

The background of the cover is a vibrant purple with large, swirling, lighter purple patterns. In the center, the words "NOT ALONE" are written in large, bold, white capital letters. Surrounding the text are several stylized illustrations of people in formal attire. At the top, a man in a black suit is dancing with a woman in a bright blue dress. To the right, a man in a dark purple suit is dancing with a woman in a pink dress. At the bottom, a man in a black suit is dancing with a woman in an orange dress. On the left, a man in a blue jacket is talking to a woman in a black jacket and green skirt, who is holding a glass. Another man in a red suit is standing nearby. The overall scene depicts a lively social event.

# NOT ALONE

The logo for The Housing Corporation features a stylized blue building with a white roof and a sunburst icon to its left. Below the building, the text "THE HOUSING CORPORATION" is written in a blue, serif font with a white outline.

THE HOUSING  
CORPORATION

## **Not Alone**

***A Good Practice Guide to working with  
people with Dementia in Sheltered Housing***

*by Annette McDonald and Jacqueline Curtis*

The Anchor logo consists of a large, stylized red letter 'A' with a white outline. To its right, the word "Anchor" is written in a red, serif font with a white outline. Below "Anchor", the tagline "working with older people" is written in a smaller, white, sans-serif font on a dark red background.

**Anchor**  
working with older people

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# Introduction

The change in national policy from providing care for older people to promoting independence through prevention and rehabilitation underlines the importance and value of sheltered housing in terms of community health and social care. Sheltered housing offers increased security, emergency call provision, communal facilities and a resident scheme manager, whilst enabling people to retain their independence, autonomy and life in the community. It accommodates an increasing number of physically and mentally frail older people including those with dementia.

In 1995 a research study *Brighter Futures* (Kitwood, Buckland and Petre.1995) examined the factors that contribute to the effectiveness of sheltered housing in supporting people with dementia. The study concluded that sheltered housing “has been found to be a successful environment in which those with dementia can live with well being.” However for this to be possible scheme managers required training in issues relating to dementia and the person with dementia needed to be accepted socially by the other tenants and able to access care services which met their needs. Ensuring that the care needs of a person with dementia are recognised and provided at an early stage of their illness is essential if they are to live as independently as possible.

In 1997 the Housing Corporation, through an Innovation and Good Practice Grant, commissioned Anchor Trust to carry out a project, building on the findings of *Brighter Futures*, to produce a good practice guide and training pack for scheme managers working with tenants with dementia. Details of the project are given at the back of this guide.

Good practice is hard to define and constantly evolving but it is easy to identify through the positive impact it has on individuals’ quality of life and physical and psychological well being. This guide does not provide solutions but, based on a set of values and principles, it sets out the attitudes, skills and knowledge which enable scheme managers to work effectively with care providers, families and other tenants to support older people with dementia in sheltered housing.

## **Why ‘Not Alone’?**

Dementia can have an isolating effect, not only on the individual who experiences it, but on the warden or scheme manager on whom that individual often relies for support. The title of this good practice guide ‘Not Alone’ reflects firstly the fact that this condition is more common than many people imagine. It also acknowledges and aims to assist the considerable number of dedicated and committed wardens and scheme managers who provide support to those with dementia. By showing these examples of good practice we hope this guide will further support them in the invaluable role they play.

# Values and principles

The good practice guide is based on the following principles which guide Anchor Trust's approach to mental health:

- We will ensure that older people who have used or are in contact with mental health services do not suffer discrimination in accessing and using Anchor's housing, care and support services.
- We will provide staff with appropriate and ongoing training and support to enable them to understand and respond appropriately to people with dementia. We will ensure that all services, policies and procedures reflect the need to promote positive mental health and enable staff to operate in a sensitive and appropriate manner.
- We will ensure that customers, and staff who are in regular contact with customers, are aware of statutory and voluntary services in their area and how to access them.
- We will support initiatives and partnerships with other organisations which will contribute to the better understanding of dementia.
- In developing specialist services for particular groups of older people with dementia, Anchor will ensure that the resources and expertise are available to provide such services to a high standard.
- Expectations of the quality of life for older people who have dementia should not be below that of any other person. Services must be of a consistently high standard and positively demonstrate the value and importance of older people with dementia from all cultures and ethnic backgrounds.
- Every person with dementia is an individual. Individual preferences, needs, wants and abilities must be identified. Appropriate and effective packages of care must be provided. Individual life histories must be preserved to provide continuity between past, present and future.

# Understanding dementia

## Introduction

The age profile of people living in sheltered housing is very different than 15 years ago. In 1984 only 10% of Anchor's sheltered housing tenants were aged over 85 years but by 2001 this had risen to 28%.

The incidence of people with dementia living in sheltered housing is increasing because people are now moving into sheltered housing at a later age. This means that many tenants are both physically and mentally frailer, and though able to live alone, often require a number of supportive services. To assess the need for services for someone with a physical disability is relatively straightforward. Although they may not want to feel dependent on other people to help them they understand and appreciate the need for help and will usually accept the services offered.

Dementia can remain "hidden". It is often diagnosed late in the progression of the disease, if at all, and denied by the person experiencing dementia and sometimes their families. However if the signs and symptoms of dementia are recognised at an early stage, the person developing dementia is more likely to accept help whilst they have some insight into the problems they are facing.

As people age a small amount of forgetfulness, confusion and loss of short-term memory is normal. Developing dementia is not an inevitable part of ageing. It is important to remember that just because an older person becomes forgetful, this does not necessarily mean that they are developing or suffering from dementia. In this section information is given on the causes and effects of dementia.

## The incidence of dementia

Although it can affect people of all ages, dementia is rare before the age of 65. The incidence of dementia does however increase sharply with age.

*Estimated prevalence of dementia in England and Wales*

<b>75 – 79 years</b>	<b>6%</b>
<b>80 – 84 years</b>	<b>13%</b>
<b>over 85 years</b>	<b>25%</b>

Women in the older age group are slightly more likely to develop dementia. The incidence of specific types of dementia may also be higher in some ethnic groups.

The majority of people with dementia live in their own homes supported by their families. Only 34% of people with dementia live in hospital, residential care or nursing homes.

## Types of dementia

Dementia occurs as a result of damage to, or the death of cells in the parts of the brain that deal with our thought processes. Dementia affects everyone differently but broadly speaking there are 4 stages:

- **Minimal:** where the person has some difficulty in recalling recent events and may mislay or lose things.
- **Mild:** where the person's recent memory is very poor and they are sometimes confused or disorientated.
- **Moderate:** where the person is usually disorientated in time and place, and has difficulty in reasoning and understanding. Sometimes they are incontinent and their emotional control deteriorates.
- **Severe:** where the person is totally disorientated, unable to communicate in normal speech, may fail to recognise close relatives, and is incontinent and completely dependent on others for personal care. Some people with severe dementia may become aggressive or violent to others. As the dementia progresses, the person can become immobile and totally physically dependent. The length of time individuals spend in any of these stages will vary and the order in which the symptoms of the disease arise will also vary.

The majority of people with dementia living in sheltered housing will be suffering from minimal or mild dementia, although with the provision of flexible care, people with moderate dementia can be supported to live independently.

The most common forms of dementia in older people are Alzheimer's Disease and vascular dementia.

**Alzheimer's Disease accounts for 50%-60% of all cases of dementia.**

**Vascular dementia accounts for 20% of all cases. It is caused by a series of tiny "strokes". The loss of functioning experienced by the person depends on which area of the brain has been affected.**

There are several other forms of dementia including Lewy Body Dementia. However, with this type of dementia some people experience visual hallucinations and symptoms common to Parkinson's Disease. It is hard to differentiate between different types of dementia and many older people will not have a formal diagnosis. A conclusive diagnosis can only be made on post mortem.

Dementia can also be the result of other illnesses. These include genetic diseases such as Huntington's Disease and Parkinson's Disease; a medical condition such as a brain tumour; or as a result of alcohol or drug misuse.

### *Good practice*

It may be helpful to remember that on average people live for seven or eight years following a diagnosis of dementia but there are wide individual variations. For many people the disease progresses slowly and a diagnosis of dementia does not mean that the person cannot continue to live in sheltered accommodation with care and support.

## Is it dementia?

*Dementia is a disabling disease characterised by some or all of the following symptoms:*

- deterioration in concentration, memory and reasoning.
- difficulty in completing simple tasks and solving minor problems which can cause frustration and distress.
- continued forgetfulness and confusion.
- lack of orientation in time and place sometimes leading to a change in routine e.g. sleeping during the day and going out at night.
- changes in mood and behaviour, possibly becoming elated, tearful or suspicious.
- in a very small number of cases a person with dementia may become verbally or even physically aggressive.
- difficulty finding the right words and understanding verbal communication.

The symptoms listed above can often be present in other conditions, which if promptly treated or addressed can lead to a significant improvement in an older person's mental state and functioning.

## Infections

Chest, urinary tract and other infections can produce temporary confusion including delusions and hallucinations, as a result of a rise in temperature and possible dehydration.

## Depression and anxiety

It is not uncommon for older people suffering from treatable conditions such as depression and anxiety to be wrongly diagnosed as suffering from dementia. Older people are more likely to suffer from depression if they are in poor health, lack social support or have long standing problems such as poor housing, poverty and disability, particularly if accompanied by constant pain.

- "Depression is the most common mental health problem in older people" (Audit Commission 2000). Apathy, mood swings, erratic and confused behaviour are some of the symptoms of depression that may be wrongly attributed to dementia. An early sign of dementia may be increased agitation but this too may be a sign of a depressive illness or anxiety state. All these can be treated.

### *Good practice*

Early recognition of the signs of dementia is essential if older people with dementia are to be maintained within sheltered housing.

If you suspect that a person may be developing dementia suggest that they visit their GP to discuss any problems they may be having.

## Visual and/or hearing impairment

Declining sight, including the development of cataracts can lead to older people being unable to recognise people or places or misinterpreting what they see. Deafness can lead to misunderstandings or misinterpretation of conversations, and repeating questions because the answers haven't been heard.

## Other physical causes

Constipation, dehydration, poor diet and diseases such as anaemia can result in some degree of confusion in some older people.

## Alcohol and medication

Prescribed and "over the counter" medication, such as sleeping tablets and tranquillisers, and even small amounts of alcohol can cause confusion, unsteadiness and toxicity in older people whose tolerance declines with age. These symptoms may be exacerbated when alcohol is taken in association with some medications. In a very small number of cases an older person may experience hallucinations.

There are also social factors which can lead to an older person showing signs of confusion, distress and an inability to carry out simple tasks which may be wrongly attributed to dementia. These include social isolation, discrimination and abuse. More information about these areas are given later in this guide.

### *Good practice*

Confusion and difficulties in an older person's social and personal functioning are not always due to dementia. Treating many physical and psychological conditions will usually result in an older person regaining their health and well being. Identifying and treating depression correctly is important, as it is often mistaken for dementia.

Be aware of the other factors that might be presenting in a way to suggest dementia.

Reassure a tenant who is worried that they may be getting dementia that there are other causes of memory loss and confusion.

It is important that significant changes in a tenant's mood or ability to cope are recognised and that they are encouraged to seek help from their GP as soon as possible.

# The effects of dementia

## Introduction

A great deal has been written about how dementia impacts on the person with dementia and their carers. However within a sheltered housing scheme the scheme manager and other tenants will be affected by working with and living in close proximity to people with dementia. Understanding how dementia may affect the individual, their families and other tenants is crucial if scheme managers are to support people with dementia in sheltered housing. No less important is the knowledge of how supporting people with dementia impacts on scheme managers and their families.

## The effects of dementia on the individual

*Dementia can be regarded as a disabling disease resulting in:*

- **difficulties in communicating**
- **difficulties carrying out simple tasks**
- **confusion and disorientation**
- **problems with memory, concentration and judgement**

The effects of dementia and the progress of the disease will vary considerably from person to person. However the level of disability can be compounded by the manner in which the person with dementia is viewed and treated. Practical solutions can assist people with dementia in relation to social withdrawal and coping with the tasks of daily living. If however a person with dementia is to continue living successfully in sheltered housing the way they interact with people with whom they are in regular contact, is crucially important. People with dementia who are denied the opportunity to assert themselves as valued and respected individuals will often become depressed, withdrawn and frustrated.

## Social withdrawal and isolation

In the early stages of dementia people are often distressed and anxious. Although recognising that they are unwell, they may be uncertain about what exactly is wrong with them. Withdrawing from social contact with other people often happens at this stage. One of the first things that a scheme manager or neighbour may notice is that a person who regularly socialised in the lounge may no longer do so.

*A person with dementia may withdraw from social contact for a number of reasons including:*

- **feelings of shame or embarrassment at their inability to make themselves understood, carry out conversations and remember who people are**
- **people with dementia may be unable to converse in situations where there are a number of people talking at once or when the television or radio is on**
- **protection of themselves or others from embarrassment due to diminishing control over their behaviour**
- **the need for a safe and familiar environment and the fear of feeling or getting lost**
- **invoking hostile reactions and intolerance in others**

However it may be that other people may exclude a person with dementia. Exclusion, deliberate or otherwise may be seen as a way of protecting them from embarrassment but may also result from the stigma associated with dementia. People with dementia can find themselves increasingly segregated and living and socialising with a group of people with whom they share only the one common characteristic — dementia.

*This segregation may result from:*

- overprotection — a person with dementia is seen as vulnerable, their behaviour may be unpredictable and unacceptable to other people.
- stereotyped and ageist attitudes.
- the provision of specialised services and being refused access to mainstream and community resources.

## Coping with everyday living

It is behind the tenant's front door that the effects of dementia are often most apparent. A scheme manager may find that where he or she had always been welcomed into a tenant's flat, they may no longer be invited in. The difficulties in understanding, co-ordination and memory experienced by people with dementia often mean that things are knocked over or put in inappropriate places. Basic skills such as cleaning and cooking may become increasingly difficult and may eventually be lost altogether. It is however important for people with dementia to have a sense of being meaningfully occupied.

Occupation provides a sense of purpose to life without which a person can become bored and apathetic. Many people with dementia find their sense of purpose eroded by:

- having things done for them instead of being encouraged to do them for themselves.
- being pushed into doing things that are not personally meaningful for them.
- being denied new opportunities.

### *Good practice*

Encourage the person with dementia to join in social activities in the communal lounge that are small scale and not too noisy. If possible enlist the help of a neighbour or friend to accompany the person. A short visit may be all a person with dementia can manage; do not press a person to stay if they wish to return to their flat.

Find out if there is a local befriending scheme run by the Alzheimer's Society, Age Concern or another agency. Ask the person with dementia if they would appreciate a short visit in their flat.

### *Good practice*

Give a person with dementia time and space to keep doing as much as they can. Encourage but don't take over. Uncluttered spaces, particularly in kitchens and bathrooms help people whose vision and co-ordination is poor. See-through plastic containers, clearly labelled, may help them to find tea and sugar etc. Glass containers should be avoided for fear of breakages.

Labelling and listing are useful to help people carry out at least some domestic chores. Signs on doors and drawers and lists of the steps to take for each task may be helpful. Remember risks can be minimised but not ruled out altogether.

Offer to help the person with dementia clear up any mess they have made. They may have difficulty in thinking through the steps they need to go through and may become flustered and confused. Don't get too alarmed by any apparent lack of routine or slips in their standard of housekeeping.

When carrying out the daily call to the flat remind the person of any activities they are undertaking that day and which day of the week it is.

Share these tips with carers and families. Home carers too may not have been trained to work with people with dementia and may benefit by knowing how they can help.

# The effects of dementia

## Losing a sense of identity

Knowing who they are, where they came from and having a sense of continuity with the past is essential if a person with dementia is to maintain a sense of his or her own status and rights.

Many people with dementia find their identity eroded by the actions, reactions and interactions of others. For example by:

- being called by first names, pet names or inappropriate titles
- having de-personalising labels attached to them — 'demented', 'a wanderer' etc.
- being spoken to in a patronising tone of voice or mode of speech
- being ignored, dismissed or having people speak over their heads or for them

### *Good practice*

If a tenant who has always been known as Mrs Smith develops dementia do not assume that she would now like to be known by her first name.

Bring subjects into conversations that the person with dementia may be able to converse about. Remind them of activities they carried out yesterday or last week as well as things that may have happened 40 or more years ago.

Speak directly and calmly to the person with dementia and give them time to respond. Don't finish their sentences. Be aware that losing the thread of the conversation may embarrass them.

## Losing the opportunity to exercise choice

A sense of continued control and autonomy over life is an important means of personal validation. However, many people with dementia find themselves denied the opportunity and support to make choices and control their own lives by:

- having assumptions made about their capability and competence to make their own decisions
- having others speak and decide things for them; often in their best interests but not always what they would want
- a lack of accessible information and a lack of appropriately skilled people to assist and support understanding and communication
- a limited and inflexible range of services
- overprotection, being denied the opportunity to take risks, and the belief that others 'know what's best' for them

### *Good practice*

People with dementia need time to assemble their thoughts and words. When requiring a response allow time which will afford the person a chance to make a decision.

Don't accept that the family or carers always know what is best for their relative or friend. If given the clear information and time a person with dementia will often succeed in expressing their wishes.

## The effect on carers and families

Many carers of people with dementia are themselves older people. Up to 60% are husbands, wives or long term partners. Carers of people with dementia are recognised as generally experiencing greater stress than other groups of carers, with nearly half of them suffering with a mental health problem themselves.

Caring for a person with dementia is a difficult, exhausting and emotionally draining task. Dealing with the effects of dementia in the individual leads to changes in relationships and interactions as other people begin to treat them differently. Like the people they care for, carers become socially isolated and may experience a high degree of distress and mixed emotions such as anger, loss and fear of the future, especially when dementia is first diagnosed.

Carers state that the most difficult problems to cope with are personality changes, lack of everyday conversation, criticism, excessive demands and difficult behaviour such as aggression, disturbance at night, incontinence and wandering.

The needs of carers are the same as for anyone else - comfort, attachment, inclusion, occupation and identity. However some carers deny their own needs, becoming protective of the person for whom they care, refusing help and eventually experiencing physical and emotional exhaustion. Carers from minority ethnic groups are unlikely to accept respite care and day services unless they are provided in a culturally sensitive manner.

Even when a person with dementia lives alone in sheltered housing there may be a high level of care provided by the family who may show some of the signs of stress listed above.

### *Good practice*

- Provide carers with information about local groups which can offer support and information, for example the Alzheimer's Society, and Age Concern.
- Ensure that carers know that they are entitled to an assessment of their own needs by a social worker or other professional trained in carer's assessment.
- Encourage carers and families to access all the support and benefits that they are entitled to.
- Suggest to carers who are finding it difficult to cope that they might find that both they and the person they care for benefit from a short period of respite care or attendance at a day centre.
- Make your role as a scheme manager clear to families and carers. It is important that they know what is a reasonable and realistic service to expect from you. Clarify the boundaries — in writing if necessary.
- Identify and record the care input provided by the family. Ask them to let you know if this is withdrawn for any reason and what other arrangements have been put in place.
- If the carer or family goes away ensure that you have a number recorded so that you contact someone in an emergency.
- Obtain the consent of the tenant before imparting any information that they may wish to keep confidential. If the matter is such that you feel that the family should know, discuss the issue with your manager or a health or social care professional before breaking a confidence. Always inform the tenant prior to sharing information with their carers and/or family.
- Agree with the tenant and their family the circumstances and methods of giving and receiving information.
- Respect family boundaries. Some tenants may not wish to have contact with their family and family members may not wish to have contact with their relative/parents.

# The effects of dementia

## The effect on other tenants

In a survey in the West Midlands, 22% of scheme managers reported that complaints, hostile attitudes and lack of tolerance from other tenants led to a person with dementia having to leave their housing scheme.

### *Meetings with tenants revealed the following:*

- Many older people living in sheltered housing have a good knowledge of dementia and its implications obtained through the media and through caring for relatives or friends.
- Concerns were expressed about the safety of neighbours with dementia especially in relation to 'wandering' from the scheme, sometimes inappropriately dressed, particularly in cold weather.
- Some tenants feel the responsibility of living in close proximity to a person with dementia. They are constantly 'on the lookout' and worrying about the person with dementia. For some tenants, who had been carers, this raised painful memories.
- Anger was expressed towards families who did little to support their relative with dementia and visited infrequently. Tenants saw good family support as being essential if a person with dementia is to live in sheltered housing. If given, the person with dementia appeared to be more likely to be accepted by their neighbours.
- Although people with dementia were cited as putting an unreasonable burden on scheme managers, it was also acknowledged that tenants who were most demanding were not necessarily suffering from dementia.
- A few tenants stated that they made an effort to include neighbours with dementia in social activities within the scheme but these appeared to be in the minority.
- Although some sympathy and concern was expressed the majority of tenants appeared to believe that sheltered housing was not the place for people with dementia once their behaviour impacted on the well-being of other tenants.

Many people move to sheltered housing seeking increased security, peace and quiet. The behaviour of people with dementia can be distressing and frightening, as well as causing disturbance and a perceived risk. In some schemes scheme managers reported that people with dementia are frequently blamed for incidents such as allowing strangers into the scheme, even though they were not responsible.

### *Good practice*

Act as a positive role model for tenants and demonstrate that you value and respect all tenants including people with dementia.

Invite health and social care staff to give talks about dementia that address general queries and fears.

Ask the Alzheimer's Society to provide information and support to all tenants.

Try and set up a system whereby a small number of understanding tenants support a person with dementia getting involved in social activities. Some tenants felt that if they offered to do this on one occasion, the expectation was that they should continue to do so.

Try and minimise disruption to other tenants by working with health and social care staff to ensure that the person with dementia receives all the care and health services they need. Problems such as disruption at night may be addressed by keeping the person with dementia active during the day or by the use of prescribed medication.

Listen to and address tenants' concerns but respect confidentiality and do not take sides.

Ensure that, if the person with dementia is being unfairly blamed for incidents that they are not responsible for, that the record is set straight.



# Working effectively with older people with dementia

## Introduction

The attitude, skills and knowledge of the scheme manager are key factors that ensure that people with dementia can live in sheltered housing. Although working with people with dementia can at times be challenging and frustrating many scheme managers find it rewarding to see people, who might in other circumstances be living in residential care homes, living independently with support. This section will not cover all the situations that scheme managers will be coping with on a daily basis but will provide a foundation from which scheme managers can build up their knowledge and skills base.

## Respecting and understanding the person with dementia

Older people with dementia are no different from other people. They are unique individuals, with their own experience of life that may include bringing up a family, serving during the war or running their own business. They have feelings, likes, dislikes and needs like everyone else. However they are likely to feel vulnerable and need support and reassurance. It is important that the people with whom they are in close contact help them to retain their sense of identity and self worth. The experience of dementia is different for everyone. The abilities, preferences and interests of the person need to be taken into account, as does the fact that these may change as the symptoms of dementia change. A sensitive and flexible approach on the part of those who provide care and support is required if people with dementia are to live successfully in sheltered housing.

*It is important to remember that:*

- all people, including those with dementia, have a life story and unique experiences.
- our sense of who we are is closely connected to our name and we often have a strong preference for how we are addressed.
- many people have a cultural or religious background which if not respected may cause offence and distress.
- all adults should be treated as adults. People with dementia have the right to be treated with respect and courtesy at all times no matter how advanced their dementia.
- focusing on the remaining abilities of a person with dementia helps them to retain self respect.
- everyone has a right to privacy, information and choice.
- dementia affects thinking and memory and does not mean that people no longer have feelings.
- people with dementia need to feel respected and valued for what they are now as well as who they were in the past.

### *Good practice*

- Find out as much as you can about the background, preferences and lifestyle of the person.
- A person with dementia may be able to give you a great deal of information, for example through looking at photographs. Remember that past memories can also be upsetting.
- Families may be happy to give you background information and there may be other tenants in the scheme who knew the person when they were younger.
- Without breaking confidences, provide other people who are involved in the care of the person with background information as well as information on their current lifestyle, abilities and preferences.
- Ensure that you and others address the person in a way that they recognise and prefer. People who come from other cultures may have a particular way of using names and addressing people in order to show respect. If this is the case make other people in contact with the person aware of this.
- Establish if the person with dementia has cultural or religious customs or beliefs so that these can be respected. These may relate to observing times for prayers and festivals. They may also be demonstrated through preparation of food, diet and different ways of undressing, washing etc. If you are aware that this is the case ensure that home carers providing personal care know and observe these customs.
- Communicate with people with dementia on an 'adult to adult' basis. Refer to the section on communication for further information on good practice.
- Focus on what a person can do — their abilities. Involve them in activities they can manage and enjoy. Failing can be humiliating for all of us. People with dementia require encouragement but will often be able to complete a task if they can do it in their own way at their own pace. Do things with a person rather than for them.
- How we appear to others is important and often bound up with our self-respect. If a person with dementia is inappropriately dressed encourage them to change or rearrange their clothing. Both woman and men feel a good deal better if they are well groomed. Make sure that if a hairdresser visits the scheme that everyone has an opportunity to have a haircut.
- Make sure that the person's right to privacy is respected. Even if you or a carer have a key knock on the door before entering.
- Even if you are unsure whether a person understands what you are saying consult them on matters that concern them. Give information clearly and slowly, checking if possible that the person understands. If you are asking the person to make a choice, phrase questions in such a way that only a "yes" or "no" answer is required.
- People with dementia will be sad or upset at times. Try to understand how they feel and support them. It is patronising to try and 'jolly' them along. In the early stages of dementia people will often try to describe how they feel and discuss their fears and anxieties. Don't brush these feelings aside. Listen, and if you feel that they would benefit from talking to someone else other than their family persuade them to talk to a health visitor, counsellor or another sympathetic professional.
- It helps a person to feel valued and respected if those around them are flexible and tolerant. Make time to listen and chat, show some affection as appropriate.

## Communication

Many people with dementia frequently cannot find the right words or remember someone's name. This can often be a source of frustration and difficulty for both the person with dementia and their carers.

Much of the behaviour which may be labelled difficult, is an attempt by the person with dementia to communicate. In working with someone with dementia it is important to be aware of the ways people communicate non-verbally by observing their body language.

Carers and families often find the loss of communication skills distressing. Relatives may be called by different names. Carers and families may try and interpret, sometimes without success, what the person with dementia is trying to tell them. This can be upsetting for both parties.

Fact and fiction can become blurred as dementia progresses. It is not uncommon for people with dementia to give an explanation for an event that is patently untrue. This is not a deliberate falsehood but simply an attempt by the person to understand confusing events or "fill a gap" in their memory. This is referred to as "confabulation".

It is also important to remember that there may be specific issues which affect people from black and minority ethnic groups with dementia. People for whom English is not their first language, even though they have lived in the UK for a very long time, sometimes revert to their original language or even lose their ability to understand and speak English. They may also have greater difficulty expressing themselves and intermix languages.

It is worth remembering that problems with sight, hearing and ill-fitting dentures or other mouth problems can make communication difficult. Pain, illness and side effects of medication may also affect a person's ability to communicate.

### *Good practice*

- Encourage and listen carefully to what a person with dementia is trying to tell you. Let them finish their sentence and if necessary check back with them to see if you understood correctly.
- Ensure that you have engaged the attention of the person before you start to communicate. Make eye contact and position yourself so that they can see you clearly. Many older people unknowingly 'lip read' as their hearing deteriorates.
- Remember that people with dementia have difficulties in separating out background noise. Mute the TV or radio and do not try to have important conversations in a crowded room.
- A person with dementia will read and be sensitive to your body language. Try to communicate calmness and confidence — if you are tense or agitated this may upset the person with dementia. You can pick up clues about how the other person is feeling from their facial expression, the way they hold themselves and how they move.
- Always try to acknowledge the feelings/emotions behind the conversation.
- Speak clearly and calmly using simple, short sentences. If the person doesn't understand what you are saying, phrase it differently rather than keep on repeating the same words.
- Diffuse difficult situations relating to miscommunication by taking some of the responsibility for any misunderstanding and possibly using shared humour.
- Always show respect for the person with whom you are communicating. Be kind and reassuring without being patronising and avoid criticising or making them feel small. Do not speak down to, across or ignore people with dementia when you are talking in a group.

### *Good practice specifically relating to people from black and minority ethnic groups*

- Always get to know the individual as much as possible.
- Be aware that an individual's behaviour might be related to their cultural and ethnic background.
- Never assume anything e.g. that a person's immediate family shares their culture or experience.
- Access appropriate ethnic support for the individual, but also be aware that younger care workers of the same ethnic origin may not necessarily fully understand the specific needs of the older person with dementia.

## Adapting the environment

The environment in which people live has a significant effect on their lifestyle, behaviour and mood. Many of the older style sheltered housing schemes have corridors and closed doors, all of which look the same. For many older people, especially those with dementia this can be very confusing. People may not like to ask directions and admit they are lost. They may try to enter another person's flat genuinely mistaking it as their own. The lights in corridors could be mistaken by a person with dementia as daylight and lead to them walking round the scheme at night.

*All older people like to feel safe and comfortable in their home. The recommendations given below will assist all tenants not only those with dementia.*

- If possible have some quiet areas where people can sit and have a chat or watch the 'world go by' without background noise from a TV or other disturbance.
- Make sure that stairwells and corridors are well lit. This can help to prevent falls.
- Paint corridors and floors in different colours. Use primary rather than pastel colours which can appear similar to a person with poor vision.
- Ensure that the floor number is clearly displayed opposite the lift so that it can be seen when the lift door opens.
- Ensure that toilets, laundries, waste rooms, lounges etc. are clearly signposted using words as well as symbols which may not be recognised by older people.
- Ensure light switches for bathrooms and toilets are clearly marked and the alarm cord is labelled as such.
- When a person first enters a scheme spend some time helping them to find the route from their flat to the front door, the lounge and service areas e.g. laundry, waste room. It may be helpful to write these routes down.
- Encourage all tenants to individualise their front doors in a way that feels appropriate to them.
- Ensure that clocks and calendars are correct and maps and information are current. Christmas cards, for example, should not be displayed in February!
- Ensure the scheme reflects the culture and age of the people living there. Tenants should be consulted on what they would like in terms of décor.
- Older people often like to see old photographs of the area as it used to be. Discussing shared experiences with other people may result from seeing a picture of the butcher's shop 50 years ago.

## Living alone

Most people are happiest when living in their own home. A person with minimal dementia will probably be able to move into sheltered housing and if provided with support in the first few weeks will settle and successfully maintain their independence. However for some people a move may cause increased confusion and a marked deterioration in their functioning.

A person with dementia living alone will almost certainly require some degree of help with daily living activities and possibly personal care. The family and / or home care workers may provide this. Services that can offer support should be contacted at an early stage, not when a crisis develops.

It should be remembered that although hazards can be minimised with thought and planning, a certain degree of risk is inevitable if a person with dementia is to retain their independence. It is therefore essential that this is fully discussed with family members who will need to understand and agree on acceptable levels of risk.

Whilst recognising that the role of the scheme manager is not to provide care it maybe helpful to consider the following points when a person with dementia is being supported in sheltered housing.

### *Good practice*

- A regular daily routine, visits and arrangements for going to a day centre or out shopping provide stability and security for a person with dementia.
- An uncluttered living area will help to avoid spills and accidents resulting from impaired co-ordination. If possible put ornaments and vases of flowers on shelves at the sides of rooms and keep the centre of all rooms clear of flexes and small furniture. It often helps if cupboard doors and drawers are clearly labelled on the outside.
- People with dementia need regular health checks. They may not be able to recognise when they are feeling unwell. Hearing aids, glasses and dentures need to be checked. Foot care is important.
- Ensuring that a person living alone is taking their medication at the right time and in the right quantity can be problematical. It helps if the person is only taking medication that the doctor feels is really necessary. Community care workers are often not allowed to administer medication. There are compartmentalised boxes in which medication can be labelled and placed in separate doses. A reminder at the correct time, possibly by the scheme manager or by a phone call from a family member may assist. All out of date or no longer required medication should be disposed of.
- People with dementia will often need help managing their money. They may forget to pay bills or for their home care. Families usually deal with these matters on behalf of their relative but in the absence of family, or if a scheme manager believes that money is being mishandled in any way, social services should be contacted.
- Memory aids such as useful telephone numbers and the names of key people (the scheme manager for example!) should be clearly displayed.
- It is important that people eat regularly and have a least one proper meal a day. This can be arranged with a meals service but it may be necessary for someone to check that it is being eaten not just thrown away. It is also important that out of date food is disposed of.

# Working effectively with older people with dementia

## Helping a person to maintain skills

As dementia progresses people are likely to find certain tasks increasingly difficult. Although the role of the scheme manager is not to provide care they may have an influence on the way care is given by families and home carers. There will also be times when a person with dementia is involved in activities and tasks, for example during a social event in the communal lounge. The way a scheme manager works alongside a person with dementia will act as a role model for others. People with dementia may be able to cope with a task if it is broken down into stages. For example, washing up or drying crockery but not being able to put it away in the right cupboard.

### *Good practice*

- Encourage the person with dementia to do as much as they can for themselves. Focus on what they can rather than what they can't do. Give tactful reminders and simple instructions. People will feel useless and upset if they are being 'managed' or criticised.
- Familiar surroundings, a regular routine and a relaxed atmosphere contribute to ensuring that a person with dementia can maximise their potential to undertake tasks.
- If a person is beginning to find undertaking certain tasks difficult due to disability or dementia an occupational therapist may be able to advise on equipment and adaptations and maybe work with the person to adapt or maintain their skills.
- People with dementia will be able to join in some social activities. Although they may not be able to play complex card games they may enjoy simpler games, bingo, jigsaws, creative activities and music. In order that they can participate as fully as their functioning allows, try and ensure that they have a person, maybe a fellow tenant or a friend, to support them.
- It is tempting to take over when someone is struggling with a task. Resist! Offer assistance by doing the activity with them making them feel involved.

## The role of the scheme manager

In the context of sheltered housing the role of the scheme manager, and the services provided as part of this, are essential in encouraging and maintaining social skills, social inclusion and continuing inter-personal relationships for tenants with dementia.

The role of the scheme manager is changing from the previous function of 'good neighbour' to that of a skilled, trained and experienced housing professional. The title in many instances has changed to scheme manager to reflect this.

The typical duties of a scheme manager would include:

- Buildings maintenance, repairs and housing related work
- Hands-on emergency and crisis response
- Social and emotional support
- Social inclusion and activities organisation
- Accessing and liaising with statutory support services
- Daily checks and calls

In addition, in terms of managing people with dementia, the scheme manager's value is that of a vital and consistent point of familiarity at the centre of service provision. The support a scheme manager provides to a tenant with dementia may include:

- Advice and reassurance
- Emotional and behavioural support
- Reassurance, orientation and validation
- Conversation and companionship
- Social inclusion and activities support
- Occasional hands-on personal care
- Out-of-hours crisis support
- Encouraging and prompting nutritional and self care
- Prompting medication

The scheme manager's role is not only to provide 'internal' support within the scheme but also to bridge the gap to external agencies. Their advocacy on behalf of their tenant can be crucial in accessing appropriate care. Agencies can often overlook, under-value or misunderstand this role. In particular a scheme manager will have extensive knowledge of, and can offer vital information about the tenant which can assist formal assessment. This will include:

- Observations of the individual in their natural home environment.
- Knowledge of routine, structure and habit.
- Changes in behaviour, emotional and mental health.
- Relationships with other tenants.
- Family contact and input.
- Domestic and social capability.
- Background and recent circumstances.

Thus a scheme manager's inclusion in the care planning process, and their contribution to subsequent monitoring and review of the care plan itself, is an important part of the process of allowing people to maintain their independence in their own homes.

Finally, *Brighter Futures* (Kitwood, Buckland & Petre. 1995) specifically linked the morale and job satisfaction felt by scheme managers to the sense of well-being in tenants with dementia. The exhortation for providers to ensure high levels of job satisfaction for their scheme managers bears repetition here and, encouragingly, there is evidence that scheme managers who have evolved into empowered scheme managers are experiencing more job satisfaction than before. This in turn is giving all tenants a stronger sense of scheme services being tailored to individual needs, from which those with dementia clearly benefit.

### *Good practice*

- Recognise the contribution made to community care for people with dementia by housing, housing workers and scheme managers.
- Promote the scheme manager as a housing and care professional.
- Identify and record the service delivered, and ensure this is included in the care planning and review process.
- Identify and clarify the role of the scheme manager in the care planning and review process.
- Actively participate in care conference reviews.
- Keep objective and comprehensive records.
- Present objective, accurate well evidenced observations.
- Support the person with dementia to state their views.
- Enable the family to put forward their needs.
- Know, understand and make others aware of the policy and procedure of the organisation.
- As the needs of the individual change ensure care plans are reviewed and updated regularly.

## Looking after yourself

When people with dementia live in sheltered housing there may be unrealistic expectations on the part of the tenant themselves, their family and health and social care workers. The project work that supported this guide found that scheme managers often undertook tasks for people with dementia that are above what they are expected to provide. At the tenants meetings concerns were expressed on the demands made on scheme managers by people with dementia.

Although not recognised as a carer, scheme managers often carry similar feelings of anxiety especially when they are not at work. Other tenants may also place excess demands on the scheme manager through complaints, justified or otherwise, and wanting the person with dementia to be cared for outside the scheme.

Many scheme managers have families and balancing all these demands is very stressful. Even though it may feel as if you are coping well with these pressures they could build up and affect your health. It is easy to ignore your own needs when so many demands are being made on you but it is important to take steps to safeguard your own well-being to enable you to carry out your job effectively and retain your self confidence.

### *Good practice*

- Ensure that you know what help is available for the person with dementia and how this can be accessed.
- Make clear your role to health and social care staff. If services are not being provided or delivered after the individual has been assessed as needing services find out why. It may be that health and social care staff regard that the person with dementia can call on the scheme manager and treat them as having a lower priority than a person living alone in the community.
- Make your role clear to family and friends and ensure that they understand that the responsibility for the tenant does not rest with you. Make it clear that you value the support that they give and if necessary suggest ways in which they could help if they are not doing so.
- Ensure that you receive support from within your working environment rather than taking your problems home. Hopefully your manager will listen, support and advise you or you may have access to a scheme manager support network or your employers counselling service. You may also be able to get support from your local branch of the Alzheimer's Society.
- If you find yourself in a situation which is confrontational or particularly stressful take some time alone afterwards to settle down. Have a cup of tea, talk to someone who will understand or a take a short walk.
- If you feel that are becoming stressed, anxious or not sleeping, see your doctor. It is easier to tackle these problems at an early stage rather than when you are feeling overwhelmed and that you can't cope.
- Keep an account of extra hours you work and make arrangements with your manager to take this time back.
- Do the things that we all should do to stay healthy:
  - Pace yourself and don't aim for perfection
  - Take time for yourself
  - Eat a well balanced diet
  - Take some exercise every day
  - Take all your leave entitlement
- Remind yourself that you are managing a complex job and sometimes very difficult situations. To be a successful scheme manager you need to be tolerant and have strengths and skills that many other people do not possess.
- Above all remember that you do a job that is valued by many people and contributes to ensuring that older people are able to remain living as independently as possible.



# Difficult or unusual behaviour

## Introduction

The majority of people with dementia living in sheltered housing have support from carers, families, the scheme managers and other tenants. It is usually only when the person's behaviour causes distress or impacts on the other people in the scheme that the issue about whether they can continue to live in the scheme arises.

*Examples of this behaviour include:*

- Walking about or 'wandering'
- Aggressive behaviour
- Incontinence
- Lack of inhibition
- Refusal to accept services
- Intrusive behaviour

Most of this behaviour is an attempt to communicate feelings or needs. Understanding the reason for a person's behaviour often helps others to cope with it; in many cases behaviour can be managed or even prevented. It is always important to remember that the person is not being deliberately difficult. But working with these situations is stressful and scheme managers need to be able to obtain help and support easily.

## Walking about or wandering

It is sometimes forgotten that for many older people walking has been an essential part of their lifestyle. People walk to keep fit, relieve tension, help them to sleep or just for enjoyment. For some it formed part of their employment. However for people with dementia walking is often regarded as risky. It is important to remember that most people with dementia retain their road sense, are rarely involved in traffic accidents nor do they become lost for long periods of time. Walking seems to be a phase of dementia that many people go through, but this phase is often quite short lived.

### *Good practice*

Find out from the family if a person has a regular pattern of walking — time of day and route and make a record of this. Record any details of likely destinations (old home address, work place etc.)

It is illegal to restrain a person by locking them in. If the person is determined to leave, it is better not to confront them as this may lead to them becoming upset or even aggressive. Sometimes it is helpful to accompany them a little way and then persuade them to come back for a cup of tea. Try and arrange for a family member or friend to accompany the person on a walk on a regular basis.

Ensure that the person carries some form of identification. For example the name and phone number of a person who can be contacted if needed in case they get lost. This could be sewn into a jacket or a handbag so that it is not easily removed.

Agree with the family the procedure to be followed if a person disappears for any length of time. Ask them to give you a recent photograph that you can give to the police if necessary.

### **Reasons for walking**

- When they first move to a new place a person with dementia will probably feel lost and disorientated, walking around is an attempt to become familiar with their new surroundings. This should disappear over time. Problems are more likely to occur if the signposting and layout of the scheme are poor — making the new environment 'hard to learn'.
- Sometimes people with dementia might set off for a purpose but then forget that purpose. They may also forget that their carer or relative has told them that they are going out and may set out to look for them. It is likely they will be very anxious in this event.
- A person may walk because they are bored, feel the need for exercise or are continuing a habit. Sometimes people walk to alleviate stiffness or pain.
- People with dementia sometimes walk, searching for someone or something related to their past or because they feel that they have a task to perform.
- They may also walk or pace around because they are very agitated or anxious or as a side effect of some medication.

## Aggressive behaviour

People with dementia may appear to over react to situations and sometimes behave in an aggressive manner. This usually takes the form of becoming very agitated or shouting. Very occasionally a person may lash out or kick or punch another person or property. Whatever the form of the aggression those affected will feel distressed and anxious about the best way to cope and prevent a reoccurrence. It helps to understand the possible reasons for an aggressive outburst and what preventative measures can be taken.

### *Aggressive responses may occur when a person with dementia feels:*

- frustrated, under pressure or humiliated because they can no longer cope with a simple task;
- their independence is being threatened. This can arise when help is being given to assist with what have been essentially private functions e.g. washing, dressing and going to the toilet;
- criticised or judged because they have made a mistake or forgotten something;
- frightened or bewildered due to change in routine, noise or contact with too many strange people;
- tired or in pain and unable to express their feelings.

Aggression can also be a visible demonstration of a person avoiding or refusing to do a task they have been asked to do, or of asserting their right and determination to do something others are trying to stop them doing.

### *Examples of preventative measures include:*

- Providing an unrushed, stress-free environment; avoiding excessive noise and too many people; behaving in a calm non-critical and tactful manner and avoiding confrontation.
- Ensuring that other tenants realise that both the environment and the way they interact with a person with dementia has an effect on their behaviour.
- Looking for signs of increased agitation or restlessness and offering reassurance.
- Trying to ensure that the person has access to exercise and activities which they can cope with.
- If you suspect they are ill or in pain, try and persuade them to see their GP or discuss your concerns with health professionals who may be in contact with the tenant.

If a person with dementia does display aggressive behaviour you must concentrate on coping with it as calmly and effectively as possible. In a scheme it may be difficult to call for help and it is important that you do everything you can to minimise the risk to yourself, other tenants and the person with dementia.

Afterwards remember that the person with dementia probably has no memory of the incident though they may feel a sense of unease for a time. Although it may be difficult, try to behave in a calm, reassuring manner and refrain from attempting to discuss the episode with the person concerned.

Take time for yourself. You will probably feel shaken and upset. Have a cup of tea, go for a walk or find some other way of settling yourself down. Remember you must record the facts and inform your manager.

If this behaviour becomes more frequent discuss this with the person's family and seek help from health or social care professionals who may be able to suggest other ways of preventing or managing aggressive behaviour.

Remember that aggressive behaviour is rarely personal and you are not to blame. Don't feel guilty or bottle up your feelings. Discuss them with someone who will understand. Hopefully this will be your manager but maybe you will feel more comfortable talking to a fellow scheme manager, someone from your local Alzheimer's Society or another professional.

### *Good practice*

Being aware of what triggers an outburst and taking preventative measures to avoid them is the best solution, but of course this may not always work.

### *Good practice*

- Stay calm and do not enter into an argument or get angry.
- Reassure the person and try to distract them.
- If a person with dementia is physically aggressive give them plenty of space. Leave the room for a few minutes if necessary.
- On no account try to restrain them.

# Difficult or unusual behaviour

## Incontinence

Although some people with dementia develop incontinence it is not inevitable and may be due to reasons other than the dementia. Some physical reasons for urinary incontinence include:

- Urinary tract infections which usually respond to treatment.
- Prostate gland problems in men which may require treatment.
- The side effects of some medication.
- Severe constipation with places pressure on the bladder. All older people, including those with dementia, who are not eating regular meals and drinking plenty of fluids are prone to constipation.
- Faecal incontinence is rare and always justifies further investigation by the GP.

In some cases people with dementia may become incontinent on an intermittent or regular basis because they forget to go to the toilet or don't know where it is. In the later stages of dementia they mistake other receptacles, such as the wastepaper bin, for the toilet.

### *Good practice*

- Encourage the person to see their GP to eliminate treatable causes of incontinence. If there are no treatable causes the GP may refer them to a community nurse or continence adviser who can assist with the management of the problem.
- Make sure that toilets in the scheme are clearly labelled and have handrails for ease of use.
- Be aware that fidgeting and getting up and down may indicate that the person wishes to go to the toilet. A gentle reminder of where it is located may be helpful.
- Advise the family and carers that the person is having problems with continence. Hiding soiled garments is not uncommon. Mattresses and bedding may require protection and special pants can be worn if needed. A commode by the bed at night might be helpful, or leaving a light on in the bathroom.
- Remember that most people find incontinence embarrassing and distressing. Be tactful, sensitive and reassuring when dealing with this issue.

## Refusal to accept services

It is almost impossible for someone with dementia to live independently if they refuse to accept support from their family or care services. Although people with dementia have a right to refuse services in the same way as all citizens, it is important that they are helped to understand that refusing services may result in them having to live elsewhere. In some cases refusing to accept services is not so much a refusal of the services themselves but a refusal to accept the need for those services. Receiving care may seem to them to emphasise increased dependency and raise self-awareness of their decreasing mental and physical abilities.

A person with dementia might refuse services for a number of reasons including:

- Believing they are managing perfectly well on their own and not recognising that they are not able to undertake tasks they did before.
- Thinking that they cannot afford services or not wanting to accept 'charity'.
- Having the carer visit at a time they find inconvenient or if the way that the care is delivered is unacceptable to them. For example the carer may do things for them instead of helping them to do things for themselves or they may be insensitive when carrying out personal care.
- Perceiving that they are becoming a burden and believe that by accepting services that it is the beginning of being moved into residential care.

Refusal to attend day centres is not uncommon for a person with dementia. The familiarity and security of their home is important and they often find going out, especially with someone they don't know, and mixing with other people very stressful.

### *Good practice*

- It is often easier to persuade people to accept services when they are in the earlier stages of dementia and understand that this is the way that they can remain living independently. If they later refuse, remind them that it was a joint decision and gently remind them of the possible consequences of continuing to refuse services.
- Develop a good working relationship with care managers and workers so that you can influence the way care is delivered. For example making them aware of the person's routine, likes and dislikes. Try and find out why the person may be refusing to accept help, and exactly what they are refusing - meals, domestic help, bathing, day care. Previous lifestyle, preferences and culture should be considered when services are being refused. It may be that the person feels that the service has been imposed on them and that they had little or no choice in the matter. The service could possibly be delivered in a different way that the person with dementia finds more acceptable. A discussion with a care manager or social worker could be helpful in this respect.
- If refusal is because the person objects to paying or forgets to pay, discuss this matter with their family and care manager who may be able to make arrangements for payments to be made on their behalf. Remember that Disability Living and Attendance Allowance are available in order to pay for extra care.
- If the person with dementia is refusing services because they do not have a rapport with the care worker or they do not like the way the care is being delivered, this needs to be addressed tactfully with the worker concerned or the care manager.
- Services are likely to be refused if there is a lack of consistency in the staff, meaning that they are unlikely to be able to build up a relationship with the person. This practice should be brought to the attention of the care manager.
- If a person is refusing to attend a day centre it may be because of concern over changes in routine, or anxiety about the journey or concern that they can get ready in time. These issues may be resolved through discussion with the care manager.
- If day centre attendance is primarily to provide social contact then a regular visit from a "befriender" or relative could assist the person to socialise more within the scheme.

## Intrusive behaviour

One of the reasons people with dementia can no longer be supported in sheltered housing is the impact their behaviour has on other tenants. Examples of behaviour that people find difficult to cope with are:

**Repetitive questioning and behaviour** – asking the same question over and over again or repeatedly packing and unpacking bags. This may be due to short term memory loss i.e. the person doesn't remember that they have already asked the question or they can't remember what the answer was. It may also be due to anxiety or insecurity. Some repetitive behaviour may relate to a former job or activity.

**Hallucinations or delusions** – a minority of people with dementia see and/or hear people or things that are not there. They may also believe things that are not true. This may result in a person talking, laughing or crying without apparent reason. Hallucinating and delusional beliefs are more likely to occur in cases where the person is suffering from vascular dementia.

**Hiding things** – sometimes people with dementia deliberately hide things to keep them safe and then forget where they have put them, or that they have hidden them at all. They may also hide food. It is likely that this behaviour once again is the result of feelings of insecurity.

**Suspicion** – this can be particularly trying and may lead to accusations of stealing, plotting and abuse. Whilst it is important to explain to others that unfounded accusations may be caused by dementia, accusations should not automatically be dismissed but should be reported and investigated.

**Lack of inhibition** – in some cases dementia may result in a person being unable to judge situations correctly resulting in behaviour that is inappropriate. Within a sheltered housing scheme it is often socially or sexually inappropriate behaviour that causes embarrassment to other tenants, leading to the person becoming socially excluded.

### *Examples of this behaviour include:*

- Undressing or appearing inappropriately dressed which may indicate that a person has become confused as to where, when and how to dress. They may also be removing clothes because they are hot, uncomfortable or in some cases because they want to use the toilet.
- Fiddling with their flies or underwear which may also indicate that they want to go to the toilet.
- Swearing or spitting.
- Sexually explicit behaviour.

Balancing the support you give a person with dementia with the effect that their behaviour is having on other tenants is very difficult. Whilst the reasons can often be given as to why people with dementia behave in certain ways, it does not always mean that such behaviour can be managed or minimised.

### *Good practice*

- Inform the person's family of the changes in behaviour which are beginning to cause concern or distress. This may be a task best undertaken by a health or care professional working with the person. If you decide to talk to the family, discuss this with your manager first. Extreme sensitivity will be required. You may not be believed or the family may find it very difficult and distressing to cope with the knowledge, for example, that their parent or relative is behaving in a sexually explicit manner.
- Keep an objective record of incidents and episodes of behaviours that cause concern or which result in complaints from other tenants. Keep both the care manager and your manager informed.
- If the situation arises where it becomes clear that the person can no longer be supported in the scheme ask the care manager to take action. This could entail a reassessment of health and social care needs of the person with dementia, speaking with the family and/or convening a case conference.
- If the needs of the person with dementia can only be met in a nursing or residential care home this does not imply failure on your part. If you have known the person for some time you may feel that you have lost a friend as well as a tenant. Hopefully you will be able to talk about this with your manager or fellow scheme managers, who may very well have experienced similar situations.



# Services available and how to access them

## Introduction

The provision of health and social care services for older people is based on providing support and care in the community to enable them to live independently for as long as possible. To this end a range of services can be provided in any local area to meet the needs of people with dementia and their carers. The majority of services are provided in the community by social services, primary care services and the voluntary and independent sectors. Specialist mental health services for older people are provided by NHS Trusts.

Not all services are available in every area and the way services are accessed and arranged may vary from place to place. Increasingly, due to the new partnership working arrangements between health and social services, single access points for referrals to integrated health and social care services are in place.

Many scheme managers will be aware that how services are accessed and provided is subject to change and keeping up to date can prove problematical. However for people with dementia to be supported in sheltered housing it is essential that scheme managers know how and where to access services.

## Primary care services

Primary care services are based in GP surgeries or health centres. The type of services provided will vary but the core team includes:

- GPs who may work alone or be members of a group practice
- Practice manager and support staff
- Practice nurses
- Health visitors
- District nurses and Community Psychiatric Nurses

Other team members may include:

- Care managers or social workers
- Specialist mental health workers
- Continence advisors
- Podiatrists or chiropodists

Community link workers are often employed in areas where there are special needs, for example in areas with a high number of residents from black and minority ethnic groups.

Nurse practitioners who have been through extended training in order to diagnose and treat more common illnesses are joining primary care teams.

GPs and other primary care staff, health visitors and community (district) nurses are often the first professionals that older people and their carers discuss problems with. How a

### *Good practice*

If you feel able to, share any concerns you have regarding the health of a tenant with them in the first instance and encourage them to visit their GP. Suggest that they write their symptoms down so that they are able to present a clear picture of what they are experiencing. It is often helpful if a close family member accompanies an older person to see their GP in cases where they may forget the purpose of their visit or misrepresent their symptoms.

If you are unable to persuade a tenant to see their GP ask if you might talk to their family about your concerns.

The relationship between a GP and his or her patient is based on confidentiality and trust. Many GPs will not visit a patient at the request of a scheme manager unless they know that the person concerned has given their permission for the GP to be contacted. However they may ask another member of the primary care team, for example a health visitor to call.

If you are unsuccessful in persuading a tenant to see their GP make sure that they receive their annual "over 75 years" health check often carried out by a nurse with specialist training in health issues as they relate to older people. Many older people feel more comfortable discussing their problems with nurses and health visitors rather than GPs.

NHS Direct can be accessed by phone or the internet and can provide help, information and advice to scheme managers on local services and how to access them.

GP responds and acts is often dependent on their level of knowledge about dementia, but this is changing and GPs are increasingly likely to use diagnostic tools to diagnose health problems. GPs in particular may have known the person for years and can give support and advice as well as prescribe medication. Even if someone is receiving care from the specialist services, for example a community mental health team, the GP continues to have a role in monitoring their progress and looking after their general health.

## Community care services

The local authority social services department usually provides or commissions another agency from the independent or voluntary sector to provide a range of personal and social care services including:

- Home and personal care services
- Day care
- Residential respite care for designated periods or in an emergency
- Residential and nursing home placements
- Housing adaptations
- Provision of equipment such as walking frames, commodes etc.
- Meals services delivered to a person's home or provided through a lunch club

Social services provision for older people often focus on working with people with dementia and those who are physically frail. In some areas services may be provided through joint health and social care resource centres.

## Home care services

Flexible and sensitively delivered help with personal care, cleaning and other domestic activities is key in supporting older people with dementia in their own homes. Services are "means tested" and older people are sometimes reluctant to pay for services even when they are in receipt of enhanced benefits to pay for care. Service provision can range from a few hours of help with housework to intensive personal care provided through the day. In some areas home care services may be provided at night.

## Access to home care services

Access to these services is usually via an assessment carried out by a care manager or social worker who will also determine whether the person with dementia needs other services such as attendance at a day centre, equipment, meals services etc. A home care manager will then usually visit a client to establish the exact nature of the services to be delivered and arrangements for payment. If the tenant is confused or forgetful it is usually helpful to have someone with them at this time. Referrals for a social care assessment can be made in a number of ways and most departments will take self referrals and referrals from families and scheme managers in addition to referrals from GPs and other health care staff. In some areas community advice telephone lines can be the way into finding out what services are available and making a referral.

Difficulties often arise when there are a number of different carers providing the service and when they have little or no training in working with people with dementia.

# Services available and how to access them

## Home care services (cont)

Sometimes people with dementia:

- fail to recognise and accept their need for home care services.
- fail to recognise the home care worker — especially when workers change frequently or arrive inconsistently.
- refuse to comply with the home care worker.
- behave in a way that the home care worker is unable to manage.
- fail to remember if a worker has visited, or what tasks they have carried out.
- make an accusation against a home care worker.

Specialist home care services for people with dementia are now being set up in some areas. One of the factors which leads to a person with dementia being admitted to long term care is their refusal to accept services.

### *Good practice*

- Introduce yourself to home care organisers, managers and workers and ensure that you make them aware of your role in relation to the tenant.
- Ensure you know the times the service will be delivered and the tasks that will be carried out. Ask for a copy of the care plan.
- Offer to introduce the tenant to a new worker.
- If a person with dementia is refusing services they and their family need to be made aware that this might affect their ability to remain in the scheme.

## Day provision

Day provision either in NHS day hospitals or day centres run by social services, or independent or voluntary organisations may be one of the most important services available for people with dementia in sheltered housing. Many day hospitals and centres provide dedicated services for people with dementia as the needs of people with functional mental health problems, such as depression and anxiety, are different to those of people with dementia. They provide not only a service to the person with dementia but also respite for tenants and scheme managers especially if the behaviour of the person with dementia is intrusive within the scheme. Older people may be reluctant to attend for day care especially if transport arrangements are poorly organised.

A number of therapeutic approaches may be provided within specialist day care centres and hospitals. People with dementia can benefit from:

- reality orientation which has been shown to improve people's functioning if carried out in a consistent and comprehensive way.
- reminiscence and life review which can help people with dementia to retain a sense of identity when their short-term memory is lost.
- validation therapy which requires the acceptance of a person's experience as valid and real, including their memories and feelings. The interaction, including non-verbal communication has led to a more compassionate approach to understanding and coping with dementia.
- Snoezelen which uses sensory experiences; light and sound usually in a dark room and a variety of material for touching tasting and smelling. It has been shown to have positive effects on the behaviour, mood and cognitive performance in some people with dementia. Other creative therapies, for example music and art therapy, can be helpful.

Day centres may provide care for people over a long period of time with a focus on providing social activities, incorporating some therapeutic interventions and personal care, such as bathing and hairdressing services. Some people attending day centres show the similar high dependency needs as

those in residential care homes, indicating that day centres are an important provision to maintaining people in their own homes. Some day centres may permit carers to work by extended opening hours and opening at weekends to allow family carers to have opportunities to socialise.

Access to day centres is usually via an assessment by a social worker or care manager.

NHS day hospitals usually provide assessment and treatment on a time-limited basis. However in some areas they may provide services on a longer-term basis if there is a lack of day centre provision available. Access to day hospitals is via a GP, consultant psychiatrist or other health care professional.

### *Good practice*

- If a person with dementia attends a day centre or hospital, establish when the transport will be collecting the person and bringing them home.
- Remind a tenant in good time in the morning if they are going for day care.

## **Community mental health teams**

Community mental health teams (CMHTs) usually provide the core of the specialist mental health services provided by NHS Trusts. Members of CMHTs include:

- Psychiatrists
- Community psychiatric (or mental health) nurses (are also increasingly working within GP/Primary care teams)
- Social workers
- Psychologists
- Occupational therapists
- Support workers

The membership of CMHTs may vary from area to area. Some teams may specialise in providing an assessment, treatment and care service to older people with mental health problems including those with dementia.

## **Access to specialist mental health services**

Referrals to CMHTs are usually by GPs or social services. Few CMHTs will accept referrals directly from potential service users, families or scheme managers.

## **Outpatient clinics**

Although traditionally provided on a hospital site increasing numbers of specialist outpatient clinics, particularly those for older people, are situated in community and primary care premises.

Some consultant psychiatrists prefer to carry out 'domiciliary visits' to assess and treat people with dementia in the patient's home to enable them to get a clearer picture of the person's level of functioning.

In some areas specialist memory clinics are provided on an outpatient basis. Full membership of a team would include medical, psychology, nursing and occupational therapy staff. In addition to assessment and screening these services prescribe anti-dementia drugs and monitor patient's progress.

# Services available and how to access them

## Sheltered housing with care

It is now possible to receive care over a 24-hour period from a team based in a sheltered housing scheme. This is most usually available for people with physical disabilities but may suit people with mild to moderate dementia if they have moved to the scheme before they became too confused and disorientated.

## Respite care services

Respite care is most often provided in residential care or nursing homes depending on the needs of the individual. Occasionally it can be provided in a person's own home for weekends or evenings by agencies such as Crossroads. Although generally regarded as a service for carers it can also provide assessment, therapeutic and rehabilitation opportunities for people with dementia.

## Access to respite care

A person with dementia living in sheltered housing should be assessed for respite care services on the same basis as a person living in any other housing setting. Care managers or social workers usually undertake assessments for respite care services. A community nurse will undertake a further assessment if a person requires nursing care.

## Support for carers

The Carers' Recognition and Service Act 1995 gives carers the right to an independent assessment of their needs, separately from the needs of the person they are caring for. In reality many local authorities have failed to set up the process by which this should happen. However recent policy has reinforced the requirement on local authorities to put systems in place although it does not necessarily mean that the services that they are assessed as needing will be in place.

Surveys of carers indicate that they place emotional support as the service they most value. However they also need information about the nature of the illness, services available and how to gain access to them.

The National Institute of Social Work has identified ten key requirements of carers.

- Early identification of problems
- Comprehensive assessment of needs for help including social and medical needs
- Medical help for treatable problems
- Prompt referral to other services that can provide help
- Information, advice and counselling
- Continuing support and review
- Regular help with domestic and personal tasks
- Regular breaks from caring
- Financial support — assistance in claiming benefits
- Permanent residential care when it becomes necessary

Although some services for carers such as information and respite care are provided by the statutory and independent sectors, a great deal of specific services for carers are provided by the voluntary sector, such as The Alzheimer's Society and Age Concern. In some areas carers can now attend courses which help them to care more effectively and manage their own stress.

## Hospital and continuing care provision

### NHS inpatient care

Although the policy is to support people for as long as possible in their own homes, occasionally people with dementia may be admitted to hospital for assessment, for treatment or to stabilise their behaviour. The majority of people requiring continuing or long-term care receive this in residential care or nursing homes. Only if a person's needs cannot be met in another setting, for example if they have sustained difficult behaviour or associated physical or sensory impairments would they receive continuing care in a NHS hospital. Some respite care for people with dementia who require nursing care is available in NHS provision.

### Residential care and nursing homes

People with dementia who cannot be supported even with intensive care packages are likely to be admitted to residential care and nursing homes for long-term care. Some homes specialise in the care of people with dementia.

## Other services

Other services that are available for people with dementia and their carers include counselling, advocacy, befriending schemes and other forms of social support. Once again access to these services may be dependent on where the person lives. These services are usually provided by the voluntary sector and a useful list of organisations is provided at the back of this guide. Information on benefits and rights can be obtained from local Citizen Advice Bureaux or from specialist officers sometimes employed by the local authority.

# Older people from black and minority ethnic groups

## Introduction

The age profile for black and minority ethnic groups varies according to their pattern of immigration to Britain and in some cases there may be only a small number of older people from some cultures living in the United Kingdom.

However this pattern is changing and services that are sensitive and respect the needs of older people with dementia from black and minority ethnic groups will need to be developed. Contrary to the commonly held assumption that “families look after their own”, one third of an Afro-Caribbean group surveyed had no children in this country. Although Asian people do seek support from within their own family and community, Asian people are no more able to care for their own ill and disabled relatives without assistance. The situation is similar to the indigenous population. Families of many older people from black and minority ethnic groups are too busy working to look after them and even where extended family networks exist, caring is usually undertaken by one carer.

## Cultural context

What is termed “illness” in one culture may be perceived and explained in very different terms in another culture. Concepts of mental illness are integral to the belief and value systems of the culture within which they are based and must be viewed accordingly. For example in Western cultures, body and mind are usually treated separately, although a more holistic approach is being introduced. In many ethnic cultures mind and body are regarded as one and are treated as a whole. In some cultures dementia may not be recognised as a distinct illness.

In terms of ethnicity the term “Asian” is often used as a generic term to cover people from India, Pakistan and Bangladesh. All these countries have within them a wide diversity of cultures, religions and languages.

## Issues

### Communication

Problems with language are often underestimated. Some older people from black and minority ethnic groups have poor literacy skills and understanding of English. Some may not know how to spell their own name in English. This is a major problem in all aspects of care from diagnosis to provision of appropriate treatment. For example, counselling support is not realistic through an interpreter.

In some cases where dementia or other psychological impairment is present, older people may revert to using their heritage language and this can lead to increased isolation if their younger family members are unable to communicate with them.

### Life experiences

Racism is an everyday reality for people from black and minority ethnic groups. Many will have suffered abuse, both physical and verbal, experienced rejection and discrimination and may have been unable /unwilling to access support from statutory services.

Many people will experience financial problems due to working in poorly paid jobs and possibly sending back to their country of origin money to support their relatives. They may not be able to access benefits or pensions in this country if they have insufficient or no National Insurance contributions. Many people are unaware that they can claim benefits.

Women may have stayed at home looking after their families and had little contact with the indigenous population. They may have only mixed with people from their own culture, and may not speak English despite having lived here for some years. As women often outlive men, they can face serious problems as their environment becomes increasingly strange and isolating.

## **Diagnosis**

An increasing number of studies reveal that establishing a diagnosis of dementia particularly in older people from the Indian sub continent is fraught with problems and there is research which suggests that dementia is less prevalent in this population but when it does occur is more likely to be Vascular Dementia than Alzheimer's Disease. There is a lack of validated mental health diagnostic tools that are not based on "European norms" and some tools have been found to give a high false positive dementia diagnosis in poorly educated older people. Reasons for this include:

- Asking questions to establish possible levels of memory impairment. For example the name of the Prime Minister. Older people from minority ethnic cultures may have no knowledge of this but may be able to give the names of the leaders in relation to their own cultural background. Some older people may have little concept of the western calendar, not recognising months or dates, possibly not even knowing their own birth date.
- Misdiagnosis is more likely when health professionals who have little or no understanding of the culture, values and beliefs of the older person, undertake assessment. The individual and/or their family may explain their symptoms in a way which is not clearly understood by health and social care staff. Predominant symptoms may be conveyed as physical and treated accordingly.

## **Depression**

The incidence of depression amongst older people from black and minority ethnic cultures is believed to be high. In many cases they may have come to this country as young adults intending to return home when they had concluded the working stage of their life. Although they may have experienced culture shock and depression when they first arrived, the need to work, look after their families and possibly send money home left little opportunity for these feelings to engulf them. These feelings may re-emerge when people have more time to contemplate their lives. The realisation that they may never return to their country of origin is for many older people deeply distressing.

# Older people from black and minority ethnic groups

## Availability of services

Only in a few parts of the country where there are large black and minority ethnic populations, are services being developed which are especially geared to the needs of ethnic elders.

Service deficits include a lack of:

- culturally appropriate training for health and social care professionals who can refer and assess older people.
- easily available multi-lingual interpreting services.
- bilingual and ethnic staff in health and social care settings who can work to minimise misunderstandings, improve communication and act as role models in working with ethnic elders.
- provision of clubs, day centres and sheltered housing which caters for specific ethnic groups.
- culturally acceptable domiciliary care.
- illustrations and signs in different languages in health centres, hospitals, day centres and in sheltered housing.
- meals services which offer a culturally realistic choice of meals both in domiciliary services and day care.
- services such as advocacy and carers support relevant to people from minority ethnic groups.

### *Good practice*

- Allow plenty of time for the person and their family to get to know you, what you do and how you carry out your role.
- Try to be aware of the responsibilities felt by other members of the family towards a person requiring help.
- For many ethnic elders their spiritual leader may play a large part in supporting and advising them. They can also provide people working with an older person with helpful information in relation to their beliefs, culture and customs.
- Consider the significance of your gender when visiting a person in their home. Also be aware of any particular customs that it is necessary to observe. For example removing your shoes.
- When communicating with anyone whose first language is not English remember that misunderstandings can easily arise. Keep questions short and use open ended questions e.g. Can you tell me about....? Avoid questions which invite a simple "yes" or "no".
- Deal with one idea and one topic at a time and check that the person you are talking with has understood you by asking them to tell you what they heard. If necessary repeat what you are saying more simply and if appropriate give an example of what you mean.
- The written word may be useful in some instances. Some people may be able to read but not speak clearly; whilst others can read but cannot understand the spoken word.
- If communication is presenting difficulties try and establish whether interpreting services are required and if they are available. Possibly an adult from the family could assist. Never ask children to act as interpreters. If you are working with an interpreter take care to be clear and check with them that the older person has understood what you wish to convey.
- Be aware of possible racist behaviour that may be overtly or covertly displayed by other tenants or people working with the person with dementia. In some cases it may be necessary to point out to the individual concerned that their attitude or behaviour can cause distress and hurt. Often though it is sufficient to point out by your own behaviour that you find this unacceptable.



# The research project which informed this guide

## Background

An action research project, funded by an Innovation and Good Practice Grant from the Housing Corporation, was carried out over a two year period with sheltered housing staff and managers in the West Midlands. scheme managers and housing managers from Anchor, Nehemiah and ASRA Housing Associations provided the information to support the research that underpins this good practice guide and training materials.

The project took into account *Brighter Futures* (Kitwood, Buckland and Petre. 1995) a research study which concluded that sheltered housing “has been found to be a successful environment in which those with dementia can live with well being.” Brighter Futures maintained that the success or otherwise of a person being able to live in sheltered housing accommodation depended on a complex mix of “social dynamics, personality, physical environment, scheme manager job satisfaction and training and service availability.” This project focused specifically on practice, training and support for scheme managers in relation to supporting older people with dementia in sheltered housing.

## Aims

- To produce a good practice guide based on current and collaborative models of working between scheme managers and other service providers. This is to be based on a set of agreed values and principles.
- To design a set of training materials relevant to the needs of scheme managers and housing managers, as housing professionals, working with health and social care professionals to support older people with dementia in sheltered housing.

## The project

Over a two-year period scheme managers from 55 housing schemes contributed to the 4 stages of the project. A variety of methods were used to obtain information including structured questionnaires, interviews with scheme managers and focus group meetings. In addition meetings were held with tenant groups to ascertain how they viewed living with people with dementia.

From the initial fact finding processes the following information was obtained:

- Numbers of people with dementia that scheme managers perceived or knew were living in sheltered housing; the care they received, including the level of support given by the scheme managers themselves.
- Difficulties scheme managers experienced in supporting people with dementia.
- Issues which resulted in people with dementia leaving sheltered housing.
- Scheme managers’ perceptions of different aspects of their job.
- The different ways in which scheme managers worked both generally within the scheme and more specifically with tenants, families and external agencies.
- scheme managers’ perceptions of their needs for training and support.

The areas of work for the focus groups to undertake evolved from the information received. The objectives for each focus group were to:

- Promote peer support and share common experience, current practices and difficulties.
- Encourage reflective discussion and critical questioning of personal attitudes and awareness.
- Increase confidence and ability to work effectively with health and social care professionals.
- Identify and develop collaborative best practice.

Within the groups scheme managers and managers shared information and experiences relating to:

- Understanding dementia and its effect and impact on others.
- Working effectively with people with dementia, including those from black and minority ethnic groups.
- Services which are available and how to access them.
- Understanding behaviour and working with unusual or difficult behaviour.

## Summary

The project concluded that people with dementia could effectively live in sheltered housing if consistent community care services are provided which meet the needs of the individual. The scheme manager's role is essential to ensuring the provision of services but there are areas of misunderstanding relating to the responsibilities of health, social services and housing in working with people with dementia.

There are inconsistencies in the way that scheme managers themselves and housing associations view their role and subsequently other professionals rarely understand the role of the scheme manager. Until there is further clarity and definition of their role as a housing professional working within community care they are unlikely to be fully involved in care assessments, monitoring and reviews. Scheme managers are often left to fill the gaps in service provision thus hiding the need for befriending, social support and advocacy for tenants in sheltered housing.

Working practice and availability of services in relation to people with dementia is variable and joint protocols relating to providing services based on empowerment and promoting independence need to be developed.

Overall the project found many examples of scheme managers working to support people with dementia to live autonomously, successfully and with a sense of well being in sheltered housing.

# Where to get further advice

## **Age Concern England**

Astral House, 1268 London Road, London SW16 4ER  
Tel: 020 8679 8000

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## **Alzheimer's Society**

Gordon House, 10 Greencoat Place, London SW1P 1PH  
Tel: 020 7306 0606

*The leading care and research charity for those with dementia and their carers.*

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## **Association of Crossroads Care Attendants Scheme**

10 Regent Place, Rugby  
Warwickshire CV21 2PN

*Regional centres throughout the UK providing practical support and help for carers.*

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## **Carers National Association**

20-25 Glasshouse Yard, London EC1A 4JS

Tel: 020 7490 8818

Helpline (1-4pm): 020 7490 8898

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## **Counsel and Care**

Twyman House, 16 Bonny Street, London NW1 9PG

Tel: 020 7485 1566

(10.30am-4pm)

*Advice and information on home and residential care for older people, carers and professionals.*

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## **MIND (National Association of Mental Health)**

Granta House, 15-19 Broadway, Stratford, London E15 4BQ

Tel: 020 8519 2122

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## **The Mental Health Foundation**

20-21 Cornwall Terrace, London NW1 4QL

Tel: 020 7535 7400

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*Mind and the Mental Health Foundation both produce booklets about dementia and other mental health problems which may affect older people.*

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