

The care and support of the dying patient in Calderdale and Huddersfield Hospitals (CHFT)

Introduction

This leaflet explains how we care for somebody in hospital when we believe they are in the last days of life. We understand that this is a difficult time and hope that it will support you and help answer some of the questions you may have.

For the purpose of this information leaflet, we refer to your loved one, partner or friend as your relative.

If the ward staff looking after your relative are concerned that they are in the last days of life, they will talk to you about the care your relative will receive. You may already have known for some time that they may be dying, or the news may come as a great shock.

Our medical and nursing teams are committed to caring for your relative with compassion and dignity, and in a manner which respects their expressed wishes.

The ward staff looking after your relative will develop a personal care plan to ensure that they receive the best care in their last days of life. At our Trust we have a care plan on our electronic patient records (EPR) called the Last Days of Life Document. We will involve your relative in the development of this plan, when possible, and discuss it with you. The Palliative Care team may be contacted to further support a person in the last days of their life, but this is not always necessary.

Please ask any questions, no matter how insignificant you think they may be.

The last days of life

When a person is dying, it is very important that we provide care according to their individual needs and wishes. Some people may have thought a lot about how they want to be cared for in their last days of life. They may have shared these wishes with you. If so, it is very important that you discuss these with the ward staff looking after your relative.

Everyone is different, so it's not possible to say exactly what will happen when someone approaches the end of their life. But in the last weeks and days before death, it's common to experience certain changes. Overleaf are some things that patients and their relatives often have questions about.

Place of care

Some people have a clear idea of where they want to spend their last days. Some would prefer to die at home or in their nursing home - others prefer to stay in a hospital or a hospice.

These thoughts may change over time. Some people may be too unwell to be moved from hospital. The ward staff will do their best to accommodate individual wishes and will talk to you about what is practical. If your relative wants to stay in hospital, where possible, every effort will be made to move your relative into a side room if this is their wish and one is available. Unfortunately, the hospitals have only a limited number of side rooms available, and these are often occupied by patients who have an infection.

Eating and drinking less

When someone enters the last few days of life, they often lose interest in food and drink. This is a normal part of the dying process. It can be hard to sit by when a loved one stops eating and drinking, even when we know they are dying.

We will help your relative to eat and drink for as long as they are able and want to. Most people don't become dehydrated or need a fluid drip in the last days of life, even though they drink very little. The medical and nursing team will assess your relative's needs on an individual basis and will be happy to talk to your relative and you about it.

Keeping the mouth clean and fresh is very important for comfort and mouth care will be carried out by nurses on the ward. The nurses can show you how to do this if you would like to be involved.

Medications and tests

When a person is dying, doctors review their medications to assess whether they are still needed. Some medications may be stopped. If medications are necessary and your relative is unable to take them by mouth, they may be given by injection instead.

A range of medications can be prescribed to be given when the need arises. These are usually used to treat any troublesome symptoms, such as pain, nausea or breathing difficulties. Sometimes a device called a syringe driver is used if your relative needs a continuous infusion of medications to help control symptoms.

Where possible we will try not to disturb your relative, so we may stop any unnecessary tests and observations, such as blood pressure monitoring or blood tests.

Changes in breathing

You may notice changes in your relative's breathing in the last days and hours of life. Their breathing can become noisy, which occurs because your relative is no longer able to swallow their secretions (e.g., saliva), in the normal way. As air moves past this, it can make a noise. This does not usually cause them any distress because it often happens when people become less conscious and less aware. If their face and forehead look smooth and relaxed, we can be assured that they are comfortable. It is often harder and more distressing for people sitting by the bedside than for the person who is ill. Changing your relative's position may help with this and nurses can also give an injection to help slow the formation of more secretions.

You may also notice that your relative's breathing becomes less regular, including long pauses between breaths. This is normal but, if you have any concerns, please speak to ward staff.

Pain

Many people are fearful that pain worsens in the dying phase, but this is very rarely the case. The doctors and nurses will review this regularly and will ensure that medication is available to relieve any pain that your relative may have.

Restlessness and agitation

Sometimes people can become restless or agitated shortly before their death. The doctor or nurse looking after your relative can help with this by addressing the cause and making sure they have the medication they need to ensure that they are not in pain, anxious or frightened.

Comfort and support

When someone is dying it is quite normal for their condition to vary from day to day, or even hour to hour. Sometimes your relative may find it difficult to use a toilet or be unable to empty their bladder. In this instance there is an option to pass a catheter into the bladder to drain this. Often people become drowsy and spend much of their time sleeping. Even if they appear to be sleeping, they may still be aware of your presence, your voice and your touch.

The ward staff will do everything they can to make sure that your relative is comfortable.

If you are worried at any time that your relative seems distressed or that they are uncomfortable, please let one of the nurses or doctors know. If there is anything we can do to support you, please let us know and we will do our best to help.

At such a sensitive time you may wish to be involved in a practical way. If you feel able to take part in giving care, for example by giving drinks or moistening the mouth, our teams will support you to do this.

Visiting your relative and updates on condition from ward staff

Ward staff will be happy to give you information about your relative's condition. It helps if one of the family can co-ordinate this and speak with the ward staff to prevent multiple telephone calls. Please make sure that ward staff have your contact details so they can inform you of any changes in condition. The visiting times tend to be relaxed when your relative is receiving end of life care. We would ask you to help by making sure that there are not too many visitors at the bedside at any one time. If you have any concerns about visiting, please speak to the nurse in charge of the ward. At times you may be asked to leave the bedside during cares or ward rounds, particularly if your relative is in a bay with other patients, due to reasons of confidentiality.

Visiting can be very tiring. It is understandable to be worried and to feel helpless at times, but it is important to take care of yourself. Try to rest as often as possible and eat sensibly. We suggest if you are visiting with other friends or family that you consider taking it in turn to be at the bedside.

Should you wish to bring children to visit please check with the nurse in charge first.

Overnight accommodation

You may wish to stay with your relative overnight - please discuss this with a member of staff on the ward.

If your relative is nearing the last hours of life, the ward staff will be able to offer you a comfortable chair or a fold away bed at the bedside for your comfort. If you are travelling long distances to visit the hospital, and have no relatives to stay with, there are numerous guest houses situated close to the hospital.

Chaplaincy

The chaplains provide pastoral and spiritual care, available for all patients, families and their loved ones. You do not have to follow a particular faith and we will always respect your background and beliefs.

What do we offer?

- A confidential, supportive listening ear when you need to talk.
- Chaplaincy End of Life Companions are specially trained volunteers who will accompany your relative in the Last Days of Life. This may involve having a conversation if your relative feels able, reading or simply sitting with them, being a quiet presence so they are not alone. If you would like an End of Life Companion to visit and spend some time with your loved one please contact the chaplaincy team, or ask the ward staff to do this on your behalf. Please be aware that this is a voluntary service so subject to the availability of the End of Life Companions but we will do our very best to arrange this for you.
- If your relative or yourself follow a religious tradition the multi-faith chaplaincy team are able to offer appropriate prayers, sacraments and rituals for the end of life, which can offer comfort and peace. We are also able to provide faith resources such as Bibles and other Holy Books, prayer cards, devotional booklets and prayer beads.
- The Chapels and Multi-faith prayer rooms are always open, whether for prayer and reflection or simply a quiet space for whatever you need it to be. Please ask at reception for directions.

Calderdale Royal Hospital - the chapel and prayer rooms with ablution facilities are on the 1st Floor above the front entrance to the hospital.

Huddersfield Royal Infirmary - the multi-faith Hope centre is in the main hospital entrance to the right of reception.

If you would like to see a chaplain, please ask the ward staff. Alternatively, you may contact the chaplaincy team directly by contacting the hospital switchboard and ask to be transferred to the chaplain on duty.

Calderdale Royal Hospital – 01422 357171

Huddersfield Royal Infirmary – 01484 342000

What will happen when my loved one dies?

Even though you know your relative is dying and you can try to prepare yourself, it is hard to know how you might feel when they die. Some people feel shocked or numb, while other people might feel overwhelmed with sadness or even anger. It is also normal, particularly if it has been a long illness, to feel a huge relief. You may find it helps if you have already thought of someone you can call who can be with you to support you at this time.

After the death we would encourage you to spend time with your relative if you would like to do so. Although this is likely to be a very emotional time, there are still some formal things that need to happen. The first is confirming that the person has died. This is called verifying the death. Once the death has been verified, the nurses who have been caring for your relative will prepare their body to be taken to the hospital mortuary.

You will be given a copy of the Trust's bereavement booklet Information for families after a bereavement. This booklet is a practical guide on what do after death and provides further information and advice about the next steps and support available.

Your relative will be moved to the mortuary within 2 - 4 hours of their death. If you or your family wish to view your relative in the mortuary, you will need to make an appointment. The ward staff can advise you about this or see the information below.

To make an appointment please ring the appropriate switchboard.

Calderdale Royal Hospital 01422 357171

Monday - Friday 12.30 - 16.00
Ask for the Mortuary Staff

Huddersfield Royal Hospital 01484 342000

Monday - Friday 08.00 - 12.00
Ask for the Mortuary Staff

If you need advice about viewing your relative at other times, please ring the switchboard and ask for the on-call mortuary staff.

Practical issues

Keeping in touch with the ward

We will ask for your contact details, as keeping you up to date is very important to us. You can also contact us by calling the hospital switchboard and asking for the relevant ward, or by calling the ward directly. Please ask the team looking after your relative for the ward contact number.

Calderdale Royal Hospital : 01422 357171

Huddersfield Royal Infirmary: 01484 342000

Car parking

The staff on the ward can provide you with one free parking permit in order to reduce the costs of parking at the hospital. Please ask the nurse caring for your relative or friend for a permit.

Cash machines

A cash machine is in the main reception areas at both hospitals.

Meals and refreshments

If possible, we will offer you refreshments on the ward. However please see information below for shops and cafes within the hospital

HRI

Stop & Shop – Monday - Friday 7.30 - 17.00
Saturday & Sunday 10.00 - 16.00 (Inc Bank Holidays)

Café 1831 – Monday - Friday 7.30 - 19.00
Saturday & Sunday 9 - 17.00

Southside Diner - Monday - Friday 8.00 - 15.00 (Breakfast 8.30 - 11.00) (Lunch 12.00 - 14.00)
Cold sandwiches after 14.00
Closed all weekend

CRH

WH Smith – Monday - Friday 8.00 - 20.00
Saturday & Sunday 9.00 - 19.00

Union House Coffee Shop – Monday - Friday 7.30 - 19.00
Saturday & Sunday 9 - 19.00

Ingleton Falls Restaurant – Monday - Friday 9.00 - 14.00

Costa Express – 24hrs Hot and cold drinks, pastries & snacks

Toilet facilities

There are several public toilets located on the Ground Floors of each hospital. However, you may not wish to leave the ward so please ask a nurse on the ward for access to nearby facilities.

Tell us what you think

We hope that you have found this leaflet helpful. If you have any questions or you would like to speak to a member of the team caring for your relative, please ask a member of ward staff. If you have any concerns that you would like to discuss in confidence, please contact our **Patient Advice and Liaison Service (PALS)** for information and advice.

If you have any comments about this leaflet or the service you have received you can contact :

The Hospital Palliative Care Team

Huddersfield Royal Infirmary

Telephone (01484) 342965

www.cht.nhs.uk

If you would like this information in another format or language contact the above.

Potřebujete-li tyto informace v jiném formátu nebo jazyce, obraťte se prosím na výše uvedené oddělení

Jeżeli są Państwo zainteresowani otrzymaniem tych informacji w innym formacie lub wersji językowej, prosimy skontaktować się z nami, korzystając z ww. danych kontaktowych

ਬ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਪ੍ਰਾਚੂਪ ਜਾਂ ਭਾਸ਼ਾ ਵਿੱਚ ਲੈਣਾ ਚਾਹੁੰਦੇ ਹੋ,
ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਉਪਰੋਕਤ ਵਿਭਾਗ ਵਿੱਚ ਸਾਡੇ ਨਾਲ ਸੰਪਰਕ ਕਰੋ।

اگر آپ کو یہ معلومات کسی اور فارمیٹ یا زبان میں درکار ہوں، تو
برائے مہربانی مندرجہ بالا شعبے میں ہم سے رابطہ کریں۔

"إذا احتجت الحصول على هذه المعلومة بشكل مغاير أو مترجمة إلى لغة مختلفة فيرجى منك الاتصال بالقسم
المذكور أعلاه"