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Supporting the family of people with dementia

Caring for a person with dementia can be a devastating task. That person may be a parent or spouse who has been known and respected and it is difficult watching the deterioration. In the later stages there may be physical problems, including the indignity of incontinence. The person may seem most ungrateful and even aggressive and this can be hurtful for the carer.

The purpose of this article is to help the professional understand the problems faced by relatives and carers of those with dementia, and to give information about sources of help and support for them. See the separate [Dementia](#) article for further information about the condition itself.

Definition

"Dementia is a triad of problems: memory loss, decline in some other aspect of cognition and difficulties with activities of daily living. More formally, dementia is defined as a syndrome (that is, a distinct pattern of symptoms and signs) that can be caused by many brain disorders, most of which progress gradually over several years. Symptoms have usually been present for at least six months, and activities of daily living are impaired by the decline in memory and thinking."^[1]

The symptoms affect people in three ways:

- Cognitive impairment - affecting:
 - Memory
 - Language
 - Attention
 - Thinking
 - Orientation
 - Calculation
 - Problem-solving ability
- Psychiatric and behavioural problems:
 - Changes in personality
 - Changes in social behaviour
 - Emotional changes
 - Hallucinations and delusions
 - Aggression
 - Depression
 - Agitation
- Difficulty with daily living:
 - Dressing
 - Driving
 - Eating
 - Shopping

Problems families or carers may face

Early loss of memory

In the early days the pattern of memory loss for a person with dementia is characteristic:

- Memory of recent events is impaired whilst memory of distant events is intact.
- The brain stores short- and long-term memory in different places, so the person may be able to recount in great detail and with great accuracy details of their youth and perhaps wartime experiences, but they cannot remember what they had for breakfast.
- One of the early manifestations of this is losing things; the person puts something down and forgets where it is.
- Intelligent people in particular develop techniques to overcome impairment of memory. One technique is to make lists. Many people make lists, including women around the menopause. Therefore it should not be assumed that everyone who makes lists is suffering incipient dementia.
- Being forgetful is embarrassing and people may try to hide it. They may try to avoid new places and new things, as in familiar surroundings the long-term memory may see them through. They may even fill in gaps in the memory with wonderful and superficially very plausible stories but more detailed scrutiny will show them to be untrue. The ability to compensate can be most impressive and the true degree of memory loss and intellectual impairment may be hidden very effectively. When compensation is no longer adequate there appears to be a very rapid decline. This is more apparent than real because the true level of impairment was not appreciated when it was being well covered.

Difficulties with medication

- Elderly people often take medicines and are often on multiple medication. This means taking a number of tablets at a number of different times a day.
- It is very easy to get confused, even with fairly good mental faculties, but any deterioration increases the risk considerably and taking drugs incorrectly may aggravate confusion.
- Chaotic taking of medication may be a presenting feature.
- Those with cognitive decline may have little idea what they are taking and what those tablets are supposed to do.

Driving

- Driving is a very complex skill and manoeuvres (such as turning right across the traffic) require complex computation. People with short-term memory loss or intellectual impairment should not drive but convincing them of this may be very difficult.
- Assessing a person's ability to cope really needs formal but simple testing, as simply talking to a person may give a false impression of a very affable and competent individual whilst, in reality, there are great gaps in memory and understanding.
- The help of a doctor with tests such as the [mini mental state examination \(MMSE\)](#) may give a more accurate picture and it may come better from a professional than from the family.
- Losing the right to drive is a blow to self-esteem that may be resisted.

Other dangers

As memory fails there are a number of dangers that may occur:

- Sometimes people get lost when they are out and are vulnerable and frightened.
- At a later stage they may be inclined to wander, possibly inadequately dressed and in oblivion of dangers such as traffic.
- There is difficulty coping with money and the unscrupulous may take advantage.
- They may turn on the gas and forget to light it.
- It may not seem the right time in life to give up smoking, but cigarettes can be forgotten and start fires.
- Alcohol may aggravate the features of dementia. It does not have to be banned but its effects must be borne in mind.

Change in personality

It is not simply memory or intellect that suffers; the disease of the brain can affect higher centres that control matters such as personality and inhibitions:

- The person may become rude and aggressive. This can be very hurtful to those who are simply doing their best to help.
- They may pick a physical fight despite their obvious physical inability.
- Outbursts of violence against carers add injury to insult.
- The natural reaction to the rude, aggressive and possibly even violent person is to leave them to get on with it themselves. Carers and relatives have the difficult task of trying to put their pride to one side and remember that it is the disease that is doing this and not the person they once knew.
- Lack of inhibitions can lead to overt sexual talk and behaviour that are totally out of character with the previous personality.
- When a parent starts getting sexual this can be embarrassing and upsetting.
- There may also be most hurtful and unfounded allegations of sexual infidelity by others.
- This is especially likely where alcohol is an important factor.
- The frontal lobes of the brain are responsible for personality and social inhibitions and so it is unsurprising that in [frontotemporal lobe dementia](#) (formerly called Pick's dementia) these features are especially marked. There may also be apathy and antisocial developments such as theft.

Deterioration

As the brain deteriorates, it ceases to perform so well in tasks demanding manual dexterity. This is called apraxia:

- There is inability to wash and dress.
- Buttons are particularly difficult for the person with apraxia.
- It is often around this stage that aggression is a feature, especially in Alzheimer's disease. This can be very hurtful and difficult to manage.
- Co-ordination becomes impaired and there is an increased risk of falls.
- Ability to feed oneself is also impaired.

Terminal stages

In the final stages there will be complete loss of independence and ability to cope:

- Originally there was loss of short-term memory whilst long-term memory appeared intact; however, all memory becomes severely affected and even long-standing friends, spouse and family are no longer recognised.
- Incontinence of urine is usual. Double incontinence may occur.
- Difficulties with swallowing and with clearing secretions may lead to chest infections and resistance is low.

At this time there may be mixed emotions. There is sadness at the loss of someone close and dear but also often a sense of relief that it is over. People may feel guilt when experiencing this, and need reassurance that it is not wrong to feel relief and it is important not to feel guilty at having that feeling.

Types of help families or carers may need^[2]

Emotional support

This can be provided by:

- Friends and family.
- GP.
- Counselling.
- Support groups (area-specific details available on the Alzheimer's Society website).

Getting breaks

- Family and friends may be able to help.
- GP or social services can arrange assessment for respite care or routine relief.

Keeping healthy

- Eating well and getting regular exercise.

- Sleep – advise people to discuss with their GP if having difficulties sleeping either for practical or mental reasons.
- Mood – encourage relatives to seek help from their GP if feeling low, depressed, or anxious, or if they feel they are struggling to cope.

Financial help

- Carers are entitled to request flexible working.
- Benefits – Citizens Advice Bureau or the GOV.UK website (see below for both) may be able to provide information about benefits, pensions, etc.
- Paying for care – social services will be able to discuss financial implications and help available.

Carers assessment

- Carers should be offered an assessment of their own needs^[3]. This is carried out by social services. This is their right under the Community Care Act of 1990 in England and Wales.
- Social services assess how needs can be met. For example, this might involve arranging respite care, meals at home (formerly 'meals on wheels'), adaptations to the house, considering placement for the person with dementia in a care home, etc.

Money and wills

- A will is valid only if it was made by a person *of sound mind*. Hence, it is important that a person with dementia should make a will at an early stage.
- Whilst still of reasonably sound mind, people may wish to make [advance decisions](#) with regard to their later management. Although the legal standing of such documents is still not entirely clear, it may facilitate later management.
- The [Mental Capacity Act](#) of 2005 governs decision-making on behalf of adults, where they lose mental capacity at some point in their lives or where the incapacitating condition has been present since birth^[4].

- At a later stage the person will be unable to manage their own finances and it is best to make alternative arrangements for another to take over before this is reached. A Lasting Power of Attorney (LPA) is an important legal document that enables a person who has capacity and is over 18 to choose another person or people to make decisions on their behalf^[5]. They may cover either property and financial affairs and/or health and welfare.
- If this has not been done but the person is beyond understanding financial matters it is possible to get a Court of Protection Order (see below).

Accessing advice and support for families and carers

The Alzheimer's Society website (see below) has an enormous wealth of information to help, advise and support families and carers of people with dementia. Steering people towards this website will be extremely helpful for many issues. Some of the many areas with which the society and its website can provide help include:

General advice

There are many advice leaflets on how carers and family members can help. These include information on how best to help and look after a person with dementia.

- Valuing the person, which includes:
 - Information about trying to be flexible and tolerant.
 - Listening to the person with dementia.
 - Showing affection.
 - Finding activities which can be done together.

- Showing respect:
 - Using the person's preferred name and form of address (ie first name vs title and surname).
 - Establishing cultural and religious preferences – dress, food, religious occasions, appropriate touch and gestures, etc.
 - Not patronising or talking down to the person with dementia, but being kind and reassuring.
 - Avoiding talking over the head of the person with dementia about them as if they weren't there.
 - Avoiding scolding and criticising.
 - Respecting privacy.
 - Being sensitive if help is needed with personal activities such as washing or going to the toilet.
- Helping the person with dementia make simple choices.
- Looking for activities and tasks the person with dementia can manage and enjoy. Doing things WITH them rather than FOR them where possible.
- Helping the person with dementia look their best, which impacts positively on their self-esteem.
- Looking after oneself while still caring for a person with dementia.

Specific advice

This is available on subjects such as:

- Washing other people.
- Dressing other people.
- Coping with incontinence.
- Coping with changing relationships.
- Managing unusual behaviour.
- Sex and dementia.

- Mental Capacity Act, Power of Attorney and Advance Decisions.

Accessing support

Information is available on:

- Local support groups – carers can be put in touch with other people experiencing similar problems, and support groups for carers.
- Benefits.
- Accessing and paying for care, both at home and in care homes.
- Grief and bereavement.

GPs should be able to refer to social services for a carer's assessment, as well as make their own assessment of any way they may be able to help.

National Institute for Health and Care Excellence (NICE) guidance states that, 'Carers of people with dementia who experience psychological distress and negative psychological impact should be offered psychological therapy, including cognitive behavioural therapy, conducted by a specialist practitioner.'^[3]

Useful organisations for obtaining help and advice:

- Alzheimer's UK
- Age UK
- Carers UK
- Citizen's Advice Bureau

Further reading

- [Donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease](#); NICE Technology appraisal guidance, March 2011 – updated June 2018
- [Age UK](#)
- [Dementia and memory problems](#); Royal College of Psychiatrists, 2013
- [Apply to the Court of Protection](#); GOV.UK
- [Carers UK](#)

- [Citizens Advice Bureau](#)
- [Benefits; GOV.UK](#)
- [Dementia Friends](#)

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