Teesside HOSPICE

When someone is dying

Information for relatives & carers

We wanted to share with you the changes that happen before death, the care given and how you can help.

How do professional carers know someone is dying?

When someone with a severe illness is nearing the end of their life there are usually some signs which suggest death is near, such as:

- Extreme fatigue, spending more time asleep
- Not eating or drinking
- Physical changes such as changes in breathing and the skin
- Being more withdrawn, confusion or restlessness

When we think that someone is likely to be dying, the focus of care will be on their comfort.
Each individual is different and there will be some uncertainties.
The dying experience is unique to each person.
Our aim is to provide the best quality of care and comfort to someone who is dying, and to do our best to provide that care where the person wants to be. This could be at home or in the hospice.

We will keep you fully informed and involve you in discussions about the plan of care, as much as you want to be, so that you understand why decisions are being made. We will review the care plan regularly.

We will ask you who should be contacted if your relative or friend's condition changes, and if you're happy to be contacted at any time during the day or night.

If you have any questions or concerns, please speak to a member of staff at any time.

Focus of care

When someone is dying their comfort is the focus of our care. We will try to provide comfort measures with minimum disturbance to your relative or friend. It is usual to stop doing some observations such as temperature, pulse and blood pressure measurements and tests like blood tests at this stage of someone's life. Instead we will make regular observations of their comfort and check if they have any symptoms. These might include pain or breathlessness, a noisy or rattly chest, and sore areas of skin.

Please let us know if you feel any of their needs are not being met or if they appear distressed.

You're important in your relative or friend's care, and we want you to feel included.

Food and drink

When someone is dying they usually stop feeling hungry and thirsty. At this point, the clinical team will give careful consideration to the possible benefits and disadvantages of giving fluids and nutrition by artificial means (such as a drip). This decision will be reviewed regularly. When someone is dying, artificial nutrition and hydration will not stop them dying and may cause problems such as skin swelling or noisy breathing.

If your family member or friend is awake and interested in food and drink, then it is a good idea to help them have a little of what they fancy. Their appetite may be reduced so no one should push them to have more than they would like. As someone gets weaker swallowing will become more difficult and there may be a risk of choking. Nursing staff can assess further and support with this. Eventually your relative or friend will be asleep more than awake and their mouth can become dry. We will provide mouth care to keep their mouth feeling moist and comfortable. You can help with this care if you wish.

If you're worried about any of the care related to eating and drinking, or you do not understand the decisions that have been made, please ask any of the team caring for your family member or friend.

Physical changes

When someone who is dying reaches the very last stage of their life they will become drowsy and spend more time sleeping.

Breathing

When death is close, breathing patterns may change. Sometimes there are long pauses between breaths or the tummy muscles take over breathing. Breathing may become noisy and produce a rattling sound due to mucus (phlegm).

These changes can be upsetting for family and friends but often do not seem to distress the dying person. Change of position or certain medication can help with this.

Skin

Their skin may change colour and feel cool prior to death.

Over time, their sleep will become deeper and eventually they will be unable to be woken. Most people do not wake up again at this stage and die peacefully and comfortably in their deep sleep.

Confusion and restlessness

Some dying people drift in and out of consciousness, others are restless. Please let a staff member know if you're worried that your friend or relative is distressed. Medication can be used to relieve distress.

Monitoring care in last days of life

At Teesside Hospice we use a care plan designed specifically to guide and monitor the care of patients who we feel are likely to be dying and in the last days of their life.This plan is called the 'Assessment, Care & Treatment at the end of life' ACT document.

The plan prompts the care team to consider all the physical, social, psychological and spiritual care needs of the dying person as well as the needs of their loved ones. This is to make sure everything possible is done to provide relief of distress and avoid unnecessary tests or procedures. Instead we will make regular observations of their comfort and check if they have any symptoms. When someone is in the last days of life there are many treatments, such as resuscitation, that will no longer be beneficial or appropriate and comfort measures will take priority.

When someone is dying we will review their medication and stop medicines that are no longer needed or beneficial. Some people will have previously had symptoms such as pain and sickness and it is important that we continue to treat these as they are dying. Giving medication as a continuous infusion under the skin from a supply in a pump called a syringe driver is a safe way of continuing to manage symptoms. Some people develop new symptoms when they are dying. These may include pain, sickness, breathlessness, agitation, and a noisy or rattily chest. Medication used to treat these symptoms may include morphine for pain and midazolam or a similar sedative drug for breathlessness or agitation. We may also use anti-sickness medications if needed and drugs that dry up chest secretions. It can be difficult to predict who will get these symptoms so it is usual to prescribe medication 'just in case' it is needed. We have to balance the benefits of these medications to treat symptoms with the possibility of side effects like sleepiness or dry mouth. Most people become sleepier as they're dying, so it is important that we do not confuse the normal sleepiness of dying with the side effects of medication. If your relative or friend has needed medication for symptoms on several occasions we normally start an infusion through a syringe driver as described above.

If you have any concerns or questions about the medication being used, please ask.

The ACT document supports the care team to monitor the dying patient's comfort on a regular basis and to check your understanding of the care being given. You're important in your relative or friend's care, and we want you to feel included in this.

If you feel any needs are not being met or you have any questions or concerns regarding the care or treatments being provided, please discuss this with a member of staff.

Can a person go home to die?

It's possible to arrange end of life care to be delivered at home. If this is something you would like to discuss, please speak to a member of staff as soon as possible.

What can a relative or friend do?

As a relative or friend, just being there will help. If you want to, you can be involved in the person's care for example, washing hands and face, combing hair and keeping their mouth clean and moist or any aspects of care you would like to do.

Even if a person appears to be deeply unconscious, it is possible that they can still hear what is being said. You should talk as if they can hear you.

The time over which the dying phase happens can be variable and may be difficult to predict. While caring for your relative or friend it is very important that you also take care of yourself and take time to eat and rest.

What support is available?

All members of staff are here to support you as well as your relative or friend at this difficult time. You may all want the opportunity to discuss what is important to you at this time regarding wishes, feelings, beliefs and values.

Chaplaincy support is available if required so please ask a member of staff to liaise with your faith leader or we can contact JCUH chaplaincy team. You're also welcome to call in someone you know to help.

There is the room for reflection in reception available for private prayer and reflection or simply to sit and relax in peace and quiet. There is a prayer book for people to write prayer requests in and religious symbols are available on request. If you would like more privacy in the room the glass doors can be shut or you can use the Quiet Room along the corridor behind the reception area.

What should I do when death happens?

If you think the person has died and a member of staff is not immediately present, we would encourage you to tell a member of staff straight away. They are here to help and support you.

Members of the nursing team will confirm that the person has died. A doctor will complete a certificate of the cause of death. If there are no doctors present on the unit when the person dies (e.g. during the night), the death will be certified when a doctor is next on duty. Sometimes this may be several hours later, however, if it is necessary a doctor will certify death at any time.

Family members and those close to the person who has died are encouraged to spend as much time as they need with their loved one. The staff will then wash the person and prepare the body. The family and friends may be asked how they would like the person to be dressed (clean night clothes or particular day clothes).

The family can gather together the person's belongings to take home, or, if they prefer, the staff can do this on their behalf. If there are particular objects which you would like to be left with the person who has died (e.g. wedding band, other jewellery, letters etc.), please let the staff know.

You will be asked whether the person is to be buried or cremated and also who the funeral directors are to be. We would ask that you contact the funeral directors initially when the person has died to let them know that you would like to use their services and request that the funeral directors contact the hospice. Hospice staff will then be able to contact the company when it is appropriate for them to take the person to their own chapel of rest. If there are other members of the family who would like to visit the person at the hospice before they are transferred by the funeral director, please let the staff members know. This is usually possible for several hours following the death of the person.

Staff will advise you later on what other arrangements you need to make and will give you a pack that includes a number of leaflets including, 'THCF Bereavement Information' that has practical help and advice about bereavement. We will provide you with a bereavement pack following death but if you would like one sooner please just ask a member of staff.

We are regulated by CQC who can ask for information about us and our patients.

www.teessidehospice.org

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