

When someone may be dying



Care in the last hours or
days of life

Information for patients, relatives and carers

This information in this booklet is for people who are being cared for in a hospital, home, or care home setting.

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How this booklet can support you

This booklet will help you understand what is happening in the final days and hours of someone's life, to feel more prepared and less worried. Sometimes this information can be difficult to take in, particularly at a time when you may be experiencing a range of other emotions. You can read this booklet in your own time or share with family and friends who are not part of conversations with staff.

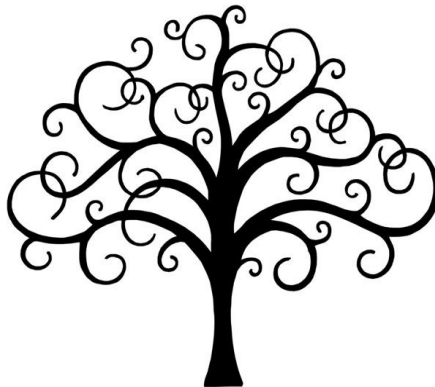
The care team refers to any of the healthcare professionals looking after your relative or friend. The team may include:

- General Practitioners (GPs)
- District nurses
- Palliative care nurses
- Hospital doctors
- Ward nurses
- Care home staff
- Chaplains
- Hospice at home
- Occupational therapists and or Physiotherapists.

Recognising the possibility that someone might be in the last days or weeks of life

When someone is dying, we understand you may have questions or concerns. Their care team is happy to answer these or listen to any fears or worries at any time. You and those important to you can expect to be treated with respect and compassion by all members of the team.

It can be difficult to know when someone is approaching the last weeks or days of life. The nurses and doctors look for a number of changes in their condition. These include, increasing weakness, sleepiness, a reduction in eating and drinking and difficulty taking medication. The nurses and doctors will take into account how quickly these changes are happening and whether there is any other reason for them. While many people can deteriorate steadily, others may suddenly and unpredictably.



What to expect when someone is in the last days of life

Symptoms in the last days of life are often similar no matter what the cause of the person becoming ill was.

Changes to medication

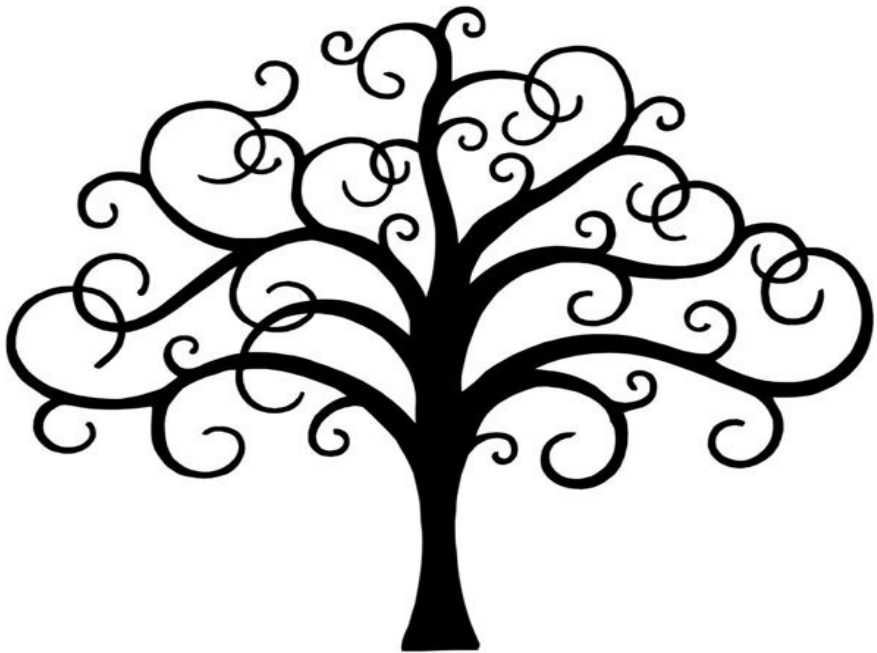
If it is felt that someone is likely to be in the last days of life, the team will review their medication and treatment to ensure the focus of their care is on comfort, safety, and dignity. If the dying person can discuss what is important to them - for example, being awake as much as possible or having no pain - then we will talk this through with them. The team will carefully consider what treatment is going to provide the most benefit to them.

Some medications may help symptoms and will be continued as long as possible. Others may no longer be helpful or may cause unwanted side effects. In this case they will be stopped. Medications that become too difficult to swallow will be stopped or given in a different way. These decisions are made by the care team and will be discussed with the patient, and those important to them to ensure that what is important to the patient is considered in the decision.

Medications will be prescribed to relieve pain, sickness, fluid build-up in the throat, breathlessness, or anxiety. These will only be given if the dying person appears to be experiencing any of these symptoms.

These can be given either by mouth or by a small injection under the skin (subcutaneous injection). Small doses of medication are used to start with, and doses are altered, as necessary. If several doses are needed to control a symptom, then we will give the medication in a syringe driver pump (see page 7). Some of these medications may cause side effects such as increased sleepiness.

Please speak to the patient's doctor or nurse if you have any concerns about giving medications to the dying person during their end-of-life treatment.

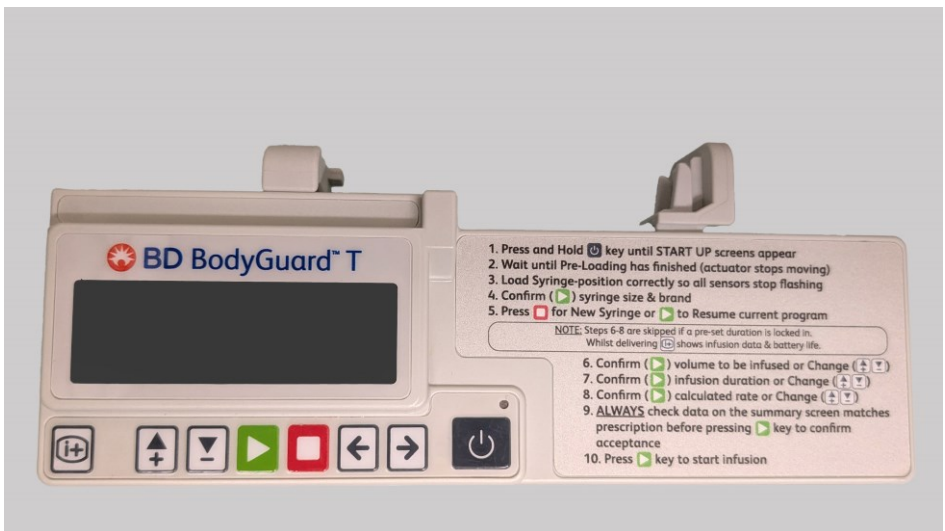


Syringe drivers

Many medications that are helpful in controlling symptoms can be given continuously in an injectable form, using a small battery driven pump called a syringe driver. A syringe driver delivers the medication required under the skin. The medication is absorbed, from there into the body. A combination of medications to manage different symptoms can be put in a syringe driver and the doses changed as needed.

A syringe driver is changed every 24 hrs. Do not worry if you hear the alarm to say it is coming to an end. The health care professionals will change it.

Image of BD BodyGuard T syringe driver:



Sleeping

It is likely that the dying person will sleep for longer and longer periods as they approach the end of life. This sleep will eventually deepen, and they may no longer respond to you, becoming completely unconscious. This can last for several days. This is part of the natural dying process and happens even if people are not on any medication. Even if they are not opening their eyes, the dying person may still be able to hear you, or sense you are close to them.

It may be reassuring for them to hear your voice. Some people may like hearing music or television programmes, or they may prefer peace and quiet. Keep the environment calm by not having too many people in the room at once and avoid bright lighting as this can cause anxiety even when someone is unconscious.

Eating and drinking

As a person becomes weaker, their appetite for food and drink steadily reduces. This is normal but can feel difficult for you as a carer, as we often want to give people food to help them feel better. When someone is dying, food does not make them feel better. It may help to offer them smaller portions or foods that are softer and easier to swallow. For example, ice lollies and ice cream melt in the mouth and can be more easily swallowed. You or the team can offer food and drinks regularly for as long as is desired.

It is important someone is sitting up when receiving food and drinks to make sure that they do not choke.

As time goes on, their appetite will usually disappear completely, and they may become unable to swallow. We do not often give fluids artificially through a 'drip' (a cannula is inserted into the veins and liquid is given directly through this) when people are in the last days of their life. It does not normally help symptoms, mouth dryness, or prolong their life. It can sometimes cause symptoms such as breathing problems or swollen limbs.

Family members, friends and carers can help keep the person comfortable by regularly moistening the patient's lips using a small amount of un-perfumed lip balm (or water-based lubricant if the person is on oxygen therapy) to prevent cracking. It is also helpful to regularly wet the inside of the person's mouth and around their teeth with a soft moistened toothbrush or a water-soaked cotton bud. As long as this does not cause distress, this can be done even when the person has lost consciousness. Check for sore areas and white patches on the tongue, gums and inside the cheek. If you are unsure what to do, please ask a member of the care team and they will show you.

If you have any concerns about your relative or friend not eating or drinking, please do not hesitate to speak to a member of the care team.

Nausea and vomiting

Sometimes people can feel sick or be sick when they are dying. If the person is being sick, and unable to sit up, if you feel confident to, you can, turn them onto their side to protect their airway, or ask staff for help to do this. There are medications that can be given to help relieve this.

Pain

Some people may be in pain when they are dying. If they are less conscious, they may make strange faces or groan to show this. There are medications that can be given to ease pain. Always check their positioning in bed to see if this can help. They may be too weak to move, and this can cause discomfort. Consider if they have any areas that are known to hurt, for example a bad back, and remember this when positioning them. This can be done in the home setting with pillows and blankets. If you need help with this, you can contact the care team for advice.

Restlessness

Sometimes people in the last days of life can become restless or agitated. It can be frightening to look after someone who is restless. If this occurs, it is important to look for a cause, such as pain, anxiety, a need to change position or go to the toilet. It is important to alternate their position from lying on their back to each side.

If the person has an incontinence pad, it should be checked to see if it is wet, to see if they have been going to the toilet. Try to reassure the dying person by talking to them calmly and sitting with them. Touch can be effective too. If no cause is found and the dying person does not settle, the care team may be able to prescribe a small dose of sedating medication.

Breathlessness and coughing

Difficulty breathing and/or a cough can be another cause of agitation and distress and can make it difficult to communicate. The dying person may not be able to talk to you but if you think they can, give them time to respond. You can offer reassurance by talking calmly and opening a window to allow fresh air in. If possible, sit the person up with pillows rather than lying flat as this can help reduce the sensation of not being able to breathe.

Changes in breathing

Occasionally, in the last days of life there can be a rattly wet noise when a person breathes in and out. This is due to a build-up of mucus or saliva at the back of the throat, which they are no longer able to cough up or swallow. Whilst this noisy breathing can be upsetting to hear, it does not usually distress the person themselves.

Changing position can help and sometimes medication may be used if the noise is upsetting for the family and carers.

Their breathing pattern may also change. It can become fast, slow, or irregular. Sometimes there may be long pauses between breaths. This can be a sign that time is getting shorter. You may find some of these changes worrying, but they do not usually cause any discomfort to the person. If you feel that there is distress, please let the team know and they will review this.

Looking after yourself

Caring for a dying person can be exhausting both physically and emotionally. It is important for you to take time out to eat and rest. Try to share the care with other people when possible and remember it is OK to leave the person's side to have a break.

Resuscitation

As the end-of-life approaches, the heart and breathing naturally slow and stop. In this situation, cardiopulmonary resuscitation (CPR) would not be effective in prolonging life and would prevent a natural, peaceful, dignified death. The care team will discuss this with you and document any decisions. Neither you nor the person important to you are required to sign any document regarding decisions as this is a medical form. This form will be kept in the patient's notes or in the home to share with other professionals.

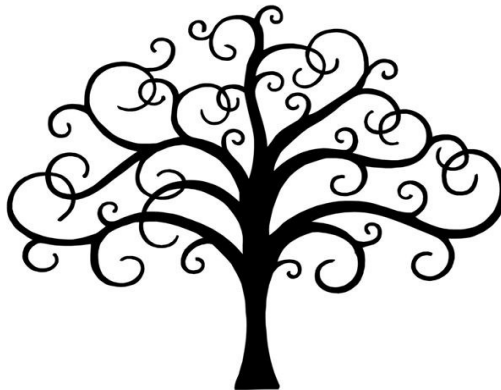
The Last Days of Life Documentation

Care of the dying person is supported by the 'Last Days of Life Documentation.' This ensures the care is individualised and is focussed on relieving their symptoms, maintaining comfort, and meeting their physical, psychological, social and spiritual needs. Our aim is that the dying person is peaceful and comfortable at the end of their life, and that those important to them are well supported.

Comfort Bags

If the person important to you is in hospital, comfort packs are available on each ward and include essential supplies that can help make your own stay more comfortable. Please ask us for one.

If the person important to you is in another setting, please reach out to us and we may be able to supply you with the bag if not available elsewhere.



The Autumn Project- supporting end of life care

One of York and Scarborough Teaching Hospitals Teaching Trusts priorities is for patients to live well and die well. It is not always possible to have the use of a side room while in hospital. The Autumn Project aims to provide privacy and dignity and consider what is important to you and those who are important to you.

The project was launched in January 2021 by the Trust to support patients at the end of life and those important to them. It is being supported by York & Scarborough Hospitals Charity who have received donations specifically for the project, including in memory of people's loved ones.

The palliative care teams are leading the project and making progress to ensure it is in place on every ward within both York, Scarborough, and our community hospitals. The Autumn Project improves the quality of care for dying patients and those important to them as they spend their last days together, as well as providing consistency of care across the wards. The aim of the project is to make sure staff are confident in providing end of life support so that they can play their part in making a more positive experience for the person who is at the end of their life.

With the consent of the dying person (if they are still able to give consent) or those important to them, an autumn leaf symbol (see picture below) is placed on their curtain or side room door so that everyone involved in their care can easily see that this patient is receiving end of life care. The Autumn Project encourages better communication, alerting healthcare teams that the patient or those important to them may need extra support at this difficult time.



End of life care is everyone's business. All health care workers have a responsibility to ensure patient wishes are met. We recognise that how end of life care is provided will remain in the memory of their family and carers.

Things to consider

The experience of someone dying is different for everyone, and everyone approaches it in a different way.

Being there

Some people talk to their families and friends about whether they would like people to be with them when they die; some feel that they want to be alone. If this has not been discussed, you can think about what feels right to you. It is alright to want to be with the dying person all the time, and it is alright not to want to be there. This is a personal choice with no right or wrong approach.

Please let the team know if it is important to you or the dying person that you are with them at the point that they die, or if you prefer not to be there.

Usually, when people are dying, they undergo steady physical changes, for example in the way that they look, their skin tone, and their breathing pattern. However, sometimes people can die suddenly. If they had wanted you to be there, or if you wanted to be there at this point but this does not happen, do not blame yourself as it can be difficult to predict.

Sitting at the bedside can be exhausting so try to eat, drink and take regular breaks. Organise a regular email or set up a way to update family and friends, for example this could be a WhatsApp group.

In hospital or care home consider bringing small children for a brief visit and inviting older ones. With planning, pets are welcomed to visit patients at the end of life which can be a comfort to the patient - please ask for more information about this from your care team.

If you would find it helpful to talk about the emotions you are experiencing, please speak to a member of the care team. Staff are here to support you.

Talking to us about what matters most

This might be around spiritual or religious needs, or it might be about the dying person's interests and preferences for things such as their appearance, music, lighting, sleeping position or bed covers. If there are things that you feel are important, no matter how small, then they are important to us too.

If the dying person is in hospital, please feel free to bring in photographs, music, or favourite things. Discuss with the care team if the dying person may benefit from their pet visiting. If it is important to have quiet time together or for you to be physically close to the person, then please let the healthcare team know. They will do their best to make this happen.

You may have been involved with physically caring for the dying person up until this point. If you would like to stay involved or step back, please talk to us about it, so that you are involved as much as you want to be.

Visiting arrangements

Ward visiting times are more flexible when visiting someone in their last days of life, please discuss this with the ward team. If you are parking on a paid hospital site please let the ward team know so they can allow you concessionary parking.

Staying overnight with patients who are in hospital

If you would like to stay overnight with the dying person, please speak to a member of the nursing team so that they can make arrangements for this.

Pastoral, Spiritual and Religious Care

The Spiritual Care and Chaplaincy team are available for all patients in hospital and family members 24 hours a day, regardless of your religious beliefs.

They will support and listen to you and help you talk through anything that is important to you at this time.

Contacting the Spiritual Care and Chaplaincy Team

If you would like to contact the hospital chaplaincy team direct with a non-urgent message, you can call them on:

York Hospital 01904 725579

Scarborough Hospital 01723 342500

An answer machine is available for you to leave a message. If you need to call the team urgently, please ask a member of staff to contact switchboard for the on-call chaplain.

Tissue donation

We recognise that it may be difficult to think or talk about tissue donation, particularly at this time. Most people may not realise that tissues such as skin, bone and heart valves can dramatically improve the quality of life or even save the life of others.

Almost anyone can be considered as a tissue donor, however, there can be some rare exceptions. Tissue donation usually happens within 24 hours after death. To ensure that all donated tissues are safe, the donor's medical and lifestyle history is assessed. This protects the person receiving the tissue.

For further information please contact the National Referral Centre for Tissue and Eye Services on 0800 432 0559.

When the person dies

How you may feel

Everyone reacts to grief/bereavement differently and it is normal to experience either a variety of emotions or none. You might experience shock, disbelief, numbness, sadness, anger, loneliness, or a sense of relief.

You might also experience shock physically. For example, you may feel dizzy or sick. Shock may cause some people to react in an unexpected way when they first hear the news of a death; some people laugh hysterically, particularly children. There is no 'normal' way to react; do not feel pressure from yourself or others to act in a certain way or expect anything of yourself other than to express what you are feeling.

As a way of coping with the news of a death your feelings may become numb. This may mean you feel like you are dreaming, or the event seems unreal. Sometimes this can make it hard to cry or feel any sort of sadness – that is normal too.

If in hospital, there is no need to let the nursing team know that the person important to you has died until the time is right for you. For some this is immediately after death, for others this is sometime afterwards. You can be with the person in the room after they have died for as long as feels right for you.

Care after death

If there is anything that you or the person important to you would like to happen after they have died, please speak to the care team and/or funeral directors. This includes any cultural or religious traditions.

If in hospital or care home the care team will provide further information on what to do following a patient's death.

What to do if a patient dies at home

When death is expected, once the person important to you has died, contact your district nursing team.

York and Selby area contact Community Care Team on 01904 721200 (available 24 hours a day).

Scarborough and Ryedale area contact Customer Access Service (ask for the district nursing team) on 01653 609609.

East Riding City Health Care Partnership (ask for community nursing) on 01482 247111.

A doctor, nurse or paramedic will attend to verify death. Once this has happened you are then able to contact the funeral directors.

All deaths are reviewed by an independent doctor called a medical examiner. The GP will contact the medical examiner service and provide details of proposed cause of death. The medical examiner will review the medical record and ensure that an accurate cause of death is documented on the Medical Certificate of Cause of Death.

The Medical Examiner or Medical Examiner Officer will contact you once the Medical Certificate of Cause of Death has been completed to discuss the circumstances surrounding the death of the person important to you and what is documented on the Medical Certificate of Cause of Death.

There will be an opportunity to ask any questions that you may have or to comment on the care they received.

Please then contact the Registrar's office to make an appointment to register the death of the person:

York: 01904 553190

Scarborough and Ryedale: 0300 131 2131

East Riding of Yorkshire: 01482 393600

<https://www.gov.uk/register-a-death>

Our commitment

We will:

- Clearly identify the doctors and nurses responsible for caring for the person important to you.
- Identify those people that the dying person wants us to share information with and those to be involved in discussions about care.
- With consent, ensure you can discuss, should you wish, the patient's medical condition, the options available, and your preferences about the care the dying person receives.
- Communicate with you regularly.
- Listen carefully to your comments and concerns.
- Regularly assess the person that is dying to ensure that comfort and dignity are maintained.
- Endeavour that any prescribed medication is:
 - Reviewed regularly.
 - Prescribed promptly to ensure good symptom control.
 - Given in the smallest doses appropriate for the symptoms, and only for as long as the patient needs it.

- Where appropriate seek advice from the Specialist Palliative Care Team.
- If the dying person can swallow safely, they will be supported to eat and drink.
- Ensure that, if the dying person is not able to eat and drink, the medical team have discussed whether giving fluids via a drip would be helpful or harmful.
- Provide emotional and practical support to those important to the dying person.
- Respect and seek to meet any cultural, spiritual and faith requirements of the dying person and those important to them.
- If wished, contact the chaplaincy team to offer or suggest ways emotional/listening/spiritual support can be given to you and those important to you during this time. You do not have to 'be religious' to be offered this support. (You can, if you wish contact chaplaincy direct through the numbers on page 18 in this booklet).

Contact Information

York Hospital
Telephone: 01904 631313

York Hospital Specialist Palliative Care Team
Telephone: 01904 725835

York Community Specialist Palliative Care Team
Telephone: 01904 777770

Scarborough Hospital
Telephone: 01723 368111

Scarborough Hospital Specialist Palliative Care Team
Telephone: 01723 342446

St Catherine's Community Specialist Palliative Care
Team Scarborough
Telephone: 01723 356043

Ward Contact Number:

.....

Other Information or Contact Numbers:

.....

Space for your notes

Please use this space below to list any questions you may want to ask the doctors and nurses:

Tell us what you think of this leaflet

We hope that you found this leaflet helpful. If you would like to tell us what you think, please contact:

York Hospital Palliative Care Team,
York Hospital, Wigginton Road, York, YO31 8HE, or
telephone 01904 725835.

Teaching, training and research

Our Trust is committed to teaching, training and research to support the development of health and healthcare in our community. Healthcare students may observe consultations for this purpose. You can opt out if you do not want students to observe. We may also ask you if you would like to be involved in our research.

Patient Advice and Liaison Service (PALS)

PALS offers impartial advice and assistance to patients, their relatives, friends and carers. We can listen to feedback (positive or negative), answer questions and help resolve any concerns about Trust services.

PALS can be contacted on 01904 726262, or email yhs-tr.patientexperienceteam@nhs.net.

An answer phone is available out of hours.

Leaflets in alternative languages or formats

If you would like this information in a different format, including braille or easy read, or translated into a different language, please speak to a member of staff in the ward or department providing your care.

Patient Information Leaflets can be accessed via the Trust's Patient Information Leaflet website:

www.yorkhospitals.nhs.uk/your-visit/patient-information-leaflets/

Owner	Specialist Palliative Care Team
Date first issued	July 2014
Review Date	January 2028
Version	5 (issued January 2025)
Approved by	End of Life Lead Nurse
Document Reference	PIL 882 v5

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