the program aims to develop partnerships with local health services regarding falls-related issues. Programs include:

- falls awareness-raising activities
- promotion and program development of physical activity for older people
- training and education of health care workers
- facilitating policy and procedure change within aged care services and local government.

CHAPTER EIGHT

The Impact of Falls on Older People: How To Assess the Risks and Implement Prevention Strategies

Keith Hill, Jennifer Schwarz, Robyn Smith, Belinda Gilsenan, Karen Bull

THE FACTS

Falls and their consequences are a major public health problem among ageing people. Australian and overseas studies of community-dwelling ageing people have found that approximately one in three people aged 65 years and over fall each year, with 10 per cent having multiple falls, and more than 30 per cent experiencing injury requiring medical attention (Campbell et al., 1989; Dolinis et al., 1997; Kendig et al., 1996; Lord et al., 1993; Prudham and Evans, 1981; Tinetti et al., 1988). Furthermore, fear of falling has been identified in at least 30 per cent of community-dwelling ageing people (Kendig et al., 1996; Tinetti et al., 1994) and this can result in self-restriction of activity level.

The effects of falls are costly to the individual in terms of:

- health
- function
- quality of life.

Falls are costly to the community, with management of injurious falls in Australia estimated to cost $AUD 2369 million annually (Fildes, 1994). National targets for reducing falls-related deaths and hospitalisations for Australians aged 65 years and over were established as part of the National Health Priority Area program in 1992. While falls-related deaths have declined since then, falls-related hospitalisation rates have increased (Australian Institute of Health and Welfare, 1997).

Falls increase with age, with approximately 25 per cent of those aged 65–74 years falling per year, compared with more than 50 per cent of those aged over 90 years (Campbell et al., 1981). Furthermore, injury patterns change with age. In those aged 65–70 years, the incidence of Colles' fractures resulting from falls is approximately the same as the incidence of hip fracture. However, with increasing age, the proportion of hip fractures increases markedly (Riggs and Melton, 1986). Hip fracture is potentially one of the worst outcomes from a fall. Fewer than half of those with a hip fracture regain pre-fracture level of function within 12 months (Magaziner et al., 1992). These figures highlight the ongoing challenge in terms of physical, psychological, and economic impacts of falling, both for ageing people and for practitioners involved in falls prevention programs.

RISK FACTORS FOR FALLING

Falls are multifactorial in aetiology. According to Schwarz (1995) falls are due to a combination of:

- drug side effects
- intrinsic factors
- extrinsic factors.

Based on the work of a number of researchers (Campbell et al., 1989; Koski et al., 1998; O'Loughlin et al., 1993; Tinetti et al., 1995; Vellas et al., 1998) intrinsic risk factors for falls and injurious falls can be said to include:

- increasing age
- history of previous falls
- medical conditions affecting mobility (including stroke, Parkinson's disease, and osteoarthritis)
- polypharmacy
- use of specific psychotropic medications
- visual impairment
- cognitive decline
- both low or high activity levels.

Extrinsic falls risk factors include any environmental object involved in a fall, such as trips over obstacles, slips on wet surfaces, and falls due to inadequate lighting. They also include falls due to participation in activities associated with a high falls risk, such as placing a chair on a table to replace a light globe. Extrinsic factors have been reported as being the major factor in approximately 50 per cent of all falls (Lach et al., 1991), although if comprehensive evaluation for intrinsic factors is undertaken this figure is likely to be considerably lower. With increasing age, there is an increase in the proportion of falls where the major factor is intrinsic (Campbell et al., 1981).

HEALTH PROMOTION AND FALLS PREVENTION

From a public health perspective, there are a range of activities that can be undertaken by all individuals, irrespective of the presence of falls risk factors, which may reduce falls rates. This approach concentrates on primary rather than on secondary prevention. Primary prevention endeavours to provide information and opportunities to the population as a whole, or a discrete population, to encourage behaviour modification. Examples of this approach as it pertains to falls prevention include:

- a media program promoting
    1. participation in physical activity or exercise for all persons
    2. regular eye checks amongst ageing people to optimise vision
    3. strategies for wise use of medicines
    4. safe footwear
- the distribution of home hazard checklists encouraging ageing people to assess and modify their environment
- the development of public hazard reporting strategies for use by, and for the benefit of, the entire community.

FALLS RISK SCREENING TOOLS

In contrast to the health promotion approach which targets the broader population, other falls prevention programs may target individuals with one or more falls risk factors. Early identification of those at risk, with subsequent introduction of a targeted falls prevention program, can result in targeting resources to those at greatest risk. A good screening tool should provide a framework for the identification of falls risk factors for an individual, and to guide subsequent management in terms of further assessment or targeted multi-strategic intervention. The tool also needs to be reasonably accurate in the correct classification of fallers and non-fallers. Cwikel and colleagues (1998) developed a useful falls risk screening tool to be used in a community setting. It evaluated:

- the number of falls in the past 12 months
- whether any of these falls caused injuries
- the presence of 'near falls' in the past 12 months
- slow walking speed
- unsteady gait pattern.

Another more detailed falls risk screening tool on trial at present in community settings is the Screening Assessment for Falls Evaluation (SAFE) (see Appendix 8.1 and resource list). The SAFE is designed to be used by community workers to evaluate a range of risk factors under the broad classifications of falls history, intrinsic factors, extrinsic factors, and activities of daily living.

COMPREHENSIVE ASSESSMENT

1. Medical assessment

Given the multifactorial aetiology of falls, the medical assessment needs to consider the potential interaction between drug side effects and intrinsic and extrinsic factors (Campbell et al., 1995; Schwarz, 1995). Intrinsic factors include age-related physiological decline and disease states, both acute and chronic.

Age-related changes that increase falls risk include:
- decreased visual acuity
- decreased visual contrast sensitivity
- impaired visual depth perception
- decreased joint proprioception and vibration sense
- increased reaction time
- decreased muscle strength.

It should be noted that, despite deterioration in each of the systems involved in balance with increased age, these changes are relatively small. Balance abilities of healthy ageing people remain at a good level (Hill et al., 1999) and provide the capacity for leading active lifestyles. It is the presence of disease states (acute or chronic) which have a greater impact on balance abilities and falls risk in ageing people.

Acute diseases that increase the risk of falls include:
- delirium
- hypotension from any cause
- vestibular dysfunction, e.g. viral labyrinthitis.

Chronic diseases that increase the risk of falls include:

musculoskeletal	osteoarthritis
	foot disorders
	osteomalacia
neurological	dementia
	stroke
	Parkinson's disease
	cervical myelopathy
	peripheral neuropathy
vestibular	Meniere's disease
	benign paroxysmal positional vertigo
visual	cataracts
	macular degeneration

cardiovascular	postural hypotension
	arrhythmia
psychological	depression
	anxiety, including fear of falling

Drug side effects that can increase an individual's risk of falls include:

postural hypotension	diuretics
	antihypertensives
	minor and major tranquillisers
	antidepressants
	drugs for Parkinson's disease
sedation	minor and major tranquillisers
	antidepressants
	anticonvulsants
	alcohol
cerebellar dysfunction	anticonvulsants
	alcohol
parkinsonism	major tranquillisers
	antiemetics
	vestibular suppressants

History taking is vital. First, it is important to exclude syncope or loss of consciousness as the cause of the person falling over, as these will require specific medical management. If the person has cognitive impairment or poor recollection of the fall, then it is essential to try to obtain a history from others who may have observed the fall. It is important to ask specifically about fear of falling, as this information may not be provided without prompting.

Dizziness assessment

Dizziness is common among ageing people, with approximately one in five community-dwelling people aged more than 65 years reporting dizziness at least once each year (Sloane et al., 1989). It is important to determine whether what is being reported is true vertigo — a perception of the room spinning, or themselves spinning — or some other sensation, such as light-headedness. Common causes of true vertigo include peripheral vestibular problems such as Meniere's disease, benign paroxysmal positional vertigo, and vestibular neuronitis; and central vestibular problems such as a brainstem stroke, and multiple sclerosis. Clinical assessment of the ageing person with vertigo includes a detailed history of symptoms and provocative manoeuvres — the Hall Pike manoevre (Brandt, 1993), the vestibular stepping test (Fukuda, 1959) and the Clinical Test of Sensory Integration of Balance (Shumway-Cook and Horak, 1986).

Physical assessment

A comprehensive physical assessment should be made of any ageing person who:

- is falling
- is at risk of falling
- is unsteady when walking
- has difficulties with functional activities
- is dizzy
- lacks confidence in their mobility.

The aim of the physical assessment should be to identify whether performance is within normal age-matched limits, and to determine which factors may be contributing to impaired performance.

Balance measurement

Balance is defined as the ability to maintain the body's centre of gravity over the base of support (Nashner, 1993). Balance may be static (in which there is no overt body movement other than postural sway) or dynamic. Dynamic balance may be considered under the broad classifications of self-generated perturbations (such as reaching or stepping) or externally generated perturbations (such as withstanding an unexpected push). Effective balance is a complex task for which an accurate assessment cannot be made from a single test. Rather, a series of tasks which mimic the types of perturbations commonly seen in falls should be incorporated into a balance assessment. As a minimum, a balance test battery should incorporate a measure of:

- static stance
- dynamic bilateral limb stance
- dynamic single limb stance
- response to external perturbation.

The selection of the most appropriate balance tests also needs to be based upon the functional level of the person being assessed. Examples of commonly used clinical tests of balance, as well as normative scores for healthy ageing people, have been reported by Bernhardt et al. (1998). More recently, observation of balance and mobility performance during dual tasks, that is, when concentrating on another task, have been shown to be useful in discriminating fallers and non-fallers (Lundin-Olsson et al., 1998).

Gait analysis

Gait is often affected by balance impairment. In particular, gait speed and stride length are usually reduced. These parameters can be quickly and easily measured using a stopwatch and a marked-out distance. More sophisticated gait analysis equipment is required to quantify:

- symmetry of gait timing (Evans et al., 1997), which is often affected by
- unilateral pain or muscle weakness
- duration of double support phase of gait, which is often increased in people with balance dysfunction.

Gait analysis may be examined in greater detail by evaluating gait performance over a specially developed obstacle course (Rubenstein et al., 1997).

Muscle strength evaluation

Muscle strength is a key measure in the assessment of the ageing person with a history of falls or imbalance. The most commonly used method of evaluating leg muscle strength is the Oxford Scale (Hoppenfield, 1976). However, the limitation of this method is the lack of objectivity, and limited retest and inter-rater reliability. Others have used timed functional tasks. For example, McMurdo and Johnstone (1995) used the time taken to complete 10 sit to stands from a 45cm-height chair as a measure of functional leg muscle strength. Lord and colleagues (1994) have used a simple strain gauge measure to evaluate quadriceps strength. More expensive measurement tools are available to quantify leg muscle strength. Hand-held dynamometers provide a portable, quick and easy-to-use digital readout of muscle strength (Connelly and Vandervoort, 1997). There are also large computerised machines available to quantify leg muscle strength, although these are not commonly available in the clinical setting.

Activity

Given the association between fear of falling and reduced activity level (Tinetti et al., 1994a), a review of activity level should form part of the assessment of an ageing person at risk of falling. The Human Activity Profile (Fix and Daughton, 1988) provides a useful baseline measure of activity level and has been shown to be responsive to change in a sample of ageing women undergoing a walking program (Hamdorf and Penhall, 1999).

Feet and footwear assessment

A key component of the assessment of the ageing person at risk of falling is a screen of the feet and footwear. These are the interface between the individual and the ground, and problems will limit the effectiveness and efficiency of balance responses. Balance performance is significantly better either barefoot or in low-heeled shoes than in high-heeled shoes (Lord and Bashford, 1996). Good footwear should be worn both indoors and outdoors, and should fit well, incorporating low broad heels, support under the arches, and a patterned non-slip sole.

Problems in the feet will also affect the integrity of balance responses.These can include pain, flattened longitudinal or transverse arches, bunions, corns and ulcerations. In many situations, assessment and management by a podiatrist can improve the functional weightbearing of the feet, resulting in improved foot/shoe contact, and ultimately, improving balance ability. Ageing people with sensory loss, including those with peripheral neuropathy and diabetes, need to take special care of their feet.

3. Psychological assessment

Approximately one-third of community-dwelling ageing people report some level of fear of falling (Kendig et al., 1996;Tinetti et al., 1994a). Fear of falling has been identified as the greatest fear in this group, above other commonly reported fears such as fear of being robbed, and fear of financial difficulties (Walker and Howland, 1991). Reduction in activity level is a common consequence of fear of falling, and in severe cases can result in a person who was completely independent in all instrumental activities of daily living subsequently becoming housebound. If unchecked, moderate reduction in activity level can result in deconditioning, both in terms of muscle strength and balance abilities, which can further increase an individual's risk of falling.

It is important to note that fear of falling is an appropriate response in a person with moderate balance impairment. The key findings clinically are when fear of falling is low in a person who has high risk of falls (commonly seen in some ageing people with cognitive impairment or poor self-monitoring), or when fear of falling is high in the person who has minimal balance impairment. In either case, successful clinical management is dependent upon early and accurate identification of the level of fear of falling.

The development of the Falls Efficacy Scale (Tinetti et al., 1990) was an important advance on previous efforts to quantify fear of falling, in that:

- fear of falling was assessed as a continuum from nil to extreme fear of falling instead of being rated as dichotomous
- it was considered situation specific, that is, an individual may not be afraid of falling in some situations such as walking around the house, but may be very fearful in other situations such as reaching into a high cupboard.

The Falls Efficacy Scale has been expanded to include higher level activities commonly reported by ageing people as the activities they first start to limit when fear of falling is developing, such as crossing roads, using stairs, and using public transport (Hill et al., 1996).

3. Functional performance and environmental considerations

The majority of falls in healthy ageing people occur outside the home (Hill et al., 1999), whereas the greatest proportion of falls in frailer ageing people occur within the home (Speechley and Tinetti, 1991). As such, falls prevention programs targeting environmental factors may need different strategies in these two groups (Bath and Morgan, 1999) .

Tasks such as personal and domestic activities in and around home, as well as activities in the community, place continual demands on the balance and strength of the ageing person. In addition, the design and layout of the environment also place demands on the person. Consideration needs to be given to circulation space, and the placement of items for reach and access. Comprehensive assessment of a person's functioning within their environment should be carried out for people with identified falls risk factors. This assessment is best performed in the client's home, with proposed interventions established in conjunction with the client. Efforts to reduce risk will have little or no impact without the understanding and acceptance of the ageing person that falls are a problem, and that actions need to be taken to reduce the individual risks relevant to the person. The assessment is commonly performed by an occupational therapist, trained in functional and environmental assessment in the home and community. Inherent in this is the need to consider circumstances of previous falls and the ageing person's desire to participate in certain activities. Detailed assessment of the person's abilities and limitations need to be matched against their lifestyle, approach to activities, and self-monitoring, in addition to the supports available to minimise risk where necessary. Assessment of falls hazards forms only part of the overall functional and environmental assessment required to assess fallers. Generalised checklist home hazard assessments, such as the Westmead Home Safety Assessment (Clemson, 1997) can guide a therapist's observations regarding falls hazards for the ageing person, and the accompanying manual (*Home Falls Hazards*) provides an important framework for the assessment.

Hazards in public places can place individuals at risk of falls, and therefore also warrant attention. It is important to consider the urban environment because feeling unsafe when entering the community can be a significant factor contributing to the ageing person's becoming housebound and further reducing activity levels. Ageing people can successfully have outdoor environmental hazards such as uneven footpaths or overhanging branches removed or rectified via local councils. Ease of reporting hazards away from the home is important, and the formation of Safety and Access Committees can facilitate interaction between ageing people and local councils on safety issues such as design problems and hazards.

FALLS PREVENTION PROGRAMS — ARE THEY EFFECTIVE?

1. Programs targeting behavioural modification

Falls prevention education programs aim to promote the message that many falls are preventable, rather than inevitable, and that early identification of falls risk is preferable to waiting for the first fall to occur before undertaking preventive actions. This is an important message for health professionals as well as ageing people and the community at large. Education programs have generally involved health professionals and/or ageing people (peer educators) presenting falls prevention information using a variety of formats. Information is provided on the risk factors for falling and strategies to adopt to reduce risk, along with information on available services to facilitate risk reduction. This may include contact details and referral processes for accessing occupational therapists, physiotherapists, and other service providers. Another strategy has been the development and distribution of product lists indicating the availability and cost of safety products, such as non-slip mats, which can facilitate action following an education session.

While there is some evidence that programs targeting behavioural modification can have some effect on intermediate outcomes, such as knowledge of falls risk factors and changes in behaviour (Stevens et al., 1992), there is limited evidence that this approach, in isolation, can reduce falls rates (Wolf et al., 1996). An example of an effective large-scale community falls prevention program was the Stay On Your Feet (SOYF) program implemented by the North Coast Public Health Unit in New South Wales (now Northern Rivers Institute for Population Health and Research). SOYF incorporated a number of strategies including an education program delivered en masse through various mediums and, on a more intimate level, via peer educators (van Beurden et al., 1998). This program reported both reductions in falls, as reported by individuals, and reduction in falls-related hospitalisations, compared with a control community.

2. Programs targeting medical factors

In general, all ageing people who experience a fall should be reviewed by their general practitioner, whether or not an injury is sustained. This is to ensure there is no underlying medical cause which may have contributed to the fall. Systematic questioning should include:

- falls history
- circumstances
- precipitating symptoms
- injuries sustained
- effect on confidence
- medication use.

A brief review of the main risk factors for falls should also be undertaken, as well as referral for further investigations if indicated.

As falls are multifactorial in nature, the medical assessment is only a component of a comprehensive intervention program. However, the doctor is often the first health care professional consulted following a fall, so the doctor is usually pivotal in coordinating referral to other services, such as an occupational therapy home visit to identify risk factors within the home, or a physiotherapy referral for an exercise program.

3. Programs targeting physical factors

Exercise is a commonly utilised intervention aiming to reduce falls risk in ageing people. It is important to consider specificity of training. Generally, the health benefits associated with a specific type of exercise program are related to the type of exercise undertaken:

- To improve muscle strength, a program should incorporate strength training (Judge et al., 1994).

- To improve flexibility, the program should focus on muscle and joint flexibility exercises (Morey et al., 1991).

- To improve cardiovascular fitness, a program should utilise activities such as walking (Hamdorf and Penhall, 1999).

In each of these instances, significant improvements have been demonstrated in ageing people. However, rarely have these changes been associated with reduced falls rates. In contrast, there is increasing evidence that exercise programs which incorporate some degree of balance training can be effective in reducing falls rates (Province et al., 1995). This has been demonstrated in both group and individual home exercise programs (Lord et al., 1995; Campbell et al., 1997).

Individualised home exercise programs should be tailored to the person's problems as highlighted in the assessment process, and are usually developed and monitored by a physiotherapist. Safety during the performance of the exercises, and ability to comprehend the exercise as prescribed, are paramount considerations in determining whether a client may benefit from this form of exercise. Generally, these exercises should challenge the person's balance deficits, but be performed in a safe setting, often with a bench or chair on each side, and the wall approximately 15 cm behind the person's back. To benefit an individual's balance, hand support should not be used, except to steady if overbalancing occurs.

Dizziness is also commonly associated with balance dysfunction. Balance retraining and desensitising programs have been shown to significantly reduce balance dysfunction and handicap (assessed using the Dizziness Handicap inventory — see Jacobson and Newman, 1990) in subjects with a range of acute and chronic vestibular problems (Strupp et al., 1998; Murray et al., submitted). Desensitising exercise programs incorporate frequent mild reproduction of symptoms by performance of provocative manoevres at a speed and amplitude which induces very slight dizziness. Particle repositioning is also often effective for people with benign paroxysmal positional vertigo (Herdman, 1997).

4. Programs targeting psychological factors

Fear of falling has commonly been managed indirectly through a physiotherapy balance training program, or a community training program with occupational therapy support. In many cases, these approaches can result in improved confidence (Tinetti and Powell, 1993). However, in more severe cases, clinical psychology programs may be indicated to manage the fear of falling, as in other types of fear such as agoraphobia. There have been no well-controlled studies evaluating the effectiveness of this form of intervention.

5. Programs targeting environmental review and modification

One of the most commonly incorporated falls prevention strategies has been assessment of the home for falls hazards, with appropriate modifications, including installation of aids such as rails, non-slip mats, and night lights. Only one randomised controlled trail has identified a significant reduction in falls among those with a history of falls, using a home falls risk assessment and modification by an occupational therapist, which included a focus on behavior modification (Cumming et al., 1999). Falls were equally reduced both within the home and away from home, indicating that the behavioural modification may have been a critical factor. A case control study identified reduced falls rates among ageing people having home modifications (Thompson, 1996). Programs are likely to be more successful if they match the intervention closely to the identified risk, and focus on the person moving within their environment, rather than solely on the environment as the main cause of falls.

Environmental modifications to minimise falls risk should target areas away from the home as well. Environmental audits of footpaths, shopping areas, parks and other public areas have the potential to reduce falls rates. In response to identified problems, councils need to adopt a management strategy to review and act on falls hazards in public places. There have been no well-designed studies evaluating the effects of these initiatives on reducing falls rates.

6. Programs targeting multiple risk factors

Given that falls are often multifactorial in nature, it seems obvious that programs which target a range of falls risk factors are more likely to reduce falls rates than those targeting a single risk factor. Several multiple factor falls prevention programs have demonstrated significant improvements in falls rates. Tinetti et al. (1994b) utilised individualised home exercise program, medication review, and home hazard modification in a randomised controlled trial of ageing community-dwelling people, and identified a significant reduction in the proportion of fallers and increased time to first fall, as well as significantly reduced fear of falling in the experimental group. Similarly, Hornbrook et al. (1994) provided group exercise, home hazard review, and behavioural risk education classes, and found reduced falls rates in the experimental group.

Specialist falls clinics have developed as a systematic multiple risk factor management approach for people with increased risk of falls (Wolf-Klein et al., 1988; Hill et al., 1994; Tideiksaar, 1996). A comprehensive multidisciplinary assessment serves as the basis for the development of individualised management programs. Common management strategies at one clinic included referral for allied health programs (33 per cent), home assessment (28 per cent), home exercise programs (27 per cent), medication change (15 per cent) and referral for a personal alarm (9 per cent), as well as a range of other options including gait aid change, referral for podiatry or clinical psychology assessment, and use of hip protectors (Hill et al., 1994). Several non-randomised studies have identified reduced falls rates in falls clinic samples (Wolf Klein et al., 1988; Tideiksaar, 1996). A recent randomised controlled trial of a medical and occupational therapy assessment of ageing people at risk of falling found a significant reduction in falls rates (Close et al., 1999).

7. Injury minimisation programs

Unfortunately, it is not possible to prevent all falls. Therefore, it is important to consider ways of preventing injuries or reducing the severity of injuries in people who continue to have a high falls risk. Fractures, especially hip fractures, are among the most devastating injuries caused by a fall. Bone mass and strength decrease with age, and it is important to consider the treatment of both osteoporosis and osteomalacia.

Hip protectors have been developed to protect the femur from the impact of a fall. Hip protectors incorporate shock-absorbing pads, made of either cloth or high-density plastic, sewn into specially designed underwear so that if a person falls onto them the energy of the fall is dissipated away from the femur. A randomised controlled trial in nursing home residents demonstrated a 50 per cent reduction in hip fractures with the use of hip protectors (Lauritzen et al., 1993). None of the residents in the intervention group sustained a hip fracture while wearing the hip protectors, however there were problems with compliance. Further studies assessing both compliance and acceptability are underway at present in both community and residential settings.

A number of ageing people who fall over have difficulty getting up again, even in the absence of a major injury or physical deficit. Lying on the ground for a long time after a fall can result in increased mortality rates (Wild et al., 1981), and complications such as dehydration, pressure sores, hypothermia and fear of falling. Devices such as personal alarms are useful so that a person who falls can summon help quickly. It is also possible to teach ageing people strategies to assist them in getting up off the floor after a fall (Reece and Simpson, 1996).

TRANSITION BETWEEN HOSPITAL AND HOME

While falls have been identified as a major problem for community-dwelling ageing people, there is evidence that falls rates are even higher for ageing people in hospital (Tutuarima et al., 1997). Reasons for this may include:

- the impact of an acute health problem such as stroke, pneumonia, or urinary tract infection
- the consequences of a precipitating fall (injury or loss of confidence)
- lack of adjustment to an unfamiliar environment.

Falls risk screening is critical to identify those most at risk on admission to hospital, and in targeting falls-minimisation strategies to these people. A useful screening tool which has been developed for use in the hospital and residential care setting forms part of the Falls Risk Assessment Tool (see Appendix 8.2 and resource list). Strategies which may minimise falls risk among ageing people in the hospital setting include:

- balance assessment and management programs
- medication reviews
- environmental audits
- staff training programs targeting falls prevention
- additional monitoring procedures
- development of risk management plans as part of care plans
- early involvement of allied health.

Effective discharge planning is also critical to minimise risk on returning home from hospital. This will often include a home assessment, and communication with, or referral to appropriate services and service providers following discharge.

AUSTRALIAN RESOURCES/CONTACTS

1. Australian Falls Intervention Database, includes a critical appraisal of recent falls prevention programs (Gilsenan et al., 1999). For further information, telephone 03 9389 7148 or visit NARI's web page (http://www.nari.unimelb.edu.au/).

2. Falls prevention web page, produced by the Joanna Briggs Institute (http://www.joannabriggs.edu.au/FALLS/index.html).

3. Falls prevention networks, which exist in some Australian states, provide both researchers and service providers with opportunities to discuss various approaches to falls prevention and the latest research results.

4. Stay On Your Feet booklet developed by Northern Rivers Institute for Population Health and Research, New South Wales. Telephone 02 6621 7231.

5. Training packages for peer educators, exercise leaders and home and community care workers, developed by Southern Public Health Unit, Western Australia. Telephone 08 9792 2500.

6. Standing On Your Own Two Feet is a resource package and video, the latter including ageing people discussing strategies they have adopted to reduce their risk of falling. It was developed by the Australian Pensioners and Superannuants Federation. Telephone 02 9211 7711.

7. Balancing Acts is a video and resource package developed for general practitioners by a conglomeration of organisations including the Royal Australian College of General Practitioners. Telephone 03 9214 1414.

8. Hip protectors, supplied by Hornsby Ku-ring-gai Hospital, New South Wales, (telephone 02 9477 97680); or supplied by Royal Adelaide Hospital Health Promotion Unit, South Australia, (telephone 08 8222 5193).

9. Falls Risk Assessment Tool (FRAT pack) for use in aged care settings, including hospitals, developed by Falls Prevention Service, Peninsula Health Care Network, Victoria. Telephone 03 9788 1260.

10. Screening Assessment for Falls Evaluation (SAFE — pilot version): A falls risk screening tool currently on trial in community settings by the Falls Prevention Service for the Foothold on Safety Program — Peninsula Health Care Network. Telephone (03) 9788 1260.

11. An analysis of research on preventing falls and falls injury in older people: community, residential and hospital settings. Hill K, Smith R, Murray K, Sims J, Gough J, Darzins P, Vrantsidis F, Clark, R (2000): *Report to the Commonwealth Department of Health and Aged Care.* Canberra. Also available from the Commonwealth Department of Health and Aged Care's web page (http://www.health.gov.au/pubhlth/strateg/injury/falls/index.htm).

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APPENDIX 8.1 SCREENING ASSESSMENT FOR FALLS EVALUATION (SAFE)

Page 1 of 2

Client's name Address Phone Date of birth __________________	Initial Review (circle one) Date of assessment ______________________ Primary diagnosis ________________________ Relevant medical history _________________

Usual mobility aid:
Indoors___________________
Outdoors__________________

Medications ______________________________
Prescribed by whom? ____________________
When?____________________________________

Previous/Current services: PT/OT/Falls

Source of referral_________________________

When?_________________________

Social situation___________________________

Information obtained from: client/carer/observation (circle) Other (please explain)

RECENT FALLS: Number in past: week_____ month____ 3 months_____ 12 months_____

Detail most recent falls **first** by circling appropriate word(s) **(Location/Other cause)**

Time ago _____ Trip: Slip: Lost balance; Leg/s gave way; Dizziness; Transferring; Obstacle _________
Time ago _____ Trip: Slip: Lost balance; Leg/s gave way; Dizziness; Transferring; Obstacle _________
Time ago _____ Trip: Slip: Lost balance; Leg/s gave way; Dizziness; Transferring; Obstacle _________

ANY NEAR FALLS? No/Yes If Yes, describe what happened. ____________________________

INTRINSIC FACTORS (Information can be obtained from client, carer or direct observation.)

Medical:

• Symptoms of dizziness	No/Yes______________________
• Fluctuating function during the day?	No/Yes______________________
• Person/Carer has difficulty managing medications?	No/Yes______________________
• Any falls or near falls of unknown cause?	No/Yes______________________
• Unsteadiness on first standing?	No/Yes______________________
Gait/Balance/Transfers:	
• Incorrect/Inappropriate/Insufficient use of mobility aid?	No/Yes______________________
• Sways when walking or 'furniture' walk?	No/Yes______________________
• Complains of weakness or reduced sensation in one or other leg?	No/Yes______________________
• Complains of tripping when walking (no obstacles present)?	No/Yes______________________
• Has ill-fitting or unsupportive footwear/painful feet?	No/Yes______________________
Vision:	
• Has difficulty seeing steps or obstacles around house?	No/Yes______________________
• Walks in dim light?	No/Yes______________________
• Reports no vision assessment in the last 12 months?	No/Yes______________________
Attitude:	
• Lacks insight into general safety/Unconcerned re falls?	No/Yes______________________
Nutrition:	
• Unexplained weight loss?	No/Yes______________________
• Poor appetite?	No/Yes______________________
Cognition:	
• Difficulty following instructions and/or confusion?	No/Yes______________________
• Poor monitoring of own safety?	No/Yes______________________
Continence:	
• Urgency/nocturia/accidents? (circle)	No/Yes______________________
Fear of falling:	
Fear of/Restricting activities client appears capable of doing?	No/Yes______________________

Medications:

Does client take 2 or more of the following: anti-depressants, Parkinson's disease drugs, diuretics, sedatives, antihypertensives, psychotropic drugs? No/Yes (please circle)

Subscore A _______ (1 point for each Yes response)

SCREENING ASSESSMENT FOR FALLS EVALUATION (SAFE) Page 2 of 2

EXTRINSIC FACTORS

Environment:

- Indoor hazards present (e.g. cluttered rooms, rugs, cords)? No/Yes____________________________
- Outdoor hazards present (e.g. uneven ground, obstacles) No/Yes____________________________
- Restricted trafficways indoors? No/Yes____________________________
- Poor lighting indoors/outdoors? No/Yes____________________________
- Difficulty climbing steps to house? No/Yes____________________________
- Difficulty on/off bed/chair/toilet and/or into/out of shower ? No/Yes (circle)________________

Other comments ____

Subscore B______ (1 point for each Yes response)

ACTIVITIES OF DAILY LIVING

Task analysis:

- Any activity client feels unsafe performing? No/Yes____________________________
- Difficulty reaching/bending/carrying items? No/Yes____________________________
- Unsteady when rushing or turning quickly ? No/Yes____________________________
- Difficulty standing to safely wash hair/shower/dress? (circle) No/Yes________________________
- Unable to get up from the floor? No/Yes____________________________
- Leaves residence <once per week? No/Yes____________________________
- Walks <5 times a week for at least 15 minutes? No/Yes____________________________

Risk-taking behaviour:

- Participates in tasks that appear dangerous for level of ability? No/Yes_________________________

Independence profile:

- Receives assistance for personal care? No/Yes____________________________
- Receives supervision for mobility/any activity? No/Yes (give details) __________________________
- Current home services (circle):
  None / MOW / RDNS /Home Help /Linkages /PACS /Gardening Other
- Support considered insufficient for needs? No/Yes (by whom)___________________________

Subscore C_______ (1 point for each Yes response)

Total SAFE score (total of subscores A,B,C)______

The SAFE score indicates the number of falls risk factors present at time of assessment and is intended for comparison at review assessment regarding the number of reversible risk factors modified following intervention.

High SAFE score = high number of risk factors.
Low SAFE score = low number of risk factors

Management Plan

Problem	**Action plan/Referral**

ASSESSOR____POSITION____________________

Next review date_____________________________

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APPENDIX 8.2 FALLS RISK ASSESSMENT TOOL (FRAT) FOR AGED CARE FACILITIES

Page 1 of 2

FALLS RISK ASSESSMENT TOOL (FRAT) FOR AGED CARE FACILITIES

Name:____ **D.O.B**____________________
Address:____
____ **Date:**____________________

PART 1

Choose one statement in each category and circle appropriate score

RISK FACTOR	LEVEL	RISK SCORE
RECENT FALLS (if any falls have occurred fill in p 2 overleaf)	none in last 12 months	2
	one or more between 3 and 12 months ago	4
	one or more in last 3 months	6
	one or more in last 3 months whilst in-patient/resident	8
MEDICATIONS (sedatives, anti-depressants anti-Parkinson, diuretics antihypertensives)	not taking any of these	1
	taking one	2
	taking two	3
	taking more than two	4
PSYCHOLOGICAL STATE (anxiety, depression ↓cooperation, ↓insight or ↓judgment **esp.re mobility)**	does not appear to have any of these	1
	appears mildly affected by one or more	2
	appears moderately affected by one or more	3
	appears severely affected by one or more	4
COGNITIVE STATUS (m-m: Hodkinson Abbreviated Mental Score)	m-m score 9 or 10/10 OR intact	1
	m-m score 7–8 mildly impaired	2
	m-m score 5–6 moderately impaired	3
	m-m score 4 or less intact severely impaired	4

RISK SCORE: /20

(Low risk: 5–11, medium risk 12–15, high risk: 16-20)

AUTOMATIC HIGH RISK STATUS: (if ticked, circle ***HIGH*** in Risk Classification at bottom of page)

Current Problems:

? Recent change in status/medications affecting safe mobility ? Severe dizziness

ADDITIONAL RISK FACTORS		COMMENTS
Vision	? Intact	? Difficulty seeing steps/contrast
Mobility	? Assessed and safe	? Appears unsafe
Transfers	? Assessed and safe	? Appears unsafe
ADLs	? Consistent safe approach	? Risky behaviours
Activity	? Opportunity to mobilise	? Inactive
Environment	? Assessed and safe	? Assessment required
Nutrition	? Normal weight/good appetite	? Loss of weight/low appetite
Continence	? Intact or well managed	? Urgency/nocturia/accidents

SUPERVISION STATUS: *(Circle)* **UNSUPERVISED / SUPERVISED**

RISK CLASSIFICATION: *(Circle)* **LOW / MEDIUM / HIGH**

FALLS RISK ASSESSMENT TOOL (FRAT) Page 2 of 2

PART 2

HISTORY OF FALLS (in past 12 months) No/Yes. If yes, please explain

Location: (please circle) **Indoors / Outdoors**

Estimated total number of falls in the past 12 months ________________________

CIRCUMSTANCES OF FOUR MOST RECENT FALLS: (Past residence or current)

Information obtained from______________________________Carer/Family member/Other
(please circle)

If other, please explain………………………………………………………………………

(Circle below) (Location/Comments/)

Last fall: Time ago _____Trip Slip Lost balance Collapse Leg/s gave way Dizziness____________ _
Previous:Time ago _____ Trip Slip Lost balance Collapse Leg/s gave way Dizziness _____________
Previous:Time ago _____Trip Slip Lost balance Collapse Leg/s gave way Dizziness _____________
Previous:Time ago _____Trip Slip Lost balance Collapse Leg/s gave way Dizziness _____________

MANAGEMENT PLAN

(If necessary, utilise the Risk Checklist and suggested strategies in the FRAT PACK to help complete this section.)

PROBLEM LIST	INTERVENTION STRATEGIES / REFERRALS

TRANSFERRED TO CARE PLAN : **YES** **NO**

Assessed by: Planned review date:_______________

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KEREN DAY

Registered Nurse Division 1, Bachelor of Nursing, Postgraduate Diploma of Advanced Nursing (Primary Health Care, Women's Health), Graduate of the Promoting Continence Course (Royal District Nursing Service, Melbourne)

Continence Nurse Consultant, Ballarat Health Services, Ballarat, Victoria

Keren has had more than 11 years' experience as a Continence Nurse Consultant during which time she has worked at the Royal District Nursing Service (Melbourne), the Victorian Continence Resource Centre, the Western Continence Service (Western Hospital in Melbourne) and in her present position at the Regional Continence Service based in Ballarat.

Keren has been involved in government working committees to develop continence services at state and federal levels. She has enjoyed being involved in continence course development and has participated in lecturing and clinical facilitation of students over a number of years.

Keren's professional interest is in women's health and she hopes to find ways in the future to further combine this with continence promotion and research.

Keren has two daughters and at present she is balancing parenting, part-time work and studying for her master's degree in nursing.

CHAPTER NINE

Incontinence

Karen Day

Being continent, that is, being able to store and pass urine and faeces at socially acceptable times and places, is a complex and important human skill. It is one of the first skills of independent living that we learn as small children, and certainly a developmental milestone that causes great joy and excitement for our parents. One of the reasons that being incontinent becomes a negative experience is because it implies a 'step backwards', a loss of this independence and maturity. Add to that the fact that we are talking about a bodily function that involves excrement, which is linked with dirt and subject to strict social rules and taboos (Lawler, 1991), and we have a complex health problem. It is not surprising therefore that incontinence is:

- often hidden
- rarely discussed
- generally not handled well by either health care professionals or the community.

Incontinence is something that nurses and personal care workers encounter frequently. Cleaning up the mess and keeping the person comfortable is an important part of the nurse's or carer's role. However, we must also know:

- what incontinence is
- who it affects
- why it happens
- what we can do about it.

Good care can do much more than keep someone clean, dry and comfortable. It is possible to improve and even cure a person's incontinence problem. Even more importantly, in some cases, good care can even prevent incontinence from developing.

When considering how to deal with the problem of incontinence we must also acknowledge that it is one that occurs on a physical, psychological and social level. Our care for those who live with incontinence therefore must incorporate all these elements. It must also include more than the individual who experiences it. Very often it becomes an enormous problem for the carers, family and friends. While incontinence may not be a problem that is specifically life threatening, it is one that deeply affects people's quality of life and as such it deserves much more than a 'mop-up' approach.

A DEFINITION OF INCONTINENCE

Through the work of the International Continence Society (ICS), a generally accepted definition of incontinence has been developed. The ICS defines urinary incontinence (in the words of Anderson et al., 1988) as

> the involuntary loss of urine which is objectively demonstrable and a social or hygiene problem.

Faecal incontinence can be defined, similarly, as the involuntary loss of bowel control at an inconvenient place and time. Most of the discussion in this chapter relates to urinary incontinence. Faecal incontinence is an important health need and really requires a chapter of its own to do it justice. The reference list at the end of this chapter suggests some books on faecal incontinence.

INCONTINENCE AND COMMUNITY AGED CARE

The changing face of health care and aged care and the current funding priorities mean that, increasingly, care provision occurs in the home and the community. This is especially true for care of the ageing. Urinary incontinence is just one of the significant health problems that many ageing people face.

Incontinence, by its nature, is, for most people, a difficult problem to admit to and discuss. Embarrassment, social taboos and ignorance are just some of the factors that drive people to keep it a hidden problem rather than to seek help. Many people successfully keep their incontinence a private problem for many years. They are often very resourceful in the strategies they employ to contain and hide their urine and bowel loss. It may be that it is only when such people are institutionalised, for whatever reason, that the problem of their incontinence, which may have been present for many years, becomes public. But those of us who work in community aged care encounter the 'hidden' problems as we enter the privacy of a person's home. It is rare that community services are initiated to deal with a continence problem. It is more likely that the services are first invited into a home setting for a general reason (such as showering assistance or Meals on Wheels) and once there are faced with a situation compounded by incontinence.

There are many ways that those of us involved in aged care in the community may first become aware of a client's incontinence problem, and it may be not because they have discussed it with us. While a person may successfully keep a problem hidden from so many outside their home, for those working in their home the clues are often there to be discovered. A number of scenarios come to mind.

- The carpet in a client's home is wet and odorous. At first you assume the problem is the cats and dogs that have the run of the home.

- You discover wet sheets while changing the bed, or wet clothing hidden in the cupboard.

- You notice the increasing washing load and the soiled clothing even though nothing has been said.

- Maybe your client, who previously enjoyed outings, is reluctant to leave home and you don't know why.

Often the question aged care workers in the community ask is not 'How do I know when a person has an incontinence problem?' but 'How do I talk to them about it? Do I confront them? Do I tell my supervisor? What should I do?'

There are some particular challenges to managing incontinence in community aged care. In a private home, the person is in charge. It is their space and they have a right to their privacy and to make choices about what care they will and will not accept. Despite the evidence, they may continue to deny that they are incontinent or refuse to talk to anyone (such as their GP or a continence adviser) about it. Another challenge is that people's care needs often exceed the scope of the care available. A continence management plan therefore may be quite limited by the fact that a carer may be present for only a few hours a day. Also, despite increased government funding for care provision in the community, there are still often considerable costs of continence management that may need to be borne by the incontinent person or their family. Sometimes optimum continence management and containment is simply not possible for a person because he/she is unable to afford it.

WHOSE PROBLEM IS IT?

Prevalence

Most of the work in the field of incontinence to date has related to urinary incontinence and most of the literature and statistics address bladder problems alone. Unfortunately, we are still some way behind in our knowledge about faecal incontinence. We do know that its incidence is lower than that of urinary incontinence. Norton (1997) reports that somewhere between 1 and 2 per cent of the population are affected. However, given that faeces is an even more taboo subject than urine, it is not surprising that it is an even more hidden problem and even less socially acceptable. Fortunately this is beginning to change, with more attention being focused on this next frontier of continence management. Some recent work (such as Cavarra et al., 1998) attempts to rectify this situation.

Considerable research has been carried out around the world regarding the incidence and prevalence of urinary incontinence. However there is significant variation in what is reported as incontinence and we need to take care when comparing studies (Mohide, 1992). We can say, though, that incidence does increase with age and alters in different care settings. In people aged between 15 and 64 years of age, 1.5–5 per cent suffer from urinary incontinence. In those older than 60 years who still live in the community, we can expect 15–35 per cent to be incontinent. The prevalence is much higher in the same age group living in institutionalised care — 50 per cent and greater (AHCPR, 1996). There is some Australian research available that supports these results (Millard, 1998), however, some are of the opinion that there is still some work that needs to be done on the experience of incontinence in the Australian context (Fonda and Direen, 1998). All in all, it is estimated that more than 1 million Australians experience urinary incontinence of some degree. However you look at it, this is an alarming thought.

Urinary incontinence is a problem that extends across the entire population. It affects men and women of all ages. However, there are certain groups in the community that are more prone to developing incontinence. Those most at risk of this are:

- children
- pregnant women
- menopausal women

- those with disabilities
- those in institutional care
- the ageing (who are affected disproportionately).

While it is not possible to predict with any accuracy whether and when a person is likely to develop an incontinence problem, there are certain risk factors. Button et al. (1998) searched the literature to develop a list of established risk factors for urinary incontinence in adults. They include:

- smoking
- pregnancy
- parity (number of births)
- body mass index
- race
- previous surgery (to the pelvic area)
- family history of childhood enuresis
- exercise.

The researchers also included a list of more directly causative factors that are also, by nature, risk factors:

- ageing
- constipation
- urinary tract infections
- impaired mobility
- impaired cognition
- institutionalisation.

Attitudes to incontinence

There are many firmly held myths and beliefs about both urinary and faecal incontinence that have been challenged as we have learned more about the problem. It is commonly believed that incontinence is:

- a normal part of ageing
- a normal part of being a woman and having children
- untreatable
- a condition that will get better by itself
- uncommon — 'I must be the only person with the problem because no-one else talks about it'.

We know that fewer than 10 per cent of people with incontinence seek help, often because of the myths. It is not uncommon to hear stories of women who have suffered with the problem for decades — 'ever since I had the children' — believing that 'it was to be expected'. People may avoid disclosure because they fear they will be treated as a 'smelly old person'.

It is commonly believed that once someone is known to be incontinent, the only solution is placement in a nursing home. People need to be reassured that these really are myths. The reasons for being institutionalised are complex and rarely can be put down simply to incontinence. However, there is some weight to the idea that incontinence (and most often faecal incontinence) becomes the last straw for people and their carers being able to cope at home. Rather than these being reasons to keep the problem hidden, people should be urged instead to seek help.

These myths also lead to unhelpful attitudes being held by health professionals and carers. One of the most disturbing is the passive acceptance that 'nothing can be done'. This leads to nurses and carers resigning themselves to merely 'mopping up' and not being prepared to put any effort into assessment and management. Some carers and nurses believe that two-hourly toileting and use of pads is the only solution — 'that's the way we've always done it here'. Another worrying attitude that needs to be challenged is that people who are incontinent are 'lazy' or that the problem is behavioural. While it is true that this may be possible, it is the exception when this is the primary cause of the incontinence. All other possible and probable causes of the person's incontinence need to be excluded before the conclusion can be reached that incontinence is a behavioural or voluntary problem. Such negative attitudes, and others such as anger and disgust, do not promote good continence care.

One important point to make is that just as people with the problem are reluctant to talk about incontinence, so health professionals and carers are reluctant to ask about it. Of course people may not speak of their problem even when given the opportunity, but we need at least to create opportunities for them to tell us. To do that, we need to be comfortable with the issue ourselves; we need a positive attitude and some idea of what we will do when a person does admit that they are incontinent.

TYPES AND CAUSES OF INCONTINENCE

We have already said that being continent is a complex skill. One of the reasons it is complex is because being continent involves more than just the bladder. To be continent we need to be:

1. aware of the need to pass urine — which involves transmission of a signal from the bladder and a conscious recognition of that signal and what it means
2. able to get to the toilet — this involves knowing where to go and being able to get there in time
3. able to store the urine during the time from awareness to toileting
4. able to undress and get onto the toilet in time

5. able to empty the bladder on cue once on/at the toilet
6. able to complete the process by wiping, redressing etc.

This process involves not only the bladder, but also:

- the urinary sphincters
- the nerves between the bladder and the lower spine where the reflex control centre for the bladder lies
- the spinal nerve pathways
- the brain
- the muscles of our limbs.

Incontinence is a symptom, not a disease or a condition itself. We know that headaches are symptoms of numerous causes which range from the very mild and reversible (e.g. too much red wine the night before, or eyestrain or fatigue) to the very serious (such as extreme high blood pressure or a brain tumor). Similarly, incontinence is caused by an enormous range of conditions. In order to know how to treat and manage the problem, it is vital to try and understand what is causing it. Table 9.1 shows some of the various causes. They can be classified in a number of ways. The table is not an exhaustive list and the causes are often interconnected.

Table 9.1 Causes of incontinence

Medical causes Poor mobility, e.g. stroke, arthritis, fractures Medications, e.g. sedatives, diuretics Constipation and faecal impaction Diabetes Obesity	**Urological or gynaecological causes** Urinary tract infection Bladder stones Bladder tumour Urethral strictures Enlargement of the prostate gland Pelvic muscle weakness Pelvic trauma, e.g. traumatic birth, pelvic surgery Oestrogen hormone deficiency Prolapse Unstable bladder
Neurological causes Stroke Parkinson's disease Brain tumour Multiple sclerosis Peripheral nerve disorders, e.g. diabetic neuropathy, alcohol neuropathy Spinal cord injury	**Environmental causes** Inappropriate furniture height Physical barriers and restraints, e.g. bedrails or harnesses Excessive distance to the toilet Poor or absent signage to the toilet Poor lighting Clothing that is difficult to manipulate Lack of staff to assist with toileting
Psychological causes Dementia Confusion Depression Stress and anxiety	

Adapted from Fonda D, Wellings C (1987): *Urinary Incontinence.* Melbourne: AECD Publishing (Ausmed Publications), p. 7–9, 11 and 14).

Norton (1996) developed another helpful way of considering the main causes of urinary incontinence by dividing them into three main categories:

1. physiological bladder dysfunction (e.g. an unstable bladder, stress incontinence, outflow obstruction, underactive bladder)
2. factors influencing bladder function (such as urinary tract infection, faecal impaction, drug therapy, endocrine disorders)
3. factors affecting the ability to cope with the bladder (such as immobility, the environment, mental function, inadequate patient care).

Urinary incontinence can be categorised into four main types:

1. urge incontinence
2. genuine stress incontinence
3. overflow incontinence
4. functional incontinence.

Urge incontinence is the involuntary loss of urine associated with a strong desire to void. The person usually loses a fairly large volume of urine and becomes quite wet when they are unable to suppress the bladder urge. A person with urge incontinence typically has urinary urgency and frequency and often says that they 'can't hold on' in time to make it to the toilet. This condition is also referred to as an **unstable bladder** or may be given the medical diagnosis of **detrusor instability**.

Genuine stress incontinence is defined as the involuntary loss of urine associated with a rise in abdominal pressure (such as with a cough or sneeze or laughing). The bladder itself is quite relaxed and isn't contracting. This type of incontinence, frequently experienced by women, is typically the loss of small amounts of urine at the same time as coughing, laughing, lifting, jumping etc.

Overflow incontinence occurs when the bladder cannot empty, either because the bladder muscle (the detrusor) is not able to contract and expel the urine, or because there is some obstruction in the outlet that the urine cannot get past. The volume of urine builds up until the pressure is great enough to push some urine out, much like a dam overflowing. Typical symptoms include hesitancy when starting to void, poor or interrupted urinary stream, frequency, nocturia, and not feeling completely empty at the end of a void. The urine loss usually experienced with overflow incontinence is more like a frequent or constant dribble than a big 'gush' as in urge incontinence.

In **functional incontinence**, the bladder function itself is not a problem. It is factors such as reduced mobility, confusion, or obstacles in the environment that are the culprits. An example of this would be the person with severe arthritis whose reduced mobility and dexterity means that they are so slow to get to the toilet that they are wet by the time they reach it.

The mechanisms that cause each of these incontinence types are different, therefore the treatment and management strategies we use will need to be different and carefully selected if we expect them to work. We need a thorough and individual assessment upon which to base our management strategies, especially if a person is likely to have more than one type of incontinence at a time. Individual management based on a thorough assessment is the key.

WHAT CAN WE DO ABOUT INCONTINENCE?

Assessment identifies the factors that are affecting the person's ability to be continent and enables a diagnosis of the type of incontinence upon which we can base a plan of management.

As we go through the assessment process, we need to try and find the answers to the following questions:

1. What is happening?
2. What is the cause of the incontinence?
3. Can the problem be fixed or improved?
4. What is going to be the best management, i.e. how can we fix or improve the incontinence?
5. If the incontinence can't be prevented or cured, what is going to be the best way to contain the problem?

The knee-jerk reaction when an incontinence problem is first identified is often to say 'What pad will we use?' Although this is an important factor to consider in making a person comfortable, this is not the place to start.

A plethora of continence assessment tools or forms has been developed to assist us in answering these questions. Whatever form or tool or framework is used needs to include the factors listed in Table 9.2.

Table 9.2 Continence assessment framework

- Incontinence sufferer's perception of the problem
- Functional assessment —what is the person capable of? (including mobility, dexterity, mental status and personal care needs)
- Social situation
- Medical history (including surgical, obstetric/gynaecological and urological history)
- Current medications (prescribed and unprescribed and how they are actually taken)
- Dietary and fluid intake
- Bowel status, including any current bowel management used
- Bladder status — how often is the person wet, how wet, how many times do they void, characteristics of the urinary stream etc.

The depth to which you need to explore the problem depends on:

- your level of knowledge and training
- the care setting
- the type of client you are caring for.

The trick is knowing what is appropriate for you and your situation and knowing when and where to ask for the help to go to the next step.

Assessment: stage 1

Getting the basics for continence in place

We must check out the basic factors we know have an impact on ability to maintain continence. When these 'basics to maintaining normal bladder function' are in place, some incontinence will be cured and, importantly, some incontinence will be prevented.

1. Fluids

All normal adults should maintain a daily fluid intake of at least 6–8 glasses (1. 5–2. 0 litres) but not more than 2.5 litres daily (unless otherwise advised by a doctor). It is advisable also to limit the consumption of caffeine (through tea, coffee, caffeinated soft drinks etc.) and alcohol because of the effect these substances have on the bladder. Caffeine is an irritant to the bladder, increasing the sense of urgency and inability to hold on. It is also a diuretic, increasing the volume of urine produced. Alcohol is also a diuretic and affects the entire central nervous system including the centres in the brain that control the bladder.

Questions to ask:

- ***How much is the person drinking? (too much/too little?)***
- ***What are they drinking?***
- ***When are they drinking it?***
- ***What do they like to drink (in order to promote best possible intake)?***
- ***Do they need assistance/reminders to drink?***

2. Toileting habits

Practising healthy toileting habits helps to prevent as well as improve problems. These include ensuring that the person doesn't go to the toilet 'just in case' but only when he/she feels the urge. A person must take his/her time actually going to the toilet, making sure that the bladder is completely empty each time. Knowing what is normal and not toileting too frequently or infrequently is part of this. It is normal to go to the toilet 4–6 times per 24 hours and to pass about 300–500 mls each time. At night we should be able to sleep through or go to the toilet only once.

Position on the toilet is also important. The best position to promote effective emptying of the bladder each time is sitting with feet slightly elevated on a small stepstool, leaning forward with legs slightly apart and elbows on knees. This enables the best possible pelvic position on the toilet and aligns the bladder and bowel with their outlets so that gravity assists evacuation. Straining to empty the bladder or the bowel should be avoided at all times as this may weaken the pelvic floor muscles.

Questions to ask:

- ***Does the person toilet in response to an urge to go?***
- ***How many times does a person go to the toilet each day?***
- ***When they toilet, do they pass an amount within the normal volume range?***
- ***Does the person take adequate time when going to the toilet?***
- ***In what position does the person toilet?***

The best way to answer some of the above questions is to complete a bladder chart or a continence chart which documents over a period of at least 2–3 days a person's bladder and incontinence pattern (see over).

USE OF BLADDER/CONTINENCE CHARTS

Bladder or continence charts are useful tools that may be used at any level of assessment and evaluation. As well as being used in assessment, they can be used to direct and monitor management such as a bladder retraining program. The period of time over which bladder charts are collected depends on:

- the purpose of the chart
- the setting
- who is going to be keeping the chart.

Bladder charts can take many forms and some are extremely complex. Again it depends on the purpose of the chart and who is going to be using it. Regardless of what they look like, all charts need to provide some basic information:

- frequency of voiding

- frequency of incontinent episodes
- voided volumes
- some sort of explanation of what is recorded on the chart.

Fluid intake is also often included on a bladder chart.

A typical bladder chart looks like this:

Date: 4/12/00				
Time	Volume passed in toilet	Dry	Damp/Wet/Soaked	Comments
2.00 a.m.	350 mls	✓		
5.00 a.m.			S	Woke up already wet
7.00 a.m.	100 mls	✓		
10.30 a.m.			W	Attempted to toilet, couldn't hold on and wet on the way — nothing left to pass when got there
12.15 p.m.	200 mls	✓		
4.30 p.m.	250 mls	✓		Out shopping. Very urgent, but managed to hold on
6.30 p.m.	100 mls	✓		
10.45 p.m.	150 mls		D	Very urgent, lost some (damp) getting to toilet but still able to void

3. Bowels

Maintaining regular bowel function is an important part of preventing both urinary and faecal incontinence. Constipation is one of the most common causes of urinary and faecal incontinence, so avoiding or treating constipation may improve urinary problems. The simplest and best way to do this is by ensuring the basics of bowel management are in place:

- eating a high-fibre diet
- drinking enough fluid
- taking daily gentle exercise
- avoiding constipating substances such as some drugs and foods.

Once again, best possible positioning on the toilet (see above) makes the actual emptying of the bowel as easy as possible.

Questions to ask:
- ***Does the person have a regular bowel action (not necessarily daily)?***
- ***Are the bowel actions soft but formed?***
- ***Are the bowel actions easy to pass, i.e. no straining or pain or discomfort?***
- ***What has been the person's previous pattern?***
- ***Are they well positioned on the toilet?***

Assessment: stage 2

Screening for the common causes

Once the basics for continence are in place, if the problem persists, it is time to check for some of the common causes of incontinence.

1. Medications

Obtain a medical review of any medications taken, as some commonly prescribed medications may be causing or worsening incontinence of the bladder or bowel. Medications that can have a constipating effect include iron tablets, some antidepressants, analgesics, and diuretics, which can increase urinary urgency and frequency and urge incontinence. Bladder emptying may be impaired by medications that have an anticholinergic action, such as some antidepressants. Sedatives may also be part of the problem.

Questions to ask:
- ***Do the person's medications need reviewing?***
- ***Are there some prescribed medications that may be affecting the person's incontinence?***

2. Mobility

Getting to the toilet may be hampered by reduced mobility. The condition causing the immobility may be able to be treated or better managed from either a medical or functional point of view. The person may benefit by being medically assessed or having a physiotherapy or occupational therapy assessment. For example, a person's arthritis may be better controlled or better pain management may be possible. They may also find a stick or a walking frame improves their ability to get around the house, and thus increase their speed to the toilet.

Questions to ask:

- ***What do you think lies behind the decline in mobility?***
- ***Has the immobility been assessed by an appropriate professional?***
- ***If mobility is improved, do you think continence will improve?***

3. Cognition

Impaired cognitive function may contribute in a variety of ways to the person's continence problem.

- Reduced memory may mean that the person forgets on the way to the toilet what it is that they are doing, or they may forget where the toilet is.

- Maybe their inhibition is affected which could result in inappropriate voiding.

- Perhaps they can't seem to work out what this feeling from their bladder means and what to do with it, but it seems to make them restless or agitated.

- Perhaps they are not aware of any sensation.

These are all different problems and need to be managed in different ways in order to achieve continence. A medical assessment is often indicated, especially if the confusion or changes have occurred quickly, as the underlying cause may be treatable.

Questions to ask:

- ***How long has the reduced cognition been a problem?***
- ***Has the cognitive problem been properly assessed?***
- ***What exactly is it that the person can't do because of the cognitive problem?***
- ***Is it possible to compensate for this cognitive loss somehow with a management strategy (e.g. using appropriate signage, prompted toileting)?***

4. Environment

We need to apply a common-sense eye over the environment around the person who is incontinent to see if factors such as distance, obstacles, routine and carer availability are contributing to the problem. Sometimes issues such as lack of privacy, difficulty opening the handle on the toilet door, height of the toilet seat, space to manoeuvre in the toilet, and steps, just to name a few, become barriers to continence. Some of these barriers we can remove (e.g. fixing the handle on the door), others we have to work around.

Questions to ask:

- ***Does the environment, routine etc. offer any barriers to the person being continent?***
- ***Can these barriers be removed or overridden?***

5. Urinary tract infection

A urinary tract infection (UTI) is one of the common causes of urinary incontinence. Everyone with urinary incontinence should have their urine tested routinely for infection early in the assessment process. A urinalysis dip stick will indicate whether further laboratory testing (through the local doctor) is required. The person's symptoms will often be a good indicator, however, we need to be aware that an infection may not be obviously symptomatic. The most common symptoms of a UTI are burning or discomfort while passing urine, and cloudy and offensive-smelling urine. Remember though that more general symptoms such as increased confusion and fever may be signs of a UTI.

Questions to ask:

- ***Does the person complain of burning/pain while passing urine?***
- ***Does the urine smell/look strange or different?***
- ***Has the urine been tested recently?***

6. Constipation and impaction of faeces

Constipation is frequently a causative factor in both urinary and faecal incontinence. If there is no improvement with the basics of good bowel care in place (see above), there needs to be further assessment of the problem. Constipation can be defined as the absence of at least one normal bowel action and is characterised by the difficult passage of a dry, hard stool as a result of the delay in its passage through the bowel. A period of charting recording the frequency, timing and characteristics of bowel motions is therefore helpful. Charting fluid and dietary input at the same time as bowel pattern is useful in helping to determine cause. The constipation may result from a variety of reasons and in a number of ways. So, prior to commencing management, we need to know what we want to change:

- Do the bowel motions need softening, or bulking up?
- Does the lower end of the bowel need to be stimulated to help evacuation?
- Would some lubrication and improved positioning help?

Involving the person's GP is often advisable as an abdominal and rectal examination and a plain abdominal x-ray will assist in determining the severity and extent of the problem.

Questions to ask:

- ***How frequent and regular are the bowel motions?***
- ***What consistency and size are the bowel motions?***
- ***Does the person experience any difficulty passing the stool?***

7. *Seeking specialist help*

If the above screening steps don't achieve any improvement, it is important that specialist help is sought. Regional and local continence services provide a clinical service when it is required. Make sure that you know where your local continence service is and how to contact them. The National Continence Helpline run by the Continence Foundation of Australia can provide you with advice about any specific person and their problem and can put you in touch with your local continence clinicians: National Continence Helpline, telephone 1800 33 00 66, website www.contfound.org.au

Assessment: stage 3

When a problem doesn't respond to initial efforts to put the basics for continence in place nor to screening for the known common causes of incontinence, specialist continence assessment is required. Don't hesitate to call on a continence specialist or service to help you provide the care your client requires. They will address a number of areas as appropriate.

Taking it further — specialist continence assessment

1. *Bladder dysfunction*

Assessing for specific bladder dysfunction, such as an unstable bladder or undercontractile bladder, will include taking a more detailed history, making a physical examination and measuring voiding flow rate and residual volumes. Some continence services will also offer urodynamic investigation (a test that assesses bladder function by measuring pressures inside the bladder during its filling phase and then while it empties).

2. Bowel dysfunction

Assessing bowel dysfunction, such as anal sphincter impairment, and dealing with constipation and impaction that does not respond to earlier strategies will involve a more detailed history and physical examination. A plain abdominal x-ray will often form part of this level of assessment. A surgical opinion may be sought which may involve further testing such as anal pressure (manometry) studies.

3. Biodynamics of elimination

Assessment of the biodynamics of voiding and evacuation of the bowels involves detailed observation of position and the sequencing and use of muscle groups that need to coordinate for complete evacuation of the bladder and the bowel.

4. Use of continence aids and appliances

Most carers will be aware of some of the continence products available. A continence nurse adviser will be able to assist in selecting products from the large range available (see box).

WHAT TO DO — THE MANAGEMENT/TREATMENT OPTIONS

The goal of managing incontinence is quality of life for all concerned — the person who experiences incontinence and their family and carers. The aim is also continence. While 'dryness' is not our aim, continence is, and it is achievable even in an elderly and dependent population. We can say this because there are number of ways that continence can be defined and understood:

1. **Independent continence:** The person, through treatment or management strategies carried out by themselves, is continent or dry.

2. **Dependent continence:** A person achieves continence by the implementation of a management strategy carried out by another person (i.e. the carer) without whom the person would again be incontinent.
3. **Social continence:** Although the person is not 'dry', by the use of appropriate management strategies that may include continence aids and appliances, they are comfortable. Furthermore, their incontinence is not obvious to others and it does not stop them from undertaking any activity in which they wish to be involved.

SELECTING A CONTINENCE PRODUCT

There is no such thing as the 'ideal' pad or product for containing incontinence across the board. There is a multitude of products available and the key to choosing the most appropriate product is knowing the person and his/her problem. As with all other aspects of continence management, the choice will be based on an individual assessment. It is important to note also that a person may use a number of different products and types of products as their condition changes and their activities dictate.

When helping to choose the right product for a person, you must consider the following factors:

- gender
- physical size and shape
- amount and character of the incontinence (e.g. large volumes in gushes)
- lifestyle/activities
- clothing generally worn
- independence with use/application/toileting
- laundry/storage/disposal facilities
- finances
- availability of supply
- personal likes and dislikes.

The large range of continence products available includes:

- disposable pads and pants/diapers for both urinary and faecal incontinence
- washable pads and pants
- condom drainage
- absorbent bed and chair pads
- urinary catheters, both intermittent and indwelling
- faecal collectors and anal plugs
- bladder neck support devices and urethral plugs.

Information about the range available can be obtained through your local continence service, directly through companies and suppliers or through national and state centres of the Continence Foundation of Australia (National Continence Helpline: 1800 33 00 66, website www.contfound.org.au

In general, independent continence is achievable for many people. However, when caring for the elderly or the disabled, dependent continence is the more realistic goal for most. Social continence should be achievable for everyone, no matter what their living situation.

Management: stage 1

Laying the basic building blocks

1. Fluids

To ensure that the person's fluid intake is part of the solution and not the problem, make sure that adequate fluids (6–8 cups per day) are available, taking into account their likes and dislikes. Ensure assistance to reach and drink is provided as required. Offering small, frequent drinks may be easier to cope with when attempting to increase fluids. Ensure that the majority of fluid intake is not caffeinated fluid. Try decaffeinated fluids, herbal alternatives etc.

2. Toileting

When possible, toilet in response to the urge to go. Avoid going just in case. Give the person plenty of time and privacy. Provide a footstool and encourage them to lean slightly forward when sitting on the toilet to promote the best possible position.

3. Bowels

Promote a good bowel habit and avoid constipation by eating a balanced diet. This includes a good breakfast that will stimulate the first gastrocolic reflex of the day, and about 30 grams of fibre each day. Daily activity further assists transit time of food through the intestine.

4. Pelvic floor muscles

Another important basic for women in particular is a healthy pelvic floor. Women can ensure best possible pelvic floor muscle tone by making pelvic floor muscle exercises part of their daily routine and by maintaining a normal weight for their age. It is also important to not put undue strain on the pelvic floor by avoiding heavy lifting or repeated straining with chronic constipation. Fact sheets (in various languages) about how to do pelvic floor exercises are available from the Continence Helpline free of charge.

There are some other ways in which everyone who cares for a person with incontinence can help ease the problem. While they may not be reducing the problem directly, the following strategies must not be underestimated for their ability to improve a person's quality of life:

- offering empathy
- providing education and information about incontinence in a way they understand which challenges the myths and the negative attitudes
- ensuring a person's privacy and dignity at all times.

Management: stage 2

Overcoming the common causes

1. Medications

Ensure that the treating doctor has been contacted to review medications. It is important to make sure that if changes are made, the person understands that this is the case and why they have been made in order to ensure that they then take what has been prescribed.

2. Mobility

Immobility may be improved by treating the underlying cause, where possible. A referral to an appropriate medical or allied health professional may achieve improved function. Assisting the person to use their mobility aids appropriately may speed their journey to the toilet enough to help them avoid incontinent episodes.

3. Cognition

Once we have identified how a person's cognitive impairment is impacting on their ability to be continent, we will know what management strategies may improve the situation. Management strategies could include prompts in the form of appropriate signage, verbal cues and directions from staff, or actually toileting the person in response to a signal from them (e.g. pacing or plucking at trousers) or at timed intervals based on a bladder/continence chart.

4. Environment

Interventions with regard to the environment are again largely common sense and based on an assessment that looks broadly at the incontinent person in their context. Appropriate modification and improvement of the environment will take into account as much as possible such issues as distance, obstacles, assistance, privacy and carer availability. Improving the environment in order to promote continence may include improving caregiver attitude and knowledge through education.

5. Urinary tract infection

If a UTI is present, as well as informing the person's treating doctor, there are some other strategies we can use to support medical treatment.

- Encouraging extra fluids can help (unless contraindicated), especially in the early stages of an infection.

- Drinking fluids that can alter the pH of urine, such as lemon barley water, may help because they make it more difficult for organisms that commonly cause UTIs to live in such an environment. Cranberries are being used increasingly to combat and prevent UTIs and can be taken in juice, tablet or capsule form.

- Other supportive strategies include nonrestrictive pants and clothing, eliminating the use of talcum powder and perfumed soap, and ensuring the use and regular changing of quality continence products.

6. Constipation and impaction of faeces

Constipation and impaction need to be treated with the appropriate agent, taking care to ensure that the mechanism of constipation is determined. Decisions about use of medications to treat constipation and impaction need to be made in consultation with a nurse and the person's doctor.

Management: stage 2

Taking it further — specialist continence care

1. Bladder dysfunction

Management for specific bladder dysfunction such as an unstable bladder or an undercontractile bladder may include bladder retraining, or a pelvic muscle rehabilitation program and use of medications. It may also include the use of catheterisation (both intermittent and indwelling) although this is generally a management option used as a last resort.

2. Bowel dysfunction

Management of bowel dysfunction such as anal sphincter impairment, reduced transit times etc., may include further dietary manipulation, and use of appropriate medications and muscle re-education. Surgical options may be appropriately explored for treatment for some people.

3. Biodynamics of elimination

The person may need to be re-educated regarding the way they go about emptying their bladder and bowel. It has to do with positioning and the use of appropriate muscle groups and muscle coordination.

4. Use of continence aids and appliances

If the goal of continence management is quality of life, for many people whose problem cannot be resolved the use of appropriate continence aids is the way that quality of life can be achieved. Having taken into consideration all the factors listed earlier, the process of selecting and trialling the use of an appropriate product or continence aid begins. Often coming up with the right combination of products for an individual takes quite a bit of fine tuning, and the experience and expertise of a continence nurse adviser is helpful. The adviser will also be able to help the person access any potential avenues of financial assistance to fund their continence products.

CONCLUSION

Urinary and faecal incontinence present enormous challenges both to those who suffer them and to those who care for sufferers. Incontinence is a multifaceted problem that affects people on a physical, psychological and social level. Because of social taboos and lack of recognition of incontinence as a serious health issue until recent years, incontinence has been a hidden problem. People still conceal their struggle behind the privacy of their front doors. However, with changes in health care delivery, community workers are walking through people's front doors and finding that one of the significant care issues is often incontinence. We can do much more than mop up puddles, change beds and buy packets of pads. It is within the scope and ability of all community-based carers to provide the basic building blocks for continence.

FURTHER INFORMATION ON THE NATIONAL CONTINENCE HELPLINE

1800 33 00 66

The National Continence Helpline is a telephone information, referral and counselling service managed by the Continence Foundation of Australia and funded by the Commonwealth government's National Continence Management Strategy under the *Staying at Home* Aged Care Package.

The Helpline is a free-to-caller service staffed by qualified continence nurse consultants. The Helpline offers a national service from 8 a.m. to 8 p.m. (Australian Eastern Standard Time) seven days a week.

The Helpline is confidential and aims to provide relevant and current information on incontinence and related issues for all callers, whether they are health professionals, carers or members of the general public.

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CHRISTINE BIGBY

Bachelor of Arts (Honours), Master of Social Work, Doctor of Philosophy

Senior Lecturer in the Department of Social Work and Social Policy, LaTrobe University, Bundoora

Dr Christine Bigby works in the Department of Social Work and Social Policy at the Bundoora Campus of LaTrobe University. She has extensive experience as a social work practitioner in both direct service and policy development. Her primary research and practice interest for the last 10 years has been older carers and ageing people with intellectual disability. Her doctoral research examined the informal and formal sources of support for middle-aged and older people with intellectual disability and the nature of their transition from parental care in mid-life.

Chris has sound links to policy and practice in the field of intellectual disability and a track record of research and consultancy projects. She has published widely in key disability journals both in Australia and overseas. Chris is president of the Victorian Branch of the Association for the Study of Intellectual Disability. She won the Association's National Research Award in 1993.

CHAPTER TEN

Sustaining Supportive Networks: The Challenge of Continued Community Living for Older People with Intellectual Disability

Christine Bigby

INTRODUCTION

The lifespan of people with intellectual disability has increased dramatically in the last 50 years, from an average of 22 years in 1931 to 66 years in 1997 (Carter and Jancar, 1983; Janicki et al., 1999). Thus ageing people with intellectual disability are a relatively new group in the community, and the current cohort is the first to survive into later life in any sizeable number. Professionals working in community care from the health, disability or aged care sectors have little knowledge about this group or experience of working with them. Little policy and few service development strategies are in place to address their particular needs.

People with intellectual disability are a diverse group who embark on the ageing process from many different starting points in terms of place of residence, employment history, family constellations and health status. For example they live in a range of settings including:
- large institutions
- specialist community-based accommodation such as group homes and hostels
- generic congregate care settings such as boarding houses and privately funded supported residential services
- private homes, alone or with family or friends.

However, the majority of adults with intellectual disability live at home with parents throughout young adulthood and into middle age, despite being born in an era of institutionalisation.

Enabling those already living in supported accommodation to 'age in place' is a formidable task confronting disability service systems. Supports must be reconfigured to take account of the physical decrements associated with ageing, changing health needs and 'retirement' from full-time employment or attendance at day activity programs. New combinations of staff expertise — incorporating knowledge of aged care and disability, architectural adaptations, and new mixes of day and residential support — are required to create optimal environments to allow people with disabilities to age successfully. The challenges, regardless of place of residence, are to:

- maintain informal networks, community links and inclusion in the community
- facilitate participation in activities of choice
- ensure the retention of skills and a maximal level of functioning and health.

Attainment of successful ageing in place for those already in supported accommodation is an issue that primarily confronts residential service systems rather than community-based professionals.

Ageing poses major challenges for people with intellectual disability who remain at home, as they are more likely than ever before to outlive their parents and, during middle age, lose their lifelong advocates and primary carers. The tasks of supporting older carers to plan for the transition from parental care and assisting them to 'let go' are complex and multifaceted (for example, see Bigby, 2000; Bigby and Ozanne 1999; Bigby et al., 1999; Janicki, 1996). Research suggests that parents do not relinquish care until forced to do so by death or incapacity, and that most formulate informal plans which negotiate the commitment of a family member or friend to oversee the future wellbeing of their adult child with intellectual disability. Such plans are open ended and seldom make more concrete arrangements for the day-to-day provision of support with tasks of everyday living. Few parents make what might be considered comprehensive plans for the future (Bigby, 1996). Parents who continue caring are, on average, 86 years old when they relinquish care and their adult children are aged, on average, 53 years when the transition from parental care occurs.

As a group, ageing carers are less stressed than other carers and anxiety about the future (rather than current caring tasks) is their major source of anxiety (Seltzer and Krauss, 1994). Many are out of touch with disability services and distrustful of professionals. Despite this, the transition from parental care, for most people with intellectual disability, is a gradual process, managed informally without recourse to formal services. Crisis and resultant trauma of a sudden transition to being managed by formal services rather than by informal network members is comparatively rare (Bigby, 1996). Nevertheless it is this type of transition that is most often seen by community-based professionals.

Research in Victoria challenges the commonly held assumption that adults with intellectual disability require 'placement' at the time of transition from parental care, suggesting that more than half remain living in the community (Bigby, 1996). In Bigby's study, at the time of transition, of all the adults in the study:

- 61 per cent continued to live in a private home
- 21 per cent moved to aged care accommodation
- 18 per cent moved to specialist disability accommodation.

Of those who remained in private homes half lived with other family members, primarily siblings, and the rest lived alone with formal and informal sources of support. At the time of their transition only a few adults were 'old' according to the usual chronological definition of 65 years. Approximately half were over 55 years and met the younger definition of 'older' that is commonly used in respect of people with intellectual disability. At this stage their need for support with activities of everyday living stemmed from the loss of a lifelong primary carer and their lifelong disability rather than from age-related loss of functional abilities or poor health.

It is this group, who remain in the community after the loss of parents, many of whom have never used formal disability services, with whom community-based human service professionals are most likely to come into contact. The major task confronting professionals is to support continued community living and avoid premature or unnecessary entry into institutional or congregate care; although, at times, recognition of the necessity of moving to a more intensively supportive environment and assistance to locate and make the transition to an alternative living situation may also be important. Older people with intellectual disability have many of the characteristics of 'highly vulnerable clients' for whom Rothman (1994) suggests the objectives of practice are optimisation of their potential within existing limits rather than the more traditional aims of cure or adjustment. Such practice has intensity not found with other groups, requires involvement of lengthy duration, and encompasses a breadth of needs rather than focusing on one aspect of a person's life. It involves individual help, such as practical assistance, skill development and emotional support as well as broader tasks such as community linkage, social network development, service coordination and advocacy. These tasks are not fundamentally different from those fulfilled for other groups of ageing people in the community but additional understanding and skills are required to work successfully with ageing people with intellectual disability. This chapter explores the impact of intellectual disability and ageing, and the issues that may arise in working with this group in the community.

THE IMPACT OF INTELLECTUAL DISABILITY

Across cultures and time, diverse labels are used to refer to people with intellectual disability, reflecting differing constructions and understandings of the problems this impairment poses for individuals and society. Many labels have derogatory overtones such as 'moron', 'idiot', 'imbecile', 'retarded' and 'mentally deficient'. 'Mental retardation' is still the dominant term in the US. In the UK the phrase 'people with learning difficulties' is most commonly used.

Considerable confusion often exists between intellectual disability and mental illness. As many as 22 per cent of people with intellectual disability also have mental health problems (Wen, 1997). A person with intellectual disability has a low level of conceptual, practical and social intelligence. This means they have substantial limitations in present functioning and fundamental difficulty in learning and performing certain daily life skills. The formal legislative definition in Victoria is found in the *Intellectually Disabled Persons Services Act,* 1986:

> Intellectual disability in relation to a person over the age of 5 years, means the concurrent existence of — (a) significant sub-average general intellectual functioning; and (b) significant deficits in adaptive behaviour — each of which became manifest before the age of 18 years. (3(4)).

'Sub-average general intellectual functioning' is defined as not higher than two standard deviations below the population average, and 'adaptive behaviour' includes such things as communication, self-care, home living, social skills, community use, self-direction, health and safety, functional numeracy and literacy, leisure and work.

In practical terms, this definition means a number of things:

- People with intellectual disability have difficulty thinking in a conceptual or abstract way. They are very concrete thinkers who find it hard to deal with complex ideas as well as to generalise, forward plan, predict obstacles and deal with the unexpected. For example, a person may learn to use public transport for a particular journey but without support be unable to generalise this skill to reach another destination.

- People with intellectual disability learn everyday tasks at a slow rate; they may require prompting, sequenced steps, or structured routines and environments to facilitate completion of tasks.

- Many cannot read or write and have limited numeracy skills or comprehension of value, price or money. This means they have difficulty budgeting and managing their finances.

- Communication skills may be limited and many people with intellectual disability have difficulty learning or understanding the nuances of social interaction. Poor social skills and transgression of social etiquette are therefore quite common. For example someone with intellectual disability may contact a worker or friend frequently, perhaps two or three times a day, or make seemingly simple non-urgent requests out of hours. People with intellectual disability may be prone to overstepping boundaries of social or professional relationships by seeking greater intimacy or have expectations that roles beyond those conventionally expected of workers will be fulfilled.

- Without regular support people with intellectual disability may have difficulty in maintaining levels of personal hygiene, domestic cleanliness, household management and diet that are acceptable to in-home support workers. This can be confronting, challenging standards expected by workers or relatives, and raising questions of what are acceptable living conditions. It may also pose ethical dilemmas regarding protective intervention, which require risk taking and personal choice to be weighted against protection and personal safety.

Untangling the inherent impact of disability from the effect of restricted external opportunities, life experiences and consequences of being a person with a disability are difficult. For example, many people with intellectual disability exhibit poor self-control and anger management, and inappropriate social behaviour. Such behaviour is as likely to result from childhood separations, emotional deprivation and the absence of positive role models in segregated environments as from low intellectual abilities.

It is important to note that other personal capabilities such as health and temperament may not be affected by intellectual disability and that limitations coexist with strengths in other adaptive skills and capabilities. Fundamental too is the recognition that all people with intellectual disability have the capacity to develop and, with appropriate support over a sustained period, their level of functioning will generally improve (AAMR, 1992). The social model of disability also suggests that much of a person's disability stems not from their physical or intellectual impairment but from the organisation of the social world they inhabit. For example, the increasingly complex competitive world of the new century, which values and rewards high achievement and is reliant on written or electronic words for communication, excludes rather than includes those with poor cognitive skills. When technology such as ticket machines and automatic tellers replaces tram conductors and bank tellers the result is often the erection of additional barriers for people with intellectual disability and the loss of crucial human supports that enabled their participation in everyday life. Thus, overcoming disability must be tackled by effecting social and attitudinal change as well as by providing individualised training and supports (Rioux, 1997).

CHARACTERISTICS OF AGEING PEOPLE WITH INTELLECTUAL DISABILITY

The current cohort of ageing people with intellectual disability was born between the 1920s and 1940s. These people grew up in a period of pessimism regarding their potential, with few educational opportunities or family support services available. A sharp contrast exists between their experiences and those of children with intellectual disability in the 1980s and 1990s. Thus each generation brings a different set of life experiences and opportunities to their ageing process. Missed opportunities and protection rather than development and risk taking are themes often discussed by siblings of this generation of older people (Bigby, 2000). For example, one sister said,

> It just makes you realise, that had things been available for Amy as they are now, the potential that could have been realised.

A brother said,

> Dad wouldn't let him do anything himself and mum wouldn't let him if Harry wanted anything, one of them would do it like combing his hair or having a shave . . . or even getting dressed and that, he was never allowed to do what I think he should have been allowed to do . . . they [parents] were too good if you can put it that way . . .

People with intellectual disability have few opportunities for employment or to accumulate savings and superannuation for their old age. Most do not marry or have offspring and so in later life lack the two most common sources of informal support — spouses and children. The social networks of people with disabilities who remain at home with parents are dominated by family members and insulated from the broader community (Grant, 1993). They share many network members with their parents and consequently their informal social networks are comprised of people from the same or an older generation. Their friendships tend to be tied to particular contexts such as locality or day programs and are vulnerable to disruption when the person moves from that context. This may be accentuated by the failure of family and professionals alike to recognise the existence and significance of independent friendships between people with intellectual disability. All these factors have implications for the type of support they are likely to require and their ability to remain and age successfully in the community once their parents die or become incapacitated.

Perceptions of 'old age' differ. Aged care services are generally geared towards provision of services for those aged 70 years and older, but many staff in disability services would regard a person as 'older' when they are as young as 45. These differences are related to a relative lack of experience of ageing in the disability field and the myth that people with intellectual disability age prematurely. Research indicates that generally this is not so and that people with intellectual disability age in a manner similar to that of the general population (Adlin, 1993). They suffer from the same age-related chronic and acute health issues but experience higher rates of hypothyroidism, cerebrovascular disease, epilepsy and Parkinson's disease and have high rates of untreated health conditions (Cooper, 1997a; 1997b, 1998; Ashman et al., 1996). This highlights their poor access to sensitive and appropriate health care.

People with Down syndrome experience premature ageing and as many as 45 per cent suffer from early onset dementia of the Alzheimer type (Dalton et al., 1993). However, assumptions should not be made. Careful assessment and diagnosis are crucial as many treatable conditions such as depression or thyroid problems mimic symptoms of dementia. Diagnosis of dementia in people with intellectual disability is difficult and requires particular skills. Valuable resources in this respect are the comprehensive practice guidelines for clinical assessment and care management of Alzheimer's and other dementias among adults with mental retardation developed by Janicki and his colleagues (1996).

The majority of ageing people with intellectual disability are the younger old, rather than the frail aged and because of this they often fall between the disability and the aged care service systems. As one sister remarked about her brother when she tried to find appropriate services for him:

> Everybody has a bit of a mental block when you say he is 55. They said he doesn't fit into intellectual disability services, they didn't have much to offer and he's too young for aged services.

MAINTAINING COMMUNITY LIVING

For some ageing people with intellectual disability the post-parental care phase of their lives is a time of broadened opportunities and widened horizons (Bigby, 1997). Freed from the restrictions of supporting or living with elderly parents and with the support of a younger generation of key informal supporters with more optimistic expectations of their capabilities, some will make new friends, enter into intimate relationships for the first time, develop and exercise additional skills, and experiment with widened participation in community life. They are often able to remain in the community until significant age- or health-related changes occur to their own support needs or to the supportive capacity of those in their informal networks. For example, a sibling may be unable to continue supporting the adult with a disability if their own health or that of their spouse begins to fail. Nevertheless, the post-parental care phase can also be a period in which people with intellectual disability are vulnerable to an array of losses and potentially restrictive experiences. According to Bigby (1997) these include:

- control by others, be it family members or formal service providers
- loss and disruption of social networks
- mobility of residence and consequent loss of locality connections
- placement in inappropriate and unstimulating environments
- discrimination and rejection by other ageing people
- poor health and untreated conditions.

Continued community living can be a short-lived experience for some. For example, in Bigby's study, an average of 13 years after transition from parental care the proportion remaining in the community had fallen from 61 per cent to 26 per cent. Community living may be sustained only tenuously by finely balanced formal and informal supports. A characteristic of those who sustain successful community living is the establishment and maintenance of a broad supportive network, which fulfills, albeit in a different manner, the myriad roles previously undertaken by parents. At a minimum, these are the dual roles of oversight of wellbeing and reliable, proximal support with tasks of everyday living. A supportive network must therefore have the capacity for oversight of the person's situation, plus negotiation and coordination with formal services, as well as consistent support with instrumental tasks such as personal care, and domestic and household management. A supportive network must have the flexibility to deal with the unexpected, and include some members with sufficient commitment and freedom from organisational ties to tackle the unjust and ensure the best interests of the person with intellectual disability are always at the forefront of any intervention and their rights are upheld. To achieve this it is crucial that networks comprise both formal and informal sources of support and that responsibilities are spread across members, so that no one person or organisation bears an untenable load or exercises unchallengable authority over the person's life. The role of a community-based professional worker is one of network formation, maintenance or orchestration and includes:

- assembling and negotiating access to an array of formal supports, ranging from home help to luncheon clubs

- resourcing and supporting others in the network, both formal and informal members
- balancing needs and mediating conflict between the person with the disability and family members or services providers
- extending and maintaining the network by ensuring that members and functions are replaced when lost because of age or other contextual changes.

The following vignettes demonstrate the successes and pitfalls of maintaining community living for ageing people with intellectual disability and illustrate the challenges confronting community-based human service professionals in sustaining supportive networks.

VIGNETTE

Katherine has a strong, supportive network with informal members who are committed to her and maintain a close monitoring role on both her overall wellbeing and her tasks of daily living. Formal services complement the informal support provided to Katherine, and a senior citizens centre lunch program provides a vital shape to Katherine's days.

Katherine is 60 years old. When her mother died she continued to live in the family home with her brother. After neighbours expressed concern to the local council about the state of the house and Katherine's care, a social worker introduced her to the senior citizens club where she attended for lunch every day.

Her brother died a few years later and Katherine moved to live with her sister several suburbs away. The sister died several years later. When this happened, Fiona, aged 74, the president of the senior citizens, who had known Katherine for almost 20 years, took charge of her affairs, organising her sister's funeral and eventually tracking down a lost brother, now in his 80s, in a distant country town.

Katherine remained in her sister's rented flat with the support of a local case management program which organised for a domiciliary worker to visit every week to work out her budget and assist with paying bills and the shopping. Katherine continued to travel to the senior citizens centre every day for lunch. Fiona felt she was isolated from the locality she knew best and advocated for her to gain a place in a small older persons' housing complex near the centre.

Katherine has been living in the complex for 5 years now. Another active member of the club lives in an adjacent unit and she drops in on Katherine at home regularly, or Fiona does. A domiciliary worker assists with domestic tasks and shopping every week and Katherine's days are structured around her attendance at the club to lay the tables and have lunch. Katherine has few budgeting skills and Fiona has organised to give her half her pension at a time and has requested that no-one at the club lend her money. Katherine loves to wonder around the shops close to the centre, and buy ornaments and stuffed animals. Katherine has no friends at the centre and does not join in the bingo or other activities. She has no literary or numeracy skills. Her personal hygiene is poor and Fiona often has to remind her to shower or change her clothes. She potters around at home in the afternoons, watches TV and enjoys gardening. She has much the same food for tea every night.

VIGNETTE

In contrast to Katherine, Phyllis's supportive network, though larger, was less effective in sustaining her in the community. Lack of a key informal network member with a strong commitment to Phyllis was a major deficit in her supportive network. No-one took an active role in extending her informal sources of support or monitoring her situation regularly. As a consequence, how she coped on a day-to-day basis was unknown. Her supportive network was diverse and though it provided strong support for social activities it lacked a member with a strong coordination and resourcing role. Few of the workers in her network had an understanding of intellectual disability and therefore had unrealistic expectations of Phyllis. They found it difficult to cope with her behavior or accept her poor domestic skills. As a result, she received sporadic, less intensive assistance with too little direction and less routine than she required.

Phyllis was an only child and her closest relative other than her mother is a cousin. Phyllis has never worked but stayed at home and helped her mother with the housekeeping. Her father died in his late 70s. When Phyllis was 59, her mother, who was then 92, moved to a nursing home. The welfare worker from the local older persons community centre assisted in the move and organised support for Phyllis.

Phyllis sustained many of the previous social activities and the social network she had shared with her mother. A member of the church congregation picked Phyllis up every Sunday and took her to church as well as occasional other activities during the week. She attended the same weekly activities at the elderly persons centre as she had with her mother. She also tried a number of other specialist groups for people with disabilities suggested by the welfare worker but did not fit well into these.

The welfare worker organised Meals on Wheels and home help to assist with domestic tasks and, for a short period, a specialist outreach service provided some support. The welfare worker did not play a strong coordination or resourcing role in respect of in-home support services. Phyllis's cousin visited occasionally but did not step in and play a significant role in her life, nor was she encouraged or supported to do so. The church minister remained on the periphery of Phyllis's support network providing emotional support rather than taking a proactive or instrumental role in assuring her wellbeing.

Phyllis experienced tremendous difficulty in managing the day-to-day tasks required to maintain a household and care for herself. The condition of the house deteriorated as it became cluttered with rotting food, rubbish and dirty clothes. The support provided by domiciliary services was not sufficiently intensive or frequent and failed to compensate for her lack of regular cleaning and laundry routines. No-one in her network was sufficiently aware of Phyllis's daily management skills to ensure she received an adequate level of support and no-one visited regularly enough to monitor how she was coping.

For a while Phyllis bought the same groceries every week from a list established by one worker, and her cupboards were full of certain items such as jam and detergent. Some domiciliary workers were reluctant to take a more directive role in her life by, for example, reorganising her weekly shopping or advising her on diet. The turnover of support workers was high and Phyllis had frequent arguments with them and was sometimes quite aggressive towards them. When this occurred they left, leaving the week's tasks unfinished. Regularly workers refused to go into the house because of its poor state. Phyllis used the telephone a great deal to stay in otuch with the welfare worker and members of the church community and ran up a horrendous bill. Despite her regular social activities, Phyllis spent many hours at home alone.

Phyllis survived on her own for 18 months, but readily agreed to move into an older persons' hostel when this was suggested by the welfare worker. It took many months of searching to locate a hostel willing to accept Phyllis. The welfare worker continues to be in contact with her, acting as her advocate. Phyllis has no assets and is reliant on her pension. Although she is the sole beneficiary of her mother's will, her mother is still alive and the administrator refuses to use any of her mother's estate to ease Phyllis's dire financial situation.

- How may Katherine's supportive network be at risk in the future and how can this be reduced?
- Why was Katherine's network more successful in sustaining her in the community than Phyllis's?
- How could Katherine's friendships and social activities be extended?
- What legitimacy does Fiona have to organise Katherine's financial affairs? Does a more formal arrangement need to be put in place?
- Did it place too great a strain on Phyllis to remain at home alone?
- Was she placed at too great a risk?
- How could she have been supported more adequately to stay in the community?
- How might her relatives and other informal network members have been melded into a more effective support system for her?
- What other alternatives to an aged persons' hostel might have been considered for Phyllis when it became necessary to find a supportive environment?
- Why is it important that the welfare officer remain in touch with Phyllis or that she find an informal replacement network member to do so?

These are just some of the issues to consider in relation to Katherine, Phyllis and others like them with intellectual disability who are ageing in the community.

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CHRISTINE CROSBIE

Registered Nurse, Registered Midwife, Graduate Diploma of Health Education, Master of Educational Studies, Member of the of Australian Diabetes Educators Association

Director Education Services, International Diabetes Institute, Caulfield, Victoria, Australia

Christine has worked in the area of diabetes education for 19 years. In this time she has been instrumental in establishing the client and health professional education programs at the International Diabetes Institute. She is particularly interested in the development of client-centred integrated models of care that are efficient in terms of health, cost and resources.

Christine has provided diabetes consultancy services at state and national level in Australia, as well as internationally. She has also been actively involved with the planning of postgraduate diabetes education programs and continues this interest in an advisory capacity.

CHAPTER ELEVEN

Diabetes and its Impact on the Ageing Person

Christine Crosbie

INTRODUCTION

Diabetes affects approximately 800 000 Australians. Approximately 400 000 have identified diabetes, while the remaining 50 per cent are as yet undiagnosed. Diabetes prevalence increases with age (Hiltunen et al., 1994). In Australia the proportion of persons 65 years and over is set to rise dramatically. It is predicted that by the year 2051 there will be a 12–15 per cent increase in this population group, while those aged 85 years and older will have increased from 10 per cent in 1997 to approximately 19 per cent by 2051 (ABS, 1999).

Increased life expectancy in addition to a sedentary lifestyle contributes to the increasing prevalence of Type 2 diabetes. Diabetes has become a major public health issue in Australia, and indeed, much of the developed world. By 2010 it is predicted that worldwide there will be more than 230 million people with diabetes (McCarty et al., 1996).

WHAT IS DIABETES?

Diabetes is a condition affecting carbohydrate, protein and fat metabolism. Classic symptoms, when present are:
- thirst
- passing copious amounts of urine
- extreme tiredness.

Other symptoms include:
- skin infections

- thrush (oral and/or genital)
- visual disturbances
- weight loss in those with Type 1 diabetes.

There are two main types of diabetes mellitus known as Type 1 and Type 2. Type 1 diabetes (formerly called insulin-dependent diabetes) accounts for approximately 10 per cent of total cases while Type 2 (formerly known as non-insulin-dependent) accounts for about 90 per cent of cases.

Type 1 diabetes can occur at any age, but mainly occurs in those aged 30 years or younger. People with Type 1 diabetes have no endogenous insulin production and require insulin injections for survival. In addition to insulin replacement, management also includes a healthy eating plan. Physical activity is advocated for the positive general health benefits it confers. Type 1 diabetes is classified as an autoimmune disease of unknown aetiology.

In contrast, Type 2 diabetes occurs mostly in people over 30 years of age. In Type 2 diabetes there is resistance to the action of insulin as well as a relative lack of insulin. Type 2 diabetes is managed with a program of healthy eating and weight reduction (where appropriate). Where this combination is insufficient to control blood glucose oral anti-diabetic agents may be added. In some cases it may be necessary to add insulin injections with or without an anti-diabetic agent. It is important to note that this does not mean that these individuals have Type 1 diabetes, but rather require insulin injections to control blood glucose levels.

The exact cause of Type 2 diabetes is also not known, however it is clear that a person carries a genetic predisposition to the disease. This, together with one or more environmental determinants such as increasing age, physical inactivity or central distribution of body fat, increases the likelihood of developing diabetes (Zimmet, 1983).

Many with Type 2 diabetes have what is called the 'metabolic syndrome'. This is a combination of:

- Type 2 diabetes or impaired glucose intolerance
- hypertension
- central obesity
- dyslipidemia (high levels of fat in the blood).

This combination is called the 'deadly quartet', in that it significantly increases the risk of morbidity and mortality related to cardiovascular disease (CVD). For this reason treatment of these people needs to focus not only on control of blood glucose but on reducing the other risk factors for CVD. This message is supported by the findings of the United Kingdom

Prospective Diabetes Study (UKPDS) and presents a challenge to health care professionals (UK Prospective Diabetes Study Group, 1998).

It is clear that uncontrolled diabetes can lead to damage of the circulatory and nervous systems. This in turn may result in damage to the:

- eyes
- kidneys
- feet
- cardiovascular system.

Diabetes is a leading cause of heart disease and stroke.

Diabetes complications are related to the duration of the disease and the presence of other risk factors including:

- elevated blood glucose
- elevated blood pressure
- elevated blood fats
- smoking.

The UKPDS has clearly demonstrated that significant reductions in the rate of diabetes complications can be achieved through aggressive management of risk factors.

The UKPDS (1998) also showed that, nine years after diagnosis, 20 per cent of persons with Type 2 diabetes have macrovascular complications while 9 per cent have retinopathy. This supports the argument that macrovascular complications are of great concern in those with Type 2 diabetes.

SCREENING AND DIAGNOSIS

The diagnosis of diabetes is often 'missed' in the elderly population, as there are often no obvious symptoms, or those symptoms present are mistaken for part of the natural ageing process. In particular, ageing persons in care are at risk where symptoms such as mental confusion, urinary incontinence, nocturia and extreme lethargy are often confused with existing health issues. The ageing person can also present in a hyper-osmolar coma which is characterised by:

- elevated blood glucose levels, usually above 25mmols/L
- extreme dehydration and elevated plasma osmolarity
- ketones and acidosis being absent
- extreme lethargy
- confusion.

Carers and health care professionals need to be alert to diabetes risk factors, and ensure 'at risk' individuals are screened annually or earlier if symptoms consistent with diabetes are noted.

Routine screening of ageing people for diabetes, followed by prompt diagnosis, has the potential to reduce the incidence and severity of diabetes complications and positively impact on quality of life.

DIABETES MANAGEMENT

In times past, health professionals thought that a more relaxed approach to diabetes control in the elderly was feasible, as they would often not live long enough to succumb to the complications. While this may still be the case for those over 80 years of age, increasing longevity, together with the fact that many have existing diabetes complications at diagnosis, has altered the thinking of medical practitioners.

The aim of management for the older adult, regardless of age, is to maximise quality of life by promoting and facilitating:

- good blood glucose control (glycohaemoglobin less than 7 per cent) to maintain health and prevent development of diabetes complications
- diabetes self-management
- regular screening, detection and management of diabetes complications.

In the frail aged the focus of the management plan is on achieving a level of control whereby the individual is asymptomatic and free of hypoglycaemic episodes. Striving to achieve blood glucose levels slightly above the normal range is considered safe practice.

These aims are best facilitated through a team approach to diabetes management with the person with diabetes actively contributing to the care plan. Where this is not possible it is imperative that a family member, friend or health care professional act in this capacity to ensure the rights of the individual are protected.

The care team need to constantly balance the competing benefits and risks of health management decisions against morbidity and mortality associated with uncontrolled diabetes. Management decisions need to be made individually, based on the social, emotional and physiological status of the person with diabetes, together with any concurrent disease or disability.

What all health professionals should know

What to eat

While diets for diabetes have been somewhat complex in the past, the emphasis is now on a healthy eating plan. The nutritional goals for diabetes include attaining and maintaining:

- a reasonable body weight
- optimal blood glucose control
- optimal blood lipid control.

In Australia, dietary guidelines have been developed with the nutritional needs of all adults in mind. Of these guidelines, those specifically relevant to diabetes are:

- Enjoy a variety of nutritious foods.

- Eat plenty of breads and cereals.

- Eat a diet low in fat, in particular saturated fat.

- Maintain a healthy body weight by balancing physical activity with food intake.

- Limit alcohol intake.

- Eat only moderate amounts of sugars and foods containing added sugars.

- Choose low-salt foods and minimise the use of salt.

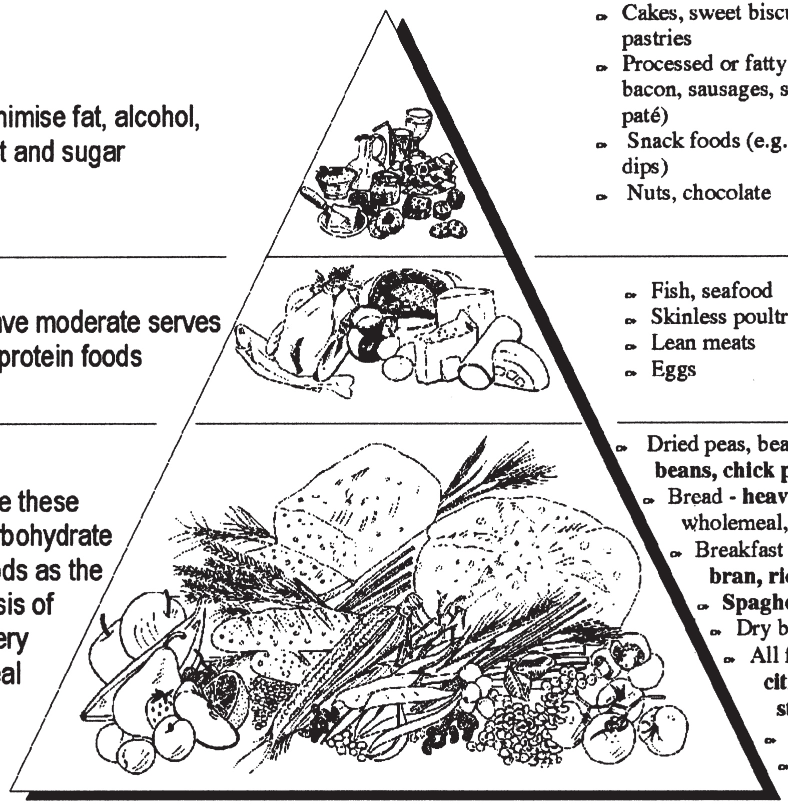
The dietary guidelines can be described in terms of the healthy food pyramid (see Figure 11-1). For those with diabetes, it is recommended that meals be based on the carbohydrate foods found in the EAT MOST section such as breads, rice, pasta, dried peas, beans and lentils, cereals, starchy vegetables and fruit. Including at least one low glycaemic index food (in bold print) at each meal will assist blood glucose control.

Foods found in the EAT MODERATELY section include skinless poultry, lean meat, fish and low-fat dairy products. Foods that are high in fat, sugars, salt and alcohol are found in the EAT LEAST section. These foods should be kept to a minimum.

When planning meals for the older adult it is essential to consider:

- the level of diabetes control being aimed for

Figure 11.1 The healthy food pyramid



EAT LEAST Minimise fat, alcohol, salt and sugar

- Butter, margarine, oil, cream
- Cakes, sweet biscuits, pastries
- Processed or fatty meat (e.g. bacon, sausages, salami, paté)
- Snack foods (e.g. chips and dips)
- Nuts, chocolate
- Salad dressing, mayonnaise
- Alcohol
- Confectionery
- Soft drink, cordials
- Sugar, honey, jam, jelly
- Salt

EAT MODERATELY Have moderate serves of protein foods

- Fish, seafood
- Skinless poultry
- Lean meats
- Eggs
- Milk
- Yoghurt
- Cheese
- Ice cream

} *LOW FAT varieties*

EAT MOST Use these carbohydrate foods as the basis of every meal

- Dried peas, beans and lentils e.g. **kidney beans, haricot beans, chick peas, baked beans**
- Bread - **heavy wholegrain**, rye, **heavy fruit loaf**, wholemeal, **pumpernickel**
- Breakfast cereals **e.g. rolled oats, barley bran, oat bran, rice bran, untoasted muesli,** shredded wheat
- **Spaghetti and pasta**
- Dry biscuits - low fat varieties
- All fruit - fresh, dried, canned **e.g. apples, pears, citrus fruits, grapes, cherries, firm bananas, stone fruit**
- Grains-**barley, buckwheat, bulgur,** couscous
- Rice-brown, **basmati, doongara**
- Vegetables - fresh, frozen, canned, dried e.g. broccoli, cauliflower, onions, potato, pumpkin, salad vegetables, **sweet potato, corn, yam**

Adapted from the Australian Nutrition Foundation

INTERNATIONAL DIABETES INSTITUTE

Foods in bold are better choices of carbohydrate foods. Include at least one of these at each meal. Discuss suitable brands with a dietitian.

- co-existing medical or other problems
- level of independence
- quality of life.

Each person has a unique set of needs that can be accommodated with careful planning. A dietitian can be particularly helpful in guiding people with diabetes to achieve a healthy and individualised eating plan.

Many diabetes care centres, associations and treating doctors will supply their clientele with dietary information that is either written or available online. Supermarket tours conducted by dietitians are also a popular strategy for educating people to make appropriate food choices through the art of label reading. Ask your local diabetes educator or community health centre for details of available nutrition-related services.

For those who are unable to prepare meals for themselves, there are many practical alternatives available, such as:

- a variety of low-fat, nutritious and tasty convenience meals from the supermarket
- local or private Meals on Wheels services that can be tailored to individual nutritional requirements and budgets.

Where there are additional concerns such as weight loss, altered dentition, poor appetite, altered taste and constipation or diarrhoea, it is necessary to clearly identify what the medical priorities are. Diabetes management may not be the priority. Agreement and flexibility on meeting nutritional requirements is the key to maintaining quality of life.

It is essential to remember that food has an important social context within our society. Ageing people need to be encouraged to enjoy food as part of this social context without feeling compromised by complex and prescriptive diet plans.

Physical activity

Many ageing people seem to believe that advancing age negates their ability to be physically active. Physical activity increases cardiovascular fitness, lipid profile, wellbeing, flexibility and bone and muscle strength, which is particularly important in ageing people to help minimise the risk of injury. In Type 2 diabetes physical activity has the added advantage of improving blood glucose control and assisting with weight management in obese individuals.

In the otherwise healthy adult the recommendation is to accumulate a minimum of 30 minutes of activity on most days of the week. Moderate-intensity activities such as gardening, walking, golf and swimming can confer positive health benefits. A thorough medical examination, including an electrocardiogram, is recommended for those commencing activity for the first time. Where there are existing complications (such as foot problems, retinopathy or cardiovascular disease) specially tailored activity programs devised by a physiotherapist are advised, to minimise risks such as retinal hemorrhage or a cardiovascular event.

Following medical clearance the advice is to start slowly, with approximately five minutes' activity for the first few days and building up the time increments. Warm-up and cool-down activities need to be included to prevent injury. A combination of activities that are designed to increase muscle strength, that incorporate stretching and that are aerobic in nature are likely to be most beneficial.

Additional considerations in preparing for physical activity include:

- education about foot care
- injury prevention
- appropriate footwear
- prevention of hypoglycaemia for people on certain types of diabetes medication.

Physical activity also needs to be promoted in the frail aged for reasons similar to those above. The goal is to maintain circulation and mobility, with activities designed by a physiotherapist to maximise abilities. People who are less mobile, for whatever reason, can be shown how to carry out muscle-strengthening activities while sitting in an armchair. People should be encouraged to perform these activities several times a day.

Medication

When physical activity and a healthy eating plan are not sufficient to control blood glucose levels an oral anti-diabetic agent (ADA) is commenced. In obese people, the drug of choice may be metformin, a biguanide. Frequently used sulphonylureas include Glicazide and Glipizide. Most of the sulphonylurea group of ADAs are potent and need to be used with care in ageing people. The choice of ADA is made on the basis of:

- glucose control
- presence of symptoms
- weight
- concurrent illness.

It is not unusual for treatment to consist of two or more ADAs combined with antihypertensive, lipid-lowering drugs and low-dose aspirin. Insulin is added when a combination of ADAs at maximal doses is insufficient to control blood glucose. In Type 2 diabetes the longer the person has diabetes the less able the pancreatic beta cells are to secrete adequate amounts of insulin, resulting in beta cell failure. Outcomes of the UKPDS trial have prompted many clinicians to consider that ageing patients should be moved to insulin therapy earlier than was previously practised (UKPDS, 1998).

In ageing people, it is particularly important that the decision to commence insulin be made on the basis of benefits to be gained versus risk of hypoglycaemia. Insulin administration has always been a concern in the elderly. Altered vision and flexibility can reduce the accuracy of drawing up accurate doses. In addition, Puxty and colleagues (1983) have shown that the need to mix insulins compounds the problem of dose accuracy. Premixed insulins and insulin pens are useful in these situations. Alternatively family members, support persons, community or domiciliary nursing services are recommended.

Given the number and combinations of medications an elderly person may be taking, it is necessary to consider how to promote adherence to drug therapy and safety with administration. Some commonly used strategies include:
- using multi-dose containers
- arranging for family or support persons to supervise medication where necessary
- involving a local pharmacist who may offer support with medication queries and monitoring frequency of script processing.

The general practitioner needs to monitor possible interactions of drugs and reinforce the need to take medications on a daily basis as prescribed.

Monitoring diabetes control

Glycaemic control can be monitored using a technique called self-blood glucose monitoring (SBGM) in combination with a laboratory test known as glycohaemoglobin (HbA_{1c}).

SBGM can be performed using visually read strips or using a portable glucose monitor. There are numerous brands and models of glucose-testing equipment available to choose from. Choice is often made based on preference, cost of equipment, functional capability and level of independence. A diabetes nurse educator can assist in assessing the most appropriate equipment needs. Regardless of the chosen method it is essential that the individual is educated in the use of the equipment and that follow up and support are available. Where access to a diabetes educator is difficult or not available, community nurses, local doctor or pharmacist may be able to help. Glucose results need to be documented and taken to medical appointments.These can then be used as a basis for discussion, and treatment alterations.

Frequency of testing needs to be individualised, based on:
- personal preference
- treatment option
- control
- level of support needed to perform the test.

HbA_{1c} is an indicator of the average blood glucose for the preceding two-month period. A doctor can order this test up to four times per year. In the ageing person who is unable to cope with SBGM, the HbA_{1c} results alone are used to guide diabetes therapy.

It is well recognised that urine glucose results correlate poorly with plasma glucose levels. For this reason urine testing for glucose is not recommended. Urine testing is, however, recommended to test for the presence of ketones in Type 1 diabetes during illness.

In the healthy older adult the level of glycaemic control should be no different from that of the general diabetes population. Current recommendations are for fasting levels of blood glucose less than 7mmol/L and HbA_{1c} levels less than 7 per cent. In the frail aged, where the treatment goal is different, the recommendation is for fasting blood glucose levels less than 7.8 mmol/L and a two-hour post-meal level less than11.1 or if on insulin, up to 15mmol/L (WHO, 1985) and HbA_{1c} closer to 8mmol/L.

Hypoglycaemia

Hypoglycaemia (low blood sugar) occurs only in those treated with some ADAs or insulin. It cannot occur in those treated by diet alone.

Hypoglycaemia occurs when the blood glucose level falls below 3.5mmol/l. Common symptoms include:
- shaking
- sweating
- dizziness
- faintness
- pins and needles around the mouth
- palpitations
- headache.

Many people may experience only one or two of these symptoms and the pattern can change with each episode. Others have no symptoms at all, and are at risk of the hypoglycaemia proceeding to a more advanced state with confusion, altered vision, uncharacteristic behaviour or even fitting and coma. Hypoglycaemia unawareness is not uncommon in the elderly (Meneilly et al., 1994). This may be related to the frequency of hypoglycaemia, as well as to the duration of diabetes and its effect on the autonomic nervous system and counter-regulatory response to low blood glucose, which is altered with increasing age (Meneilly and Tessier, 1995)

Treatment consists of ingesting some quick-acting sugar to raise the blood glucose level. Treatment can be self-administered in most instances. Suggestions include:

- 3 barley sugar (chewed)
- 5 jelly beans
- a small glass of ordinary lemonade or concentrate glucose drink (not diet drink).

If these are not available anything sweet can be used. Chocolate bars will raise blood sugar but are high in fat and will contribute to weight gain. For this reason they are not recommended as routine treatment of a 'hypo' (hypoglaecemic attack).

The blood glucose level needs to be monitored closely to assess the response. After treatment with fast-acting sugar, if a satisfactory response is not attained within five minutes, repeat the treatment.

To maintain the blood glucose levels within the normal range a longer acting carbohydrate food needs to be eaten. If the attack occurs close to mealtime it is recommended that the meal be eaten earlier; otherwise an additional snack, such as a piece of fruit or a sandwich, needs to be eaten.

If the person is unconscious, nothing should be given by mouth. The patient should be placed in the 'coma' position and either given an intramuscular (IM) injection of glucagon or an ambulance should be called. In this instance it is important to ensure the airway is maintained open until further assistance arrives.

Hypoglycemia can be caused by:

- missing or delaying meals
- an excessive dose of ADAs or insulin
- unplanned activity
- drinking alcohol on an empty stomach
- drug interactions, e.g. warfarin or sulphonamide antibiotics that

displace sulphonylureas from plasma binding sites. (Aspirin has a similar effect but hypoglycaemia is not seen in the low dose used for cardiac protection.)

Hypos are mainly preventable with careful planning. Education is imperative in providing the knowledge and skill level to prevent hypoglycaemia. In the ageing person, reliance is on the carers to plan strategies around hypo prevention. Something as simple as ensuring meals are on time will help prevent the occurrence of hypoglycaemia.

Where the ageing person is at risk of hypoglycaemia it is better to 'sacrifice' optimal control for the safety of the individual.

Sick days

Episodes of illness (such as infections, colds or flu) will impact on blood glucose control. These occasions require additional diabetes management to prevent further deterioration of control leading to a metabolic emergency.

As for all persons with Type 2 diabetes there are some simple guidelines to follow that can be implemented easily within the home environment.

- Blood glucose levels should be tested every 2–4 hours and the results documented.

- Diabetes medication should be continued even if the patient is not eating.

- A fluid intake is required of one glass of unsweetened liquid per hour. It's not important if the patient is unable to eat or is uninterested in solids for a few days.

- If blood glucose levels remain over 15 mmols/L for 24 hours or more, or if there is vomiting or if a change in mental alertness occurs, the doctor should be contacted.

- Contact doctor if concerned.

Prompt attention to the above guidelines will facilitate reversal of the situation.

In times of illness, support and direct assistance (e.g. help with testing blood glucose), from a family member or friend is recommended.

Temporary support can be arranged through local community domiciliary services or the GP. Depending on the illness, insulin may be needed on a temporary basis to control blood glucose.

Foot care

In those with diabetes, regular foot hygiene and injury prevention is crucial to prevent complications. Each day the elderly person or carer needs to ensure:

- feet are examined to detect any change in color, temperature, presence of swelling, cuts or abrasions
- feet are washed with a mild soap and dried well (soaking is not recommended)
- feet are moisturised using a lanolin-based emollient
- excessive moisture between the toes is treated with methylated spirits.

Foot inspection may be more difficult for the elderly person with visual disturbances, reduced mobility and flexibility, obesity and altered neurophysical status. While ageing people may be able to self-care in other areas, assistance is frequently required with foot care. This often extends to nail care. For those with diabetes nail care needs to be attended to regularly and with precision to prevent injury. Where nails are particularly tough and difficult to manage it is recommended that the services of a podiatrist be sought on a regular basis.

In some community facilities and local government areas there are groups of nonprofessional people who cut nails for the elderly. On the whole this is a valuable resource; however, in those with diabetes, particular care needs to be taken. Those who take care of the feet of elderly people with diabetes must be properly trained and must be aware of normal and abnormal pathology.

All persons cutting nails need to be educated in correct nail cutting technique. The current recommendation is to follow the curvature of the nail. Rough edges are then filed using an emery board.

A pumice stone is recommended to reduce callus formation. If callus formation is excessive or corns are present then treatment from a podiatrist is essential. Home remedies such as corn pads can be dangerous for the person with diabetes because they can damage healthy skin around the corn, leading to ulcer formation.

Additional recommendations to promote foot health:

- Wear cotton or wool socks to maintain warmth but enable the foot to breathe.

- Avoid walking barefoot.
- Wear well-fitting shoes appropriate for each activity. Lace-up shoes offer more protection and stability for the elderly.
- Inspect and feel the inside of footwear to ensure there are no foreign objects or torn linings that could cause injury.
- Use a large mirror to assist with foot inspection.

If minor injury does occur clean with mild antiseptic, and cover. Monitor the healing process each day. If the wound fails to heal within a few days or any redness, swelling, or pain occurs then it is important to consult a doctor or podiatrist IMMEDIATELY.

If a major injury occurs, such as an extensive cut or laceration, apply pressure to the area with a clean dressing to stop bleeding. Seek medical assistance immediately.

Ulcer formation and amputations can, in many instances, be prevented with regular foot care surveillance and prompt attention to injury.

People with poor circulation, nerve damage or previous foot problems are considered 'at risk'. As such, they require regular treatment from a podiatrist for all their foot care needs.

IMPACT ON THE PERSON

Diabetes has the potential to significantly impact on an ageing person's quality of life. The relationship between glycaemic control and diabetes complications is now well documented (Turner et al., 1996). Where complications are present the impact is frequently greater, requiring additional medical care, support and medication. The cost of such additional care is an issue for some ageing people.

Diabetes complications are often associated with disability, for example, visual impairment or limb amputation. Fear, anxiety, anger and depression are common emotions generated by such disability, compounded by the presence of multiple health concerns, limited financial resources, lack of social support and the isolation imposed by the disability.

There is ample evidence to suggest that depression and cognitive impairment are regular features of poorly controlled diabetes (Testa and

Simonson, 1998). Ageing people with diabetes deserve to have vigilant assessment and management of their condition to ensure that they are able to function at their optimum capacity and attain a state of maximum wellbeing. Decisions concerning the management of the disease need to consider the entire physical, social and emotional status of the ageing person, balancing these with the attendant health risks of poorly controlled diabetes. Central to such decisions is the involvement the ageing person is encouraged to take in self-management.

Ageing people need to be encouraged to maintain involvement in their care, promoting independence and self-efficacy to whatever level is possible. The role of family members and health professionals is to support and encourage independence and participation in self-care.

IMPACT ON THE CARER

Ageing people requiring care are somewhat at the mercy of those responsible for their care. This situation necessitates a current knowledge of diabetes management and care from attendant health care professionals. In addition, those preparing meals need some guidance to ensure the provision of healthy and nutritious meals. Carers need to be alert to potential complications of diabetes (e.g. sick days, foot injuries, side effects of insulin administration) and must know how to respond to these situations so as to minimise problems.

Carers also need to liaise with family members and treating health care professionals, particularly the GP, who is often best placed to coordinate care. The frail aged, just like the rest of the community, have the right to high-quality diabetes care.

Carers themselves need access to professional development opportunities that assist them to maintain their diabetes knowledge and skill levels. Policies and protocols that address the care of those with diabetes should be in place to promote consistency of care and best practice.

IMPACT ON THE COMMUNITY

The major impact on the community is the cost diabetes contributes to the health bill, both in direct and indirect costs. In 1987, in the United States, it was reported that the bill for diabetes was in the vicinity of US $90 billion annually (ADA, 1993). It is well recognised that costs are set to escalate worldwide unless clear and rigorously evaluated mechanisms are put into place to stem the current Type 2 epidemic that is taking hold in developed and developing countries.

RESOURCES

There are several groups/individuals, both professional and lay, that can act as useful resource persons for those with diabetes and/or their carers. These include:

- community diabetes support groups often attached to diabetes organisations and community health centres
- diabetes centres/services
- domiciliary services such as district nurses
- professional associations, such as The Podiatry Association, who can identify local members
- national diabetes bodies who can advise on local services, information needs and support groups
- general practitioners
- low-vision services, who can advise on aids and other appropriate services
- local government, which can provide a range of support services.

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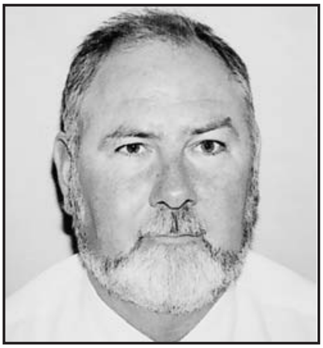
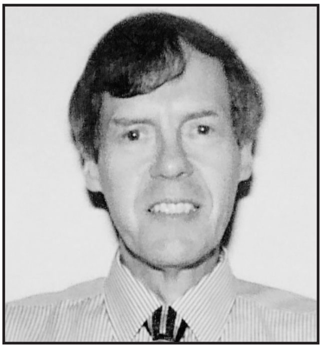


Mike Hazelton



Michael Clinton

MIKE HAZELTON

Registered Nurse, Bachelor of Arts, Master of Arts, Doctor of Philosophy

Associate Professor and Head of the School of Nursing at Curtin University of Technology, Perth, Western Australia

Prior to his current job, Mike Hazelton was Associate Professor and Head of Nursing at the University of Tasmania. Mike is a well-known contributor to mental health nursing both in Australia and abroad and has published widely on mental health issues in the fields of nursing and sociology. At present he is Editor of the *Australian and New Zealand Journal of Mental Health Nursing.*

MICHAEL CLINTON

Registered Nurse, Bachelor of Arts (Honours), Doctor of Philosophy

Professor and Director, Centre for Nursing Research and Development at Curtin University of Technology and Professorial Fellow in Clinical Nursing at the Sir Charles Gairdner Hospital, Perth

Michael Clinton is a nurse and sociologist with nursing, nurse education and health service management experience in the United Kingdom, New Zealand and Australia. His current research interests are mental health, aged care and advanced clinical nursing practice. Michael is President of the Australian and New Zealand College of Mental Health Nurses.

CHAPTER TWELVE

Mental Health and the Older Citizen

Mike Hazelton
Michael Clinton

INTRODUCTION

Australians are growing older but there is no need for despair because most ageing people live independent and satisfying lives (Edwards, 1996; Australian Bureau of Statistics, 1998). Generally, the message is — use it or lose it! People who stay active outside the home, and maintain their interests, remain well to an advanced age. However, it would be a mistake to believe that health problems do not increase with age (Australian Bureau of Statistics, 1998). Despite improvements in nutrition and health care, and regardless of better living conditions, the fact is that most people who are ill are elderly (Australian Institute of Health and Welfare, 1998). There are also psychiatric conditions that affect people as they grow older (Kaplan and Sadock, 1998; Australian Institute of Health and Welfare, 1998). Therefore, it is useful to consider the mental health problems that can occur in old age and the care required in the community.

But before describing psychiatric conditions in the older person, it is important to mention something about our approach that is novel. We are interested not only in the mental health problems found in older people, but in how those problems affect citizenship. Before describing some of the more frequently occurring psychiatric conditions in later life, we will, therefore, say something about what we mean by citizenship. Later in the chapter we will take up the question of citizenship again when we discuss community care.

CITIZENSHIP AND MENTAL HEALTH

Teachers, historians and government officials, among others, have recently displayed a renewed interest in citizenship. While the reasons for this interest vary across groups, according to Turner (1990), all understand the concept as a combination of social rights and obligations that determine:

- legal identity
- social membership
- access to scarce resources.

While discussions of citizenship are often highly theoretical some commentators have attempted to apply the notion to concrete social issues. Burke and Salvaris (1997) identify three components to citizenship:

1. legal status, e.g. formal citizenship, and rights and duties
2. social membership, e.g. access to institutions, services and resources
3. civil ethics, e.g. sense of social responsibility.

Effective functioning in each of these domains indicates the extent of a person's social and civic wellbeing. A number of commentators have recently drawn attention to the ways in which ill health may adversely affect a person's standing as a citizen through limiting the capacity for social participation and affecting the ability to access scarce resources (Turner, 1999; Hazelton, 1999a). Psychiatric conditions are often profoundly disabling and older people with mental illness exhibit particular vulnerabilities. Old age accompanied by mental illness is likely to result in curtailed personal autonomy. Lifelong competence in accessing and managing the resources necessary for social wellbeing may be disrupted and a sense of community belonging may diminish as motivation, judgment and cognition are disrupted by psychopathology. The link between citizenship and health has also been acknowledged in recent mental health policy in countries such as Australia, where it is now asserted (Barham, 1991:100) that:

> severe mental illness need no longer be a barrier to ordinary human recognition and the entitlements of citizenship

PSYCHIATRIC CONDITIONS

Anxiety, depression, dementia and delirium are four of the more important psychiatric conditions affecting older people. The information on psychiatric conditions that follows is based on a comprehensive guide to mental disorders (Kaplan and Sadock, 1998).

Anxiety

The anxiety disorders are a group of psychiatric conditions that are not confined to the elderly. Although their symptoms do not involve changes in the personality of the person, they nevertheless have serious effects on a person's quality of life. Although these disorders often have their onset in middle age, it is not unusual for them to appear about the time a person reaches the age of 60 (Kaplan and Sadock, 1998).

Phobias are the most common anxiety disorders and affect 4–8 per cent of people of the age of 65. They are best regarded as long-term, unwarranted fears that occur in everyday situations. Each phobia has a name that reflects the source of the person's fears (Kaplan and Sadock, 1998). For example, people who are afraid of open spaces are said to have agoraphobia, people who are unreasonably afraid of high places have acrophobia, people afraid of strangers have xenophobia, and so on. Each of these names is derived from the Greek word for the thing or situation that gives rise to the person's fears. Fortunately phobias are readily treated with techniques that focus on changing the thoughts and behaviours of the person (Kaplan and Sadock, 1998). For example, the person can be taught to substitute pleasant thoughts for anxious ones, and can learn to relax in the presence of whatever it is that causes their fears. The technical term for such treatment is cognitive behavioural therapy or CBT. However, drugs called anxiolytics can help. Valium is an example of this group of drugs.

Although phobias might sound amusing, they are in fact profoundly disabling. A person with agoraphobia may go many years without going out of the house. This creates dependency on family members and neighbours, and the ability to go out alone recedes as each day passes. Therefore the person becomes lonely and isolated and is unable to do the shopping, cannot go to hairdressers and has no opportunity for recreation outside the home. It is not difficult to see how a person living under such circumstances would experience severe limitations in citizenship because their capacity for social membership and civic wellbeing diminishes over time. People may of course choose to isolate themselves. Whether intervention is required depends on whether the person is able to care for himself or herself adequately. What 'adequately' means in this context is contentious. However, the principle that should guide intervention is that the person is incapable of maintaining the quality of life that is acceptable to them and is placing themselves or others at risk of harm.

Phobias differ from anxiety in their:
- intensity
- specificity
- degree to which they impair normal functioning.

Whereas anxiety is a normal human feeling associated with stress and can generally be regarded as a form of worry or fear, phobias result in the same experiences of irregular heartbeats (palpitations), sweating, muscular tension, faintness and difficulty in breathing but are specific to particular situations, such as those that have been identified above. Phobias generally produce more intense physical and psychological distress and can be more debilitating. Suffers are often secretive about their condition and are often unwilling to talk about it.

Other anxiety disorders affecting the elderly are post-traumatic stress disorder and obsessional-compulsive disorder (Kaplan and Sadock, 1998). Post-traumatic stress disorder affects elderly people when they have lived through an event that threatens their sense of personal integrity. Elderly people who have experienced home invasion, who have been run down by a car, or who have suffered other personal trauma are at risk. But the traumatic event need not be recent. There are still lots of World War II and Vietnam veterans who wake up in a panic as experiences of war recur in their dreams.

Obsessions are irresistible anxious thoughts that cannot be resisted or put out of mind. Compulsions are repetitive behaviours that are performed in response to an obsession. Therefore, a person with obsessional-compulsive disorder might be troubled by the persistent and unreasonable thought that everything around them is infected and will give them a terrible disease. Their response might be to engage in frequent and unnecessary handwashing, possibly to the extent that their hands are raw with all the scrubbing.

Depressive disorders

Depression to the depth of a psychiatric disorder affects up to 15 per cent of ageing people. According to Kaplan and Sadock (1998), common features of depression include:

- eating and sleeping problems
- loss of weight
- lack of energy
- lack of interest in normal activities
- (sometimes) false beliefs or delusions.

Furthermore, late-onset depression of the kind found in ageing people is likely to recur.

The physical symptoms in depressive disorders in ageing people are something to note because depression might explain problems that are otherwise unexplained (Kaplan and Sadock, 1998). This does not mean that a diagnosis of depressive disorder should be made when there is no other reason for the person's symptoms. It means that depression should be regarded as a potential cause of physical symptoms in an ageing person who has a previous history of good health.This is because ageing people are particularly vulnerable to depressive episodes that include fears about their health and distressing physical symptoms. Low self-esteem and feelings of guilt, often about things that happened long ago, frequently accompany such symptoms (Kaplan and Sadock, 1998). These feelings can result in thoughts of suicide.Therefore, suicide should be regarded as a possibility in any ageing person who is depressed.Although there is much concern about deaths by suicide among younger males, it is sometimes forgotten that the second highest suicide rate for males in Australia is in men aged over 85 years (Bishop, 1999).The suicide rate increases in men over the age of 75 and peaks in those over 85;for every 100 000 men in this age group 40 take their own lives. Suicide in men aged over 75 is three times more common than among women in the same age group. Furthermore, men who complete suicide generally choose more violent methods than women in the same age group (firearms and hanging rather than the use of poisons).

Depression can be a feature of mental illness and is sometimes caused by the side effects of medication. Drugs used to treat high blood pressure, steroids and hormones, analgesics (drugs that treat pain) and drugs used to treat infections can all cause depression (Kaplan and Sadock, 1998).Alcohol and other substance abuse disorders might be related to underlying depression, and the sleep disorders associated with advanced age can be a related problem. Antidepressant drugs are an effective treatment for depression in the elderly, but when they are ineffective electroconvulsive therapy (electroshock treatment or ECT) is also used.As all antidepressant drugs are likely to be effective in treating depression in the elderly, the choice of drug often depends on known side effects (Kaplan and Sadock, 1998). One of the tricyclic group of drugs, such as nortryptyline, is often preferred because it is unlikely to cause low blood pressure and fainting attacks. However, careful observation is needed for all ageing people who are taking antidepressants as side effects can be troublesome. If the tricyclics do not work, other groups of antidepressants can be tried and sometimes amphetamines are used (Kaplan and Sadock, 1998).

However, depression is not just one illness, but a number of different illnesses. It differs from sadness in its intensity and in its tendency to persist without intervention. It is rare for someone to say they are depressed.They are much more likely to present with physical symptoms and to believe that they have a serious physical illness. Other forms of presentation include:

- abuse of alcohol or drugs
- changes in activities and behaviour
- failure to care for oneself.

Depression is always more intense than the unhappiness experienced due to disappointment or a change of circumstances and generally requires targeted medical intervention because it can persist for years if left untreated. It can come on without apparent cause or might be triggered by a distressing experience such as bereavement in the family. Depression is often found in people who have previously coped well and in people who have a supportive network of family and friends. Typical symptoms include:

- low spirits
- loss of enjoyment of life
- poor appetite
- lack of concentration.

Poor appetite may lead to loss of weight and sleep disturbances are common. Feelings of hopelessness and despair may lead to thoughts of suicide. Ageing people who talk about suicide, who have made one or more previous attempts, who talk about planning suicide and who are physically well enough to act on their plans, are particularly at risk. On the other hand, a person who has none of these risk factors should not be regarded as not being at risk. Care should be taken to ensure that ageing people who are at risk of suicide are not left alone, that they are assessed and treated for depression if necessary and that they are supported until the risk of suicide subsides.

Dementia

The risk of dementia increases with age from about five people in every 100 at age 65 to about 20 people in every 100 in the over 80s (Kaplan and Sadock, 1998). The most characteristic feature of dementia is a worsening and irreversible impairment of intellect. The features of the condition involve not only deterioration in thinking, but also in memory, in the use of language and in the ability to find one's way about in familiar places such as one's own home. Other common disturbances are agitation, restlessness, wandering and sometimes violence (Kaplan and Sadock, 1998) in the form of hitting out at relatives, friends and people who care for the ageing in the community. Dementia is generally caused by deterioration in the brain due to old age, but alcohol, tumors, medications and chronic infections can all play a part. AIDS is another major cause of intellectual impairment. However, dementia is not one condition but a group of conditions that have different causes.

Dementia of the Alzheimer's type is the most common and best known. People with the condition experience a gradual onset and progressive decline in their intellectual functions (Kaplan and Sadock, 1998). Others do not notice these changes at first. They become obvious as deterioration sets in. Initially the person might not be able to take in new information. Later the person might have difficulty in understanding and using language correctly. Eventually the person's personality becomes affected. Depression, obsessions and suspiciousness are all common (Kaplan and Sadock, 1998).

The cause of Alzheimer's disease is unknown and there is no treatment that will reverse its effects. However, caring relatives and nurses can help to slow the deterioration (Bird, 1998). Reviews indicate that up to 25 per cent of suspected dementias are reversible (Creasey and Waite, 1994). Furthermore, newer cholinergic agents can be modestly effective in improving or delaying decline in cognitive function. Moclobemide, vitamin E, seligeline and Ginkgo biloba have all been cited as effective in achieving clinical improvement (Woodward, 1999). The affected person can be occupied for short periods and can engage in conversation, especially about their younger days and past significant family events. Readers are referred to chapter 15 for further information regarding dementia.

Delirium

The acute confusional states associated with delirium are frequently poorly recognised and badly treated, sometimes because they are mistaken for dementia. The hallmarks of delirium are disturbances of consciousness and changes in cognition that develop rapidly. Classically, delirium has a sudden onset (hours or days) and is rapidly relieved when the cause is eliminated. It should be remembered that delirium is a syndrome, not a disease, because it has many causes that produce similar symptoms (Kaplan and Sadock, 1998). Acute confusional states have intracranial and extracranial causes (see Table 12.1).

Table 12.1 Causes of acute confusional states

Intracranial causes	**Extracranial causes**		
	Drugs	**Poisons**	**Deficiencies**
Epilepsy Concussion Infections, e.g. meningitis, encephalitis	Anticonvulsants (used by people with epilepsy) Hypertensive agents taken for high blood pressure Antiparkinsonian agents used to treat Parkinson's disease Antipsychotic drugs used to treat schizophrenia Insulin Opiates Sedatives, including alcohol and steroids	Carbon monoxide Heavy metals, e.g. mercury (now relatively rare)	Thiamine Nicotinic acid Vitamin B_{12} Folic acid

Urgent medical attention is required by any person who quickly develops an impaired memory, becomes disoriented, or whose cognitive ability fluctuates widely over a period of 24 hours. Identification and removal of the cause usually produces improvement within 3–7 days and symptoms typically abate completely within two weeks.

THE MENTAL HEALTH OF OLDER PEOPLE AS AN ISSUE OF CITIZENSHIP

In countries such as Australia the notion of citizenship is often associated with expectations of self-sufficiency. If citizens have (civil, political and social) rights, they also have obligations. Thus, while citizens enjoy certain freedoms, they are also expected to be responsible for their own economic, social and emotional wellbeing. 'Good citizens' are

- financially secure
- socially engaged
- civic minded.

However, these civic virtues are likely to be seriously affected by the types of mental health conditions outlined above.

Mental health services have traditionally been separated from other health services and given low priority. Traditionally, in the era of the asylums, it was often a case of 'out of sight, out of mind'. While significant improvements have occurred in mental health services in recent years, ageing people with mental illness continue to be identified as a particularly vulnerable group, for whom services remain inadequate. Given demographic predictions for the next few decades, which include an ageing population and rising illness acuity levels, the development of comprehensive, community-based, consumer-oriented mental health services for ageing people would seem a priority (Edwards, 1996).

Mental illness is likely to adversely affect performance in each of the three components of citizenship referred to at the beginning of the chapter:

- legal status
- social membership
- civil ethics.

While the capacity for personal autonomy in respect of managing one's finances, voting at elections and entering into contracts is usually not questioned on the basis of old age alone, this can change dramatically when mental illness comes into the picture. Severe mental illness is often associated with the loss (either voluntarily or involuntarily) of some civil, social and political rights and responsibilities. These are aspects of legal status that may never be regained in the ageing person with a psychiatric condition, especially if the condition remains unrecognised or is poorly treated. Effective social participation requires the building up of a complex set of life skills and knowledge over many years, ranging from the basic capacity for self-care through to communication skills, occupational skills, intellectual skills, human relationship skills and many others. Again, mental illness can seriously affect performance in each of these areas. Mental illness experienced in later life can result in the inability to care for oneself physically, socially, psychologically and economically. Reduced capacity in these areas may be accompanied by diminished sense of place in one's community. At the same time there is a significant social loss as an individual's stock of personal life skills and experience is no longer available to relatives, friends and the wider community.

WHAT SHOULD BE ASSESSED?

Given the range of physical, social and psychological functions that can be adversely affected by mental illness, a systematic and comprehensive approach to mental health assessment is required. While an expectation that all health professionals should be equipped to conduct such an assessment is perhaps unrealistic, the capacity to undertake a basic assessment is desirable. In the box overleaf is a brief outline of the types of questions that may be asked in assessing the mental health of an ageing person.

The answers to these questions will provide information likely to be of considerable use to general medical practitioners, community health nurses and specialist mental health staff attending elderly persons with suspected mental health problems and disorders. An introduction to mental health assessment in the older person, including the use of mental status assessment formats, can be found in Hazelton (1999b).

The vulnerabilities of old age can be especially serious when compounded by a psychiatric condition (Human Rights and Equal Opportunity Commission, 1993). Ageist (discriminatory) assumptions can be greatly amplified by the stigma of mental illness. Moreover it is well known that labels — especially psychiatric diagnostic labels — can have serious social consequences for those so identified (Hazelton, 1999a). Unfortunately, the source of discrimination can often be traced to family members, friends and health professionals, as well as to wider community attitudes towards the ageing and the mentally ill. All too often family members are asked to provide health history/health assessment information rather than the ageing person being asked themselves (Reed and Clarke, 1999). Failure to

Personal details: Name, sex, age, living situation and marital status

Previous mental health history: Has the person had a psychiatric admission, or psychiatric treatment in the past?

Current problem/s: What does the person perceive to be their current problem/s?

Drug and/or alcohol use: Is the person currently using drugs and/or alcohol? If so, what, how much, how often, when was the last use?

Disturbances of daily life functioning: Is the person currently experiencing problems with sleep, nutrition, bladder or bowel use, work, self-care, hygiene?

Social support: Does the person maintain regular social contact? How available is social support?

General appearance: Is the person appropriately clothed? What is their level of hygiene and cleanliness? What is their physical condition and posture?

Behaviour: Is the person cooperative, angry, evasive, withdrawn, or restless?

Awareness of surroundings: Is the person aware of the time and date, where they are and who they are?

Memory: Does the person seem to be experiencing any problems with memory?

Thought: Does the person seem to be experiencing any unusual thoughts or beliefs, or patterns of thinking?

Mood: Does the person seem unusually excited or elated, or sad and withdrawn? Does the person seem emotionally volatile?

Judgment: Does the person seem able to make sound decisions and to problem solve?

account for an individual's personal experience of illness often results in inadequate and inappropriate treatment (Weir and Oei, 1996). Moreover, many health professionals display therapeutic pessimism (i.e. the assumption that significant improvements following treatment are unlikely) towards the ageing, especially when the person is receiving treatment for a psychiatric problem. Of equal concern is the extent to which conditions associated with positive treatment outcomes in younger age groups, such as depression, often go undetected in the elderly (Human Rights and Equal Opportunity Commission, 1993:511).

There is no doubt that mental health care will continue to be mainstreamed, and that many, perhaps the majority, of health care and welfare workers will come into regular contact with people experiencing some form of psychiatric condition. While the need for specialist mental health professionals will remain, increasingly these will be found in small-scale acute care psychiatric facilities in general hospitals, or in community-based services. In most cases people experiencing mental health problems will not be admitted to hospital, but will be treated at home, with the assistance of family and other social supports. While it will be possible to consult specialised mental health services (e.g. psychiatrists or community mental health nurses) the majority of those suffering psychiatric conditions will be treated by non-specialist providers such as general medical practitioners.

Of equal importance to acquiring basic psychiatric technical skills and knowledge is the development of mindsets in which health workers assume that improvements are possible in the majority of cases of ageing people suffering mental illness. While therapeutic optimism certainly presents a challenge in relation to conditions such as dementia, in cases such as depression, which are much more treatable, it is possible that we could see significant improvements in the burden of disease of the elderly in Australia. It is perhaps for this reason that national health policy in Australia has recently identified depression as a priority area. All mental illnesses are serious and have the potential to greatly affect a person's capacity for social participation and civic wellbeing. Ensuring that all health care workers have acquired basic psychiatric technical skills and knowledge is a very good first step in ensuring that the majority of ageing people who are affected by a mental health illness have every chance of making a full recovery.

CONCLUSION

Anxiety and depressive disorders, dementia and delirium are common mental health conditions that affect ageing people. However, there are grounds for optimism because, with the exception of dementia, complete recovery is possible. As the age of the Australian population increases and mental health services continue to be mainstreamed, it will be necessary for health workers, including those employed in community aged care, to develop basic mental health knowledge and skills. Of equal importance is the acquisition of the mindset that mental health is an issue of citizenship. By taking citizenship as the guiding concept for community aged care, it will be possible to ensure:

- that the rights of the ageing are protected
- that they can access the mental health services they need
- that the community is aware of its duty to support ageing people in need.

At the same time, the concept of citizenship affirms the importance of the ageing person contributing their experience and expertise to the wellbeing of the community.

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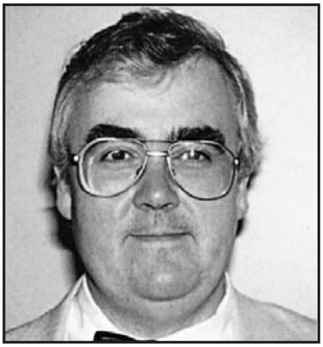

MICHAEL J MURRAY

Bachelor of Medicine, Bachelor of Surgery, Fellow of the Royal Australasian College of Physicians.

Consultant Geriatrician and Manager of In-patient Services — Medical, St George's Health Service, and on staff at St Vincent's Hospital, Melbourne

Michael has a strong belief in the importance of the hospital–community interface and is involved in chairing a number of committees including:

- Uniting *Care* Community Options
- the Lynden Aged Care Association
- the Victorian branch of the Australian Association of Gerontology.

Michael has a deep interest in continence and is

- Director of the Regional Continence Service
- Chairperson of the Continence Foundation of Australia (Victorian branch)
- Chairperson of the Continence Physicians Interest Group — a special interest group of the Australian Society of Geriatric Medicine.

CHAPTER THIRTEEN

Parkinson's Disease and Brain Attack

Michael J Murray

INTRODUCTION

As we age there is an increase in the likelihood of both episodic ill health and chronic illness. Whilst we recognise that chronic conditions do become widespread in aged care, the challenge is to limit the functional consequences and to continue to optimise one's quality of life. Parkinson's disease (a progressive neurodegenerative disorder) and stroke (a potentially catastrophic and disabling acute event) are common conditions responsible both directly and indirectly for significant morbidity and mortality. In this chapter I will outline the principles of management of these conditions occurring in ageing people living in the community. Such principles can also be applied to other similar disease states.

PARKINSON'S DISEASE

Parkinsonism is a cluster of characteristic symptoms and signs which include:

- poverty of movement (bradykinesia)
- muscular rigidity
- tremor.

Whilst there are a number of secondary causes of the symptom cluster, by far the most prevalent condition is idiopathic Parkinson's disease. The other conditions which may fully or in part mimic the disease include:

- vascular parkinsonism, occurring, perhaps, secondary to cerebrovascular accidents (CVAs) or strokes
- drug-induced parkinsonism, precipitated by a drug such as haloperidol (Serenace®).

Aetiology

Parkinsonism becomes more common with age. In developed countries about 2 per cent of people aged 85 or more suffer from it (Mutch et al., 1986). A number of factors have been proposed in the aetiology of Parkinson's disease.

- Initial reports suggested a genetic basis but twin studies refuted this (Marttila et al., 1988) More recent work, however, has suggested genetic factors may play a part (Stoessl, 1999).
- Environmental factors gained additional following after the appearance of a form of parkinsonism amongst young drug users exposed to a designer drug, methyl-phenyl-tetrahydropyridine (MPTP) (Langston et al., 1983). Current opinion appears to suggest that there may be a role for exogenous and endogenous toxins in the development of Parkinson's disease (Stoessl, 1999).
- It has been suggested that Parkinson's disease may be an exaggerated manifestation of normal ageing, or perhaps (more likely) it is the interplay of all the genetic and environmental factors acting within the ageing brain that ultimately results in Parkinson's disease.

Whilst the aetiology remains unresolved the damage in the brain which gives rise to the clinical symptoms is more clearly understood. There is a loss of brain cells (neurones), principally dopamine-producing cells, resulting in an imbalance between dopamine and acetylcholine, two chemical messengers of the brain (neurotransmitters). As a result of this progressive change in chemical messengers and the effects on chemical receptors, the normal balance of muscular control is affected thus giving rise to the typical symptom cluster.

Diagnosis

The diagnosis of Parkinson's disease is clinical and based upon the presence of cardinal features (Koller and Montgomery 1997), but, as with many conditions, diagnosis can be difficult early on when symptoms may be subtle and variable. As in other slowly progressing medical conditions it is the initial uncertainty and the delay in a definitive diagnosis which patients and their families can find vexatious. Unfortunately this is not totally unfounded as at least one study found 25 per cent of those initially diagnosed with classical Parkinson's disease actually had other Parkinson-like syndromes (Playfer, 1997).

It is, however, the impairment associated with the symptoms that has the potential to impact on quality of life, creating a disability, and it is the belief of the inevitability of this disability that creates fear of the condition within the community.

Common problems and their management

Bradykinesia and disequilibrium with impaired balance reflexes, together with muscular rigidity, are frequently cited as major problems to patients. Bradykinesia within the home environment can have significant impact where a person needs to switch between the multiple small tasks involved in day-to-day activities such as meal preparation and hobbies. These problems can be exacerbated by the development of muscular rigidity and/or tremor which, although predominantly occurring at rest, can carry over into activity. The disequilibrium and rigidity substantially increase the risk of falls and may result in injuries including fractures. This is especially common in tasks associated with altered balance or changes in centre of gravity such as dressing, transferring from bed or chair, and turning and reaching for objects, particularly if any such action is performed relatively quickly and the necessary movements are inadequately planned. All symptoms may be exacerbated by:
- stress
- anxiety
- ill health.

Management strategies directed at balance and poverty of movement include:
- accurate diagnosis and treatment of all contributing factors
- pharmacological management (principally levodopa) to reduce the bradykinesia
- multidisciplinary assessment with review of a person's environment both to reduce hazards and, more importantly, to provide strategies and environmental modifications to make tasks easier.

Education for the person and carer(s) about additional strategies and utilisation of community resources such as specialist Parkinson's management clinics, Falls and Balance Clinics and multidisciplinary community rehabilitation centres, together with direction to community self-help groups, literature and other forums, can significantly empower a person, adding confidence to the belief they can manage current and any future disease-related difficulties.

Whilst symptoms impacting on mobility are often the most troublesome and potentially create the greatest impact on independence, many of the other symptoms can also be distressing. Micrographia or abnormally small writing, which trails off rapidly to become illegible, can limit letter-writing ability, and in advanced Parkinson's disease a shopping list or even one's own signature may be nearly impossible to decipher.

Slowing of gastrointestinal motility and other gastrointestinal difficulties are a frequently experienced but often overlooked or under-reported problem, particularly in more advanced Parkinson's disease, as many people do not associate their difficulties with the disease. In Parkinson's syndromes, as in some strokes, there can be impairment in swallowing and risk of aspirating food, potentially causing pneumonia. Swallowing difficulties, especially associated with coughing or choking, need a formal swallowing assessment, usually by a speech therapist. Thin fluids such as water, tea and coffee can be the most difficult to swallow safely where there is an impaired swallowing reflexes or incoordination of the swallow. This can be assisted by dietary modification (with thickened fluids) and texture modification (e.g. vitamised diet). However, as with many problems, a balance may need to be established between safety and a person's acceptance of the required modification because some patients may feel that such changes diminish their quality of life. Whilst it may sound trivial, few tea or coffee drinkers would find thickening of their favourite brew to be acceptable. In some cases poor acceptance of dietary modification can contribute to impaired nutrition and inadequate fluid intake.

There can also be delayed gastric emptying with early satiety and therefore a potential for nutritional deficiencies through reduced meal sizes. Constipation is a common complaint in the ageing but more common in those with Parkinsonism. With reduction in gastrointestinal motility the resultant constipation in mild cases may require a dietary review looking at increasing fibre and fluids and occasionally, in more severe cases or where associated with frank faecal incontinence (usually secondary to overflow) or faecal smearing, aperients and motility agents such as cisapride may become necessary (Jost, 1997), though recent concerns regarding potential cardiac side effects need to be considered.

Urinary incontinence secondary to detrusor instability, or voiding difficulties due to outflow obstruction, can become major bars to socialisation and rapidly diminish quality of life. Assessment by an experienced clinician or, where necessary, a continence service, to exclude other contributing factors (including constipation and medications) and consideration of therapy (such as bladder retraining and/or pelvic floor exercises), together with some pharmacological therapies outlined in chapter 9 can ease these difficulties.

Sleeping difficulties can occur for many reasons, with time and patience needed on the part of the person, carers and health professionals. Poor sleep can result from motor difficulties, that is, the person may have difficulty turning in bed and thus cannot get comfortable. This is a common complaint. Review of the night attire, mattress, and bedclothes should be undertaken. Aids which may assist include satin inserts in the sheets to decrease friction when turning and provision of bedsticks for a person to pull up on. Medication should be reviewed, looking at drugs or formulations with a longer half-life, or a modification of dosage schedule, as well as possible drug interactions or side effects. Sometimes it is the attitude or expectations of the person hoping for 12 hours of uninterrupted sleep which are unrealistic. Altered mood as a cause or contributing factor needs to be considered.

Altered mood with, at one end of the spectrum, sadness related to real or perceived decline in quality of life and independence and, at the other overt, depression, are commonly seen in Parkinsonism or any other chronic medical condition. Experience and common sense tells us that when a person and their carers are placed under increasing pressure by chronic and/or progressive health problems their ability to both manage and implement strategies can be eroded.

The hallmarks of quality care continue to be:

- accurate diagnosis of health issues
- identification and amelioration of factors contributing to the illness becoming a disability
- empathic continuing management of the person and their carers within their social setting.

The provision of understandable and relevant information, and access to appropriate services and resources, will assist a person to deal with their illness in the best possible way.

The incidence of dementia and other neuropsychiatric dysfunctions (including delusions, agitation, delirium and hallucinations) are significantly increased in people with long-standing Parkinson's disease (Juncos, 1999). Whilst the figures vary (in part depending on the group sampled and the exclusion criteria used), at least one prospective study found that as many as 30 per cent developed dementia during the five-year follow-up period (Stern et al., 1993). As with all presumed complications of chronic conditions, other causes of potentially reversible confusion and cognitive impairment should be excluded. Depression, intercurrent infection and side effects from current drug therapy should be sought, as these are common and treatable, and many drugs, especially those used in the treatment of

Parkinson's disease, can produce confusion even in doses that have been stable for some time.

Issues in pharmacological management

The main thrust of drug management in Parkinson's disease remains symptom control. Neuroprotection with prevention of disease progression remains elusive though a number of newer agents and some older drugs appear to confer some benefits. Drug therapy for the most part offers little or no benefit to those with vascular parkinsonism and for those with drug-induced parkinsonism withdrawal of the causative agent where possible will usually cure the symptoms. Whilst the most commonly used agent in Parkinson's disease — levodopa (e.g. Madopar, Sinemet) — does not appear to alter the clinical course of the disease it is effective for most of the cardinal symptoms (Lang, 1998), particularly those associated with bradykinesia though less so for tremor. Levodopa should be commenced when symptoms warrant, with most clinicians placing emphasis on maximising function (Agid, 1998). A sustained-release levodopa formulation is considered by some to be first-line therapy in the ageing (Silver and Ruggieri, 1998). L-deprenyl (selegiline) has been shown to temporarily delay the need for levodopa's use though this is generally short lived (Poewe and Wenning, 1998). Other dopamine agonists such as bromocriptine have been used but the side-effect profile in the ageing, particularly with respect to confusion and postural hypotension, is often a problem and is generally worse than with levodopa alone (Conley and Kirchner, 1999).

Variability in a person's muscular control, ranging from too little movement (freezing and rigidity) to excessive or abnormal muscle movements (dyskinesias), necessitates:

- a review of current drug therapy and dosing regimens
- a check on drug compliance
- consideration of alternative or supplementary agents.

Where such variability exists there appears to be significant benefits, with newer dopamine agonists emerging which will help smooth out motor fluctuations. It may well be in the future that these agents become first-line drug therapy in Parkinson's disease.

Given that cognitive impairment is common in all forms of parkinsonism, and that the drug regimens used are frequently both complex and time dependant, problems with patient compliance are extremely common. Common errors include missed or excessive doses of one or more of a person's drugs and since all of the agents used have significant potential to cause side effects (some of which can be identical to the disease process), assistance with such devices as a multi-dose container or directly supervised therapy may be required.

STROKE

Stroke is common and, for most adults with first- or second-hand experience, is a foreboding condition. Whilst the morbidity and mortality have been falling significantly, in part related to a combination of improved risk factors and better acute and sub-acute multidisciplinary management, much of the decline in death rates seen in the industrialised world remains unaccounted for (Bonita and Beaglehole, 1986). Nevertheless because stroke remains a major cause of morbidity and mortality there has been, in recent years, a push to heighten awareness of strokes in terms of acute management and neuroprotection with the coining of the term 'brain attack'.

Aetiology

There exist two major sub types of strokes:

- haemorrhage, where the rupture of a cerebral vessel results in bleeding
- occlusive (more common), where the obstruction is caused by local, usually small-vessel damage or atherosclerosis, or as a result of a clot travelling through progressively smaller vessels until it forms a plug blocking further flow and resulting in cerebral infarction.

There can be transient or short-lived symptoms which resolve within 24 hours and can occur episodically or precede a larger stroke, often referred to as a mini or small stroke or a transient ischaemic attack (TIA).

Multiple risk factors have been associated with cerebrovascular disease. High blood pressure (hypertension) has been identified as the major precipitant of strokes, with there being a linear relationship between blood pressure and stroke risk (Hock, 1999). Management of hypertension has been one identified factor in the reduction of stroke risk, particularly in the haemorrhagic-type stroke, which carries the worst prognosis. Until recently the management of hypertension in the elderly was somewhat controversial, however trials carried out in ageing people have clearly demonstrated benefit for all but the very elderly (more than 84 years old), who have yet to be studied (Shep Co-operative Research Group, 1991).

Whether age itself is an independent risk factor, or the resulting vascular disease and other co-morbidities associated with age are the cause, remains unclear. It is, however, known that the functional disability or handicap resulting from the stroke rises with age. Chronic atrial fibrillation, both alone and when combined with other heart problems such as rheumatic heart disease or cardiac failure and other conditions which allow a blood clot to form within the heart, carries significant increased risk of occlusive stroke related to emboli. Any other condition which promotes blood vessel damage or inflammation, such as smoking and diabetes, has also been found to be an independent risk factor.

Common problems and their management

Like Parkinson's disease the community management of stroke within the ageing is largely targeted at the management of the impairment, that is the damaged limb or system and the prevention of this becoming a disability. Disability is referred to by the World Health Organisation as a lack of ability to perform normal function, thus potentially leading to a diminution in quality of life with its social and psychosocial consequence.

Major advances in stroke management have occurred in:
- the rapid assessment of impairment
- the targeting of an individual's problems
- the reduction in subsequent complications
- a team approach with coordination of care, involvement of and support to the carers, discharge planning and the provision of support where necessary within the person's community or alternative placement.

The region of the brain affected and the degree of damage caused determines the disability. Although early on after a stroke the resulting symptoms can give an indication as to likelihood or degree of recovery, this can only be indicative and experience suggests a period of time is necessary before the accuracy of a prognosis reaches an 'acceptable' level. Whilst there are always exceptions the maximal account of recovery occurs early on within the first few weeks after a stroke, with improvement in most areas tapering off and tending to plateau within a few months.

After careful identification of the stroke-related disabilities it is in part the expertise of the multidisciplinary team — including physiotherapists, occupational therapists, speech therapists, social workers, nurses and doctors — to assess the person and determine if the deficits will benefit from rehabilitation. Rehabilitation is limited in part by the availability of resources. In the case of a mild stroke with little functional disability it may be advantageous to utilise community-based resources such as community rehabilitation centres. At the other end of the spectrum, where there is severe ongoing disability, particularly in areas of cognition and perception, there may be a very limited role for a formal rehabilitation program.

Management of common stroke syndromes

Motor deficits

Mention strokes and most people think of hemiplegia (paralysis of one side of the body). This is probably the most recognised and apparent outcome of a stroke and it illustrates well general principles of community management.

Where there is involvement of the motor cortex or pathways of motor control, weakness can result. Depending on the site of the stroke this can involve one or both limbs on that side of the body to varying degrees and may be confined to strength or involve other modalities such as sensation and coordination. Whilst impairment of function of the arm can be a major psychological stressor and have associated problems such as chronic shoulder pain, it is the loss of leg function which is potentially more disabling. The ability to transfer (e.g. from a bed to a chair) and to walk can have a major impact on resultant quality of life. Whilst a person's independent function is important, physical support from carers, appropriate walking aids and modification of a person's environment can be critical in determining outcome and successful reintegration into a preferred environment. In our community there should be no-one who, following a significant stroke, has not undergone discharge planning where support to the person and their carers, provision of necessary aids (including consideration of pressure-relieving devices), environmental modifications and consideration of ongoing rehabilitation has not occurred. However some people remain too dependant to be managed within their home environment or with the available resources.

Swallowing

Impairment in swallowing or dysphagia is common early on following a stroke. Whilst for 80 per cent this improves significantly over time (Harvey, 1998), there remains some who, following assessment and consideration of food texture modification (thickened fluids and vitamising, as discussed under Parkinson's disease), may require a more permanent solution. The overwhelming bulk of evidence supports the use of a percutaneous gastrostomy (PEG) or a tube into the stomach through the abdominal wall rather than a long-term nasogastric tube. Whilst accessing community services for swallowing assessment can be difficult, periodic speech therapist review may be required, particularly in those cases of poor acceptance or where, for cost reasons, the tube's premature removal may be desired.

Communication

Difficulties with communication following a stroke can take many forms and, as in dominoes, all the components need to be reviewed. After poor hearing has been excluded the problems are usually:

- receptive (or understanding)
- expressive (or in verbalising)
- in articulation of the speech
- in a combination of deficits.

In the community setting the availability of rehabilitation options is very limited though some community rehabilitation centres offer limited speech therapy or group sessions from which home 'exercise' programs done in conjunction with a carer or support person can be practised.

Sight

Visual impairment, usually a visual field loss, is common following a large stroke and can be easily missed. Awareness on the part of the person, their carers and therapists teaching compensatory strategies and appropriate environmental modifications can limit the impact of the problem.

Incontinence

Incontinence, either worsening a previous problem or creating a new one, requires a comprehensive assessment and management strategy (Brittain, 1998). There are a number of community-based continence services or independent practitioners to assist in achieving continence and limiting its adverse impact on quality of life. Management options are outlined in chapter 9.

Cognitive changes

Unfortunately cognitive changes, disinhibition and other frontal lobe syndromes, and disorders of mood ranging from sadness to grief and depression are extremely common and potentially debilitating, impacting on the person and carers alike. Awareness and institution of management strategies (including behavioural modification, counselling and support), together with appropriate drug therapy, may be required. Whilst the aim is to reduce the extent of the disability and optimise quality of life, available resources may limit this. Community resources include the local general practitioner, acting as coordinator, utilising, where necessary, specialist services which may include (depending on availability):

- mood or depression clinics
- cognitive assessment and dementia management services (CADMs)
- psychogeriatric/aged care or geriatric assessment services
- private specialist services.

Most people, at least in capital cities or large urban areas, also have direct access to a range of support groups that may be disability focused, such as the Continence Foundation or the Alzheimer's Association, or more generalist, such as church or community groups.

Regular holistic review with assessment of current and evolving disabilities (often best coordinated by a local general practitioner in whom the ageing person has confidence) enables appropriate management to be implemented early and facilitates liaison with appropriate community and specialist resources. This can also provide significant reassurance both to those with chronic disabilities and to their carers. Information needs to be provided in an easily understood format and at a rate that is not overwhelming nor encouraging pessimism or hopelessness in what the future might bring.

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GEOFF SUSSMAN

Graduate of the Victorian College of Pharmacy, Member of the Pharmaceutical Society of Australia, Member of the Society of Hospital Pharmacists, Member Sports Medicine Australia, Associate Fellow of the Australian Institute of Pharmacy Management, Member of the Australian Pharmaceutical Science Association, Justice of the Peace

Senior Associate and Director of Wound Education and Research in the Department of Pharmacy Practice, Monash University, Melbourne.

Geoff Sussman has been involved in wound management for more than 25 years and has vast experience in clinical pharmacy. He has undertaken clinical research, product evaluation and clinical practice, and has published widely on the topic. He is the author of the wound environment chapter in a textbook on wound care published in USA in 1998 and has written a new section on wound dressings and wound care in the *Australian Pharmaceutical Formulary.*

Geoff is Immediate Past President of the Australian Wound Management Association and is a Co-founder and Director of the Wound Foundation of Australia. He was awarded the 1998 Pharmacy Practice Foundation of Australia Medal of Excellence for his work in wound management. He is an Associate of the National Ageing Research Institute.

CHAPTER FOURTEEN

Wounds and Leg Ulcer Care for Ageing People

Geoff Sussman

INTRODUCTION

Wounds in general and leg ulcers in particular are a common problem in the ageing members of the population. To fully understand the nature and causes of these chronic wounds it is essential to consider the main physiological effects of ageing on tissue and the factors that influence healing.

As the body ages a number of systems within tissue deteriorate and diminish in their ability to function. The main areas are:

- reduction of hair follicles and a consequent loss of sebaceous glands, resulting in a loss of the secretion necessary to maintain the natural oils that keep the skin soft, supple and hydrated
- reduction of blood vessels
- loss of sweat glands.

The result of these tissue changes is that the skin becomes thinner, brittle, avascular and more prone to injury.

It is essential to ensure as the skin ages that appropriate measures are taken such as not using soap or other alkaline pH products that will increase the drying and therefore cracking of the skin, but using appropriate moisturising agents to ensure suppleness and to minimise the drying effects of the ageing process on the skin.

INTRINSIC FACTORS THAT INFLUENCE WOUND HEALING

Wound healing is affected by intrinsic and extrinsic factors. Intrinsic factors that influence healing include:

- health status
- immune function
- diabetes
- age factors
- body build
- nutritional status

1. Health status

Arterial circulation supplies oxygen, nutrients and cells to the tissues. Venous circulation removes the waste products and CO_2. Without good circulation healing becomes a problem.

Anaemia, regardless of type, reduces the capacity of the blood to provide oxygen to the tissues, since haemoglobin transports oxygen to the cells. As a number of other blood cells — e.g. white cells and platelets — are critical to the healing process (both directly, and indirectly by their production of growth factors or other functions), anaemia may certainly be a problem.

2. Immune function

Normal immune system function is required for the inflammatory and cleansing phases of healing. A reduction in immune function, probably due to a reduction in the number and activity of the white blood cells, slows the cleansing of the wound bed and reduces the ability of the body to fight invading pathogens.

3. Diabetes

Diabetes is a major problem for people with chronic wounds. Diabetics have:

- a delayed capillary response to injury
- reduced cellular function at the injury site
- defects in collagen synthesis and wound strength.

This can be attributed to age, obesity, malnutrition and vascular disease; however, hypoglycaemia (caused by reduced insulin availability and increased insulin resistance) appears to be a major predisposing factor in delaying healing in diabetic patients.

4. Age factors

As we age our skin and tissue change. First we lose the sensory cells, then we lose the secretory cells which are so essential for the maintenance of skin moisture and flexibility. We lose the vasculature within the skin and we lose hair follicles. The skin becomes far more prone to destruction, by physical or chemical means.

5. Body build

Because adipose tissue is poorly vascularised, an obese patient will have a great deal of trouble healing because there are few blood vessels to deliver oxygen and nutrients to a wound site. Underweight people may also experience difficulties in the healing process because of their malnutrition. A balanced diet is essential for healing.

6. Nutritional status

Nutrition is one of the most important factors in the healing of wounds. Proteins, vitamins, carbohydrates, fats and fluids all play a vital role in wound repair. Of the vitamins and trace elements, vitamins C, A, K and B are particularly essential in the maintenance of bodily function, and consequently, wound healing.

Vitamin C deficiency will impair fibroblast production and collagen synthesis. Vitamin C strengthens and promotes the formation of new blood vessels and plays a role in immunity and in the fight against infection.

Vitamin A aids in the movement of macrophages in the wound, plays a role in collagen synthesis, facilitates granulation and may counteract the local anti-inflammatory effects of steroids. Deficiency in vitamin A can impair epithelialisation.

Vitamin K is necessary for the normal formation of thrombin, a component for blood clotting.

Vitamin B complex is necessary for the formation of antibodies, as well as for white cell function.

Trace elements — such as iron, copper and zinc — are all necessary for cell proliferation and tissue regeneration.

- Iron is necessary for haemoglobin synthesis; iron deficiency can lead to anaemia.
- Copper is necessary for collagen synthesis.
- Known zinc deficiency will show a retardation in the synthesis of collagen and a reduction in epithelialisation.

EXTRINSIC FACTORS THAT AFFECT WOUND HEALING

Extrinsic factors that influence healing include:

1. mechanical stress infection
2. debris
3. temperature
4. desiccation
5. maceration
6. infection
7. chemical stress
8. systemic medications, both stimulatory and inhibitory
9. other factors.

1. Mechanical stress

When a patient is immobile and pressure is exerted locally (especially over a bony prominence for more than two hours, at a pressure exceeding 30 mm of mercury), localised microvascular ischaemia will occur, causing tissue destruction both at the surface and deeper into the wound and leading ultimately to a pressure sore. Equally, shearing forces and friction occur when the tissue below the skin is forced to move while the skin itself is restrained by contact with a surface such as the bed sheet. This is particularly evident in a patient's heels.

2. Debris

Debris — whether slough, eschar, scab, wound dressing residue, gauze fibres or sutures — will impede wound healing. The presence of debris will prolong the inflammatory phase, as well as predisposing the wound to infection. Debris is also a physical barrier to the healing process and should be removed, either surgically or by the use of hydrogels, proteolytic enzymes or hydrocolloids.

3. Temperature

The optimum temperature for the growth of human cells is 37 degrees Centigrade. It is therefore essential to maintain the wound environment at body temperature. A drop in body temperature will lead to peripheral vasoconstriction, affecting the flow of blood through the wound and markedly reducing the activity of growth factors and proteases.

4. Desiccation

If a wound dries, healing is either delayed, or will cease. Exposed, dry wounds are more inflamed, painful, and itchy, and have more scab material during the early stages of wound healing. Desiccated wounds present several barriers to efficient wound healing, which can be overcome by maintaining a moist environment.

5. Maceration

Maceration may be caused by:
- incontinence
- perspiration
- excessive exudation.

If there is maceration this will cause the destruction of tissue and slow the healing process. It is essential to maintain a moist environment without excessive exudation.

6. Infection

The presence of erythema, discharge, fever, pain and an elevated white blood cell count (and sometimes odour) is evidence that the wound is infected. If clinical signs of infection are present, the use of systemic antibiotics is mandatory. If there are no clinical signs of infection there is little reason to use either systemic or topical antibiotics. An exception to this may be the use of very specific topical antibiotics in very specific cases to reduce the level of bacteria in wounds of compromised patients.

7. Chemical stress

Iodine, peroxide, chlorhexidine, alcohols, hypochlorites and acetic acid are commonly used antiseptics and cleansing agents. Use of these agents is often responsible for delayed healing, since they are non-selective in their activity and will kill healthy cells as well as bacteria. It is preferable to avoid the prolonged use of these products on a granulating wound. Their use even in infected wounds is somewhat dubious as research has shown that, although they may reduce the surface load of bacteria in an infected wound, they do not penetrate below the surface and therefore have no real effect on the infection in the tissue itself. They may be of use in dilute forms when applied to some chronic wounds, left in place for no more than five minutes and then washed off.

8. Systemic medications

The effects of systemic medications on a healing wound vary greatly. Often medications prescribed for a condition that is unrelated to the wound may have side effects which could either stimulate or inhibit healing.

The stimulatory drugs affect:
- inflammatory response
- epithelialisation
- fibroblast activity
- fibrinolysis
- cell stimulation.

The inhibitory drugs affect:
- tensile strength
- capillary proliferation
- cell activity
- fibroplasia.

Systemic medications — stimulatory

Medications that are known to have stimulatory effects include:
1. vitamin A
2. vitamin C
3. zinc
4. growth factors.

1. Vitamin A

Vitamin A has been known to stimulate both humoral and cell-mediated immune mechanisms, and there have been some studies to show that it can reverse the effects of oral corticosteroids. It will reverse the stabilising effect of lysosomal membranes, and re-stimulate fibroplasia and epithelialisation.

2. Vitamin C

Vitamin C is one of the most important agents in wound healing.

- It is involved in the stimulation of fibroplasia.
- It is required for the hydroxylation of lysine and proline during collagen synthesis.
- It influences resistance to infection.
- It is essential for both neutrophil and fibroblast function.
- It strengthens and promotes new blood vessel formation.

3. Zinc

Zinc is an important agent in wound healing because it is an important part of the structural integrity of protein. Zinc is essential for the functioning of at least 200 enzymes, and plays a vital role in vitamin A metabolism. It is involved in the cross bonding of collagen and is known to promote re-epithelialisation. Patients with a known zinc deficiency may show a decrease in synthesis of both DNA and RNA, and a decrease in the activity of collagen-synthesising polyribosomes. Zinc should be added to an oral treatment only if clear indications of zinc deficiency are present.

4. Growth factors

There continues to be considerable research in the area of growth factors. It is now clearly understood that growth factors play an important role in wound healing, although at this stage it is not clear as to their precise role. Growth factors may be divided into two groups.

(a) The tissue-generated growth factors

These growth factors include the:
- platelet-derived growth factor
- macrophage growth factor

- fibroblast growth factor
- transforming growth factors alpha and beta
- epidermal growth factor.

(b) The haematopoietic growth factors

The factors in this group are

- granulocyte colony stimulating factor
- granulocyte macrophage stimulating factor
- erythropoietin.

They have been used particularly in the management of anaemias associated with renal failure patients under haemodialysis, and as a rescue for cancer patients undergoing chemotherapy where they increase the blood cell population to minimise the risk of infection.

Systemic medications — inhibitory

Corticosteroids, including the various forms of cortisone such as prednisolone, prednisone etc., are a group of drugs used widely for a number of indications. Corticosteroids inhibit fibroplasia and formulation of granulation tissue. Low dosage may interfere by causing mild anorexia but high doses have a major effect on wound healing because of their interference with fibroplasia, vascular proliferation, delayed epithelialisation, delayed contraction and an increase in susceptibility to infection. If an anti-inflammatory steroid is used during the inflammatory phase, this will result in the failure of leucocyte migration (e.g. polymorphs, macrophages) into the wound, diminishing fibroplasia and neovascularisation. Topically applied steroids inhibit fibroblast proliferation and collagen synthesis, and may also cause peripheral vasoconstriction.

The adverse effects of smoking and the potentiation of cancer in various parts of the body have been understood for many years. However, it is clear that the toxic constituents of smoking — such as nicotine, carbon monoxide and cyanide — have a dramatic and inhibiting effect on healing. Even low usage will cause a reduction in peripheral blood flow for a period after each cigarette is smoked. Nicotine will diminish red blood cells, fibroblast and macrophages, and increase platelet adhesiveness. This will produce cutaneous vasoconstriction. Carbon monoxide has an affinity for haemoglobin 200 times that of oxygen. This will have a major effect on the oxygen-carrying capacity of the blood and will lead to a potential ischaemia. Hydrogen cyanide inhibits enzyme systems necessary for oxygen transport at the cellular level, as well as oxidative metabolism. Smoking can therefore be a major cause of the non-healing of wounds.

General recommendations

The main difficulty is in knowing what to do for the management of patients who are taking concurrent medications and have non-healing ulcers. Here are some basic rules.

1. When indicated, use drugs to enhance healing.

2. Where possible, avoid drugs that inhibit healing, even if this is possible only for the short term.

3. If this is not possible, realise that the wound may not heal but it can be managed so that there is as little pain and discomfort as possible and local issues such as exudate are managed.

9. Other factors

Other factors include such lifestyle choices as drinking alcohol and smoking.

- Excessive and/or chronic alcohol intake can lead to health problems affecting wound healing. Alcohol-induced digestive problems may lead to malnutrition and anaemia. Liver damage can result in chronic disturbances because of a reduction in platelet levels and subsequent circulatory damage which may reduce circulation below that required for wound healing.

- Smoking will also have a major negative effect on wound healing.

WOUND TYPES

The majority of wounds fall into two general categories, acute wounds and chronic wounds.

Acute wounds

The most common acute wounds in ageing people are skin tears. These are a direct result of the ageing of the skin and may develop from the simplest types of trauma. The skin is so thin and friable that it will separate even when low levels of friction are directed to the surface of the skin.

The management of skin tears should, as a general rule, not involve the adhesion of a dressing onto the surrounding skin as its removal may result in a new area of skin damage. The are several important issues in the management of skin tears.

- Clean the area to remove any debris or contamination.
- Apply a topical antiseptic and wash off after five minutes.
- Bring the damaged edges together with a few strips, preferably an elastic type.
- Cover the area with a non-stick or low-adherent dressing, e.g. foam dressing, hydrocolloid dressing or hydroactive dressing.
- Hold the dressing in place with a lightweight cohesive bandage.

Dressings used with this method usually may be left in place for 5–7 days before needing to be changed.

Chronic wounds

Leg ulcers

Leg ulcers have a number of different causes, including:
- venous insufficiency
- arterial disease
- diabetes mellitus
- vascular complication of auto-immune disease (such as rheumatoid arthritis)
- malignant disease
- trauma
- deliberate self-injury.

Venous ulcers

Venous ulcers result from the breakdown of the venous circulation of the leg. The leg is unable to force blood through the various connecting veins via the bicuspid valves by muscular contraction.

- Deep veins are supported by thick connective tissue and their surrounding muscle masses.
- Superficial veins dilate easily under sustained back pressure.
- Communicating veins connect the two systems.

- Valves, usually bicuspid, are found in all three systems and they may become damaged, thickened or may degenerate with age. Thrombosis causes their destruction.

General features of venous ulcers

Venous ulcers are most often found in the gaiter area of the leg and, where there is a history of varicose veins, are usually irregular in shape but not painful. Oedema is often present. The skin is often stained around the ulcer area, the result of past fractures or trauma with a possible silent, deep-vein thrombosis. Skin changes such as eczema, atrophy blanche (white stippled scars on the skin), ankle flare and distended small veins on the medial aspect of the foot are often attendant factors. The main feature is a lack of venous return caused by a malfunction of the valve system either in the deep or the peripheral system.

Ischaemia, or arterial ulcers

The death of skin automatically follows occlusion of its arterial blood supplies unless this is gradual enough to allow a collateral blood supply to be established. Atheroma (thickening) is the most common cause of arterial ulcers of an ischaemic nature.

The main causes of reduction in arterial circulation are shown in Table 14.1.

Table 14.1 Causes of reduction in arterial circulation

Cause	Description
Extramural strangulation	Scar tissue or other factors may cause strangulation of the arterioles or fibrosis resulting from long-standing, chronic oedema. Chronic infection may also obstruct arterial flow.
Mural changes (to vessel wall)	Atherosclerosis or plaque formation reduces blood flow until thrombosis, embolism or infection causes complete closure.
Intramural strangulation	Small vessels are occluded by changes in blood viscosity, platelet adhesiveness or fibrinogenesis, seen especially in small painful ulcers of the feet and ankles.

General features of arterial ulcers

Arterial ulcers are very painful, especially at night. This is as marked in small ulcers as in larger ulcers. Their edges are sharply defined, and the ulcer is ‘punched out’. The base is often covered with slough. This may deepen to bare the tendons. There may be a history of intermittent claudication (pain on exercise), dependent foot (dusky foot) white on elevation, or peripheral vascular disease. The skin is often shiny and friable. Uncontrolled diabetes and smoking are significant factors causing arterial insufficiency. Healing is often slow and may depend on control of the underlying cause.

Some examples of arterial ulcers are:
- traumatic ulcers on the shin and ankles
- ulcers following fractures
- ulcers caused by ill-fitting callipers or braces
- diabetic foot ulcers
- steroid ulcers
- post-burn ulcers
- ulcers caused by intra-lesional injections (in an area with an already impoverished blood supply).

Other kinds of leg ulcers

It is important to note that between 10 and 15 per cent of leg ulcers are of mixed aetiology.

Infections may lead to ulceration, and they are often hard to heal because of:
- associated oedema
- cellulitis
- thrombophlebitis
- diabetes
- underlying vascular disease
- rheumatoid diseases especially in bed-ridden patients
- general conditions of the skin in elderly patients — often associated with malnourishment.

Complications include:
- infection
- eczema and irritant dermatitis
- haemorrhage
- neoplasia.

Other causes of leg ulcers

In addition to the more common forms of ulceration, there are a number of less familiar causes. These are as follows:
- trauma — an initial cause that can develop into an ulcer usually because of other complications, such as underlying poor health and skin condition, but can also occur as a result of inexpert compression bandaging

- vasculitic ulcers — as a result of other medical conditions such as rheumatoid arthritis and polyarthritis
- infections of the skin that can produce ulcers if the necrotising type of bacteria is present
- haematological problems (thalassaemia or leukaemia)
- polycythaemia and skin conditions such as pyoderma gangrenosum.

Some ulcers may be as a result of neoplasia, and some may develop into non-healing ulcers. The most common of these are squamous-cell and basal-cell carcinomas. Ulcers may also result from lymphoedema, caused by a reduction in the function of the lymph vessels to drain extracellular fluid and the resulting oedema.

Treatment of ulcers

The overall aims are to:

- treat the underlying disorder
- control the infection
- debride surgically, autolytically or enzymatically
- apply dressings.

Principles of treatment

- Maintain a clean site (by debriding slough and physically protecting the ulcer area).

- Prevent the area from drying out (most especially the surrounding skin).

- Maintain rigorous pressure-care procedures.

- Assist granulation (so that the damaged skin can be closed as rapidly as possible).

The choice of dressings should be based on the simple rule of C D E (see Table 14.2).

Table 14.2 The C D E rule for dressing wounds

What to observe	What to assess for
Colour	Pink, red, yellow, green or black?
Depth of the wound	Superficial, partial thickness, full thickness or a deep cavity?
Exudate of the wound	Dry, slight, low, moderate or highly exudative?

Table 14.3 indicates the types of dressings that should be used.

Table 14.3 Identifying and managing wounds

Wound type (by colour & exudate)	Aim of treatment, and comments	Dressings to use according to wound depth	
		Superficial	**Cavity**
Black, low exudate	*Aim: To rehydrate and loosen eschar* Surgical debridement is the most effective method of removing necrotic material. Dressings can enhance autolytic debridement of the eschar.	Amorphous hydrogel Hydrocolloid Proteolytic enzyme	
Yellow, high exudate	*Aim: To remove slough and absorb exudate* Use hydrocolloids with or without paste or powder for the deeper wounds. Hydroactives, alginates and enzymes will help remove the slough and absorb the exudate.	Hydrocolloid Alginate Hydroactive	Hydrocolloid with paste or powder Alginate Hydroactive cavity Foam cavity dressing
Yellow, low exudate	*Aim: To remove slough, absorb exudate and maintain a moist environment* Hydrogel in particular will rehydrate the slough. Hydrocolloids, hydroactives and enzymes will aid in autolysis.	Amorphous hydrogel Sheet hydrogel Hydrocolloid Hydroactive	Amorphous hydrogel Conforming hydrogel Hydrocolloid with paste
Red, high exudate	*Aim: To maintain a moist environment, absorb exudate and promote granulation and epithelialisation* Foam dressings, alginates and hydroactive dressings help control exudate; use hydrocolloids with paste or powder for deeper wounds.	Foam Alginate Hydroactive	Foam cavity dressing Alginate Hydrocolloid with paste or powder Hydroactive cavity
Red, low exudate	*Aim: To maintain a moist environment and promote granulation and epithelialisation* Hydrocolloid, foams, sheet hydrogels and film dressings will maintain the environment. It is possible to use a combination of amorphous hydrogels with a foam cavity dressing in deeper wounds.	Hydrocolloid Foam Sheet hydrogel Amorphous hydrogel Film Zinc paste bandages can be used in superficial granulating wounds.	Hydrocolloid with paste or powder Amorphous hydrogel Foam cavity dressing
Pink, low exudate	*Aim: To maintain a moist environment, and to protect and insulate* Foams, thin hydrocolloids, thin hydroactives, films and simple non-adherent dressings will provide the necessary cover.	Film Foam Thin hydrocolloid Thin hydroactive Non-adherent Zinc paste bandages	
Red unbroken skin	*Aim: To prevent skin breakdown* Hydrocolloids and film dressings provide the best protection.	Film Hydrocolloid	

NB The choice of secondary dressing will depend on the nature, position and level of exudate. In general terms, film dressings and non-adherent dressings are suitable for low-exudating wounds but not in high-exudating wounds. Foam dressings are useful over amorphous hydrogels and alginates. The use of gauze as a secondary is limited, especially over hydrogels or alginates, as the gauze will reduce the ability of the dressing to function at its optimum level.

The other consideration is the method of dressings retention. If the surrounding skin is good then the dressing may be held in place with good-quality tape. If the skin is poor then a tubular bandage or a lightweight cohesive bandage is suitable.

Pressure wounds

Of all of the chronic wounds seen in practice, surely the most preventable are the pressure wounds. The essential part of the prevention is patient assessment and active intervention in the case of high-risk patients.

Pressure wounds can range from the simple blister most of us may have experienced over the years from footwear to the extensive pressure sores experienced by bedridden patients suffering from such afflictions as:
- stroke
- spinal injury
- multiple sclerosis
- dementia.

It has been estimated that 6 per cent of all patients treated in hospital develop a pressure wound but, sadly, this number increases to about 30 per cent amongst the ageing.

A pressure wound develops when the capillary blood flow to the skin and tissue over a bony prominence is decreased for a sufficient period of time. The capillary pressure in the arterial blood system is some 32 mm of mercury, and in the venous system about 12 mm of mercury. It therefore requires a pressure of only about 30 mm of mercury to restrict the arterial blood flow. The consequence of this restricted blood supply is a reduction in oxygen supply and nutrition to the tissue, accompanied by the problem of waste products not being removed from the site. The result of this is hypoxia, tissue acidosis and increased capillary permeability, which allows intravascular fluid to escape, causing oedema and cell death.

The main causes of pressure wounds are:
1. pressure
2. friction
3. shear
4. moisture.

1. Pressure

Direct pressure on tissue over a bony prominence in excess of 30 mm of mercury will cause ischaemia in the surrounding tissue. This will occur not only from a patient being in bed, but also lying on a trolley or sitting in a chair. The extent of tissue damage will depend on the intensity of the pressure, and the length of time the pressure remains unrelieved. The tissue can tolerate pressure for short periods of time; however, even low pressure over a long period of time will have some detrimental effect.

2. *Friction*

Friction occurs when the top layers of skin are worn away by continued rubbing against an external surface. This can manifest itself in a simple blister or tissue oedema, or an open pressure wound. This can be caused by ill-fitting footwear, or even by bed linen.

3. *Shearing forces*

Shear occurs when the skin remains in place, usually unable to move against the surface it is in contact with, while the underlying bone and tissue are forced to move. This force will contribute to the destruction of deep tissue and the obstruction of blood vessels in a manner similar to direct pressure. This type of pressure injury is seen in patients left sitting up in bed or on a chair, where gravity causes the patient to slide down but the skin adheres to the bed linen or the surface of the chair.

4. *Moisture*

Continued exposure to moisture will cause maceration of the skin, which affects the skin's ability to function and it becomes more prone to damage. Macerated skin is much more likely to stick to bed linen. Moisture may come from urinary incontinence, faecal incontinence, perspiration, or wound exudation.

Risk factors

The major risk factors for the development of pressure wounds are

- lack of mobility
- changes in the skin
- physiological factors.

1. Lack of mobility

Lack of mobility may occur because of:

- paralysis
- sensory defect such as neuropathy (with the patient unable to feel pain or pressure) or patient immobility (when a patient is restrained or in traction and unable to change position)
- other chronic diseases, such as arthritis or obesity, which can reduce the ability of an individual to move well.

2. Changes in skin

Skin changes will develop from incontinence and perspiration, but also as a result of less-than-ideal bodyweight. Underweight patients have little fat or muscle to prevent the effects of pressure.

3. Physiological factors

Physiological factors can include:

- nutritional deficiencies due to malnutrition — resulting in a reduced intake of proteins, fluids, electrolytes, vitamins and a consequential breakdown of tissue to compensate
- systemic disease, such as diabetes, anaemia and vascular disease, which results in a reduced blood supply
- hypoxia with a reduced blood oxygen supply, as in chronic respiratory diseases.

Risk assessment

The most important management principle in pressure wounds is to identify any patient at risk of developing such a wound. There are a number of assessment tools which may be used to aid in the identification of such patients. The most commonly used assessment tools are Norton, Waterlow and Braden. Each of these tools rates the patient against a number of criteria such as:

- mobility
- activity
- mental status
- incontinence
- physical condition
- nutrition.

From these various ratings a total score is established so that the 'at risk' patient can be identified. Once a patient has been identified as at risk, action must be taken to remove or alter any risk factors that can be changed, and to provide a suitable surface for the patient to be placed on.

Pressure sores

A pressure sore is a localised area of cellular damage resulting from direct pressure on the skin, causing pressure ischaemia, or from shearing forces caused by mechanical stress to the tissue. An external pressure which exceeds the mean capillary pressure of 28–38mm Hg is sufficient to cause tissue damage if it is maintained for long enough periods, particularly in debilitated patients. Any period exceeding two hours is likely to cause trauma. For cachectic, debilitated or terminally ill patients, tissue damage may occur in much less time than this.

The classification of pressure sores is as follows:

Stage 1: Blanching hyperaemia

Momentary light finger pressure on the site of erythema, following a prolonged period of pressure on the skin, causes the skin to blanch, indicating that the skin's micro-circulation is intact.

Stage 2: Non-blanching hyperaemia

The erythema remains when light finger pressure is applied, indicating that some micro-circulatory disruption superficial damage, including epidermal ulceration, may be present.

Stage 3: Ulceration progresses

The ulceration progresses through the dermis to the interface with the subcutaneous tissue.

Stage 4: Ulceration extends into the subcutaneous fat

Underlying muscle is swollen and inflamed. The ulcer tends to spread laterally, temporarily impeded from downward progress by deep fascia.

Stage 5: Ulceration extends into the deep fascia

Infective necrosis penetrates down to the fascia. Destruction of muscle now occurs rapidly.

Factors affecting healing

As with the general healing process, as well as the prevention of healing, there are intrinsic and extrinsic factors that can delay the healing of pressure wounds.

The intrinsic factors include:
- immobility
- malnutrition
- altered consciousness
- incontinence

- advancing age
- debilitating illness — anaemia, decreased resistance to infection, cardiovascular disorder and poor nutritional state.

The extrinsic factors include:

- unrelieved pressure
- shearing forces
- repeated application of force
- friction.

No matter how appropriate the wound dressing regime, delayed healing is inevitable if the underlying cause of the pressure sore is not alleviated. At the very least, every attempt should be made to minimise the degree of damage in a pressure wound.

Patients most susceptible to pressure sores include those with the damage indicated in Table 14.4.

Table 14.4 Patients most susceptible to pressure sores

Type of sore	**Type of patient**
Spinal cord	Paraplegics
Cerebral	Patients with hemiplegia or unconsciousness
Nutritional	Patients with obesity or malnutrition
Medical conditions	Patients suffering from arthritis or diabetes
Drug related	Patients suffering alcohol or steroid abuse
Orthopaedic	Patients suffering fractured proximal femur or poorly applied traction and plaster
Psychiatric	Severely depressed patients
Vascular	Patients with peripheral vascular disease or venous congestion
Post-surgical	Patients who have had major abdominal and neurosurgery

Risk factors

Adjuvant factors include:

- pressure points on immobilised patients or long-term in-patients
- incontinence
- dry or friable skin
- nutritional status and physical condition
- age

- diabetes mellitus or peripheral vascular disease
- presence of bad flexural contractions and history of chronic ulcers
- general disease
- obesity
- hypertension
- anaemia and hypoproteinaemia
- zinc depletion
- personal attitudes and habits
- infection.

Management

The presence of necrotic tissue or an excessive slough should be treated by surgical debridement and removal of the necrotic tissue, or the use of hydrogels such as Intrasite gel or Duoderm® gel to rehydrate the slough, necrotic tissue and eschar. This can be assisted by hydrocolloids, with a combination of one of the hydrocolloid pastes and a hydrocolloid dressing, such as Duoderm® or Comfeel®. Failure to remove necrotic tissue or slough will prevent the healing of a pressure wound.

Infection is always a potential problem for a debilitated patient with a pressure sore. The infection may be treated either locally or parenterally. Depending on the type of infection, the use of metronidazole gels of approximately 0.7%–0.8% metronidazole in a hydrogel will help to remove any anaerobic bacteria that may be present in the pressure sore. If there is cellulitis around the pressure sore, then systemic antibiotics are indicated.

Excessive exudation may also delay the healing of a pressure wound. It is common practice to pack a pressure sore with gauze, either on its own, or in combination with topical antiseptics. This is inappropriate. If a pressure sore is highly exudative, use a foam cavity dressing or an alginate, hydroactive or hydrofibre dressing.

If a patient is assessed as high risk it is essential to initiate the use of particular devices, such as special air mattresses, water beds, air-fluidised beds, low-pressure air beds, or alternating pressure, ripple-type mattresses whether fixed or air-pressure driven. These types of devices will prevent the development of a pressure sore or at the very least prevent it from becoming too severe.

The sites of pressure sores are usually:
- post-sacral (lower back)
- post-calcaneal (ankle)
- trochanteric (upper femur)
- post-ischeal (buttocks).

Other issues in management are:

- to reduce or relieve pressure
- the frequent turning of patients
- reduction of friction and shear.

Incontinence should be well managed, and perspiration controlled. Nutritional support where necessary is essential and where other underlying medical conditions are present all other medical support should be maintained.

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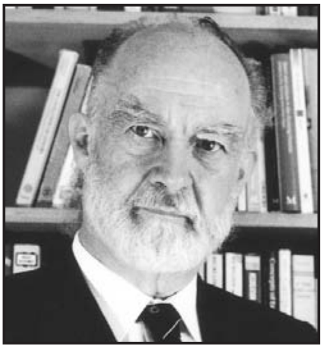

Elery Hamilton-Smith

Theresa Cluning

ELERY HAMILTON-SMITH, AM

Professor and Honorary Research Fellow, Lincoln Gerontology Centre, La Trobe University, Melbourne, Australia

Elery Hamilton-Smith has wide-ranging interests in social policy and social development and has been a visiting professor at many universities in North America and Europe. His long-standing interest in leisure services for ageing people led to his involvement in a research program on improving the lot of people with a dementing illness. That research culminated in the development of the ELTOS (Enhanced Living Through Optimal Stimulus) theory and the book *Rethinking Dementia — an Australian approach* (of which he was joint Editor) with its companion kit *Teaching About Dementia*, both published by Ausmed Publications and both of which have sold widely in Australia and are now beginning to penetrate overseas.

Elery is now exploring the application of the ELTOS guidelines to better home care for people with dementia.

THERESA CLUNING

Registered Nurse, Registered Midwife, Diploma of Applied Science (Community Health and Maternal and Child Health), Bachelor of Applied Science (Advanced Nursing), Master of Educational Studies, Fellow of the College of Nursing Australia

Theresa has worked in many roles in various areas of health care including acute hospitals, residential care, community health, academia and community case management.

She has been involved with many people who have dementia and with those who care for people with dementia. She has always been humbled by the amount of care and love shown by those caring for someone with dementia, particularly when the loved one's core personality is gradually and certainly fading. It is often heart breaking for the carer to witness.

CHAPTER FIFTEEN

Responding to Dementia

Elery Hamilton-Smith
Theresa Cluning

WHAT IS DEMENTIA?

Dementia is a state of being, characterised by changes in everyday behaviour, including:

- a decline in cognitive capacity and understanding
- confusion
- forgetfulness.

Although dementia appears to be most commonly based in some form of damage to the tissue of the brain, it is shaped by the culture, personal history and immediate social and physical environment of the affected person.

To help clarify the common confusion about the nature of dementia, it is definitely not correct to see it as a disease. If one wants to use medical terminology, the correct term would probably be 'syndrome', describing a complex set of interrelated effects upon the individual. More particularly, dementia is not the same thing as Alzheimer's disease, although the two are closely associated in about 70 per cent of those who have dementia. In the remaining 30 per cent many other diseases or forms of brain damage are implicated, including:

- multiple strokes (known as multi-infarct dementia)
- accident-related trauma
- Down syndrome
- Parkinson's disease
- Creutzfeldt-Jakob disease
- Pick's disease

- AIDS
- Huntington's Chorea.

There is a great deal of similarity in the dementia resulting from all of these associated diseases or conditions, and precise diagnosis of the underlying brain damage may prove extremely difficult.

Although recent research has done much to clarify our understandings of dementia, there is still more that we do not know than we do know. For instance, we do not understand the processes through which Alzheimer's disease may give rise to dementia, or why some people with extensive brain damage as a result of Alzheimer's disease do not develop dementia.

So, dementia must be seen as a complex process of change in the human condition. The early stages of its onset are often an extremely frightening and unhappy time for the affected person, but this awareness of change is usually relatively short lived as the person moves into a new reality. The impact upon their partner or other family members is often extremely traumatic and the basis of a continuing feeling of loss and tragedy. Dementia is not just an individual problem — it is a family and community problem. The extent to which dementia is widely seen as a tragedy and something to be feared probably exacerbates the negative feelings associated with the affected person's awareness of the onset of the condition.

Many of the problems associated with dementia arise from the negative perceptions which our society has. We become so focused upon the loss of mental functioning, that we fail to recognise the extent to which many personal resources and abilities survive, and we do not look for the new abilities which may arise as a positive element in dementia. Because we commonly see dementia as a 'disease' which is driven by damage to brain tissue, we fail to recognise the major ways in which it is shaped by the physical and social environment in which the affected person happens to be living. We are also likely to focus upon any personality changes which occur and to ignore the essential continuity of the person's lifetime patterns.

THE INDIVIDUAL PERSON

Dementia usually first appears as confusion about one's immediate surroundings, often associated with forgetfulness. Although often identified as the loss of short-term memory, it is often much more characterised by confusion. The difference is well illustrated by the humorous comment, 'It's not dementia if you forget where your car keys are, but it might be dementia when you find them but can't remember what to do with them.'

Although the idea of short-term memory loss is upheld as a central feature of dementia, this is a gross oversimplification. All of us remember best the things which are truly important to us. We all find semantic memory — the memory of names and labels — to be the most difficult. Incidents remain with us more easily; long-practised procedures and skills probably last longest. So dementing people will forget words and names, and many incidents, but they may retain a great deal of their skills and long-practised procedures. They will often retain highly positive or highly negative emotional feelings. Frequently a number of memories may become tangled together in the process of confabulation, where various elements of life experience are unified into a new, but often well-integrated story.

Sometimes the onset of dementia will be triggered by:

- a traumatic event, such as loss of a spouse
- a significant accident, such as a broken hip or a motor vehicle accident
- having major surgery under general anaesthetic.

However, there is no evidence that these kind of incidents actually cause the dementia, they may simply bring a latent or incipient dementia to the surface.

The first step is to ensure that a full and accurate diagnosis is made. Many general practitioners inevitably lack the necessary expertise or experience to make an adequate diagnosis. Although a number of simple tests have been devised and are widely used, these are only useful for preliminary screening purposes. Full diagnosis demands a lengthy interview and history taking, sometimes accompanied by a brain scan. This is extremely important because some people may move into a dementia-like state as a result of depression, a brain tumour, or some other curable condition. An incident from the family of one of the authors illustrates this:

John was diagnosed as having Alzheimer's-type dementia, but over the next few months he exhibited extremely rapid decline together with some impairment of posture and movement, neither of which is to be expected in normal dementia. Referral to a psychogeriatric specialist showed a small tumour in a critical area of the brain which was removed surgically. John recovered to his former self within a few days.

Diagnosis may also reveal that the problem has resulted from a series of minor strokes due to blood clots lodging in the brain. In this case, appropriate medication, which reduces the likelihood of clotting, can greatly reduce the likelihood or frequency of strokes and so reduce the extent of the resulting dementia. This usually demands regular checkups to assess the impact of the medication and to ensure that dosage remains at the right level.

Although many textbooks may describe the course of dementia as a series of clearly defined stages, this is always an oversimplification and an attempt to fit with the artificial model of dementia as a disease. In fact, dementia is a very individualised condition. 'Normal' ageing always involves the accumulation of individual preferences, values and behaviours; we become more different from each other as we age. When the unpredictable expression of dementia is imposed upon those differences, then differences increase still further. It is much more important to fully recognise the individual personality, which emerges as dementia commences and develops, than to try to make the person fit into some preordained and systematic classification. Dementia is also a fluid and changeable state in itself, so the person may well change, either gradually, abruptly or sporadically. But there is a broad pattern about which we can generalise — always remembering that people may diverge from the overall pattern in an infinite number of ways.

Over a period of some months after onset, there will be a period of moving in and out of dementia, being aware of the changes taking place and so often being depressed, angry or sorrowful. But this awareness of change disappears as the dementia becomes more fully established. The extent of change at this stage may be relatively slight, although usually characterised by continuing confusion and forgetfulness, but may be much more extreme, with anger or various other kinds of 'disturbed' behaviour being displayed.

As dementia progresses, it is not uncommon to see:
- aggression
- frenetic behaviour
- meaningless repetition of words or actions
- constant questioning
- occasional hallucinations
- paranoia
- denial.

However, this kind of behaviour is almost always a reaction to the current social environment. It may be simply an expression of:
- confusion
- boredom
- frustration.

Sometimes it will be the working out of past experiences being recalled, and in the case of those who have had a particularly traumatic experience (e.g. those who lived through the European holocaust), it may be truly agonising and extremely difficult to moderate. Dementia may also be coupled with episodes of depression or, in some instances, continuing depression. Others will exhibit an increase in happiness or a special interest and pleasure in some aspect of everyday life. Many people have a continuing ability to read, so we must never assume that reading is out of the question. There are also instances where the dementia releases new or previously hidden interests and abilities, such as musical or artistic talent. If the social environment is right, then many people will be able to live a reasonably good life.

One of the little-recognised but important elements of dementia is the phenomenon of transient clarity. This is a temporary movement back into 'normal' understanding and communication. Most importantly, it may happen immediately prior to death, even following a long period of apparent unconsciousness.

Joan was a volunteer worker at a nursing home. She had been asked to spend an hour each time she was at the home sitting with Rhonda, who was blind, approaching death and appeared to be totally unconscious. Joan felt she should try to register her presence, so she always wore the same perfume, held the lady's hands and talked to her throughout the hour-long visit. Then came the night when it was clear to nursing staff that death was imminent, so Joan received a phone call asking if she wanted to come in. She drove to the home, and as she entered Rhonda's room, Rhonda reached out to her, and said, 'Thank you so much for coming to visit me these last few weeks', slumped back on her pillow and died.

Two vital principles emerge from this.

- The first is that we should never assume a person with dementia is not aware of what is going on and what people are saying, even when they appear unconscious.

- The second thing is that loved ones should always try to be present when death is imminent — it is probably very important to the dying person, even if they do not communicate as Rhonda did.

At the same time as the dementia changes day by day, and also slowly progresses into further decline, so the physical condition of the person may also decline as a result of:

- normal ageing
- advance in the dementia-associated deterioration of the brain
- unrelated medical conditions.

It is vital that the full range of medical and other health care is still provided to the dementing person. The dementing person may well have some difficulty in communicating changes in their own health simply because, just as with any one of us, the change occurs gradually and is not easily recognised. This means that continuing observation and regular checkups are demanded rather than just asking people how they feel.

Finally, although the underlying disease condition, such as Alzheimer's disease, may cause death, it is often the case that death is actually due to pneumonia or to other concurrent illnesses. This further underlines the importance of continuing overall medical assessment and care.

THE CARER

The primary carer may be a spouse or partner, a son or daughter, sometimes the daughter-in-law, or occasionally a neighbour or friend. Sometimes this care is provided with sensitivity and continuing love:

Naomi and her husband were married in 1937, then spent the whole of World War II in two different internment camps, followed by six months of searching for each other across Europe. They have never been separated since, and when Naomi developed dementia some 15 years ago, Erich cared for her alone and without resorting to community support services. They remained happy and able to communicate with each other, and their situation only came to light when Erich, concerned at his increasing age and the fact that he might die, leaving her alone, went to a welfare agency to arrange for someone to make a daily phone call to check that all was in order.

Conversely, the need for care may well be either resented or extremely difficult to provide for:

Joan decided to give up an enjoyable job in order to care for her father. She resented having to make this decision, and now finds herself becoming increasingly cut off from her friends. Her resentment has increased. This expresses itself in her being extremely short-tempered, blaming her father for his behaviour which she now sees as being staged simply to make trouble. She constantly abuses him verbally and on occasion has struck him in a fit of temper. Although he is regularly in tears, he rejects any suggestion that he should move into residential care because he wants to remain in his lifetime home. The household has now reached a crisis point as Joan's husband has announced his intention to leave the house.

Sometimes the care of a relative may be cause for debate and division within a family.

Heather believed her mother, who lived alone in an apartment, was in dementia. Mother sometimes failed to prepare meals for herself for several days, or left saucepans on the stove until they burned out, failed to wash her clothes, and no longer talked very much when Heather visited. It was clear that she needed care, but Heather was suffering from multiple sclerosis and knew that the extent to which she could help was limited. She spoke with her brothers and sisters, all of whom said, '. . . There's nothing to worry about — Mum is just getting old.' When Heather tried to insist that they take the matter more seriously, they simply responded with anger. The family GP also supported the brothers and sisters in their view. Following a discussion with me [Elery Hamilton-Smith] *and a visit together to her mother, Heather arranged for a second opinion from a reputable psychogeriatrician, and this confirmed that her mother was fully advanced into Alzheimer's-type dementia. We managed to set up a family meeting, and ensure that the new diagnosis was understood and accepted. The family were then able to share responsibility, and eventually arranged for their mother's admission to residential care.*

No matter how positive or negative the caring experience may be, it represents an enormous demand upon the time, physical strength and emotional, psychological and spiritual resilience of the carer. One book written for carers talks of 'the 36-hour day' as a dramatic way of capturing the continuing pressure of caring. There is also good evidence that dementia of a spouse or partner is likely to result in more acute and protracted grieving than death.

THE ROLE OF THE COMMUNITY AGED SERVICES PROFESSIONAL

Community-based agencies work together to assist ageing people with dementia to stay at home until they are at a quite advanced level of dementing illness. Unfortunately, in our experience, unless the caring family have the resources to provide intensive support when required, it is impossible for someone living alone to stay at home indefinitely. The necessary financial, environmental and people power resources to keep them happy, safe and physically well often do not exist at this point in history. Although many more people with live-in support are remaining at home, the amount of support required is considerable and often the carer is unable to provide the level of support required.

There are also special issues about family relationships. In some families, care at home is a highly rewarding experience for everyone and is a very satisfactory way to proceed. In others, care at home may be destructive for all concerned and may well lead to physical abuse of either the carer or the dementing person. Most situations, of course, lie somewhere between these two extremes, with a deal of difficult and demanding work for the carer who experiences both good days and bad days. However, community workers must be alert to the possibility of abuse because they may well be the only people who have the opportunity to recognise signs of abuse.

Therefore, one of the main roles of a community worker is to provide support, education and advice, whilst at the same time monitoring the progression of the dementing illness and the capacity of the carer to continue to care. In particular, community workers must be very aware of the pressures under which primary carers operate. They need continuing patience on the part of professional care workers and a great deal of emotional support. They will also need practical support, including a weekly respite period so that they can catch up with shopping and other family business, and have time out for relaxation. Regular periods of longer respite are also necessary for most carers so that they can relax, have a holiday and 'recharge their batteries'.

PRINCIPLES IN DEVELOPING A CARE PLAN

Just like all of us, the person with dementia needs:

- continuing respect as a real person
- love, expressed through comfort with continuing attachment and inclusion
- a continuing sense of self, with identity and a meaningful lifestyle.

The very basic requirement of effective care is thus continuing **communication** which will convey respect, love and acknowledgment of the continuing self. Remember that real communication is always a two-way process, and should involve:

- listening and talking
- watching, and using our own body language in a positive way
- being touched or held while touching and holding in appropriate ways.

All of these express not just ideas but feelings about the other. The assumption that the person with dementia just does not understand any longer and cannot express an opinion of their own is downright wrong. Similarly, the assumption that the dementing person has lost all short-term memory is totally wrong.

When I first met Alice, she talked volubly with me, albeit in her own language which I could not understand. I next saw her a week later, when she greeted me warmly, calling me by name, and continued talking with me in the same way. This became a regular ritual, and it suddenly made sense to me when she said to a compatriot, 'Elery is a good friend because he always has time to talk with me.' I next realised that if another person did not pause to chat with her, she became extremely angry and quite difficult to manage, sometimes for hours afterwards.

In reflecting upon my conversations with Alice I came to realise that it was not the content of conversation which mattered to her, but the process of feeling she was in touch with people.

Another important point is not to ask questions which can be answered simply by a yes or no. Such a question, for many people, will evoke a yes, even when that is not the appropriate response. Just as in Alice's case, it is often much more a reflection of the relationship with the carer than a statement of factual content. (In some respects, talking with a person with dementia is like talking with someone who does not speak English well. If you ask a question that demands a yes or no answer, you will get the answer 'yes' because the non-English speaker wants to please you and thinks this is the way to do it. The response has nothing to do with the question. Often the question is not understood at all.)

Many people with dementia can talk quite lucidly about various topics and most, by one means of communication or another, can make their preferences and needs very clear. By watching and listening, we can thus understand many needs and respond to them.

Given this understanding, we need to develop a **common agreement** amongst all those involved in care — family and support staff — as to the most appropriate ways of dealing with particular issues and the daily routine which should be observed. Establishing consistency and continuity in the routines of life reduces confusion, stress and uncertainty, and this is of fundamental importance.

Respecting the individual means accepting their view of the world. This is commonly known as **validation**, confirming as far as possible the perceptions and values of the individual person rather than arguing with them. Imposing our reality upon them is both pointless and damaging. It is a failure to respect them as real people and a denial of their own personal rights. However, particularly in the early stages, some aids to maintaining contact with everyday time and routines may be helpful, even though their use will diminish progressively.

At the same time, in all these patterns, we must maintain flexibility and respond to change. To assume that the same routines will always work, or that the individual always has the same understanding of their world is courting disaster.

One day, Betty was gazing out the window, and when the visiting nurse started talking about the weather, Betty responded by saying, 'Why are all those people getting on the bus?' The nurse could not see a bus, but knowing about validation, she said, 'Oh, they are probably off on a picnic.' Then she made a note to inform other carers about it, so every time Betty was looking out the window, they talked with her about the bus. One day, the usual nurse was sick, and so a relieving nurse attended to Betty, who took her to the window and asked, 'Can you see a bus out there?' The answer, of course, was negative, and Betty said, with obvious relief, 'Thank God. Everyone keeps talking about a bus out there and I thought I was going out of my mind!'

Again, the important lesson is to not assume a stable reality, but always to check on the current state of play as part of everyday conversation.

Underlying all of this discussion, one of the most important objectives in care is to **reduce confusion, anxiety or stress**. Not only does stress exacerbate the confusion of dementia, but is all too likely to result in so-called 'disordered' behaviour and this in turn sets up a vicious circle of inappropriate responses and continuing stress. Stress makes people unhappy and has many negative impacts upon physical health, ranging from the simple fact that a person experiencing stress will not eat or sleep properly to the hidden but much more fundamental problem that stress reduces the effectiveness of the immune system. A person under stress is much more subject to minor and major infections.

So daily routines should be simple and consistent and fit with the time patterns preferred by the dementing person. Food should be chosen to fit the tastes of the individual. Remember that the number of taste buds and hence the sense of taste diminishes as we age and so food may need to be more tasty to maintain the same pleasure and motivation to eat well. Disturbing features of the environment should be minimised. The process should follow this sequence:

- Watch for confusion, frustration, anxiety, annoyance, anger or fear.
- Identify the causes.
- Eliminate, reduce or moderate the causes.

- Provide support and comfort during any transition.

Identify and make available **experiences of daily living** that are joyful and satisfying to the person concerned. These will often be major interests which have been maintained and pursued for many years, although sometimes a totally new interest and skill may emerge and be pursued with real energy and competence.

Ted had spent his life operating a haberdashery stall at various metropolitan markets. When he developed dementia, he soon became extremely restless living at home. He was constantly on the move, bad-tempered and very clearly not happy. His wife, Mary, recognised that he was missing the normal routines which had been his life, but could not see any way in which he could return to these. It was suggested to her that she should put his trestle table up in the lounge room and bring out his remaining stock and cash tray. She did so, and on the very first day, Ted unpacked his stock, laid it out on the table, and started selling to imaginary customers. At the end of the day he carried his cash tray out to the kitchen table and 'counted' his money just as he had always done on coming home at the end of the day. This pattern continues consistently, with any family members or friends who visit being co-opted as real customers. Mary says, 'It is just like children playing shop and that makes me sad, but at least Ted is truly happy again.'

Men will often pursue something related to their work; women will often want to continue cooking, or to sew, knit or embroider. But some may take up a totally new activity. We can recall a lady who learned to play the piano, another who sang for several hours each morning and still another who took up painting and actually earned a very good income from her sales. There are several who have written poetry or prose which has even achieved commercial publication. While this level of achievement is rare, it emphasises the extent to which we must not see a dementing person as having lost all functional abilities, but rather search for ways in which they can achieve satisfaction through either old skills or new ones. Other aspects of the sense of self may involve ways of relating to people and maintaining social linkages, or seeking spiritual understandings. Other useful ideas include:

- reminiscence
- humour
- silence
- rituals
- celebrating special events
- story-telling
- playing familiar games
- pets
- soft toys.

When Mickey had to go to hospital for a major operation, her granddaughter arrived to visit her bringing a toy pig with a curly tail. The pig was soft and cuddly and one of the nurses said she knew exactly what Mickey was trying to say when she described her pig as 'a foamy ham' instead of a furry pig. Pig quickly became known to all the doctors and nurses. Their comments obviously gave Mickey real pleasure and a sense of being someone of note within the busy hospital.

Finally, remember that anything that will keep people moving about actively for part of every day is very highly desirable. Regular and consistent physical exercise does make an immense difference to continuing health. It does not need to be highly energetic — strolling gently, swimming, dancing (again gently) are ideal. One of us has a mother in her 90s who insists on walking about two kilometres a day, in the course of which she does her shopping. She enjoys almost perfect health, largely as a result.

In summary, a good care plan will provide for:
- patterns of communication
- common agreement about care routines
- validation (confirmation) of the person's own reality
- reduction of confusion, anxiety and stress
- meaningful experience in daily living.

THE PRACTICAL CARE PLAN

The following suggestions are an amalgam of ideas and strategies from various sources and the practice experience of ourselves and colleagues working within the community. They are designed to be used to assist people with dementia living with carers or alone. To demonstrate, we are examining how best to look after 'Ellen', who has dementia.

To assist Ellen with day-to-day orientation

The following suggestions come with an inherent principle: never argue with Ellen about details. They are usually unimportant, the discussion will make everyone feel more disturbed and it is counterproductive. However, you may find you can sometimes use a gentle approach to re-orient her to time and place. Therefore, use some of the following strategies after developing insight into the person's unique situation and needs.

- Arrange for daily delivery of newspapers. These help with day and date, particularly during the early memory loss stage. Some people with profound memory loss can read dates and make sense of this information. Make sure Ellen can read and the papers are in the language she is retaining.

- Purchase a large clock with the month and date clearly displayed, place it where she usually sits and make sure it is at the correct height. Also, make and use a day of the week flipchart and place it near her favourite sitting place.

- Have a large diary or visitors book in the home to be written in by anyone who visits; family, friends and professionals. This allows all involved to communicate with each other and comment on any change in Ellen's condition. For example, someone may have thrown out an excess of uneaten meals alerting others to the fact that Ellen is not eating well.

- Keep a weekly schedule (perhaps prominently displayed on a noticeboard) of when and where Ellen goes — social club, church, family lunch, day centre etc. This assists everyone involved to know whether Ellen should be at home or not, so that if she is missing a search can be commenced. Also, make sure irregular and infrequent visitors are aware of the processes. From my experience it is often these visitors who unknowingly set off the false alarm bells, by taking Ellen out for a 'quick drive' or 'a snack'. Of course this socialisation is to be encouraged, as long as the regular community carers are aware of the change.

- Maintain an up-to-date weekly care schedule for her and keep it where she can see it clearly (maybe on the fridge), stating who is involved, from what agency, when they visit, and what is their role.

- Photographs of people and places relevant to Ellen may assist both you and Ellen, particularly, when you are trying to explain who you are, who you are talking about and where Ellen may be going.

How to try to prevent Ellen wandering in danger: the challenge is to provide security not prison

Particularly during the early stages of a dementing illness it is inappropriate in our opinion to significantly curb Ellen's freedom, in an effort to prevent anything untoward happening. Ellen has lived with the risks involved with normal living all her life. The difficulty for community workers is to try to live with the responsibility of encouraging normality and social stimulation but at the same time closely monitoring changes in cognitive ability. Therefore, balancing these with Ellen's risk-taking behaviour is a challenge to all concerned.

Many community workers who have experience in supporting dementing people to stay at home as long as possible could recount stories about people who walk down to the shops, the Senior Citizens centre or a friend's home every day, at the same time, and return at the same time. The big worry is when, for whatever reason, they turn left instead of right and become completely lost. This is a stressful situation for all concerned. If Ellen is lost and confused, the family will, of course, be anxious and distressed and you will be anxious, distressed and concerned about Ellen, her family and your professional responsibility. At this point we need to ask ourselves who are we protecting by knee-jerk responses which may lead to premature admission to a residential facility — the ageing person, the family or ourselves?

This is a dilemma faced regularly in the community. We believe it is better to monitor Ellen's situation closely, using your knowledge, experience and gut response to predict what will happen. Prevention, of course, is the preferred strategy to have in place. For example, you may arrange to:

- have someone walk with Ellen
- have a community bus pick her up
- have a personal carer come as early as necessary to help with some household jobs and then offer to drive her to her destination.

Working with dementing people requires flexibility, creativity and, at times, subterfuge. This can sometimes present an ethical dilemma for us as professionals but each one of us must work through that issue.

Of course we are aware that some people with quite reduced cognitive abilities are so fleet of foot that they can be out of sight before you know it. But if you are contemplating restricting Ellen's environment, reflect on the uniqueness of her situation and ask yourself what you are trying to achieve by restricting her activities. If your answer, after discussion with colleagues and family, is 'yes, she is now in regular real danger', action needs to be taken. Also, remember that this stage will pass relatively quickly, particularly if Ellen has Alzheimer's disease. Over time she will become more frail, which has its own challenges, but her 'disappearing ability' will be markedly reduced.

In case Ellen wanders and appears to be missing

- A current photograph is essential for families and agencies involved to keep on file. It should be a full-length photograph of Ellen, taken alone, reflect her usual appearance in everyday clothes, standing beside a doorway to give anyone looking for her some perspective regarding height and appearance.

- It is also essential to contact the local police station and give them a copy of Ellen's photograph and contact details, particularly whilst she maintains her physical fitness and is used to walking long distances around her neighbourhood.

- Place personal information in her handbags (or if 'Ellen' is 'Allen', in his wallet). Make sure she has your card, family contacts and details advising any one who may offer assistance on trams, trains, buses and in the street who to contact, what to do, and how to approach Ellen. The community consists of many kind, observant people who will help a confused, lost person. It is up to community workers and families to anticipate this situation and make the good Samaritan's role easier.

- Arrange to have an identity bracelet made for Ellen, with the contact information clearly imprinted on it. It should have the appearance of a lovely piece of jewellery and, if possible, be given as a gift, by someone Ellen loves.

- If possible have identification sewn on Ellen's clothes. This not always an easy option but if Ellen is injured and taken to hospital it will prove a most useful strategy.

HELP WITH DAILY LIVING

Any ageing person who needs help with the activities of daily living and personal care should have the person attending to the care 'hand picked' by the person arranging the care. (For someone with dementia, if you cannot match the skills and personality of the care worker with the unique needs of Ellen, it may be destabilising and often is counterproductive to have a paid carer involved.) It is imperative to take the time to find the right people, then brief, support and educate them well during the progress of Ellen's dementia. It is also important to have continuity of care. There should be at least two paid carers who know Ellen well to allow for annual leave and any illness.

Some basic issues regarding Ellen's day-to-day care

The familiar is what usually makes all of us relaxed and happy. Therefore, we need to find out about Ellen and what she finds familiar. Whilst change to her routine may suit us, her family and carers, we need to remember it will not be familiar or suit her. Therefore, we should aim to work with what is working to make her care mould to her needs, not the other way around.

It takes time and a gentle approach

- In consultation with her primary carers establish an overall aim and goals for assisting Ellen. Set realistic time lines to develop and implement the various strategies that will assist Ellen in her day-to-day life.

- Make sure that you, as the community professional, liaise regularly with Ellen and the paid carers and listen to what they say. They must all feel that their input is valued.

- Remember it may take weeks or months of gentle social visiting, outings, and home care before Ellen will allow the paid carer to assist her with personal care. It is best to take a soft and gentle approach with Ellen.

- Try to keep Ellen involved with social living. But make sure it is in an environment in which she is not stressed by false expectations about appropriate social behaviour. It has been our experience that some people who would have shunned group activities in the past often respond well and enjoy the non-threatening company of a well-run dementia-specific day centre. Frequently, family members say, ‘Oh, it’s great. I can’t believe Mum (or Dad) is liking the centre so much!’

  Recently one of the authors was involved with a woman called Denise, who had socially isolated herself for quite some time. Her creative and committed community case manager took her to afternoon tea with the ladies at a dementia-specific day centre. This went on for a few weeks with the time spent getting longer each visit. Eventually Rosemary, the case manager, left Denise by herself at the centre while Rosemary ‘attended to some business’ for a few hours. Denise, whilst often very confused, has blossomed socially and now attends the centre every Tuesday and Saturday and enjoys herself immensely. When the paid carers visit each morning and change the days-of-the-week flip sheets (to assist Denise’s orientation) she wants it to be Tuesday or Saturday. It could be argued that Denise would benefit either from an increase in time spent at the day centre or from residential care. But at this time, Denise appears to be safe and well at home while enjoying herself when she goes out.

It's always more than personal and home care

- Personal care is not just bathing or showering, it also involves making sure Ellen has her fingernails manicured, her hair trimmed and kept in a style she likes and recognises as her own, her skin is kept supple and examined regularly and she has regular visits to her local doctor as well as any necessary dental care, podiatry etc.

- Personal care also means noting and caring for any bruising or scratches and making sure you know the possible cause of any fall. Ellen's environment should be made as safe as possible (see chapter 8, 'The impact of falls on older people: how to assess the risks and implement prevention strategies'). Any bruise or scratch may indicate that she has wandered out of her own safe environment.

- Ellen may be at risk from any form of elder abuse, so be observant, be vigilant and be prepared to act as an advocate when necessary (see chapter 4, 'Legal and ethical issues and their impact on the care of the ageing person in the community').

- Maintaining continence, both urinary and faecal, will be a challenge at times but there are many strategies that can be used to assist Ellen (see chapter 9, 'Incontinence').

- General house cleaning and clothes and linen washing will now often be beyond Ellen's ability to initiate or manage. This does not mean she cannot assist with these tasks, but it does require diplomacy on the part of the carer to turn this activity into a mutually satisfying task

It's always more than ensuring adequate hydration and nutrition

- Ellen will not be able to initiate when it comes to providing an adequate intake of nourishing food and appropriate fluids. Therefore, you need to assess her likes and dislikes and supply what she will eat, in a form she can see is food and that is culturally appropriate. This means when community-based food services deliver meals in foil containers, the meals need to be plated, kept at the correct temperature and heated and served by someone other than Ellen.

- It is imperative for her physical wellbeing that Ellen's fridge and its contents are monitored and (if possible) a regular clean-out is arranged. Ellen may be a little difficult when it comes to the fridge so it may be necessary to have the most appropriate person assist her with this task.

This issue can present some ethical dilemmas, which all of Ellen's carers need to address individually and or collectively. For example, she may be quite happy to have her daughter-in-law help her but not her son. Alternatively, a paid carer may be able to assist. Occasionally it may be necessary to do the job without Ellen's knowledge. Of course this should only be done when all other strategies fail, as Ellen should be involved as much as possible with all her care and decision making.

- Someone should take responsibility to monitor Ellen's body weight. If she should lose weight she will require prompting to eat. Strategies that may work include having finger food readily available, experimenting with more tasty food, or introducing new dishes.

- In the summer Ellen will very quickly become dehydrated. This is a major health problem and it may lead to urinary tract infections, which may increase her level of confusion. Therefore, you will need to increase the number of monitoring visits during the day. Leave glasses of her favourite cool drink in strategic places around the house. Ask and remind family and paid carers to sit with Ellen and share a cool drink.

- Ellen is a social being and all her life has enjoyed eating with others. Arrange as often as possible for her to share a meal with others — family, friends, neighbours, church groups, senior citizens and other visitors to dementia day centres. Of all the possible strategies to assist Ellen to maintain her level of food intake, this will work best.

- Ellen may also forget she has eaten and will gain excess weight. She will then need to have her food intake monitored and be prompted about having recently eaten. For example, it may be necessary to leave the previous meal's dirty dishes and tea or coffee cups visible to Ellen. This is tangible evidence to allow her to see that she has eaten. She may also have been in the habit of having a biscuit or two with her tea or coffee and these patterns will need to be acknowledged and worked around gently.

- Someone will need to plan and purchase Ellen's food and personal items regularly.

- Ellen may experience constipation which will require treatment. The best treatment, however, is prevention through an appropriate amount of dietary fibre, sufficient fluids and exercise.

- Ellen may also continue to enjoy her lifetime habit of smoking and/or drinking alcohol but she will require monitoring of her intake and patterns of use. She may gradually stop smoking but until she does there is always a risk of fire. Also, she may forget she has had her usual alcoholic drink for the day and have much more than she intended.

One of the authors had experience with a couple of women, Barbara and Rosie, who were found dazed and wandering their respective neighbourhoods. These particular women did not have a history of any problems with alcohol. One always had a sherry and the other a glass of white wine before dinner. The problem was that as their dementia increased, they lost track of what time it was and of how much alcohol they were drinking.

Safety around the home

- Ellen's competency regarding managing gas, electricity and heating needs to be monitored regularly. It is possible to have a plumber place a special attachment onto a gas stove so that it cannot be used by Ellen unless someone else is with her. This may be counterproductive and distress Ellen. It may be simpler to purchase a microwave which someone other than Ellen would use to heat her meals.

- It is important to keep Ellen warm in winter. The most effective and safest methods are central heating (or an enclosed unit) programmed to start and finish at certain times. At the same time it may be necessary to remove Ellen's favourite two-bar electric heater and anything else that could present a fire hazard. Also, I have seen too many singed pieces of clothing and linen (as a result of drying in front of a heater) to not know the importance of assisting Ellen with personal and household washing and drying.

- Ellen is not capable of operating a personal alarm system so as she is living alone you will need to arrange to have a key safe placed somewhere that is well lit and accessible but not visible from the road. Only those people who work regularly with Ellen should have access to the code. All community workers require a police check, but remember to be vigilant about Ellen's personal effects and property.

- Ellen may have an adored pet that provides her with stimulation and company but someone else will have to take responsibility for the daily and cyclic care of Spot, Fluffy or Tweety.

Medication issues

- As well as physical health assessments, it is imperative Ellen has her medication reviewed regularly by her general practitioner.

- She will also need help at some point to take her medication; taking the correct drug, in the correct dose and at the designated time and day. Initially a seven-day system, such as a multi-dose container, can be prepared by the local pharmacist in conjunction with her general practitioner but Ellen may require prompting from a family member or paid carer to actually take the medication.

- If Ellen continues to live alone, she may eventually require daily visits by a registered nurse to dispense the medication. The nurse may then choose to use a locked box kept in a safe place to store the medications.

- Any non-prescription medications should be removed from Ellen's house to prevent her from self-medicating inappropriately. Remember that non-prescription medications or out-of-date prescribed medications may be anywhere in her home.

Sleeping

- Ellen may have sleep disturbances and altered sleep patterns. If she lives alone this will not be a major issue; if she lives with other people it will be problematic. Establishing a daily pattern of eating, exercise and retiring to bed around 10.30 p.m. should help. Remember, as an ageing person, Ellen may need only 5–6 hours of sleep each night. Therefore, if she goes to bed at 8 p.m. she will definitely be up at 2 a.m.

- As well as ensuring Ellen's day is as free as possible from stress and tension, make sure she has a gradual winding-down phase. Include the usual activities anyone performs before retiring. She may benefit from listening to music, reading or watching her favourite TV program as well as just sitting quietly.

Driving

- Ellen may be driving her car and it may still be quite safe for her and others but her ability to drive must be formally assessed and monitored continuously. This is usually done by an accredited occupational therapist. Contact your regional government licensing department for further advice.

- Ellen will probably lack insight into her driving abilities so it will become the responsibility of those around her to make sure she is not endangering herself and others. This will require tact and, at times, subterfuge.

- Ellen may not have driven for years, but her car reminds her of her husband and contains happy memories. It is important for her to keep it in the garage or driveway but it must not be able to be driven by her — either remove the appropriate key or disengage the motor.

Finances and decision making

- If Ellen does not have a family member attending to financial matters and does not have an enduring power of attorney, she will require an administrator to be appointed.

- Until this time, community paid carers will need to ensure Ellen's household accounts are paid and she has sufficient funds to pay for day-to-day items. Personal care workers can take her shopping and assist her to 'do' her banking. Direct debiting is invaluable for paying cyclic accounts and utilities.

- Ellen may also require a Public Advocate appointed as a guardian when she is unable to give informed consent for medical interventions in crisis situations.

- If Ellen does not have a family who will arrange and be responsible for residential care, or if there is a family disagreement about where Ellen should be living, an application must be made to the relevant body such as the Office of the Public Advocate to have a guardian appointed to make this difficult decision.

Acute illness issues

When Ellen requires planned or sudden acute hospital care it is usually problematic and her confusion will increase. Unfortunately, Ellen cannot be adequately prepared for this event psychologically or emotionally. Whilst many health professionals working in hospitals will understand and help Ellen settle into their routine, she will find it almost impossible to adapt. Ellen's level of dementia, plus the often low ratio of staff to patients, plus illness, plus noise, plus no-one truly knowing Ellen, results in challenges for all concerned. What can you do?

- Whether there is a planned or a sudden admission make sure Ellen's personal details and specific needs are described in writing and followed up by verbal communication. Develop a formal two-way communication protocol with your local hospital. If Ellen has to go to hospital unexpectedly your relationship with the hospital will (hopefully) ensure that you will be notified of her admission as soon as possible.

- Someone will need to prepare and take Ellen's personal items to the hospital then arrange to have her laundry done, any pets taken care of and her home made secure.

- Although the illness or condition that precipitated her admission may be treated, Ellen will probably come home more confused and distressed. Be ready to have more available of what you know she likes — rest; solitude; outings; morning teas with carers; visits or phone calls from family and friends; emotionally, psychologically and spiritually uplifting experiences. Basically, she needs to readjust following what is usually a frightening and destabilising experience. But also remember she will usually be much better after a few days.

WHEN IS IT TIME AND IS IT NECESSARY FOR ELLEN TO HAVE RESIDENTIAL CARE?

This is the question everyone faces. Should Ellen go in early in her dementing illness, when she may be able to adapt to a new environment, or does it make no difference?

We are inclined to return to our overarching viewpoint — Ellen is unique and should be cared for with this in mind. Therefore, monitor her progress. Ask yourself:

- Is she reasonably safe?

- Does she appear happy?

- Is she fearful?

- Does she recognise home as home?

- Is her wandering away telling you she does not feel secure any longer in the place she called home for 30 years?

- Can the primary carer continue to care?
- Can the community's resources be increased sufficiently to maintain Ellen safely now?
- Is her physical deterioration clearly at the point where she now requires continuous, skilled personal and nursing care?
- Will the carer accept residential care?

There will be other issues you may now be thinking about, but the preceding are some we all need to consider. We are always disappointed personally and professionally when someone like Ellen is rushed into residential care. This happens most often because of the carer's inability to care usually due to their own sudden illness or death. From the perspective of both the ageing dementing person and the carer, a well-thought-out and planned transition from community to residential aged care facility is essential.

This means allowing carers time:

- to ponder
- to look at various options
- to have a period of respite to allow the principal carer to begin the process of letting go of the day-to-day care and responsibility
- to *know* that this is the right time.

We are aware that we are speaking about the carer's needs and often it is the carer that the community professional assists and liaises with regularly, particularly during this transition process. Carers are often consumed by feelings of guilt before, during and after someone enters residential care — guilt because they are relinquishing the day-to-day care to other people; guilt because they made promises to themselves and others that they can no longer keep; guilt because they are physically, emotionally, psychologically and spiritually tired and are starting to see some relief in sight for themselves. Experience has shown us that the degree of involvement and loving care does not appear to lighten this burden of guilt for carers. Therefore, it is a key component of the community professional's role to anticipate and assist carers with and through a difficult process (see chapter 6, 'Ageing people giving and receiving care').

FEEDBACK LOOP

To keep her physically well and safe Ellen must have regular care and monitoring. Developing an open feedback loop among all concerned is essential. To assist with this process the key players (besides Ellen, her family and/or her primary carers) must be identified. These may include:

- friends
- a community case manager
- her general practitioner
- the community nursing service
- paid community carers
- service provider agencies
- health practitioners from all disciplines
- the regional aged assessment service and or memory loss clinic
- a geriatrician
- a psychogeriatrician
- a neuropsychologist.

The feedback process, which can incorporate formal and informal contact, will enable everyone to be aware of the ongoing situation so that they can act appropriately when there is any alteration in Ellen's dementia and general wellbeing.

LIFE ENHANCING

Most of all, caring for Ellen in the community means finding out what activities she likes to do — she may love classical music, looking at the beach or bushwalking. Try to arrange quality-of-life-enhancing as well as life-maintaining activities. A community health professional needs to be working towards enhancing and enriching Ellen's life, not only caring for her environment and her physical being.

FURTHER READING

Crisp J (2000): *Keeping in Touch with someone who has Alzheimer's.* Melbourne: Ausmed Publications.

***This very new publication provides an invaluable practical guide to maintaining communication with people who have dementia*.**

Garratt S, Hamilton-Smith E (eds) (1995): *Rethinking Dementia — an Australian approach.* Melbourne: Ausmed Publications.

Kitwood T (1997): *Dementia Reconsidered.* Buckingham, UK: Open University Press.

These two books present an integrated theory of dementia based in the social sciences, together with a set of guidelines for effective care — the kind of approach that underlies this chapter.

Harding N, Palfrey C (1997): *The Social Construction of Dementia: Confused Professionals?* London: Jessica Kingsley.

This critical review discusses the mythology of dementia and the confusion between the largely bio-medical pathological approach and current socially based integrated theories.

Mace N, Rabins P (1981): *The 36-hour Day: a family guide to caring for persons with Alzheimers's Disease, related dementing illnesses and memory loss in later life.* Baltimore, Maryland: The Johns Hopkins University Press.

Sherman B (1993): *Dementia with Dignity: a handbook for carers.* Sydney: McGraw Hill.

Both of these provide excellent practical advice for anyone caring for a person with dementia, particularly in their own home.

Taylor B (1998): Dementia care — how nurses rate: domiciliary carers' perceptions of the nursing care needs in acute settings of relatives with dementia. *Collegian* 5(4):14–21.

Whilst this research-based article has a nursing focus, its findings are relevant to any professional working with a confused person in an acute setting.

GAIL HESSELL

Registered Nurse, Postgraduate Certificate in Palliative Care (New Zealand)

Care Team Manager, Eastern Palliative Care, Melbourne, Victoria

Gail did her registered nurse training at Auckland Hospital in New Zealand and her postgraduate qualifications in palliative care at Wellington, New Zealand. She had extensive surgical and medical nursing experience in hospitals in New Zealand as well as community-based experience, commencing in 1987 as a Charge Nurse of Community Health Services in Wellington. In 1992 she came to Australia where she has held senior positions at Melbourne City Mission and Melbourne Eastern Palliative Care Service.

At present Gail is a senior executive member at Eastern Palliative Care, with associated portfolio responsibilities, and is co-located at the Angliss Hospital in Ferntree Gully, an outer eastern suburb of Melbourne. She is responsible for the leadership, management, and coordination of an integrated interdisciplinary team providing palliative care to community clients.

Gail is committed to challenge, and to the sharing of specialised knowledge and expertise with mainstream work practice in our changing health environment. She is the proud mother of two supportive children. She believes that through their exposure to her work they have gained sensitivity and understanding in dealing with people's life challenges.

CHAPTER SIXTEEN

Cancer and Palliative Care

Gail Hessell

WHAT IS PALLIATIVE CARE?

Palliative care, as a philosophy of care, is the combination of active and compassionate therapies intended to comfort and support individuals and families who are living with a life-threatening illness. During periods of illness and bereavement, palliative care strives to meet physical, psychological, social and spiritual expectations and needs while remaining sensitive to personal, cultural and religious values, beliefs and practices. Palliative care may be combined with therapies aimed at reducing or curing the illness or it may be the total focus of the care.

Palliative care is planned and delivered through the collaborative efforts of an interdisciplinary team including the individual, family, caregivers and service providers. It should be available to the individual and his/her family at any time during the illness and the period of bereavement.

While many service providers may be able to deliver some of the therapies that provide comfort and support, the services of a specialised palliative care program may be required as distress, discomfort and dysfunction increase.

Effective palliative care also provides to caregivers and service providers the opportunity for support in working through their own emotions and grief related to the care they are giving.

(This statement formed part of the mission statement of the Melbourne Eastern Palliative Care Service — now part of Eastern Palliative Care — and we tried to make it the basis for the service we provided. The statement is based on the definition of palliative care used by the Canadian Palliative Care Association.)

Palliative care:
- affirms life and regards dying as a normal process
- neither hastens nor postpones death
- provides relief from pain and other distressing symptoms
- integrates the psychological, emotional and spiritual aspects of client care
- offers a support system to help clients live as actively as possible until death
- offers a support system to help the family cope during the client's illness and in their bereavement.

The experience of our service is that palliative care providers care for an ageing population, especially over the age of 65 years. There has been an increase in community palliative care services to meet this need. Most clients and their families access palliative care services because of cancer-related illness, but we believe that our expertise should be available to clients suffering all forms of life-threatening illness, and their families. As this change of focus is becoming more widely understood, palliative care providers in Victoria have experienced significant increases in admission figures.

Referrals to our service can be self-directed or, following client consent, can be made by:
- family members
- local doctors
- hospitals
- treating specialists
- allied health professionals.

Referrals are made directly to the service in the relevant locality. Peak bodies such as Palliative Care Victoria can assist in determining the appropriate agency funded to deliver service in any geographical area in Australia or New Zealand if boundaries are uncertain (e.g. Eastern Palliative Care, as a large regional agency, is funded to provide service in the eastern region of metropolitan Melbourne). If health professionals are working with ageing people in a community setting it is important to contact the local palliative care agency, when indicated, to gain an understanding of the palliative focus and to develop strong working relationships in the best interests of the clients.

Following receipt of a referral from any of the above sources, clients are contacted by a member of our multidisciplinary team (most often a nurse) and in-patient or home assessments are arranged with the particular service disciplines requested. Referral sources, when assisting in the continuum of care, may have raised at the time of referral, with the client and the family, identified priorities, and may have mentioned the benefits from involvement of a palliative care team.

Palliative care workers acknowledge the distressing impact of being informed of a new diagnosis, often with poor prognosis, and, following informed client consent, early palliative care support encourages the development of a relationship. Clients and their families can make informed choices regarding their own individual needs during any point of their illness as increasing symptoms require ongoing monitoring and care.

When clients access palliative care services there may be specific areas of need. By providing multiple service entry points there is a clear demonstration that we have the capacity to:
- diversify skills
- provide an equity of access to the wider community
- remain client focused and responsive to the growing need.

A diagnosis of terminal cancer disrupts family routines in many ways, as treatments and hospital visits become necessary. As the illness progresses the family relate to each other in different ways, with emotional reactions covering a wide range of feelings such as:
- confusion
- anger
- denial
- depression.

It is important to consider the complexities of a family's situation and address all the issues of priority to them in an effort to relieve physical pain and mental anguish.

A major problem when an ageing person has a life-threatening illness is the impact on the family and the carers, who need to organise activities around the changes that have taken place to maintain a balance between family and individual needs. Frequent visits to health care providers and health care facilities can impact on the family's capacity to manage their normal day-to-day activity. This can mean frequent absence from the family home or workplace, as sometimes-lengthy diagnosis is determined. It is at this time that the ageing person is vulnerable and may be more dependent, requiring assistance with activities of daily living though the cause of their illness is unknown. Very often clinical onset of illness may have a sudden presentation with complaint of a change in health status that will involve a visit (or visits) to the local family doctor, with diagnosis often sought during an in-patient stay in hospital.

In the ageing population these days there are many people who do not have a family member in the home to provide support. Increasingly there is one ageing person caring for another while both are experiencing ill health. There are also many ageing people who live alone and are faced with the prospect of declining health and the need to review future care options. This process can be a confusing and frightening experience if there is no family member or carer advocate to support the ageing person facing terminal illness.

Palliative care staff are sometimes confronted with an ageing client's wish to die alone. This can be challenging for someone who is providing what is considered appropriate, client-focused care. This situation has occurred for our service on occasions. In each case it has been approached in a manner of informed choice and we have formed a close working partnership with those associated with the care. The general practitioner, who is a very central team member in the provision of community care, becomes the most pivotal person in circumstances such as these.

The generalist networks that have cared for ageing people in the past become integral resources in the future planning of their palliative care needs.

DIRECTIONAL SERVICE CHANGES IN THE COMMUNITY

The provision of palliative care in the state of Victoria in Australia has undergone recent major change, with the tendering process established in 1997 setting a reform agenda for palliative care service delivery.

The Victorian Department of Human Services generally considered the industry too specialist and insular and lacking integration with other mainstream providers, resulting in limited access and equity for clients. Whilst acknowledging the dedication and contribution of those working in the field, the Department considered that the traditional one-dimensional service structure no longer aligned with community expectations or government policy and direction. With the need for palliative care expanding rapidly, it was no longer possible for delivery to be by a specialist service only. For services to respond creatively, new frameworks had to be established and developed to guarantee integration and improved service provision. The knowledge and expertise developed by palliative care specialists needed to be extended to and shared with other providers.

This challenge has encouraged services to provide fresh views and creative opportunities for improved inter-service collaboration for the purpose of meeting the expectations of government and the changing social environment and the needs of current and future clients.

Palliative care agencies have taken different approaches in their service provision but the range of services listed below can generally be accessed in the community setting. Services can be provided individually or can be combined, according to the needs of the individual and their family and carers:

- palliative care nursing — planned home visiting to provide skilled competency in all aspects of symptom management and support; on-call arrangements 24 hours a day, seven days a week
- palliative care medical consultancy and liaison with general practitioners
- personal care to assist with hygiene and respite
- client support workers providing social work and pastoral support
- volunteers trained in palliative care (working in complementary therapies, client and family support, care team support and bereavement administration)
- complementary services such as massage, meditation, and music therapy
- group programs, such as meditation, for carers and bereaved partners
- loan of specialist equipment, e.g. syringe drivers to deliver medications, commodes, bathroom aids, oxygen concentrators etc.

Palliative care is provided through an interdisciplinary coordinated approach and focuses on the needs of the terminally ill person and their family to:

- maximise quality of life
- alleviate pain and suffering
- offer comfort and support through the period of bereavement.

The aim is to develop a palliative care service system which will provide access to all forms of skill and knowledge, continuity of care, and an appropriate range of interlocking services and specialist support to ensure that clients and their families experience little or no anxiety in the utilisation of a wide range of services.

Victorian state funding to the palliative agencies ensures services are delivered at no cost to the client and the family but fundraising and donation monies provide additional service initiatives over and above budgeted core service.

To interlock services effectively formal relationships have been forged with a number of community and health care providers. Palliative care services have for some time worked closely with the local nursing service, The Royal

District Nursing Service, with formal shared-care agreements in place to better coordinate care and deliver the highest level of service so that clients can remain at home for longer and have choice about where they die. Both organisations have multidisciplinary components and can offer a wide range of services to enhance the provision of high-quality palliative care in the home setting through strategies designed to improve care management for clients and families. The interlocking of both organisations gives the client access to services related to specific needs, e.g.:

- diabetic consultancy
- medical consultancy
- counselling
- increased nursing support.

Entering into shared-care arrangements and collaborating with generalist providers demands that interpersonal relationships be open and direct, that feedback is timely and informed and that liaison is always looking to strengthen relationships. Staff of each organisation need to have an understanding of each other's demands. At all times the needs of the client are paramount so all assessment, procedures, practice and documentation must work towards meeting the client's needs.

Individual client and family assessment becomes extremely important when determining the planning of care that will provide a clear understanding of the disease process, its impact and the overall adjustment required in a family to provide informed choice, consensus, satisfaction and stability.

In response to the state government's request to demonstrate better efficiencies and approaches there has been an initiative from one service (Eastern Palliative Care) to co-locate the community services alongside hospice beds and acute beds on a hospital site. With staff and volunteers working at times across both settings of care, the outcomes for clients have proved very positive. These days volunteers work in partnership with staff within the interdisciplinary team. These volunteers bring with them significant skills and life experience.

HOW TO WORK TOGETHER IN THE COMMUNITY

When case management is considered outside the traditional palliative care agency model, interface with other agencies is crucial. Under the multidisciplinary framework of the past clients were often expected to achieve multiple but sometimes conflicting goals by various professional disciplines and services often working independently of one another.

If the importance of another agency's contribution is acknowledged and respected then arranging a co-joint assessment can prove to be extremely beneficial in determining the ongoing planning of care.The level of the care relationship that may have preceded any palliative care referral is valued and is seen as an opportunity to work alongside the other agency to provide additional services and consultancy support and to complement the care already in place. Case management discussion can decide the ongoing shared-care objectives of the organisations involved in the development of a package of care that remains client focused at all times. Networks that have provided care in the past for those who are now ageing (along with family members, friends and community groups) become integral resources in the future planning to meet the needs of these people as they near the end of their life. An example of this sharing of resources is those local governments that, in collaboration with their local palliative care service, have implemented initiatives to support and educate council-employed personal care attendants in caring for those receiving palliative care.

Ageing clients without family or carers often encounter difficulties with their illness because of the absence of a strong advocate. In those cases the relationships that have been built with generalist services, such as aged care support personnel and the general practitioner, become an important bridge when delivering appropriate palliative care.

Palliative care practice fosters a flow of giving and receiving through community and relationships, and many social factors, either in the immediate environment of the client and/or in the general community have an impact on the client, their family and their carers. For example, at present, the distribution of in-patient hospice beds does not serve well the needs of our clients living in the far east of the region we serve. Government funding has been provided specifically to purchase services that will allow these clients to stay in their own communities. Occasionally we have purchased bed days in the clients' local hospitals to allow family and friends to visit much more easily than would be the case if those clients had to move to a hospice away from their local community. Such practices on our part increase our profile with local communities and the people we serve often 'give' in return by becoming volunteers for our service or by engaging in fund-raising activities to assist our service to continue to provide the best that we can.

In a multicultural society such as ours it is important that respect and dignity is demonstrated to families from non-English-speaking backgrounds (NESB). One important initiative has been the development of specialist NESB palliative care services working in collaboration with the Anti Cancer Council. Recruitment of multilingual staff and volunteers is now meeting this specific area of need. Another development is the availability of information regarding palliative care service delivery in many languages.

Palliative care is funded to provide specialist support to nursing homes and extended care facilities which are 'home' to many ageing people. Often it is difficult for staff who have cared over time for people who are now dying to acknowledge the need to change the focus of the care. There is a significant difference between caring for someone who is elderly and frail and caring for someone who is elderly, frail and dying. Regional nurse consultants attached to our regional palliative care service are deliberately providing education and support to these residential aged care facilities just as they act in a consultant role to generalist and primary-level services working in the community.

CANCER

Cancer is a common name for all malignant tumours which are locally invasive and infiltrate surrounding tissue. The tumours can lack differentiation and appear very atypical with their erratic growth, which may be slow or rapid. Metastases or secondary spread are frequently present with malignant tumours, threatening life by their location and impingement on vital system structures. Multiple metastases can be invasive and fast growing and they often occur after therapy.

Malignant tumours usually induce a syndrome of anorexia and weight loss in ageing people who may already be frail. Wasting clients have impaired immune systems and are prone to repeated infections with cancer sometimes disseminating along vessels to body cavities.

Diagnostic procedures can involve tissue sampling to stage and determine the spread of the malignancy and provide relief of any advancing disease. Each ongoing treatment needs to be informatively reviewed for its appropriateness.

Radiotherapy using ionising radiation effectively stops a tumour from dividing by damaging DNA. Tumour cells have limited ability to recover so this treatment is often very useful in palliating pain. Clients are informed of potential side effects — such as lethargy, nausea, and possible skin and mucosal reactions — and are instructed on how this can be managed to ensure optimum comfort.

Chemotherapy interrupts the cycle of the cell, which prevents normal DNA being made, so cells cannot divide and produce a tumour. Because the chemotherapeutic agents are cytotoxic they affect normal tissue as well and can produce side effects of:

- nausea
- vomiting
- stomatitis
- anaemia
- neutropenia
- hair loss.

In the ageing palliative care client many factors are taken into consideration before embarking on any treatment. The treating specialist will consider:
- biological and chronological age
- general health and nutritional status
- the presence of other associated medical problems
- social circumstances
- psychological factors.

Treatment options are nearly always discussed at the time of diagnosis. This can be a very stressful time. Clients are often in a state of shock as they try to understand the profound impact on their lives of the decisions they must take. Reactions can include episodes of:
- anger
- sadness
- withdrawal
- depression.

At all times the client and family are encouraged to participate in the decision making concerning the provision of care for the client. Sometimes treatments are noncurative; they are palliation to provide relief of troublesome symptoms.

CANCER AND OTHER PALLIATIVE CARE ILLNESSES AFFECTING THE AGEING PERSON

Cancer and other illnesses requiring palliative care are generally compounded in the elderly by the problems of the ageing process. Cancers situated in the bowel, lung, prostate and breast are common in this population group.

A proportion of ageing clients who receive palliative care services for non-cancer-related illness understand that they are dying. Palliative care staff care for clients with:
- end-stage heart failure
- end-stage renal failure
- end-stage respiratory disease.

An ageing client dying with any major organ failure can experience pain, breathlessness or anxiety and the medications often used are those used to allay symptoms in cancer-related disease.

As we grow older we are less agile, we eat less, we sometimes cannot think as quickly as we used to and inactivity can lead to social isolation and real loneliness. These distressing feelings can lead towards introspection and fear and, when compounded with a diagnosis of terminal illness, the very practical issues of living day by day can become overwhelming.

Advances in the treatment of cancer have improved longevity and quality of life but in the older generation cancer can still provoke images of pain and suffering. Very often the psychosocial pastoral dimension of the care we provide is invaluable in supporting the fearful elderly client.

Palliative care team members include client support workers who provide not only emotional support and but also advocacy to assist with the link to available community resources such as Meals on Wheels, home help, and financial and legal advice.

Pastoral care focuses on the spiritual aspects of one's journey from life to death and includes both religious care and spiritual care, recognising that a person's spiritual life may or may not be aligned to a particular religious system. At certain times in our lives we all search for understanding and meaning and this is perhaps more so during terminal illness, so an opportunity to share this confusion with someone outside of the family or support network is always available.

Most of our clients harbour some degree of hope as they progress through their illness, a hope we may call 'realistic' hope. When we use this term we know that clients facing terminal illness remain hopeful that they will fulfill special times with their family. That reality may mean the birth of a grandchild or celebrating an anniversary or birthday. Clients themselves may have found a source of inner peace but find the need at times to wait until their family catches up with their dying. With the acknowledgment as one grows older that one is faced with the certainty of death, 'hope' can be redefined by the ageing person as 'realistic' hope long before family members acknowledge the shift. The role of the palliative care team members assisting in this process can be described best as 'presencing' or 'being with' the client.

The nursing members make up the largest component of staff involved in any palliative care team. Through their involvement in frequent reassessment and support, relationships and trust are developed quickly:

many a conversation with a concerned and anxious family member has been held in the privacy of a bathroom, or on the nature strip just as the nurse is about to leave. The provision of good palliative care is having the capacity to anticipate potential outcomes and the palliative care nurse specialist is trained in this area.

In every aspect of care covered at every visit, opportunity is afforded for a palliative care team member to listen and provide support. The earlier a client is referred to us the sooner we can begin to build up rapport and trust. As people age and become aware of their shortening lifespan they reminisce. These memories can be a source of satisfaction or pain, but the experienced listener has the skill to share the moment. Communication and listening skills are essential in dealing with the sensitivity issues involved. The concept of a life review has been associated with the ageing process and this can be a very effective way of communicating with the terminally ill person. While all of us develop our communication and listening skills as we socialise and mature through our own life experiences, I would encourage health care professionals to seek formal study in counselling as it can be an invaluable part of the process of palliative care.

Other forms of complementary therapy available — such as massage, meditation or music therapy — have the capacity to reach people with pain, limited cognitive capacity, or communication difficulty and can be a great source of comfort. For families or carers to share music together can produce special moments and memories. Our service has a special video that was made with one of our clients singing her favourite songs along with all her three generations of family just two days before her death. The video captured a special memory for them to keep.

THE TEAM APPROACH

My role and responsibility as Care Team Manager in my palliative care service is to ensure the efficiency and effectiveness of my whole team. Staff from each discipline represented in the team report directly to me, including the volunteers. Team unity promotes team support and with so much innovative change in our industry over recent years we have had to deal with staff uncertainty and challenges to old practices while at the same time encouraging creativity.

Seeing palliative care as creative and forward looking makes us feel an openness to doing things differently, with a capacity to fully develop a network of relationships never before experienced.

VIGNETTE

Alice was a 96-year-old lady who lived with her younger sister Bet in Alice's family home. Both were widowed for many years and had been constant companions in their twilight years. Local council personal care assistants visited to attend to hygiene needs and housework.

Alice's local doctor had been attending Alice for many years, and referred her to our service when he acknowledged her long-standing condition of heart failure was no longer responding to treatment. He expected that Alice would need increasing support to be able to remain in her own home and Bet would also need support through her sister's period of deterioration and death and then her own bereavement.

Alice was presenting with increasing symptoms of chest pain and shortness of breath following minimum exertion. She was bedfast and dependent and anxious about having to leave Bet to manage after her death.

Alice's symptoms settled following introduction of some low-dose morphine and the use of home oxygen via a concentrator. She remained comfortable but very frail as she spoke of her tiredness and the length of a very long, rewarding life. It was a special time where she was aware, with a twinkle in her eye, that telling us her life story, because of its longevity, would mean our having to keep returning to hear it unfold. At each visit Bet was included in the story telling and the sharing of her sister's care. Alice's council workers had become a close, supporting network and time was taken by our staff to keep them updated and informed of the deteriorating changes.

Application to a community case-management agency assisted with the provision of brokerage dollars to provide additional personal care assistant hours for the constant care that was required. My nurses visited daily to monitor Alice's symptoms as her impending death became very apparent.

Bet maintained a constant vigil by her sister's bedside. She wished to be with Alice at all times, to support her in her dying as she had always done in life. When Bet left the room briefly Alice chose that moment to die very quietly. At first Bet was very distressed by this but following our gentle support and, on being informed that very often death occurs just this way, Bet commented that her sister always thought of her first before doing anything.

Alice’s home death was managed well because of the collaborative efforts of several services and primary health providers. It is just one example of what this chapter tries to encompass.

INDEX

Most older people prefer to live indepedently, to stay in their own homes, but to do that they often need community support, even if they remain relatively healthy into very old age. In fact it must be a goal for any community to set up cost-effective systems to assist ageing people to continue living in their own homes and to put in place affordable, efficient and compassionate care.

Ageing at Home is written for professionals and other interested people who care for the frail elderly who choose to remain at home. The book is easy to read and provides practical ideas for helping not only the ageing person but also those who are caring for that person. The wide range of authors who have contributed chapters include geriatricians, community-based professionals and academics. Their writing has grown out of their practical experience. They have provided prompt sheets, assessment tools and tables that deal with topics as diverse as wound care and overall care needs.

If your job takes you into people's homes to offer them assistance or you are a professional or family carer, then this book is for you.

Theresa Cluning began her professional life as a trainee nurse at the Mercy Hospital in East Melbourne during the 1960s. That training and subsequent experience as a registered nurse gave Theresa a clear understanding of why it is important to enter each caring relationship openly and to acknowledge the uniqueness of each person and situation. To this day much of Theresa's job satisfaction comes from assisting people to deal with physical, emotional, psychological and spiritual challenges. In her work with clients/patients she has attempted to make a positive difference in their lives.

Theresa has worked in many areas of clinical nursing in hospitals, in the community and in residential care. She has been a community agency manager and case manager, and an academic at Monash University. At present she is working with younger families in a community setting on the Mornington Peninsula, south east of the city of Melbourne.

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