

The Last Days of Life

Information and advice for relatives and carers

Palliative Care

Death is a sensitive subject, and one that many people are not comfortable discussing. This leaflet will give you some information about questions we are frequently asked. We hope that you will find it useful during this difficult time.

Reduced eating and drinking

When someone is in the last days of life it is usual for the amount they eat and drink to reduce. At this time food and drink may no longer be required or wanted. It is important not to force food and drink as this may cause further distress. Drips and feeds may no longer be appropriate and the stopping of these will be discussed with you.

To keep the person's mouth moist and clean and to keep them comfortable, mouth care will be provided by the nursing staff in hospital, and if you would like to take part in this please let the nurses know so they can teach you how to do this. If your relative is at home the community nurses will teach you how to give mouth care to them, and will support you with this.

Increased sleep

Your relative may have started to sleep more and may be drowsy when awake. You may find they are less able to respond and interact with you, however they will often be aware of familiar people around them and take comfort from this. Eventually they may become unconscious and can stay like this for hours, and in some cases days.

Changes to breathing

As a person comes to the end of their life their breathing pattern changes. Although everyone is different, generally the gaps between each breath will become longer, until the breathing stops. At times there may be periods of faster breathing, long pauses between breaths, yawns and sighs; these are all normal. If at any point you become concerned please tell a member of staff (if your relative is in hospital) or contact the District Nurse message-taking service (if your relative is at home).

Occasionally people may have some noisy 'gurgling' breathing which can often be upsetting for relatives and carers, but is not distressing for your relative. It is caused by a build-up of phlegm (mucus) at the back of their throat. Medication may be used to reduce the amount of mucus, or a change of position can also help, but often the breathing continues to be noisy.

Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR)

When the medical staff have identified that a patient is dying, and no more active treatment can be given, they will often start a Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR) order. This means that when the person dies, there will be no action taken to

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restart the heart (resuscitation) and the patient will be allowed to die with dignity. The decision will usually be discussed with the patients relatives/carers.

If your relative is at home, it is very important that the GP discusses this with you. If this is not discussed your relative could be transferred to hospital inappropriately meaning that their last days are in hospital, which may not be their preferred place of care. Please speak to the GP or the Community Team Nursing team if you have concerns.

Treatments, tests and appointments

The medical team will continually review the treatments, medications and tests that your relative is having and may decide that it is no longer appropriate to continue some of them. Those that are no longer of benefit will be stopped. This is to avoid any unnecessary disturbances and to provide as much comfort as possible.

If you have any concerns about this, staff will be happy to discuss this with you.

If your relative is at home, travelling could cause distress at this stage. If they have any outpatient appointments a family member will need to contact the department to inform them of the situation. The department will then give any advice needed about the appointment.

Supportive Care Pathway

You may find your relative has been started on the Supportive Care Pathway. This means that the care they are given will be focusing on relieving their symptoms, maintaining comfort and meeting their physical, psychological, social and spiritual needs. The aim is for your relative to be peaceful and comfortable as end of life approaches. The pathway also aims to identify the needs of carers and help them to support their relative.

Your relative will be prescribed medication to relieve symptoms commonly experienced at this time including pain, sickness, distress and breathlessness. These medicines can be given by injection or using a device known as a syringe driver if your relative struggles to swallow as they become weaker.

Tissue Donation

We realise that this is a difficult time for you to think about this, but you may want to consider that it may be possible, after death, for your loved one to donate tissue to others. This is often corneas which are used to restore sight. If you feel this is something your loved one may have wanted, please discuss with a member of staff.

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Personal Support

Death, dying and bereavement can cause many kinds of distress – often these are caused by emotional or spiritual pain. For some people, early support helps prevent more difficulties at a later date.

The hospital employs a team of chaplains who offer a listening ear for all people who are affected in any way. They can be called day or night by your ward staff. Just ask. For religious needs, we can provide chaplains from the following faith traditions: Christian, Hindu and Muslim. Other faith leaders are also welcome to visit.

For bereavement support in the community please speak with your GP or one of the Community Nursing Team for support.

Further Support

We hope this leaflet has been of use to you and if you feel you would like to discuss your relative's care or would like further support, please do not hesitate to speak to one of the following people:

If your relative is in hospital:

- A member of the ward nursing team
- Hospital Palliative Care Team (0121 507 2511 or 5296)

If your relative is at home:

- Their GP
- District nursing team
- Community Palliative Care Team

Sources used for the information in this leaflet

Department of Health, 'End of life care strategy', 2008

If you would like to suggest any amendments or improvements to this leaflet please contact the communications department on 0121 507 5495 or email: swb-tr.swbh-gm-patient-information@nhs.net



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ML4797

Issue Date: October 2014
Review Date: October 2016