

in touch with social services. If there has been a change in either your own or the person with dementia's situation and you need more help or different kinds of services, get in touch with social services at once, whether or not there is a regular review.

Carers

The Carers and Disabled Children's Act 2000 came into force on 1 April 2001. This provides carers with new rights and enables local authorities to help carers to care. The Act states that:

- Carers aged 16 or above have a right to an assessment of their needs.
- Local authorities should provide services for carers.
- Local authorities may charge for these services.
- Instead of receiving the service, carers can ask for a direct payment allowing them to organise services themselves.
- Local authorities can give vouchers for short breaks.

The legislation allows local authorities to provide services for the carer in addition to extra services for the person they are caring for. The carer's assessment considers whether the carer has any needs in relation to the care they provide and whether the local authority should be meeting those needs.

New legislation for carers places additional duties on councils when they are assessing carers. Since 1 April 2005, councils must inform carers of their right to an assessment of their own needs. Councils must also take into account whether the carer works or wishes to work or undertake education, training or leisure activities.



Complaints

Each local authority has a complaints procedure, which you can use if you are not happy with any aspect of the services provided. You can use this procedure if you are told that the person you care for will not receive an assessment and you think they are entitled to one, or if the services you need are not provided or are unsatisfactory.

The local authority will explain how to use the complaints procedure. However, try to sort things out on a personal level, as there may have been a failure in communication or a misunderstanding. If you use the local authority complaints procedure and are dissatisfied with the results there are other avenues of complaint. However, these are usually very complex so ask advice first.

VOLUNTARY ORGANISATIONS

These are charities and other non-statutory bodies that provide many services to supplement those provided by health and social services. There are too many to list here, and they vary from area to area, but some examples are:

Local information and financial advice

Your nearest Citizens Advice Bureau

Carers' support groups

Age Concern*

The Alzheimer's Society (specialises in dementia*)

Carers UK*

Dementia Relief Trust*

Mind*

The Princess Royal Trust for Carers*

Getting a break

Age Concern*

British Red Cross Society

Crossroads*

Women's Royal Voluntary Service (WRVS)

For information on schemes local to your area, contact your town hall or Citizens Advice Bureau.

*Contact details given in *Useful organisations* pp.91–93.

PROBLEMS AND WHO CAN HELP

Medical help for someone with dementia

1. Finding out what's wrong

diagnosis of the illness

your GP will make the initial diagnosis and may refer you to a hospital specialist for an assessment

2. Regular health care

to keep a check on the progress of the illness and any other minor complaints that might be treatable.

GP, practice nurse, district nurse

3. Nursing care at home

help with bathing, getting out of bed

domestic home care agencies

dressing sores, etc.

health visitor, district nurse

general health advice, e.g. about diet, constipation, keeping safe and avoiding falls, etc.

health visitor, dietitian, GP

help with emotional and behavioural problems

community psychiatric nurse

assessment for equipment such as a commode or walking frame

occupational therapist (social services or health)

difficulty in walking caused by lack of foot care

chiroprapist

Your GP or specialist should put you in touch with most of these people. You can contact the health visitor directly at your local health centre or clinic and you can contact the occupational therapy department through social services

PROBLEMS AND WHO CAN HELP

Personal support for carers

1. Carers' assessments

a chance to talk to someone about what would help you social services

2. Getting a break

sitters, minders, care attendants come into your home for a few hours a day to give you the chance to get out social services, voluntary organisations

day care where the person with dementia is taken to a local day centre for an agreed number of days a week allowing you to go to work or have some time for yourself social services, local health authority, voluntary organisations

short-term residential care (sometimes called respite care) where the person with dementia goes to a home or hospital for a period of between a weekend and a month, possibly on a regular basis social services, local health authority, voluntary organisations

permanent residential care where the person with dementia goes into a home social services, local health authority, voluntary organisations, private nursing or rest homes

3. Carers' emotional problems

someone to talk to social workers, practice nurses, doctors, health visitors and other health workers may be sympathetic listeners, there may also be specific counselling services available.

PROBLEMS AND WHO CAN HELP

Some voluntary organisations provide trained counsellors. There is a growing network of carers' groups set up by voluntary organisations and some health authorities and social services departments. Carers UK and the Alzheimer's Society provide excellent support in this area

Some people may find religion a comfort

PROBLEMS AND WHO CAN HELP

Practical help

1. Help in the home

home care to assist with personal care, practical help around the house and shopping

social services

community meals or meals-on-wheels will provide one hot meal for an agreed number of days a week, usually only for the housebound

social services, voluntary organisations, WRVS

2. Safety

a brief demonstration of the correct method of lifting or moving the person with dementia could avoid injury to both of you

district nurse or physiotherapist

bath aids – grab handles for the side of the bath, bath seat, bath mat, non-slip mat for inside bath, shower fitment hand rails for stairs and more major adaptations to your home such as installing a hoist or a downstairs toilet

occupational therapist for larger items; other items from bathroom shops, department stores, etc.

adaptations for cookers and fires

local electricity and gas boards, social services

PROBLEMS AND WHO CAN HELP

3. Incontinence

treatment/management	GP, continence adviser
incontinence pads	district nurse, continence adviser, local Primary Care Trust, chemist shop
commodes	voluntary organisations, local health authority
special clothing for protection or to make dressing and undressing easier	district nurse who can also tell you where you can buy them
laundry services, where available, may provide and wash bed linen	social services, local health authority

PROBLEMS AND WHO CAN HELP

Financial help

You should get independent advice from your local Citizens Advice Bureau on what and how to claim *before* you go to the relevant office. Help the Aged produces free advice leaflets including *Can You Claim It?*, which provides excellent advice in this area. Carers UK's website, Carers Online, also provides some useful background information on benefits. Go to www.carersuk.org or see *Useful organisations* on p.91

Citizens Advice Bureau

Income Support is a cash benefit to help people who do not have enough money to live on and who are not working 16 hours a week or more. It can be paid to top up other benefits, or earnings from part-time work, or if you have no money at all. Pension Credit is available to people who are aged 60 or over. Contact your local Jobcentre Plus, social security office or Pension Service office for further information

Department for Work and Pensions

Disability Living Allowance (DLA) is a tax-free benefit paid out regardless of income for people under 65 who have an illness or disability and need help with personal care and getting around. DLA has two components:

Department for Work and Pensions

- A care component (payable at one of three rates)
- A mobility component (payable at one of two rates)

For more information see the leaflet *Disability Living Allowance*, available from social security offices and post offices.

PROBLEMS AND WHO CAN HELP

Attendance Allowance is a cash benefit for people disabled at or after the age of 65 who need a lot of looking after because of their physical or mental disablement. There are two rates – a lower one for people who need a lot of looking after by day or night, and a higher one for people who need a lot of looking after day and night. It is paid regardless of income and savings and can be paid on top of other benefits, including Income Support. See the leaflet *Attendance Allowance*, available from social security offices and post offices

Department for Work and Pensions

If you need help in completing the forms it may be a good idea to make an appointment with your local Citizens Advice Bureau (CAB). Many CABs are happy to help people with this task

Citizens Advice Bureau

A Disabled Persons Tax Credit (DPTC) is available to people who are able to do some work but have a disability that puts them at a disadvantage in getting a job. It is a tax-free, income-related benefit for people who are working for at least 16 hours a week or more. For more details get claim pack *Disabled Persons Tax Credit*, DPTC/BK1, from the Inland Revenue, your local social security office or post office

Inland Revenue

Carer's Allowance is a taxable benefit paid to people aged 16 or over who are caring for a severely disabled person for at least 35 hours a week. The carer must be earning no more than £82 a week after the deduction of allowable expenses and the person in their care must be getting the middle or highest rate of Disability Living Allowance care component or Attendance Allowance or Constant Attendance Allowance. For more information get claim pack DS 700 *Carer's Allowance*, from your local social security office

Department for Work and Pensions

You may not get the Carer's allowance if you are already getting another benefit paid at the same or higher amount, such as State Pension. However, you may be able to get a carer premium or extra money for caring added to some social security benefits. Do speak to your local Jobcentre Plus, social security or Pension Service office about this. In some cases the person cared for may lose some of their benefit if Carer's Allowance is paid. Seek advice if this is the case

PROBLEMS AND WHO CAN HELP

Financial help *continued*

Home Responsibilities Protection is a way of ensuring that people don't get less state pension because they take time off work to look after someone who is sick or disabled. It is available for complete tax years for which a person is caring – for at least 35 hours a week – for a sick or disabled person who is getting the middle or highest rate of Disability Living Allowance or Attendance Allowance or Constant Attendance Allowance for 48 weeks or more. For more information get CF 411 *Application Form for Home Responsibilities Protection*, from your social security office or post office. Someone who is getting Carer's Allowance will not need to claim Home Responsibilities Protection as they will be credited with National Insurance contributions

Department for Work and Pensions

Further information about social security benefits and entitlements can be found on the Department for Work and Pensions website: <http://www.dwp.gov.uk/lifeevent/benefits/>

If you do not have access to the web, please contact the DWP Public Enquiry Office, phone: 020 7712 2171 (Mon–Fri 9.00 am–5 pm). Or write to: Department for Work and Pensions, Correspondence Unit, Room 112, The Adelphi, 1–11 John Adam Street, London WC2N 6HT.

It is sometimes possible to draw up a **Deed of Covenant**. This is a tax-free means of paying money from one person to another.

You should seek advice on drawing up a Deed of Covenant from a solicitor or accountant

Council Tax. If the degree of disability is severe, people with Alzheimer's disease may be exempt from the tax. There is also Council Tax Benefit for those on low incomes. For more information, get the latest *Council Tax Information Sheet* from Help the Aged (see *Useful organisations* on p.91).

Your local council office

PROBLEMS AND WHO CAN HELP

Housing Benefit. If you are a tenant you may be able to get help with your rent Your local council office

Assistance with residential care-home fees. If the person you care for enters residential accommodation and requires help with care-home fees then you need to contact your local council's Social Services Department. The Social Services Department will carry out a care needs assessment first and then determine if they qualify for financial assistance. If they do qualify then they will work out what you will have to pay on the basis of a national set of charges for residential accommodation rules. Generally, the Social Services Department will agree the fees and will ask the resident to make a contribution

The local social services have the discretion to disregard the value of the resident's home where appropriate, for example, if you are someone who is a companion of the resident and have given up your own home in order to care for someone who now needs to enter residential accommodation. The value of a resident's home is not automatically taken into account for the financial assessment if it is occupied by the resident's partner or a relative who is over 60, an incapacitated person or someone aged under 16.

It is also recognised by local social services that, if a person needs temporary care, the local council has the discretion to charge a fee level that ensures that the partner staying at home, who may be a carer, is left with sufficient income to live on by adjusting the resident's personal expenses allowance.



GENERAL GUIDELINES FOR CARING

A key to caring for someone with dementia is understanding what it feels like to have dementia and acknowledging that they may be depressed and anxious at times if they realise what's happening to them.





Problems may include:

- Loss of memory, a declining power to think and general confusion. This affects their ability to know what they are doing, why they are doing it and how to do it. As a result, tasks may be carried out incorrectly or dangerously, may be left unfinished or not attempted at all.
- Difficulty holding a conversation and expressing themselves. This leads to an inability to explain their difficulties and to ask for appropriate help.
- Loss of physical co-ordination. This leads to difficulty and possible risk or danger in carrying out actions.
- Embarrassment and frustration about declining abilities, and resentment of having to be helped. This may lead to attempts to conceal their difficulties, resistance to offers of help and a refusal to carry out certain tasks at all.

KEEP THINGS NORMAL

A diagnosis of dementia does not necessarily mean someone no longer has mental capacity or that you must suddenly start treating the person like an invalid. In fact, you should try and make a point of keeping things as normal as possible for as long as possible. Carry on any pursuits that you have both found enjoyable, such as going to the pub, theatre or cinema, listening to music, singing or dancing, unless, or until, it stops being a pleasure.

Introduce new activities if they seem appropriate – people with dementia often enjoy the company of small babies or children, and animals.

RETAIN INDEPENDENCE

There are two major reasons for retaining the person's ability to carry on independently for as long as possible. First, it helps them to retain some sense of dignity and self-respect, and may avoid frustration being brought on by feeling helpless. Second, it makes less work for you – the more they can do for themselves, the less you have to do for them.

Encourage them to carry on with things they can manage. When something becomes too difficult, don't give up on it completely – it could be broken down into smaller or easier bits. But be sure to recognise when something really is beyond them. Don't show them up or put them in a position where they fail. Praise them when they complete a task successfully or for any help they can give you.

Cut down on what they do on their own slowly, and reluctantly, for as one carer said: 'Once you stop something, you've only to stop it once and that's it.'

All the same, it is no kindness to the person to expect them to continue making decisions that are beyond their capabilities. Brace yourself and start to decide what has to be done when the doctors confirm that the person with dementia can no longer manage for him- or herself.

AVOID CONFRONTATION



There will be many occasions when you and the person with dementia will have disagreements. You might think it's time they changed their dirty clothes, but they don't agree. They believe someone's stolen money from their purse, you know they haven't. They insist it's perfectly all right to go out shopping dressed in their pyjamas, you'd rather not be with them when they did!

In fact, arguing usually won't get you very far. It generally leads only to frustration and aggressive feelings for both of you. It's far better to avoid confrontation whenever you can. Try not to contradict them if they say strange or silly things. Distract their attention if they want to do something inappropriate by changing the subject, or moving them away from the source of the trouble – the chances are that in a moment or two they'll have forgotten what it is they wanted to do anyway.

Experienced carers have lots of suggestions about how to persuade a reluctant person to do what the carer wants. Avoiding confrontation can be a spur to your imagination.

AVOID CRISES

There will be occasions when the person suddenly seems to get more confused, to behave particularly badly or to cry for no apparent reason and be unable to explain why. These may be caused by crises in their

lives – events that seem normal enough to those unaffected by the disease, but alarming to someone who is already confused.

A crisis might be having to hurry to get somewhere on time; meeting too many people at once, even if they are people familiar to them; or going into new and unfamiliar surroundings.

Some of these crises can be avoided. Always try to leave plenty of time to prepare for an outing, or to get a task done. Make sure that only one or two friends or relations visit at once. Accompany the person to new places. If you take them away on holiday, try to go somewhere where both your problems and theirs will be understood. Above all, try and stay calm yourself.

There will be times, though, when crises cannot be avoided, for example, when you are to have a break and a sitter comes in, or the person you care for is to go to a new day centre. On these occasions simply try to reduce the disorientation they are likely to feel by using a family friend or neighbour as a sitter, or by introducing a stranger in slow stages and with you present. The introduction to a day centre or hospital should also be made gradually.

Don't avoid making any changes at all or stop your social life just to avoid crises for the person with dementia. Sometimes they are inevitable and may be best for them – or for you – in the long run.

ESTABLISH ROUTINES

Routines are vital in caring for someone with dementia. Doing the same thing at the same time every day helps them to remember, and so helps you in your task. And if life is predictable and familiar, there is less chance of increasing confusion.

MAINTAIN A SENSE OF HUMOUR

'The greatest thing I found ... I could get my wife to laugh at everything she did wrong. Everything she did silly, like trying to get her knickers on over her head, I'd say "What are you putting them over there for?" And she'd say: "I'm sure I'm going daft" and we used to laugh.'

There may be times when you can see the lighter side of things, and it is important for your own mental health that you maintain the ability to laugh. The person with dementia may still be able to enjoy a good joke or a funny situation too, and it will do you both good to laugh together.

Of course, laughing WITH someone is quite different from laughing AT them, which no one should ever do.

MAKE THINGS SIMPLER

A person who is already confused will find making straightforward decisions, or carrying out relatively simple tasks, over-complicated and difficult. Taking a bath, for example, involves many separate actions, from putting in the plug to turning on the taps and obtaining the right temperature, getting undressed, and so on.

Try to simplify things: don't offer too many choices (two is probably enough), break tasks down into short,

simple sections; if a task becomes too difficult ask them to do only part of it.

Make things simple for yourself too. Don't fight lots of battles at once but try and solve problems one at a time. That way you stand a better chance of success.

MAKING THINGS SAFER

The dementia patient's difficulties increase the risk of accidents in the home and you should take great care to make your home as safe as possible.

Loss of physical co-ordination increases the likelihood of falls, so you should check your home for danger zones, such as a loose banister rail, slippery floor mats, awkwardly placed furniture, or carpets that may not have been fixed down securely. You may need to have an extra stair rail fitted, along with handrails in the bath and toilet.

Loss of memory and thinking ability can give rise to risks from a number of everyday activities. A person with dementia may turn on the gas fire but forget to light it; they may drop lighted matches into a waste-paper basket; they may scald themselves on a boiling kettle. Some of the solutions are obvious – switch off the gas at the mains when you go out, don't leave matches around, hide kettle flexes. The list is a long one, and largely a matter of common sense. You should review your home for all potential accidents and take action to avoid them.



Useful information on avoiding slips, trips and broken hips is available from Help the Aged, at www.helptheaged.org.uk/Health/HealthyAgeing/Falls/default.htm. Or call the DTI Publications Orderline for an information leaflet on 0845 0150010.