



counsel + care 
for older people, their families and carers

guide

Information from Counsel and Care: 9

Memory loss, depression, 'confusion' and dementia

Memory loss is not an inevitable part of ageing, but it does happen to people in older age, generally as the result of dementia and other related conditions. Dealing with memory loss can be difficult, and it can be very distressing, both for the person themselves, and their family and carers.

This guide explains why people may experience memory loss, depression and 'confusion' and what can be done to maintain living patterns. It also covers the different types of dementia and what support is available to someone with dementia and their carers.

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Your donations, legacies and payroll giving enable Counsel and Care to get the best care and support for older people, their families and carers

Counsel and Care is a national charity; however the creation of the Scottish Parliament, and the Welsh and Northern Ireland Assemblies means there are differences in the ways each region cares for and supports older people. The information in this guide applies essentially to England although there may be similarities with Scotland, Wales and Northern Ireland.

We also produce five separate guides for both Scotland and Wales covering the community care assessment of need process; paying care home fees and making a formal complaint which are the key areas where the policy and legislation differ significantly to England. All of the guides we publish can be downloaded from www.counselandcare.org.uk/helping-you/guides or posted to you by calling our guide orderline on 020 7241 8522.

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1 Memory loss

Although older people do sometimes experience memory loss it is not an inevitable part of getting older. Short-term memory loss may be prompted by a difficult time, such as bereavement, or being worried about something. Once this period has passed, concentration and memory difficulties should also improve.

However, if symptoms begin suddenly or they persist or increase, it is important to speak to a GP about your concerns. It may be that symptoms are caused by something that is treatable, such as an infection, a thyroid gland problem, depression or stress. If depression, dementia or a physical illness is affecting your ability to cope with everyday life skills, then you can request a full assessment of your individual needs from the council social services. This assessment should identify the difficulties you are experiencing and what support in the form of community care services can be provided. For more information about assessments of need, see section 5.6 of this guide and our guide **Assessment and services from your local council** (guide number 12).

2 Depression

2.1 What is depression?

Depression can affect anyone and can make someone feel low, empty and unable to cope, or in extreme cases, suicidal. Depression affects people in different ways. Symptoms may include:

- Ongoing sadness or feeling low
- Feelings of worthlessness, low self-esteem, or low self-confidence
- Tearfulness
- Not sleeping at night, or sleeping more than usual
- Waking very early in the morning
- Poor concentration
- Poor memory
- Problems with eating and appetite – not feeling like eating, or eating too much as a way to comfort yourself
- Feeling anxious and worried
- Not wanting to go out, or join in with social activities, or do things that you normally enjoy

Although not always recognised, depression affects older people just as much as younger people. This may be due in part to older people having to deal with bereavement, or perhaps retirement and loss of social networks. Older people may also have to deal with health and

mobility problems, or sensory loss, which could result in them becoming isolated and lonely.

Sometimes the symptoms of severe depression are mistaken for dementia. If you have dementia you could also feel depressed. If you think you may be suffering from depression you can ask your GP to carry out a health assessment or refer you to a suitable medical practitioner. If depression is diagnosed, then you should ask your GP to explain to you the range of treatments available.

2.2 Treatments for depression

There are a number of treatments you could explore if you are given a diagnosis of depression.

2.2.1 Counselling and support groups

Counselling gives you the opportunity to talk freely and in confidence to a person who is not a friend or relative. The counsellor is trained to listen to you. You can tell them how you are feeling and they then can assist you to resolve the problem. Counselling can help you become more aware of why you are feeling or behaving the way you do, and help you to become more accepting of your feelings and more satisfied with your life. The counsellor should not judge in any way or try to tell you what to do.

There are many different types of counsellors, depending on the training they have had. It is important to find one that you can feel comfortable with, although you may have limited choice if you have counselling via the NHS or a voluntary organisation. Counselling can be conducted over the telephone or face-to-face. It can be a 'one-off' session, or regular meetings over a period of a few weeks or several months.

There is evidence to show that you or your relative may respond better to psychological or 'talking' therapies if the therapist has particular experience of working with older people.

Self-help support groups also can give you an opportunity to talk with others who are feeling the same way or going through similar problems.

Research has shown that some medical professionals still have an ageist attitude towards older people who have depression or mental health problems, which mean the older patient may be automatically prescribed anti-depressant medication without consideration given to treatment by any of the talking therapies. If you would prefer to seek help from a counsellor or a psychologist for your depression, then you should discuss this with your GP. The National Institute for Health and Clinical Excellence (NICE), an independent organisation commissioned by the Department of Health to develop clinical guidelines and guidance on public health and technology appraisals,

has recommended that older people should be entitled to be offered the full range of services for treatment of depression including psychological treatments.

Counselling through the NHS

If you feel that counselling may help you, your GP may be able to refer you to a counselling service. Although counselling is not available everywhere, many GP practices employ counsellors or can refer you to a psychotherapist or a clinical psychologist. Some GPs may not mention counselling but you can ask them to make a referral. Counselling through the NHS is free of charge. There can be long waiting lists for counselling on the NHS.

Counselling through voluntary organisations or charities

Some charities offer counselling for specific problems, such as Cruse Bereavement Care, which specialises in bereavement issues (tel.: 0844 477 9400; www.crusebereavementcare.org.uk). Try your local library, GP notice board, a local branch of Age Concern or Age UK (tel.: 0800 169 65 65; www.ageuk.org.uk) or Mind Association (tel.: 0845 766 0163; www.mind.org.uk) for such organisations in your area. (Their details may also be available in your local telephone directory.) Counselling through voluntary organisations or charities may be free, or there may be a small charge, or charges may be made on a “sliding scale” depending on your income.

Private counselling

Another option, if you can afford it, is to see a private counsellor. Details of individual counsellors are available from the British Association for Counselling and Psychotherapy (tel.: 01455 883 316; www.bacp.co.uk). It is important that the counsellor is qualified and registered with the BACP. Many private counsellors or psychotherapists will offer an initial consultation to enable both parties to decide if they think a programme of counselling/psychotherapy will be helpful.

2.2.2 Psychotherapy, psychology and psychiatry

If you or your relative are diagnosed with severe or chronic depression, you may be referred to an NHS psychotherapist, psychologist or psychiatrist who will be able to provide more intensive long-term therapy in order to analyse and help you or your relative to understand the origins and roots of the depression. A psychiatrist who is working with patients aged 65 and over is known as a psycho-geriatrician. There can be long waiting lists for psychotherapy and psychology on the NHS.

2.2.3 Cognitive Behavioural Therapy (CBT)

This is increasingly the treatment therapy most favoured by the NHS as it is short term, cost effective and can be beneficial in the treatment of a variety of mental health problems such as depression, anxiety, panic disorder, phobias, post traumatic stress and obsessive compulsive disorder. CBT can help you change negative thought patterns that lead to certain feelings or behaviour patterns. An NHS

patient is usually offered between six to eight sessions of CBT. If you think this may help you then you can discuss with your GP whether a referral for cognitive behavioural therapy is appropriate for you.

2.2.4 Medication

Sometimes depression can be caused or aggravated by an imbalance of chemicals in the brain. Anti-depressant medication could help to correct the imbalance.

Anti-depressants can only be prescribed by your GP or a psychiatrist. You may have to take them for six months or longer to treat the depression properly. There can be side-effects from taking anti-depressant medication, for example, you may feel sick, or you may feel more agitated. If this happens, contact your GP promptly, but do not stop taking the medication until you have spoken to your GP and they have agreed you should stop. They will advise you how to reduce the level of medication safely, or change to another sort of medication. You must let your GP know if you are taking other prescribed medicines as anti-depressants can sometimes have an adverse effect on other medications. You should also let your GP know if you are taking any over the counter medications or any alternative herbal remedies.

2.3 Loneliness leading to feelings of depression

Feeling lonely may occur if you live on your own, or you find it difficult to meet people. Some suggestions to combat this may

include:

- Your local council social services department will be able to tell you about social clubs, and day centres in your local area. Contact your local library or local branch of Age Concern or Age UK (tel.: 0800 169 6565; www.ageuk.org.uk) to find out what voluntary clubs are available in your area. Dial-a-Ride and community transport schemes can be used to get to clubs. Again, contact your local council social services department or Age UK for details of transport schemes in your area.
- Befriending schemes provide trained volunteers to visit you in your own home, join you on an outing, or telephone you for a chat. To find details of your local befriending scheme, contact Counsel and Care's VitalLinks network of older people's befriending schemes (tel.: 020 7241 8535; email: vitallinks@counselandcare.org.uk). Your local branch of Age Concern or Age UK (tel.: 0800 169 65 65; www.ageuk.org.uk) may run a scheme in your area.
- Contact the Elderly (tel.: 0800 716 543; www.contact-the-elderly.org) is a charity which organises Sunday outings for older people who are isolated or housebound.
- Think about offering a home to an unwanted pet for companionship. The RSPCA and local pet rescue organisations may be able to help you choose a suitable pet. The Cinnamon Trust (tel.: 01736 757900; www.cinnamon.org.uk), or the Pet Fostering Service in Scotland (tel.:0844 811 9909; www.pfss.org.uk), run schemes to foster a pet if you needed to

go into hospital. The Peoples' Dispensary for Sick Animals (tel.: 0800 731 2502; www.pdsa.org.uk), the Blue Cross (tel.: 01993 822 651; www.bluecross.org.uk) and RSPCA (tel.: 0300 1234 555; www.rspca.org.uk) run subsidised veterinary services if you are on a low income and your pet is unwell.

- If you feel socially isolated you may wish to consider volunteering your skills to a charitable or not-for-profit organisation in your local area. If you have specific skills then you may want to look for relevant organisations to offer your help. Most areas have a local Volunteer Centre. Contact details may be found under the letter 'V' in your local telephone directory or call Volunteering England for details of your nearest Volunteer Centre (tel.: 0845 305 6979; www.volunteering.org.uk). Or look at the national volunteering database, "Do-it", www.do-it.org.uk. Your local branch of Age Concern or Age UK may also be looking for volunteers to help run social clubs or befriend other isolated people. Charity shops in the high street are often seeking volunteer help. The Retired and Senior Volunteer Programme (RSVP) is a national organisation that supports people aged 50 and upwards to find voluntary work, (tel.: 020 7643 1385; www.csv-rsvp.org.uk).
- Physical exercise can be a good antidote to mild depression in addition to maintaining agility and mobility and the opportunity of meeting up with other people. The National Institute of Health and Clinical Excellence (NICE) has recommended that primary care trusts and local authorities

promote exercise programmes for the over 65s in their area. The NICE recommendation on physical exercise is aimed at improving the mental health of older people. It recommends that older people and their carers should be advised by appropriate professionals on how to exercise safely for 30 minutes a day broken down into 10 minute bouts on at least 5 days a week. Ordinary every day activities can be included in this exercise, such as shopping, housework, gardening and cycling. If you want to improve your exercise routine, you may wish to join a local walking scheme of low to moderate intensity. Your GP surgery or local council may be able to advise you about walking schemes, such as Health Walks, with trained leaders, or you may find information about these schemes in your local library. Or you could have a look at Walking for Health's website, and use their "Walk Finder": www.whi.org.uk. Regular swimming is also recommended, and many local councils offer concessionary rates at swimming pools to people aged 65 and over. Various exercise classes and aerobic water activities may be taking place at your local swimming pool. Along with exercise, a good nutritious diet and regular eating of meals will help to counteract the effects of mild depression. If you are suffering from poor sleep patterns or anxiety then you should discuss this with your GP in order to seek treatment or solutions.

- Depression amongst residents living in care homes is often poorly recognised or undiagnosed in spite of the fact that

research shows that a very high number of people living in residential care suffer from depression. If you think that you or your relative is depressed, you can ask for the care home to arrange a GP assessment with a view to diagnosis and treatment, and you can also discuss with the care home manager if a care package can be arranged which will provide more activity, social interaction and stimulation.

3 'Confusion'

Older people with dementia are often described as 'confused'. Whether or not you have dementia, symptoms of 'confusion', such as dizziness, not recognising where you are, having muddled thinking or feeling tearful and agitated may be common.

If these symptoms develop in a short space of time they may be caused by a physical illness, such as a chest or urine infection, or not eating or drinking enough. Medical help should be sought from the older person's GP as soon as possible so that the condition can be diagnosed, treated and brought under control.

The symptoms of 'confusion' could also be a result of a reaction to any tablets or medicine being taken. If you are prescribed any new medication, your GP should check that it will not react against something you are already taking. If you do experience side-effects, speak to your GP immediately.

4 Dementia

4.1 What is dementia?

The term dementia is used to describe conditions that cause the progressive loss of mental ability. Dementia will often affect the ability to remember, learn, think and reason. It may also cause a gradual loss of social skills. There are many different types of dementia.

Sometimes the symptoms of dementia develop slowly and the start of the condition is difficult to pinpoint. In other cases, dementia can develop suddenly and progress quickly. In either case, the effect on the person with dementia, their family and carers can be very distressing.

Dementia can affect people at any age, but is more likely to happen the older someone becomes. At the moment, no one knows what causes dementia, and there is no cure, although treatments and medication are available and can help slow the development or symptoms of the disease.

It is important to remember that dementia is not an inevitable result of old age and that most older people will never suffer from any type of dementia. If you or someone you know has been given a diagnosis of dementia which you do not agree with, you should make sure you talk to the GP and understand the reasons for this diagnosis.

4.2 Types of dementia

There are many different causes of dementia, but the most common types and their symptoms are listed below.

4.2.1 Alzheimer's disease

The most common form of dementia is Alzheimer's disease, which affects about 700,000 people in the UK. It is estimated that by the year 2025, that number will rise to one million dementia sufferers in the UK. Alzheimer's disease is a physical disease, which causes death of the brain cells leading to a progressive decline in mental ability. The causes of Alzheimer's disease are not fully understood and are still being researched. It is likely that a combination of factors, including age, genetics, diet and overall general health affect whether someone gets dementia.

The symptoms of Alzheimer's disease vary from one person to another. It often starts with the person becoming more forgetful or having problems finding the right words. They might become worried about change and be unable to make decisions. They may also become more irritable and easily upset. As the disease progresses, their short-term memory may deteriorate and they may become confused about time and place. They might also start to lose their ability to understand other people and to make other people understand them. Their personality may appear to change; they may resist assistance or behave in an unusual way. They may not be able to carry out basic living

tasks, such as washing and dressing, and may become dependent on someone else for their care needs.

There are treatments available for Alzheimer's disease. Currently, as a result of the NICE guidelines, dementia medications are not prescribed on the NHS to people who have mild to moderate symptoms of Alzheimer's disease. However, the Alzheimer's Society and the relevant pharmaceutical companies have been campaigning for people in the early stages of Alzheimer's to have NHS access to these drugs. Even if you or your relative is in the early stages of dementia, you should still raise the possibility of obtaining treatment with the older person's GP. The Alzheimer's Society (tel.: 0845 300 0336; www.alzheimers.org.uk) can offer information about these treatments.

4.2.2 Vascular dementia

Vascular dementia is caused by damage to the blood vessels that carry oxygen to the brain, and it is usually triggered by either a major stroke or a series of smaller ones (referred to as multi-infarct dementia). It is more common in people with a history of problems with their circulation or high blood pressure. Multi-infarct dementia usually leaves some of the brain's abilities intact. While there is no way to repair the damage already done to the brain, medical treatments may slow down or prevent the development of further symptoms. A distinctive characteristic of vascular dementia is its 'step-wise' progression. This means the symptoms are not gradual, but increase in a series of sudden changes.

4.2.3 Dementia with Lewy bodies (DLB)

This accounts for 10-15% of dementia cases. Like Alzheimer's, this is a physical disease of the brain, which is not fully understood. People who have it will show symptoms usually associated with Alzheimer's disease. However, they may have major fluctuations in their abilities, sometimes on a daily basis. They will also typically suffer from symptoms usually associated with Parkinson's disease (stiffness, tremors and slow movements) and experience hallucinations. Diagnosis of DLB is difficult and people are often initially diagnosed as having Alzheimer's or vascular dementia. The symptoms, in particular the hallucinations, stiffness and trembling associated with Parkinson's may provide the basis of a correct diagnosis. A brain imaging test may also be recommended. It is important that DLB is diagnosed correctly as sufferers can have an adverse reaction to certain types of medication.

4.2.4 Other forms of dementia

There are rarer cases of dementia caused by a variety of other things: other degenerative brain diseases; damage to specific parts of the brain; alcoholism; HIV/AIDS; or head injury.

4.3 Symptoms of dementia

Although dementia usually develops over a long period of time, not everyone will be affected in the same way. Some people may experience a rapid decline in their mental ability. However, dementia caused by Alzheimer's disease can take 10 to 15 years to develop and

may only become apparent if the person experiences a trauma, such as moving home, or a bereavement. Some of the symptoms of dementia may demonstrate themselves in the following ways:

- **Learning** – the ability to learn new skills can be affected, for example, difficulties with learning how to use a microwave, or a new piece of equipment.
- **Memory** – many people become more forgetful, particularly about the recent past, for example, whether they have taken their medication or not.
- **Communication** – speech is often affected. People experiencing dementia may find it difficult to express what they want or to understand other people. This may cause feelings of frustration.
- **Personality and behaviour** – many people experience significant swings in their emotions. For example, they may become suddenly tearful or angry. Other people may become withdrawn and delusional and believe things are happening which are not. Others may walk around, but forget their purpose (sometimes called 'wandering'). They may forget faces and names, even of familiar people. Others may experience very few personality changes or emotional difficulties.
- **Disorientation** – some people find they have a problem understanding time and place. Because of this, they may get lost or do things at an inappropriate time.
- **Depression** – this can affect a person's ability to concentrate and cope with life.

- **Personal care** – many people with severe dementia find it difficult to complete tasks in the correct order. They may need assistance preparing meals, washing, dressing and going to the toilet.
- **Judgement** – as the dementia progresses, the person’s ability to make judgements about the risks to themselves from hazards may diminish. For instance, they might not be able to use the cooker safely but are unaware of this.
- **Mobility** – as the illness progresses the person’s ability to keep their balance and walk steadily may deteriorate.
- **Continence** – although lack of continence can be caused by a number of reasons, a person with dementia may experience problems with continence because they may not recognise the need to use the toilet. If they have difficulty learning new skills and remembering learnt skills, they may not be able to locate the toilet. This issue is particularly important for a person with dementia who is moving into a care home.

Many people who are in the early stages of dementia will only experience slight forgetfulness, mood swings and occasional out-of-character behaviour. People with advanced dementia are often severely affected and may require 24-hour care at home or in a care home which employs staff specialised in dementia care.

4.4 Diagnosis of dementia

If you are worried that you or someone you know may have dementia, speak to the GP as soon as possible. They will be able to check whether you or the person you are concerned about is demonstrating signs of dementia and will investigate the cause of the symptoms. Sometimes, the symptoms are caused by other treatable conditions, such as depression, thyroid gland disorders or a reaction to certain drugs. It is very important that the possible other causes are investigated.

The GP will normally refer you or your relative to visit a psychiatrist who specialises in the care of older people for a full diagnosis – a psycho-geriatrician. You or your relative may be referred to a memory clinic, where professionals from a wide range of specialties will carry out thorough investigations to demonstrate the most likely cause of memory loss, and can then begin the appropriate treatment. In order to be clear about the diagnosis, the psychiatrist may ask you or your relative to visit the assessment unit or memory clinic over the course of a few weeks. Also, a community psychiatric nurse (CPN) may visit you or your relative at home.

More specialist advice about dementia can be obtained from the Alzheimer's Society (tel.: 0845 300 0336; www.alzheimers.org.uk).

4.5 Making decisions for someone who has dementia

If you have a relative with dementia, you may find that you need to make some decisions on their behalf, if they are unable to decide for themselves, or communicate their decision. To make care decisions on behalf of a relative, you will need to have in place a Lasting Power of Attorney (see below). There are rules in place to protect the person with dementia, as well as the person making decisions, and guidelines for the appropriate way to make these decisions. These rules are set out in the Mental Capacity Act 2005, which came into force in October 2007. Family members and professionals who need to make a decision for someone who has dementia have to comply with this legislation. Guides have been issued by central government for professionals, families and advisers on how the Mental Capacity Act should be followed. For further information on these guides, contact the Office of the Public Guardian (tel.: 0845 330 2900; www.publicguardian.gov.uk).

4.5.1 Assumption of capacity

The Mental Capacity Act 2005 starts with the assumption that everyone has what is called 'capacity' (the ability to make informed decisions) unless it is proven otherwise. The decision about someone's level of capacity can be made by a psychiatrist or a relevant medical professional, a social worker or a formal carer and should take into account the individual circumstances of the situation. In the event of important decisions about the person's future or treatment, it may be advisable to have a formal assessment of capacity undertaken by a

medical professional such as a psychiatrist or psycho-geriatrician (a psychiatrist who specialises in working with older people). Someone may have capacity to make some decisions, but not others. For example, a person may not remember who the Prime Minister of the United Kingdom is but can be clear about whether or not they want to move into a care home.

4.5.2 Independent Mental Capacity Advocate

The Act has created the role of an Independent Mental Capacity Advocate (IMCA), who can help support people make important decisions when there are no family or friends who are able to represent their views. The purpose of an IMCA is to support a person who lacks capacity when important decisions have to be made by the NHS and local authorities regarding serious medical treatment and future care plans such as moving into a hospital or into a care home. Under the Mental Capacity Act, the NHS and local authorities will have a duty to appoint an IMCA for people who lack capacity before taking these types of serious decision. In some circumstances, IMCAs can also become involved in care reviews and adult protection cases. The NHS and local authorities must pay due regard to the IMCA's recommendations.

The Department of Health website (www.dh.gov.uk) provides a list of contact details for appointed IMCAs throughout the UK, under the heading of Independent Mental Capacity Advocate Services:

www.dh.gov.uk/IMCA.

For more details on the IMCA role, please see guide **25: Independent advocacy**.

4.5.3 Lasting Power of Attorney

The Act has also created a new role of Lasting Power of Attorney (LPA), where a person can give legal authority to someone who they trust to make health and personal welfare decisions, as well as financial decisions on their behalf, for a time when they lack capacity. The person nominating an LPA should do so when they still have capacity. This should be someone they feel they can trust to make decisions in their best interests in the future when they are no longer able to do so themselves. For more information, please see section 4.6 of this guide and our guide **Money and welfare – managing my affairs if I become ill** (guide number 33).

4.5.4 Advance decisions

The Act has also created the principle of being able to make advance decisions where people can opt to refuse future medical treatment. The decision about what health treatment is appropriate and available continues to remain with the health professionals. For more information, see section 7 of our guide **Money and welfare – managing my affairs when I become ill** (guide number 33)

In Scotland, the Adults with Incapacity (Scotland) Act 2000 covers these issues.

4.5.5 Deprivation of liberty safeguards

From April 2009, older people who lack capacity to consent to arrangements made for their care and/or treatment in a care home or hospital will have legal protection under the Deprivation of Liberty Safeguards (DoLS) amendment to the Mental Capacity Act 2005.

This is an important change as under the new regulations, the aim is to make sure that older people who lack capacity are only deprived of their freedoms where there is *no* other way to care for them or provide treatment to them safely and all other potential options have been considered and disregarded as unable to meet their needs.

If, to protect them from harm, an older person can only be cared for in a way that takes away their freedom to the extent that it deprives them of liberty, the care home or hospital must make a formal application to either the local council or the primary care trust for a series of deprivation of liberty safeguards (DoLS) assessments which are carried out by independent 'best interests' assessors. A relative or interested carer can also request that a DoLS assessment is carried out if they believe that the older person is being deprived of their liberty. For more information, please see section 8 of our guide **Money and welfare – managing my affairs when I become ill** (guide number 33).

4.6 Managing the finances and care of an older person lacking ‘mental capacity’

It is possible to make arrangements for a member of your family, or any other representative, to handle your financial affairs, whether or not you have dementia. If you do not lack mental capacity you could set up Power of Attorney (PoA). A PoA can have access to your bank account, can make payments, withdraw money, and sign cheques on your behalf. A PoA is usually time-limited and is used, for example, if someone is ill or injured and unable to conduct their own financial affairs but is expected to recover. If the older person is losing the capacity to make financial decisions for themselves it is possible to apply for a Lasting Power of Attorney (LPA). This must be arranged whilst the older person still has capacity to make the decision. A solicitor would be involved with this process.

4.6.1 Lasting Power of Attorney

Lasting Power of Attorney was formally created from October 2007 and replaces Enduring Power of Attorney (EPA), which involves a third party making financial decisions on behalf of someone who has dementia. If a person currently holds an EPA, this will continue to remain as such and will not automatically change to the status of an LPA. Power of Attorney (PoA) will continue to exist as it does presently, but ceases to be valid once the person on whose behalf it is held has lost capacity. Contact the local Citizens Advice Bureau (www.citizensadvice.org.uk) or Solicitors for the Elderly (tel.: 0870 067

0282; www.solicitorsfortheelderly.com) to find a solicitor who can organise this.

There are two types of Lasting Power of Attorney (LPA) that can be set up: one for finances and one for personal care and welfare. The same person can be attorney for both, but you have to apply on different forms for each one. Both need to be registered with the Office of the Public Guardian (tel.: 0845 330 2900; www.publicguardian.gov.uk) before they can legally be used. The LPA for finances can be used for the person while they still have capacity, but the LPA for care and welfare can only be used by the attorney once the person has lost capacity.

4.6.2 Court-appointed deputy

A LPA can only be arranged when the older person is thought to have the mental capacity to make this decision. If you are a friend or relative of someone who has been assessed by a suitable professional as being unable to make decisions, and there is no LPA already set up for them, you will have to apply to the Court of Protection on their behalf. The court will appoint a deputy (usually a relative) to support them. In a case where a person has lost capacity but does not have someone who has been nominated to have LPA, court-appointed deputies can take decisions about the same things. For details of the Court of Protection, contact the Office of the Public Guardian (tel.: 0845 330 2900; www.publicguardian.gov.uk). Also, see guide **33: Money and welfare: managing your affairs if you become ill** for more information.

4.7 Dementia and the Mental Health Act

Occasionally, the symptoms of dementia may accelerate and cause you or your relative to behave in such a way that you may put yourself or someone else at risk. If this situation occurs, then it may be necessary for you to be hospitalised while an assessment of your mental health needs or appropriate treatment takes place. You may admit yourself informally for in-patient treatment, or you may be compulsorily detained under a section of the Mental Health Act 2007 (MHA 2007). The most likely compulsorily sections relevant to people with dementia are Sections 2, 3 and 4 of the Mental Health Act 2007, and Section 117 in regard to after care services.

4.7.1 Nearest Relative

The MHA section 26 defines who will be considered to be a 'Nearest Relative' to a patient who is being compulsorily detained in hospital. This is the first surviving person from the following list in descending order. The Nearest Relative does not necessarily mean the same thing as the next-of-kin.

- Spouse or civil partner or a live-in partner of more than 6 months
- Son or daughter
- Father or mother
- Brother or sister

- Grandparent
- Grandchild
- Uncle or aunt
- Nephew or niece
- Non-relative who has lived with the patient for 5 years and over

The MHA 2007 has given new powers to patients to apply to the courts to displace their 'Nearest Relative' if they believe that this designated person will not act in their best interests. A patient who lacks mental capacity can now be legally represented in these court proceedings.

4.7.2 Applying for compulsory detention

You can only be compulsorily detained in hospital under the procedures of one of the relevant Sections of the Mental Health Act. An approved mental health professional (AMHP) (under the MHA 2007, an AMHP no longer needs to be an Approved Social Worker. Provided the person has the necessary qualifications, registration and experience, a psychiatric nurse, psychologist and occupational therapist may now also qualify as an AMHP.), or the Nearest Relative, can apply for a person exhibiting mental health problems to be detained for assessment, provided they have seen that person within the previous 14 days. A compulsory admission to hospital must also be authorised by two doctors, one who is usually a psychiatrist and the other who is preferably known to the patient, such as your GP. One of the two medical recommendations must come from an

approved doctor under Section 12 of the Act who has specialised experience in the diagnosis and treatment of mental disorder.

Section 2 of the Mental Health Act

If you or your relative is admitted to hospital under a Section 2 of the MHA, you can be detained for assessment and treatment for a maximum of 28 days. However, if an approved doctor believes that you require further assessments, the section can be extended for a further 28 days. The AMPH must make all reasonable efforts to inform your Nearest Relative if you are detained under this section and to advise them of their powers to apply for your discharge.

Section 3 of the Mental Health Act

A Section 3 can be applied for by the Nearest Relative, or AMHP acting on behalf of a Nearest Relative, in the same way as a Section 2, it may also be authorised by the responsible medical professional following a period of assessment carried out under a Section 2. Section 3 means you can be detained in hospital for treatment for up to six months. This section can then be renewed for a further six months, and then for a year at a time. Where practicable, the Nearest Relative must be informed by the AMPH that an application for a section 3 is being made. If the Nearest Relative objects to this application, it cannot go ahead unless an application is made to the county court to have the Nearest Relative displaced. The Nearest Relative may still be able to appeal to the First-Tier Tribunal in England or Mental Health Tribunal in Wales to have the person

discharged from the Section.

Section 4 of the Mental Health Act

A Section 4 can be implemented in the case of emergencies where only one doctor can be found. In these circumstances the AMHP would apply for the emergency detention and the doctor would approve it. Under a Section 4, a person can only be detained for 72 hours so that a full Mental Health Assessment takes place.

4.7. 3 Section 117- of the Mental Health Act - After care services

The health authority and the local council social services have a responsibility to arrange for after care services and support for someone who has been detained under a Section 3 of the MHA. This support is provided free of charge to the patient and may include the costs of residential care in a care home. Section 117 should continue as long as the mental health condition of the patient remains. This duty can also apply to patients who have been discharged from the Section 3 while still in hospital, but who have remained in hospital as an informal patient. Section 117 after care services are reviewed regularly, but cannot be withdrawn without a proper assessment of the patient by both the health authority and the local authority. Both authorities must be satisfied that the person's mental disorder has improved to the extent that he or she no longer requires the after-care services. However, the courts have stated that in the case of dementia, it would be difficult to see a situation where improvement of the mental disorder would become a reality (*R v Manchester CC*,

ex p Stennett, High Court). The same conclusion has been reached by cases brought before the Local Ombudsman.

4.7.4 How to challenge compulsory detention

If you or your relative is detained in hospital, the MHA managers at the hospital must try to make sure that you or your Nearest Relatives are informed of your rights. This information may be given to you by your responsible clinician, nursing or other staff such as the Mental Health Act administrator or your social worker. You should receive written information about the Mental Health Act and the ward can provide you with a list of mental health legal practitioners, as well as access to an Independent Mental Health Advocate (IMHA).

You can challenge a section in all or some of the following ways:

- You can make a request to the health professional in charge of your care to discharge you
- You can apply to a First-tier Tribunal if you live in England or a Mental Health Tribunal if you live in Wales. You can ask hospital staff on your ward, or request an Independent Mental Health Advocate or the hospital's Mental Health Act administrator to assist you in finding a solicitor who can represent you at the tribunal. See above for more details on how to find a solicitor.
- You can ask the hospital manager to discharge you. The manager can convene a meeting of relevant hospital representatives and staff. You should be able to take a family member, friend or advocate with you to this meeting. A

solicitor may be able to attend for free if you are preparing for your case to be heard by a tribunal. However, the hospital manager cannot overrule the decision of your responsible clinician. You can also use the opportunity of the meeting to express to the hospital managers concerns that you have about your care and treatment.

- Your Nearest Relative can seek to discharge you from compulsory detention in hospital. To do this, the Nearest Relative must put their objections to your compulsory detainment in a letter addressed to the hospital managers. However, the responsible clinician can overrule this action on medical grounds. Your Nearest Relative can also apply to the tribunal for your discharge.

The Mental Health Review Tribunal operates independently from the hospital which is detaining you. The tribunal panel will look at the information placed before them; take account of your views or those of your Nearest Relative and also the legal duties imposed by the Mental Health Act before coming to a decision about whether or not you should continue to be detained in hospital. If you are detained under a section 2, the tribunal hearing must take place within a week. If you are detained under a section 3, the hearing should take place within eight weeks, or even sooner if the case is considered urgent.

4.7.5 Guardianship

Section 7 of the Mental Health Act 1983 allows the local social services authority, or a named individual to be appointed Guardian of a person with a mental disorder on the recommendation of two doctors and an application of an AMHP or Nearest Relative. Section 37 allows a court to make a Guardianship order.

A Guardian has three powers. These are:

- The power to require the patient to reside at a specified place
- The power to require the patient to attend specified places for medical treatment
- The power to require access to be given to the patient by a doctor or an approved mental health practitioner.

However, a Guardian has no authority to make decisions about medical treatment and has no control over a person's financial affairs. A Guardianship Order will initially last for six months and then be renewed for another six months. After this time, it can be renewed annually.

A Guardianship Order cannot proceed if the Nearest Relative objects to it unless they are displaced by the authorities and their powers are transferred to another person. You or your nearest relative can appeal to a First-tier Tribunal in England, or Mental Health Tribunal in Wales, if you wish to challenge the Guardianship Order. A Guardianship Order must end if the tribunal does not believe you have a mental disorder or it is unnecessary as you do not pose a risk to yourself or others.

5 What help is available to the person with dementia?

Living with dementia or caring for someone with dementia can be difficult, and can cause stress, financial hardship and a sense of isolation. It is important to try to obtain as much support as possible. The following sections explain what support is currently available.

5.1 National Dementia Strategy

The Department of Health's first-ever National Dementia Strategy was launched in February 2009. It is an ambitious five-year plan aiming to increase awareness of dementia, ensure earlier diagnosis and better treatment and transform the quality of dementia care services.

Proposals include:

- a dementia specialist in every hospital and care home
- mental health teams to assess people with dementia
- memory clinics in every area
- better dementia care training for staff
- personal support and advice from a dementia care advisor.

The real long-term benefits for people with dementia will depend on the resources available to implement these plans. At present, £150 million has been ring-fenced for the first two years of the five-year plan.

5.2 Support from the National Health Service

If you have symptoms of dementia, your GP should refer you to the local hospital's psychiatrist for older people, or the memory clinic, if there is one in your area. (See section 4.4 of this guide for further information.) If you are diagnosed with dementia the psychiatrist will provide advice on medication that might help to control the condition or slow down the development of the disease. You may also be provided with other services such as respite care or support from the local council social services. This can include the following:

- **A community psychiatric nurse (CPN)** to give advice and support.
- **Day hospitals.** People with severe dementia may be offered a regular place in a day hospital where they can receive nursing care and therapy as well as lunch and leisure activities. This support can also help the carer, by giving them a regular break from their caring role.
- **Respite care.** The NHS and your local council social services can also offer periods of regular respite care in a hospital or nursing home.
- **District nurses.** District nurses will visit a person in their own home to provide nursing care, such as changing dressings or giving medication.
- **NHS continuing healthcare.** If you have severe dementia, you may be entitled to NHS continuing healthcare either in a hospital, a nursing-home or in your own home paid for by the

NHS. The Department of Health has set a national criteria and framework for eligibility which every strategic health authority should follow. For more information, see our guide **Continuing Healthcare: should the NHS be paying for your care?** (guide number 27)

5.3 Support from your local council social services

The social services department at your council must carry out a community care assessment if it appears that you or your relative may need their services. You can ask for an assessment on your own behalf or on behalf of someone else. An assessment should look at all of your, or your relative's, care needs in specific areas known as 'domains'. This should include housing needs, cultural or religious needs and psychological and emotional needs. This type of assessment is now carried out in accordance with the terms of the Single Assessment Process (SAP), which means that health and social care professionals should work together on one assessment. After an assessment, the local council social services should produce a written care plan explaining the type of help you or your relative need and the services available. For more information, please see our guide **Assessment and services from your local council** (guide number 12).

Some of the services which may be available include:

Home care. This can include help with personal care, such as dressing or bathing. Some councils may also offer help with housework and shopping. Sometimes, a private or voluntary agency will provide these

services on behalf of the council. Please see our guide **Home Care Agencies: what to look for** (guide number 15) for more information.

Day centres. Councils often provide day centres and many centres cater especially for people with mild to moderate dementia. They provide food and activities and may be able to provide support if you need assistance with personal care, such as having a wash or a bath.

Aids and adaptations. Occupational therapists can advise on and arrange for equipment and home improvements which can make it easier for you to carry on living at home. See our guide **Housing: adapting your home to stay independent** (guide number 28) for more information.

Telecare. Telecare and assistive technology are products which can help a person with dementia or physical disability to remain independent and at home for longer. This is particularly important if the person with dementia is living alone as the telecare sensors which are placed in the home can detect if something is wrong and trigger an alarm which will send an emergency call through the telephone line to either a monitoring centre or in some cases, to a relative or carer. The monitoring centres are manned 24 hours a day by trained operators, who can interpret what the problem is and can communicate and advise the individual on what to do, or if necessary, alert a relative or carer to the situation or to call the emergency services.

The local council social services can assess you or your relative for eligibility to telecare aids. The assessment would be carried out by a social services staff member or an occupational therapist. If the person's assessed needs meet the local council eligibility criteria, then the appropriate telecare package can be provided as part of the care package.

Telecare can help people with dementia and their carers in a variety of ways. This 'smart' technology can help you or your relative remain independent and safe within the home and can delay the need to move into residential care. Telecare can also bring reassurance to carers who know that they will be alerted by the call centre if their relative is at risk of harm.

Assistive technology is very cost effective, and local councils have received government grants to develop and promote its use in care packages. The first place to contact regarding information and eligibility to a telecare package of care is the local council social services department. The Disabled Living Foundation (tel.: 0845 130 9177; www.dlf.org.uk) provides free and impartial advice about aids and equipment, including telecare products, for older and disabled people and their carers. Age UK can also provide free advice on suitable telecare products (tel.: 0800 169 6565; www.ageuk.org.uk). For more information, please see section 3.9 of our guide **Help at home: what may be available in your local area** (guide number 14).

Telecare can also be used effectively in residential care homes where residents with dementia are prone to wander during the night or to have falls. If you have concerns about your relative's safety in a residential care home, you may wish to discuss the issue of installing suitable telecare products in your relative's room with the care home manager or with the local social services department.

Respite care and holidays. Social services departments also must look at the needs of carers. If you have a carer, they can ask for an assessment of their own needs for support to enable them to pursue activities outside of their caring role. Social services can arrange for you to go into a care home or to a day centre to give your carer a break. For more information, see our guide **Carers: what support is available** (guide number 10).

The local council social services department usually charges for their services. However, government guidance states that whatever the council charge must be 'reasonable' and not cause any financial hardship. If you have concerns about the charges you are being asked to contribute, contact Counsel and Care's advice service (tel.: 0845 300 7585).

5.4 Independent advocacy

People who lack capacity can often benefit from the assistance of an independent advocate. This is someone who can act in the interests of

the person who lacks capacity, and can make sure their opinions and wishes are taken into consideration. An independent advocate may be particularly helpful in situations where there is dispute amongst family members as to the best future care of a relative, or when there is conflict about future care decisions between the older person and the professional or statutory care services. An independent advocate can try to establish the wishes and needs of the older person and represent their points of view to the professionals.

The advocate should be trained in dealing with people who have dementia, and will try to communicate with the individual as far as possible to establish their opinion about their care and welfare. Where this is not possible, the advocate will act in the best interests of the person to achieve a positive outcome. You can contact Action for Advocacy (tel.: 020 7820 7868; www.actionforadvocacy.org.uk), who may be able to signpost you to particular advocacy groups in your local area. The Older People's Advocacy Alliance (OPAAL) (tel.: 01782 844 036; www.opaal.org.uk) can provide details of local advocacy organisations. Your local branch of Age UK may also provide an advocacy service. It is important that you inform the advocacy service if your relative is a person with dementia. For more details, please see our guide **Independent advocacy** (guide number 12).

5.5 Support from the voluntary sector

In many areas, voluntary and charitable organisations provide services to support people with dementia and their carers. A good starting

point to find out about these services is to contact your local council social services department or your local branch of the Alzheimer's Society.

The Alzheimer's Society is a national organisation set up to help and support people with dementia and those caring for them. They produce a wide range of booklets and guides on dementia and the caring of dementia patients. Their national office can provide specialist advice. They have a network of branches throughout the country, which offer a range of services, such as advice and support groups for the carers. Contact the central office for details of your local office (tel.: 0845 300 0336; www.alzheimers.org.uk). If you live in Scotland, contact their central office, Alzheimer's Scotland (tel.: 0808 808 3000; www.alzscot.org).

Carers UK is a national organisation providing advice and support to carers. It also runs support groups where you can talk to people in similar circumstances (tel.: 0808 808 7777; www.carersuk.org). The helpline is open on Wednesdays and Thursdays.

Branches of **Age Concern** or **Age UK** run local groups and services such as good neighbour schemes, lunch clubs and advice services. You can contact the national office to obtain details of your local group (tel.:0800 169 65 65; www.ageuk.org.uk).

The Parkinson's Disease Society provides advice and information to people who have Parkinson's Disease and their families and carers. It also can also give information about local support groups (tel.: 0808 800 0303; www.parkinsons.org.uk).

There may be other services provided by other voluntary groups depending on where you live. Your local library or council Social Services should be able to tell you about these.

5.6 Financial help

People with dementia are particularly vulnerable when it comes to managing their money and may need practical support with this. You may have extra expenses, such as paying for care, so it is important to make sure you are receiving all the benefits you are entitled to.

5.7 Disability benefits

Attendance Allowance is a very important benefit for people with dementia. It is paid to people aged 65 and over who are in need of care or supervision in order to avoid putting themselves or others in danger, or who need help with personal care such as washing, dressing, eating, going to the toilet or communicating their needs. It is not a means-tested benefit; it is determined solely by your care needs.

Someone with mild dementia might qualify if they are becoming forgetful. They could become a danger to themselves by leaving the

gas on or the front door open and, therefore, would need supervision. If you are under 65, you can claim Disability Living Allowance (DLA). If you need help completing these forms, contact your local Citizens Advice Bureau (www.citizensadvice.org.uk) or Age Concern or Age UK (tel.:0800 169 6565; www.ageuk.org.uk) who may be able to put you in touch with a local agency that can help you.

You do not have to have someone providing support to you to claim Disability Living Allowance or Attendance Allowance; you just have to be in need of care or supervision. To obtain a claim form contact the Benefits Enquiry Line on 0800 882200 or call the Attendance Allowance and Disability Living Allowance helpline on 08457 123456. For more information, please see our guide **Disability Benefits: Attendance Allowance and Disability Living Allowance** (guide number 3).

If you are living alone and are eligible for both Pension Credit and Attendance Allowance, you may also be eligible for a Severe Disability Premium attached to your Pension Credit. For more information, please see our guide **Pension Credit** (guide number 2).

5.8 Council tax

If you are claiming Attendance Allowance, it is possible that you might be able to obtain a reduction in your council tax bill. For more information, please see our guide **Council Tax Benefit and Housing Benefit** (guide number 22).

5.9 Collecting benefits

Benefits are paid into a nominated bank or building society account, and it is possible for you to arrange for a third party to collect the money from this account. The bank or building society can arrange for this.

For those people receiving benefits and who are considered unable to act for themselves, the Department of Work and Pensions (DWP) can appoint another person to claim and receive and spend the money on that person's behalf. You can get further information about appointees from the DWP (tel.: 0800 88 22 00; www.dwp.gov.uk). An appointee can only deal with the receipt of benefits on someone else's behalf.

6 Caring for someone with dementia

6.1 The carer's feelings

It can be difficult to accept that someone you care about has dementia. It is also likely to be distressing to care for someone who is changing, especially if the person you care for no longer recognises people they are close to.

Although many carers find their role fulfilling, caring for someone with dementia can lead to feelings of anger, resentment, frustration and guilt. It may help to accept that these feelings will happen rather than trying to suppress them. There is, however, no easy solution to the problems and frustrations that carers face when dealing with complicated and distressing symptoms of an illness. Although the person with dementia may not be able to make sense of what is happening, they will still be able to sense atmosphere and tension.

It can help to direct feelings of anger and frustration in a positive way. If you have enough time and support, you may wish to exercise or go for a walk to relieve these feelings. If you provide substantial and consistent care for someone with dementia, you are eligible for a Carer's Assessment from your local council social services which will look at providing you with support for the person you care for to enable you to carry out these activities. For more information, please see our guide **Carers: what support is available** (guide number 10).

Many people may feel embarrassed if a person with dementia behaves inappropriately in public places. It can help if you tell friends and neighbours about the illness. It may help if they understand why someone behaves in a particular way.

Listed below are a number of ideas that you may find helpful. You can obtain more advice about each subject from the Alzheimer's Society (tel.: 0845 300 0336; www.alzheimers.org.uk).

6.2 Financial help for carers

If you care for someone with dementia for 35 hours or more per week, you might be able to claim Carer's Allowance. For more information, please see our guide **Carers: what support is available** (guide number 10).

6.3 Communication with someone who has dementia

Sometimes it can be difficult to communicate with someone who has dementia because they get confused or cannot speak their thoughts clearly. There are some things that you can do to help, however, by doing simple things like making sure that any hearing aids, glasses or dentures they may have are working properly. Speak clearly and slowly to the person with dementia rather than raising your voice, or alternatively, they may find it easier if you write down what you want

to say to them. Offering simple choices is often an effective way of having meaningful interaction with them.

6.3.1 Body language

Body language and touch can be very important to communicate with a person with dementia, especially if they have difficulty understanding spoken communication. However, some people may feel threatened by this method. Again, it depends on the individual. You can contact the Alzheimer's Society (tel.: 0845 300 0336; www.alzheimers.org.uk) for advice on communicating with a person with dementia.

6.3.2 Past memories

Talking about the past can be a valuable experience for you as the carer and the person with dementia. Although dementia is responsible for memory loss, it is usually the short-term memory that is most severely affected. The person with dementia can normally remember some things from the past. Reminiscence therapy focuses on these memories. It can be comforting for both of you to talk about the past and share experiences. Using old photographs, postcards, music and even visits to places related to the past can help the reminiscence experience. In rare cases, for example, where a person is experiencing dementia related to post-traumatic stress disorder, recalling memories can cause distress. The Alzheimer's Society can provide more advice on this and other therapies (tel.: 0845 300 0336; www.alzheimers.org.uk).

6.4 Practical 'tips' when caring for someone with dementia

6.4.1 Safety and hygiene

A person with dementia may forget to look after themselves properly. It is important for the carer to help the person in a respectful, dignified and safe manner to manage tasks such as keeping clean and comfortable. It is important to make sure that:

- The bathroom is warm.
- There are non-slip rubber mats in the bathroom.
- There are grab rails on the side of the bath and toilet. (You can either contact your local social services department for this, or alternatively they can be bought and fitted quite cheaply privately.)
- The cold water is run in the bath before the hot.
- Respect and dignity are offered at all times.

As hygiene is such a personal matter, it may be difficult for the carer to supervise or wash the person with dementia. For example, a daughter may find it difficult to have to bathe her father. If this is the case, contact your local council social services to request an assessment of need and the possibility of a male home care worker to assist with bathing.

6.4.2 Dressing

Laying out clothes in the right order can make it easier for a person to dress themselves. Some people find that using slip-on shoes and easy fastening clothes (such as those with Velcro instead of small buttons) makes dressing easier. It is also important for the person with dementia to choose the clothes that they like to wear, remembering to ensure they are suitable for the weather conditions.

6.4.3 Eating

This can become a problem as some people with dementia can lose their appetite or find it difficult to use cutlery or to swallow. You should make sure that their dentures fit properly. It will also be easier for them if the table is laid simply and there is just one set of cutlery on the table. You can buy specially designed cutlery, which makes eating easier (an occupational therapist or the Disabled Living Foundation – tel.: 0845 130 9177; www.dlf.org.uk – may have more information for you on what is available). You can prevent indigestion and restlessness if you give the person you are caring for plenty of time to finish their meal. The person will feel more settled and more secure if they eat at the same time every day.

If the person with dementia appears to develop swallowing problems, contact their GP to request a referral for an assessment by a speech and language therapist who specialises in swallowing problems.

6.4.4 Continence

Incontinence can also be a problem for someone with dementia. It is always important to check first that a treatable medical condition is not causing the incontinence. If the condition is not treatable, you should contact the continence advisor through the GP. There are a number of aids available to help with this problem, such as kylie sheets (one-way bed sheets) and incontinence pads (which are available from the NHS). You can get information and advice about continence issues from The Bladder and Bowel Foundation (tel.: nurse helpline: 0845 345 0165 and counsellor helpline: 0870 770 3246; www.bladderandbowelfoundation.org). For more information, please see our guide **Health Difficulties: how to cope with changing needs** (guide number 8).

6.5 Behaviour associated with dementia

6.5.1 'Wandering'

It is quite common for people with dementia to be described as 'wandering'. This is when the person with dementia may be motivated to start something, but because of the effects of the dementia, there may be a breakdown in their ability to complete the task. The effect of this may cause the person with dementia to become agitated and distressed, and they may appear restless. These symptoms may be worrying for the carer, especially if the person tries to leave their home. An understanding that the person with dementia is not 'wandering,' but may in fact be 'searching' for something may

help to cope with the symptoms. Another reason for the behaviour may be the physical need for exercise, which can be alleviated by making sure the person goes on regular accompanied walks or other forms of exercise. The Alzheimer's Society can offer advice on this subject (tel.: 0845 300 0336; www.alzheimers.org.uk).

6.5.2 'Aggressive' Behaviour

Some people with dementia can present behaviour that appears aggressive. This is a symptom of the illness which is usually present for a set period of time and may appear or disappear at any stage of the illness. Aggressive behaviour is often the result of resistance to something they feel frightened about. As the carer, if you can identify what the person with dementia feels fearful about, you may be able to calm them. The psychiatrist or community psychiatric nurse may also be able to advise and help. You may find it helpful to discuss the issues at a carers' support group with other carers experiencing these difficulties. The Alzheimer's Society can provide details of local support groups and information on coping with aggressive behaviour (tel.: 0845 300 0336; www.alzheimers.org.uk).

7 Accommodation

Many people with dementia may eventually need to move into accommodation developed with their particular needs in mind if they become too ill or their behaviour is too difficult to manage at home.

7.1 Sheltered housing schemes

In some areas, sheltered or supported housing schemes have been developed which provide specialised help and care for people with dementia. For more information, contact the Elderly Accommodation Counsel (tel.: 020 7820 1343; www.housingcare.org), or your local council social services.

7.2 Care homes

Many care homes cater specifically for the needs of people who have dementia. You can obtain a list of all of these care homes in England and Wales from the Elderly Accommodation Counsel (tel.: 020 7820 1343; www.housingcare.org). You can also obtain inspection reports from the Care Quality Commission (tel.: 03000 616161; www.cqc.org.uk), and these may help you decide which homes to visit. The Alzheimer's Society can also provide a list of specialist care homes (tel.: 0845 300 0336; email: enquiries@alzheimers.org.uk). Care homes registered for people with dementia may be described as EMI homes. This is an old term that stands for the Elderly Mentally Infirm.

If you are thinking about moving into a care home, you should contact the council social services to request a care needs assessment. If your relative has dementia, you can make a referral on their behalf to social services. If you need a place in a care home, you will also be financially assessed to decide how much you have to pay towards your care. For more information, please see our guides **Assessment and services from your local council** (guide number 12), **Care Home Fees: paying them in England** (guide number 16) and **Care Homes: what to look for** (guide number 19).

7.3 NHS continuing healthcare funding

The NHS can provide funding which covers the cost of ongoing health care treatment outside of hospital settings. This can be provided in a care home with nursing if the needs of the person with dementia are severe, complex, unstable and require the input over a 24-hour period by a member of a multi-disciplinary medical team. However, NHS continuing healthcare can also be provided in the person's own home if their symptoms of the dementia and behaviour meet the continuing healthcare criteria.

It is important to remember that that the Department of Health's national framework for NHS continuing healthcare funding makes it clear that this type of funding can be granted to someone who has dementia, as in the past there was a tendency for health authorities to focus predominantly on physical health needs in regard to eligibility.

If you think that your relative meets the criteria for NHS continuing healthcare funding, you should ask the doctor in charge of their care for an assessment to take place. To be eligible for the funding, the individual has to meet national criteria and the assessment must be carried out according to the national framework. For more information, please see our guides **Continuing Healthcare: should the NHS be Paying for Your Care?** (guide number 27) and **Continuing healthcare: understanding the assessment process** (guide number 40).

Our advice workers can advise on a wide range of issues affecting older people, their relatives and carers. Counsel and Care produce a range of guides which can be downloaded from our website www.counselandcare.org.uk, or requested by calling our guide orderline on 020 7241 8522.

This guide is not a full explanation of the law and is aimed at people over 60.

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