

# Caring for adults in their last days of life

Information for the public

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## About this information

NICE guidelines provide advice on the care and support that should be offered to people who use health and care services.

Providing care for people who are dying, and supporting the people who are important to them, are profoundly important. You might be reading this information if you have found out that you might not have long to live, or you want to plan for how you would like to be cared for during your last days of life. You might also be reading this if someone close to you, such as a member of your family or a close friend, is in the last stages of their life, or may be soon, and you want to know what care they should be getting.

People who are nearing the end of their life are entitled to high-quality care wherever they are being cared for. It is important that their wishes are respected and they are involved in decisions about their care, whenever possible. Care should be focused on maintaining the person's comfort and dignity, and any symptoms they have should be managed. Some people may have already thought about their care and may have made some decisions and plans for the end of their life.

This information describes the care that people should receive in the last 2 to 3 days of their life (as set out in the NICE guideline on [care of dying adults in the last days of life](#)).

You might also like to read NICE's information for the public on [patient experience in adult NHS services](#). This sets out what adults should be able to expect when they use the NHS. We also have more information on the NICE website about [using health and social care services](#).

## *Your care team*

A range of professionals who have skills and knowledge in different areas of treatment or support may be involved in caring for people during their last days of life. These could include GPs, community nurses, specialist doctors and nurses, hospice staff, care home staff, hospital staff, therapists, pharmacists and social care staff.

## **Recognising when someone is in the last days of their life**

Recognising when someone is close to death means the right support can be given to them and also to their family, friends and other people who are important to them. It will also help the person who is dying to make any plans for how they want to be treated and cared for. It is not always possible to know for sure that someone is in their last days of life and it is hard to predict exactly when someone will die.

There are some symptoms and changes that happen to people which can be signs that they are close to death. Sometimes they might feel more tired and drowsy, and want to spend lots of time sleeping. They might start to slip in and out of consciousness. Some people become very weak and less able to move around. Their breathing might change and become shallower or less regular, or it might become noisy from fluid collecting in the throat or chest. Some people become very quiet and withdrawn; others become restless and agitated. Often people lose their appetite and can lose a lot of weight; they might stop eating and drinking altogether.

Some of these changes might be distressing, but help should be available to relieve any symptoms and keep the person comfortable. There is more information about this in the section on [help to stay comfortable](#).

If someone is dying, they should be checked every day for symptoms and changes that might show that they are close to death, and also for signs that they are not getting any worse or might be improving.

If someone is likely to die very soon, this should be explained to them by a member of their care team honestly and in as much or as little detail as they want. They should be able to have the people important to them with them when they have this discussion, if they wish. Because it is often difficult to know how long someone has left to live, any uncertainty about this should also be explained. There should be plenty of time for questions and to talk about any fears or anxieties.

People should know how to contact staff involved in their care if they need to, and a list of [questions](#) that people might want to ask has been provided with this information.

## Discussing and planning care

### *Making decisions about care and support*

It is important that people are involved in decisions about their care in the last days of their life, if that is what they want, and that their wishes are respected. Their doctor or another member of the care team should talk to the person who is dying about the care and support they would like and, if the person agrees, involve their family members or other people important to them in these discussions. This might include particular treatments or identifying who should make decisions for them if they are no longer able. Sometimes decisions are already included in an 'advance statement', which has details about the care a person would like at the end of their life and what is important to them.

Sometimes extra support is needed in the last days of life, such as having meals delivered or a carer staying during the night. There should be a discussion to decide what is needed and available as early as possible.

There should be experienced staff available to help with making decisions. Extra help should also be available from a specialist if it is needed.

### *Making a care plan and keeping it updated*

All of the discussions and decisions made about care should be recorded by the care team in an individual care plan covering the last days of life.

People sometimes change their minds about the care they would like or their needs may change as time passes. They should be given plenty of chances to keep discussing the care they would like, and their care plan should reflect any changes.

A list of [questions](#) that people might want to ask when discussing their care plan and making decisions has been provided.

## Help to stay comfortable

During the last days of life, people often experience changes in their thoughts and feelings as well as physical changes. Some people do not experience pain or any other symptoms in the last days of their life. Others might get new symptoms, or their existing symptoms might change. Sometimes symptoms happen because of the person's condition or illness, or because of another physical problem or side effect of treatment. Other symptoms can happen because of natural changes to the body at the end of life. Managing these symptoms and changes, and helping people to stay as comfortable as possible, is an important part of their care.

This might involve treating symptoms, such as pain, or care to stop the person's mouth and lips from becoming dry and sore, or encouraging them to drink if they want to, so they don't get dehydrated. Family and friends may wish to help with the person's care, for example by giving sips of water or helping to clean the person's teeth or dentures, and they should be shown how to do this safely.

New tests should not be started in the last days of life, unless they are essential to help with the person's care.

### *Managing pain and other symptoms*

Although not everyone has symptoms, some are common in the last days of life, such as pain, dehydration, nausea and vomiting, breathlessness, feelings of anxiety, agitation and delirium (when a person can be confused or struggle to understand or remember, or their personality may change).

If someone has any of these symptoms they should be offered treatment to help them to stay as comfortable as possible. The care team should check for possible causes of the symptoms and explain which treatments might help. The best treatment might involve taking a medicine, but other types of treatment may be tried too. For example, sometimes simple things like using a fan or opening a window might help with breathlessness, or changing a person's position might help with noisy breathing or to relieve pain. Sometimes a treatment will help with whatever is causing the symptom. Other treatments might be given just to help relieve the symptom and make the person more comfortable.

### *Pain relief*

Not everyone is in pain in the last days of their life, but if someone is they should be offered help to relieve it quickly. Sometimes things like a full bladder can cause pain, and this should be relieved as soon as possible.

Painkillers can often help to relieve pain. To decide on the best type of painkillers for the person, an assessment should be carried out to find out how much pain they are in, and they should be asked how they would like to take their painkillers.

### *Managing breathlessness*

Sometimes breathlessness is caused by problems that can be treated, such as fluid in the lungs, and treatment should be offered to help. However, even if a particular cause is not found, help should be given to relieve breathlessness, and the person may sometimes be offered medicine for this.

Oxygen won't usually be given to help with symptoms of breathlessness, unless the person also has low levels of oxygen in their blood, for example from a lung condition.

### *Managing nausea and vomiting*

If the person has nausea or vomiting their doctor should check for possible causes, such as stomach or bowel problems or side effects of treatments, and discuss the different treatment options with them. Medicine may sometimes help, although some medicines may have side effects, such as drowsiness. When deciding on the best treatment, the doctor should check for possible problems with other medicines being taken and discuss with the person any possible side effects.

### *Managing anxiety, delirium and agitation*

People often feel anxious in the last days of their life, and may feel agitated or become delirious (when a person can be confused or struggle to understand or remember, or their personality may change). The doctor should check for possible causes, such as psychological problems or physical problems (for example sometimes agitation is caused by pain or a full bladder) and discuss the possible treatments with the person.

For some people a medicine may be offered to see if that will help. If that doesn't work or if it causes unwanted drowsiness, the doctor should ask for advice from a specialist.

### *Treating noisy breathing*

Sometimes saliva or mucus builds up in the person's throat or chest and can't be cleared, making a noise during breathing (which is sometimes known as a 'death rattle'). This is unlikely to cause any discomfort to the person, but it might be upsetting, particularly for the people who are important to

them. There should be a chance for them to talk about any fears or concerns with the care team, and any treatments that might help should be explained.

The doctor might suggest trying a medicine if noisy breathing is upsetting to the person who is dying. Checks should be made often (ideally every 4 hours and at least every 12 hours) to see if it is helping and to detect any problems caused by the medicine, such as a dry mouth, delirium or drowsiness. If there are problems or it isn't working after 12 hours it might be stopped or a different medicine may be tried.

### *Keeping people hydrated*

If someone becomes dehydrated it can make them feel very dry and uncomfortable, and can sometimes make them confused or delirious, which can be very upsetting. It is important to avoid this and keep people comfortable, so signs of dehydration should be checked for every day and help should be given help to keep their mouth and lips moist.

However, some people may not want to drink in the last days of their life, and swallowing may become difficult. People who do want to drink should be given help to carry on drinking if they can still swallow. While they are drinking it is important that they are checked for problems with swallowing or drinks going down the wrong way.

If someone has problems swallowing or can't manage to drink enough, they can become dehydrated. Their doctor might suggest giving them fluids through a drip or tube to see if this helps. This might help make them more comfortable, but for a person who is already at the end of their life, it won't necessarily help them live longer and it might not be the best option for everyone. The doctor should explain that it is not known for sure whether the person might take longer to die if they are given fluids in this way, or if dying might happen sooner without them.

There are also some possible side effects that might affect people when they are given fluids in this way (such as too much fluid in the body tissues). These should be explained and there should be the opportunity to talk about any concerns or worries.

When someone is getting extra fluid through a tube or drip, they should be checked every 12 hours. The amount of fluid might be reduced or stopped if the side effects are causing any problems, or if they decide they don't want it anymore.

## Taking the right medicines in the best way possible

### *Stopping medicines that aren't needed*

Often people are taking medicines to treat the conditions they have. When they reach the last days of their life, they might not need to keep taking them all, especially if the medicine isn't helping them to stay comfortable. Their doctor should talk with them about which medicines they might stop taking that may no longer be helpful.

### *Using new medicines*

Before starting a new medicine, a doctor should check for any problems that might be caused by taking the medicine at the same time as other treatments or for distressing side effects the medicine might cause. The doctor will discuss the benefits and any side effects of the medicine, including whether some side effects might or might not be acceptable, for example, increased drowsiness caused by medicine for pain or nausea and vomiting might not be a problem for some people but might be unacceptable for others. They should also take into account whether the person has any cultural or personal preferences that might affect the choice of medicine.

Once the medicine is started, checks should be carried out at least once a day to see if the symptoms are improving, to make sure the right amount of medicine is being given and to check for any side effects, such as a dry mouth or unwanted drowsiness. If symptoms don't improve quickly or there are unwanted side effects, a member of the care team should get advice from a doctor who specialises in caring for people in the last days of their life.

### *Deciding how medicine should be given*

Medicines should be given in the most comfortable way possible. This can depend on the person's condition, if they can swallow or are being sick, and how they would prefer to take their medicine. They may need to have a patch on the skin or be given their medicine by injection if they can't swallow. A syringe pump (for continuous use) might be used when medicines are needed several times a day.

### **Medicines prescribed in advance ('just in case' medicines)**

Medicines are sometimes prescribed in advance for symptoms that might happen in the future. These medicines are often called 'just in case' medicines and may be provided in a specially marked container called a 'just in case' box. Providing medicines in advance means that there is no delay in

getting medicines that might be needed quickly to help with symptoms. This may be particularly important for people who are not in hospital.

'Just in case' medicines should be prescribed individually for a person's needs. When deciding to prescribe any medicines in advance, a number of things should be taken into account, such as whether there are likely to be any new or changing symptoms, any possible risks and benefits of medicines, and whether medicine is likely to be needed urgently. Where the person is being cared for and how long it would take to get medicines to them should also be considered.

Before 'just in case' medicine is given, checks should be carried out to make sure that the medicine is still the right type for the person's symptoms. After they are taken, checks should be carried out at least once a day to see if their symptoms are improving or if there are any side effects.

## Questions to ask about care in the last days of life

- What help can I get for symptoms such as pain, sickness, breathlessness, anxiety, confusion, agitation and noisy breathing?
- Can I refuse or ask for a particular treatment?
- Why have I been offered a particular type of treatment? How long will it take to work?
- Are there any side effects to the treatments I am being offered?
- What happens if the treatment I'm offered makes me feel too sleepy?
- Will my care be different depending on where I'm being cared for?
- Can I choose where I wish to die?
- What happens if I change my mind about earlier decisions I made about my care?
- Can I choose who stays with me as I near the end of my life?
- Is there someone I can talk to about my fears and anxiety?
- If I am given a 'just in case' box, does it mean I am going to develop symptoms?
- What will happen if I become too ill to make my own decisions?
- Will having fluids through a tube or drip help me at the end of my life?



## *Questions for family members, friends or other people important to the person who is dying*

- What can I do to help and support the person who is dying?
- Is there any additional support available that I as a carer might benefit from or be entitled to?
- Will I be kept informed of the person's wishes?
- Will I be told when the person is likely to die?
- Does the person who is dying need to be told that they are in the last days of life?

## **Sources of advice and support**

- Age UK, 0800 169 6565  
[www.ageuk.org.uk](http://www.ageuk.org.uk)
- Compassion in Dying, 0800 999 2434  
[www.compassionindying.org.uk](http://www.compassionindying.org.uk)
- Cruse Bereavement, 0844 477 9400  
[www.cruse.org.uk](http://www.cruse.org.uk)
- Dignity in Dying, 0207 479 7730  
[www.dignityindying.org.uk](http://www.dignityindying.org.uk)
- Living Well Dying Well, 01273 479 114  
[www.lwdwtraining.uk](http://www.lwdwtraining.uk)
- Marie Curie, 0800 090 2309  
[www.mariecurie.org.uk](http://www.mariecurie.org.uk)
- Organ Donation, 0300 123 23 23  
[www.organdonation.nhs.uk](http://www.organdonation.nhs.uk)

You can also go to [NHS Choices](#) for more information.

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## Accreditation

