What to expect

Sheldon Unit
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Introduction

This booklet provides information for families and others in relation to caring for a person at the end of their life. It contains information concerning symptoms that may be experienced, the care and support which may be given and also some questions that have been frequently asked at this difficult time.

It is important for the doctors and nurses to understand what it is that is important to you and your family/others.

What happens when a person is dying?

Individual experiences in the last days of life can vary from person to person and it is very difficult to predict exactly what will happen and when. However, there are some common signs and symptoms which may indicate that a person is entering the last days/hours of life. Knowing what to expect may help to relieve anxiety and allows better planning.

- the dying person may become very sleepy and spend most or all of their day in bed resting and sleeping. Periods of being awake may reduce and eventually the person may be deeply asleep all of the time
- they may have difficulty swallowing or not want to eat and drink
- they may struggle to take any tablets or medicines by mouth
- they may lose control over their bowels and bladder
- sometimes the person may show signs of being distressed or restless
- their breathing may change and can sometimes become noisy
- their hands, feet, legs and arms may feel cold to the touch
- the person may become confused or disorientated
- they may experience a variety of emotions
• their beliefs, faith or religion may become particularly important at this time

• they may lose interest in their surroundings and withdraw from people and their environment.

For many people, although dying is very peaceful it can be upsetting to watch a person go through these changes. This is part of the natural dying process and does not necessarily mean that they are uncomfortable or in distress. The doctors and nurses looking after the person in the last days of life will be checking for any changes and will do all that they can to make the person as comfortable and dignified as possible.

Stopping medicines

A person may have been taking medicines for many months or years and these may need to be stopped or changed if they are no longer helpful. The doctors and nurses will discuss this with you. In addition, we may no longer be carrying out routine observations such as blood sugar measurements as they may no longer be of any benefit and may cause unnecessary distress.
• Changes in breathing

The breathing pattern can change as the body slows down. Breathing may be fast, shallow or deep and there may be pauses between breaths. Should breathlessness be experienced there are simple measures that may help; these include opening a window, using a fan and changing position. The person may require a small dose of morphine. This is usually given for pain but it can also be used to treat breathlessness and can be very effective. This may be given by an injection under the skin. Oxygen requirements may be reassessed and for some people oxygen may no longer be needed. However for some it may still be helpful.

• Chest secretions

Everyone makes secretions (fluid) in their chest and throat. When someone is in the last days of life, the normal secretions that they have cannot be cleared and they make the person sound ‘chesty’. This is due to a build up of fluid in the air passages. The breathing can sound noisy but is not normally distressing for the patient. Changing position of the patient may help, as can some types of medication, which are intended to dry up these secretions. These can be given by injection.

• Pain

Not everyone who is dying will have pain. Even if the person has difficulty communicating it is usually possible to tell if they are in discomfort and the doctors and nurses can check for this. If there is pain it is reassuring to know that there are several ways of relieving it. Changes in position may help the person in pain, however for others it may be best not to change their position. This will be assessed on an individual basis. Medicine such as morphine can be useful and given by injection if needed.
• Distress and restlessness
As part of the natural dying process the person may become confused, distressed or restless. Sometimes hallucinations may occur, which can be difficult for the family and others to see but these symptoms can be helped. The doctors and nurses caring for the person will check for any other causes which may be contributing to the distress.

• Sickness and vomiting
When a person is at the end of their life they may feel sick. There are many possible reasons and the doctors and nurses will assess this on an individual basis. The person may feel sick when they are moved or certain smells may trigger sickness. Medicines can be prescribed to help relieve this symptom via injection.

• Bowels
Due to weakness (and as the person’s condition deteriorates) they may not be strong enough to use a toilet or commode. Often the bowels slow down and do not work as normal. Bowels will be assessed by the doctors and nurses with the aim of maintaining dignity.

• Bladder
As the body naturally slows down the person may pass little or no urine and the urine may become very dark in colour. Due to weakness, it may be too distressing to assist the person on and off a commode or toilet. In order to maintain dignity and comfort, pads can be offered.

For some people it may be kinder to have a catheter to drain urine from the bladder, which will preserve their energy and ensure that they remain dignified and comfortable. If appropriate this will be discussed with the family and others. Catheters can also be used for people who have signs of retaining urine, which can also cause distress and restlessness.
Eating and drinking

Based on a person’s condition their need to eat and drink may become less. Some people may be able to take small amounts of food and drink, others may only be able to take sips of fluid and some may not wish (or be able) to take anything at all.

It would not be usual to start a drip at this time, but this would be discussed with you. Each person will be individually assessed by the doctors and nurses to make sure their comfort is maintained therefore it is important to provide good mouth care and ensure that the mouth is clean and moist. Gels and saliva sprays may be given to help with this. Families and others can be taught to clean the person’s mouth if they wish.

Using a syringe driver to give medicines

Sometimes a syringe driver (a small portable pump) may be set up by your doctor or nurse. The syringe driver is used to deliver a constant dose of medicines (usually over 24 hours) and may contain more than one type at a time. A very small needle will be inserted just under the skin in the tummy or arm through which the medicines will be given. A syringe pump means that the person can have the medicines they need and so will not need to have lots of individual injections. The medicines and their doses will be reviewed each day before the pump is refilled to make sure the person is receiving the most appropriate type and dose of medicine for them at that time.
End of life comfort measures

What matters most to you and your loved one is essential information to help ensure all the staff who are providing care meet you and your family’s needs. Some families and others may want to be involved in assisting the nurses with comfort and care. If you do, please tell the nurses. Families may want to record familiar sounds, children, grandchildren or family members who cannot be present either singing or simply talking to the person; playing favourite music can be soothing. Children are very welcome to visit to say goodbye to a loved one, but please discuss this with a member of staff should you have any concerns as to the suitability of this.

Religious, spiritual, emotional and cultural needs

When someone is approaching the end of their life they may find talking to someone can provide support. Often this support comes from family and friends but sometimes it helps to talk to someone who is independent.

You or your loved ones may also wish to have any religious and spiritual needs supported by your own faith representative. Please make this clear to those involved in the care of your loved one.

Care after death

The death of someone close to you is very significant and everyone reacts very differently to the situation. After a person has died they will be seen by a doctor or nurse, who will ensure that appropriate care (or ‘last offices’) are carried out in line with national and local legal guidelines.
They will also ask if anyone in the family wishes to assist with this aspect of care, as certain cultures require this to be considered. Should you have any particular spiritual, cultural or practical wishes following death then please discuss these with a member of the nursing team. The intention is to deliver care sensitive to the cultural and religious needs, and personal preferences of the dying person and their family and others.
Frequently asked questions

Q. What happens if my relative gets better?

Occasionally a person’s condition can improve. If a person’s health appears to improve, then they would be assessed by a doctor and/or nurse to explore the possibility of moving onto a more appropriate place of care or back home to family to enjoy some quality time in a more familiar surrounding.

Q. What do I tell the children?

Talking to children about a person approaching the end of life can be challenging and exactly what you tell them often depends on their age. Generally it is best to be as honest as possible with children; this may be distressing and sound harsh but it can help children deal with things after the death a little better. The team caring for the person can advise you further regarding specialist support to help your children.

Q. How long can/should we stay with the person once they have died?

There is no right answer to this question; although (for legal reasons) we need to discuss a plan for transfer to an appropriate place of care for our deceased, there is no immediate hurry to leave our premises after the death of a family member. Some families wish to spend some personal time with their loved one, and arrange for other family members to arrive to say goodbye whereas others feel that they have stayed long enough and want to leave quite promptly. In either case, please discuss your wishes with a member of staff and we will endeavour to help you fulfil them with the dignity, privacy and respect that our patients deserve.
Q. What would happen if the person deteriorated and I wasn’t around?

If you are not around when your loved one deteriorate, then (should you wish it) the nurse in charge would contact you to discuss the situation and invite you to come in to spend the last moments together. During the time between a phone call and arrival, we observe the patient very closely, addressing any symptoms that may occur. We do not leave our dying patients alone, but slowly withdraw our presence once the family arrives to allow them time together.

Q. What happens to my loved one’s personal belongings?

The personal belongings may be taken as appropriate by the next of kin.

Q. Can the person hear and communicate with us even if they seem deeply asleep?

People vary; the truth is, we really can’t be sure either way so we assume that they can still hear and understand conversations in the room to help maintain the patient’s dignity.

Some people communicate by squeezing hands until they are too weak to do so, some may still be able to communicate verbally a little. As their condition deteriorates further, they will be able to communicate less. Sense of hearing is a fairly strong sense and it can be comforting for them to hear familiar voices from family and friends. It may also be appropriate to play some favourite music. It is unlikely that they will always be able to continue to communicate with you as their condition deteriorates.
The National Council for Palliative Care (NCPC) is the umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland. It also leads the Dying Matters Coalition (www.dyingmatters.org) which aims to help transform public attitudes towards dying, death and bereavement in England and Wales.

The Leadership Alliance for the Care of Dying People (LACDP) was formed to provide a focus for responding to the independent review into the Liverpool Care Pathway’s report and consists of 21 organisations including those statutory organisations to which the panel addressed recommendations, as well as representatives from the voluntary sector, who were invited to join the Alliance to develop, support and contribute to its work.

Sheldon Unit Registered Charity No 1069427

We hope this information has helped you in some way and answered some of the questions you may have in mind at this very difficult time. If there is anything else we can help you with, or if you just want a chat about your loved one in our care, please ask for the nurse in charge or to speak with a member of our medical team.

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