When a person is in the later stages of dementia (also known as advanced or severe dementia) they are likely to be much more frail. They will probably rely on others for much of their care. The later stages can be hard to define and everyone will go through them in their own way.

However, a person in the later stages is likely to experience severe memory loss, problems with communication and daily activities, and greater changes in behaviour and physical problems than in the earlier stages.

Some people may not want to know what to expect in the later stages and it is important to respect this. However, knowing what to expect can help the person and those supporting them to plan ahead for the treatment and care they may want.

This factsheet is for anyone supporting someone in the later stages. It includes information on symptoms in the later stages of dementia and the care and support available. It also includes advice on how to support the person and plan ahead for the later stages. For information on end of life care see factsheet 531, End of life care.
Contents

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The later stages of dementia

The progression of dementia

Dementia is a progressive condition. This means it will get worse over time because of damage to the person's brain, and this will have a big impact on the person's mental abilities (including memory and communication).

The speed at which dementia worsens varies widely. There are some differences between the different types of dementia – Alzheimer’s disease, for example, seems to have the slowest progression on average. There is also variation from person to person. For more information see factsheet 458, The progression of Alzheimer’s disease and other dementias.

Symptoms in the later stages

People in the later stages of dementia become increasingly frail and depend more on other people for support. As dementia progresses and causes changes to the person's brain, they may struggle to do many of the things they used to. However, even in the later stages the person may experience moments of lucidity (being aware of their situation) and some of their abilities may return temporarily. The person's reactions are likely to be influenced by their environment and how they feel. For example, they may react more positively if they are in a familiar environment or one where they feel comfortable.

People in the later stages of dementia often experience problems with the following.

Memory

By the time the person reaches the later stages of dementia, they are likely to have significant memory loss and cognitive difficulties. Recent memories may be lost completely (for example, what they had for breakfast or when they last saw a friend) and they may only remember parts of past memories.

The person may believe they are living in an earlier time period from their life (for example, when they were at school). This can mean they say
things and behave in ways that don't make sense to those around them. The person may also confuse those around them for someone else (for example, thinking their partner is their sister). The person may respond and experience emotions related to how they felt in the past. The person’s emotions are often related to how they’re currently seeing their situation – for instance, they might become distressed because they believe they need to go and collect their children from school but they are being prevented from doing this.

The person may no longer be able to recognise themselves or other people such as their partner, friends and family. This may also be due to them believing they are in a different time period, and this can be very difficult for the person and those around them. The person may become upset when looking at themselves in the mirror or think there are strangers in the house, for example. It can be extremely difficult when someone with dementia is not able to remember their own family or close friends. Don’t take this personally. This memory loss is caused by the progression of the dementia. Even if the person with dementia is not able to place someone they are still likely to experience feelings they associate with that person. For example, they may still be prompted when they see someone familiar to feel safe and happy around them. Keeping in touch with the people they know where possible will help them to continue to have these positive feelings and enjoy their company.

Concentration, planning and orientation

The person may also develop increasing difficulties with other mental abilities, such as concentrating, planning and organising. For instance, they may only be able to carry out simple activities, or not be able to concentrate for too long. They may be increasingly disorientated and have difficulties recognising where they are. They may have a limited understanding of time.

Meaningful activities

However, the person may still get enjoyment from past hobbies, interests and activities. Find opportunities to make these meaningful. This could be doing anything that the person benefits from whether this is enjoyment, fulfilment or comfort.
Even if they are restricted with what they can manage, they can still enjoy the feelings and sensations of an activity. For example, they may enjoy the feel of wool even if they can no longer knit, or listening to favourite songs even if they can’t sing along. In the later stages people may respond more to things that stimulate their senses (sight, hearing, smell, touch and taste), than to words. Think of ways to stimulate the person’s senses and help with how they feel in that moment. For example, they may enjoy stroking a pet, tasting their favourite food or looking at familiar photos.

Communication

In the later stages of dementia the person is likely to have more problems with verbal communication. They may not understand what is being said to them and are less likely to be able to respond verbally as they may have limited or no speech. They may repeat the same phrase or sound, or may only be able to repeat a couple of words. Some people may start talking lots but their words don’t seem to make sense. In this case, try to identify the feelings that the person is trying to get across and respond to these. For example, if the person is smiling and chatting happily, respond to them in the same way.

Although the person may not be able to communicate verbally, they may still be able to show their needs and emotions in other ways. Rather than speaking, they may use behaviour, facial expression, gestures and sounds to try and communicate how they are feeling and what their needs are.

Try to support the person to communicate as much as possible. It can help to observe their body language, behaviour and facial expressions. Knowing the person and how they communicate will help you both to enjoy time together. It’s important to keep communicating with the person and look for opportunities for meaningful engagement (see ‘Meaningful activities’ above). Finding ways to engage the person’s senses can help.

When you’re thinking about how to communicate with the person, bear in mind their needs and background – including their cultural needs. For example, people from some cultural backgrounds may feel uncomfortable or distressed if you’re too close to them when communicating with them.
Tips: communicating with a person in the later stages of dementia

- keep eye contact when communicating
- non-verbal communication (such as gestures, facial expression and body language) can help
- smile
- use appropriate physical contact (such as holding hands) to let the person know you are there and offer reassurance
- don’t rush – allow plenty of time and look for non-verbal clues from the person
- even if you don’t think the person can follow what you’re saying, continue talking to them clearly. They may still feel a certain way even if they don’t fully understand what you’re saying
- consider responding to them in the way they respond to you (‘mirroring’ them).

For more information on communicating with a person with dementia see factsheet 500, Communicating.

Mobility

Dementia is likely to have a big physical impact on the person in the later stages of the condition. They may gradually lose their ability to walk, stand or get themselves up from the chair or bed. They may also be more likely to fall. These problems can be caused by dementia, medication, other medical conditions (for example stroke), sight loss, balance problems and the environment. However, not all people will have problems with mobility.

Many people with dementia (especially in the later stages) find themselves staying in one position for a long time (such as sitting in a chair) and not moving around much. This means they are at risk of pressure ulcers (bedsores). If you notice a pressure ulcer or have concerns speak to the GP or community nurse. They can be easy to prevent early on, but if they go unnoticed they can get worse and become painful and infected. For more information see factsheet 512, Pressure ulcers (bedsores).
As a person's mobility decreases they are also at risk of infections and blood clots. The person should be supported and encouraged to move around as much as they are able, for example through support to walk or chair-based exercises. An occupational therapist or physiotherapist can help with this. For more information see factsheet 529, Exercise and physical activity.

Ask for advice on the best ways to support the person to move without injuring themselves. Speak to the GP, or a community nurse, occupational therapist or physiotherapist for more advice. An occupational therapist can give advice about equipment and adaptations to help with mobility. For more information see factsheet 429, Using equipment and making adaptations at home.

**Eating and weight loss**

Eating and drinking becomes more difficult as dementia progresses. A person in the later stages of dementia is likely to experience a range of difficulties with eating including loss of appetite, pain and symptoms related to the dementia.

Many people with dementia lose weight in the later stages. Weight loss can affect the immune system and make it harder for the person to fight infections and other illnesses. It can also increase the risk of falling and make it harder for the person to remain independent.

People in the later stages of dementia may also develop difficulties with swallowing (dysphagia) and chewing. People with swallowing problems are at risk of choking and of food or saliva going down the windpipe, causing an infection. Swallowing difficulties can be common in the later stages as the person’s muscles and reflexes no longer work properly. They can be distressing for the person and those supporting them. If the person is having difficulties it’s important to speak to the GP – they may refer the person to a speech and language therapist or nutritional specialist. For more information see factsheet 511, Eating and drinking.
The person should be supported to eat and drink for as long as they show an interest and can do so safely (even if they just take a mouthful or a sip). There are ways to help make this easier for the person. For example:

- choosing a plate that is a different colour to the food (so they can see it more clearly)
- giving the person enough time
- putting the drink in their hand if they are struggling to see it.
- changing the consistency of food and drinks (for example serving it in liquid or puree form. Only do this following advice from a professional such as a dietitian or speech and language therapist.

Eating and drinking can still bring the person pleasure, even in the later stages. It’s important to support them to eat and drink things that they enjoy. Many people’s tastes will change as they get older and as dementia progresses (for example, they might start to prefer sweet food).

Think about the person’s oral health as this will have an impact on their ability to eat and communicate (as well as helping with their general health and wellbeing). If the person has poor oral health it may lead to pain, which could mean they don’t want to eat or they behave in ways that are out of character. For more information see factsheet 448, Dental care and oral health.

People in the later stages of dementia may behave in ways that are out of character. These behaviours can be difficult to understand and there are often different reasons for them. They may be a sign that a person’s need is not being met (for example, they are in pain), or that they are confused or distressed. Often behaviour is a means of communication and can be a result of the person feeling a certain way (for example scared or anxious).
Toilet problems and incontinence
As dementia progresses people may find it harder to use the toilet and may experience accidents or incontinence. This could be urinary incontinence (urine leaking by accident), faecal incontinence (faeces leaking by accident) or both. Incontinence may be an occasional leak or a total loss of control.

Having dementia doesn’t mean a person will definitely become incontinent, but there are a number of reasons why they could be, or have problems using the toilet. These include various medical conditions, many of which can be treated. Possible causes include:

- urinary tract infection (UTI)
- 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, speak to the GP. If a cause can’t be found, ask for a referral to a continence adviser. They can offer advice and help with managing the situation including incontinence pads and other aids. For more information see factsheet 502, Continence and using the toilet.

Changes in behaviour
People in the later stages of dementia may behave in ways that are out of character. These behaviours can be difficult to understand and there are often different reasons for them. They may be a sign that a person’s need is not being met (for example, they are in pain), or that they are confused or distressed. Often behaviour is a means of communication and can be a result of the person feeling a certain way (for example scared or anxious).
Every person with dementia will behave in different ways, but changes in their behaviour may include the following.

- **Distress or agitation** – this may be because the person is confused about where they are, who they are with or what they are meant to be doing.

- **Sundowning** – the person may become more agitated and confused in the late afternoon and early evening. This can be caused by a range of factors including disturbance to the body clock, too much or too little sleep, or medication. It may help to give the person something meaningful to do at this time of day and make sure the environment is suitable (for example, not too dark or too light). Going outside during the day (if possible) can help.

- **Aggression** – the person may react aggressively for a range of reasons – for example, they may be in pain or feeling threatened, may not understand what is going on (for example, if a carer tries to change their clothes without explaining why) or trying to communicate a need. For more information see factsheet 509, *Dementia and aggressive behaviour*.

- **Repetition** – the person may repeat certain behaviours (for example, carrying out the same activity or making the same gesture over and over). This may be because they feel anxious or want comfort. Their natural interaction with their environment may have been disrupted (for example by memory loss) and the behaviour is a way to make sense of what is going on. It can help to look for meaning behind the behaviour and try to remain calm and patient.

- **Hallucinations and delusions** – some people with dementia experience hallucinations, in which they see, hear, smell, taste or feel things that are not really there. However, sometimes the person may not be hallucinating but mistaking what they have seen for something else (for example, they may see a dark rug and think it is a hole in the ground). Others may develop delusions, where they strongly believe things that aren’t based on reality but feel real to them (for example, they may be convinced that someone is stealing from them). Talking calmly to the person, offering reassurance and meaningful activity (such as going for a walk or doing something around the house) can help. If you think the person is experiencing hallucinations or delusions see the GP. For more information see factsheet 527, *Sight, perception and hallucinations in dementia*. 
Restlessness — many people with dementia become restless and may fidget or pace up and down. This could be for a range of reasons such as pain or discomfort, needing the toilet, a need for more physical activity or problems with their environment (for example if they are just sat in the same place with no stimulation for much of the day). It may also be because the person used to move around a lot as part of their job. It may help to encourage exercise (such as going for a walk every day) or meaningful activity including activities related to past roles, interests and hobbies, as well as new interests.

The person may move their hands much more often. They may constantly wring their hands, pull at their clothes, tap or fidget, or touch themselves inappropriately in public. This can be a sign of a need — for example, the person may pull at their clothes because they are too hot or need the toilet. A rummage box, containing objects related to the person’s past such as pictures, jewellery or souvenirs, may help as it gives the person an opportunity for moving their hands.

Ways to manage changes in behaviour: tips for carers

The reasons for these types of behaviour may not always be clear. They may be due to, or a combination of, difficulties caused by dementia (such as orientation problems), mental and physical health, habits, personality, interactions with others and the environment. Try and understand what may be causing the person’s behaviour, and think about whether they have any unmet needs.

- Ensure that any glasses or hearing aids are clean and functioning properly. Arrange regular sight and hearing checks.

- Check whether the person’s medication is appropriate or whether they might be ill or in pain (see ‘Health problems’ below). A visit to the GP to rule out any physical problems is a good idea.

- Check that they are not being disturbed by too many people, too much activity, loud noises, sudden movements or an uncomfortable environment (for example, one that is too hot or too bright).
Consider whether they may be bored or in need of stimulation. Engage the person in meaningful activities. Gentle activities such as a hand massage, listening to their favourite music or stroking a soft piece of fabric may help.

Make sure the person is comfortable – for example not in pain, too hot, cold, hungry, thirsty, or needing the toilet.

For more information see factsheet 525, Changes in behaviour.

Health problems

There are a number of common factors during the later stages of dementia that can affect a person’s health. These include problems with movement (see ‘Loss of mobility’ above), the side effects of medication and illness (such as infections) or discomfort and pain. The person may also develop health problems related to age, such as arthritis and rheumatism.

Side effects of medication

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

Anyone who is concerned about the effects of the person’s medication should talk to their GP. It may be possible to change the dose or the medication. For more information see factsheet 408, Drugs for behavioural and psychological symptoms in dementia.

Illness and discomfort (including pain)

Infections such as urinary tract infections (UTIs) can increase confusion in people with dementia, and can also speed up the progression of the condition. They are also common in the later stages. It is important that infections are quickly diagnosed and treated.
A person in the later stages of dementia may be unable to communicate to others that they are feeling unwell or are in pain. However, there may be a change in their behaviour that is a sign of this. Observing the person and looking for any changes in them can help you to notice any problems. If you think the person may be unwell or in pain, speak to the GP.

If the person with dementia is unwell and there is a sudden change in their mental abilities or behaviour that lasts several hours, it is often a sign they have delirium. Symptoms of delirium include:

- not paying attention or concentrating
- confused and muddled thinking
- disturbed language (for example, speech that doesn’t make sense)
- change in consciousness (for example, feeling drowsy or much more alert)
- change in the person’s sleep/wake cycle
- hallucinations and delusions.

The symptoms will change as the day goes on (for example, the person may be agitated earlier in the day but be lethargic later on). The symptoms are often better in the morning than the evening. If the person suddenly becomes confused or develops these symptoms they should see a doctor immediately.

A person still feels pain in the later stages of dementia even though they may not be able to verbally communicate it. The person may be unable to tell you they are in pain, and as a result they may start to behave in ways that are unusual. It’s important to consider pain as a cause and make sure that it is properly managed.

Many people in the later stages aren’t given enough pain medication and may be left in pain that could otherwise be treated. Common causes of pain in people with dementia include urinary tract and other infections, constipation and other conditions (for example arthritis). If you think the person may be in pain, speak to a GP about medication and non-drug approaches (such as massage) that may help.
Treatment and care

Medication
There is good evidence that drugs commonly prescribed for the treatment of Alzheimer’s disease known as the cholinesterase inhibitors (donepezil, rivastigmine and galantamine) have benefits for people in the later stages of the disease. Many doctors now continue to prescribe these for severe Alzheimer’s disease.

Memantine is also recommended for people in the later stages of Alzheimer’s disease. It can slow down the progression of symptoms including difficulties with everyday activities and disorientation. There is some evidence it can also help with symptoms such as delusions, aggression and agitation.

Memantine is recommended in the guidance used by health professionals as part of NHS care for the treatment of severe Alzheimer’s disease, or in the moderate stage of Alzheimer’s where drugs such as donepezil cannot be taken.

There is some evidence that both memantine and cholinesterase inhibitors (known as ‘combination treatment’) can be helpful. However, the guidance for health professionals does not recommend combination treatment.

Memantine is not suitable for people with other types of dementia.

For more on the drug treatments available see factsheets 407, Drug treatments for Alzheimer’s disease, and 408, Drugs for behavioural and psychological symptoms in dementia.

Planning for care in the later stages
If the person with dementia has made their wishes known regarding care in their later stages, you can support them and help them to meet these plans. These may consist of various things.

In England and Wales people can write an advance decision. This is sometimes written as ADRT – advance decision to refuse treatment – and used to be known as a living will or advance directive. They can also write an advance statement to express their wishes and preferences.
about future care (though this is not legally binding). They may also wish to appoint a Lasting power of attorney for health and welfare.

For more information see factsheets 463, *Advance decisions and advance statements* (which includes a form to create an advance decision), 460, *Mental Capacity Act 2005*, and 472, *Lasting power of attorney*.

In Northern Ireland people can also make an advance directive and advance statement. They may appoint power of attorney under the Northern Ireland system, Enduring power of attorney. For more information see Northern Ireland factsheet NI467, *Financial and legal tips*, and factsheet NI472, *Enduring power of attorney and controllership*.

If the person with dementia has made their wishes known regarding care in their later stages, you can support them and help them to meet these plans.

Where will the person be cared for?
As the person’s dementia progresses, think about the most suitable place for them to live based on their wishes and needs, as well as the support available to them. This includes whether other people are able and willing to care for them. The local authority can carry out an assessment of need for everyone who may be in need of community care support.


Wherever the person is cared for, if staff have information about the person and their life, condition, behaviour and routines, they will be able to provide better, person-centred care. Alzheimer’s Society has a support tool called *This is me* (1553) that can be used to record this information for a person who has communication difficulties. 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. It is also helpful to communicate regularly with the professionals caring for the person.
People in the later stages of dementia can live and be supported in different places. Find out whether the person’s needs can be met in these settings.

- **Their own home** – some people continue to live at home with support from carers and/or health and social care services. Devices and equipment can sometimes support the person to remain at home. For more information see factsheet 437, *Assistive technology – devices to help with everyday living.*

- **Sheltered and extra care housing** – sheltered accommodation and extra care housing should have 24-hour emergency help available via an alarm system. Extra care housing also includes care and support on site (for example, meals may be provided).

- **Care home** – staff in care homes (including residential and nursing homes) can provide help with personal care (such as washing and dressing). Nursing homes have a qualified nurse on duty 24 hours a day. If the home is registered as a care home with dementia care, they should have staff qualified in supporting people with dementia. The person with dementia will still be able to access NHS services.

- **Hospice** – care in a hospice focuses on reducing physical and psychological distress and providing support to those who are important to the person. Hospice care is for people who have an illness that is no longer treatable, sometimes including people with dementia. Often this is near the end of a person’s life. For more information see factsheet 531, *End of life care.*

- **Hospital** – people with dementia are less likely to be cared for in hospital for long periods during the later stages. However, they may have short stays in hospital, often because of another illness. If this is the case, make sure hospital staff are aware of the person’s dementia and other information about the person.

If you’re thinking about the person moving in the later stages consider the impact this will have on them. Adjusting to a new environment in the later stages can be challenging. It’s important that the person lives somewhere suitable for them where their needs can be met.
If you are concerned about any aspects of the person’s care, ask the service or organisation providing the care for their complaints procedure. If, after following this procedure, you feel that your complaint has not been properly addressed, you can take the complaint further. The next steps should be explained in their complaints procedure.

**Looking after yourself**

Caring for a person in the later stages of dementia can be rewarding, but also very challenging. When a person with dementia moves into residential care, it can have a big impact on the carer as well. It is important to seek support for any feelings you might have. For more information see factsheet 523, *Carers: looking after yourself*.

**Other useful organisations**

**Age UK**

**England**
Tavis House
1–6 Tavistock Square
London WC1H 9NA

0800 169 80 80 (general enquiries)
0800 169 2081 (advice line)
contact@ageuk.org.uk
www.ageuk.org.uk

**Wales**
Age UK Cymru
Tŷ John Pathy
13/14 Neptune Court
Vanguard Way
Cardiff CF24 5PJ

029 2043 1555 (general enquiries)
0800 022 3444 (advice line)
enquiries@agecymru.org.uk
Northern Ireland
Age NI
3 Lower Crescent
Belfast
Northern Ireland BT7 1NR

028 9024 5729 (general enquiries)
0808 808 7575 (advice line)

Provides information and advice for older people in the UK.

**Carers UK**
20 Great Dover Street
London SE1 4LX

0808 808 7777 (Adviceline, Monday–Friday 10am–4pm)
advice@carersuk.org
www.carersuk.org
www.carersuk.org/forum (online discussion forum)

Provides information and advice to carers about their rights and how to access support.

**Dementia UK**
Second Floor, Resource for London
356 Holloway Road
London N7 6PA

0207 697 4160
info@dementiauk.org
www.dementiauk.org

Provides Admiral Nurses to support families living with dementia.
The later stages of dementia

EAC FirstStop
3rd Floor
89 Albert Embankment
London SE1 7TP

0800 377 7070
info@firststopadvice.org.uk
www.eac.org.uk

FirstStop Advice provides independent, impartial and free advice and information to older people, their families and carers about housing and care options in later life.

Hospice UK
34–44 Britannia Street
London WC1X 9JG

0207 520 8200
info@hospiceuk.org
www.hospiceuk.org

Hospice UK is the national charity for hospices in the UK. They provide information and support and can help people find a local hospice.

Office of the Public Guardian (OPG)
PO Box 16185
Birmingham B2 2WH

0300 456 0300
customerservices@publicguardian.gsi.gov.uk
www.gov.uk/office-of-public-guardian

Protects people in England and Wales who may not have the mental capacity to make certain decisions for themselves, such as about their health and finance.
Alzheimer’s Society National Dementia Helpline
England, Wales and Northern Ireland:
0300 222 1122
9am–8pm Monday–Wednesday
9am–5pm Thursday–Friday
10am–4pm Saturday–Sunday

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