

# **Understanding what happens when someone is dying**

## **Information for Relatives, Friends and Carers**

Named Consultant/GP: \_\_\_\_\_

### **Introduction and facilities**

While looking after your relative or friend we can see that there has been a change in their condition and so we are concerned that they may be dying. We want to provide care that respects the dignity, privacy, choice and confidentiality of each person, their family and their friends.

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 home, in a care home, in hospital or in a 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. Please feel free to ask us any questions that you may have at any time.

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

We will give you information about visiting arrangements and car parking, and facilities for your comfort such as refreshments, toilet and bathroom facilities. If you are unsure, please ask.

### **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 (like temperature, pulse and blood pressure measurements) and tests (like blood tests and X-rays) 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 are important in your relative or friend's care, and we want you to feel included in this.

## **Medication**

When someone is dying we will review their medication. It is normal at this stage to stop giving some medicines which are no longer needed. This may include medication for long term conditions, such as high blood pressure or cholesterol, and vitamins and other supplements. Some medication, such as treatments for Parkinson's disease, may need to be given by another means. This could be as a patch instead of tablets. Some conditions like diabetes still need to be monitored but in a different way, and the treatment plan is changed to recognise that someone is less active, and naturally eating and drinking less as they die.

Some patients have already experienced symptoms like pain, breathlessness or sickness. These symptoms still need to be treated when they are dying. The treatment may need to be given in a different way if someone can no longer swallow tablets or medicines. Giving medication as a continuous infusion under the skin from a supply in a pump called a syringe driver is a safe way of giving medication at this stage.

Some people develop new symptoms when they are dying. These may include pain, sickness, breathlessness, agitation, and a noisy or rattly chest. Medication used to treat these symptoms may include morphine (or other painkiller) for pain and midazolam (or a similar sedative drug) for breathlessness, agitation, restlessness. We may also use anti-sickness medications if needed and drugs that dry up chest secretions. It may 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 more sleepy as they are dying, so it is important that we do not confuse the normal sleepiness of dying with the side effects of medication. If you have any concerns or questions about the medication being used, please ask.

The medication that is used will be chosen depending on your friend or relative's condition and other health problems. The aim of using these medicines is to keep your relative or friend free of any pain or distress. Small doses can be given as injections just under the skin. If your relative or friend has needed medication for symptoms on several occasions we normally start an infusion through a syringe driver as described earlier.

## **Food and drink (nutrition and hydration)**

When someone is dying they usually stop feeling hungry and thirsty. Sometimes when people have been very ill they have been given food and fluid by means of feeding tubes into the stomach or small bowel, or through a 'drip' giving the fluid into a vein. This is referred to as 'clinically assisted nutrition and hydration' and is done to help someone recover from a serious illness. However when someone is dying, the situation is different and clinically assisted nutrition and hydration will not stop them dying. In some situations they can actually cause problems without any benefit. So we have to think carefully about what sort of nutrition and hydration is safe and useful to give. There are times when giving a small volume of fluid under the skin ("subcutaneous fluids") is appropriate. These are clinical decisions, made by the consultant and the whole team providing care and explained carefully to the patient if possible, to weigh up the potential benefits and the possible risks involved.

If your relative 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 and so no one should push them to have more than they would like. Sometimes as people become weaker near the end of their lives their swallowing muscles also become weaker. They may need help to eat and drink, for example getting in the right position or trying different consistencies. They may need help sitting up so that it is easier for them to swallow. The nursing team will be able to help you adjust the bed and your relative or friend's position to enable this.

Sometimes, because of weakness or the effects of the illness, people are so weak that there is a chance that food or drink can go into their windpipe ("down the wrong way") instead of being swallowed safely into their stomach. We have to think carefully about whether this possibility could do more harm than good, especially if there is a risk of choking.

Eventually your relative or friend will be asleep more than awake. When they are drinking less, and with the effects of some medications, their mouth can become dry. To help this to feel better we will provide mouth care to keep their mouth feeling moist and comfortable. It is still really important to clean the teeth, using a soft brush and a non-foaming toothpaste. You are welcome to help in this care so please ask the nurses to show you what you can do.

When a person stops eating and drinking it can be hard to accept this is happening even when we know that they are dying. If you are 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 relative or friend.

### **Spiritual / cultural / faith needs**

Your relative or friend and you may want the opportunity to discuss what is important to you all at this time regarding wishes, feelings, faith, beliefs and values.

If you would find it helpful there is support available from a Chaplain or religious advisor now and after your relative or friend has died. Our Chaplains welcome the opportunity to provide support for people of all faiths or of no faith at all. We know that for some families to observe the practices of their culture and faith it is important to take the person who has died home as soon as possible after death. We will do everything possible to support your wishes in this part of their care. Occasionally there are medical reasons why this may be difficult. Please tell us about your wishes so that we can do whatever we can to meet them.

### **Physical changes at the end of life**

When someone who is dying reaches the very last stage of their life they will become drowsy and spend more time sleeping. Their breathing pattern may change and it can become irregular and sometimes noisy. The person has less strength to cough to clear their chest. Changes in position may help this. The noisy or ratty breathing can sometimes be more upsetting for family and friends sitting with the person who is dying than it is for the person themselves, depending on how deeply asleep they are. Please

ask us if you are worried about your relative or friend's breathing. Over time, their sleep will become deeper and eventually they will be unable to be woken. Their skin may change colour and feel cool prior to death, especially on their hands, feet and ears. Most people do not wake up again at this stage and die peacefully and comfortably in their deep sleep. The time over which this happens can vary and is difficult to predict. We would encourage you to take time to look after yourself during this period.

### **Questions or concerns**

Caring well for your relative or friend is important to us.

Please ask if there are any questions that occur to you, no matter how insignificant you think they may be or how busy the staff may seem. This may all be very unfamiliar to you and we are here to explain, support and care.

We recognise that you may want to stay with your relative or friend to provide comfort or care. Please discuss this with the nursing team who are usually able to arrange flexible visiting times, or for you to be able to stay with them as much as you would like.

### **Comments / compliments / concerns or complaints**

The Newcastle upon Tyne Hospitals NHS Foundation Trust is concerned about the quality of care you receive and strives to maintain high standards of health care.

However we do appreciate that there may be an occasion where you, or your family, feel dissatisfied with the standard of service you receive. Please do not hesitate to tell us about your concerns as this helps us to learn from your experience and to improve services for future patients.

### **Patient Advice and Liaison Service (PALS)**

This service aims to advise and support patients, families and carers to help sort out problems quickly on your behalf. This service is available. Please ask a member of staff for further information.

Produced by:

Alex Nicholson & Charlotte Doddrell on behalf of the Northern England Supportive, Palliative and End of Life Care Network

NFH328  
September 2020