

The later stages of dementia

During the later stages of dementia most people will become increasingly frail due to the progression of the illness. They will also gradually become dependent on others for all of their care. Knowing what to expect can help everyone to prepare. It can enable the person with dementia to think about the kind of treatment and care they might want, and allows them to write an informed advance decision before they reach this stage so they can have input into how they will be cared for. It also allows carers and family to think about these aspects too.

The later stages of dementia can be a distressing time for carers and relatives. There is support available if you need it. Alzheimer's Society's National Dementia Helpline can provide information, support, guidance and signposting to other organisations. Details are at the end of this factsheet.

Symptoms in the later stages

Each person with dementia experiences the illness in their own individual way. The symptoms described below do not necessarily indicate that a person is in the later stages of the disease, as several of them can also be experienced in the earlier stages. However, these symptoms are very likely to occur in the later stages of most dementias.

Memory loss

Memory loss is likely to be very severe in the later stages of dementia. People may be unable to recognise those close to them or even their own reflection. They may no longer be able to find their way around

familiar surroundings or identify everyday objects. However, they may occasionally experience sudden flashes of recognition.

The person may believe that they are living in a time from their past, and may search for someone or something from that time. It can be helpful for those around them to use this as an opportunity to talk about the past and try to reassure the person.

Even if a person has severe memory loss, they may still be able to appreciate or respond to stimuli such as music, scent and touch. It is important to continue to talk to the person, even if they can't respond. (See factsheet 526, **Coping with memory loss.**)

Problems with communication

The person with dementia will experience increasing problems understanding what is being said to them and what is going on around them. They are likely to find it difficult to communicate with other people. They may gradually lose their speech, or they may repeat a few words or cry out from time to time. However, verbal language is only one way of communicating. The person's expression and body language may give clues about how they are feeling. Many people can still receive and return emotional signals long after they have lost the ability to speak.

Those around the person should continue talking to them as normal, even if they don't think that the person is able to understand. This helps to preserve their dignity. There may still be moments when the person seems to make an appropriate response. (See factsheet 500, **Communicating.**)

Loss of mobility

Many people with dementia gradually lose their ability to walk and to perform everyday tasks unaided. One of the first signs of this is that they shuffle or walk unsteadily. They may also seem slow or clumsy and be more likely to bump into things, drop objects or fall. A stroke, arthritis or the effects of a fall may also affect a person's mobility.

Some people with dementia eventually become confined to a bed or chair. Those who are caring for the person should seek advice from a physiotherapist or community nurse on how to help the person to move without injuring the person or themselves.

An occupational therapist can give advice about equipment and adaptations to aid mobility. (See factsheet 429, **Equipment, adaptations and improvements to the home.**)

Eating and weight loss

Most people with dementia lose weight in the later stages of the illness, although occasionally people eat too much and put on weight. Weight loss can affect the immune system, making it harder for the person to fight infections. It may also increase the risk of falling and make it harder for the person to remain independent.

It is important to ensure that the person is getting enough food and liquid. They may need help and encouragement with eating and drinking. Problems with chewing and swallowing are common in the later stages of dementia due to the person's muscles and reflexes no longer working properly. These problems can cause the person to choke on food or develop chest infections, so it is important to seek help.

The GP or community nurse may wish to refer the person to a speech and language therapist or to a nutritional specialist. Nutritional specialists can advise on a special diet or, if the person is unable to eat or drink normally, they can carry out an assessment to see whether or not having foods or liquid through a tube would be beneficial.

(For more information see factsheet 511, Eating and drinking.)

Problems with continence

Many people lose control of their bladder in the later stages of dementia. Some also lose control of their bowels. This may happen all or most of the time, or may just be a case of occasional leakage.

Incontinence is not an inevitable symptom of dementia, but there are a number of reasons why someone with dementia could become incontinent. These include various medical conditions, a number of which are treatable. Possible causes include:

- urinary tract infection
- severe constipation
- side-effects of medication
- prostate gland trouble
- forgetting to go to the toilet or forgetting where the toilet is
- not recognising the need to go to the toilet.

If a person develops problems with continence their GP should refer them to a community nurse or local continence adviser who can give advice and help with getting incontinence pads and other aids. For more information see factsheet 502, **Managing toilet problems and incontinence**.

Unusual behaviour

People in the later stages of dementia sometimes behave in ways that others find unusual or puzzling. 'Puzzling behaviour' varies from person to person but some common examples are described below. For more information see factsheet 525, **Changes in behaviour**.

- The person may become more agitated and confused in the late afternoon and early evening. This is sometimes known as 'sundowning'. Those caring for the person sometimes find it helps to give the person more individual attention at this time, or to arrange extra help at this time of day. The person may be more prone to walking about at this time.
- The person may react aggressively if they feel threatened or cannot understand what is going on around them. (See factsheet 509, **Dementia and aggressive behaviour**.)

- The person may rock backwards and forwards, use repetitive movements or keep calling out the same sound or word. If they are calm, this may simply be a useful coping mechanism. However, if the person seems tense, they may be distressed. If this happens, it is important to check their physical needs, comfort and well-being. Feelings of pain, constipation, hunger and dehydration are key triggers for changes in behaviour.
- Some people experience hallucinations, in which they see, smell, hear, taste or feel things that are not really there. Others develop delusions, in which they experience distorted ideas about what is happening. If the person is distressed, distracting and comforting them can help. (See factsheet 527, **Sight, perception and hallucinations in dementia**).
- Some people are restless because they need more physical activity. They may feel calmer if they are helped to walk at different times throughout the day or to do gentle exercises, or if they can rock themselves in a rocking chair, for example.
- Excessive hand activity becomes more common. The person may constantly wring their hands, pull at their clothes, tap or fidget, or touch themselves inappropriately in public. A rummage box, made of an old shoe box or biscuit tin and containing objects that are related to the person's past such as pictures, knitting wool or tools (if they are safe), may help to keep their hands occupied.
- The person may have long periods of physical inactivity where they remain still, with their eyes open but not engaged in any other activity.

Tips: Helping minimise discomfort and distress

The reasons for these types of behaviour are not always clear, but they may be partly due to the progress of dementia and partly due to distress. There are several things to consider that may help:

- Make sure that the person's glasses are clean and hearing aid is functioning properly, if they use these.

- Check whether the person's medication is appropriate or whether they might be ill or in pain (see 'Health risks' below).
- Check that they are not being disturbed by too many people, too much activity, harsh lights, loud noises or abrupt movements
- Consider whether they may be bored or in need of stimulation. Gentle activities such as a hand massage, listening to their favourite music or stroking a soft piece of fabric may help.
- Most importantly, make sure the person is comfortable – for example, not too hot or too cold, hungry or thirsty, or needing the toilet.

Health risks

There are a number of factors common during the later stages of dementia that can cause problems for the person's health. These include immobility, the side-effects of medication and illness or discomfort.

Immobility

If the person with dementia remains in the same position for too long – for example, in a bed or chair – they may develop pressure sores. Pressure sores need immediate attention, as they can easily become infected and painful. Contact a community nurse straight away if you notice any signs of them. It is important to help prevent pressure sores by making sure the person with dementia moves their position frequently. (See factsheet 512, **Pressure ulcers (bed sores)**.) Other common skin problems include fungal infections and itching.

As people become less mobile, they are also more likely to develop infections and blood clots, which can be fatal. Helping the person to walk or to make arm or leg movements while sitting in a chair can help. An occupational therapist or physiotherapist can advise on safe forms of exercise and our factsheet on **Exercise and physical activity** (529) also gives some examples.

Side-effects of medication

All drugs can have side-effects and some of the drugs that are frequently prescribed for behavioural symptoms in people with dementia can have severe side-effects and may increase the person's confusion. Some people in the later stages of dementia are prescribed doses of drugs that are too high, or drugs that are no longer appropriate to their needs.

Anyone who is concerned about the effects of the person's medication should talk to their GP. It may be possible to alter the dose or change the medication. (See factsheet 408, Drugs used to relieve behavioural and psychological symptoms in dementia.)

Illness and discomfort

Infections can increase confusion in people with dementia. Infections can also speed up the progression of dementia. It is therefore important that if a person with dementia develops an infection it is quickly diagnosed and treated.

A person in the later stages of dementia may be unable to communicate to others that they are feeling unwell. A sudden change in behaviour or increase in confusion is often a sign that something is wrong. Sometimes infections can cause a person with dementia to become severely confused. This is known as 'delirium'. Delirium usually develops over one or two days. Symptoms of delirium include:

- agitation or restlessness
- problems concentrating
- hallucinations or delusions
- becoming unusually sleepy or withdrawn.

Anyone who suspects that the person is ill should contact their GP immediately.

Even if the person is not ill, they may be uncomfortable or in pain. For

example, they may be constipated, have sore gums or teeth, or be wearing uncomfortable shoes. If you suspect that the person may be in pain or discomfort, it is important to discuss this with the doctors or nurses responsible for their care.

Treatment and care

Medication

The anti-dementia drug memantine is used to treat severe Alzheimer's disease, and may be used to treat moderate disease in some cases. It can help stabilise the condition and maintain important skills such as feeding and walking, and may improve symptoms of aggression and restlessness. In 2011, memantine was recommended by the National Institute for Health and Clinical Excellence (NICE) as part of NHS care for the treatment of severe Alzheimer's or moderate disease where drugs such as donepezil cannot be taken. Access to the medication may still vary across the country.

Where will the person be cared for?

Many people in the final stages of dementia live in a care home, although some may be in hospital or a hospice and an increasing number live at home with support from health and social care services.

- Home – If the person's loved ones feel able to provide care for the person at home, they need to make sure that adequate community nursing and other forms of support are available. This information is available from the GP and social services.
- Care homes – Some residential care homes and most nursing homes are prepared to care for people with dementia at the end of their lives. Most residential care homes have access to specialist NHS staff, such as continence nurses and speech and language therapists. Nursing homes also have access to specialist NHS staff but in addition to this also have a qualified nurse on duty 24 hours a day. Some treatments that are available in a hospital (see 'What care or treatment may be offered?' below) may not be available in a

care home or nursing home.

- Hospital – Most people with dementia who are admitted to hospital during the final stages are actually admitted because of another illness. If this is the case, it is important to make sure that hospital staff are aware of the person's dementia and any usual behaviours and routines. Sharing information about the person and their life is also important.

Alzheimer's Society has a leaflet called This is me which can be used to record this information. When completed, it provides a snapshot of the person with dementia, giving information about them as an individual, such as their specific needs, preferences, likes, dislikes and interests. The leaflet can be downloaded from alzheimers.org.uk/thisisme or ordered by phoning 01628 529240.

- Hospices – Hospices offer end of life care when the illness is no longer treatable. End of life care (which is often called 'palliative care') focuses on reducing physical and psychological distress and providing support to the family. Most people in the later stages of dementia require a high level of nursing care, which can be provided at home by the district nursing team or in nursing homes. A few people will have rather more complex symptoms or social problems, which may benefit from specialist input from hospices or palliative home care services. If in doubt, contact your local hospice to discuss the person's needs.

If staff are not used to dealing with someone with dementia, the person's partner or family may need to discuss their needs with the nurse in charge of the ward. Meanwhile, the person with dementia will need reassurance and a calm, simple explanation of what is happening.

What care or treatment may be offered?

If someone in the later stages of dementia becomes seriously ill, there may be a discussion about whether to try to prolong their life or to allow them to die naturally. Only the doctor can make the final

decision about whether to give or withhold treatment in the final stages of dementia. However, the views of relatives and of the person with dementia should always be taken into account where possible.

If a lasting power of attorney has been set up, the doctors must consult with the attorney before initiating or withdrawing any treatment. It may also be helpful if the person with dementia has put their wishes in writing at an earlier stage in the illness. See 'What you can do: advance decisions and lasting powers of attorney' below.

End of life treatments may include:

- resuscitation after a heart attack
- antibiotic treatment for pneumonia
- oxygen therapy for shortness of breath.

Resuscitation may be unsuccessful in people in the final stages of dementia, and even when it is successful, there is a risk of causing further brain damage.

What is likely to cause the person's eventual death?

The life expectancy of a person with dementia is unpredictable, and the disease can progress for up to around 10 years. It is estimated that a third of people with dementia at any one time will be in the later stages of the disease. Although dementia is a life-shortening illness, another condition or illness (such as pneumonia – an infection in the lung) may actually cause a person's death. This other condition or illness will most likely be listed as the cause on the person's death certificate. Pneumonia is listed as the ultimate cause of death in up to two-thirds of people with dementia.

The person's ability to cope with infections and other physical problems will be impaired due to the progression of the disease, and the person may die because of a clot on the lung or a heart attack.

However, in some people no specific cause of death is found, other than dementia. If the person is over 70, ageing may also be given as a contributing factor. Alternatively, the death of a person with dementia could be caused by a condition that is completely unrelated to their dementia.

Depending on the circumstances and the practices of the doctor, dementia may be entered on the death certificate as the sole or main cause of death, or as a contributing factor. If it has not been mentioned, you can ask the doctor to include it if you wish.

What you can do: advance decisions and lasting powers of attorney

In England and Wales people can write an advance decision to refuse treatment (sometimes written as ADRT and previously known as a living will or advanced directive). This sets out the types of treatments they would not want doctors to provide at the end of their life. This is important as it means that people in the early stages of dementia have the opportunity to shape and make choices about any palliative care that they may need as the illness progresses. It also enables healthcare professionals to provide the best person-centred care and treatment they can. Person-centred care is an approach that focuses on the person as an individual.

In Northern Ireland people are able to make an advance directive, which is similar to an advance decision. An advance decision (or advance directive) needs to be made when the person is still able to make decisions for themselves so it is important to start thinking about it early on.

For more information see factsheet 463, **Advance decisions and advance statements** (which includes a form to create an advance decision) and 460, **Mental Capacity Act 2005**.

In addition to making an advance decision to refuse treatment, people in England and Wales may also make a lasting power of

attorney (LPA) which appoints someone to make decisions about their treatment and care on their behalf – once they have lost the ability to do so for themselves. This can include decisions about refusing life sustaining treatment. For more information see factsheet 472, **Lasting Power of Attorney**. LPAs are not available in Northern Ireland. People in Northern Ireland should contact Alzheimer's Society's Northern Ireland office for more information about the alternatives.

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This factsheet has also been reviewed by people affected by dementia. A list of sources is available on request.



Alzheimer's Society National
Dementia Helpline

England, Wales and Northern Ireland:
0300 222 11 22

9am–8pm Monday–Wednesday
9am–5pm Thursday–Friday
10am–4pm Saturday–Sunday

alzheimers.org.uk

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