



**University
Hospitals Sussex**

NHS Foundation Trust



**COMFORT
CARE**

Supporting care in the last days and hours of life

Palliative care

Information
for relatives and carers

What is this information about?

This information is about the comfort care that your relative may receive in their last days and hours of life.

It explains:

- What comfort care is.
- What the benefits and burdens of care and treatment might be for your relative.
- What symptoms your relative may get and how we, and you may be able to help relieve them.
- How we will help your relative to maintain their privacy and dignity and meet their other needs, such as spiritual or cultural needs, that they may have.
- The types of comfort care that we may give your relative and how you can help with this.
- Changes that you may notice in your relative that can be a sign that they are close to death.
- How we care for your relative, and for you, after your relative has died.

Why have I been given this information?

You have been given this information because the doctors and nurses have explained to you that your relative's condition has changed. They believe that the person you care about may be in their last days or hours of life.

This is a difficult and emotional time for everybody.

It can be hard to know what to say and do.

Nurses, doctors and other ward staff will work as a team to support your relative and are here to help you by talking through any worries and concerns.



There are suggestions for how you can be more involved in your relative's care throughout this information. They appear in boxes like this.

Please be aware that in this information, when we say 'your relative' it may also refer to a friend.

What kind of care will my relative get?

The ward staff will do all that they can to help. They will make sure that your relative is comfortable and always treated with dignity and respect. Staff will always try to respect your privacy.



Please share any known wishes with the ward staff. This may include what is important to your relative. For example, where they would wish to be cared for at the end of their life.

Who will plan my relative's care for their last days and hours of life?

Ward staff will make a plan for your relative's care. They will work closely with your relative and other people important to your relative.

Your relative will have a care plan that is right for them and takes their needs and wishes into account. This is known as a 'comfort care plan'.

The comfort care plan:

- includes things that are important to your relative
- lets the ward staff know what these things are
- helps to make sure that your relative always gets care that is right for them.

We will involve you and your relative in discussions about the comfort care plan. We will review the plan often and make any changes to it that are needed.

What will you do to make sure that any treatment or care that my relative gets is a benefit and not a burden to them?

Hospital staff will aim to give your relative only the care and treatments that are right for them.

All care and treatments come with both potential benefits and burdens.

For example:

- some medicines have side-effects
- taking blood tests could cause pain
- getting out of bed might feel like too much effort for your relative.

When a person is unlikely to get better, we review all the treatment and care we are giving them. This is to make sure that the burden these may cause does not outweigh their benefits.



Tell us anything you think may help the hospital ward staff care for your relative; for example, leaving a light on at night or using a pillow from home.

What changes might there be to the medicines that my relative is having or to how they have them?

- Your relative may have been taking some medicines for a long time. Ward staff will talk with you about whether some of these can be stopped if they are no longer helpful.
- We will check your relative for any symptoms they may have. We may give them medicines to relieve their symptoms. We will tell you about the most usual side-effects that the medicines have.
- We will give your relative enough medicine for their comfort, but no more than they need.

Giving medicine through a syringe pump

If your relative finds it difficult to swallow, we may give them medicine by injection or using a syringe pump. A syringe pump is a small portable pump.

The syringe pump gives a steady dose of medicine beneath your relative's skin. We may give them more than one medicine at a time through the syringe pump.

We will not give your relative medicines that they do not need.

What symptoms might my relative have during their last days and hours of life? What can hospital staff (and relatives) do to help relieve them?

There are some symptoms that many people have in their last days and hours of life. Not everyone who is dying will have them.

These symptoms may include:

Pain: Your relative may not be able to tell us that they are in pain. Even so, it is often possible to tell that they are feeling discomfort by looking at their facial expressions and movements. If your relative appears to be in pain, ward staff will look for the cause. We can relieve their discomfort by, for example:

- changing the position they are lying in
- giving them medicine if it will help.

Restlessness and agitation: When people are dying, they can become confused or restless. They may see or hear things which are not really there (hallucinate). These can seem familiar and a comfort to them. Sometimes they may upset them. If so, we can usually relieve these symptoms.

You can gently reassure your relative by:

- holding their hand
- talking to them
- reminding them of where they are and that they are safe.

If these things do not seem to have worked, nursing staff can give your relative medicine to relieve these symptoms. They should explain to you that the medicine is likely to make your relative sleepier.

Sometimes your relative may just want some peace and quiet. At these times you can help by keeping visitors, noise, and touching your relative to a minimum.

You, and other family or friends, can help to reassure and comfort your relative. For example, you could try:



- playing them some of their favourite music
- bringing them things from home such as some photographs, a blanket or a radio
- giving them a hand massage
- talking to them or playing them messages so they can hear the voices of family and friends.

Noisy breathing: Your relative may have a noisy rattle to their breathing. This is because mucus or saliva builds up in their chest or throat. They can no longer clear it by coughing or swallowing.

Hearing your relative's noisy breathing can be upsetting. However, much like a person who snores when they are asleep, it is unlikely to distress your relative.

If they are distressed by it, changing their position is often the best way to help. We can also give them medicines.

If your relative appears distressed by their breathing, you can help by trying:



- pressing the bell to call a nurse or finding a member of staff
- reassuring your relative
- opening a window or using a fan.

Breathlessness: As with noisy breathing, simply opening a window, using a fan or changing your relative's position may help.

We can also give your relative medicine which can help.

We may check again to see how much oxygen your relative needs. Giving oxygen can help some people, but for others it may no longer help.



If you feel at any point that your relative has any symptoms or discomfort of any kind do tell a member of staff as soon as you can.

How will my relative's religious, spiritual, emotional or cultural needs be met?

Your relative's care plan should include what gives shape and meaning to their life.

Please do let staff know if there are values, beliefs, rituals and traditions that are important to your relative.



Tell us about any religious practices, rituals or music your relative likes, or if, for example, seeing a pet could help. Please talk to staff about anything that you think is important.

You may find support from a spiritual adviser or a chaplain helpful now, when your relative dies, and after their death.

The chaplaincy team provides spiritual care and pastoral support to people of all faiths and none. They can help you answer any questions that you may have or simply provide a listening ear.

If you feel you would benefit from talking to a chaplain, please ask a member of staff to arrange this.



Your relative may prefer to be cared for in a side room. The ward staff will try their best to make this possible, but side rooms are not always available.

How will you respect my relative's and my own privacy?

Ward staff recognise that precious time you have with your relative is now short.

You are likely to find that ward staff enter your relative's room less often.

They will limit the things that they do for your relative by not doing things that are no longer helping.

They will respect your privacy and try not to disturb you.



If, at any point, you need a member of staff, for your relative or for yourself, please press the nurse call button.

Comfort Care

What care will you give my relative?

The comfort care that we will give your relative may include:

Repositioning and turning: If your relative is unable to move themselves, ward staff may need to help with a change of position.

Doing this often can help prevent bedsores.

If your relative appears to be comfortable ward staff may think that moving them often could cause some discomfort.

They may only reposition your relative when they:

- are uncomfortable
- need a wash
- need a change of clothes, bedding, or both.

Tests and checks (observations): Some of the tests and checks (such as checking your relatives blood pressure) that we have been doing may no longer help. They may distress your relative without having any benefit to them. If this is the case, we will stop doing any checks that your relative does not need. We will only do those needed for their comfort.

Going to the toilet: Your relative may not be strong enough to use a toilet or commode. In the last days and hours of life people may poo less (and less often) as their bowels slow down.

They may also pee less, and their pee may be very dark in colour.

Sometimes your relative may lose control of their bowels and bladder. They may pee or poo when they do not mean to, or without knowing that they are.

We may give your relative pads to keep them as clean, dry and dignified as we can.

Sometimes people who are dying cannot pee or poo. This can cause them distress. Ward staff will check whether your relative has constipation. If they do, we may give them painkillers or laxative (medicine to help them to poo) as a suppository (a capsule of medicine put into their bottom).

If your relative can no longer pee, it may be more comfortable for them to have a urinary catheter (a tube which drains pee from their bladder).

Mouth care: Your relative's mouth may become dry. This is usually because they are sleepier which can make them breathe through their mouth more. Their dry mouth is not usually caused by them having too little fluid in their body (being dehydrated).

Moistening your relative's mouth with water, brushing their teeth, and putting salve on their lips can help.

Ward staff will give your relative mouthcare often.



If you would like to help with mouth care for your relative, please tell the ward staff.

Your relative may prefer having their mouth moistened with their favourite drink, rather than water.

What changes might I notice in my relative in the days and hours before their death?

Every person's death is different, but the end of life is usually gentle.

It can be a great comfort to see how calmly everything happens.

Of course there will be sadness, but to see someone die peacefully can help with grieving.

It can be worrying if you do not know what to expect at this time. There are some signs or changes that can show when a person may be near to death.

Changes in breathing: A person's breathing can change as the body slows down. Breathing may be fast, shallow, or deep. There may be pauses between breaths.

You may notice the abdomen (tummy) muscles rise and fall instead of the chest. If breathing appears to be hard for your relative, remember that this is more distressing to you than it is to them.

Appearance: A dying person's skin may change colour. It can also change temperature and become hot, moist, or slightly cool before they die.

Sometimes, when a person stays in bed for a long time or their organs are not working as they used to fluid can collect in the arms or legs. This makes the arms or legs swell.

Needing less food and drink: As people approach the end of their life, some may find the effort of eating and drinking too much.

We will support your relative to eat and drink for as long as they are able and wish to do so.

When your relative no longer needs or wants to eat and drink it can be hard to accept, even when we know they are dying.

Their body may not need or be able to use food and fluid in the same way anymore. If this happens, your relative may not feel hungry or thirsty. They may be more comfortable not eating or drinking at all.

Having fluids through a drip may help some people but for others it may not be helpful.

We will decide if giving your relative fluid through a drip is the best thing for them. We will only give them fluids where it is helpful and not harmful.

We will talk with you, and your relative, if possible, to explain this decision.



You can help by offering your relative food or drink if they want it and letting them refuse it if they do not.

Becoming more sleepy and drowsy

As a person approaches the end of life, they will often spend more time asleep. They may also seem drowsy or less alert when they are awake. This usually starts slowly but can sometimes happen more quickly.

Periods of sleep may lengthen and in the end the person may become unconscious. Some people may only be unconscious for a few hours. Others may be unconscious for several days. These changes are part of the natural dying process. They do not usually cause distress to the person.

Even if they are not responsive, your relative may still be aware of your presence. Gentle touch and speaking softly can reassure and give comfort.



It is widely believed that people who are dying may still be able to hear. It may be comforting for your relative to be spoken to, read to, or to listen to music, even when they are no longer awake.

After your relative has died

What happens, and what information and support can I get after my relative has died?

Care after death

After your relative has died, the ward staff will speak to you about what happens next. They will give you an information booklet called 'What to do after someone has died'.

You will be given time to spend with your relative. Please speak to the nursing staff if there are any spiritual, cultural or practical wishes you wish to talk about.



Please speak to the nurse or doctor if you have any questions or concerns.

What practical support can UHSx give me while I am visiting?

At UHSx (University Hospitals Sussex NHS Foundation Trust), we do not just care for our patients. We also care about the people close to them. We are here to support you in any way we can by:

- Providing car parking. Please ask a member of staff if you have not been offered a permit or given your car details to our parking team.
- Offering advice about quiet areas, should you wish to spend some time away from the bedside. Please ask about our quiet spaces and gardens around our hospitals.
- Trying to provide a comfortable chair, mattress or folding bed (if available) if you are staying overnight or for long periods of the day. Please let a member of staff know if you need any toiletries.
- Offering advice about the various outlets around our hospitals where you can buy food and drink. Our housekeeping staff will also be happy to offer you tea and coffee.



Please let us know if there is anything else we can do to support you.

Below is some space for you to write anything to remind you of questions you would like to ask us.

What should I do if I have a problem or concern?

Please talk with the nurse in charge of the ward first.

The Patient Advice and Liaison Service (PALS) can also support you.

Contact them on:

Princess Royal Hospital **01444 448678**

Royal Sussex County Hospital **01273 696955 Ext. 64511**

St Richard's Hospital **01243 831822**

Worthing Hospital **01903 285032**

Acknowledgements

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