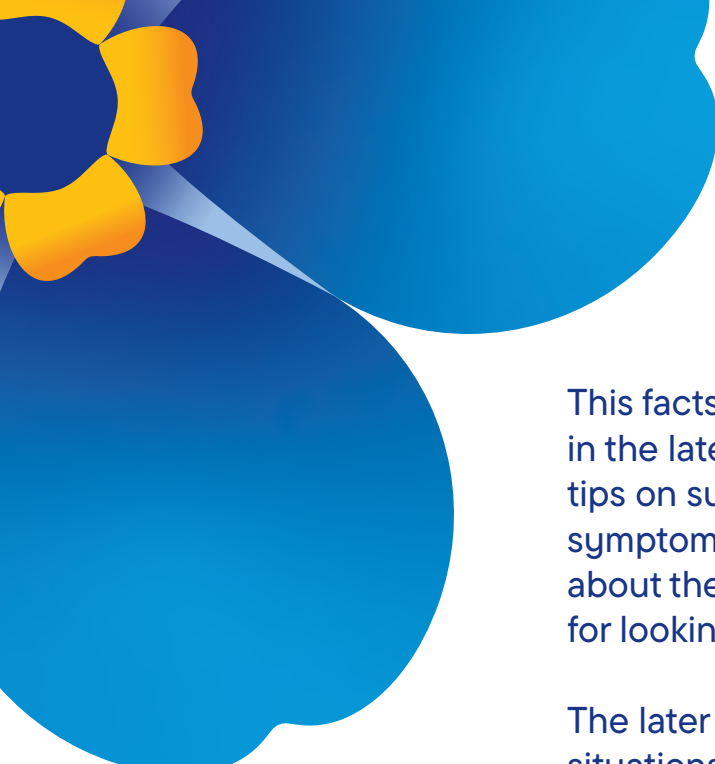


Supporting a person in the later stage of dementia



**Alzheimer's
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Together we are help & hope
for everyone living with dementia



This factsheet is for carers who are supporting a person in the later stage of dementia. It includes practical tips on supporting a person with different late-stage symptoms and health problems. It also has information about the care and support available, as well as advice for looking after yourself.

The later stage of dementia can cause distressing situations for the person with dementia and their carers. Some of the information in this factsheet may be upsetting. However, understanding more about this stage of dementia can help you get the right treatment and care for the person with dementia. You can make changes and put support in place for them and for yourself.

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1 Why does dementia progress?

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The later stage of dementia (also known as 'advanced' or 'severe' dementia) can be hard to define and everyone will go through it in their own way. When the person reaches this stage of dementia, the condition is likely to cause considerable difficulties in most aspects of their life. This means the person will rely on others for much of their care and may eventually need full-time support with daily living.

Dementia is a progressive condition. This means its symptoms may be relatively mild at first but they will get worse over time. This is because the diseases that cause dementia spread to different areas of the brain over time and more symptoms develop. Already-damaged areas of the brain also become more affected over time, causing any current symptoms to get worse.

It can be helpful to think of this progression in three stages: early, middle and late. However, these are just a guide. Dementia doesn't follow an exact or certain set of steps that happens in the same way for every person. Even when the person's dementia is very advanced, they can also have moments of lucidity (being aware of their situation) and some of their abilities may return temporarily.

Dementia affects every person individually so the speed at which dementia worsens varies widely from person to person.

For more information see factsheet 458, **The progression and stages of dementia**.

You may face some particularly challenging and distressing situations when you are supporting a person in the later stage of dementia. The way to approach any situation like this will vary depending on:

- the type and stage of the person's dementia
- the symptoms the person is experiencing
- the person's personality and specific circumstances
- your own personality and how you feel about the situation.

This means this factsheet may not cover every situation that you may face. For personalised advice and support call our support line on **0333 150 3456**.

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2 Supporting a person in the later stage of dementia

Everyone's experience of dementia is different and the person's experience in the later stage will be unique to them. This section describes common ways symptoms of dementia progress in the later stage of dementia and includes suggestions for how you can help.

Symptoms of later-stage dementia include:

- severe memory loss
- problems with communication
- difficulty carrying out daily activities
- more changes in behaviour than in the earlier stages of the condition
- more physical problems caused by not eating or drinking enough, loss of mobility and inactivity.

Delusions (strongly believing things that aren't true) and hallucinations (sensing things that are not really there) may also start to happen or get worse in the later stage of dementia. The person may also become more confused, which can lead to them becoming more distressed, anxious or aggressive.

These changes can be difficult to cope with, both for you and the person you are supporting. However, understanding how the person's dementia may progress and preparing for changes can help you to manage them. There are also practical things you can do to make the person feel comfortable, safe and engaged. Support is available to help both you and the person when things change.

Memory

By the time the person reaches the later stage of dementia, they are likely to have significant memory loss and cognitive difficulties.

They may forget recent events completely (for example, what they had for breakfast or when they last saw a friend) and they may only remember parts of past memories. They may also misremember people and events and begin to 'confabulate' – which is when a person fills in memory gaps with false information which they believe to be true.

The person may believe they are living in an earlier time of their life (for example, when they were at school). This is known as time-shifting and can lead them to become confused about what they are seeing and feeling, and relate this to stronger past memories. Time-shifting may cause the person to:

- say and do things that don't make sense to others
- confuse people for someone else
- respond to events and experience emotions in ways related to incidents from their past or how they felt then.

The person may also no longer be able to recognise themselves or other people, such as their partner, friends and family. This may cause the person distress when looking in the mirror, or make them feel like they are surrounded by strangers.

For more information on time-shifting see factsheet 527, **Changes in perception.**

It can be extremely difficult when someone with dementia is not able to remember their own family or close friends, or when they say things that you know are not true. Try not to take these changes personally. Remember that these difficulties are caused by the progression of the person's dementia.

Tips for supporting the person with memory loss in the later stage

- **If the person confabulates, it is usually best not to contradict them.** Keep in mind that they are not trying to lie or deceive you, they are saying what they genuinely believe.
- **Try to keep the person in touch with people they know where possible.** Even if they are unable to fully recognise someone or remember their name, they can still have positive feelings that they associate with that person. Being around someone familiar may prompt the person to feel safe and happy.
- **If the person becomes distressed or frustrated because they can't remember something, gently reassure them.** Also consider changing the topic of conversation or activity.
- **It can help to introduce yourself every time you see the person.** This will reduce any anxiety they may have around remembering names or their relationship to others.
- **If the person believes they are in an earlier time period, it can be useful to find out about their life history.** Understanding their past can help you to understand how they are interpreting the present and how they are feeling. It may also explain certain phrases they are using or questions they are asking.

For more information see factsheet 526, **Supporting a person with memory loss.**

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Concentration, planning and orientation

The person may also develop more difficulties with other mental abilities in the later stage of dementia, such as concentrating, planning and organising. They may only be able to do simple activities, or be unable to concentrate for too long. They may also have difficulty following the steps of an activity – such as making a sandwich, doing household chores or playing a game.

The person may also become more disorientated and confused. This may include getting confused about time and place. For example, they may be unsure about the year, month or time of day. They may also not recognise where they are living, especially if they have moved quite recently. This can cause distress, anger and frustration.

Tips for supporting the person with concentration, planning and orientation in the later stage

Even if the person is having difficulty with their thinking abilities, they can still engage in meaningful and enjoyable activities.

Changing the subject or doing something different with the person can also be a helpful distraction if they are getting confused about time or place.

Trying to persuade the person of factual details may cause further distress or arguments. Instead, try to reassure the person that they are safe and engage them in an activity they enjoy. The following suggestions may help you to engage the person in meaningful activities.

- **The person may still get enjoyment from their hobbies, interests and activities if you can adapt or simplify them.** For example, you could use board games or touchscreen apps that are specifically designed for people living with dementia.
- **If you are introducing new activities to the person, consider what they can and cannot do.** For example, if the person cannot concentrate for long periods, then a film they haven't seen before may not be suitable. A sketch show, clips from television programmes on favourite topics or genres (such as nature or comedy) or films they know and enjoy might be better.
- **Try to make activities meaningful for the person by looking for things that they enjoy, or get fulfilment or comfort from.** For example, they might enjoy watching or listening to religious services, sporting events or music they love. You might be able to find video clips of the country or town where they grew up. They might also enjoy activities related to their interests, work they used to do or groups they were involved in.

- **Even if the person cannot fully do an activity, 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 the smell of food even if they can no longer cook by themselves. The person may respond more to things that stimulate their senses (sight, hearing, smell, touch and taste), than to words. Think of ways to do this – for example, they may enjoy stroking a pet, listening to music, the feel and scent of hand lotion or looking at familiar photos.

For more tips and activity ideas see booklet 77AC, **The activities handbook**.

Communication

In the later stage of dementia, the person is likely to have more problems with verbal communication (communicating with words). They may have limited speech and only use certain phrases or the same few words. Or the person may lose the ability to speak completely.

The person may also not understand what is being said to them or they may understand but not be able to respond with words. This can cause the person frustration and distress.

As dementia progresses, many people with dementia will communicate their needs non-verbally through facial expression, body language, and gestures. Some people might begin to make noises such as groans, cries or shouting out. This is known as 'disruptive vocalisation' and can be upsetting to witness. If the person seems to be in distress when this is happening, speak to their GP so they can look at whether there is a physical cause for this. For example, if a person is in pain or uncomfortable, they may vocalise it in this way.

Tips for communicating with a person in the later stage

Pay attention to the person's body language, facial expressions and gestures for clues as to how they are feeling or what they're communicating. The person may not be able to fully express themselves using words or sounds, or they may be completely non-verbal.

It can also be useful to think about the person's environment. For example, is the room too hot or cold, and do they seem comfortable in the clothes they are wearing?

Try to support the person to communicate as much as possible. It's important to keep communicating with the person and look for ways of keeping them connected to other people or with things that mean something to them (see page 4). Finding ways to engage the person's senses can help.

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When you're thinking about how to communicate with the person, bear in mind their needs and background – including their cultural and spiritual needs. For example, some people may feel uncomfortable if you're too close to them when communicating.

Other tips include:

- **Keep eye contact** when communicating.
- **Make sure you are in a calm and quiet environment if possible** – preferably a familiar one to the person.
- **Keep in mind your own non-verbal communication** (such as gestures, facial expression and body language) and how this might be coming across to the person.
- **Use objects, photos, videos and sound clips** that will attract and interest the person and help them understand what you are saying. Pictures and symbols that the person can point to can help them to communicate a need – such as needing to use the toilet or have a drink. They can also help the person to let you know that they are feeling pain.
- **Don't rush** – allow plenty of time and look for non-verbal clues from the person.
- **Use physical contact if appropriate** (such as holding hands) to reassure the person.
- **Continue talking to the person clearly**, even if you don't think they can follow what you're saying. They may be able to understand even if they can't respond. Even if they can't understand, your voice might be calming for them.
- **If the person is responding to you positively (for example, smiling or nodding) but you can't understand what they are communicating, consider responding to them in the same way ('mirroring' them).** You can reinforce their feelings in this way.

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

Mobility

The later stage of dementia is likely to have a large physical impact on the person. They may gradually lose their ability to walk, stand or get themselves up from the chair or bed. They are also more likely to have a fall. These problems can be caused by:

- dementia symptoms – for example, problems remembering how to get up from a chair and changes in perception
- medication
- other medical conditions – for example, a stroke
- sight loss and sensory changes
- balance problems
- an uncomfortable environment – for example, being in a room that's too hot or too cold.

Many people with dementia (especially in the later stage) also find themselves staying in one position for a long time (such as sitting in a chair or lying in a bed) and not moving around much. This means they are at risk of stiff joints and pressure ulcers (bedsores).

Tips for supporting the person with mobility in the later stage

- **Try to help them to change position regularly.** This can help to improve blood circulation and relieve pressure on certain areas of their body. It might also help to encourage them to do gentle exercises to increase range of motion. Speak with the GP before starting any exercises of this type.
- **Check regularly for any rashes, discolouration of the skin or pressure ulcers.** If you notice a pressure ulcer developing or you have concerns, speak to the GP or community nurse. Pressure ulcers are easier to treat early on, however if they go unnoticed they can get worse and become painful and infected. Pressure-relieving mattresses and cushions are available following an assessment by a district nurse or occupational therapist. For more information about preventing, diagnosing and treating pressure ulcers, see the NHS website at www.nhs.uk
- **Ensure the person is supported and encouraged to move around as much as they can** – for example, by supporting them to walk or with chair-based exercises. Increasing the person's mobility can lower their risk of infections and blood clots. An occupational therapist or physiotherapist can help with this. For more information see factsheet 529, **Physical activity and exercise**.
- **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**.

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Eating, drinking and weight loss

A person in the later stage of dementia is likely to experience a range of difficulties with eating and drinking. This includes loss of appetite, pain and other symptoms related to dementia such as having difficulties recognising food and forgetting the process of eating and drinking itself.

People in the later stage of dementia may also develop difficulties with swallowing (dysphagia) and chewing. This is because the person's muscles and reflexes no longer work properly. People with swallowing problems are at risk of choking and of food or saliva going down the windpipe, causing an infection. If the person has difficulty recognising food items, they may put non-edible items in their mouth which can also cause choking.

Swallowing and chewing problems can be very distressing for the person and those supporting them. If the person is having these problems, it's important to speak to the GP. They may refer the person to a speech and language therapist, dentist, or nutritional specialist. For more information see factsheet 511, **Eating and drinking**.

Many people with dementia lose weight in the later stage. 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 falls and make it harder for the person to remain independent. If you feel the person's weight loss might be caused by a health problem, rather than any eating difficulties, speak to the GP.

Tips for supporting the person with eating and drinking in the later stage

The person should be supported to eat and drink as independently as possible. This should be done for as long as the person shows an interest in eating and drinking, and can do so safely (even if they just take a mouthful or a sip). There are ways you can help make this easier for the person. For example, you could:

- **change the texture 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 a speech and language therapist
- **choose a plate that is a different colour to the food and table** – so they can see it more clearly
- **consider using products that are designed to help people with dementia** – for example anti-spill cups and adapted cutlery. You can find these products on our online shop at shop.alzheimers.org.uk

- **give the person enough time** as well as gentle prompts
- **encourage eating and drinking** by placing a drink in the person's hand if they are struggling to see it, or reminding them how to hold a fork or spoon.

Eating and drinking can still bring the person pleasure, even in the later stage. 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, many people with dementia start to prefer sweet food.

The person's oral health is very important as this will have an impact on their ability to eat and communicate. It will also help with their general health and wellbeing. If the person has poor oral health it may lead to pain, which could mean they have difficulty eating even soft foods. For more information see factsheet 448, **Dental care and oral health**.

Incontinence and problems using the toilet

By the later stage of dementia, the person may find it harder to use the toilet and may develop incontinence. This could be urinary incontinence (pee leaking by accident), faecal incontinence (poo leaking by accident) or both. Incontinence may be an occasional leak or a total loss of control. This can cause distress for both the person with dementia and their carer.

Tips for supporting the person with toilet problems and incontinence in the later stage

Dementia can cause a person to forget to go to the toilet, forget where the toilet is, or struggle to recognise the need to go to the toilet. However, having dementia doesn't mean a person will definitely become incontinent. There are also a number of other reasons why a person with dementia may become incontinent or begin to have problems using the toilet.

Trying to understand why a person is having toilet and continence problems can help you to support them. Possible reasons include the following:

- **The person may have trouble finding the toilet and not get there in time.** This can happen when the person is in an unfamiliar place as well as when they are at home. It is usually a good idea to know where the toilets are when going out with the person. Using a sign or picture on the toilet door at home can also be helpful.

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- **The person might have difficulty remembering the process of using the toilet** – for example they might sit down while still wearing their trousers or skirt. Try to speak with the person to find out if they are having trouble with a particular aspect of going to the toilet. This can help you to provide the support that the person needs. Then, if possible, leave the person to use the toilet in private.
- **The person may have a medical condition that is causing incontinence.** Many of these conditions can be treated, they include:
 - a urinary tract infection (UTI)
 - severe constipation
 - side effects of medication
 - prostate gland problems.

Speak to the GP if the person develops problems with continence or constipation. If the GP doesn't find a cause, they might refer the person to a continence adviser, or you can ask for this. This adviser can offer help and advice with managing the situation including incontinence pads and other aids. For more information see factsheet 502, **Continence and using the toilet**.

Supporting a person with washing and dressing in the later stage

In the later stage, a person with dementia is likely to need more help with personal care and dressing. Some people may become fully dependent on others for help with these daily activities. This can be difficult for you both to adjust to, as these are private activities and the person may feel uncomfortable needing this type of support. If you also find this difficult, think about getting support from other people, including professional carers. This may help to maintain relationships.

There are ways to help and support a person while respecting their personal preferences and dignity. For more information see factsheet 504, **Supporting a person with washing and dressing**.

Changes in behaviour

People in the later stage of dementia may increasingly behave in ways that are different to usual or out of character. You may find these behaviours difficult to understand and it may be very upsetting to see the person behaving in this way.

However it's important to remember that there are often many different reasons for changes in behaviour. They may be due to a combination of difficulties caused by the person's:

- dementia (such as confusion about where they are)
- mental and physical health
- personality and habits
- interactions with others
- past life events
- environment.

Any changes in behaviour may also be a sign that the person has needs that are not being met. For example, they may be feeling pain or discomfort, or may be hungry or thirsty. Often behaviour is a means of communication and things that seem out of character for the person can sometimes show how they're feeling at the time – for example they may be scared, anxious or sad.

Changes in behaviour in the later stage

Changes in their behaviour in the later stage may include the following:

- **distress or agitation** – the person may become tearful, call out, or seem generally unsettled and unhappy
- **sundowning** – the person may become more 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, poor lighting in the room, or medication (see 'Sleep problems' on page 13)
- **aggression** – this may be verbal (for example, swearing, screaming, shouting) or physical (for example, hitting, pinching, scratching, hair-pulling, biting or throwing things). For more information see factsheet 509, **Aggressive behaviour**
- **repetition and fixation** – the person may repeat certain behaviours, or get obsessed or very focused on certain things. For example, they may repeatedly carry out the same activity such as checking they have their handbag, or constantly worry about whether they have enough food in the house

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- **hallucinations and delusions** – some people with dementia experience hallucinations, in which they see, hear, smell, taste or feel things that are not really there. 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. For more information see factsheet 527, **Changes in perception**
- **restlessness** – many people with dementia become restless and may fidget or pace up and down. The person may move their hands much more often – for example, they may constantly wring their hands, pull at their clothes, tap or fidget, or touch themselves inappropriately in public.

Changes in behaviour can be some of the most challenging aspects for you and the person with dementia to cope with. If you feel unable to provide the support the person needs or if you need more help, call our support line on **0333 150 3456**. You can also contact your local authority social services team. For more information see the section 'Treatment and care' on page 16.

Tips for managing changes in behaviour in the later stage

Trying to understand what may be causing the person's behaviour and whether they have any unmet needs or difficulties with the environment can help you to manage changes in behaviour. The following tips may be useful.

- **Check that any glasses or hearing aids are clean and work properly.** Arrange regular sight and hearing checks.
- **Think about whether the person might be ill or in pain.** Talk to the GP to rule out any physical problems.
- **Check that the person is 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).
- **Ask the GP if the person's medication is right for them.** The GP might need to change their medication or adjust the dose.
- **Think about the circumstances when the person is showing certain behaviours.** For example, there might be things that someone in particular says, or ways that they do things that causes the person distress. They may also become upset when they get too tired.
- **Think about the person's past experiences** and how this may be affecting their behaviour. For example, if they become upset about having enough food, maybe in their past they often did not have enough food.

- **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 (see page 18). For more activity ideas see booklet 77AC, **The activities handbook**.
- Make sure the person is comfortable – for example not too hot, cold, hungry, thirsty, or needing the toilet.

For more information see factsheet 525, **Changes in behaviour**.

Sleep problems

A person in the later stage of dementia may have a number of problems with sleep. They might find it difficult getting to sleep, sleep less deeply or for less time, or wake up often through the night. Some people with dementia may begin to sleep much more than they used to, or get into a cycle of sleeping during the day and then not being tired enough to sleep at night.

Dementia can disrupt the person's sleep directly by affecting production of the sleep hormone melatonin, which helps a person to feel sleepy. As dementia progresses, the person's brain may make less melatonin, which makes it harder to fall asleep. The person's sleep can also be indirectly affected by dementia. For example, if the person feels confused or agitated, they may not be able to get to sleep, or may be restless and wake constantly throughout the night.

For more information see factsheet 534, **Understanding sleep problems, night-time disturbance and dementia**.

Tips for supporting the person with sleep problems in the later stage

Sleep problems in dementia can be difficult to treat. This is because there may be many different causes, and because medication is not very effective. However, you can help the person by supporting them with a healthy sleep routine. Here are some suggestions on how to do this:

- **Treat any underlying conditions** – many health conditions can make it harder for the person to sleep. Reduce pain or discomfort with painkillers, gentle heat or massage. Ask your pharmacist or the person's GP if you are worried that any medicines might be contributing to their sleep problems.
- **Keep a routine** – having a routine during the day and at bedtime can help when a person's body clock doesn't work as well as it should. Do regular activities at the same time each day – for example, playing a game together after breakfast or listening to the radio together in the afternoon.

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- **Make use of natural daylight and fresh air** – going outside or being by an open window in the daytime, ideally in the morning, can help to set the person's body clock.
- **Engage the person in activities** – doing things the person finds enjoyable and interesting during the day helps to reduce daytime sleepiness (see page 4).
- **Make sure the person isn't hungry, thirsty or too full.**
- **Make the bedroom sleep-friendly** by keeping it quiet, dark and at a cool temperature.
- **Do relaxing activities at bedtime.**

Over time, the person may need more support with sleep problems, especially if your own sleep is often disturbed. If the person is frequently up in the night or has other severe sleep problems it may be possible to have a live-in or visiting carer. This person will look after them during this time to help you to have a good night's sleep.

Alternatively this may highlight the need for the person to move into residential care. See 'Planning for care in the later stage' on page 19 for more information.

Caring for a person with dementia who has sleep problems can be very challenging for you and the person. Make sure you look after your own wellbeing too – see page 22 for more information.

Illness and discomfort (including pain)

Infections such as urinary tract infections (UTIs) are common in the later stage of dementia. They can increase confusion in people with dementia, and can also speed up the progression of the condition. It is important that any infection is quickly diagnosed and treated.

A person in the later stage of dementia can still feel pain or discomfort even though they may be unable to communicate this verbally. As a result they may start to behave in ways that are out of character for them (see page 11). They may also avoid certain activities that cause them pain, such as walking or eating.

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, and being easily distracted
- confusion about where the person is or what time it is (disorientation)
- confused and muddled thinking
- sudden changes in mood
- changes in language use (for example, talking but not making sense) or sudden inability to follow a conversation

- change in consciousness (for example, feeling drowsy or much more alert)
- suddenly not being able to do things as well as they have been (such as walking or using a fork)
- 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 less severe in the morning than the evening.

If the person suddenly becomes confused or develops these symptoms they should see a doctor immediately. For more information about delirium go to [alzheimers.org.uk/delirium](https://www.alzheimers.org.uk/delirium)

Supporting the person with illness, pain and discomfort in the later stage

Observing the person and noticing changes in their behaviour can help you to spot any pain, illness, or other causes of discomfort such as constipation or arthritis. If you think the person may be unwell or in pain, speak to the GP as soon as you can. Signs of pain could be:

- wincing or grimacing when moving or doing certain activities
- changes to skin tone – either paler or more flushed than usual
- sores in or around the mouth, or other parts of the body
- changes to body temperature or swelling in certain areas
- sudden increase in agitation, anxiety or restlessness
- shouting or calling out
- problems with getting to sleep or staying asleep.

If you know the person, anything they do that indicates they are uncomfortable may also be a sign of pain.

There are ways to manage pain in the later stage of dementia and to help improve the person's quality of life. This might include changing the environment, massage, dietary changes or medication.

Many people in the later stage aren't given enough pain medication and may be left in pain that could otherwise be treated. If you feel that the person is showing signs of pain or discomfort, speak to the GP so that they can look into possible causes and potential treatments. See from page 16 for the different types of treatments

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3 Treatment and care

By the later stage of dementia, a person is likely to need more care and support from a range of professionals and services. This will usually become full-time as their needs increase.

As in any stage of dementia, care and support for the person should always be 'person-centred'. This means it should be focused on the individual person, as well as how they are affected by their condition. It should take into account the person's life history and background, relationships, needs and preferences. This includes their ethnic and cultural background, sexuality, gender identity, and religious and spiritual beliefs.

You might find it difficult to rely on more professionals to support the person. You may worry that they won't understand the person or treat them as an individual. However, by talking about the person and explaining their needs and preferences to everyone involved in their care, you can help these professionals provide the best person-centred care.

We have a support tool called **This is me** (code 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. You can get a copy at alzheimers.org.uk/thisisme or by calling **0300 303 5933**.

Treatment for a person with dementia can involve medicine or other types of approaches, in many cases a combination of both.

Medicines

There is good evidence that medicines commonly prescribed for the treatment of Alzheimer's disease and Lewy body dementia (dementia with Lewy bodies or Parkinson's disease dementia) have benefits for people in the later stage of these conditions. This includes people with mixed dementia that includes any of these types. These medicines are known as the cholinesterase inhibitors (donepezil, rivastigmine and galantamine). Many doctors now continue to prescribe these for later-stage Alzheimer's disease and Lewy body dementia.

Memantine is also recommended for people in the later stage of Alzheimer's disease and Lewy body dementia, or in the middle stage where medicines such as donepezil cannot be taken. It can slow down the progression of symptoms including difficulties with everyday activities and confusion. There is some evidence it can also help with symptoms such as delusions, aggression and agitation.

Cholinesterase inhibitors and memantine are not recommended for people with frontotemporal dementia, vascular dementia, or other types of dementia. However, other medicines, such as antipsychotics and antidepressants, can be prescribed and might be helpful. There are also many ways to treat a person in the later stage that don't involve medicine (see page 18).

For more on the medicines available see factsheets 407, **Medicines to help memory and thinking**.

Side effects of medicines

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

If you are concerned about the effects of the person's medication, you should talk to their GP. It may be possible to change the dose or the medication. For more information see factsheet 408, **Antipsychotic drugs and other approaches in dementia care**.

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Other treatments

Other approaches to treating dementia symptoms and changes in behaviour can improve the person's physical and emotional wellbeing, as well as their mood. It can also help the person to focus on their skills and interests rather than their dementia. All of this can help the person to live well for as long as possible with their symptoms.

These approaches that can have benefits for people in the later stage of dementia include:

- **music and creative arts therapies** – such as painting or drawing, playing musical instruments, and music or drama therapy
- **reminiscence** – where the person records their life experiences and memories
- **life story work** – where the person talks about or reflects on their past, with the help of things like photos, familiar objects or music
- **doll or animal therapy** – this can involve the person holding or 'caring for' a doll or a toy animal. This can inspire feelings of love and connection, and help the person feel a sense of purpose and fulfilment.

Consider what activities suit the person's individual interests, personality and abilities. Some activities may need to be adapted for the person. They may also find it easier to participate online rather than in person, or in one-to-one sessions rather than in a group.

The availability of these therapies and activities vary widely by area. To see what therapies and activities are available in your area go to alzheimers.org.uk/dementiadirectory or see 'Other useful organisations' on page 23. You may be able to apply to or refer the person to these services yourself. GPs and other health and social care professionals can also refer the person to local services that offer these treatments.

Hobbies, interests and activities that the person enjoys can also help them to live as well as possible in the later stage. Sensory activities such as the smell of essential oils or the feel of different textures or fabrics can be pleasurable and comforting for someone in the later stage. Sensory boxes that are created around someone's hobbies or previous work role can be a useful tool. For tips on how to engage the person doing things they enjoy see page 4. For a wide range of other activities ideas see booklet 77AC, **The activities handbook**.

Planning for care in the later stage

It may be upsetting to think about future care for a person in the later stage of dementia. However, planning ahead can help you to ensure the person's wishes and needs are met as well as possible.

Respecting the person's wishes and preferences

If the person with dementia has made their wishes known regarding their care in the later stage, it is important to support them and to help them to meet these plans. These wishes should be shared with the professionals supporting you too.

A person with dementia may have made their wishes clear in a number of ways. If the person lives in England or Wales they can make:

- **an advance decision** – this allows the person to refuse specific medical treatment in the future. For example, they may decide they do not wish to have CPR (resuscitation) or any form of artificial feeding. This used to be known as a living will or advance directive, and is legally binding
- **an advance statement** – the person can use this to express their wishes and preferences about future care, however this is not legally binding
- **a Lasting power of attorney** – the person may wish to appoint a Lasting power of attorney for health and welfare although this will depend on whether they have the 'mental capacity' to consent to this. If they are not able to consent, then you may be able to apply to become a deputy to make specific health or welfare decisions for them instead.

For more information see factsheets 463, **Advance decisions and advance statements**, 460, **Mental Capacity Act 2005**, 530, **Deputyship**, and 472, **Lasting power of attorney**.

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

The availability of care and support services for people in the later stage of dementia will vary by area. The most suitable types of care and support will depend on the person's individual needs as well as your needs as a carer.

Asking for information and advice as soon as possible will help you to plan ahead for care and support. You can call our support line on **0333 150 3456** to find out what's available in your area or use our local services directory at **alzheimers.org.uk/dementiadirctory**

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Your local authority can carry out an assessment for care and outline a care plan of what needs you and the person have. The plan also shows what care and support could meet those needs. For example, it might suggest mobility aids around the home, visits from carers, or respite care. The local authority will also carry out a financial assessment to determine whether they will pay for some or all of a person's care. Following this, they might organise and provide the care, or fund the care by giving direct payments.

For more information about assessments for care see factsheets 418, **Assessment for care and support in England**, W418, **Assessment for care and support in Wales** or NI418, **Assessment for care and support in Northern Ireland**. For information about paying for care see factsheets 532, **Paying for care and support in England**, W532, **Paying for care and support in Wales**, or NI532, **Paying for care and support in Northern Ireland**.

Spiritual and religious needs

As a person's dementia progresses into the later stage of the condition, they may begin to think more deeply about their spiritual needs. They may reconnect with a previous faith or wish to keep carrying out spiritual practices they have always followed. It is important to support them with this and respect their beliefs.

They may no longer be able to attend religious services in person, however there may still be ways that they can engage. For example, a priest, imam or other religious figure may be able to visit them. There may also be online services that they can watch, or religious music that they enjoy listening to.

Be aware of these needs and make sure they are respected and supported, including by any carers or professionals involved in the person's care. Advance statements (see page 19) can be used to help with this.

Choosing care and support settings

As the person's dementia progresses, it might be necessary to think about the most suitable place for them to live. People in the later stage of dementia can be supported and cared for in different places. It is important to consider the person's wishes about where they want to live, what needs they have, as well as the support available to them.

It is also helpful to think about the care and support they might need in the future. This includes whether other people are able and willing to care for them.

There are many places that may meet the person's needs. For example:

- **the person's own home** – some people continue to live at home with support from carers, health and social care services, or a combination of both. Devices and equipment can sometimes support the person to remain at home. For more information see factsheet 437, **Using technology to help with everyday life**
- **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. For more information see factsheet 476, **Care homes: when is the right time and who decides?**
- **hospice** – care in a hospice focuses on reducing physical and psychological distress 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. Hospices also provide support to those who are close to the person. For more information see factsheet 531, **End of life care**
- **hospital** – people with dementia may be admitted to hospital during the later stage, 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. For more information see factsheet 477, **Hospital care**
- **mental health setting** – in some very rare cases where a person is putting themselves or others at risk, they may be taken into a setting providing specialist mental health care under the Mental Health Act. For more information see factsheet 459, **The Mental Health Act 1983**.

If you're thinking about moving the person to a new living environment, consider the impact this will have on them. Adjusting to a new environment in the later stage can be challenging, although it is important to balance this with the benefits such as a higher level of care. For example, moving into a nursing home may mean the person is safer than if they stayed at home with carers coming in.

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If you are concerned about any aspects of the person's care, speak with the service or organisation providing the care. If they are unable to resolve the concerns, consider asking 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. You can be supported in any complaint by an advocate. They are independent and can be located through social services.

Looking after yourself

Caring for a person in the later stage of dementia can be rewarding, but also very challenging. You may find it difficult to see the changes in the person's mood and behaviour, and the decline in their abilities. This can be both mentally and physically tiring for you.

It's important that you're able to have a break from time to time. For example, you could ask friends or family members to spend some time with the person. You may also want to find out about other support options such as local day centres, clubs or professional care. For more information see factsheets 462, **Replacement care (respite care) in England, W462, Respite care in Wales** or NI462, **Respite care in Northern Ireland**.

When a person with dementia moves into residential care, this can also have a big impact on those caring for the person. You may feel many different emotions, including loneliness, sadness, a sense of relief, and a loss of identity about your changing caring role. You may also feel guilty that the person was not able to be looked after at home. It is often a time of adjustment for everyone. It is important to seek support if you need it and to talk to someone about the situation and how you are feeling. This might be a friend, family member, your GP or a trained counsellor. You can also call our support line on **0333 150 3456**.

Support groups for people caring for a person with dementia can be a helpful way to speak to other people in a similar situation. You can search for groups in your area at **[alzheimers.org.uk/dementiadirctory](https://www.alzheimers.org.uk/dementiadirctory)**

Online discussion forums can also be a good way of sharing your feelings and getting practical suggestions. You can also join our online community, Dementia Support Forum at **forum.alzheimers.org.uk**

For more advice on looking after yourself see factsheet 523, **Carers – looking after yourself**.

Other useful organisations

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Age UK

0800 678 1602 (advice line, 8am–7pm)

www.ageuk.org.uk

Wales – Age Cymru

0300 303 44 98 (advice line, 9am–4pm Monday–Friday)

advice@agecymru.org.uk

www.agecymru.org.uk

Northern Ireland – Age NI

0808 808 7575 (advice line, 9am–5pm Monday–Friday)

advice@ageni.org

www.ageuk.org.uk/northern-ireland

Age UK, Age Cymru and Age NI aim to improve later life for everyone through information and advice, services, campaigns, products, training and research.

Carers UK

0808 808 7777 (helpline, 9am–6pm Monday–Friday)

advice@carersuk.org

www.carersuk.org

www.carersuk.org/forum (online discussion forum)

Carers UK provides information and advice to carers about their rights and how to access support.

Dementia UK

0800 888 6678 (helpline, 9am–9pm Monday–Friday,

9am–5pm Saturday and Sunday)

helpline@dementiauk.org

www.dementiauk.org

Dementia UK is a national charity committed to improving quality of life for all people affected by dementia. It provides Admiral nurses who are mental health nurses specialising in dementia care.

Elderly Accommodation Counsel (EAC) FirstStop Advice

0800 377 7070

info@firststopcareadvice.org

www.firststopcareadvice.org.uk

EAC 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.

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Hospice UK
020 7520 8200
www.hospiceuk.org

Hospice UK provides information and support and can help people find a local hospice.

Office of the Public Guardian (OPG)
0300 456 0300
customerservices@publicguardian.gov.uk
www.gov.uk/opg

The OPG 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 finances.

Rare Dementia Support UK
020 3325 0828
contact@raredementiasupport.org
www.raredementiasupport.org

Rare Dementia Support (RDS) supports people affected by seven rare dementias. These are: Familial Alzheimer's disease (FAD), frontotemporal dementia (FTD), familial frontotemporal dementia (fFTD), posterior cortical atrophy (PCA), primary progressive aphasia (PPA), Lewy body dementia (LBD) and Young-onset Alzheimer's disease (YOAD). RDS provide free information, advice and support groups for people living with these conditions and for their carers.

Factsheet 417

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To give feedback on this factsheet, or for a list of sources, please email publications@alzheimers.org.uk

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We are reviewing this publication. If you would like to give us any feedback, you can email us at publications@alzheimers.org.uk or call us at 020 7423 7455

At Alzheimer's Society we're working towards a world where dementia no longer devastates lives. We do this by giving help to everyone who needs it today, and hope for everyone in the future.

We have more information about **Adjusting to caring for someone with dementia.**

For advice and support on this, or any other aspect of dementia, call us on **0333 150 3456** or visit **alzheimers.org.uk**

Thanks to your donations, we're able to be a vital source of support and a powerful force for change for everyone living with dementia. Help us do even more, call **0330 333 0804** or visit **alzheimers.org.uk/donate**



Patient Information Forum



Together we are help & hope
for everyone living with dementia

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