

Coping with Dying

End of Life Care / Chief Nurse



This leaflet has been designed to give you important information about the dying phase and to answer some common queries you may have.

Information for patients and visitors

Introduction

The professionals involved in your care / the care of someone close to you feels that you / they are reaching the last days of life.

In order to try to reduce the anxiety which often comes from the unknown, this leaflet describes some typical features of the process of dying.

It anticipates questions you may wish to ask and it will hopefully encourage you to seek further help and information from the team caring for your loved one.

The Changes Which Often Occur Before Death

The dying process is unique to each person but in most cases there are changes or characteristics which help to indicate that a person is dying.

Any one of these signs can be attributed to something other than dying so please remember that the events to be described here are happening to a person whose condition has deteriorated as the result of a life limiting illness.

The main changes that indicate that life is coming to an end fall into 3 categories:

1. Diminished Need for Food and Drink / Loss of Ability to Swallow
2. Changes in Breathing Pattern
3. Withdrawing from the World

1. Diminished Need for Food and Drink

Initially, as weakness develops, the effort of eating and drinking may become too much and at this time help with feeding may be appreciated.

Your relative/friend will be supported to take food and fluids by mouth for as long as possible.

When someone stops eating and drinking it can be hard to accept even when we know they are dying. However they may not want or need food and/or drink and decisions about the use of artificial fluids via a drip will be made in the best interest of your loved one. This decision will be discussed with you and reviewed regularly.

In the dying phase the ability to safely swallow will usually be lost and at this time the route that necessary medications are given will need to be changed to sub cutaneous which means injecting just under the skin.

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2. Changes in Breathing

Sometimes breathlessness may be experienced however this can be relieved with medications or in some instances, following assessment, oxygen.

Occasionally, in the last hours there can be a noisy rattle to the breathing. This is due to a build-up of secretions that the patient is too weak to cough up. Change of position and medications may help with this however it can sometimes be more distressing for loved ones to listen to than it appears to be for the person dying.

If a person is "mouth breathing" their lips and mouth can become very dry. Moistening both with a damp sponge and the use of lip salve will give comfort.

3. Withdrawing from the World

This can be a gradual process. You may find your loved one spends more time sleeping and is drowsy when awake.

Their apparent lack of interest in their surroundings is part of the natural process of dying, which can also be accompanied by feelings of tranquility. Though there may be an increased alertness at some stage in the days before death. It is very individual to the person.

Eventually they may lapse into unconsciousness and may remain so for a surprisingly long time. This may be days for some or for others, shorter.

When death is very close the breathing pattern may change with long pauses between breaths, or the abdominal (tummy) muscles will take over the work; the abdomen will rise and fall instead of the chest. If breathing appears laboured remember that this is more distressing for you than for your loved one.

The skin can become pale and moist and may be slightly cooler prior to death and most people will not rouse from sleep but die peacefully, comfortably and quietly.

Reference Section

End of Life: a guide. Macmillan / Marie Curie. 2015.

An information leaflet for relatives / carers. Marie Curie Palliative Care Institute Liverpool 2012.

Contact Details for Further Information

Ward Contact Number (if applicable)

Community Nursing Team Contact Number (if applicable)



Information for patients and visitors

Patient Advice and Liaison Service (PALS)

The Patient Advice and Liaison Service offers confidential advice, support and information on any health related matters.

If you have a comment, concern, complaint or compliment about the care or service you have received from the Trust you can contact the PALS team as follows:

Telephone: 03033 306518

Email: nlg-tr.PALS@nhs.net

There are also offices at both the Diana Princess of Wales Hospital (near the main entrance) and Scunthorpe General Hospital (on the C Floor, near the outpatient department), should you wish to visit.

Please note: PALS should not be contacted for clinical advice relating to the content of this leaflet. The service should be contacted directly in the first instance.

Northern Lincolnshire and Goole NHS Foundation Trust

Diana Princess of Wales Hospital
Scartho Road
Grimsby
DN33 2BA

Scunthorpe General Hospital
Cliff Gardens
Scunthorpe
DN15 7BH

Goole & District Hospital
Woodland Avenue
Goole
DN14 6RX

03033 306999

www.nlg.nhs.uk

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