

End of life care

Factsheet 531LP
July 2021



When a person with dementia is approaching the end of their life, it can be a very difficult time for them and the people around them. This factsheet is for you if you're caring for a person with dementia. It looks at what happens when the person is nearing the end of life, and when they die. It covers what you can do to support them and other close family or friends, and some of the issues to consider.

You may find it hard to think or talk about many of these things. It may be upsetting to read some parts of this factsheet. But having these important conversations with the person, and planning ahead, can mean they have a better experience at the end of their life. It can also be helpful for you and for others close to the person.

Around this time you will probably be dealing with a range of different health and social care professionals. It will really help if there is good communication between all of the people involved in providing the person's end of life care.

Contents

- Planning for the end of life
- Palliative and end of life care
- Dementia as a life-limiting condition
- Recognising when someone is reaching the end of their life
- Communication
- Physical needs
 - Pain
 - Eating and drinking
 - Infections
 - Delirium
- Making decisions
 - When the person has not set out advance care planning
- Coping with death for carers, family and close friends
 - Place of death
 - The person's environment
 - Your feelings
- What to do after the person has died
- Other useful organisations

End of life care

Planning for the end of life

Planning for the end of life is important for anyone who has a life-limiting condition. For a person with dementia, it's important to try and have these conversations early, while it's still possible to make shared decisions. However, many people don't feel ready to think ahead about dying. In this case, knowing the person's values, wishes and beliefs more generally can help when decisions need to be made on their behalf (see 'Making decisions' on page 15).

There is more on making choices about future care (known as 'advance care planning') in factsheets 472, **Lasting power of attorney** and 463, **Advance decisions and advance statements**. For more information on things to think about in the future, including planning for the end of life, you could also show the person with dementia booklet 1510, **Planning ahead**.

Palliative and end of life care

Palliative care is for anyone diagnosed with a life-limiting condition, including dementia. It focuses on making a person's quality of life as good as possible by relieving discomfort or distress. A person can receive palliative care for any length of time, from a few days to several years. It may be offered alongside other medical care, especially in the earlier stages of dementia. Any palliative care in place will continue alongside end of life care.

End of life care aims to support a person in the later stages of a life-limiting condition to live as well as possible until they die. It aims to enable the person to die in the way that they would have wanted, giving priority to the things that matter most to them. It also supports family and carers during the final stages, as well as after the person has died. End of life care can last for just a few days or weeks, but for many people it may continue for months or even years.

4 End of life care

End of life care should support the person to live as well as possible until they die, especially:

- their physical needs, including pain relief and management of other symptoms
- their emotional needs, including managing distress
- their relationships with others, including who they would and wouldn't like to be with them
- their environmental needs, such as their surroundings and community
- their cultural, spiritual or religious beliefs and practices.

Everyone supporting the person (including care professionals) should use their knowledge of the person, and any advance care planning the person has put in place.

For many people, ‘dying well’ means:

- being treated with compassion and respect
- being kept clean, comfortable and free from distressing symptoms
- being in a familiar place surrounded by those close to them.

Doing small things for the person can help a lot – for example talking to them, brushing their hair or holding their hand. Meaningful connections like this can help you be close to the person and give them the emotional support they need.

It's important to note that, if there are restrictions in place due to coronavirus, this can affect care home and hospital visiting. Not being able to see loved ones can be extremely difficult, especially if the person is nearing the end of their life. Speak to staff about how they can support you and the person at this time. For example, they may be able to allow limited visits with safety measures in place. It is likely that any restrictions that are in place will allow for limited visiting when a person is at the end of life.

5 End of life care

End of life care for a person with dementia can involve a number of different professionals working together as a team. This can include the GP, community nurses, social workers, and care home or hospital staff. Specialist palliative care professionals may also provide input for people with complex needs.

Health professionals should normally carry out a risk assessment to identify things that could worsen the person's quality of life during this time. They should also keep you updated as the person's condition changes and involve you in any decisions. If you are unable to meet with them in person, this should still happen over the phone.

There should also be an up-to-date care plan for the person. This plan should include end of life plans and should be shared with those involved in the person's care. Some local areas have special staff who co-ordinate end of life care for people with dementia. Ask the GP, community nurse or local hospice (if you have one) about what is available in the person's area.

The person's spiritual needs, practices and traditions will be individual to them. These needs should be addressed and respected as much as the medical aspects of care. Personal or religious objects, symbols or rituals (including prayer or readings) may provide comfort, both for the person and those close to them. These could also include music, pictures, smells or tastes.

Dementia as a life-limiting condition

Dementia is a life-limiting condition, but it is very difficult to know how long someone with dementia will live for. This depends on many factors.

If the person also has another life-limiting condition (such as cancer or heart failure), it may be clearer how long they may live for and how they will die. A person may die from another condition at any stage of having dementia. Because of this, they may die before their dementia symptoms become very advanced.

A person in the later stages of dementia may get worse slowly over many months. During this time they will usually:

- become more frail
- have more frequent falls or infections
- have problems eating, drinking and swallowing
- be more likely to need urgent medical care
- become less mobile
- sleep more
- talk less often.

A person in the later stages of dementia is likely to have a weak immune system. This means they have a higher risk of getting infections, which in some cases can last for a long time. One of the most common causes of death for people with dementia is pneumonia caused by an infection.

A person in the later stages of dementia may have symptoms that suggest that they are close to death, but can sometimes live with these symptoms for many months. This uncertainty makes it very difficult to plan and put things in place for the end of someone's life.

Recognising when someone is reaching the end of their life

Knowing when a person with dementia is nearing the end of their life can help with giving them the right care. However, it can be difficult to know when this time is. This uncertainty can have a big impact on how the person feels and how their carers, family and friends feel. Some symptoms of later-stage dementia can suggest the person is reaching the final stage of their condition. These include:

- speech limited to single words or phrases that may not make sense
- having a limited understanding of what is being said to them
- needing help with most everyday activities
- eating less and having difficulties swallowing
- bowel and bladder incontinence
- being unable to walk or stand, problems sitting up and becoming bed-bound.

If a person with dementia has most or all of these symptoms, they are probably nearing the end of their life. They may have other problems such as being very frail, having infections that keep coming back, or pressure ulcers (bedsores).

As someone's condition gets worse and they are within a few days or hours of dying, further changes are common. The person may:

- deteriorate more quickly than before
- lose consciousness
- be unable to swallow
- become agitated or restless
- develop an irregular breathing pattern
- have a chesty or rattly sound to their breathing
- have cold hands and feet.

These changes are part of the dying process when the person is often unaware of what is happening. Healthcare professionals can explain these changes so you understand what is happening.

Healthcare professionals can also take steps to reduce the person's pain or distress, often using medication. If the person can't swallow, then medication can be provided through patches on the skin, small injections or syringe pumps that provide a steady flow of medication through a small needle under the person's skin. Speak to a GP or another health professional about this.

Communication

In the later stages of dementia, the person is likely to have problems with communication. They may have sight or hearing problems, and there may eventually come a time when the person can hardly communicate at all as they usually would. This can make it harder to know if they are uncomfortable or in pain, for example.

However, there are ways to keep communicating. For example, the person may be able to show their needs or feelings using their body or facial expressions. They may still sense what is going on around them and be able to respond with basic gestures, such as smiling or hand squeezing. They may also become distressed if they hear harsh noises or commotion.

Communicating with the person with dementia at the end of life: tips for carers

- Don't rely on using words – if the person doesn't understand, use simple gestures, body language, facial expressions and gentle touch to express what you want to say to the person.
- Stay close to the person and maintain eye contact as much as possible.
- Look for signs that they are in discomfort or pain, such as facial expressions or sounds they make.
- Take your time, and speak slowly and clearly in short, simple sentences.
- Talk about things of interest to the person or reminisce about things from the past.
- Familiar sounds, smells or sensations may provide comfort – for example, hearing a familiar song from earlier in their life or having their skin moisturised, or their hands massaged, with a familiar product.
- Continue talking to the person, even if you don't think they can follow what you are saying. They may respond to the tone of your voice and feel a level of connection with you even if they don't understand the exact meaning of your words.
- Use physical contact, such as holding hands or a hug, to reassure the person that you are there for them. Start with small gestures, such as gently taking their hand, and look for signs that the person is happy to be touched in this way.

If the person is living in a care home and has very advanced symptoms, some care homes offer 'Namaste Care'. This offers social and emotional support through activities that still have meaning for the person or stimulate their senses. Activities might include gentle massage, washing and moisturising the person's face, brushing their hair or playing their favourite music. Talk to the care home about whether they are able to provide this kind of care.

Physical needs

The person is likely to become less physically able as their dementia progresses, and particularly as they approach the end of their life. This can be for several reasons, including other health conditions. Dementia will also often affect the person's ability to eat, drink, move around and sense things properly. They may need a lot more help at mealtimes, when they get dressed, or when they go to the toilet. There are steps that can be taken to help meet these needs and to make sure that the person is as comfortable as possible.

Pain

People with dementia are at risk of pain from a wide number of conditions. These include arthritis, pressure ulcers (bedsores), urinary tract infections (UTIs) and constipation, or other diseases that cause pain such as cancer.

Some people assume that people with dementia are less able to feel pain, but this is not true. A person with advanced dementia might not always be able to let someone know they are experiencing pain. They may not recognise where pain is coming from or why it is happening. Different people react to pain and discomfort in different ways. Carers and health and social care professionals should always look out for a wide range of signs, including:

- behaviour – being distressed, agitated, irritable, tearful, defensive, or unable to sleep
- facial expressions – looking sad, frightened or grimacing
- body language – being tense, rocking, fidgeting, clenching fists, or pulling at the part of their body that hurts
- vocal sounds – shouting out, screaming, swearing or moaning
- bodily changes – changes in breathing, high temperature, sweating or looking very pale.

11 End of life care

If the person appears to be in pain or discomfort, it is important to ask them and not just assume that they are. If communication is difficult, a healthcare professional can use a pain assessment tool to estimate their level of pain. This involves recording information about the person's appearance and behaviour, such as the signs listed on this page. Knowing the person well can also really help to identify behaviour that is unusual for them. You might recognise things that they tend to do when they are in pain, such as having a certain look on their face or becoming very withdrawn. It's important to look for possible causes of discomfort related to the person's situation or surroundings. For example:

- are they hungry or thirsty?
- are they too hot or too cold?
- could they want to use the toilet?
- is their environment calm and supportive?
- could they be anxious or upset for other reasons?

Doctors treating pain may start with paracetamol, which often works well. If this doesn't relieve the pain then they may try stronger painkillers. However, these tend to have side effects, such as disorientation, dizziness, drowsiness, slowed breathing or constipation – particularly at higher doses. This is why doctors start with lower doses and then increase them as the person needs more pain relief.

Some people may take regular strong painkillers for conditions such as cancer. If they start to show signs of pain, the dose or type of their painkillers may need to be reviewed. The doctor may either increase the dose or switch the person to a different drug. Doctors will also try to treat any medical conditions that might be causing pain, such as constipation or infections.

There are sometimes ways to make a person comfortable that may also relieve their pain. These can include very gentle exercise, massage and warm packs placed over the area that hurts.

Eating and drinking

As dementia progresses, people often develop problems with eating and drinking, such as difficulty chewing their food and swallowing safely. They may choke on food or saliva as it accidentally goes down their windpipe, and this can cause an infection in their lungs (pneumonia). To prevent this, their food may need to be blended to make it easier and safer to swallow, and drinks or other fluids can be thickened. A speech and language therapist or dietitian should be able to advise on how to do this.

It can be distressing to see that the person is no longer able to eat and drink normally. Try to remember that this is normal for a person approaching the end of their life and that they may not feel hungry if they are very unwell.

Talk to health professionals about how to provide the right food and liquids for the person, taking into consideration their cultural background and what they have said they wanted.

Tube feeding (artificial feeding and hydration)

If a person is struggling to eat and drink enough, and they are unable to swallow safely, you may need to discuss other ways of providing nutrition. The most common way of doing this is tube feeding, using either:

- **a nasogastric tube** – this goes in through the nose and down into the stomach, or
- **a PEG tube** – this goes directly into the person's stomach through a hole in their skin.

Most healthcare professionals now agree that tube feeding is not appropriate if the person's problems with eating, drinking or swallowing are symptoms of very advanced dementia. This is because tube feeding does not help to make the person more comfortable, or give them a better quality of life or longer life.

13 End of life care

There are also clear disadvantages. For example:

- fitting a PEG tube means going into hospital, which can be distressing and has its own risks of complications
- the tubes can cause discomfort or sores
- the tubes can become loose, get pulled out or cause an infection.

While it can be very difficult to decide not to feed the person by any means possible, tube feeding is unlikely to help them in any meaningful way. Any decision about tube feeding should be made with the person's best interests in mind and healthcare professionals should discuss this with those who know them best.

Mouth care

When a person is eating or drinking less, their mouth can sometimes become dry or sore. Care professionals should provide regular mouth care, keeping it moist and clean. They may provide sips of iced water or juice, or gently rub an ice cube on the person's lips, if they can still swallow. They may also apply a balm to keep the person's lips from becoming cracked and uncomfortable. This might be something you'd like to help with.

Infections

People in the later stages of dementia have a higher risk of getting infections – particularly urinary tract infections (UTIs), infected bed sores or chest infections. These are much more likely to happen if the person is dehydrated, has lost a lot of weight, has swallowing problems or doesn't move very much.

The decision about whether to use antibiotics to treat infections during the later stages of dementia can be a difficult one for doctors. They have to consider each person's situation individually, including:

- the benefits of making the person more comfortable by treating the infection
- the risks of drug side effects or other treatment complications
- how easy or difficult it is for the person to take medication
- how likely it is that the person will recover fully if the infection is treated
- the person's wishes (if known).

It's important to consider the person's best interests when they get near to the end of their life. If they have infections that keep coming back, the doctor may talk to you about whether it's in the person's best interests to treat future infections – particularly serious ones. They may point out that sometimes to get treatment, such as medications injected into the vein, the person might need to go back into hospital. This might not be in the person's best interests if they previously expressed a wish to die as peacefully as possible at home.

Delirium

Delirium is when a person's state of mind suddenly gets worse – often when they are unwell and particularly towards the end of their life.

They may become disoriented (less aware of where they are or what is happening), and easily distracted. They may become agitated or have difficulty staying connected with reality – for example, having delusions (strongly believing things that are not true) or hallucinations (seeing or hearing things that aren't really there). Or they may become very withdrawn and unresponsive.

For someone in the later stages of dementia, delirium can be hard to spot. This is because the symptoms of delirium can be very similar to those of dementia. However, the key difference is that the symptoms of dementia tend to come on slowly, over months and years. Delirium comes on in hours and minutes and can vary a lot over the day.

Delirium can be distressing to the person and those around them. It is treated in different ways depending on the causes and the person's needs. For more information see factsheet 477, **Hospital care** or go to alzheimers.org.uk/delirium

If delirium is being caused by something the medical team cannot treat, they may suggest reducing the person's distress using drugs that help them to stay calm and reduce their distress. These medications can help to give them a sense of peace at the end of their life.

Making decisions

As someone nears the end of their life there will be important decisions to make about their treatment and care. They may be able to make those decisions for themselves, but that is less likely. These decisions may include whether they should be resuscitated if their heart or breathing stops, as well as whether to accept blood transfusions, tube feeding or antibiotics for infection. They may also include where the person wishes to die, and whether any religious practices should be observed at or after their death.

Many people – including health and social care professionals – find it difficult to talk about these issues in advance. Often the person's next of kin assume that they automatically have the final say on decisions, if the person has lost the ability (known as 'mental capacity') to make them. However, this is not the case.

If the person with dementia has previously had open discussions about their future decisions, wishes and preferences (advance care planning), it will be much easier to act on these when they are no longer able to decide for themselves. The person may have expressed these using one or more of the following:

- **Advance decision** (or **advance directive** in Northern Ireland) to refuse treatment. This is a legally binding document.
- **Advance statement of wishes** (for example, in a 'Preferred priorities for care' document). This is not legally binding, but it should be taken into account.
- If the person is in England or Wales they may have made a **health and welfare Lasting power of attorney (LPA)**. If not, a health and welfare deputy may have been appointed by the Court of Protection (though this is much less common). The person appointed as their attorney or deputy will have the power to make decisions about the person's care and treatment. They should discuss these decisions with health and social care professionals and act in the person's best interests. They may be able to refuse or consent to life-sustaining treatments on the person's behalf if their appointment specifically includes that power. Health and welfare LPAs and deputyships are not currently available in Northern Ireland.

When a person is in the later stages of dementia and nearing the end of their life, their care should be based around how they are feeling, and any cultural, spiritual or religious beliefs and practices. Everyone supporting the person (including care professionals) should use their knowledge of the person and any advance care planning the person has put in place.

When the person has not set out advance care planning

If the person has not made a relevant advance decision, or if there is no LPA or deputy for health and welfare, decisions about the person's care and treatment will be made by health and social professionals.

These health and social care professionals must act in the person's best interests and should involve you in decisions about the person. They should also take into account the person's feelings and wishes, including any that are included in an advance statement or in the person's care plan. They should discuss things with you in a sensitive and straightforward way.

While certain medical treatments can be refused, nobody can refuse (or be refused) basic comfort and care (for example, pain relief or washing) or demand that a particular treatment is given.

The doctor in charge of the person's care may decide that trying to resuscitate them if their heart or breathing stops would not be in their best interests. Often this is because it's unlikely to be successful. The doctor will then make out a DNACPR (do not attempt cardiopulmonary resuscitation) order – sometimes just called a DNR (do not resuscitate) or DNAR (do not attempt resuscitation). The doctor should discuss this decision and the reasons for it with those close to the person (such as carers, relatives or close friends), or with any advocate appointed by the hospital or local council if the person doesn't have anyone to speak for them. They should also consult with any health and welfare attorney(s) or deputy.

In cases where there is doubt or disagreement over what is in the person's best interests, it may sometimes be necessary to make an application to the Court of Protection (or the High Court in Northern Ireland) for it to decide.

For more information see factsheets 460, **Mental Capacity Act 2005**, 463, **Advance decisions and advance statements**, 472, **Lasting power of attorney** and 530, **Deputyship**. If the person is in Northern Ireland see NI472, **Enduring power of attorney and controllership**.

Coping with death for carers, family and close friends

Most people find it difficult to come to terms with the person with dementia approaching the end of life. Many carers say they've already started grieving while the person is alive and as the dementia has progressed. This may be because of the dementia progressing over a long period of time, and the changes that they are seeing in the person.

You should tell health and social care professionals about your own wishes, including the need to say goodbye to the person and whether you want to be with them at the end of their life, if this is possible. You may have your own spiritual and cultural needs and as a carer, it's important that you are supported to express these and have them met.

Talk to hospital or community nurses or nursing home staff about how they can support you, including whether any spiritual or faith-based support is available. You may also find it helpful to turn to a religious leader or representative for support during this time, for example a rabbi, imam, priest or chaplain.

When you know the person is approaching the end of life, you may want to consider looking for details of a funeral director in advance. This can be a very difficult thing to do, but it can be helpful to know that you have this in place. It is one less thing to think about after the person has died, which can be a very emotional time.

The person's care arrangements and any advance care planning that they've made should mean that their circumstances are as appropriate as they can be. Think about where the person is and what is around them to make them comfortable and supported.

Place of death

A person with dementia should be supported to die in the place of their choice whenever possible. For many people this will be somewhere familiar such as their own home or the sheltered housing or care home where they live and know the people around them. If the person has previously expressed a preference, this should be included in their care plan. It's important that everyone involved in the person's care knows about this preference. In recent years, health services have become increasingly willing and able to provide palliative care in a person's home.

If the person has expressed a wish to die in their own home, talk to the professionals caring for the person about this as early as possible. This allows time for plans to be made so that the person is able to die at home.

However, if the person has complex medical problems or needs a lot of nursing support, they may be more comfortable in a hospice. These are places that specialise in providing palliative and end of life care. They support a person to die in peace and comfort with their dignity and spiritual needs met as much as possible.

Unfortunately, many people with dementia die in hospital if they are admitted at the end of their lives. This tends to happen when they develop a condition that seems treatable at first but then have complications in hospital.

Moving to a busy and unfamiliar environment such as a hospital ward is often difficult or distressing and may not be what the person would have wanted. Even if this is the case, it can be reassuring to know that the person is comfortable and in a place that is supporting them fully.

The person's environment

It can help to make the environment familiar – for example, by including familiar objects and pictures. The space should be peaceful and not overstimulating (without too much noise or clutter).

The environment should support the person to engage in different ways – interacting with other people, meeting their spiritual needs, and stimulating their senses. This may take many forms and should be based on the person and their unique interests. However, it may include:

- being near a window
- access to nature
- familiar smells
- music
- enough space for those important to the person to be with them.

A good environment should most importantly support the person's privacy and dignity. It should also have space for staff and those important to the person to be able to provide care and support. It should also allow the person to process what is happening, if possible.

In some circumstances, technological equipment can be used to help support the person at the end of life. This will depend on the individual and what works for them. Some electronic aids include:

- **pressure sensors** – these are sensors that can be placed under a bed or chair and can raise an alert when the person moves or gets up
- **fall sensor** – a device that raises an alert if the person wearing it falls over
- **sensory lights** – lights designed to give a stimulating, engaging or calming effect, which can help the person to engage with the world around them
- **tablets or computers** – images or videos on these can also help the person to engage with the world around them. They may be particularly helpful if family and friends are unable to get to their bedside.

Your feelings

Knowing when someone will die is unpredictable. When the time comes, your experience and feelings will be unique to you. It may feel very intense, quiet or overwhelming. Caring for someone at the end of their life can be a rewarding experience and a time of great closeness. Carers who have supported the person through dying and death often value this as an important memory.

What to do after the person has died

You will experience and approach bereavement in your own way. It's important that you are supported to grieve as you need and want to. After the person has died, you may experience a range of emotions, including:

- numbness
- finding it difficult to accept the situation
- anger
- regret
- guilt
- sadness
- relief
- feeling isolated
- a loss of purpose.

You may feel very strong emotions, or you may feel that you have no strong emotions left.

Sometimes, other people may assume that you've already grieved for the person with dementia as their condition has worsened. Whether or not this is something you've felt, many people will still feel grief when the person dies.

The period around the funeral is often a time when others offer most support. Afterwards you may need time to adjust to no longer caring for the person (this is sometimes called ‘delayed grief’). You may need to rebuild friendships that your caring role put on hold. You may continue to need emotional support during this time, but you may find that fewer people offer it.

Talking through feelings with family and close friends can often provide comfort, so try to tell people when you feel you need this support. You might find it helpful to join an online community where you can discuss your feelings honestly with people in similar situations. For example, you can visit Alzheimer’s Society’s Talking Point at alzheimers.org.uk/talkingpoint

If you need more support or you are worried about your mental health, ask your GP about local bereavement services or contact Cruse Bereavement Care (see ‘Other useful organisations’ on page 23). Your local carers’ centre may also be able to help. You can use our dementia directory to find local support groups at alzheimers.org.uk/dementiadirectory

For more information see factsheet 507, **Grief, loss and bereavement**.

There are practical issues to think about after a person dies. Though you may find it difficult, it is important to think about:

- registering the death
- funeral plans
- changes to financial and legal arrangements and benefits.

You can find out more from Citizens Advice (see ‘Other useful organisations’ on page 23).

The person's culture and beliefs should be acknowledged and respected. This includes how soon the person would like their funeral, whether they would like to be buried or cremated, and any rituals or ceremonies that are important to them. Talk to care staff about this.

If there are lockdowns or restrictions due to coronavirus, these may affect funerals, wakes and other events. For example, there may be travel restrictions, or a limit on the number of people that are able to attend. If this happens, you may feel you are not able to say goodbye to the person in the way you would have wanted. This can be extremely upsetting.

Speak to the funeral venue about what might be possible. For example, it may be possible for some people to attend virtually, using a video link on their computer or tablet. Finding other ways to remember the person may also be of some comfort during this time. For example, some people may like to pay their respects to the person via tributes on social media or you could create an online memory board.

Other useful organisations

Carers Trust

0300 772 9600
info@carers.org
www.carers.org

Carers Trust works to improve support, services and recognition for anyone caring, unpaid, for a family member or friend who is ill, frail, disabled, or has mental health or addiction problems.

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, advice and support for carers.

Citizens Advice

0800 144 8848 (England advice line, 9am–5pm Monday–Friday)
0800 702 2020 (Wales advice line, 9am–5pm Monday–Friday)
www.citizensadvice.org.uk

Citizens Advice can provide information and advice in confidence or point you to further sources of support. Trained advisers can offer information in a way that is easy to understand.

Cruse Bereavement Care

0808 808 1677 (helpline, 9.30am–5pm Monday and Friday, 9.30am–8pm Tuesday–Thursday, 10am–2pm Saturday and Sunday)
helpline@cruse.org.uk
www.cruse.org.uk

Cruse Bereavement Care is a national charity for bereaved people in England, Wales and Northern Ireland. It offers support, advice and information to children, young people and adults when someone dies and works to enhance society's care of bereaved people.

Dying Matters

www.dyingmatters.org

Dying Matters aims to change public knowledge, attitudes and behaviours towards dying, death and bereavement. It produces information to help people talk about death, dying and bereavement, including a ‘Preferred priorities for care’ form to complete. You can search for local services via the website.

Hospice UK

020 7520 8200

www.hospiceuk.org

Hospice UK is the national charity for hospice care. It champions and supports the work of organisations providing hospice care across the UK.

Marie Curie

0800 090 2309 (support line, 8am–6pm Monday–Friday, 11am–5pm Saturday)

www.mariecurie.org.uk

Marie Curie provides care and support for people living with any terminal illness, and their families.

This publication contains information and general advice. It should not be used as a substitute for personalised advice from a qualified professional. Alzheimer's Society does not accept any liability arising from its use. We strive to ensure that the content is accurate and up to date, but information can change over time. Please refer to our website for the latest version and for full terms and conditions.

© Alzheimer's Society, 2021. All rights reserved. Except for personal use, no part of this work may be distributed, reproduced, downloaded, transmitted or stored in any form without the written permission of Alzheimer's Society.

Factsheet 531LP

Last reviewed: July 2021

Next review due: July 2024

Our information is based on evidence and need, and is regularly updated using quality-controlled processes. It is reviewed by experts in health and social care and people affected by dementia.

Reviewed by: Dr Lynne Partington, Project Coordinator and Education Advisor, The End of Life Partnership, Dr Tony Rao, Consultant Old Age Psychiatrist, South London and Maudsley NHS Foundation Trust and Dr Jenny Smith, Consultant in Palliative Care Medicine, Countess of Chester Hospital NHS Foundation Trust

This factsheet has also been reviewed by people affected by dementia.

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

People affected by dementia need our support more than ever. With your help we can continue to provide the vital services, information and advice they need.

To make a single or monthly donation, please call us on **0330 333 0804** or go to [alzheimers.org.uk/donate](https://www.alzheimers.org.uk/donate)

Alzheimer's Society is the UK's leading dementia charity. We provide information and support, improve care, fund research, and create lasting change for people affected by dementia.

For support and advice, call us on **0333 150 3456** or visit [alzheimers.org.uk](https://www.alzheimers.org.uk)



Alzheimer's Society operates in England, Wales and Northern Ireland.
Registered charity number 296645.

