

FEELINGS OF AGRESSION AND GUILT



But, however well you adapt to the new situation, feelings of anger and aggression are certain to surface from time to time. You may feel angry that this has happened to you. You may be frustrated that more is not known about the disease so that effective treatment and a cure can be offered. Doctors and other professionals may seem unconcerned and slow to provide help, as may other members of your family. And at times you will get angry with the person and their irritating behaviour.

Sometimes carers reach a point where they are physically aggressive towards the person they care for. This is a clear signal that the carer needs a break from the situation and more support. This may be obtained from social services, Alzheimer's Society, Age Concern, Carers UK, your local Princess Royal Trust for Carers centre and many other voluntary organisations. There is also the Elder Abuse Response Line, phone: 080 8808 8141, which is available from 10.00 am–4.30 pm Mon–Fri, for those who are concerned about abusing the person they are caring for.

Losing your temper with a person with dementia is something about which carers often feel guilty, although it may be reassuring to know that most carers admit to it. People also feel guilty about many other things – for example, for the way they treated the person in the past, for resenting having to look after them, for wanting them to go into permanent care, or for wishing them to die. Feeling guilty is a common and understandable reaction when confronted with a trying and often inexplicable disease like dementia, though feeling guilty will probably do neither you nor the person you care for much good. One carer confessed that he sometimes had trouble coping but he saw no reason why he should feel guilty about being less than perfect.

'I've heard the word "guilt" used ... it gets up my nose. I don't feel guilt at all and I think it's an abomination that people should use the word guilt when a carer has been looking after someone as best they can ...'

You may also feel frightened if you have to take over making decisions in the family, which were previously made by the person concerned. Remember that specialists have told you that the person you care for can no longer manage their own life. If you don't accept the responsibility, things will not run smoothly for either of you. When you have to do it, it is reassuring how much you can accomplish, with the right support and help.

IN THE LATER STAGES

'To think of him, bless his heart, he's always been a good son and a wonderful husband ... to have this degrading business happen to him. One thing I will say – he doesn't know – which is fortunate.'

The person with dementia's personality may have changed almost beyond recognition, and they may have lost many of their faculties. This is certainly more distressing for the carer, who is keenly aware of what is happening, than it may be for the person themselves.

Sometimes, the person with dementia may have some insight that he or she is not the person they were, not in control of the situation and feel sad and frustrated. Having someone there for them is often reassuring even though sometimes this may mean not saying very much. Non-verbal communication can often mean more than what is said.

At this time you may experience a great sense of sadness and begin to mourn the loss of the person you once knew. You may also find that you can no longer cope with the situation and reach a state of despair. You may wonder what all the hard work and emotionally exhausting care are for and ask yourself: 'What's the point – wouldn't she be better off dead?'

If this happens, you should look at alternatives. Caring at home does not necessarily have to last until the death of the person in your care. If the stress becomes too great, you should consider having the person you care for looked after permanently in care homes.

You can find more information on care homes in this booklet. Turn to page 32 and *Useful organisations* on p.91. This does not mean, of course, that you will cease to care. Carers emphasise the benefits of visiting the person they have cared for in their new home and say that it can restore a relationship that has been soured by the stresses of caring.



The transfer to permanent care in a home may induce a sense of grief, almost as if the person had already died: 'When she first went in, I can only say it was like a bereavement.' But visiting regularly can be important, even if the person doesn't recognise you: 'It's a form of therapy for you – the figure of the person, although the character's gone.'

For some, this period of grieving before death will mean that you have begun the mourning process and started saying your goodbyes. This is a natural reaction to the prolonged stresses of caring without receiving a response from the person concerned. You should not let other people's opinions upset you if they do not understand your reaction. It is quite a usual one.

After the person's death you may at first feel a great relief that so much distress is over. It could be some while before the normal process of bereavement takes place. You may also have to grieve twice over – once for the person with the dementia and once for the person you knew and loved before their illness.

If you have been caring for a long time and have given up your job and much of your social life you may need help to pick up the pieces and start again. Contact Carers UK, which sometimes runs ex-carers' groups at a local level.



HELP FOR THE CARER

Looking after someone with dementia at home can be distressing, and is almost always hard work. But many carers say that they also get satisfaction from helping the person, and they still have some good times together. Certainly many carers want to keep their relatives at home until caring becomes too heavy a burden. But if you are going to care for someone with dementia at home, it is essential that you should seek help.



WHY SHOULD YOU SEEK HELP?

It is important to realise that coping at home can cause you, the carer, severe strain. You may be an older person yourself, not in the best of health, and you may have difficulty with the physical demands of caring. If the person lives alone in their own home, you will have the responsibility of running two households and the worry of wondering what is happening when you're not there. You may even have to spend a lot of your caring time travelling between your home and theirs. Having the person live with you and your family may cause tension because of the demands they make on the household.

Whatever the arrangement, caring for someone with dementia is likely to have effects on your health, family life, leisure, employment and finances. That is why you should always seek help as soon as you suspect that your relative is ill. Don't wait until you are desperate before you ask for help. An extra pair of hands, some time off for you to relax, or a bit of extra income may be enough to see you through a crisis.

Even if you don't think you need help now, find out what is available and how long it takes to arrange – in some cases it may be weeks or even months. Then when you sense you're going to need help, you can try and start the process in good time.

Always be prepared to ask for help. Services are provided because it is known that people like you

need them, and it is your right to ask for them. Also don't forget, your well-being is as important as that of the person with dementia.

There are four main areas of help about which you should know – medical, personal, practical and financial. Key addresses are provided in *Useful organisations* on p.91.



Medical help

Your General Practitioner (GP) is the first person you should contact when you suspect that your relative is ill so that you can get a proper diagnosis of their illness. Doctors vary greatly in their attitudes towards people with dementia. Some aren't interested, some are inexperienced or not very knowledgeable about the condition, others may wish to protect you from knowing the worst about the disease and so appear to be unconcerned. Others are very helpful, being both sympathetic and also providing practical help.

Carers have suggested that you need to be firm and persistent with GPs who aren't immediately helpful. If you are really getting nowhere it is legally possible to change your GP, although this is not always practically possible. If you wish to change your GP, you can simply go to a new doctor – or visit several and then choose – and then ask to be put on the list. If the new doctor agrees, then the arrangements will be made through the new doctor and the health authority. If you can't find a GP, then your primary care trust (PCT) must



assist. For details of your local PCT, call NHS Direct on 0845 46 47.

You can request that your GP (or the practice nurse) carries out an annual health check for over 75s. If you are worried about the health of a person with dementia who is over 75, this could be a good way of getting their needs assessed. At the check up, which can be done in the person's home, there should be a chance to talk about problems the person with dementia may have. If it seems appropriate, you can ask for the person to be referred for specialist assessment and treatment.

A good GP will act as a key to all the other services provided by the National Health Service. This will include referral to hospital specialists for further assessment if necessary, and for treatment. A GP can also provide access to community nursing staff who can help and advise you at home. Normally, your GP is the only person who can refer you to hospital specialists unless the person with dementia is admitted for emergency treatment. Hospital specialists can also put you in touch with community nursing staff.

It is important that as a carer you do not lose sight of the need to look after your own health and well-being. You should ensure that your GP knows that you are a carer and find out what local services are available to support you. These might be general or specific to carers of people with dementia.

You should also make full use of your local social services office, voluntary organisations and carers and support groups. You can contact all of these directly (see *Useful organisations* on p.91).

Treatment

No drug treatments can provide a cure for Alzheimer's disease. However, drug treatments have been developed that can temporarily slow down the progression of symptoms in some people. Aricept, Exelon and Reminyl all work in a similar way and are known as cholinesterase inhibitors. There is also a newer drug, Ebixa, which works in a different way from the other three – but at the time of publication of this booklet, it was not generally available on the NHS. For more information on the drugs available to treat Alzheimer's disease, the Alzheimer's Society free information sheet 407, which gives an overview of the medications available, may be helpful and is available from www.alzheimers.org.uk (see also *Useful organisations* on p.91). Alternatively, talk to someone from your local specialist dementia team. You can ask your GP how you might do this.

Sometimes, medication to calm someone is useful, but it is important to use the correct dose, as some people can be very sensitive to these drugs. Of course it's also very important to treat other illnesses, like bronchitis, quickly and you should see your GP if there is a sudden, even if minor, change.



Personal support for the carer

A major risk for carers is that you may become socially isolated. Looking after someone with dementia takes more and more of your time. Their odd behaviour may annoy or embarrass friends and neighbours who may stop calling round. You may become afraid to leave them alone at home because they have become a danger to themselves. But struggling to manage on your own increases the stress on you, and reduces your ability to cope. Stopping yourself from becoming isolated is an essential part of coping with caring.

There are three main things you can do:

- First, make sure that you get a break from caring – some time to pursue your own interests or hobbies, to visit friends, or simply to get on with everyday tasks without having to worry about supervising the other person. The break may be for just one evening a week, for one or several days a week, or even time for a proper holiday. However long, the idea is to give you a rest or the opportunity to take part in other activities. Getting a break may also help the person with dementia, offering them a chance to socialise with others and take part in different stimulating activities. Many carers find day-care useful and suggest that you start it as soon as possible so that the day-care staff can learn to adapt to any problems as they worsen. Your GP or local social services department should be able to help you arrange a break.

- Second, carers can never stress enough the benefits of talking to other people who understand your problems. Those most able to understand are obviously other carers. It is often easier to talk to people from outside the family. Carers' support groups, where carers meet regularly to share their experiences and to help each other, exist locally in many parts of the country. Where no group already exists, you might want to set one up yourself. Your GP may be able to advise you about local specialist services or alternatively the Alzheimer's Society or Princess Royal Trust for Carers (see *Useful organisations* on p.91) will be able to help and advise you on local contacts and services.
- Third, where at all possible, you should try to share the responsibility for caring with other members of your family, or with friends and neighbours. Women, in particular, often find that they are expected to care for a sick relative, though many carers are, in fact, men. Both women and men carers should encourage others to help them. Family members may not realise how hard a time you're having unless you tell them. Until you ask for help they may assume you don't need it. Sharing housework and organising care rotas would spread the load more fairly. Friends and neighbours may be able to help in many ways, particularly if you explain the illness, and its effects on the person with dementia and on you.

Practical help

Health and social services and some voluntary organisations such as Crossroads and the Dementia Relief Trust (see *Useful organisations* on p.91) may be able to offer help with a number of practical tasks in the home, like providing regular nursing care and domiciliary services. They may also supply safety aids for the bathroom or stairs, equipment such as commodes and a laundry service. If you can afford it, it is worth spending money on anything that will relieve you of daily tasks, such as a washing machine.

If you are sure that you have made full use of all possible help available at home but you are starting to find it increasingly difficult to cope, you should find out whether it will be possible to have the person with dementia cared for permanently in a care home. The availability of such care varies throughout the country, and the ways of paying for it are complex. It is very important that you seek good advice about what kind of care may be possible: contact one of the *Useful organisations* on pp.91–93.

The following is just a brief description of how care might be arranged.

If you feel you will need help with paying for residential care you should contact your local social services office. They will also advise more generally on the availability of care homes in your area. Useful organisations include the Elderly Accommodation Counsel, which maintains a

nationwide database on all forms of accommodation for older people. Counsel and Care and The Relatives (& Residents) Association also provide information.

Help the Aged provides a free Care Fees Advice Service (phone: 0500 767476). They also publish a leaflet, *Care Homes*, available by post, from Help the Aged charity shops or from www.helptheaged.org.uk. Age Concern also publishes a series of factsheets. Factsheet 29: *Finding care home accommodation* and factsheet 10: *Local authority charging procedures for care homes* are available from the Age Concern website at www.ageconcern.org.uk or free by post from Age Concern. For details of all these organisations, see *Useful organisations* on pp.91–93.

Your choice of private care also depends on what you can afford, although there is state help in many cases. You should obtain a proper diagnosis of the person's illness before they go into private care. You may have to be very persistent to obtain permanent care, so don't give up hope if you fail at the first, second or even third attempt.

Financial help

Finally, caring may substantially alter your financial circumstances. If you are working, you may have to go part-time or give up your job altogether; fuel bills may rise because more time at home means more heating; laundry costs and money spent on clothing may increase if the person with dementia becomes incontinent.



Both you and the person you care for may be entitled to extra cash in the form of welfare or disability benefits. To find out what you may be entitled to, contact your local Jobcentre Plus or social security office. You will find their phone number and address in the phone book under social security. You can also get leaflet SD1 *Sick or disabled?* from your local Jobcentre Plus, social security office, the post office or from www.dwp.gov.uk/publications/dwp/2003/sd1_oct.pdf.

You can also ring the Benefit Enquiry Line for people with disabilities (phone: 0800 88 22 00) – a freephone number that can give confidential advice to people with disabilities and their carers. It is open Monday to Friday, 8.30 am–6.30 pm, Saturday 9.00 am–1.00 pm. Advisers can go through a claim form with you over the phone and fill it in for you. If you want, they will send you information in a letter after your call. They can also provide leaflets giving more details. Information on more specific benefits is given on pp. 48–52. The Department for Work and Pensions, leaflet SD4 *Caring for someone?* is aimed specifically at carers. It is available from your social security office, post office or from www.dwp.gov.uk/publications/dwp/2003/sd4_oct.pdf.

Don't give up

The medical, practical and carer support services will vary according to where you live. Some areas are well provided with services, others less so. You should find out now what is available near you, and keep a record of how and where to make contact. There is space to

do this on the back cover of this booklet. Go to your local social services office and ask for an assessment for the services that are available – both for yourself and the person you care for. Look under your local authority in the telephone directory. Alternatively, your GP may be able to help. The library and Citizens Advice Bureau will also be able to help, and the *Useful organisations* section pp. 91–93 will give you some ideas too. Remember it is your right to ask for the medical and social services that are available in your area, and you need to take up what is on offer before a difficult task becomes impossible and leads to your own ill health.

Many carers become extremely discouraged if several attempts to get help have failed. But it is worth persevering. Most carers eventually find their way into the network and are relieved and even delighted by the help that is provided.

As always, the first step is the hardest. The support you get will be worth your extra effort.

'We'd been trying to persuade our doctor to do something for months. Finally he contacted a specialist. We didn't know anything about it – until the specialist just called on mother at home. And he's been wonderful ever since, putting us in touch with so much other help.'

A WHO'S WHO OF HELP



Your local health authority

- Your GP can refer you to the following hospital and community services.

Hospital services

- A **psychiatrist** – medical doctor specialising in mental illness for any age group.
- A **neurologist** – specialist in diseases of the brain and nervous system.
- A **geriatrician** – specialist in diseases of older people.
- A **clinical psychologist** – specialist in mental and behavioural functions of the brain.
- An **old age psychiatrist** (used to be called **psycho-geriatrician**) – specialist in mental illness among older people.

Community services

- A **district nurse** provides nursing care at home.
- A **health visitor** provides general health advice at home (you can ask to see one for yourself at your local health centre or clinic).
- A **community psychiatric nurse** provides nursing care for mentally ill people at home. Sometimes there are aids for practical care.
- A **continence adviser** offers advice about the management of incontinence.
- A **chiropodist** provides foot care.
- An **annual health check** offered by the general practice to look at the needs of people over 75.

Social services

- A **social worker** – assesses and plans the support needed by people at home. They will either arrange the support package or organise a direct or indirect payment.
- A **care manager** – usually a social worker but may be someone like a district nurse, an occupational therapist or someone from a home care organisation performing the same role.
- An **occupational therapist** – provides rehabilitation at home using daily activities.

One of the first things you need to do is to get an assessment of need carried out by your local social services office. Section 2 of the 1970 Chronically Sick and Disabled Person's Act lists the services that social services have to consider during an assessment. These include day-care and home help. Once social services have decided that someone needs any of the services listed in this Act, they have a duty to ensure that the need is met. Should the service not be available locally, then it is the ultimate responsibility of social services to ensure that the need is met by bringing in services from outside of their area. You might find Age Concern's factsheet 41: *Local authority assessment for community care services*, helpful. This is available from www.ace.org.uk or free by post (see *Useful organisations* on p.91).

Direct payments

Alternatively, from April 2003 every local authority will have to offer money to those who are eligible, instead of arranging services for them. When a local authority gives someone money in this way, it is known as a direct payment. Your social worker should discuss this option with you when they assess your care needs.

The Department of Health has published: *A guide to receiving direct payments from your local council*, (to obtain a copy phone the DH Publications Orderline: 08701 555 455, quoting reference 31006). The National Centre for Independent Living can provide further information and advice about direct payments, and refer you onto a local support service (see *Useful organisations* on p.91).

Assessment

Talk to your local social services office or hospital social worker about the assessment procedures in your area. The Carers and Disabled Children Act (2000) strengthens the rights of carers to an assessment of their own needs as carers. It gives local authorities a responsibility to support carers either by providing services to the person with dementia or to the carer directly, helping them to take a break or through a direct payment for services provided directly to them. Local authorities may also have a short-break voucher scheme set up to help support carers with breaks that are flexible and accommodate their needs.

The person (or people) carrying out an assessment will look at the needs of the person with dementia and the carer and, in co-operation with them, try to work out the most suitable package of services. There will be an assessment of ability to pay for many of these services, and the assessor will want to ensure that all available state benefits are being claimed.



Different people may be involved in the assessment. An occupational therapist may advise on dealing with practical problems, and perhaps arrange for equipment to be provided in the home. As a result of the needs assessment, a variety of help may be arranged – meals, home care, respite breaks, day care – depending on what is available locally. If the kind of help that you need is not available, you may need to work hard to have it arranged. This is sometimes easier to do in co-operation with others in the same situation.

Care plan

After the assessment is complete and any relevant discussions have taken place, the person assessing should devise a care plan with you. Make sure that you get a copy of what is agreed.

Reviews

As the situation changes, the care plan will need to be reviewed. You should be told whether social services will review these needs on a regular basis and, if so, how often and when, or whether it is up to you to get