WHAT TO EXPECT WHEN SOMEONE IS DYING

A GUIDE TO HELP YOU UNDERSTAND WHAT MAY HAPPEN AND HOW CARE MAY BE MANAGED WHEN SOMEONE IS THOUGHT TO BE IN THE LAST DAYS AND HOURS OF THEIR LIFE.

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01604 682682
nhft.nhs.uk

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Generally the following changes in the overall condition of a person help us to recognise that they may be approaching the last few days of life:

• The person may spend more time in bed as they become weaker and moving around becomes more difficult.

• They may lose interest in their surroundings and even in close family members.

• They may feel disorientated and confused. They may hallucinate and talk to people from their past, even those who have died long ago.

• The person may spend more and more time asleep until they are unconscious.

The last few days of life are precious and are often remembered in detail by those who live on. This leaflet is designed to help you know what to expect, which may be helpful to you at this difficult time.

HOW DO WE RECOGNISE WHEN SOMEONE IS DYING?

As each person’s experience of the last few days of life will be different it can be very difficult to predict exactly what will happen, or how quickly changes will occur. Some people die very quickly with little warning whilst others gradually become less well over a period of time. Occasionally people who are believed to be dying improve and stabilise.

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HOW IS CARE PLANNED AS SOMEONE APPROACHES THE END OF THEIR LIFE?

When someone is thought to be in the last few days and hours of life the priority is to ensure a peaceful and comfortable death. This will involve individualising care to take into account any known wishes of the person who is thought to be dying and the views of the people identified as important to them. Here are some of the things that may be considered important:

Food and drink
When someone enters the dying phase their body no longer has the same need for food and drink. In fact, it is normal for dying people to eventually stop eating and drinking. For those important to the dying person, this may be difficult to accept. The plan at this time will be to continue to offer food and drink to those people who can swallow without serious risk of choking or aspiration (the accidental sucking in of food or fluids into the lungs). If this is not possible, or the person does not wish to eat or drink, regular mouth care will be given to help with a dry mouth.

Review of medications
It might be that the dying person is too weak to swallow medicines and it will be easier to give those medicines which are most important by injection. Sometimes a ‘syringe pump’ (a small pump that delivers continuous medication over a 24 hour period), is used to help control symptoms, e.g. pain. Medications will be prescribed ‘just in case’ to help manage certain symptoms should they occur.

Religious and spiritual needs
The thought of death can be very frightening. If the dying person, or those important to them, has a particular religious or spiritual need, or if you just want someone to talk to at this time, it may be useful to speak to your religious or spiritual contacts – alternatively a member of the healthcare team may be able to offer support.
For most people dying is very peaceful. However, whilst not everyone experiences the following changes, many are common as death approaches. You may find some of them distressing but knowing what to expect might reassure you they are ‘normal’ at this stage:

**The person’s skin may feel cold and change colour or appearance.**

In the last days and hours of life a dying person’s hands, feet and skin may feel cold and look pale. Their skin may also become mottled, blue or uneven in colour. These are caused by poor blood circulation as the blood flow is concentrated towards the vital organs. As the kidneys become less able to process bodily fluids, certain parts of the body such as hands and feet may swell a little and look puffy in appearance. Sometimes their skin may also become very sensitive to touch.

**The person may lose control of their bladder or bowels.**

This happens because the muscles in these areas relax and don’t work as they did. At this time pads or a catheter (a tube that goes into the bladder and drains urine into a bag), may be helpful. You might also notice their urine becomes dark in colour as their kidneys start to shut down.

**The person may become restless and agitated.**

Sometimes a dying person becomes restless. This is usually caused by chemical changes in the body but the healthcare team will also want to rule out other possible causes such as constipation or difficulty passing urine. If a dying person is unable to pass urine a catheter may be necessary.

Agitation can also be caused by emotional distress and can often be managed by quiet reassurance and the presence of people who are important to them.
The person’s breathing may change.

When someone is dying their breathing pattern may change. There may be long gaps between breaths or breathing may become fast and shallow. You might notice their tummy rising and falling with each breath as the muscles in the abdomen help with the breathing process. Occasionally there can be a noisy rattle to the breathing due to secretions collecting in their chest and throat. This can often be helped by a change in the person’s position or by giving medication, but sometimes it cannot be resolved. It can be distressing to listen to but does not normally cause any distress to the dying person.

Breathing will eventually stop but it is often difficult to identify the exact moment of death. Be prepared that there may be one or two gasps after what appeared to be the last breath.

WHAT CAN YOU DO TO HELP?

You may wish to be involved in some aspects of care. For example, you might like to moisten the person’s mouth regularly with a small sponge or, if they would like, massage their hands to help them relax.

Simply sitting with a person who is dying can help to keep them calm. Remember that although they may not be able to respond, a dying person will still be able to hear you and know you are there.

If you are worried at any time about any aspects of care, or feel the dying person is distressed in any way, or if you just want some reassurance, please contact a member of their healthcare team.

Some people may not feel that they are able to be present at this time. There is no expectation or judgment to be made if this is the case. You must look after yourself and do what is right for you.
If you would like further information, the following link may be useful: Website: www.mariecurie.org.uk /help/terminal-illness/planning-ahead/preparing/what-to-expect

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Northamptonshire Healthcare NHS Foundation Trust  
St Mary’s Hospital  
Kettering  
NN15 7PW  
Telephone: 01536 410141  
www.nhft.nhs.uk

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