The care and support of the dying person in Calderdale

Introduction

This leaflet explains about how we care for somebody 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 nursing teams (or GP) who are 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 nursing teams are committed to caring for your relative with compassion and dignity, and in a manner which respects their expressed wishes.

The team looking after your relative will develop a personal care plan to ensure that they receive the best care in their last days of life - this care plan is called the Individualised Care of the Dying Document (ICODD). We will involve your relative in the development of this plan, where possible, and discuss it with you. The Specialist 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.

compassionate care

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 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. Below are some things that patients and their relatives often have questions about.

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. We 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 the nurses/carers looking after your relative. The nurses can show you how to do this if you would like to be involved.

Medications and tests

When a person is dying, the team 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 and temperature 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 a normal way. As air moves past the fluid with each breath, it can make a noise. This does not usually cause them any distress because it usually 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 the nurses can also give an injection to help slow down 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 concerns, please speak to the team caring for your relative

Pain

Many people are fearful that pain worsens in the dying phase, but this is very rarely the case. The team 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 team 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 team 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 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.

Caring for your loved one at this time can be very tiring. It is understandable to be worried and feel helpless at times but is important to take care of yourself. Try to rest as often as possible and eat sensibly.

Religious/Spiritual/Cultural needs

Your relative may follow a religious tradition or belief or have other spiritual needs. As part of the plan of care, nurses and care staff will explore any needs that are important to the dying person or family. You may want to ask for specific support from a religious or spiritual advisor, regarding special needs now, at the time of death or after death.

Not everyone that dies has a formal religious tradition or belief but any specific needs at this time should be explored.

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.

What to do after the death

Do not call 999 – this is not necessary when a death is expected.

- Call your District Nurse (01422 652291) to visit to confirm that the person has died. This is called verifying the death. If the District Nurse cannot attend promptly then a GP may be called to attend.
- Call family, friends, and any spiritual advisors you would like to come.
- Call the funeral director when the nurse (or doctor) has verified the death.

After the death we would encourage you to spend time with your relative if you would like to do so, there is no rush to call the funeral director.

You may be given a copy of the Calderdale bereavement guide. This booklet is a practical guide on what do after death and provides further information and advice about the next steps and support available.

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 Calderdale Community Specialist Palliative Care Team

Telephone: 01484 343814

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

ਜੇ ਤੁਸੀਂ ਇਸ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਪਾਰੂਪ ਜਾਂ ਭਾਸ਼ਾ ਵਿੱਚ ਲੈਣਾ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਉੱਪਰੋਕਤ 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"