

Information for patients and carers

**When someone is approaching
end of life**

End of life can refer to the last days, weeks or months of someone's life. When someone is approaching the end of their life, there are common changes they may experience.

Whilst it is not possible to predict which changes may be experienced, understanding them may help you to feel less afraid or uncertain at such a difficult time.

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Making plans

When someone is approaching the end of their life, it is important that their care is guided by their wishes.

Advance care planning can support this through discussing your needs and wishes with your loved ones and the health and social care professionals caring for you. Plans may change and that's ok; it is important that you are comfortable and supported throughout.

Talking about dying can be challenging, however, talking about what matters to you at this time may provide some comfort to you and your loved one. This can include practical matters, such as financial, either making or updating a will to ensure your wishes are met or more healthcare related. There are also resources available to help you think about these and write them down. We have included some suggestions at the end of this leaflet.

You may wish to consider memory making, this is individual and unique to you.

What matters most to you?

Some ideas for consideration of memory making could be:

- Starting a memory box, adding items that are important to you you may wish to take hand or fingerprints, a lock of hair
- Bringing an event early to celebrate, i.e. birthday, anniversary holiday celebration
- Taking a trip
- Watching a film
- Listening to favourite music or looking at old photographs

There is no right or wrong, these are suggestions and for some memory making is not an important part of making plans.

Places of care

One thing you may wish to consider are your wishes and preferences about where you are cared for at the end of your life. Your health and social care professionals can help you explore what you feel would be acceptable to you at this time and will be able to explain what different services are able to offer.

Home

A person may wish to remain at home in comforting and familiar surroundings with family and friends. If you choose to receive care at home, it is important to consider how your needs may change, and how those caring for you will be able to support with this.

Whether you are at your own home or living in a care home, you will be under the care of your GP and NHS nursing services as applicable. In a nursing home you will have nursing care 24 hours a day. If you are in your own home or residential care the district nurses will be available to support others caring for you, but this won't be 24 hours a day although they do offer an out of hours service.

Your local Hospice Community Palliative Care Team are also able to provide support. Your healthcare professionals will be able to make a referral to them if this is needed.

Hospice

A hospice inpatient unit provides palliative and end-of-life care in a safe, peaceful and comfortable setting. The specialist team of nurses, doctors and allied health professionals (AHPs), provide care 24 hours a day, seven days a week.

They also offer emotional, spiritual and social support to those who require it, including patients loved ones.

Hospital

Sometimes people at the end of their life need to come into hospital for treatment. When this happens the staff on the ward will support them with any symptoms, or any spiritual, emotional or practical needs they might have alongside giving any treatment that may be needed.

If they would benefit from additional specialist support, then a referral can be made to the hospital's palliative care team who will be able to come and see them on the ward.

Changes in the final months

Physical changes

As a life-shortening illness progresses, you may lose weight or find appetite and fluid intake reduces. You may not feel able to do your normal activities and may start to sleep more. This may cause worry for family and friends as you may stop feeling hungry or thirsty, however please be assured that this is normal as the body is beginning to slow down.

Changes to your mind and emotions

As someone starts to realise and accept that they are dying, they may begin to separate themselves from others.

For example, you may not want any visitors, even family, or you may find it hard to interact with people. You may also spend time reflecting on your life, memories and possibly any unfinished business which you may require support with.

Changes in the final weeks and days

Eating and drinking

When someone is in the last few weeks and days of their life, their body will slow down and use less energy. This means you will eat and drink less and may look thin and frail. You may also find it difficult to swallow or have a dry mouth.

Some people don't want to eat or drink or are unable to at this stage, which can be upsetting for family and friends, however this is normal and shouldn't be forced as this can increase discomfort.

How can I help?

If you are conscious, food or drinks should be offered as wanted and as you are able to swallow. Often, it is easier to have food and drink given on a teaspoon as it takes less effort to swallow. If you have concerns about eating and drinking, please discuss with the nurses or doctors involved in your care.

Mouth care is important – you may want to receive mouth care using special sponges soaked in water or drinks that you enjoy. Mouth care gels are also available; they provide a moist coating to the whole mouth and can also be used on the lips. Small pieces of ice can also be used to rehydrate the mouth.

Sickness

Some people may feel sick at this stage. Their doctor or nurse can support with finding the cause of this and may change their diet, medication or recommend relaxing activities.

How can I help?

If you are experiencing sickness, then please speak with the nurses and doctors involved in your care for this to be reviewed as often this can be managed with appropriate medications.

Weakness and tiredness

Sometimes people may spend more time in bed or in a chair as they become too tired for everyday activities, meaning they may also sleep more.

How can I help?

People can often still hear others when they talk to them gently or feel them when they hold their hand. Your loved ones can be guided by your energy levels and what activities you feel able to do.

Bladder and bowel

When someone is coming towards the end of their life they may struggle with their bladder and bowel movements and lose some control as their muscles relax. The nurses can support with ensuring that you are comfortable and maintain your dignity where possible.

How can I help?

It's helpful to talk to the doctors and nurses, as well as your loved ones themselves, regarding what is needed and who you are happy to have provide this care.

Pain

Not everyone experiences pain; some people may approach death without any pain.

How can I help?

If you are experiencing pain, talk to the doctor or nurse as this can usually be managed with the correct treatment.

Breathing

Changes in breathing are common when someone is dying. Some people may become breathless, or their breathing may become loud or noisy. For some people medication may be useful, which you can discuss with a doctor or nurse.

How can I help?

Breathing difficulties can be made worse by feelings of anxiety. Having one of your loved ones sitting with you and offering reassurance in a calm and quiet environment can be very helpful. Having a distraction like talking about memories from the past often helps you to focus on something else and slows the breathing back to normal. Opening windows or using a fan across your body (rather than directly at you) is also very helpful. The doctor or nurse may give medicine for

breathlessness. If you are breathing mainly through your mouth, it is important to continue having good mouth care and use lip balm as needed.

Mouth care can help to remove secretions from the mouth. If there continues to be noisy breathing, you can be repositioned onto your side which often helps if you are not distressed by moving. Injectable medication can also be given to help prevent new fluids (secretions) forming or slow down the rate of the breathing if this is distressing to you. This will be given by a nurse. It is not always needed and is not always effective

Changes to your mind and emotions

As a person enters the last weeks and days of life, changes to the body can also affect the brain. You may become detached, restless, confused or delirious.

How can I help?

Ensuring calm and quiet surroundings can help, as well as having your loved ones nearby offering comfort and reassurance. Some people find that having their loved ones hold their hand, or having familiar noises, items or smells around are helpful. In some cases, medication may be useful, and this can be discussed with your doctor or nurse.

The final hours

You may be worried about what to expect as you approach the final hours of your life. Family members, relatives or friends of someone who is in the final hours of life may also feel uncertain and frightened. It may be of some reassurance to know that for many people suffering a life-shortening illness, the final moments are in fact peaceful.

Loss of consciousness

Towards the end of life, many people lose consciousness but may still be aware of others around them. They can often hear what is being said around them, as well as feel when someone is holding their hand.

Skin

Blood circulation will start to slow down in the final hours meaning the skin may appear blue or mottled (different coloured patches or blotches). Hands, feet and limbs may also feel cold, which is normal.

How can I help?

You are unlikely to be distressed or aware of these changes, although they may be concerning to your loved ones. Holding hands or applying gloves and socks may be comforting to you. Gentle massage may also help if the hands and feet become swollen.

Breathing

In the final days and hours, breathing may get louder or sound quite noisy. It may cause upset or worry for those around but please be assured that it's unlikely that you would be in distress or any pain. You are likely to be unconscious and unaware of the change to your breathing.

As the moment of death approaches, breathing can slow down and become irregular. It may stop and start, or there may be long pauses between each breath. The duration of this type of breathing can differ before breathing stops.

Using syringe drivers at the end of life

Not everyone will need to have medication given regularly, but medication can help to treat pain, breathlessness, agitation, fluid in the throat or lungs, and sickness if someone is struggling with these.

Syringe drivers allow you to receive the medication you need to be comfortable during the final weeks or days of life by giving it at a constant rate. For example, sometimes people may no longer be able to swallow medicine, meaning that a syringe driver would be a suitable alternative to ensure medications are still given.

The tube is normally inserted in the arm, leg or abdomen and may cause some slight discomfort when it's first put under the skin. Once inserted the syringe driver shouldn't cause any pain but will need to be changed every day.



A syringe driver infusion pump

It is important to take care of the skin around the tube and ensure that it is dry. Please contact your nurse if the syringe driver is dropped onto the floor or in water, if the tube comes out, if the skin looks irritated, if the machine stops working or the alarm sounds.

The moment of death

When you die, those around you may notice that you look different, there may be a change to your skin tone, or your eyes may appear glazed, and you will stop breathing.

If you die in a care home, hospital or hospice, your loved ones can tell a health professional who will then be able to support them. If you are at home, your loved ones can call your GP or district nurse who will arrange to visit to confirm the death.

It is important that your loved ones take the time they need with you. They don't need to call the GP or district nurse straight away if you are at home as they may wish to spend some time saying goodbye. Family and friends may also want to sit with you and say their goodbyes.

Bereavement support

It can be a difficult and overwhelming time when someone you know dies; there are many practical elements you may have to deal with. You are unique and so is your grief, there is no 'right way' to grieve, everyone's experience of grief is different.

You may have been given the opportunity to make memories by a health care provider at end of life or into bereavement or you may wish to discuss this with your funeral director. Some people may be able to become a tissue donor after they die, this would normally take place within 24 hours for eye donation. Please speak with your health care provider or NHSBT can be contacted if you wish for information about the potential of tissue donation **0800 432 0559** for more information see

<https://www.organdonation.nhs.uk/helping-you-to-decide/about-organ-donation/tissue-donation/>

Having the support of friends and family when someone you know dies is often all the support you may need, for some talking about their loved one can help. Look after yourself and if possible, let others support you. Looking after yourself will be different for everyone, reach out and speak to others or your health care provider if needed.

There is no time limit on grief, and some people may feel they need additional bereavement support, within the first few days, weeks or months, your local hospital/hospice/GP may be able to direct you to local and national bereavement support. Be gentle to yourself.

The Good Grief Trust has many support charities that you may wish to explore www.thegoodgrieftrust.org

Helpful resources

If you wish to think about and write down what is important to you have a look at My Wishes:

<https://www.mywishes.co.uk/>



Sources of further information

www.lancsteachinghospitals.nhs.uk

www.nhs.uk

www.accessable.co.uk

www.patient.co.uk

<https://beartofresearch.nihr.ac.uk/>

<https://www.stcatherines.co.uk/>

<https://www.lscft.nhs.uk/services/service-finder-z/district-nursing-service>

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Lancashire Teaching Hospital's patient information group review leaflets regularly, if you feel you would like to feedback on this information or join our reading group please contact on email address:

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