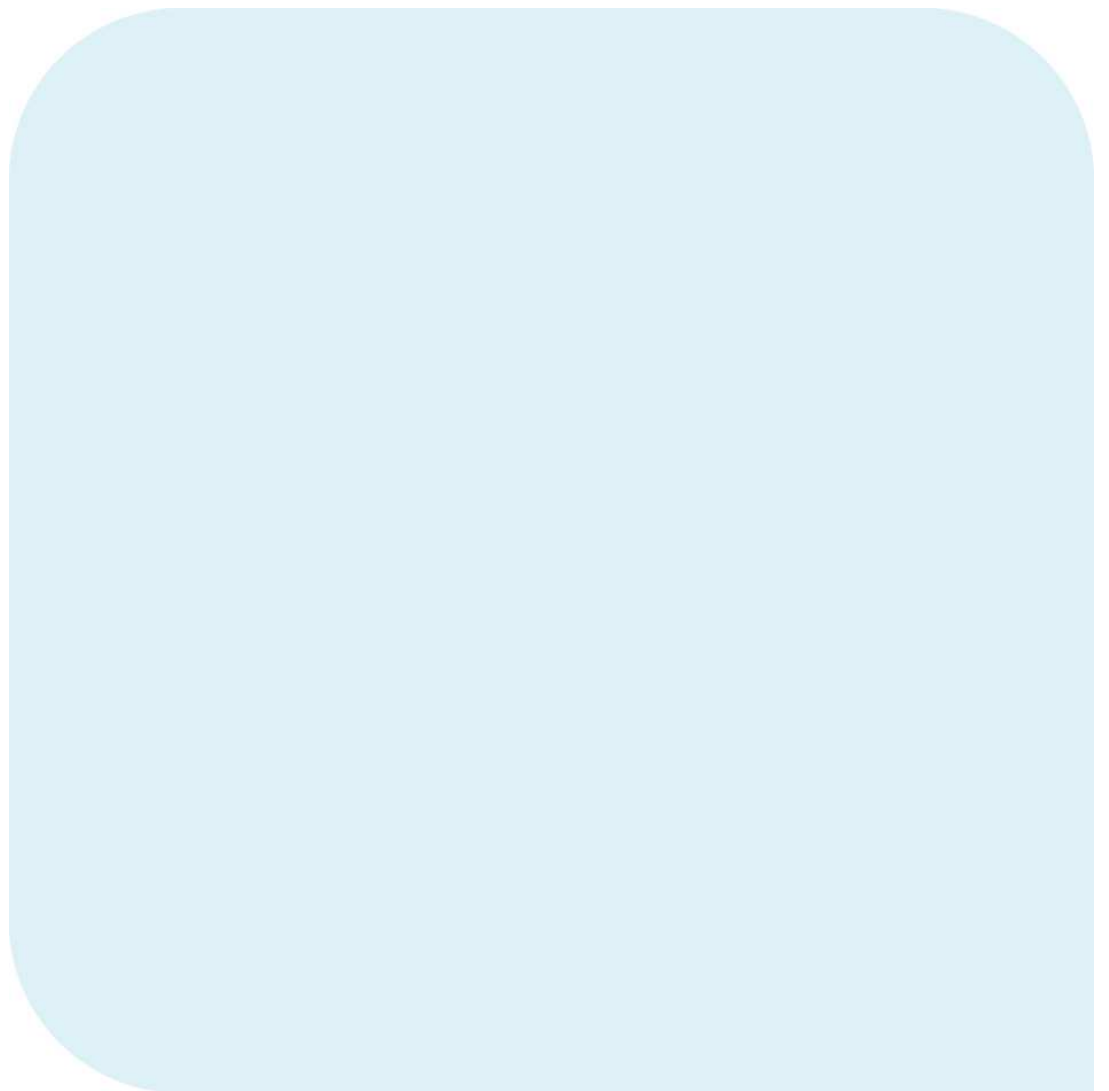


# Assessing the mental health needs of older people



The Social Care Institute for Excellence (SCIE) was established by Government in 2001 to improve social care services for adults and children in the United Kingdom. We achieve this by identifying good practice and helping to embed it in everyday social care provision.

SCIE works to disseminate knowledge-based good practice guidance; involve service users, carers, practitioners, providers and policy makers in advancing and promoting good practice in social care; enhance the skills and professionalism of social care workers through our tailored, targeted and user-friendly resources.

# Assessing the mental health needs of older people

Angela Nicholls

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Written by Angela Nicholls

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Social Care Institute for Excellence  
Goldings House  
2 Hay's Lane  
London SE1 2HB  
tel 020 7089 6840  
fax 020 7089 6841  
textphone 020 7089 6893  
[www.scie.org.uk](http://www.scie.org.uk)

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## Introduction

The Social Care Institute for Excellence (SCIE) aims to improve the experience of people who use social care by developing and promoting knowledge about good practice. Using knowledge gathered from diverse sources and a broad range of people and organisations, SCIE develops resources that it shares freely, supporting those working in social care and empowering service users.

This is an updated edition of SCIE's online practice guide to assessing older people with mental health needs. It has been revised for first-line assessors, who require accessible and accurate information and knowledge about mental illness in older people, to ensure that they, and their carers, get the right help and support.

The guide is equally accessible to older people themselves; to their carers, supporters, and families; and to all those who plan, deliver and use services for older people.

### **Working with you**

SCIE welcomes email or written comments on any aspect of this guide. The feedback will inform future practice guide updates. We are also keen to collect examples that translate key research findings and practice points into practice. You can contact SCIE at [www.scie.org.uk](http://www.scie.org.uk)

## Author and acknowledgements

The author of the main guide is Angela Nicholls, independent consultant and researcher

The 'Law and policy section' was written by Alisoun Milne, University of Kent and the 'Messages for research' section was written by Jo Moriarty, King's College London.

The revision of the guide was commissioned by Mary Sainsbury, Practice Development Manager at SCIE.

SCIE would like to also like to thank all members of the SCIE reference group for their input and insight.



## About this guide

### Who the guide is for

This guide is designed for practitioners in England who are assessing the social care needs of older people with mental health problems. It is particularly aimed at those working with older people in non-specialist settings, who are often the first professional in contact with an older person and their family and friends, and who may have limited knowledge and experience of mental health issues. The guide will also be valuable and interesting for everyone concerned with good practice in older people's services, including older people themselves, and their families and friends.

### **If you are an older person**

If you are an older person reading this guide, you may be worried about your own health or that of a family member or friend. We hope you will find the guide helpful and informative.

Mental health and emotional wellbeing are of course as important in older age as at any other time of life. Everyone has mental health needs, although only some people are diagnosed as having a mental illness. The majority of older people have good mental health, but they are more likely to experience events that affect emotional wellbeing, such as bereavement or disability.

This guide sets out to describe some of the specific mental health problems that you may experience, and gives advice to practitioners such as social workers and nurses who may need to take these problems into account when working with you.

Health and social care professionals should carry out an assessment of the needs of older people they are working with, which means talking to you about your health and any illnesses or disabilities you might have, finding out how you are managing at home and about any problems you are experiencing, and discussing with you and your family what help you may need.

Your mental health needs may be assessed as part of a general assessment. This does not mean that anyone thinks you are 'going mad' or 'senile'. But what happens to you, and illnesses you experience, affect the way you feel and your ability to cope, so they are important. If there is a problem, it is important for you and your doctors to understand what that problem is and how it might be tackled.

Many things can be done to help you with mental health needs, and your families, improve your quality of life. This guide aims to help professionals working with older people to maintain a positive outlook and gives practical suggestions for things they can do to help.

## Further information

Throughout the guide you will find references to helpful organisations, websites and literature for further reading. Organisations that produce helpful advice leaflets and factsheets especially for older people include:

- Alzheimer's Society (covering all forms of dementia)
- Help the Aged
- Age Concern

## If you look after an older person

If you look after someone else, whether or not you live with them, you may be referred to as that person's 'carer'. Some people dislike the word 'carer', believing it diminishes the relationship they have with the cared-for person as husband, wife, daughter, son or friend. Health and social care professionals use the word 'carer' as a shorthand to represent a whole range of people who look after others. This is not intended to devalue the uniqueness of your relationship with the person, but to recognise that looking after someone else brings with it particular features that professionals should take into account.

Looking after an older person with mental health needs may bring particular problems, and Section 5 discusses these. As a carer you are entitled to a separate assessment of your own needs, so, if the person you care for is having their needs assessed, make sure that you are also offered your own assessment.

## Further information

The following organisations provide information on caring and services available:

- Carers UK
- The Princess Royal Trust for Carers
- Alzheimer's Society

## Aims of the guide

The purpose of this guide is to offer quick and easy access to knowledge about working with older people with mental health needs, and to suggest practical things that can be done.

Older people's mental health is a vast field, and this guide does not attempt to cover it all. For example, the needs of older people with learning disabilities and the needs of service providers are not included<sup>1</sup>. The guide does provide:

- Basic knowledge of older people's mental health needs, including the legal context in England and key messages from research
- Good practice principles and practical suggestions for assessing and arranging services, including practice and service examples.
- Detailed information, references and resources for those who wish for further information, including useful web links and extracts from official guidance and standards.

If you are a practitioner, you may need guidelines for assessing older people with mental health needs. Although most older people do not experience mental health problems, such problems are sufficiently widespread to be a common feature in all care settings. Most older people with mild to moderate mental health needs will be assessed, and have their care needs met, in mainstream, non-specialist settings by staff without psychiatric training.

The guide aims to help practitioners in these settings develop their knowledge and skills, and think creatively about their work and the situations they encounter.

We hope that the guide is helpful, and that it will encourage practitioners to reflect on their practice, to achieve more on behalf of the older people they are working with, and to enable practitioners to get more job satisfaction themselves.

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<sup>1</sup> For information on services to younger people with dementia, older people with a learning disability and older prisoners with mental health needs, see Department of Health (2005) *Everybody's business: Integrated mental health services for older adults – a service development guide*, London: Department of Health.

## Using this practice guide

The SCIE website is divided into three columns: the left, middle and right columns. The topics that are covered in this practice guide are listed in the left hand column. Click on these to access the topics.

Within each topic there are several pages of information, which you can skip to using the navigation in the middle column. All of the links are in blue. The right hand column also has links in the lozenges, either to a PDF of the practice guide so that you can print it out, or to other relevant information. The links may also repeat those listed in the middle column just so you don't miss anything!

Where available, practice ideas and examples are included that show how agencies have tried to improve practice and solve problems. These are self-reported and unevaluated. The examples are provided by those who were consulted as part of the practice survey, and reflect their own experiences. We welcome other practice ideas for inclusion.

## Your feedback

SCIE welcomes comments on any aspect of the guide, which will inform future updates. We are also very interested in collecting examples of good practice. Please send us your [feedback](#).

## Section 1: A framework for wellbeing

Mental health problems in later life are relatively common. The Department of Health estimates that perhaps 40 per cent of older people seeing their general practitioner (GP), 50 per cent of older people in general hospitals and 60 per cent of care home residents have a mental health problem (DH, 2005)-(2).

Older people with mental health problems are more likely to end up in institutional care, they recover less well from physical problems and illness, and they are more vulnerable to abuse. 'The presence of a mental health problem is a strong and independent predictor of poor outcomes such as increased mortality, length of stay, institutionalisation and resource use' (NIMHE, 2005)-(3).

### National service framework for older people

In 2001 the government issued the National Service Framework (NSF) for Older People, which aims to:

- Combat age discrimination in health and social care
- Set standards for the delivery of care and treatment for older people.

Standard 7 relates to mental health in older people:

Older people who have mental health problems have access to integrated mental health services, provided by the NHS and councils to ensure effective diagnosis, treatment and support for them and their carers. (DH, 2001)-(4)

(For more on the NSF for older people and the policy context, see Section 8.)

There is also a NSF for mental health (DH, 1999)-(5), although this focuses mainly on adults of working age, rather than on the needs of older people experiencing mental health problems. The government recognises that more needs to be done to 'join up' mental health services and services for older people. Older people's mental health is often described as 'falling between two stools'. Older people with mental health problems face double discrimination: age discrimination and stigma about mental illness.

A national review of mental health services for older people in 2004 made this a priority within the Department of Health. In November 2005 the Department of Health issued a service development guide for integrated older people's mental health services called *Everybody's business* (DH, 2005a)-(6). This set out the principles for a comprehensive older adult mental health service, and contains useful information and good practice advice for practitioners and commissioners

of health and social care services. The key aim was to ensure that older adults with mental health problems and their carers have their needs met wherever they are in the system, without encountering discrimination or barriers to access.

The government's policy statement *Securing better mental health for older adults* (DH, 2005)-(7) emphasises that while mental illness in older age is relatively common, it is frequently unrecognised, and even when it is diagnosed, the person does not always get the right help. Because mental illness in later life is quite common, and because it often coexists with other medical conditions, the majority of mild to moderately severe mental illness is treated in mainstream settings, by staff without psychiatric training.

## Mental health and wellbeing

Good mental health and emotional wellbeing is as important in older age as it is at any other time of life. Many people fear growing older, and assume that old age is depressing and distressing, characterised by loss and disability, offering little to look forward to. But the reality is that older people are as capable as younger people of enjoying life, taking on challenges, coping with difficulties, engaging in satisfying activities, supporting each other with warmth and good humour, and making a real contribution to their families and communities, using their wealth of knowledge and experience.

For health and social care professionals, who often meet an older person for the first time during a crisis – when they are ill, or when other difficulties have become overwhelming – it can be hard to keep in mind the positive picture. Low expectations about the quality of life for older people are widespread among service providers, assessors and older people themselves ('What can you expect at your/my age?').

Assessors must remember that this is age discrimination, which leads to poor service responses and social exclusion for older people.

A number of reports in recent years have emphasised the need to focus on successful ageing, and living well in later life. The World Health Organisation's vision statement on active ageing, for example, states: 'Active ageing is the process of optimizing opportunities for health, participation and security in order to enhance quality of life as people age.' (WHO, 2002)-(8).

Not everyone agrees about what constitutes 'successful' ageing, however, and there are some suggestions that researchers in this area have not used criteria that older people themselves would endorse. *Opportunity age* (DWP, 2005)-(9), a strategy produced by the Department for Work and Pensions, promotes wellbeing and independence for older people and aims to ensure that later life is active and fulfilling. Although this is a strategy that tries to tackle age discrimination and change attitudes, there is a danger in basing the social

inclusion of older people on their explicit contribution to society as paid workers or as volunteers in the community.

The Nuffield Institute for Health has produced a report, *Living well in later life: From prevention to promotion* (Wistow et al, 2003)-(10), which argues for a switch in emphasis from avoiding higher intensity and more costly care to promoting older people's quality of life and their engagement in the community.

In 2003 the Association of Directors of Social Services and the Local Government Association issued an influential discussion document, *All our tomorrows: Inverting the triangle of care, arguing for major changes in tackling age discrimination and social exclusion through community strategies to promote the wellbeing of older people through the extension of universal services*. (Singleton and Painter, 2003)-(11)

Age Concern and the Mental Health Foundation have embarked on a broad-based three-year inquiry into mental health and wellbeing in later life. The findings from the first stage, a review of literature, policy and practice, provide some evidence of 'what works' to promote mental health in older people, such as support, social contact, participation, learning new skills and sustaining a sense of purpose.

## Key research findings

For a more detailed account, see Research Summary 1.

- Important factors that contribute to good mental health in later life are:
  - > having a role and a purpose in life
  - > having good social networks
  - > enjoying an adequate income
  - > living in a supportive neighbourhood.
- While most older people remain in good mental health, older people are more likely than younger people to experience events and illnesses associated with poorer mental health.
- Mental health has a big impact on physical health.
- There are ways to improve health and wellbeing in later life.
- Older people's views on what is important to healthy ageing include:
  - > being able to adapt to continuous physical change
  - > engaging in relationships
  - > maintaining independence and taking risks
  - > having enough money
  - > fulfilling desires and personal objectives
  - > keeping busy by taking part in meaningful activity.
- Social exclusion of older people with mental health needs is created by:
  - > poverty
  - > social isolation and loneliness
  - > lack of civic engagement



- > exclusion from basic services
- > fear of crime and anti-social behaviour in the neighbourhood
- > age discrimination.

### What you can do

Many things in older age can have an adverse impact on wellbeing, such as poor health, declining physical and mental capabilities, financial worries and loss of friends, family and social contacts. The aims of service provision should be to restore wellbeing as far as possible rather than simply meet the presenting care needs. Assessment should focus on a person's strengths as well as their difficulties. Promoting independence may not mean enabling someone to do without help, but maximising what they can do for themselves, and promoting their autonomy, self-esteem and quality of life.

If you are assessing older people, the following could help you stay positive and focus on strengths:

- Be interested in the whole person and think about what they may have been like when they were younger. Talk to them, encourage them to reminisce, so you get a sense of the person and their strengths, passions and opinions.
- Ask family members about them, to fill gaps in your knowledge and to encourage family members to remember the whole person, not only the illness.
- Think about the person's whole quality of life, not just their health and social care needs. What would give them pleasure, fulfilment, and something to look forward to? How can you help them experience such things?
- Be alert to ageism and discrimination, in yourself and your organisation. Ask yourself how services would respond if the person was a younger adult with a mental illness or a disability: would their approach be different?

## Section 2: The main problems

Mental health problems in later life can be grouped into four main categories:

### Key research findings

For a more detailed account, see Research Summary 2.

- Depression is the most common mental health problem in later life.
- Dementia is the next most common.
- Mental health problems are under-identified by professionals and older people themselves, and older people are often reluctant to seek help. So many older people experience delay before they are offered support.

If you are an older person reading this, or if you look after an older person:

Try not to be worried by the symptoms and problems described in this section. Remember, although mental health problems in later life are relatively common, most older people are not affected. Use the organisations listed elsewhere in this section to get more information, and if you are still worried about any symptoms, speak to your doctor.

### Depression and anxiety

Depression is a state of low mood that in some individuals can be severe and prolonged. There appears to be a complex interaction between external events, inner stresses, genetic predisposition and biochemical changes in the brain, which is not fully understood. People of all ages can experience depression.

Risk factors include:

- Social isolation
- Bereavement
- Pain and physical illness
- Multiple adverse events or change in circumstances
- Family history or past episodes of depression
- Alcohol abuse

Depression is the most common mental health problem of later life, affecting 10–20 per cent of older people (National Institute for Mental Health in England 2005) (NIMHE, 2005)-(12) and up to 40 per cent of care home residents, yet in older people depression is often under-diagnosed and under-treated. Older people in residential and nursing homes are two to three times more likely to

experience depression than older people in the community. (Godrey with Tenby, 2004)-(13)

Older people tend not to complain of being depressed, they are more likely to refer to physical symptoms, and some symptoms of physical illness are similar to those of depression. Physical illness is also a common trigger for depression in older people.

The most common symptoms of depression are:

- A pervading feeling of sadness
- A loss of interest in life and inability to take pleasure in things
- Tiredness and sleep problems
- Loss of appetite
- Poor concentration and memory
- Anxiety and agitation
- Hopelessness
- Feelings of guilt and worthlessness
- Thoughts of suicide.

Depression causes great mental distress and affects a person's ability to function day to day. When untreated, depression shortens life, exacerbates disability from medical illnesses, increases healthcare costs and is the leading cause of suicide among older people. When treated, quality of life improves (NIMHE, 2005)-(14).

## Suicide

Suicide is a significant risk for older people who are depressed. Older people are less likely than younger people to talk about suicide, but more likely to carry it out (Help the Aged, 2004)-(15). Older men aged 75 and over have the highest incidence of suicide – 11 per cent higher than the rates for all males aged 15 and over (Samaritans 1998).

### **Practice point**

Make sure that you always consider the risk of suicide in an older depressed person.

For more information, see:

National suicide prevention strategy for England (DH, 2002)-(16) Preventing suicide: A toolkit for mental health services (NIMHE, 2003)-(17)

## Key research findings

- Depression is the most common and most reversible mental health problem in old age.
- Older people and professionals tend to under-estimate the significance of late life depression.
- Risk factors for depression in later life include:
  - > bereavement
  - > other life events such as the onset of illness or disability
  - > financial crisis
  - > being a victim of crime
  - > moving accommodation
  - > illness of or separation from a loved one
  - > poor social support and loneliness
  - > lower socio-economic status.
- Older people, and older men in particular, comprise a higher percentage of 'completed' suicides.

## Further information

For more information on depression, see:

## Dementia

### Introduction

Dementia is an 'umbrella' term used to describe a collection of symptoms associated with physical changes in the brain that result in the gradual loss of mental functions such as memory and the ability to use words or to carry out previously familiar tasks.

Dementia encompasses a number of conditions, the three most common being:

- Alzheimer's disease, which accounts for approximately 60 per cent of cases
- Vascular dementia (20 per cent)
- Lewy body dementia (15 per cent).

The cause of Alzheimer's is not yet known. The disease is usually characterised by a gradual deterioration over several years.

In contrast, vascular dementia (or multi-infarct dementia) is typically a step-like progression, caused by a series of tiny strokes resulting in the loss of blood supply to the brain.

Lewy body dementia is similar to Alzheimer's, but with fluctuating symptoms and features similar to Parkinson's disease.

For more information on the different types of dementia, see the websites of the Alzheimer's Research Trust or the Royal College of Psychiatrists.

Dementia is mainly a disease that affects older people – 98 per cent of people affected in the UK are over 65 (Help the Aged) – and the prevalence increases significantly with age. The Alzheimer's Society calculates that while only 1 in 1,000 people under 65 will develop dementia, that figure rises sharply to 1 in 50 between the ages of 65 and 70, and 1 in 5 for people over 80. It is important to bear in mind, however, that dementia is not an inevitable consequence of ageing, and the majority of older people will not develop dementia.

Every person with dementia is affected differently, but common symptoms include:

- Forgetfulness, particularly about recent events
- Becoming confused about what day or time it is
- Not recognising people or surroundings.

Memory loss and confusion can be frightening and distressing for the older person, and may cause behaviour problems, such as agitation or aggression, or make it difficult for them to take part in normal social interaction. As the disease progresses, it is likely to affect the person's ability:

- To drive
- To perform day-to-day tasks such as shopping, cooking and looking after themselves and their home
- To read
- To talk and understand what is said to them.

Although there is no cure, a great deal of encouraging research is going on. A number of new drug treatments for dementia have been developed, and many older people who have taken part in trials, and their carers, believe they have experienced improvements in memory and alertness, if only for a short while. At the time of writing, however, there is a debate about how cost-effective these treatments are, or at what stage they provide most benefit. In January 2006 the National Institute for Health and Clinical Excellence (NICE) updated its guidance on the use of the drugs donepezil (Aricept®), rivastigmine (Exelon®) and galantamine (Reminyl®) for use in mild to moderate Alzheimer's.

## Key research findings

- Although only a minority of older people in the population as a whole have dementia, a high proportion of those using community care and long-term services are affected.
- Alzheimer's and other forms of dementia often remain undiagnosed, but there can be advantages to early diagnosis, which is becoming more usual. These include: relief to the person because he or she understands what has been happening, enabling people affected, and their families, to make decisions and plan for the future the person can be considered for drug therapy.
- People who are told their diagnosis always need follow-up support.

## Further information

If you want to know more about dementia, factsheets are available from the Royal College of Psychiatrists and the Alzheimer's Society. The Alzheimer's Society covers all forms of dementia, not just Alzheimer's, and has a range of useful publications particularly for older people and their families.

## Other psychiatric illnesses

### Further information

A small number of older people enter old age with enduring or relapsing mental illness, for example, schizophrenia or bipolar disorder. An even smaller number develop these disorders in later life.

**Schizophrenia** is a serious psychiatric condition, characterised by disordered thinking, hallucinations and delusions, apathy and social withdrawal. Paraphrenia is the name given to a form of schizophrenia with its onset in later life. Older people with schizophrenia often have often had the condition throughout their adult lives.

**Bipolar disorder (manic-depressive illness)** leads to severe mood swings, from severe depression to extreme elation. Some of the symptoms include:

- Excessively 'high' mood
- Irritability
- Decreased need for sleep
- Increased energy
- Increased talking and activity
- Racing thoughts
- Being easily distracted
- Having grandiose notions
- An impaired ability to make decisions.

It is unusual for this illness to start for the first time in later life, but it requires medical treatment at whatever age symptoms occur.

The Royal College of Psychiatrists has highlighted the lack of attention given to older people who enter old age with enduring or relapsing mental illness. Such people are 'graduating' from services for people of working age to services for older people, and are often neglected by both (Royal College of Psychiatrists, 2005)-(18). The Royal College states that many 'graduates' will continue to exhibit symptoms, and some may be suffering from the effects of long-term medication. People suffering from major psychiatric illnesses are also likely to have poor physical health and to have an increased risk of early death. Some will develop additional psychiatric problems in later life, such as dementia.

Whereas once these patients would most probably have been inpatients in long-stay psychiatric hospitals, most now live in the community in a variety of settings. Many are socially isolated and have lost contact with their families through years of illness.

The Royal College recommends that the point of transition from working age to older people's services should provide the opportunity for a review of the treatment and care needs of the individual, to include an assessment of their physical health, accommodation, need of support for activities of daily living and carers' needs.

The number of older people with long-term mental health problems or intellectual disabilities is set to increase.

### Further information

For more information on other functional mental illness and older people, see the following websites:

### Drug and alcohol problems

Not a great deal is known about the incidence of alcoholism and substance misuse in older people, including misuse of over-the-counter medication. It is often assumed that older people are not affected to any great degree by these issues, but it is more likely that the incidence is hidden. While it appears to be true that alcohol use and misuse declines with age, the use of prescription and over-the-counter drugs increases in later life. Substance use and misuse is probably the area of older people's mental health that is least researched or written about, although it may sometimes be a significant factor in assessment. Changes in attitude in younger generations mean that alcohol consumption among older people, and possibly use of illicit drugs, is likely to increase as these groups age.

While older people generally drink less than younger people, physical changes in later life mean that older people are more likely to be adversely affected by alcohol at lower levels of consumption:

- Alcohol consumption has been identified as one of the three most common reasons for falls in older people.
- Alcohol can react adversely with medication, and can precipitate an acute confusional state.
- Alcohol may also contribute to cognitive impairment in dementia.
- Alcohol problems can significantly impair the health and quality of life of older people.
- Excessive drinking puts older people at increased risk of coronary heart disease, hypertension and stroke.
- Alcohol can increase the likelihood of incontinence and gastrointestinal problems; heavy drinking can lead to self-neglect, poor nutrition, poor hygiene and hypothermia.

In addition, long-term alcohol misuse can lead to Wernicke-Korsakoff syndrome, which is a form of brain damage characterised by memory loss. The effects can include:

- Poor attention
- Self-centred and withdrawn behaviour
- Difficulties with problem solving and learning new information
- Impairment of short- and long-term memory.

Alcohol misuse often goes undetected because the symptoms, such as accidents, malnutrition, self-neglect, depression, insomnia and confusion, can be non-specific and hard to distinguish from other causes. On assessment, older people may underreport their level of alcohol use, because of the stigma attached, or because they regard alcoholic drinks as medicinal, alleviating other health problems. Family members, health professionals and care staff may ignore problems on the basis that alcohol is 'one of the few pleasures left' to an older person.

Older people are also at risk of over-medication, of both prescribed and over-the-counter drugs, particularly sedatives, hypnotics and tranquillisers. Older people may self-medicate, for instance for insomnia or other problems, but over-medication, or interactions with alcohol or between drugs, may exacerbate their problems.

### Key research findings

- Alcohol misuse has potentially severe social and health consequences in later life.
- The number of older people with alcohol problems is likely to increase.



## Further information

For more information on drug and alcohol problems in older people, see:

## Extended resumes

Derry, A.D. (2000) 'Substance use in older adults: A review of current assessment, treatment and service provision', *Journal of Substance Use*, vol 5, pp 252–262. Herring, R. and Thom, B. (1997) 'Alcohol misuse in older people: the role of home carers', *Health and Social Care in the Community*, vol 5, no 4, pp 237–245.

## Treatment and recovery

Accurate diagnosis and early intervention is important for all forms of mental ill health in older people. There may be underlying physical conditions such as viral conditions or poor nutrition, and treating these can result in improved energy and mental state. Many symptoms of physical illness can be mistaken for mental illness, and physical conditions should always be considered first. For instance, conditions such as kidney infection, thyroid deficiency or a stroke can sometimes lead to 'dementia-like' symptoms; loss of appetite and disturbed sleep may be caused by heart disease or arthritis rather than depression. Extreme worry and agitation can make some older people appear quite confused, as can a urinary tract infection.

- Early recognition of physical and psychiatric conditions can benefit the individual and avoid the use of inappropriate and disproportionate services.
- Early and accurate diagnosis of mental health problems enables older people and those caring for them to understand what is happening to them and to access appropriate treatment and help.
- Early and appropriate recognition and information lets individuals and their carers understand the present and prepare for the future.

There are treatment options for all forms of mental health problems in older people, and there is no reason for older people to be denied access to medication, or services such as counselling, which would be considered for a younger person. Even for conditions where there is as yet no cure, as with dementia, improvements in care and treatment are achievable and can make a significant difference to older people's quality of life.

'Recovery' and wellbeing approaches to mental health issues developed by younger adult service users and working-age mental health services are equally applicable to older people. 'Recovery' does not imply 'cure', but builds on the personal strengths and resilience of an individual 'to recover optimum quality of life and have satisfaction with life in disconnected circumstances'.(NIMHE,

2005)-(19) Recovery is about the development of coping skills, and about social inclusion, making it possible for people to have quality of life and a degree of independence and choice, even those with the most enduring and disabling conditions. See also 'Mental health and wellbeing – What you can do'.

In the NSF for Older People, Standard 7, the Department of Health makes it clear that an integrated mental health service for older people should encompass:

- Promoting good mental health
- The early recognition and management of mental health problems
- Access to advice and treatment from specialist mental health services when needed.

Standard 7 also says that while inpatient admission may be indicated for severe mental illness, 'the emphasis should be on promoting the independence of older people with mental health problems and supporting them, and their carers, in the community wherever possible and practical.'

For more on the NSF, Standard 7, see Section 8.

As part of the implementation of Standard 7, to increase awareness and the appropriate diagnosis of dementia and depression, primary care trusts (PCTs) are expected to produce guidance for GPs on local care pathways for the treatment of older people with depression or dementia. These should include guidance on symptoms, risk factors, treatment options, and when to refer to specialist services.(DH, 2003)-(20)

## What you can do

- Maintain a positive approach (see also 'Mental health and wellbeing – What you can do').
- Find out as much as you can about mental health in later life. Ask for training, for instance in dementia awareness, for you and your colleagues.
- Make links with the specialist services in your area for older people with mental health needs. Find out their criteria for referrals. Ask for their help or advice if you feel you need it.
- Try to put yourself in the position of the older person – how would these symptoms make you feel? Would you be frightened, worried? How would you want to be treated?

## Section 3: The assessment process

Assessing older people with mental health needs requires the same skills as any other assessment, and is based on the same principles of a person-centred approach and the individual's right to high standards of assessment and services. People with mental health needs may be more vulnerable, more anxious, more confused, and perhaps have a history of being dismissed as mentally ill. You can help by adopting the same approach as you would to anyone else, by being open, honest, respectful and empathetic.

### Key research findings

For a more detailed account, see Research Summary 3.

- Older people being assessed are likely to experience some anxiety, particularly if they believe the assessor is looking for signs of cognitive impairment.
- There is a tendency for older people's needs to be defined by professionals rather than by the older people themselves.
- Older people don't necessarily value the same aspects of an assessment as professionals.
- There are some advantages in using standardised measures.
- It is important to try to understand the older person in the context of their world.
- The most important factor is for assessors to develop good communication skills:
  - > using down-to-earth, everyday language, avoiding jargon
  - > being a good listener, able to identify underlying meanings
  - > using prompts, such as photographs
  - > allowing the person to take the lead in conversation rather than using direct questioning
  - > taking time to build a relationship with the person being assessed.

### What you can do: top tips

- Don't panic. Assessing older people with mental health needs requires the same skills as any other assessment, and is based on the same principles.
- Don't make assumptions. Be open to other possibilities.
- Address the basics. Is the person physically ill? Can they see, hear, understand you?

- Do they know who you are and what the assessment is for? What effect is the environment having?
- Slow down. Take time to build up trust. Build up a rapport over several visits. At each visit, remind the person who you are and what you talked about last time. Take time to talk around the situation – be unhurried. Do not try to move the person on faster than they can cope with.
- Explain carefully, using simple, everyday language. Avoid jargon.
- Find out about the person's life, and use prompts, for example, photos, to get the person talking. Use family members and others who know the person to fill in the gaps
- Let the person take the lead. Be careful not to guide what the older person is saying
- Listen carefully for underlying meanings; be alert to non-verbal communication such as facial expressions, body language.
- Assume the person has mental capacity, particularly when considering and assessing risks, unless and until there is evidence to the contrary.
- Involve others – family members, advocates, other professionals.

## Single Assessment Process

Standard 2 of the NSF for Older People is concerned with 'person-centred care'. It aims to 'Ensure that older people are treated as individuals and they receive appropriate and timely packages of care which meets their needs as individuals, regardless of health and social services boundaries.' (DH, 2001)-(21)

The Single Assessment Process is the means by which health and social care organisations work together to ensure that assessment and subsequent care planning for older people are person-centred, effective and coordinated. Since April 2004, all older people with health and social care needs should have those needs assessed using the locally agreed framework for the Single Assessment Process. This entails health and social care professionals working together, sharing information, trusting one another's judgement, reducing duplication, and together ensuring that the range and complexity of an older person's needs are properly identified and addressed in accordance with their wishes and preferences.

### Ideas from practice

The following extract from Birmingham's multiagency guidelines for staff is an example of what person-centred care through the Single Assessment Process should mean in practice:

Person-centred care and approaches put the **needs and views of the individual** at the centre of any professional involvement or intervention.

Practitioners working in a person-centred way would be expected to:

- Involve the person in all decisions about their care
- See the person as the expert in their own care and take account of strengths the person can bring to bear on their needs
- Provide information and carry out assessments and other processes in the person's preferred language, making necessary arrangements for interpreters/ translations/communication aids
- Ensure each person is informed of, and consents to, information about their needs and circumstances being collected and shared
- Ensure the person's contribution is not underestimated however disabled they are or whatever their level of difficulties
- Work together across agencies in the best interests of the older person
- Acknowledge and take account of the impact of a person's age, gender, living arrangements, personal relationships, lifestyle and culture – as well as their illness or disability – on their choices and needs
- Require information about needs to be given once only in building a rounded picture of the person's needs and circumstances and be of a depth and detail 'proportionate to the person's needs'
- Have key decisions and issues copied in writing, or other appropriate formats, and given to the older person
- Safeguard the person's interests when they lack capacity
- Empower the person to decide about the level of risk they are prepared to take.

© North Birmingham PCT (Single Assessment Process Birmingham Multi-agency Steering Group), April 2003

## Care Programme Approach

The Care Programme Approach was introduced in 1991 to ensure that people with severe mental health problems discharged into the community received appropriate support and treatment through proper care planning and review. With the introduction of the Single Assessment Process for older people, some practitioners have been confused about whether older people with mental health needs should come under the Care Programme Approach or the Single Assessment Process. The Department of Health issued guidance in 2004 (DH, 2004)-(22), which can be summarised as follows:

- Older people with severe mental illness due to schizophrenia or other psychoses should have their needs assessed using the Single Assessment Process, but should be care managed under the Care Programme Approach.

- For other older people with mental health problems, both the assessment and care management aspects of the Single Assessment Process should be applied.
- Adults currently under the Care Programme Approach when they enter old age do not have to switch to the Single Assessment Process.

### Further information

For more information on the Single Assessment Process, see the Department of Health's policy and guidance pages or the Centre for Policy on Ageing website.

For more information on the Care Programme Approach, see Section 8.

## Hospital discharge

### Further information

It is generally accepted that an acute hospital ward is not an appropriate environment for an older person once they no longer require acute medical care, but the need for a further period of recuperation may be necessary. Assessments of older people in hospital are therefore likely to commence before the person has fully recovered, which may make it more difficult to gauge a person's real capabilities or potential. 'Intermediate care' is increasingly being used to bridge the gap between hospital and the community, and the Department of Health now requires health and social services to ensure that intermediate care services are available for people with dementia.(DH, 2002)-(23)

However, there is a risk to older people with dementia that changes in environment and routine can be extremely disorienting and exacerbate their difficulties, so transfers of care need to be kept to a minimum. The Department of Health Change Agent Team has issued guidance on discharge from hospital and moves within hospital for people with dementia.

### Further information

Health and Social Care Change Agent Team guidance:

Discharge from hospital: Getting it right for people with dementia (Health and Social Care Change Agent Team, 2003)-(24) Moves in hospital: Getting it right for people with dementia (Health and Social Care Change Agent Team, 2003a)-(25)

## Getting the basics right

**Don't** make assumptions, **do** address the basics.

It is important to keep an open mind when assessing someone with mental health needs, and not make assumptions based on what others may have told you, or on your experience of other older people. Don't assume the person is confused because they have dementia – be open to other possibilities. Don't assume the older person knows who you are or what you are talking about; think about how you might appear to them, explain everything carefully, and be prepared to do so again the next time you meet them.

Very often people with mental health needs, and their carers, have very low expectations. Don't assume that they don't want or need help just because they don't ask for help or they have difficulty articulating their wishes. They may assume that the sort of help they really want is not available, or would not be offered to them.

As in any assessment it is important to address the basics. For instance: how is their physical health? Are they physically ill? Can they see, hear, and understand you? Do they normally wear glasses, and if they have a hearing aid is it working properly? Are they fluent in English, or is an interpreter needed?

#### **Case study**

Mrs D was lethargic, not sleeping, not eating, feeling low and tearful, and not really connecting. The practice nurse thought she was depressed and was about to ask the GP for a prescription for anti-depressants when Mrs D happened to mention feeling a burning sensation when she passed urine. She was found to have a severe urinary tract infection.

It is important to know as much as possible about a person's physical state and any medication they are taking in order to properly assess their needs. Some illnesses result in confusion or low mood, which can lead to an inaccurate picture of how the person copes when well. Chronic pain, insomnia or anxiety may make it hard for the older person to concentrate. Medication may dull the senses. Some medication for long-term mental health conditions has severe consequences – for example some medication suppresses psychosis but may make men impotent and emotionally 'flat'. All these factors can make it more difficult to get an accurate picture of the older person and their needs.

Think about the effect of the environment they are in. Does the person feel safe? What about noise levels, lack of privacy and possible distractions? If someone is in an unfamiliar environment such as a hospital, they may be confused and disoriented, and their confidence may be affected. This is especially likely to be the case if the admission to hospital was the result of trauma such as a fall or stroke, or if the person is still feeling ill.

## Communication skills

### Ideas from practice

Good communication is at the heart of assessment: listening carefully and understanding what is said, what is felt and what is helpful are essential skills for an assessor, as is the ability to explain clearly what they are doing and why. At assessment the individual and their carers are likely to be dealing with a completely unknown professional, who may not expect to have long or regular contact with them. Good communication skills are particularly important in these situations, and when the older person may be anxious, inhibited, depressed or confused, or have impaired memory or speech.

Dementia, depression or any other form of mental illness may affect an individual's capacity to communicate, but the older person will still have opinions, preferences and the capacity for feelings and emotions.

‘Sometimes you find carers surprised that you want to talk to their elderly relative with dementia – showing that you expect some communication – and how you go about it can model something for those carers’. (social worker)

You may be anxious about how to assess someone who appears confused, or has been diagnosed with dementia. The mental health problems of older age, including dementia, mean we have to use imagination and skill to communicate effectively with older people if their needs are to be understood.

**Slow down, explain carefully, find out about the person's life, let them take the lead, listen carefully.**

Good practice in communication with older people emphasises the need to work at a pace that suits the older person:

- Assessors should be mindful of the physical frailty of some older people, who tire easily. This may mean ‘little and often’ contact is the best means of ensuring the assessor understands the older person and makes himself or herself understood in turn.
- Take time to build up trust. Develop a rapport over several visits.
- At each visit, remind the person who you are and what you talked about last time. Take time to talk around the situation and don't hurry.
- Do not try to move the person on faster than they can cope with.

It is important to ensure that working practices in your team or unit allow for this slower pace when required. For many practitioners, the volume of work dictates rapid assessments through one-off visits, with little opportunity for follow-up or continued involvement. Services resulting from the assessment are likely to be provided by another organisation or section, with responsibility for monitoring



and review passed to someone else again. Working with older people with mental health needs may require you and your colleagues to think through how your working practices can be adapted to enable you to conduct assessments appropriately and effectively.

In many localities, the introduction of new assessment forms to support the Single Assessment Process and the introduction of electronic care and health records has involved major changes for staff. In some places the work involved in implementing standard assessment documentation across organisations has deflected attention from the core purpose of the Single Assessment Process, which is not about more or different paperwork or computer systems but about changes in practice and organisational culture that put the older person at the heart of decision making.

An assessment form is the record of a complex activity, not a substitute for it. So aim to have a conversation with the person you are assessing in order to find out how to help, and use your organisation's agreed assessment format to record the essence of that conversation.

### Ideas from practice

Below is an experienced practitioner's advice on how to have a conversation on a 'cold call', when first visiting a confused older person who lives alone.

- You need to invest time in the beginning: it's all about building up a relationship. You may get a lot of suspicion, and some people are very vulnerable – they open the door and think you're a relative.
- Always stress who you are and what your job is.
- Keep the contact short and gauge the response you get.
- Cars passing, clocks chiming, can all completely distract the person. Physical and eye contact can help, especially when something is distracting.
- You have to get inside the attention bubble – whatever gets you on the same wavelength. You may only get information from spontaneous comment.
- Singing a song together can be a great way of getting on.
- If they start talking to you, let them carry on.
- Don't finish sentences; don't provide words; don't rephrase your question when they're struggling to answer.
- However bizarre the message may seem, it's a communication. You'll get the meaning from tone, expression and mood as well as from words.
- Make short daily contacts: often on the third or so visit you'll be familiar and accepted.
- Get an idea what makes them tick – what point in their lives are they talking to you from?

## Understanding dementia

### Further information

A number of organisations now provide training for staff in the particular features of dementia and its impact on people's lives. Dementia awareness training should be available to all staff working with older people.

### Ideas from practice

#### **Developing empathy**

The following is an extract from Cambridgeshire Social Services Department's toolkit for training residential care staff. It aims to help practitioners understand the older person's experience from their point of view.

You and your team may know older people with dementia have the full range of emotions ... but think about it:

You have just heard your mother has died and someone is trying to get you to play bingo!

You are so ashamed you haven't been able to find the toilet – two strangers force you to take your clothes off and pretend it doesn't matter.

The door won't open – you need to get home to collect your son – the tears of frustration fall down your face – RELIEF, there's someone on the other side – you shout – they just smile and walk away.

'Manners maketh man' – you can hear your father's voice. Food and meals were central to your family life as a daughter and mother. How could you be at a table with people who spill food down their front, spit it out and this woman who keeps trying to force you to eat?

There are strangers trying to kiss you pretending to be your family – you've never seen them before – no one understands – all the people around you are conned by them.

Alarms go off all the time in this place. Should you be doing something or going somewhere? – the fire might get you!

'Why do they call me Elizabeth? ... no one does ... I'm Libby!'

(Best practice in dementia care: A training strategy toolkit © Cambridgeshire Social Services Department)

Try to understand 'difficult' behaviour such as aggression, or apparently aimless walking about (try to avoid the term 'wandering') by thinking about the possible meaning behind the behaviour for the older person.

### Changing minds

The following is a case example from Royal College of Psychiatrists Changing minds campaign:

He used to be an angry young man but now he's an angry old one. He was quite a sight in those days – printing pamphlets, shouting from the platform, struggling with the police. He was a leader of the student revolution. They took notice of him then. Now they only pay attention when he threatens the nurse with his stick.

Dementia affects the brain. The person gradually loses his intelligence, his memory and his personality. Some go quietly, others rebel. They can shout or swear or even strike out. This is distressing for people close to them.

But for the man himself? Perhaps it is better than being invisible.

(Changing minds – Alzheimer's disease and dementia © Royal College of Psychiatrists, 2003)

### Other innovations

The need for good communication skills in working with people with dementia is increasingly recognised. Much of this work has been undertaken within residential and day care services, but can also be applied to assessment services.

The Bradford Dementia Group, for example, has evolved an approach based on understanding that all observed behaviour carries a communication. Their method of working, first developed by Tom Kitwood, is called 'Dementia Care Mapping'.

The Joseph Rowntree Foundation has identified a range of communication approaches and techniques that help workers understand their clients' views and preferences: Exploring ways for staff to consult people with dementia about services.

The Alzheimer's Society's Building on strengths training package involves identifying an individual's strengths and abilities, and finding ways to support the person to retain these abilities and build on them to enhance self-esteem and independence. For example, a person with dementia may be able to continue to dress themselves so long as someone has laid out the clothes ready for them, in the right order.

The Brighton-based consultancy and training organisation Dementia Care Matters is developing an approach called 'Being Together with Dementia', based on the idea of 'relationship-centred care', in which the emphasis is on the person with dementia's relationship with their partner or other significant people. Pilots in Peterborough and Hounslow have involved facilitating couples to explore what being together with dementia means for them, and to see how this experience can be used to enhance dementia care.

For other innovations and developments in dementia care, see the work of the regional Dementia care services development centres.

### Further information

The Alzheimer's Society produces a range of advice sheets to help carers cope with particular behaviours.

The Royal College of Psychiatrists has produced a leaflet on dementia as part of their Changing Minds campaign.

## Mental capacity

Start with the assumption that older people have the capacity to make decisions for themselves, unless and until that assumption is proved wrong.

Older people with mental health problems often create anxiety and concern in those involved with them, particularly about keeping the individual and those around them safe. Effective interventions are complicated further when people have difficulty communicating with an older person, and where there are concerns about their capacity to make decisions.

You may have reservations about involving a person with mental health needs in their own assessment and in decision making about their care because of doubts about their capacity to understand or engage in what is happening and to make appropriate decisions. The Department of Health describes a person 'with capacity' as someone able to understand, retain and weigh up information relevant to the decision and its consequences. Capacity is not a fixed concept, but relates to a particular decision at a particular time. Different decisions and activities require different levels of capacity.

Where someone is judged not to have capacity, professionals are authorised to act in the 'best interests' of the person, where there is a necessity to act, under the 'common law doctrine of necessity'. Acting in what professionals consider to be the person's best interests has sometimes been a substitute for trying to establish an older person's views and involve them in the process. Friends, relatives or carers of an individual do not have any legal power to make decisions on behalf of the individual unless the individual has made provision for

this in advance, for instance through an advance directive or an Enduring Power of Attorney. As a result, family members have often had to negotiate a distinctly grey area of legality when making decisions on behalf of an older relative. In some cases this has resulted in abuse of the older person's rights.

## Mental Capacity Act 2005

The Mental Capacity Act 2005 has attempted to address some of these issues. It provides a statutory framework to empower and protect vulnerable people who are not able to make their own decisions. Guidance on the Act, which was given assent in April 2005 but will not be fully implemented until 2007, will be provided in a Code of Practice.

The Act sets out a single clear test for assessing whether a person lacks capacity to take a particular decision at a particular time, and, if a person lacks capacity, provides a checklist of factors that decision makers must work through in deciding what is in a person's best interests. It also replaces the current Enduring Power of Attorney with a new Lasting Power of Attorney covering health and welfare decisions as well as finance and property.

The Act is underpinned by five key principles, which it would be helpful for all practitioners to keep in mind when working with older people with mental health needs:

- **A presumption of capacity:** every adult has the right to make his or her own decisions, and must be assumed to have the capacity to do so unless it is proved otherwise.
- **The right for individuals to be supported to make their own decisions:** people must be given all appropriate help before anyone concludes that they cannot make their own decisions.
- The right of individuals to make what might be seen as eccentric or unwise decisions.
- **Best interests:** anything done for or on behalf of people without capacity must be in their best interests.
- **Least restrictive intervention:** anything done for or on behalf of people without capacity should be the least restrictive of their basic rights and freedoms.

## The 'Bournewood gap'

The Mental Capacity Act 2005 is partly a response to the 'Bournewood gap', which refers to the legal situation after a 1998 judgment in the House of Lords. The case drew attention to a significant gap in mental health law: mental health patients who lack the capacity to make decisions for themselves cannot consent to their treatment, but many are admitted to hospital without being sectioned

under the Mental Health Act 2005 because they accept hospitalisation and treatment compliantly.

The Department of Health's guidelines after the ruling advised:

- Informal admission of compliant incapacitated patients (under the common law doctrine of necessity)
- Regular assessment of capacity during admission
- Consultation with relatives and/or carers
- Visits by hospital managers or advocates if there is no one outside the hospital to take a continuing interest in a patient's care.

### Involving advocates

If you are a practitioner in a non-specialist setting, it is unlikely that you will be involved in determining whether an older person should be admitted to psychiatric hospital, but the issues surrounding mental capacity are relevant for all who work with older people with mental health needs. In situations where an older person lacks capacity, it would be good practice to involve an advocate to represent their interests. See the section on 'Advocacy' in Section 8 for the legal situation with regard to advocacy.

### Ideas from practice

In their publication *Hear what I say: Developing dementia advocacy services*, Dementia North and Northumbria University discuss the role of family members as advocates:

Families and carers are often thought to be the natural advocates for people with dementia. Sometimes family members can be very effective advocates: when they know the person with dementia and their wishes very well; when they care strongly about the person with dementia having their needs and wishes met; and when representing the person with dementia presents them with no conflicts of interest. However, sometimes the emotional, practical and financial complexities of family life make it very difficult for family or carers to be an advocate for a relative with dementia. (Cantley et al, 2003)-(26)

The Mental Capacity Act 2005 introduces a new role of independent mental capacity advocate for those without capacity who have no relatives or friends to act for them. In July 2005 the Department of Health commenced a consultation exercise on how the new independent mental capacity advocate service should operate.

## Further information

For more information on the Mental Capacity Act 2005, see Section 8. The full text of the Act is available on the Office of Public Sector Information website.

For more about the 'Bournewood gap' and the response of the mental health charity Mind, see the Mind website.

For more about advocacy, see the Joseph Rowntree Foundation report *Are you listening?* (Margiotta et al, 2003)-(27). For other relevant links, see Advocacy and older people with mental health needs.

## Assessing risk

### Ideas from practice

Worry about risk and danger permeates assessment work with older people. Relatives, neighbours, the public and involved professionals all experience and react to this worry. The Department of Health's consultation on the Green Paper Independence, well-being and choice suggests that service users believe that professionals are too concerned about risk, and that this gets in the way of enabling service users to do what they want to do. The promotion of a person-centred approach aims to maximise independence and minimise risk, and often involves identifying and helping to resolve conflict and disagreement over risk and danger.

### Ideas from practice

Hampshire Social Services Department's Vulnerable Adults Protection Policy provides an example of this type of approach.

Risk taking can be very positive. Objectives worth achieving for persons of any age involve the taking of risks, and the same principles apply to older people.

Consider this continuum:

<Negligence\_\_\_\_\_Risk management\_\_\_\_\_Over-protection>

On the one hand it is important not to neglect older people perceived to be at risk, but on the other hand it is equally important not to be over-protective. Somewhere in the middle lies the concept of risk management.

Hampshire's policy suggests the following framework for assessing and dealing with risk:

- What benefits do you hope to achieve with the older person (ie why is it worth taking a risk?)
- How will the benefit(s) enhance the older person's life, experience and/or dignity? How important do you (and the older person) rate the benefit(s)?
- What types of harm may occur while trying to achieve the above benefits, to the older person, to people known to the older person, to members of the public, and/or to property? Estimate how likely each type of harm is to occur. (Harm may mean physical harm, distress or embarrassment).
- What steps do you propose taking to minimise each type of harm? List each step relating to reducing the likelihood and the degree of harm.
- Who has been consulted about the risk decision? Have any major problems or disagreements been raised that have not been resolved? Describe the decisions made and action to be taken.
- Comment on how you propose to monitor the situation. What records will be kept and when will you review progress?

Staff are expected to:

- Carefully weigh the possible risks against the ways in which an individual will benefit if they take the risk.
- Take everybody's views and feelings into account in making decisions.
- Discuss openly and clearly any differences of opinion.
- Make sure that older people and other key people such as friends, family, carers and advocates know how decisions have been reached.
- Make sure that the above individuals are involved as much as possible in managing and monitoring the risk.
- Arrange the support of an advocate when the individual needs independent help to express their views.

Finally:

It is important to have a management plan for dealing with identified risks, including a contingency plan in case things go wrong, and to communicate these to all who need to know.



**Case study**

When Mrs T, a widow with Alzheimer's, moved into a sheltered housing scheme in her village, she became disoriented and frequently got lost after going out to the shops. On several occasions she was brought back by strangers having been found walking along the main road away from the village. The warden of the sheltered housing scheme was very concerned about Mrs T's safety.

On the other hand, Mrs T had always been a very active, independent person and her family believed it was important for her to continue to go out on her own. They felt that in the village, where she had lived for many years, she was well known and would be relatively safe. They agreed a plan with the warden whereby neighbours would let her know if they saw Mrs T going out, so that the warden could keep a look out for her, and they made sure that Mrs T's name and address were in her handbag, in case she got lost. Mrs T's family were willing to accept a degree of risk in order that their mother's quality of life could be maintained.

## Gathering information

The importance of involving the older person fully in their assessment remains true for older people with mental health needs, but there may be particular difficulties which the assessor will need to take into account. Getting an accurate picture of the person, how they are coping and the needs they have may be particularly difficult because:

- The experience of being assessed is likely to cause older people anxiety, and this is especially so when it appears that the assessor is looking for signs of cognitive impairment (see Research Summary 1).
- The stigma attached to mental illness may make it difficult for older people to acknowledge that they are having emotional difficulties or are worried about memory problems, for fear of being labelled 'senile'.
- Many older people fear that if they admit to finding it difficult to cope they will be 'put in a home'. Fiercely guarding their independence, they may insist they are all right and refuse all services.
- If depression has caused them to neglect themselves or their home, they may be reluctant for others to know this.
- Memory loss may mean they give a genuinely misleading account of what they can do, for instance assuring the assessor they shop and cook for themselves, forgetting that they have not performed these tasks for some while.

All this means that it is essential, in order to gain a fuller picture of the older person and any difficulties they may be experiencing, to get as much information as possible from others, including family and any other professionals involved. This information should complement and expand, not replace, what the older person has told you. It is important to explain to the older person that it will be helpful for you to get a fuller picture of their circumstances by talking to others who know them and have some involvement in their situation. Remember to get their permission to do this, and take seriously any concerns they may have.

Older people's lives and experiences do not fit into neat compartments any more than anyone else's do, and their needs frequently cross organisational and professional boundaries. The Single Assessment Process is intended to ensure that the older person experiences a coordinated approach. Practitioners working with older people are likely to be used to working alongside a range of colleagues from different health and social care disciplines and organisations, and will value the contribution of other professionals. Local arrangements for the Single Assessment Process should include a procedure for obtaining the older person's consent to share information with other professionals. (For an example, see the information sharing protocol produced by Solihull Metropolitan Borough Council, which has been adopted as a template by other West Midland authorities. Contact [vdickens@solihull.gov.uk](mailto:vdickens@solihull.gov.uk).)

## Assessment tools

### Further information

Assessment tools are standardised systems that help to identify and gauge the extent of specific conditions and provide a fair approach in response. They can be the means whereby individual and particular assessments contribute to the overall picture. They can provide systematic information on the needs across client populations and target resources. Tools include scales, checklists and interview schedules. They must be culturally sensitive, reliable and valid if they are to inform professional judgement. The use of standardised measures in current assessment practice is rare, but is increasing with the introduction of the Single Assessment Process.

Research into the use of standardised measures (Moriarty, 2002)-(28) suggests that when assessments do not include measures to screen for cognitive impairment and depression, their existence may be missed. This reduces older people's chances of being treated appropriately, and may also reduce their quality of life. High levels of cognitive impairment and untreated depression have been found among people in residential and nursing homes, among users of community care services and among home care clients.

Two of the most common screening tools used for identifying dementia and depression in older people are the Mini-Mental State Examination, which tests

memory and cognitive skills, and the four-item Geriatric Depression Scale. Some health and social care organisations have included these, or adaptations of them, in their Single Assessment Process documentation.

But it is important to recognise that these measures are only one element of good assessment practice, and that they do not diagnose dementia or depression, but merely indicate their possible presence.

The key point here is that these scales add to, rather than replace, other salient pieces of information upon which decisions about access to treatment or care are based. Alone, they are not sufficient to establish the content of need. (Cordingley et al. 2001)

### Further information

For more information about using assessment scales, see the Department of Health guidance and Standardised assessment scales for elderly people (Royal College of Physicians and the British Geriatric Society, 1992)-(29), a joint report by the Royal College of Physicians and the British Geriatric Society, based on their members' experience.

For a summary of the Social Care Workforce Research Unit review of the use of standardised measures, see *Assessing the mental health needs of older people*.

The Alzheimer's Society produces a useful information sheet on the Mini-Mental State Examination for people with dementia and their carers.

## Specialist assessment

### Ideas from practice

This guide assumes that you are a practitioner without psychiatric training who has responsibility for assessing the needs of older people, some of whom may have mental health needs. While it is likely that the majority of older people with mild to moderate mental health needs will have their care, treatment and services provided by non-specialists such as yourself, it is important to recognise when specialist services and professionals should be called in.

Department of Health guidance states:

The majority of older people with mental illness do not come into contact with specialist mental health services. To maximise care therefore requires effective management by others in contact with older people. There should be a protocol for the detection, initial assessment (incorporating contact and overview assessment within the Single Assessment Process), initial management and specialist referral of older people with mental illness, including depression and dementia. This

should be adapted for use in primary care, the general hospital, care homes, and social services ... The protocol should indicate when and how people with mental illness should be referred between different services across different agencies, with mechanisms to optimise appropriate information sharing. (DH, 2003)-(30)

To some extent how this happens will depend on the specialist services in your locality, such as the memory clinic, acute psychiatry team and community mental health team for older people, and the criteria by which they operate. You will need to find out what specialist services there are in your area for older people with mental health needs, what they do, and their criteria for referral. This information should be available in the form of protocols or care pathways (see above), but are likely to include referral to specialist services in the following circumstances:

- If you suspect someone may have mental health needs but no diagnosis has been made
- If diagnosis remains uncertain or symptoms are particularly complex
- If the person's behaviour or emotional state is creating a risk to themselves or others
- If the person's behaviour or emotional state is such that their care arrangements are likely to break down
- If problems are particularly complex or legal issues are involved.

Finally, you need to consider your own entitlement to help or advice on behalf of the older people you work with. Many specialist services now provide advice and support to workers in other settings. If you need more specialist advice or support than your own team can provide, ask for advice from your mental health colleagues.

### Ideas from practice

- In Warwickshire, community psychiatric nurses were appointed to work directly with care home staff in the support and management of residents with mental health needs.
- In Coventry, there is a hospital liaison team linking mental health specialists to general hospital staff, and a practice educator running workshops and training for ward staff.

## Section 4: Meeting needs

Effective assessment of needs requires appropriate services to meet those needs. Most older people wish to stay in their own homes and remain independent for as long as possible, with the right support, and this is also true of older people with mental health needs. Older people with mental health needs are entitled to the full range of community care and health services available to other older people, but this may require specific planning or special services. Increasingly, mainstream services such as sheltered housing are recognising that they have a role to play. Other services are adapting, or new services are being developed, to meet the particular needs of, for instance, older people with dementia.

### Key research findings

#### Dementia

For a more detailed account, see Research Summary 4.

While there has not been a great deal of systematic evaluation in recent years of which services work best for older people with mental health needs, there is some evidence to suggest that community care services such as home care and day care can be effective in supporting people with a range of needs and preventing deterioration. Services targeted at specific needs and involving continued contact appear to show greater success.

The following are some of the key findings from research:

- Older people with mental health needs want the same from services as other older service users. They want:
  - to be treated as an individual
    - > access to social contact and company
    - > access to meaningful activity, stimulation and integration
    - > to feel safe and secure
    - > to feel valued and respected.
- Services for older people with mental health needs are more effective when they are:
  - > specialist services targeted at particular groups
- provided as the result of a comprehensive assessment
- associated with follow-up visits and ongoing support.
- Service users rate highly 'low level' preventative services for their impact on quality of life, although organisations have doubts about cost effectiveness.
- No single service is the key to meeting needs. A range of good quality care services all make a contribution. For instance:
  - > specialist home care services

- > extended hours day care provision
- > respite and sitting services in the person's own home.
- Older people and their families do not get access to the right sort of information early enough.

## What you can do: top tips

- Make sure you are well informed about older people's mental health needs.
- Have useful information available for sharing with older people and families.
- Think widely when planning to meet needs – consider all types of services and organisations.
- Ensure all aspects of need are covered.
- Take time to build trust and ensure that service providers do too.
- Stay involved yourself, or make sure that someone else is appointed to do so.
- Aim for continuity of services and staff.
- Be prepared to accept an element of risk.
- Keep positive and imaginative: you can make a difference.

## Dementia

Alzheimer's Scotland has summarised the range of needs experienced by older people with dementia and their families as follows:

- Healthcare needs, including diagnosis, assessment and treatment
- Information on the illness, coping techniques, financial and legal issues, services available and planning ahead
- Advocacy support to assist in accessing services
- Practical support including rehabilitative approaches to managing memory loss, disorientation or difficulties with daily living skills
- Emotional support including one-to-one support and support groups
- Social support to combat isolation and stigma, and to ensure that they can continue their usual level and range of activities or even develop new initiatives
- Financial support to offset income loss for younger people with dementia or relatives who give up work (Alzheimer's Scotland, Action on dementia, 2003)-(31).

## Information, advice and planning

Early and accurate diagnosis enables older people with mental health problems to benefit from improved medical treatment and support (see Section 2: The main problems)

It also provides older people and their families with the opportunity to understand the present and plan for the future. This may be particularly important for people with dementia. In the past, received opinion often saw little value in early diagnosis because it was thought nothing could be done, and because breaking news about a deteriorating condition for which there is no cure can seem cruel. Attitudes are changing, however, partly because of advances in drugs treatment, but also because individuals, and their families and friends, can benefit greatly from knowing what is happening to them. Research undertaken with people with dementia found that in general they wanted to know their diagnosis and were able to find positive ways of coping with it. (Pratt and Wilkinson, 2001)-(32)

Giving people accurate and timely information, and helping them to understand their diagnosis and make plans with their families, is a crucially important role for social workers and other professionals involved in assessing older people with mental health needs and is likely to be the first task in meeting needs.

I was diagnosed as having the early stages of Alzheimer's disease. While this was a terrible blow to both myself and my wife, we were glad to have been told so that we could discuss the possible effects on our lives and plan how we could adjust to the situation. I have made an Enduring Power of Attorney and a will. I think it is important for the partner of the person with dementia to be fully informed of the diagnosis and possible effects since the partner's life is affected quite dramatically also. Fortunately for me, my wife is an intelligent and caring person with a strong personality. We have had 54 very happy years together and she is most supportive. (World Alzheimer's Day Bulletin, 21 September 2001 © Alzheimer's Society)

### Information sources

It is important for assessors and care managers to aim to be well informed themselves about the sorts of conditions older people might experience and what might help, and to have access to clear information that they can share with older people and their families. Increasingly, access to information is available from the websites of voluntary organisations and central government. Knowing where you can find information is useful for assessors. A number of sources are highlighted under 'Further information' in each page in Section 2.

Assessors and their agencies may also need to create sources of information for themselves, or for older people and their carers. An example is Cardiff's Signpost magazine for professionals and care staff working with older people using mental health services.

## Offering help

Traditional social work skills such as counselling and helping people to face and cope with significant life changes also have critical importance. Many older people are reluctant to accept the need for intervention in their lives, and this can be particularly difficult for older people with mental health needs. Older people with depression may find it impossible to imagine that anything can be done to help their situation, while older people with dementia may not understand why help is being suggested. Many older people are faced with difficult decisions about whether they can continue to live independently.

Some will be faced with the need to accept residential or nursing care, or a move to more suitable housing, while others will have the unwelcome prospect of accepting help from strangers coming into their home.

Older people with mental health needs may be particularly vulnerable and anxious in these situations, and may find it difficult to have their views and wishes properly taken into account. Persuading older people to accept the help they need while maintaining their sense of autonomy and self-respect requires skill and empathy.

### **Case study**

Mrs W had been persuaded to accept a regular home care visit as it was clear she was neglecting herself, but she found the visits irksome and could not see why she needed help. On a number of occasions she wrote to the Director of Social Services politely asking for the care to be withdrawn. On each occasion the social worker from the community mental health team for older people came to see her and persuaded her to continue. He understood and sympathised with her irritation, but he also knew from previous discussions with her that it was important to her not to feel a burden on her family. He was able to convince her that the home care visits stopped her family worrying about her, and she was prepared to accept them on this basis. Gradually the home carers became trusted by Mrs W, and as her needs increased the social worker was able to increase the visits.

## Specialist or mainstream

Specifically targeted services appear to work best for older people with mental health needs (see Research Summary 4).

A number of social services departments have commissioned specialist home care or day care services, training staff to work with people with dementia and to offer a sensitive, safe and acceptable service. Examples include Dudley, Waltham Forest and Milton Keynes. In some places, specialist hospital



discharge services for people with dementia have been set up, to ensure appropriate, safe and supported discharge home from acute hospitals. Ealing's enhanced discharge scheme is an example.

But the number of such schemes is still relatively limited and most older people with mental health needs use mainstream services. The full range of community care services should be available to older people with mental health needs without discrimination. It is essential, therefore, that all service providers understand mental health issues, and ensure their staff are specifically trained to provide an appropriate service.

### **Key research finding**

Although older people with mental health needs are at increased risk of admission to long-term care, care home staff tend not to be well informed about residents' mental health needs.

### **Ideas from practice**

- In Warwickshire, one locality used Joint Finance to put on a programme of dementia awareness training available free of charge to staff from any home care agency, care home or housing provider in the locality.
- Housing 21, a housing association providing extra care sheltered housing, appointed a dementia services advisor in 2004 to provide professional advice and support to their scheme managers in identifying and supporting tenants with dementia and promoting good practice in dementia care.

### **Residential or community care**

Residential care used to be seen as the only option for older people with mental health needs if they were no longer able to care for themselves or their families could no longer cope, particularly if an older person was considered at risk. Residential care, in a general care home or specialist unit, may still be the most appropriate solution for people who require very intensive personal care or supervision, but community-based alternatives could meet the needs of many other older people.

Many services such as sheltered and extra care housing that would not previously have accepted people with, for example a diagnosis of dementia (see below), or intermediate care, now accept people with a wide range of needs. The Department of Health has issued guidance on establishing intermediate care services for older people.

## Housing

### **Key research finding**

There are strong links between housing quality and mental health.

The role of housing, and housing-related services, in helping to meet older people's health and social care needs, is too often neglected.

Care and Repair England's 'Healthy Homes, Healthier Lives' programme aims to raise awareness of the ways in which poor or unsuitable housing can have a negative effect on older people's health and wellbeing, and to increase understanding of the services and resources available for improving housing conditions. Home Improvement Agencies exist to help older and disabled people maintain their independence by giving advice, support and practical help on repairs, maintenance and adaptations. Increasingly, Home Improvement Agencies are becoming involved in wider services such as hospital discharge schemes, 'handyperson' services and housing options advice. Research by the University of the West of England has highlighted the challenges for Home Improvement Agencies in developing their work with older people with mental health needs (McClatchey et al, 2001)-(33).

Extra care housing (ECH) – also called 'very sheltered housing' – is a new development in service provision. It is increasingly popular among older people and policy makers because it has the potential to replace residential care. It also plays a useful role in providing respite care and a base for intermediate and rehabilitative care. More importantly it has the flexibility to provide added health gains and reduce pressures on acute services, such as tackling delayed discharges from hospital. ECH is difficult to define as it covers a variety of schemes in which housing and care are integrated. It may be particularly relevant to extending community-based living for older people with mental health problems.

The availability of Housing Benefit has been central to the development of ECH. In 2003 Housing Benefit was replaced by the 'Supporting People' budget, a funding stream that provides housing-related support services to vulnerable adults. It is particularly targeted at older people.

### **Further information**

For a discussion of the issues concerning the appropriateness of ECH for people with dementia, see The challenges of providing extra care housing to people with dementia by Sue Garwood of Hanover Housing Association (Garwood, 2004)-(34).

The Office of the Deputy Prime Minister and the Department of Health have issued joint guidance on the preparation of Older people's strategies that link housing to health, social care and other local strategies.

The website of the Office of the Deputy Prime Minister has more information about the 'Supporting People' budget.

The 'Housing with Care' Learning and Improvement Network (LIN) brings together stakeholders across the country to explore and develop service provision. It has produced a range of factsheets including: Supporting people with dementia in extra care housing and Extra care housing options for older people with functional mental health problems. For more details, and other relevant resources, see the Older people – Housing page on the Health and Social Care Change Agent Team website.

The Housing and Older People Development Group has published a helpful report entitled Directory of housing advice and information services for older people.

### Widening choice and access

It is not only traditional services that can be used to meet needs. For instance, going by taxi to a further education art class might be more acceptable to an older person than being taken by local authority transport to a traditional day centre, and might meet the same objectives.

When considering widening the choice and availability of services it is important to make sure that service providers and other service users are understanding towards and supportive of service users with mental health needs. Careful planning may be required to ensure older people with mental health needs 'don't feel out of place or disregarded, or encounter dismay, hostility or rejection from other service users. This may also entail providing support and advice to service providers, families and neighbours.

### Key research finding

The community care changes have created a greater range of service providers, but there has not been a corresponding increase in the type of service generally available.

For younger adults with learning disabilities, for example, access to community facilities and 'normal' services is frequently assisted by an enabler, support worker or volunteer, and there is no reason why older people with mental health needs should not be considered for the same sort of support if appropriate. For example, a service run by South Cambridgeshire Crossroads, as part of their support to carers, provides specially trained care assistants to accompany older people with dementia to activities.

From an older person's perspective, an effective service is one that enables them to achieve quality of life and treats them with respect and dignity. Many older people value 'low level' services offering practical help, such as shopping, housework and home and garden maintenance. Increasingly statutory agencies are withdrawing these services, even within a package of care. Sometimes people receiving high levels of personal care are expected to arrange and pay for such other forms of practical help themselves. For many older people with mental health needs, this is just not realistic. Care packages need to encompass the totality of a person's life and needs, regardless of how the individual elements are provided or funded.

There are inevitably problems for assessors and care managers with limited resources and competing priorities. Professionals have to be able to deal realistically with the conflicts and pressures involved in resource allocation and unmet needs without losing their determination to achieve the best outcome possible for each individual. This may involve a more imaginative use of existing resources or working to develop more appropriate responses.

## What you can do

If services you think are needed are not available:

- Talk to existing providers about what adapting their services would involve. How difficult would it be? What are the barriers? Is there anything you can do to help?
- Identify any additional costs for providers, and ask your manager how these could be funded. See if you can use your team's care budgets to negotiate directly with providers. What source of funding might there be for new providers?
- Make it your business to understand any difficulties service providers have, and your own organisation's financial limitations. What could be done differently to overcome these? Get to know the strengths and resources of your local community. Are voluntary organisations looking to expand their remit? Does the local place of worship visit and befriend older people? Can the local vet's surgery tell you of anyone who would volunteer to help an older person care for their pet? Would the local radio station be interested in doing a programme to attract care workers? Keep a record of situations where you feel you have been unable to find the right service despite your efforts. Tell your manager, and encourage colleagues to do the same. Remember, new and better services are unlikely to be commissioned unless someone has identified the need. You are one of the people best placed to do this.

## Ideas from practice

For some examples of service innovations, see the Health and Social Care Change Agent Team's Bright Ideas section.

## Assistive technology

### Further information

Assistive technology is the name given to aids, adaptations, equipment and telecommunications within the home which assist disabled and older people with daily living tasks and help them maintain independence and quality of life. The term covers a wide range of technologies and products, from simple bath seats and stair rails to 'lifeline alarms', safety devices such as gas shut-off controls, and monitoring systems that alert a control centre if someone has or has not performed a certain action. Many innovations have been designed to protect and monitor older people with dementia who live alone or are left alone for periods, and these can play a valuable role in maintaining people at home, so long as they are not used as a substitute for the provision of personal contact, support and care.

For two years from April 2006 the Department of Health will be providing a Preventative Technology Grant to provide investment in developing telecare services within social care and support systems (DH, 2005b)-(35). Liam Byrne, Under Secretary of State for Care Services, explained the government's support for such services in July 2005: 'Telecare offers choice and flexibility of service provision, from familiar community alarm services that provide an emergency response and sensors that monitor and support daily living, through to more sophisticated solutions capable of monitoring vital signs and enabling individuals with long-term health conditions to remain at home.'

### Key research finding

Assistive technology needs to take account of the environment and be in line with service user preferences.

### Further information

For more about assistive technology, see the Foundation for Assistive Technology website, which contains an online database of over 500 assistive technology research projects, and an annual report, RAPID.

For more about telecare, see the Telecare LIN.

## Financial entitlements

An essential part of meeting needs is ensuring that older people with mental health needs, and their carers, have sufficient financial resources and are receiving all the financial help to which they are entitled. A full welfare benefits check should be an integral part of any assessment, and many older people with mental health needs will benefit from help with applications and form filling, for instance for Disabled Living Allowance (Attendance Allowance). A number of voluntary organisations such as Age Concern provide this service, but the experience of completing the forms with an older person can be helpful for a professional assessor in opening up areas of discussion about how the person is managing.

Charging for community care services provided or arranged by social services is usual but can be extremely contentious, particularly where the needs being met are the result of mental ill health or where services are provided jointly with health organisations. NHS services are free to the service user but social services are means tested. The NHS is responsible for funding continuing healthcare, but in practice there have been problems with the criteria for eligibility, and the distinction between NHS and social services' responsibilities is not always clear. The Department of Health is currently reviewing continuing healthcare guidance with a view to producing a national framework. Meanwhile practitioners will need to ensure that they fully understand the operation of their strategic health authority's criteria for continuing healthcare and the social services departments' policies relating to charging.

Direct payments can be provided by social services departments to people with social care needs so that they can arrange and pay for their care directly rather than have it provided for them. The take-up of direct payments has to date been mainly by younger adults with physical disabilities but the Department of Health is anxious to see the scope of schemes extended (DH, 2005c)-(36), and for there to be increased take-up by older people. Direct payment schemes should include support mechanisms to enable older people with mental health needs, and their families, to take advantage of direct payments if they have capacity and wish to do so. The social care Green Paper Independence, well-being and choice also includes a proposal for individual budgets as one idea for extending choice and control for people with social care needs.

## Risk taking

### Key research findings

The chance to live independently and manage their own lives should be as much a possibility for older people with mental health needs as for anyone else, and professionals and families alike need to consider how to make this achievable.

'Risk taking is part of a normal life, but too often for older people the presence of an element of risk dictates care solutions, such as admission to residential care, that might not accord with the older person's own wishes. Assessing risk, particularly where there may be concerns about an individual's capacity to make informed judgements, is an essential part of assessment and care management. See also the sections on 'Mental capacity' and 'Assessing risk' in Section 3.

- People with dementia, and their families, view risk differently from professionals.
- In-depth knowledge of a person's background helps professionals put the risk in context.
- It is important to establish trust between professionals, older people and their families.

## Continued contact

### Key research finding

Research into which models of care management work best for older people with mental health needs emphasises the importance of continued contact.

Review and monitoring of the effectiveness of services provided is an essential aspect of working with older people. Situations can change dramatically in a short time, or slowly over time. In addition, older people with mental health needs are likely to have long-term or degenerative conditions, for which the normal service model of assessment, provision of service and withdrawal until review is not appropriate.

Practitioners working in systems that do not allow them to remain involved with people they have assessed (for instance intake and assessment units or hospital discharge teams) should ensure that a care coordinator is nominated as part of the person's care plan, with responsibility for ongoing support and monitoring rather than just periodic reviews.

Continuity of care arrangements and personnel is essential for older people with mental health needs, and particularly for those with memory loss or dementia. The importance of taking time to build up trust has already been emphasised in the section on assessing needs. This applies to service providers too. Care agencies need to ensure that staff are given time to build up a relationship with the older person and that staff changes are kept to a minimum. This is one requirement with which specialist services with a limited scale and focus can more easily comply, but, if general services are being used, assessors can ensure that such conditions are specified in the contract and/or care plan.

Finally, it may be uncomfortable to acknowledge that plans go wrong, but it is important for all those involved in an assessment to know what is happening and have an agreed plan of action for changes in circumstances. Evaluation of the arrangements made, contingency plans for possible eventualities, and plans for unforeseen circumstances all need to be agreed and recorded. Professional opinions and decisions and the reasons for them need to be open and understandable.

## Case study 1

Desmond Peters (age 70) had become very worried about his wife, Sylvia (age 68), because of her increasing memory problems over the past year. She had had hypertension for many years and was on medication. Their GP told Mr Peters that his wife appeared to be in the early stages of dementia, probably vascular dementia. She then suggested that he 'phone social services to see what they could do to help.

The duty officer at the team for older people asked Mr Peters whether he had to help his wife, and Mr Peters admitted that she could still do most things for herself. He asked for information about dementia but the duty officer seemed not to know a great deal more than he did. The duty officer agreed to put the couple on the waiting list for assessment within the next eight weeks, but said that it did not sound as if they would be eligible for help from social services.

### First visit

The first visit by a social worker was difficult because Mr Peters was very anxious, and Mrs Peters still did not know her diagnosis. Therefore, and without the social worker's knowledge, Mr Peters had arranged to meet the social worker while his wife was out.

The social worker realised that at this stage Mr and Mrs Peters did not need the practical home care, home help and meals services offered by the department. However, she was aware of the high support needs of people in the early stages of dementia, and of the needs of their carers, and felt there was still a role for her in supporting the couple. This support included spending a long time with Mr Peters, attempting to answer some of his questions about dementia. She had to strike a difficult balance, describing some of the ways in which dementia can affect people, while stressing that the illness takes a different course with each individual. She 'recognised that Mr Peter might find too much verbal information all at once overwhelming, and asked if he would like some written information. But Mr Peters said he would rather talk it through.

In addition, the social worker talked with Mr Peters about whether Mrs Peters would benefit from knowing what was wrong with her. Mr Peters felt very strongly that it would only upset her, although he did acknowledge that she



sometimes seemed distressed about her memory lapses and said he would think again about this. The social worker stressed that the GP should also have a role in helping Mr Peters talk to his wife about her condition.

The social worker's approach to this issue was based partly on the view that Mrs Peters had a right to know her own diagnosis, partly on the knowledge that it would be easier to assist the couple if they were both able to participate in discussions, and partly on the view that the couple would benefit from being able to discuss the future together in an open way. However, she was aware that Mrs Peters might need support from someone other than her husband in dealing with the knowledge of her diagnosis, and began to think about who might provide this.

The social worker was able to advise Mr Peters about other services in the area that could provide support. In this case, these included the local branch of the Alzheimer's Society. Mr Peters, however, thought that the Alzheimer's Society was probably for people with a much more severe problem and that his wife might find it alarming to be with them.

The social worker arranged to visit again in two weeks' time, and Mr Peters said he would make sure Sylvia was in so they could meet. He agreed that the social worker could speak to their GP about talking to Sylvia about her diagnosis, and about how this might be handled.

### Action between visits

Between the two visits the social worker spoke to the GP on the 'phone. The GP offered to speak to the couple together about the diagnosis and to refer Mrs Peters to the community psychiatric nurses as they had more expertise in supporting people with dementia. The social worker asked the GP to 'phone Mr Peters and to discuss with him whether he wanted to take up these options.

Meanwhile, the social worker discovered that the Alzheimer's Society had just started a day care service aimed specifically at people in the early stages of dementia, meeting one day each week. The service focused on helping people come to terms with their diagnosis, providing them with an opportunity to discuss any fears and questions with each other. The social worker felt this service might be ideal for Mrs Peters.

### Second visit

On the second visit, Mrs Peters had been told by her husband that the social worker was coming to see her because she had been having difficulties with her memory. This had led to an argument between them, and when the social worker arrived she found Mrs Peters in a defensive and angry mood. Mrs Peters demanded to know what they had been doing, meeting behind her back, and

the social worker spent much of the visit trying to establish some trust between them.

She asked Mr Peters if he would mind leaving the room while she spoke with his wife, which he did rather reluctantly. This proved a useful strategy, however, as during her husband's absence Mrs Peters acknowledged that her husband worried about her because he cared about her, even if she could not see what he was fussing about.

After 20 minutes or so Mr Peters came back into the room; by this time Mrs Peters was reminiscing quite fondly about the early days of their marriage, and greeted him pleasantly. She remained unable or unwilling to acknowledge any memory problems to the social worker, however, so the scope for further discussion was limited.

## Outcomes

It had become apparent to the social worker that the person expressing the most distress to outsiders was Mr Peters, who needed information about dementia, information about support services, and most of all someone to guide him through the impact of living with a person with dementia. At this stage it was crucial that he receive support in these areas, and after discussion with him the social worker referred him to the Admiral Nursing Service.

The issue of Mrs Peters' knowledge of her diagnosis was more complicated. If she was told, this would need to be done sensitively and with follow-up support. Mr Peters eventually decided to take up the GP's offer to talk to him and his wife together, and also took up the offer of referral to the community psychiatric nurses, who worked with the couple over the following months to help them come to terms with the situation together. In the event, Mrs Peters coped well with the news of her diagnosis, and seemed less agitated about her difficulties if she was reminded that it was not her fault but because of an illness.

## Key messages

The social worker effectively had two clients, one of whom was much more able to express his needs. Although Mrs Peters did not acknowledge any difficulties initially, and may indeed have been less distressed than her husband, the social worker knew from Mr Peters that she did sometimes show distress when she forgot appointments for example. The social worker also felt that Mrs Peters had a right to know what was causing her memory problems, even if she might have difficulty retaining that information. At the same time, the social worker was aware of her own lack of expertise in this area and of the need to ensure that the issue was broached sensitively and that Mr Peters was not just left to 'pick up the pieces' afterwards. The GP also lacked confidence in this area and needed support from the community psychiatric nurses in dealing with the issue.

Simply providing Mr Peters with a list of services would not necessarily have helped him. The social worker thought carefully about what might help and why. The Alzheimer's Society seemed an obvious choice, especially when she found out about the new service, but Mr Peters was fearful of the label 'Alzheimer's'. His meetings with the Admiral nurse helped him come to terms with his wife's illness and to overcome his resistance to referral to the Alzheimer's Society for his wife.

This case demonstrates the difficulty of keeping the focus on the person with dementia, rather than listening solely to the views and preferences of the carer, important as these are. Even if Mr Peters had remained implacably opposed to referral to the Alzheimer's Society, it would have been important for the social worker to work separately with Mrs Peters and to ensure her needs were met. In this case, long-term support for the couple was provided by the Admiral nurse and the community psychiatric nurse, who focused on Mr and Mrs Peters respectively but also liaised effectively with each other.

Where people are not experiencing much difficulty with daily living tasks, and where family relationships are fairly harmonious, it is often felt that there is no role for social workers in a busy community team. In this case, the social worker was put under pressure to 'close the case' after the two visits described above. The work done during her brief involvement, however, meant that the couple were referred to other agencies who could provide support. The social worker also provided Mr Peters with information about the care services that social services could organise if they became necessary, and his good experience of her work meant he felt comfortable about approaching the department again when Mrs Peters began to need much more assistance.

## Case study 2

Mr Wilson (age 81) was referred to the hospital social work team for older people following his admission to the acute psychiatric ward for older people, under section 2 of the Mental Health Act 1983 (an approved social worker from the adult mental health team undertook the assessment). The admission followed a deterioration in Mr Wilson's mental health and an incident in which he apparently threatened his home help with a knife. Mr Wilson had been diagnosed three years previously with Alzheimer's and at that time the community-based social work team had arranged home help twice each week and Meals on Wheels. These services had remained in place but had not been reviewed.

The medical team all felt that Mr Wilson needed residential or nursing care. He was verbally abusive to them and would not allow them to assist him with personal care. Mr Wilson's son Ian (52) and daughter Sheila (47) both wanted him to return home, and Mr Wilson himself repeatedly tried to leave the ward

and talked angrily of how 'they' were keeping him a prisoner. He also said he wanted to go home, although it was not always clear what he meant by this.

Meanwhile, Mr Wilson's neighbour, who had tolerated him before he became ill but described him as having always been an eccentric, wrote to the Director of Social Services complaining about what he saw as Mr Wilson's neglect by social services and stating that Mr Wilson should not be 'allowed' to live by himself.

## Assessment

The social worker conducted a careful assessment of Mr Wilson's needs, speaking to all the agencies involved and the family, and to Mr Wilson himself on several occasions. He felt that Mr Wilson could be supported at home if the care plan was redesigned to meet his increased needs and if there was better communication between all involved. The social worker advocated for Mr Wilson's right at least to attempt living in his own home before other alternatives were considered, and succeeded in persuading the ward team to work towards discharging Mr Wilson on two weeks' trial home leave. By this stage his behaviour on the ward had to some extent settled.

Mr Wilson was discharged home following an assessment in his own home at which the occupational therapist from the ward and the social worker were present. This confirmed that he was unable to cook or prepare snacks, and needed to be reminded to drink. The care package arranged included home care three times each day and weekly visits by the community psychiatric nurse to monitor his mental health. Meals on Wheels were cancelled as Mr Wilson had not been eating them for some time. Mr Wilson's son had Enduring Power of Attorney and continued to look after his finances.

During the first week the care package seemed to work well. The home care team had initially been reluctant to work with Mr Wilson following the incident with the knife, but it had been noted on the ward that he responded better to female carers and this appeared to help. He continued to resist personal care assistance but allowed the carers to prepare food for him, prompt him with medication, and undertake a limited amount of cleaning.

## Adjusting care

However, during the second week the carers frequently arrived to find Mr Wilson had gone out. He had always enjoyed walking and seemed to have reverted to his previous habit of going for long walks around the area several times a day, from which he had so far always returned safely. When the social worker came to visit Mr Wilson after this was reported to him by the home care team, a neighbour accosted him angrily, threatening to complain to the papers about Mr Wilson's treatment.

Meanwhile, Mr Wilson's family continued to want to support him at home and to play a part in his care. The social worker agreed a strategy with them to reduce Mr Wilson's level of risk, including obtaining an ID bracelet and making sure one of them visited him in the later part of each evening to check he was home and to orientate him. The social worker and Mr Wilson's son also spoke to the neighbour and kept him informed about the care package provided, which seemed to reduce some of his anger.

It became clear that Mr Wilson's daily walks meant he would not always be in when the carers came round, thus jeopardising their ability to provide the care he needed. The social worker and home care team manager agreed they would have to monitor this situation and that it might result in a breakdown of Mr Wilson's mental and physical health. However, despite these considerations and the potential risks involved, it was felt that walking was an important activity for Mr Wilson.

A review meeting between all involved at the end of the two-week trial led to an agreement to continue to support Mr Wilson at home. It was recognised that Mr Wilson's son and daughter were crucial to maintaining him at home, especially given his patchy receipt of the home care service, and they were both referred for Admiral nurse support. It was also agreed that regular review and communication would be essential.

Over the next year Mr Wilson continued to live at home, supported by this mixture of formal and informal care. The neighbour remained unhappy about the situation but the social worker continued to advocate for Mr Wilson's rights. As Mr Wilson became less orientated, however, he had more difficulty finding his way home and on one occasion was found by police in a very confused state next to a busy roundabout. He also became less aware of where he was. When a respite stay was tried he accepted it and made no attempts to leave. Eventually he moved permanently into the nursing home where he had had the respite stay. His family were able to come to terms with this, knowing they had done as much as possible to maintain him at home.

### Key messages

The initial care package was completely inadequate to meet Mr Wilson's needs and needed to be redesigned. It may have contributed to his mental deterioration and admission to hospital.

The social worker was initially the only professional who supported Mr Wilson's wish to return home, and had to work hard to persuade the rest of the ward team. He avoided being rushed into a decision and took time to assess Mr Wilson's needs and discuss care options with his family. The use of a two-week trial period was an essential part of this strategy. It provided an opportunity both to assess Mr Wilson in his own home and to try out a care package. Constant communication during this period was vital to ensure that all elements were

working together and to establish trust. The meeting towards the end of the two weeks was also an important forum for outlining difficulties and reaching agreements about the way forward.

Mr Wilson was not able to discuss his wishes for the future, but he communicated his needs and preferences very clearly in a number of ways, for instance in his reactions to the hospital ward and the home carers. Similarly, Mr Wilson's activity of walking could have been stereotyped as 'wandering' by a less skilled social worker, but the social worker talked to Mr Wilson's family and found that it was an habitual behaviour that he seemed to enjoy. But the social worker was not blind to the risks involved and took a number of practical steps to minimise them. A more flexible home care service would have helped reduce some of the risks, for instance if carers were able to return at intervals to fit around Mr Wilson's unpredictable absences. This was not available, however.

Over the months the situation was kept under very close review, involving regular, sometimes daily communication between the agencies and family members involved. As Mr Wilson's needs changed, the care plan was amended accordingly.

The support provided to Mr Wilson's son and daughter was essential. They both benefited from talking to the Admiral nurse about their father's condition and from being taught strategies for how to respond to his behaviour. They also benefited from feeling part of a team of people working together to support their father.

The neighbour remained sceptical about Mr Wilson's continued residence at home. The social worker tried to keep the neighbour informed without breaking confidentiality but did not give in to pressure. Fortunately the social worker's manager supported his handling of the case when the neighbour complained to the director.

## Section 5: Carers

Many older people with mental health needs receive help from a family member or friend. It is estimated that three quarters of older people with moderate to severe dementia living in the community have a family carer. Looking after another person affects people's lives in many and various ways. Support to carers needs to reflect individual differences.

### Key research findings

- For a more detailed account, see Research Summary 5.
- The impact of caring may have a detrimental effect on the carer's life in many different ways.
- Carers at particular risk are:
  - > spouse carers
  - > live-in carers
  - > those caring for someone with a mental health problem
  - > those caring for someone whose behaviour is changing
  - > those caring for someone who cannot be left alone
  - > those who have a poor relationship with the cared-for person
  - > those who do not have someone in whom to confide.
- Many carers report difficulties in having their needs met.
- Practical help with day-to-day situations makes a positive difference to carers' lives.
- Individuals respond to caring in different ways, so help needs to vary accordingly.
- A single service is unlikely to meet carers' ongoing needs fully; diverse preferences require a wide range of services.
- Carers appreciate assessments that result in:
  - > access to information
  - > access to a new or additional service
  - > the opportunity to discuss their circumstances in an objective way.
- Carers feel it is important to:
  - > be included in decision making
  - > have their expertise valued
  - > know whom to contact if needed
  - > have a service that is responsive to their needs.
- Remember that not all carers identify themselves as such, and may not realise that anyone is interested in them or that there are services intended for them. Be proactive in seeking out carers and informing them what help is available.
- Recognise that carers identify themselves as such, and may not realise that anyone is interested in them or that there are services intended for them. Be proactive in seeking out carers and informing them what help is available.

## What you can do

- Recognise that carers may have difficulty recognising or pinpointing what is wrong with their relative, particularly if the onset of the problem has been gradual. Make sure they understand what is wrong with the person they are caring for: check that they have understood the diagnosis and its implications.
- Put carers in touch with any specialist organisations, for instance the Alzheimer's Society, which may be able help them with support, information and advice.
- Make sure you are well informed about what is available for carers in your area, and able to give them information about any local carers' services that may be relevant.
- Keep copies of a range of relevant information leaflets on specific problems that you can give out, for instance the Alzheimer's Society advice sheet on coping with walking about or 'wandering' or the Institute of Alcohol Studies leaflet about alcohol and older people.
- Help carers to focus on the person's strengths and abilities, and to maintain the skills that remain.
- Recognise the carer's unique relationship with the older person. With the older person's agreement, use carers as a source of information about the older person, for instance about their likes and wishes, or what they were like when younger.
- Unless the older person does not wish them to be, keep carers informed and involved at all times. Some carers are reluctant to accept help because they fear that they will be excluded and that services will 'take over'.
- If you feel that a carer's involvement is not helping the older person, be honest, but be sensitive about how you address this. Be clear that your priority is the older person, but remember that the carer may have been struggling alone with this situation long before you became involved. Make sure you:
  - Always offer the carer a separate assessment of their needs. Even if they do not take up the offer, remember they are likely to have their own needs and take these into account as far as possible;
  - Encourage carers to think about their own needs, and find ways to help them to maintain their own quality of life. Short breaks or day care for the older person are an obvious way of helping carers have some time for themselves. Encourage them to use these services;
  - Make sure that the services on offer to support carers are appropriate for the person they are caring for. For instance, short stays with strangers in an unfamiliar environment are likely to be very disorienting and frightening for an older person with dementia. A preferable option might be respite care in the person's own home.



- Carers of older people from black and minority ethnic communities are unlikely to be happy with services that are not sensitive to cultural, religious and dietary needs or that cannot communicate with the older person in their own first language. Make sure this is acknowledged and addressed by the services you arrange. (See also 'Further information' below, and Section 6 on the needs of older people from black and minority ethnic communities.)

### Further information

For more information on policy and legislation relating to carers, see Section 8.

Organisations working with carers include:

- Carers UK
- The Princess Royal Trust for Carers
- Alzheimer's Society.

### Special problems

Leeds City Council Social Services Department have produced a video portraying the types of community-based and statutory services that can be accessed by carers and service users from black and minority ethnic communities.

Carers are often in an invidious position: families are assumed to be the people in the best position to protect an older person's interests, but they do not often have a clear legal mandate to act on behalf of the older person. At present, Enduring Power of Attorney only covers financial and property matters, not decisions about health, care and wellbeing, although this will change with the implementation of the Mental Capacity Act 2005. Some carers are powerful advocates for their relative's right to live independently in their own homes; others do not want to see their relative exposed to risk and feel they should persuade the older person to accept the 'safe' option of residential care. Relationships between older people and their carers are not always positive, and occasionally there are conflicts of interest between the carer's wishes and the older person's best interests. Some older people are abused by their carers.

Relationships between carers and professionals are not always straightforward, either. Sometimes professionals take a negative view of carers, seeing them as putting their own interests before that of their relatives. At other times professionals may get drawn into acting on behalf of the carers rather than the older person, ignoring the older person and communicating directly with carers. This is more likely to happen where there are communication difficulties with the older person.

Practitioners' responsibilities will be primarily to the older person with mental health needs, but it is in the interests of the older person that the enormous contribution made by carers, often at considerable cost to themselves, should be acknowledged and supported.

There may be particular stresses associated with caring for someone with mental health needs, for example:

- Mental illness and emotional problems can alter behaviour in ways that relatives find distressing. For instance, an older person with dementia may not recognise family members, or the long-term effects of some medication may lead to a loss of sexual inhibitions. The older person may no longer seem to be the same person – no longer the person the relative had known and loved.
- Mental illness and emotional problems can alter relationships. The hopelessness, despair and apathy of a severely depressed person can be very hard to live with, for example. And forgetting that you are married or have a daughter can make it hard to maintain meaningful family relationships.
- The stigma of mental illness remains powerful in our society. It is not unusual for carers to feel ashamed or embarrassed that their relative has mental health problems, or guilty that this is the way they feel.
- The carer's own social life may be affected. Social occasions may become difficult or embarrassing, and so social gatherings or going out may be avoided.
- Changes in behaviour may mean that the older person cannot be left on their own safely, so that even a quick dash to the shops becomes fraught with anxiety.
- Day-to-day frustrations, such as endless repetition, being continually followed around, or being unable to encourage the older person to complete the simplest task, may have a serious cumulative effect on the carer's ability to cope.

### Case study

An older man with dementia being cared for at home by his wife would regularly climb out of the windows or call out to passers by that his wife was keeping him prisoner in the house. This caused his wife extreme distress. Not only did she have to deal with the impact of her husband's lack of trust and the practicalities of making sure he came to no harm, she was also afraid that her neighbours might think she was mistreating him.

## Section 6: Black and minority ethnic communities

The proportion of people aged 65 and over among Britain's minority ethnic population is growing, and as a result their specific needs are increasingly being identified. Minority ethnic communities may have higher rates of poor health than the host community, and poorer people and those less well placed to access health and social care will be more vulnerable.

### Key research findings

For a more detailed account, see Research summary 6.

- The mental health needs of older people from black and minority ethnic communities have been particularly neglected.
- There are small but significant differences in the incidence of particular health problems among different ethnic groups.
- There are lower levels of awareness of problems such as depression and dementia within black and minority ethnic communities.
- Older people and their families from black and minority ethnic communities have problems accessing help from services.
- There is insufficient evidence to date on whether integrated or separate services are more effective, but there is a need for more culturally appropriate and sensitive services.

### What you can do

- Find out the older person's preferred language, and arrange for a professional interpreter to be present. Families and friends are essential sources of information about the older person, and will have many valuable insights, but they should not be put in the position of interpreting for the older person's assessment.
- Make sure that the older person and their family has all the information they need in an appropriate format. If printed material in the right language is not available, or the older person would have difficulty reading it, consider making an audio tape of essential information in the person's own language.
- Find out as much as you can about the culture and religious beliefs of the older person you are assessing. Make links with people from their local community who can help you by explaining things and who can tell you about local sources of support within the community. Remember to maintain confidentiality.
- Get information about your services and how to access help out into the local community through the services and points of contact that are

trusted and used by people from minority ethnic communities, for instance GPs and places of worship.

- In your assessment, check that the older person's health needs have been fully assessed, and that they and their family have understood the diagnosis and any information they have been given. Don't assume that the older person and their family understand what you mean when you talk about services that may be offered, for instance home care services.
- If there is a charge for a service, explain why that is, and how it will be calculated.
- Don't assume that mainstream services will not be acceptable to older people from minority ethnic communities. Offer them, and discuss what might need to be done to ensure they are culturally acceptable.
- Talk to service providers about what they can do to make their services more culturally sensitive and acceptable. Make sure that specific requirements are detailed in the care plan and any contract, so that they can be monitored and reviewed.

### Ideas from practice

- Warwick District Council produced a video (Service information video for Asian elders, 2002)-(37) for Asian elders about local services, in Punjabi with English subtitles. It explained what services did, where they were based and how to access them.
- The manager of a Midlands residential care home with a single Asian resident was proud of the efforts they had made to meet her needs, arranging for meals to be brought in for her from the local Asian day centre, and for festivals to be celebrated. As part of a plan to attract more Asian residents, the home recruited a number of Punjabi-speaking staff, and arranged the rotas so that there was always at least one Punjabi speaker on duty. They were astonished to see the transformation in their existing resident, who had been regarded as successfully settled in, but who was now talking and laughing with staff, joining in activities and demonstrating a lively personality that had had no opportunity for expression before.

### Further information

The Race Relations (Amendment) Act 2000 places a general duty on all public authorities to promote 'race' equality and to make this aim explicit in their policies, practices and procedures. For more information on the legal and policy context, see Section 8.

The Department of Health has produced practice guidance for councils with social services' responsibilities to help them develop services for minority ethnic older people. (DH, 2002)-(38)

A report by The Royal College of Psychiatrists (Royal College of Psychiatrists, 2001)

(39) suggests that a key method of improving access to services for minority ethnic elders is through their GPs, and recommends joint meetings between GPs and voluntary groups to achieve this.

Age Concern England hosts a Black and Minority Ethnic Elders Forum promoting the interests of black and minority ethnic elders, and produces a regular newsletter.

## Needs and barriers

Different communities may have specific difficulties. For instance, higher rates of high blood pressure and diabetes among African, Caribbean and Asian people increase the risk of vascular dementia in later life, while some ethnic groups appear particularly prone to depression in older age.

A recent study of the Asian community in north west Kent by Alzheimer's and Dementia Support Services and the Mental Health Foundation (Seabrooke and Milne, 2004)-(40) researched the service-related needs of Asian older people with dementia, and the needs of their carers, and the understanding and awareness of dementia within the community.

Older people with mental health needs from black and minority ethnic communities face a number of potential barriers to effective assessment of their needs:

- There may be little awareness of older people's mental health issues within black and minority ethnic communities, for instance, Asian languages do not have an equivalent word for dementia (Seabrooke and Milne, 2004)-(41). Symptoms may therefore be unrecognised or misunderstood.
- In some communities a lack of understanding and the stigma attached to mental illness may prevent families from seeking help. This may particularly be the case where the community culture places great emphasis on self-reliance.
- Language barriers may prevent people from receiving information about what is available and how to access help. Even where printed information in minority languages is available, this may not help those older people who have a limited level of literacy in their own language.
- Unfamiliarity with social care services, which may not exist in minority cultures, may prevent people from requesting services or lead to misunderstandings about their role. Medical services, which are better understood, and free from stigma, are often considered more acceptable than social care services. Low uptake of social care services by older

people from minority ethnic communities may lead to demand being overlooked or underestimated by commissioners.

- The lack of a professional interpreting service may make it difficult for assessors who do not speak the older person's preferred language to conduct an effective assessment. The use of friends or family members as interpreters may compromise confidentiality or influence the assessment. Older people affected by dementia, who were once able to speak English as a second language, may lose the skill as their memory deteriorates. Even with good language skills, cultural differences may result in meaning and nuance being lost.
- Standard diagnostic tests for dementia, or depression, may not be culturally appropriate and may lead to inaccurate diagnosis.
- Assessors may not be able to offer a sensitive and effective assessment because they are not sufficiently familiar with the lifestyles, health, religious and cultural needs of older people and their carers from minority ethnic communities.
- No suitable services may be available where the older person's language is spoken and their cultural, religious and dietary needs met.
- Conversely, assessors may make assumptions about the lack of acceptability of mainstream services to older people and their families, and not offer them.

### **Case study**

Mrs K, an Armenian who had met her husband in Paris, spoke fluent French and English until the last years of her life, when advancing dementia and progressive memory loss took away her acquired languages and left her unable to converse with her husband and children. This was devastating for her and her family.

An inspection of community care services for black and minority ethnic older people carried out by the Social Services Inspectorate in 1998 (Department of Health Social Services Inspectorate, 1998)-(42) found that although procedures existed for involving black elders in their assessments and developing their care plans, this practice was dependent on the knowledge and skill of individual workers. Without appropriate training, knowledge and skills, some white staff did not have the confidence to make judgements about the contribution of religion and culture in the assessment of older people. In some cases staff still took the view that black and minority ethnic families 'look after their own', and there was a danger that white ethnocentric values resulted in inappropriate assessments.

## Section 7: Abuse

The Department of Health guidance on policies to protect vulnerable adults, No Secrets (Department of Health and Home Office, 2000)-(43), defines a vulnerable adult as a person over the age of 18 who 'is or may be in need of community care services by reason of mental or other disability, age or illness; and who is or may be unable to take care of him or herself, or unable to protect him or herself against significant harm or exploitation'. In 2004 the Secretary of State for Health announced the government's intention of extending this definition by removing the criterion of need for community care services.

Older people with mental health needs are some of the most vulnerable members of society, and there is increasing recognition that they may be subject to abuse or neglect by their families or paid carers or in hospitals and care homes. Much of this abuse goes unreported.

### Key research findings

For a more detailed account, see Research Summary 7.

- Older people with mental health needs are at greater risk of abuse than other groups of older people.
- The risk of abuse is greater in the following circumstances:
  - > when older people have cognitive impairment
  - > when older people are depressed
  - > when a person with caring responsibilities is drinking heavily
  - > where household relationships have always been poor
  - > when the older person is physically or verbally abusive
  - > when the older person has behaviour problems.
- Training can improve staff recognition of abuse.
- Little information is available on what help people who have been abused would value. Individuals need to be asked.

### What you can do

Abuse is defined as 'a single or repeated act, or lack of appropriate action occurring within any relationship where there is an expectation of trust which causes harm or distress to the older person' (Action on Elder Abuse, 1995). It can take many forms: physical, sexual, psychological, financial and discriminatory abuse, and neglect and acts of omission. See 'Further information' for a full list of types of abuse and their indicators.

The following advice on what you should do if you suspect abuse is taken from Kent and Medway's multi-agency adult protection policy.

In all cases priority must be given to ensuring the safety and care of the vulnerable adult(s).

Remember: Every staff member has a professional and moral duty to report any witnessed or suspected abuse to their line manager. This information should be referred to Social Services and every reported case must be assessed as a matter of urgency to determine an appropriate course of action. This assessment will take place, either during telephoned consultations with other professionals or during a formal planning meeting.

It is the function of the planning process to consider the issues as widely as possible and to plan any agreed intervention. Factors that will be considered include:

- The possibility that the alleged abuse is a criminal offence
- The impact of the alleged abuse on the vulnerable person
- The need for any emergency or other protective action
- The capacity of the vulnerable adult for self-determination
- The vulnerability of the individual
- The extent of the abuse to this or other vulnerable adults
- The length of time it has been occurring
- The risk of repeated or escalating acts involving this or other vulnerable adults
- The reliability/credibility of the information received
- The need for investigative action
- The terms of reference for the investigation
- Who will be involved in the investigation.

## Disclosures of abuse

It is possible that an older person with mental health needs may directly disclose to you that they have been abused. Even if the older person is considered to be confused, such disclosures should be taken seriously. Listen carefully to what you are being told, and even if it sounds fanciful do not dismiss it. Although some older people with mental health needs may experience memory loss, cognitive impairment or delusional thoughts, it is also possible that they have been abused in the way they describe, or that something else distressing has occurred. Be reassuring, try to understand what may have happened, but do not interrogate the person or suggest you do not believe them.

## Case study

A manager investigating possible abuse in a care home was trying to interview Mrs S, a resident who was said to be confused. In the course of the interview Mrs S asked whether her mother knew she was in the care home. The manager gently asked Mrs S the year she was born, how old her mother had been at the



time, reminded her what year it was now and helped Mrs S to work out that her mother could no longer be alive. Mrs S then reflected, 'I thought that must be the case. If my mother had known I was here, I know she would have written to me.' Although unable to provide confirmation of abuse, there could be no mistaking Mrs S's sense of abandonment and unhappiness.

Kent and Medway's multi-agency adult protection policy offers the following suggestions in the event that someone discloses abuse to a practitioner:

#### Do ...

- Stay calm and try not to show shock or disbelief.
- Listen carefully to what they are saying.
- Be sympathetic ('I am sorry that this has happened to you').
- Be aware of the possibility that medical evidence might be needed.
- Tell the person that:
  - > they did the right thing to tell you
  - > you are treating the information seriously
  - > it was not their fault
  - > you are going to inform the appropriate person
  - > you/the service will take steps to protect and support them.
- Report to your line manager, senior manager, or to social services or the police.
- At the first opportunity make a note of the disclosure and date and sign your record. You should aim to:
  - > note what the people actually said, using their own words and phrases
  - > describe the circumstances in which the disclosure came about
  - > note the setting and anyone else who was there at the time
  - > separate factual information from your own opinions.
- Use a pen or biro with black ink, so that the report can be photocopied, and be aware that your report may be required later as part of a legal action or disciplinary procedure.

#### Do not ...

- Press the person for more details, this will be done at a later date.
- Stop someone who is freely recalling significant events, as they may not tell you again.
- Promise to keep secrets: you cannot keep this kind of information confidential.
- Make promises you cannot keep.
- Contact the alleged abuser.
- Be judgemental.
- Pass on the information to anyone other than those with a legitimate 'need to know', such as your line manager or other appropriate person.

## Further information

See Types and indicators of abuse for a list based on work by the Multi-agency adult protection policy for Kent and Medway.

At present there is no adult protection legislation in England and Wales, as there is for child protection, although the Scottish Executive is consulting on the possibility of introducing such legislation in Scotland. For more information on the legal and policy context, see Section 8.

The Department of Health, in conjunction with the Home Office, has issued guidance to local authority social services departments on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse (Department of Health and Home Office, 2000)-(44).

## Institutional abuse

Sometimes older people are abused by paid carers, and all practitioners in whatever setting need to be aware of this possibility. It is a practitioner's responsibility to report abuse wherever or however it occurs. The Public Interest Disclosure Act 1998 protects workers who 'blow the whistle' about wrongdoing in their organisation.

Abuse of vulnerable adults can take place in hospitals and care homes as well as in domestic settings. In September 2003 the Commission for Health Improvement published a report on Rowan Ward in Manchester, an inpatient unit for older people with mental health needs, concerning allegations of physical and emotional abuse of vulnerable older people by staff. Issues identified as contributory factors included:

- Geographical isolation of the ward
- Low staffing levels
- Lack of training
- Lack of nursing leadership
- Lack of clinical governance.

As a result of this report a much greater priority has been given to older people's mental health services within the Department of Health, and in 2004 all strategic health authorities were obliged to review older people's mental health services in their area. The Department of Health Care Services Improvement Partnership published the findings of these reviews in *Moving on: Key learning from Rowan Ward* (Health and Social Care Agent Team, 2005)-(45) in April 2005. The recommendations include involving older people and their carers in the day-to-day running of services, to combat isolation and improve service quality.

The Commission for Social Care Inspection is responsible for setting standards and inspecting care homes and care agencies, and any concerns about abuse in care homes or by social care agencies should be reported to them.

The General Social Care Council is the regulatory body for the social care workforce in England. Under the Protection of Vulnerable Adults scheme, social care staff who have abused or neglected vulnerable adults or placed them at risk of harm are prohibited from working in care positions.

### Further information

For more information on care standards and the protection of vulnerable adults, see Section 8.

For Department of Health recommendations on protecting vulnerable older people in care homes, see *Moving on: Key learning from Rowan Ward*.

The Royal College of Psychiatrists' Faculty for the Psychiatry of Old Age has also produced a guidance note for members: *The Rowan Report: Implications and advice*.

Action for Elder Abuse provides information about the abuse of older people and offers information and support.

See the websites of the Commission for Social Care Inspection and the General Social Care Council for more information and for contact details.

## Section 8: Law and policy

This section focuses on areas of law and policy that primarily affect the treatment and care of older people with a mental illness. It is particularly targeted at nonspecialist workers who want to know more about the legal framework, including the circumstances under which a person can be detained in a psychiatric setting and what the law says about helping an older person who lacks capacity to make their own decisions.

### The broader context

#### Summary

- Most relevant legislation currently targets those in greatest need, and service provision is mainly based on assessments of need.
- Current policy trends for older people focus on:
  - > age discrimination
  - > 'person-centred' care
  - > integrating services
  - > early diagnosis and treatment, and access to specialist care
  - > conditions that particularly affect older people
  - > promoting independence and a healthy and active lifestyle
  - > effective management of medicines.
- Relatively little legislation is directly concerned with older people with a mental health problem, and although there are positive moves in this area, much remains to be done.
- Relevant legislation not specifically aimed at older people with a mental health problem includes:
  - The NHS and Community Care Act 1990, which requires local authorities to help vulnerable adults and their carers remain in the community.
  - The Disabled Persons (Services, Consultation and Representation) Act 1986, which strengthens the provisions of existing legislation and requires local authorities to meet the needs of disabled people.
  - The NSF for older people 2001, which represents a major shift in recognition of the needs of older people for health and social care services and offers a framework for the delivery of care and treatment. It is based on eight standards, one of which relates to mental health.
  - The Human Rights Act 1998, which introduces a number of basic civil and human rights for all citizens, and the Freedom of Information Act 2000, which gives people a general right of access to information held by, or on behalf of, public authorities.

## Policy trends

Broadly there are two types of legal provision for social care: **permissive**, where the law states that agencies 'may' or 'could' provide support, and **obligatory**, where the law 'requires' or lays down a 'duty' for a statutory agency. The vast majority of legislation relating to older people's welfare is permissive, and access to services is largely restricted to those 'in greatest need'. Most older people who need support from the NHS or local authority, and particularly 'long-term support, have to fulfil the agency's 'eligibility criteria' before they can be allocated a service, and most agencies must first carry out an 'assessment of need' prior to allocating a service (see 'Assessments of need' section later).

Since New Labour came into power, a number of policy trends can be discerned:

- **Rooting out age discrimination:** ensuring that health and social services are provided regardless of age and on the basis of need alone.
- **'Person-centred' care:** ensuring that older people are treated on the basis of their individual needs, circumstances and priorities, and that they and their carers are fully involved in decisions about care and services.
- **Integrating services:** older people's needs often include physical, mental and social dimensions and require responses that cut across organisational and professional boundaries.
- **Early detection and treatment of health problems and timely access to specialist care:** like the rest of the population, older people benefit from preventive early detection of ill health as well as high quality specialist care.
- Addressing conditions that are particularly significant for older people, such as strokes, falls and a number of mental health problems.
- Promoting a healthy and active lifestyle and independence.
- **Ensuring effective management of medicines** so as to improve health (Baldock et al, 1999)-(46).

While much legislation is relevant to enhancing the lives and wellbeing of older people, relatively little is directly relevant to supporting protecting older people with a diagnosed mental health problem. Although there has been a positive policy shift towards the promotion of mental health and the prevention of mental ill health in later life, there is still much to do to integrate older people's services and mental health services. The government's vision for older people's mental health services is set out in *Securing better mental health for older adults* (DH, 2005)-(47).

The following legislation, while not specifically aimed at older people with a mental health problem, is nevertheless relevant.

## NHS and Community Care Act 1990

This Act introduced a broad requirement for local authorities to help vulnerable adults remain in the community, preventing or delaying admission to institutional care. The Act requires local authorities to carry out assessments of people who 'appear to be in need' of community care services and to arrange packages of care. Most social services departments operate a set of 'eligibility criteria' that define who is eligible for an assessment of need as well as support from services. The assessment process has largely been subsumed under the Single Assessment Process, which is outlined below.

## Disabled Persons (Services, Consultation and Representation) Act 1986

This Act strengthens the provisions of existing legislation (Chronically Sick and Disabled Persons Act 1970) and requires local authorities to meet the needs of disabled people. Services covered include: help in the home; recreational facilities outside the home; assistance with transport; provision of aids and adaptations; holidays; meals; and telephones. The NHS and Community Care Act 1990 (see above) reinforces this by stating that when local authorities are assessing someone's needs for community care services, and it become clear that the person is disabled, the local authority must also consider their need for the services outlined above.

## NSF for older people 2001

The National Service Framework (NSF) for Older People (DH, 2001)-(48) represents a major shift in recognising the needs of older people for health and social care services, and offers a framework of standards for the delivery of care and treatment. The NSF states that older people who have mental health problems will have access to integrated mental health services, provided by the NHS and councils to ensure effective diagnosis, treatment and support for them and their carers. The core elements of a high quality mental health service are defined as:

- Health promotion and prevention
- Early detection, intervention and comprehensive assessment
- Access to specialist services, advice and skills, treatment and rehabilitation
- Integrated care management, including the provision of a community psychiatric nurse for older people with severe and enduring mental illness
- The organisation of specialist services and teams with emphasis on provision at home and support for carers
- Continuous development from sharing good practice and learning from experience

- Organisation of specialist services and teams with emphasis on provision at home.

### Other relevant legislation

The **Human Rights Act 1998** introduces a number of basic civil and human rights for all citizens. Article 5, 'The right to liberty and security of person', is the article that may be most likely to apply to the detention of people with mental illness or with reduced capacity. Article 8, 'The right to respect for private and family life, home and confidentiality', is also relevant and may be used to stop the removal of a frail older person from one care home to another due to closure. (It should be noted that this statutory responsibility is not shared by the independent sector, which provides most of this type of care.) The **Freedom of Information Act 2000** gives people a general right of access to information held by, or on behalf of, public authorities, and promotes a culture of openness and accountability in public sector bodies. In January 2005 members of the public gained the right to make a request for any information held by a public authority, to which the authority must respond. The authority is obliged to release such information unless it is not in the public interest to do so, it would cost a lot of money to seek it, or doing so would damage an individual's commercial interests. The Act does not provide right of access to personal information, but this may be accessed under the **Data Protection Act 1998**, subject to certain exemptions. Service users can ask for access to their case records under this Act.

### Further information

A useful summary of the key aims and implementation of the NHS and Community Care Act 1990 can be found in Lorna Easterbrook's *Moving on from community care* (Easterbrook, 2003)-(49). For more about the Human Rights Act, see the Liberty website.

The NSF for older people is available on the Department of Health website. More about the Freedom of Information Act 2000 and the Data Protection Act 1998 can be found at the website of the Information Commissioner's Office.

Help the Aged and Age Concern both provide general information on a wide range of policies of relevance to older people.

## Assessments of need

### Summary

- The NHS Plan 2000 and the NSF for older people introduced the Single Assessment Process, which aims to ensure that older people receive appropriate, effective and timely responses to their health and social care needs, and that professional resources are used effectively, minimising

duplication. There are four types of Single Assessment Process depending on level and type of need: contact assessment, overview assessment, specialist assessment and comprehensive assessment.

- The process is viewed as part of the wider process of care management, which also includes the stages of: deciding what help should be offered and what services a person is eligible for; care planning; and reviewing the care package.
- People with severe and enduring mental health problems are subject to the Care Programme Approach, which aims to provide a framework for the delivery of effective care.
- It is expected that the Single Assessment Process plus critical aspects of the Care Programme Approach will be applied to older people with severe functional or organic mental health problems.
- Carers who provide 'intensive and substantial' levels of care have a right to an assessment of their needs by their local authority under the Carers (Recognition and Services) Act 1995 and the Carers and Disabled Children Act 2000.

## Introduction

Assessments of need for welfare services have been enshrined in 'good practice' for many years and identified as an expectation in law by:

- The NHS and Community Care Act 1990, which introduced the process of care management, incorporating assessments of need for community care services
- The NHS Plan 2000 and the NSF for older people 2001, Standard 2 of which defines the role of the Single Assessment Process in delivering person-centred care (see 'Law and policy' for more about these pieces of legislation).

## Single Assessment Process

The Single Assessment Process aims to ensure that older people receive appropriate, effective and timely responses to their health and social care needs, and that professional resources are used effectively, minimising duplication. It is a pivotal mechanism:

- For health and social services staff to use to identify individuals' needs for treatment, care and support
- As the basis for the development of a 'personal care plan' (statements of service delivery and intent) agreed with the older person and held by them.

There are four types of Single Assessment Process depending on the nature, severity and complexity of need:



- Contact assessment, including the collection of basic personal information
- Overview assessment
- Specialist assessment
- Comprehensive assessment.

The process is viewed as part of the wider process of care management, which also includes the stages of:

- Evaluating the assessment information
- Deciding what help should be offered, including eligibility decisions
- Care planning and a statement of service delivery
- Monitoring
- Reviewing.

It is also regarded as a mechanism that all statutory agencies and professionals in a single area 'sign up to', so that local care and assessment systems align with the Process.

### Care Programme Approach

People with severe and enduring mental health problems are subject to the Care Programme Approach. It was implemented at the same time as care management with the specific aim of providing a framework for the delivery of effective care of adults with mental health care problems. Its role has been reinforced by the NSF for Mental Health (DH, 1999)-(50).

Although not primarily associated with older people, the Care Programme Approach is relevant because one of the criteria for inclusion is a history of self-neglect, which is often a feature of older people with severe mental health problems. It is expected that the Single Assessment Process will work in an integrated way with the requirements of the Care Programme Approach and that the Single Assessment Process plus critical aspects of the Care Programme Approach will be applied to older people with severe functional or organic mental health problems (see 'Further information' for more on integrating the Care Programme Approach and the Single Assessment Process).

### Carers' assessments

Carers who provide 'intensive and substantial' levels of care have a right to an assessment of their needs under the Carers (Recognition and Services) Act 1995 and the Carers and Disabled Children Act 2000. The former gave a carer the right to have their needs assessed at the same time as the person they care for. The latter Act gives carers a further right to an assessment even if the cared-for person refuses to be assessed. This Act also extended local

authorities' powers to provide or arrange services that support carers in their caring role.

## Further information

Further information about the Single Assessment Process can be found on the Department of Health website.

Department of Health guidance Care management for older people with severe mental health problems clarifies the relationship between the Care Programme Approach and the Single Assessment Process.

The report Integrating older people's mental health services: Community mental health teams for older people (Lingard and Milne, 2004)-(51) contains a review of recent evidence about the extent and efficacy of implementation of the Single Assessment Process alongside the Care Programme Approach.

For clear and accessible information on carers' assessments, see the Carers UK website.

## Mental health legislation

Summary Introduction Mental Health Act 1983 Reforming the Act Further information

This sub-section focuses on mental health legislation and older people. It will identify the main provisions of the Mental Health Act 1983 and highlight a number of issues of key relevance to older people with mental health problems.

### Summary

- The **Mental Health Act 1983** is relevant to relatively few older people; it applies only to people who are suffering from a known or established 'mental disorder'.
- The Act's main function is protective.
- Its power to enforce the compulsory detention of a person with a mental disorder is one of its best-known functions.
- Compulsory admission to hospital may take place when the patient is suffering from a mental disorder **and** detention is necessary in the interests of his or her own health **or** safety **or** for the protection of others.
- Only a small number of professionals are involved in applying the Act: an approved social worker and GP and/or other doctors with special training in mental health.
- The Act provides a number of safeguards for detained patients; these do not apply to informal (voluntary) patients.
- It is doubtful whether compulsory detention under the Mental Health Act should ever be used to protect an older person who is putting themselves

at risk because of mild or moderate dementia – employing other legislation designed to protect ‘vulnerable people’ may be far more appropriate.

- Although most older patients with dementia enter psychiatric hospital on an informal basis, as a consequence of being considered ‘at risk’, they may in reality be ‘detained’.
- The **Mental Health Bill 2004** aims to make significant improvements to patient care and to enable patients to get the treatment they need more effectively.
- Its guiding principles include an emphasis on informal treatment, partnership with patients and their families and community-based care.
- Key changes the Bill proposes are:
  - > to refine, target and simplify the use of ‘compulsory powers to detain’
  - > to improve patient safeguards including for those who lack capacity
  - > patients may be subject to the use of formal powers in community settings
  - > patients and their representatives will have access to specialist independent advocacy
  - > patients with severe and enduring mental health problems will have enhanced rights to a care plan
  - > carers will have a right to be consulted about their relative’s care and treatment.

There are a number of concerns about the Bill, including the use of treatment orders in the community and insufficient resources being invested in the training and provision of independent advocates.

Older people seem likely to benefit from: being able to be treated under formal powers in their own homes; clearer targeting of compulsory treatment; specialist independent advocacy; and safeguards against the risk of informal detention – an issue particularly affecting older people with dementia. A right to a care plan and the greater inclusion of carers is also positive.

## Introduction

Broadly, there are two groups of older people to whom mental health legislation applies: those who develop dementia or depression in later life, and those with ‘enduring mental health problems’ (people with a life-long mental illness such as schizophrenia or manic depression).

There are also a significant number of older people who have alcohol problems. While ‘substance misuse’ does not in itself constitute mental disorder, an older person may be ‘vulnerable’ in ways that allow legal protection to be offered via routes other than the Mental Health Act 1983 (see ‘Law and policy’)

## The Mental Health Act 1983

The 1983 Mental Health Act is the principal Act governing the treatment of people with mental health problems in England and Wales. Its primary role is protective. While the Act outlines a range of responsibilities and duties, its power to enforce the compulsory detention of a person with a mental disorder in a psychiatric hospital is one of its best known functions.

Compulsory admission under the Act may take place when the patient is:

- Suffering from mental disorder **and**
- Detention is necessary in the interests of his or her own health **or** safety **or** for the protection of others. Only one of these latter grounds needs to be met and a person need not be behaving dangerously to be compulsorily detained (Jones, 2004)-(52).

There are three admission procedures under the Act which result in compulsory detention:

- Emergency admission for assessment for up to 72 hours (Section 4)
- Admission for assessment with or without treatment for up to 28 days, which is not renewable (Section 2)
- Admission for treatment for up to six months, renewable for a further six months, and thereafter for periods of up to 12 months at a time (Section 3).

These procedures are called 'sections' as they refer to specific sections of the Act. A patient can only be admitted under Section 3 if the necessary treatment cannot be provided without detention in hospital. Patients who are discharged from a Section 3 are automatically the subject of Section 117, which requires health and local authorities to arrange a package of 'aftercare'. The purpose of this is to enable a patient to return home and re-engage with activities of daily living. It aims to minimise the risk of re-admission. (See 'Mental Health Act (1983): Key sections and grounds for detention' for further details of these orders and specific grounds for admission.)

An additional section of the Act, Section 7 (2), deals with 'guardianship'. It provides a mechanism whereby a person over 16 can have 'their interests protected and be under some control' of the local authority or a guardian appointed by the local authority. Its purpose is to ensure that a patient receives support and community care where it cannot be provided without the use of compulsory powers. It has rarely been applied to older people and its use widely varies between authorities. Last year, it was applied in 932 cases, ranging from 63 times in Lancashire to none at all in 12 London boroughs and 11 other councils.

Only a small number of professionals are involved in applying the Act. These are primarily approved social workers, GPs and doctors approved under Section 12 of the Act – either psychiatrists or others with specific training in mental health. Each professional performs an assessment of the patient's mental health and circumstances. If any one of them considers that there is insufficient evidence to warrant compulsory admission, the person cannot be detained under the Act.

The patient's 'next of kin' can also 'apply' for their relative to be detained under the Act and has the power to formally request an assessment under the Act in certain circumstances. For more about who qualifies as next of kin and what the duties and powers of a nearest relative are, see 'Further information'.

### Patients' rights

The Act provides the following safeguards for those subject to detention:

- They have to be informed as soon as practicable after admission of the reasons for their detention and rights of appeal.
- People who have been detained for more than a few days have the right to appeal against their detention to a Mental Health Act review tribunal, an independent committee comprising medical, legal and lay people, which has the power to discharge patients in certain circumstances. Patients are entitled to free legal representation in such appeals.
- The Mental Health Act Commission is a government body established to monitor the care of people who are detained, and to ensure that their rights are upheld. The commissioners make regular visits to all hospitals, and will also respond to individual requests for visits. Most hospitals also have an independent hospital managers' committee to protect the rights of detained people (see 'Further information').

These safeguards are not available to informal patients.

### Further information

For more about who qualifies as next of kin and what their duties and powers are, see Mind's leaflet *Legal briefing: The rights and powers of the nearest relative*.

For more about the Mental Health review tribunal, see MHRT's website.

### Older people and the Mental Health Act 1983

It is important to note that the Mental Health Act 1983 is only appropriate in work with older people in limited and specific circumstances.

Dementia is one of the main causes of vulnerability and dependency in later life. Late onset dementia typically progresses slowly and can take many years to develop fully. In its early stages sufferers may be forgetful and find it difficult to manage their own affairs effectively. But many older people with mild or moderate dementia continue to live in the community with appropriate help. There is also a 'grey area' when, for example, an older person has not been diagnosed as suffering from dementia but is confused and may be placing themselves at risk by leaving the gas on unlit occasionally or losing track of time (they may of course have a physical health problem that needs investigation; See Section 2: The main problems).

However, it is questionable whether it is ever appropriate to employ the provisions of the Mental Health Act 1983 to protect older people in this situation and there is no protective legislation designed to meet their needs. They may, however, be eligible for support, care or treatment from either their local social services department or the NHS under other legislation.

As noted in the 'Mental capacity' section in Section 3, when working with an older person with a progressive mental illness such as dementia it is crucial to reassess their needs and capacity on a regular basis. Taking account of the views of the person and their family and carers about the nature and effects of future deterioration is a key part of this ongoing assessment process (see Section 3 for more about this).

Most older patients enter psychiatric hospital on an informal basis with detention being reserved for those who actively object to admission. However, as a consequence of advanced dementia, many older patients require constant supervision and may even need to be restrained from leaving hospital for their own safety. This is also the case for a significant number of older people with dementia in care homes. This status is described by the Mental Health Act Commission as 'de facto detention': the older person has no practical means of exercising his/her theoretical right to leave hospital, yet they have not been 'sectioned' under the Act and so do not have the rights of a detained patient (see above).

This issue raises a number of ethical and legal challenges that were highlighted by the 'Bournewood gap [OK?]', concerning a man with learning disabilities who was detained in a psychiatric hospital for a sustained period without being the subject of a Mental Health Act 'section'. (See also the information on mental capacity below and in Section 3.)

The draft Mental Health Bill recognises this gap in the legislation and proposes to introduce separate safeguards to ensure that people who lack capacity and who require long-term care should come under the remit of the Mental Health Act Commission. It also suggests that they (and their carers) should have the right to apply to the Mental Health Act tribunal to challenge any detention and

request a review if there are concerns about the quality or nature of care or treatment.

## Reforming the Act

The Mental Health Act 1983 is more than 20 years old. In November 1999 the government issued a White Paper, *Reforming the Mental Health Act*, which was intended to act as the basis for a new Act. In June 2002 this was superseded by a draft Mental Health Bill. A revised version of this Bill was published in September 2004 for pre-legislative scrutiny; the parliamentary committee will present its report by the end of March 2005. Following the Committee's report, the intention remains to introduce the Bill as soon as parliamentary time allows. It is unlikely to be implemented until 2007.

The Mental Health Bill 2004 aims to make significant improvements to patient safeguards, provide a legal framework that is more in line with modern patterns of care and treatment, and protect public safety by enabling patients to get the treatment they need. The fact that existing legislation does not recognise that the majority of people with mental illness are treated in the community, rather than in hospital, is also relevant.

The Bill sets out a new legal framework, including the application of compulsory powers for the care and treatment of people with mental health problems. It incorporates a number of guiding principles:

- Informal care and treatment should always be considered before recourse to compulsory powers.
- Patients should be involved as far as possible in developing and reviewing their own care and treatment plans.
- The safety of both the individual patient and the public are of key importance in determining the question of whether compulsory powers should be imposed.
- Where compulsory powers are used, care and treatment should be located in the least restrictive setting consistent with the patient's best interests and safety, and the safety of the public.

The key differences between the Mental Health Act 1983 and the Bill are:

- Where appropriate, there will be new scope for patients to be treated under formal powers in the community.
- The conditions for the use of formal powers have been refined in the light of consultation, to target more clearly those people for whom compulsory treatment is truly necessary. Changes include giving patients the right to refuse electro convulsive therapy (ECT), where the patient has the mental capacity to do so. The distinction between admission for assessment and admission for treatment has been replaced by a simpler,

single route into formal powers (new procedures for the use of compulsory powers).

Patient safeguards have been improved – for the first time, all use of compulsory powers beyond 28 days must be independently authorised by the new Mental Health Act tribunal or the courts. All patients should undergo a formal assessment before an order for continuing use of compulsory powers is considered.

There is a requirement that ‘appropriate treatment’ must be available for the individual patient before formal powers can be used.

Safeguards for people with mental health problems who also have long-term mental incapacity will include the establishment of a Mental Health Act Commission. Specialist advocacy and the appointment of a nominated person will also be of particular benefit to this group of patients.

For the first time, patients and their representatives will have access to specialist independent advocacy.

The outdated concept of ‘nearest relative’ will be abolished and replaced by a ‘nominated person’ whose role it is to help the patient represent their views and apply to a Mental Health Act tribunal on their behalf. There will also be help from independent Mental Health Act advocates for patients and their nominated person.

There is a greater focus on the needs of the patient: patients with severe and enduring mental health problems have a right to a care plan within five days.

For the first time, carers will have statutory rights to be consulted at different stages of decision making about care and treatment.

The Healthcare Commission will take over the role of the Mental Health Act Commission, ensuring integrated standards of inspection.

Rigid demarcation of professional roles will be removed, in favour of a competence-based approach to new roles, to allow better use of the skills and expertise of all professional groups working in the mental health sector.

### **New procedures for the use of compulsory powers**

Where people with mental health problems may need compulsory care and/or treatment, a new three stage process will apply in all cases.



### Stage 1 – Preliminary examination

Assessment and initial treatment of a patient under compulsory powers will be based on a preliminary decision by two doctors and a social worker, or another suitably trained mental health professional, that a patient needs further assessment or urgent treatment by specialist mental health services and, without this, might be at risk of serious harm or pose a risk of serious harm to other people.

### Stage 2 – Formal assessment and initial treatment under compulsory powers

A patient will be given a full assessment of his or her health and social care needs and receive treatment set out in a formal care plan. The initial period of assessment and treatment under compulsory powers will be limited to a maximum of 28 days.

After that continuing use of compulsory powers must be authorised by a new independent decision making body, the Mental Health Act review tribunal, which will obtain advice from independent experts as well as taking evidence from the clinical team, the patient and his or her representatives, and other agencies, where appropriate.

### Stage 3 – Care and treatment order

The Mental Health Act review tribunal will be able to make a care and treatment order that will authorise the care plan recommended by the clinical team. This must be designed to give therapeutic benefit to the patient or to manage behaviour associated with mental disorder that might lead to serious harm to other people. The first two orders will be for up to six months each; subsequent orders may be for periods of up to 12 months.

### Concerns about the Mental Health Bill

There are a number of concerns about the Mental Health Bill that include:

- Objections to the use of compulsory treatment orders in the community
- Insufficient resources being invested in the training and provision of independent advocates
- No formal recognition of 'advance agreements' (directives) – these are enshrined in the Mental Capacity Act, but only for future situations when the person loses capacity.

An enforceable right for individuals to have a comprehensive assessment of their needs and to have their identified needs met with good quality and

effective services is also regarded as an essential prerequisite for improving mental healthcare.

## Implications for older people

Although it is impossible to say precisely what the implications of the new Bill will be for older people, it seems likely that the following elements may be helpful:

- Capacity to treat an older person under formal powers without having to admit them to hospital
- Clearer targeting of those people for whom compulsory treatment is truly needed
- Having access to specialist independent advocacy.

Enhanced patient safeguards, in particular an independent review of the use of compulsory powers after 28 days, will reduce the risk of people being detained in hospital for sustained periods without being formally 'sectioned' – an issue that particularly affects older people with dementia detained in hospital.

A requirement to have a care plan in place after five days also enhances the likelihood of an older person being offered treatment and services quickly and at a point where they may be effective. As older people disproportionately receive

ECT without consent, an enhanced right to refuse it may be of direct benefit. The greater involvement of the carer in the whole process of assessment, treatment and the use of compulsory powers is of particular benefit to older patients, a significant proportion of whom have long-term carers.

Overall these changes appear likely to raise the profile of older people with mental health problems and reduce the risk of both informal detention and repeated readmissions to hospital. That the Bill does not cover those living in residential or nursing care homes will be detrimental. As the majority of care home residents (DH, 2005a)-(53) do experience mental ill health, particularly dementia and depression, this is a missed opportunity.

## Further information

See their respective websites for more about the Mental Health Act Commission and the Healthcare Commission.

For more about the Bournemouth judgment and its implications, see Bournemouth patients: The common law is not enough (Hempsons Solicitors leaflet).

Towards a new mental health act is a summary of changes proposed in the Draft Mental Health Bill.

The Mental Health Alliance is a coalition of 60 service user, professional, service provider, trade union and voluntary organisations set up in January 2000 to provide a focus for campaigning on reform of the Mental Health Act. The website contains briefings and policy papers.

A useful critical review of the issues can be found at the Mental Health Foundation website.

## Mental capacity

This section outlines the key dimensions of the Mental Capacity Act 2005. With reference to older people, the Act mainly applies to people with advanced dementia and their carers.

### Summary

- An estimated two million people in the UK are unable to make decisions for themselves because of disability, mental illness, brain injury or dementia.
- With reference to older people, the Mental Capacity Act 2005 mainly applies to those with advanced dementia and their carers.
- The Act provides a statutory framework for people who may not be able to make their own decisions: it sets out who can take decisions, in which situations, and how they should go about this.
- The Act is underpinned by the following principles:
  - > a person must be assumed to have capacity unless it is proved otherwise
  - > a person cannot be considered unable to make a decision unless all 'practicable steps' have been taken to help him or her do so
  - > a decision made on behalf of a person who lacks capacity must be made in his or her 'best interests'.
- There is opposition to the Act as it stands: concerns focus on a lack of firm proposals for patient safeguards and no identified system of appeal by the person deemed to lack capacity.
- As dementia often increases the likelihood of things being done to the person rather than with or by them, the following aspects are likely to be beneficial: the emphasis that the Act places on 'decision-specific' assessment of capacity; engaging with approaches to communication that can support decision making; and maximising people's ability to make choices.
- Recognition of the need to assess an individual's capacity in a systematic way is also positive.

The key provisions of the Act are:

- A 'best interests' checklist for people acting on behalf of those people who lack capacity, which includes consideration of the person's wishes, feelings, beliefs and values, and those of their friends and family
- People can appoint an attorney to act on their behalf if they should lose capacity in the future. This provision can cover health and welfare decisions as well as financial ones
- Deputies with similar powers can be appointed by the Court of Protection to make decisions on behalf of a person who lacks capacity
- Carers and professionals can lawfully care for someone who cannot consent without incurring liability
- The creation of two new public bodies: a new Court of Protection and a new Public Guardian
- The creation of an independent mental capacity advocate to support and represent people lacking capacity who have no one else to speak for them
- Statutory recognition of advance decisions ('living wills') that enable people to set out in advance how they wish to be treated should they lose capacity in the future
- Introduction of a new offence of ill treatment or neglect of a person who lacks capacity.

## Introduction

The Act was introduced in response to widespread concerns about the limited account taken of the voices and rights of adults who may 'lack capacity' in decisions about their care and treatment. This particularly applies to decisions about psychiatric treatment and the support of people in long-term care. What has become known as the 'Bournewood judgment', dealing with the case of a man with learning difficulties detained in hospital without resort to a 'section', was a key driver to developing legislation as it highlighted the lack of safeguards for patients who have limited long-term capacity.

The Mental Capacity Act 2005 is an important piece of legislation, clarifying, strengthening and protecting the rights of people who wish to plan for their future in the event of becoming incapacitated, as well as the rights of those who currently lack capacity. It also clarifies the rights and duties of the carers and professionals who assist such people.

There are an estimated two million people in the UK who are unable to make decisions for themselves due to disability, mental illness, brain injury or dementia.

## Mental Capacity Act 2005

The Mental Capacity Act 2005, covering England and Wales, provides a statutory framework for people who may not be able to make their own

decisions. It deals with who can take decisions, in which situations, and how they should go about this.

Four principles are set out at the beginning of the Act:

- A person must be assumed to have capacity unless it is established that he lacks capacity.
- A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.
- A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
- An act done, or decision made, under this Act for, or on behalf of, a person who lacks capacity must be done, or made, in his best interests. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action. (Department for Constitutional Affairs, 2005)-(54)

The Act includes provisions for people to act on behalf of someone who cannot make decisions for themselves:

- **Best interests:** the Act has a 'best interests' checklist for people acting on behalf of others. This includes consideration of the person's wishes, feelings, beliefs and values (including any written advance statement they made when they had capacity) and taking account of the views of their friends and family. When considering what would be in someone's best interests in relation to life-sustaining treatment, the decision maker must not be motivated by a desire to bring about the person's death.
- **Lasting Powers of Attorney:** people will be able to appoint an attorney to act on their behalf if they should lose capacity in the future. This is like the current Enduring Power of Attorney, which covers financial decision making, but the Act also allows people to choose an attorney to make health and welfare decisions.
- **Court-appointed deputies:** deputies can be appointed by the Court of Protection to make decisions on behalf of a person about matters in relation to which that person lacks capacity. This replaces the current system of receivership covering financial decision making and extends it to include health and welfare.
- **Acts in connection with care or treatment:** under the Act, carers and professionals, subject to rules and limitations, can lawfully care for someone who cannot consent without incurring liability, for example by giving an injection or by using the person's money to buy essentials for them.

## Assessing capacity

The Act defines 'lack of capacity' as inability to make a decision in relation to a specific matter. This means that an individual should be assessed on their

capacity to make each decision. A person who is considered to lack capacity for a particular decision therefore may not necessarily lack capacity to make other decisions. So no one can be labelled 'incapable' as a result of a particular medical condition or diagnosis (such as dementia). It is recognised that most people – however limited their overall capacity is – are able to make many of their own day-to-day and care-related decisions, even if they may lack capacity in relation to more complex decisions in areas such as finances. Every effort must be made to communicate using whatever means necessary – to engage the person in decision making and maximise their engagement.

The Act sets out a clear test for assessing whether a person lacks capacity to take a particular decision at a particular time. It is for the person making the assertion of incapacity to prove that the patient lacks capacity. The test is 'on the balance of probabilities'.

The Act also creates two new public bodies:

- **A new Court of Protection:** the new Court will have jurisdiction in relation to the Mental Capacity Act. It will have special procedures and judges.
- **A new Public Guardian:** this new public official will take over from the current Public Guardianship Office. The Public Guardian will be the registering authority for Lasting Powers of Attorney and deputies appointed by the Court of Protection to make decisions on behalf of a person who lacks capacity, and will work with other agencies such as the police and social services to respond to any concerns.

Other provisions in the Act are:

- **Independent mental capacity advocates:** the Act provides for an advocate to support and represent people lacking capacity who have no one else to speak for them. This will apply in relation to serious medical treatment and long-term residential care and a regulation-making power allows this to be extended to other people and circumstances.
- **Advance decisions to refuse treatment ('living wills'):** advance decisions to refuse treatment enable people to set out in advance how they wish to be treated should they lose capacity. They are already legally binding under common law. The Act puts the process on a statutory basis and introduces provisions that set out exactly when an advance decision applies, and to which treatments. If a doctor has any doubt about the advance decision, he or she can provide treatment without fear of liability.
- **Criminal offence:** the Act introduces a new offence of ill treatment or neglect of a person who lacks capacity, which carries a maximum sentence of five years (55)-

The Act also has specific relevance for older people using services including care home residents. The Commission for Social Care Inspection welcomes the

intention of the Act to protect the financial and legal rights of people using services. Protection of rights is also reflected in Commission policy on national minimum standards for services; this is discussed in the later section on 'Care standards'.

### Implications of the Act for older people

A number of the key features of the Mental Capacity Act 2005 are likely to be of benefit to older people with long-term mental health problems – particularly dementia – and their carers.

The emphasis on assumption of capacity, unless proven otherwise, and on the rights for individuals to be supported to make their own decisions, are of pivotal importance. Mental vulnerability often increases the likelihood of things being done to the person rather than with or by them. The focus on 'decision-specific' assessment of capacity and the principle that no one should be labelled 'incapable' as a result of a particular medical condition such as dementia is also a crucial policy shift. The combined impact of these principles make it more likely that older people with impaired or fluctuating capacity will be involved in decisions about their care and treatment, even if more complex decisions relating to finances are managed by a third party. Such involvement should include decisions about medication, an issue about which there is widespread concern in the care home sector, where drugs can be inappropriately used as a method of control or 'chemical restraint'. Greater expectation of involvement by people with dementia also places greater emphasis on practitioners' engagement with approaches to communication that can support decision making and maximise people's ability to make choices.

Recognition of the need to assess an individual's capacity in a systematic way is also positive, as up until now there has been considerable variation both in methods of assessment and in whether capacity is routinely assessed at all. Carers should play a more significant role: their views should be taken account of in the assessment of capacity and they gain a right to be consulted about related care and treatment decisions.

The appointment of independent mental capacity advocates (IMCA) will be of particular benefit to older people with mental health problems who have no relatives or friends to act on their behalf. For older people with advanced dementia who have no relatives and live alone, an associate may perform a useful role in ensuring that decisions about care home placement is in the person's 'best interests' – another guiding principle of the Act. The Act provides a checklist of factors that decision makers must work through in deciding the 'best interests' of the person without capacity. This includes consideration of the person's wishes, feelings, beliefs and values (including any written advance statement made by them when they had capacity) and taking account of the views of family and friends.

For some older people without dementia, and those in the early stages, 'advance decisions to refuse treatment' may be a useful mechanism to ensure their wishes are recorded and taken account of in the event of loss of capacity in the future. The provision for people to appoint an attorney (Lasting Power of Attorney) to make health and welfare decisions as well as managing financial matters if they should lose capacity in the future is another useful feature of the Act. The appointed attorney will have the ultimate say in what should be done for the individual, including making medical decisions. Present law does not allow for proxy decision makers in medical matters.

The Act also introduces a new criminal offence of ill treatment or neglect of a person who lacks capacity. As dementia is a known risk factor for abuse, this is to be welcomed. There is, however, a recognition that where a person is providing care for someone who lacks capacity, they will not incur legal liability in the ordinary course of caring, for example, for bathing them or giving them prescribed medication, as long as it is in the person's 'best interests'. (See also 'Protecting vulnerable adults'.)

## Further information

For more about the 'Bournewood judgment' and its implications, see Bournewood patients: The common law is not enough (Hempsons Solicitors leaflet).

An online version of the Mental Capacity Act is available at the website of the Public Office of Information.

The Change Agent Team website lists a range of useful documents on the Mental Capacity Act, including a summary and an overview of key points.

A 'customer guide' to the Act is available on the Mencap website.

A draft code of practice is currently available from the Department for Constitutional Affairs. More detailed guidance on the implementation of the Act will soon be available to families, professionals and carers.

The Association of Directors of Social Services' website provides a 'Response' to the Bill.

The Royal College of Psychiatrists offers a briefing on the Bill.

The Making Decisions Alliance brings together a wide range of organisations and groups working with people who may, for a range of different reasons, have difficulty in making or communicating decisions. The Alliance's website contains a statement on the Mental Capacity Act.



## Protecting vulnerable adults

This section focuses on the legal and policy framework for protecting vulnerable adults (see Section 7: Abuse).

### Summary

- At present there is no adult protection legislation in the UK although the Department of Health policy document No secrets (DH, 2000)-(56) offers guidance to social services departments to help protect 'vulnerable adults' at risk of abuse by developing multiagency policies and procedures.
- Research identifies physical abuse, psychological abuse and neglect as the most common types of abuse in care homes. The misuse of medication – 'chemical restraint' – is also a recognised feature of institutional abuse.
- The Commission for Social Care Inspection has a role in ensuring abuse does not take place in service settings; abuse issues are also highlighted in the Mental Capacity Act 2005.
- The Protection of Vulnerable Adults scheme was introduced by the Care Standards Act 2000. It aims to ensure that no one is allowed to work in the care sector if they have ever abused, neglected or otherwise harmed vulnerable adults in their care or placed them at risk.
- The Sexual Offences Act 2003 makes it an offence for those engaged in providing care, assistance or services to someone with a learning disability or mental disorder to engage in sexual activity with that person whether or not that person has the capacity to consent, although this does not apply if the sexual relationship pre-dates the relationship of care, which would often be the case with dementia.

### Adult protection policy

At present there is no adult protection legislation in the UK, although the policy document No secrets (DH, 2000)-(57) offers direction and guidance to social services departments to help protect 'vulnerable adults' at risk of abuse. However, this is not, like child protection legislation, in statute.

The aim of No secrets is to ensure that key local agencies – particularly but not solely social services, health authorities and the police – work together to protect vulnerable adults from abuse, by developing local multiagency policies and procedures. The document provides guidance on how strategies for preventing and dealing with the abuse of vulnerable adults should be developed locally. The policy also describes principles around which agencies should develop their work. A key principle is that agencies should support individuals to live independently and make their own choices.

Many local authorities now have 'adult protection' policies, and when abuse is of a serious nature, 'case conferences' may be held to decide what needs to be done to ensure the protection of the vulnerable adult. (See, for example, extracts from the Kent and Medway multi-agency adult protection policy in Section 7.)

## Abuse in service settings

There is no specific data on the extent of abuse or neglect in service settings, although there have been a number of high profile cases of abuses of older people with mental health problems in hospital wards and care homes. Research identifies the most common problems as physical abuse (for example, beatings, restraint); psychological abuse (for example, withdrawal of care or food); and neglect (for example, leaving residents in soiled incontinence pads). The misuse of medication - 'chemical restraint' – is a recognised feature of institutional abuse, and this is being tackled via staff training, improvements in the quality of care, closer monitoring of the prescribing and giving of medication and enhanced rights for users and carers.

The raising of care standards and the role of the Commission for Social Care Inspection in monitoring these standards play a key role in identifying abusive regimes and practices and in reducing the risk of abuse in services (see 'Further information').

The Mental Capacity Act also has a number of powers that relate directly to protecting older people who lack capacity in both domestic and service settings (see above, 'Mental Capacity Act').

## Protection of Vulnerable Adults scheme

Provision for the Protection of Vulnerable Adults scheme is made in Part 7 of the Care Standards Act 2000. (DH, 2000)-(58) At the heart of the scheme is the Protection of Vulnerable Adults list. The scheme will act like a workforce ban. From 26 July 2004, individuals should be referred to, and included on, the list if they have abused, neglected or otherwise harmed vulnerable adults in their care or placed vulnerable adults in their care at risk of harm. By making statutory checks against the list, providers of care must ensure they do not offer such individuals employment in care positions. Protection of Vulnerable Adults checks are requested as part of disclosures from the Criminal Records Bureau.

The scheme will add significantly to current pre-employment checks – including confirming identity, requesting disclosures and obtaining references – that providers of care should carry out before offering individuals employment in care positions.

From its inception, the scheme applied to registered care homes and registered domiciliary care agencies only. It will be extended to adult placement schemes

shortly, once such schemes come within the regulatory framework of the Care Standards Act 2000. At the present time the scheme does not apply to the NHS and independent healthcare sector.

These regulations will help ensure that older people with mental health problems, particularly those in long-term care, are protected from abuse and harm.

### Sexual Offences Act 2003

The Sexual Offences Act 2003 was passed with the aim of protecting vulnerable adults and children from sexual abuse and exploitation.

A number of the Act's provisions may be relevant to older people with mental health problems, including:

- The introduction of a number of new offences to protect 'at risk' groups such as people with learning disabilities and other groups with reduced capacity such as people with advanced dementia
- Strengthening the Sex Offenders Register to ensure that the location of people who have committed serious sex-related crimes are known to the police
- Addressing the fear of sexual crime
- Strengthening and clarifying the meaning of 'non-consensual' sex and overhauling the law on consent: the Act introduces a test of 'reasonableness' on consent and a list of circumstances in which it can be presumed that consent was very unlikely to have been given, for example, when the victim was asleep.

The sections of the Act covering offences committed against those who, because of a very profound mental disorder, lack the capacity to consent to sexual activity may be relevant to older people with a 'mental disorder' who are service users. The Act specifically recognises that while the vast majority of people working in the care professions act compassionately, it is clear that some unscrupulous individuals have taken advantage of their position to commit a 'breach of a relationship of care' by sexual abuse. It is now an offence for those engaged in providing care, assistance or services to someone with a learning disability or mental disorder to engage in sexual activity with that person whether or not that person has the capacity to consent. However, this does not apply if the sexual relationship pre-dates the relationship of care: for example, where a spouse (or long-term partner) is caring for their partner following the onset of a mental disorder, for example, dementia, and continues to have a consensual sexual relationship with that person.

### Further information

For more about abuse in service settings, see the section on 'Institutional abuse' in Section 7.

The Department of Health publication No secrets offers direction and guidance to social services departments to help protect 'vulnerable adults' at risk of abuse.

The Department of Health also publishes a practical guide to the Protection of Vulnerable Adults scheme, which includes changes to the requirement for Criminal Records Bureau Disclosures.

The Commission for Social Care Inspection is responsible for setting standards and inspecting care homes and care agencies, and any concerns about abuse in care homes or by social care agencies should be reported to them.

An online version of the Sexual Offences Act is available on the Office of Public Sector Information website.

Action for Elder Abuse provides information about the abuse of older people and offers information and support.

## Advocacy

A number of separate pieces of recent legislation emphasise a need for advocacy for people with mental disorders and those who lack capacity, with the aim of supporting decision making and the process of informed consent. They include:

- The Mental Capacity Act 2005, which introduces independent mental capacity advocates
- The Mental Health Bill, which proposes the right to independent advocates for people with 'severe and enduring' mental health problems and anyone detained for more than 28 days
- The Disabled Persons Act 1986, which allows the local authority to recognise or appoint an advocate if someone has no relative or friend able to take on that role.

### Legislation on advocacy

There is currently no systematic framework to ensure that all older people have access to advocates to support decision making and the process of informed consent, whether they have capacity or not. The Mental Health Bill proposes the right to independent advocates for people with 'severe and enduring' mental health problems and anyone detained for more than 28 days (see 'Mental Health Bill'). While this offers some protection to older people with mental ill health, it does not ensure support for all older people who are detained without consent and lack of capacity.

The section on the Mental Capacity Act 2005 outlines the role of independent mental capacity advocate, who may be appointed to represent a person who lacks capacity but has no one to speak on their behalf when decisions need to be taken about serious medical treatment and long-term residential care. Sections 2 and 3 of the Disabled Persons (Services, Consultation and Representation) Act 1986 allow the recognition of advocates by the local authority and for the local authority to have the ability to appoint an advocate where the person has no relative or friend able to take on that role. However, these sections are rarely implemented.

In addition, the Health and Social Care Act 2001 provides the Secretary of State with powers to order the provision of independent advocates. However, the role of such advocates is limited to helping people through the NHS complaints procedure. They will not, for example, support people when making healthcare decisions.

See also the section on 'Involving advocates' in Section 3.

## Care standards

### Summary

- Several studies (Audit Commission, 2002)-(59) show that over 50 per cent of care home residents have dementia; up to 40 per cent may have depression.
- Raising standards in care homes – and in services more widely – has been a key policy concern for some years.
- In 2000 the Care Standards Act 2000 set up the Commission for Social Care Inspection that established a new system of national minimum standards for all residential and nursing homes and domiciliary services. Its primary function is to promote improvements in social care.
- It established a General Social Care Council to regulate the quality and standards of staff working in social care.

### Introduction

Services for older people, particularly long-term care, are increasingly focused on offering support to some of the oldest, frailest and most dependent people in UK society. In April 2003 there were 460,000 older people living in a total of 23,000 care homes in the UK. Several studies show that over 50 per cent per cent of care home residents have dementia; up to 40 per cent per cent may have depression.

Although it is not known how many older people with mental health problems use domiciliary health and social care services such as home care or community nursing, it is very likely that a significant number are at risk of

developing dementia or depression, particularly if they are aged over 80. Care standards have a role in ensuring that care homes: promote the mental health of residents, provide appropriate care and treatment for residents with mental health problems, and access primary and secondary care health services regularly.

## Care standards legislation

In the UK the quality of care for vulnerable adults, particularly in care homes, has been a key area of policy concern for some years.

The government has put a great deal of emphasis on improving standards, focusing particularly on:

- Standards of care in residential and nursing homes and other personal care services
- Standards of NHS care
- Standards of care from health and social care professionals.

The Care Standards Act 2000 came into effect in April 2002, replacing the Residential Homes Act 1984 and the Residential Homes Amendment Act 1991. The Act set up a new system of national minimum standards for services such as private and voluntary sector residential and nursing homes and, for the first time, extended the registration requirement to local authority care homes (commonly known as 'Part III accommodation'). The Act also covers regulation of personal domiciliary services, for example, helping someone wash or dress, and includes nursing agencies.

To achieve its aims, the Act set up the Commission for Social Care Inspection whose primary aim is to promote improvements in care via its triple functions of inspection, regulation and review of all social care services. It provides a comprehensive overview of social care in England and works at a local level, at a national level, and across all sectors.

The Commission for Social Care Inspection publishes regular reviews of social care provision structured around types of care and user groups. Of particular interest are inspection reports and publications reviewing national developments (see 'Further information').

The Act also established the General Social Care Council to regulate the quality and standards of staff working in social care. The General Social Care Council is the regulatory body for the social care workforce in England.

Although the General Social Care Council regulates independent sector hospital and clinics, it does not cover NHS provision. This is the responsibility of the Healthcare Commission, set up under the Health and Social Care (Community

Health and Standards) Act 2003. The commission's aim is to improve the quality of health and healthcare.

### Further information

The Commission for Social Care Inspection publishes reviewing [OK or 'reviews of'] national developments.

The General Social Care Council website includes information about care standards and training.

The Department of Health website provides PDF documents of national minimum standards for care homes and national minimum standards for domiciliary care.

Useful background information is provided by the Royal Commission's report on long-term care, With respect to old age (Royal Commission on Long-Term Care, 1999)-(60).

## Policy about carers

### Summary

- There are approximately six million family carers in the UK. Most support an older spouse or parent.
- Recent legislation has placed considerable emphasis on assessing the needs of, and providing support to, carers – particularly those looking after a relative with dementia. Specifically: > the Carers and Disabled Children Act 2000 gives local authorities discretion to meet carers needs with any service that will genuinely help them to continue to care and maintain their wellbeing. It also empowers local authorities to make direct payments to carers
- The Carers (Equal Opportunities) Act 2004 extends carers' rights to receive an assessment, access social care services and direct payments, and obtain support from health services if the carer's ability 'to provide care might be enhanced by such services'.

### Introduction

There are approximately six million family carers in the UK. Most support an older spouse or parent. A quarter are older people themselves, primarily spouses. Since the NHS and Community Care Act 1990, the contribution that carers make to supporting elderly and disabled people in the community has been increasingly recognised and responded to. Even in policies that do not directly address the needs of carers, their role is identified as important. For example, the NSF for older people states that: 'carers needs should be

considered as an integral part of the way in which services are provided for older people'(DH, 2002)-(61).

There is particular recognition of the needs of the significant number of carers of people with dementia; it has been estimated that 75 per cent of all those people with moderate to severe dementia living in the community have a family carer. Caring for a person with dementia is widely evidenced as highly physically and emotionally stressful, and for some it results in the development of mental ill health, particularly depression.

In addition to enhancement of the local authority's duty to assess the needs of carers (see Section 5), recent legislation enshrines the rights of carers to access services. The Carers and Disabled Children Act 2000 has given the local authority discretion to meet carers' needs with any service that will genuinely help them continue to care and maintain their health and wellbeing. This gives much greater scope to be flexible and innovative in the way that support is provided to carers. The Act also empowers local authorities to make direct payments to carers to meet their own needs and to provide voucher schemes for short-term breaks to allow carers the flexibility to manage their own package of support.

## Carers (Equal Opportunities) Act 2004

The Carers (Equal Opportunities) Act 2004 builds on existing rights. In summary these are:

- The right to an assessment – carers who provide regular and substantial care are entitled to a carer's assessment, which will look at their needs as a carer.
- The right to services – carers can also receive services in their own right under the Carers and Disabled Children Act 2000.
- The right to intermediate care – carers can receive free intermediate care services, and equipment up to the value of £1,000, for up to eight weeks following the discharge of a patient.
- The right to request direct payments, cash payments in lieu of social care and vouchers in lieu of break services.

The Act aims to extend carers' rights by:

- Giving carers new rights to information – Section 1 of the Act places a duty on local authorities to inform carers of their right to a carer's assessment when that authority is assessing the needs of a disabled adult.
- Ensuring that work, life-long learning and leisure are considered when a carer is assessed – Section 2 of the Act will mean that when a carer's assessment is being completed, it must take into account whether the carer works or wishes to work, any courses the carer is taking or wishes



to take, and any other leisure activities the carer undertakes or wishes to undertake.

- Giving local authorities new powers to enlist the help of housing, health, education and other local authorities in providing support to carers. Section 3 states that if a local authority requests another authority to plan services, that authority must give that request 'due consideration'. Of particular relevance to carers of older people with mental health problems is the potential for the local authority to request services to be provided by the local PCT or health trust if the carer's ability 'to provide care might be enhanced by such services'.

### Further information

Carers UK provides clear and accessible information on legislation relating to carers and their rights, and services for carers.

The Department of Health booklet Who cares? Information and support for carers of people with dementia is also available online.

For information and advice for carers of people with dementia, see the Alzheimer's Society website.

The government has published on the Carers (Equal Opportunities) Act 2004.

Carers UK also provides an outline of the implications of the Act for the NHS.

## Equal opportunities

### Summary

- The Race Relations Act 1976 makes it unlawful to discriminate on grounds of 'race', colour, nationality (including citizenship), and national or ethnic origin. The Act covers employment, education, training, housing and the provision of goods, facilities and services.
- The Race Relations (Amendment) Act 2000 places a 'general duty' on all public authorities to promote 'race' equality, for instance by consulting with minority ethnic communities and considering and monitoring the impact of policies.
- The 2003 (Amendment) Regulations to the Race Relations Act 1976 strengthen the Act by, for example, amending the definition of indirect discrimination and changing the way in which the burden of proof applies.
- The Disability Discrimination Act 1999 makes it unlawful to discriminate against a disabled person. The Act principally covers employment, services, the use and management of premises.
- The Disability Discrimination Act 2005 strengthens the Act by, for example, obliging public authorities to promote equal opportunities,

extending requirements for accessible public transport, and bringing more people under the remit of the Act.

- There is no longer a requirement that a mental health problem be 'clinically recognised'.

## Race relations

Every UK citizen has the right not to be discriminated against on racial grounds. The government wants the public sector to set the pace in the drive for equal opportunities – to lead by example.

The Race Relations Act 1976 makes it unlawful to treat a person less favourably than others on grounds of 'race', colour, nationality (including citizenship), and national or ethnic origin. In practice, most racial discrimination in Britain [or UK?] is against people from minority ethnic groups, but people of every background, 'race', colour and nationality are protected by the law. The Act provides protection from 'race' discrimination in the fields of employment, education, training, housing and the provision of goods, facilities and services.

Following the Inquiry into the murder of Stephen Lawrence, the government passed the Race Relations (Amendment) Act 2000. This legislation places a 'general duty' on all public authorities to promote 'race' equality and to make this aim explicit in their policies, practices and procedures. Public authorities – including social services departments, health agencies and housing departments – are expected to ensure that they promote racial equality in everything they do. They will need, for example, to ensure that they:

- Consult minority ethnic representatives when making significant changes to service provision in their area
- Take account of the potential impact of policies on minority ethnic groups
- Monitor the impact of policies and services on minorities and take remedial action when necessary to address any unexpected or unwarranted disparities
- Monitor their workforce and employment practices to ensure that their procedures and practices are fair and promote equality.

The 2003 (Amendment) Regulations to the Race Relations Act 1976 implemented the European Council Article 13 'Race Directive'. The regulations enhance the Race Relations Act by, for example, amending the definition of indirect discrimination and changing the way in which the burden of proof applies. There are also a number of exceptions from the legislation. (See 'Further information'.)

## Disability

The Disability Discrimination Act 1999 makes it unlawful to discriminate against a disabled person in relation to employment, the provision of goods, facilities

and services, and the use and management of premises. It also contains some provisions relating to education.

The Disability Discrimination Act 2005 amends the 1999 Act and further extends rights and opportunities for disabled people. Key provisions include:

- A new duty on public authorities to have due regard for the need to eliminate harassment of and unlawful discrimination against disabled people, to promote positive attitudes towards disabled people, to encourage participation by disabled people in public life, and to promote equality of opportunity between disabled people and other people
- Extending the requirement for rail vehicles and other types of public transport to be made accessible to disabled people, including wheelchair users
- Extending duties for landlords and others who manage rented premises to make 'reasonable adjustments' to accommodate disabled occupants
- Bringing more people with HIV, cancer, multiple sclerosis and mental illness under the remit of the Act – there is no longer a requirement that a mental health problem be 'clinically recognised'
- Amending the Blue Badge Parking Scheme for disabled people to bring them in line with arrangements in other European states.

### Further information

For more details of race relations legislation see the Home Office website and the website of the Commission for Racial Equality.

For more about disability discrimination legislation, see the Department for Work and Pensions Disability website and the site of the Disability Rights Commission.

### Further information Books and reports

Audit Commission (2000) *Forget-me-not: Mental health services for older people*, London: Audit Commission.

Easterbrook, L. (2003) *Moving on from community care: The treatment, care and support of older people in England*, London: Age Concern.

Jones, R.M. (2004) *Mental Health Act manual* (9<sup>th</sup> edn), London: Sweet & Maxwell.

Lingard, J. and Milne, A. (2004) *Integrating older people's mental health services: Community mental health teams for older people*, London: Department of Health.

Mental Health Act Commission (2003) Tenth biennial report 2001-2003: Placed among strangers – twenty years of the Mental Health Act 1983 and future prospects for psychiatric compulsion, London: The Stationery Office.

Moriarty, J. and Webb, S. (2000) Part of their lives: Community care for older people with dementia, Bristol: The Policy Press.

## Websites

Alzheimer’s Society: information about dementia, treatments and services

Institute of Mental Health Act Practitioners: specialist website on the law run by a lawyer for information on law and policy issues

Mind: information on law and policy issues and campaigns (not specialists in older people)

The Mental Health Foundation: excellent, accessible information on services, policy and the law

Department of Health: for general information on policy, government reports and reviews of the impact of policy

For general information on a wide range of policies and services of relevance to older people, see the websites of Help the Aged and Age Concern

## Mental Health Act (1983) England and Wales: Key sections and grounds for detention

Major sections of the Mental Health Act (1983)

Section 1	Section 1 of the Act outlines its remit thus: ‘the reception, care and treatment of mentally disordered patients, the management of their property and other related matters’. It also defines ‘mental disorder’ as: ‘mental illness, arrested or incomplete development of mind, psychopathic disorder and any other disorder or disability of mind’. Most sections are applied for by an approved social worker or the patient’s nearest relative and are recommended by two doctors; only one doctor is needed for Section 4.
Section 2	Allows compulsory admission and detention for up to 28 days for assessment and necessary treatment. Grounds are: the patient must be suffering from mental disorder of ‘a nature or degree, which warrants the detention of the patient in a hospital for assessment’. In addition the patient may need to be detained to protect him/herself or others.
Section	Allows compulsory detention for up to six months for treatment. Grounds

3	are: to ensure that a severely mentally disordered person receives treatment in a hospital setting; such treatment is likely to alleviate or prevent a deterioration of the condition; it is necessary for the health and safety of the patient or for the protection of other people.
Section 4	Allows emergency admission for up to 72 hours for assessment. It has similar grounds to those pertaining to Section 2 although it only requires one medical recommendation. It is not a short-cut to Section 2 and is only for use in urgent situations where any delay in seeking a second medical recommendation could be harmful to the patient or others.
Section 5	Gives a doctor (under Section 5.2) or a nurse (under Section 5.4) 'holding power' to prevent a client from discharging themselves from hospital if either think it is not in the client's best interests to leave
Section 7-10	Guardianship: a local authority or private individual can become the guardian to a person who needs protection from themselves or others due to mental incapacity. The guardian has the power to require the patient to live in a specified place or to attend for medical treatment, occupation or training.
Section 117	This section requires health and local authorities to arrange a package of 'aftercare' for patients on a Section 3. The purpose of aftercare is to enable patients to return home and to minimise the chances of their needing any future inpatient care.
Section 135	Enables an approved social worker to obtain a magistrate's warrant granting permission to enter a person's home if it is felt that the person is a risk or danger to themselves or others due to a mental disorder. Once entry is made, the order allows compulsory detention for a period no longer than 72 hours at a place of safety (hospital or police station) for psychiatric assessment.
Section 136	Allows a police officer to remove someone who appears to have a mental disorder and is a risk to themselves or others from a public place to a place of safety for a psychiatric assessment. Detention must not exceed 72 hours.

## Types and indicators of abuse

The following is based on a list developed by the multi-agency adult protection policy for Kent and Medway.

### Physical abuse: types

- Hitting, slapping, scratching
- Pushing or rough handling

- Assault and battery
- Restraining without justifiable reason
- Misuse of medication
- Inappropriate sanctions including deprivation of food, clothing, warmth and health care needs

### Physical abuse: indicators

- A history of unexplained falls or minor injuries especially at different stages of healing
- Unexplained bruising in well-protected areas of body, for example, on the inside of thighs or upper arms etc
- Unexplained bruising or injuries of any sort
- Burn marks of unusual type, for example, burns caused by cigarettes and rope burns etc
- A history of frequent changes of GPs or reluctance in the family, carer or friend towards a GP consultation
- Accumulation of medicine that has been prescribed for a client but not administered
- Malnutrition, ulcers, bed sores and being left in wet clothing

### Sexual abuse: types

- Sexual activity that an adult client cannot or has not consented to or has been pressured into
- Sexual activity that takes place when the adult client is unaware of the consequences or the risks involved
- Rape or attempted rape
- Sexual assault and harassment
- Non contact abuse for example, voyeurism, pornography

### Sexual abuse: indicators

- Unexplained changes in the demeanour and behaviour of the vulnerable adult
- Tendency to withdraw and spend time in isolation
- Expression of explicit sexual behaviour and/or language by the vulnerable adult that is out of character
- Irregular and disturbed sleep pattern
- Bruising or bleeding in the rectal or genital areas
- Torn or stained underclothing especially with blood or semen
- Sexually transmitted disease or pregnancy where the individual cannot give consent to sexual acts

### Psychological abuse: types

- Emotional abuse
- Verbal abuse
- Humiliation and ridicule
- Threats of punishment, abandonment, intimidation or exclusion from services
- Isolation or withdrawal from services or supportive networks
- Deliberate denial of religious or cultural needs
- Failure to provide access to appropriate social skills and educational development training

### Psychological abuse: indicators

- Inability of the vulnerable person to sleep or tendency to spend long periods in bed
- Loss of appetite or overeating at inappropriate times
- Anxiety, confusion or general resignation
- Tendency towards social withdrawal and isolation
- Fearfulness and signs of loss of self-esteem
- Uncharacteristic manipulative, uncooperative and aggressive behaviour

### Financial abuse: types

- Misuse or theft of money
- Fraud and extortion of material assets
- Misuse or misappropriation of property, possessions or benefits
- Exploitation or pressure in connection with wills, property or inheritance

### Financial abuse: indicators

- Unexplained inability to pay for household shopping or bills etc
- Withdrawal of large sums of money which cannot be explained
- Missing personal possessions
- Disparity between the person's living conditions and their financial resources
- Unusual and extraordinary interest and involvement in the vulnerable adult's assets

### Neglect and acts of omission: types

- Ignoring medical or physical care needs
- Failure to give prescribed medication

- Failure to provide access to appropriate health, social care or educational services
- Neglect of accommodation, heating, lighting etc
- Failure to access care or equipment for functional independence
- Failure to give privacy and dignity
- Professional neglect

### Neglect and acts of omission: indicators

- Inadequate heating, lighting, food or fluids
- Failure by carer to give prescribed medication or obtain appropriate medical care
- Carer's reluctant to accept contact from health or social care professionals
- Refusal to arrange access for visitors
- Poor physical condition in the vulnerable person for example, ulcers, bed sores
- Apparently unexplained weight loss
- Unkempt clothing and appearance Inappropriate or inadequate clothing, or nightclothes worn during the day
- Sensory deprivation – lack of access to glasses, hearing aids etc
- Absence of appropriate privacy and dignity
- Absence of method of calling for assistance

### Discriminatory abuse: types

- Discrimination demonstrated on any grounds including sex, 'race', colour, language, culture, religion, politics or sexual orientation
- Discrimination that is based on a person's disability or age
- Harassment and slurs that are degrading
- Hate crime

### Discriminatory abuse: indicators

- Tendency to withdrawal and isolation
- Fearfulness and anxiety
- Being refused access to services or being excluded inappropriately
- Loss of self-esteem
- Resistance or refusal to access services that are required to meet need
- Expressions of anger or frustration





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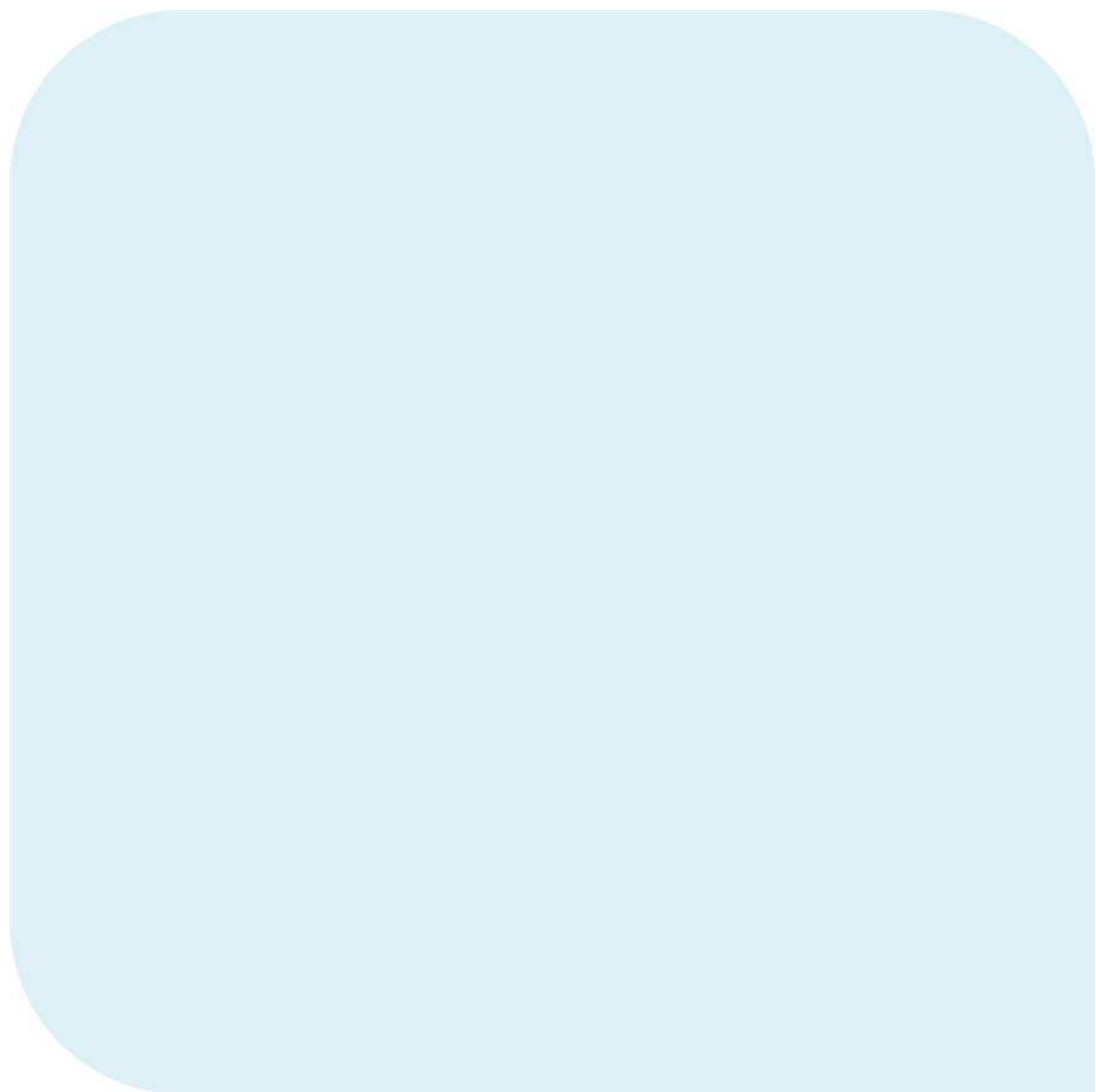
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Social Care Institute for Excellence  
Goldings House  
2 Hay's Lane  
London SE1 2HB  
tel 020 7089 6840  
fax 020 7089 6841  
textphone 020 7089 6893  
[www.scie.org.uk](http://www.scie.org.uk)  
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