Learning Outcomes

By the end of this learning unit you will be able to:

- Understand the importance of recognising when a person is dying to ensure optimum care and support
- Understand the process of dying and changes that indicate when death is imminent
- Appreciate the knowledge and skills needed to care for the dying person and their families and friends.

It is also essential that you follow the Health Protection Scotland Guidance on COVID-19 relevant to your area of practice [https://www.hps.scot.nhs.uk/](https://www.hps.scot.nhs.uk/)

Introduction

The need to be able to recognise whether a person is dying (or not) is important to ensure that the person receives the highest quality end-of-life care and is supported to have a good death. It can help to;

- ensure effective symptom control
- consider potentially reversible issues
- inform decisions regarding an appropriate ceiling of medical intervention
- ensure anticipatory prescribing is undertaken
- support discussions with the person, their family and carers
- ensure the person’s end of life wishes and preferences are respected.

It can be difficult to be certain that a person is dying. Everyone’s experience of dying is different and some people will die suddenly or unexpectedly. However, in most cases, there are some signs that can help you to recognise when someone is dying, particularly for older people who have multiple complex healthcare needs, frailty and/or dementia.

The process of dying (Slide 4)

The process of dying is progressive and not a simultaneous failure of vital organs. It can be viewed as a three-stage process:

- Changes indicating death is imminent – the last week/days
- Peripheral shutdown – day/s to live
- Central shutdown – hour/s to live.

Changes indicating death is imminent – the last week/days (Slide 5)

In the last week or days, the person may:

- Spend more of the day asleep rather than awake
- No longer be interested in eating and drinking
- Have reduced urine output
- Have episodes of new incontinence
- Be extremely tired and weak
- Have little interest in getting out of bed
• No longer be able to communicate verbally
• Become more withdrawn
• Be reluctant to see friends and family members

Alongside the changes listed above (Slide 6):
• There is multidisciplinary agreement, along with the dying person and his or her family and carers, that further investigations or treatments will be of little benefit.
• Staff caring for the person on a day-to-day basis also believe that the person is dying.
• The person him or herself may tell you they are dying.

A person in their last days of life may not experience all these changes but they might have a few at once. Just having one or two of these signs means that it is less likely that they are approaching their last days. What will become more noticeable is that the person is deteriorating day by day or hour by hour and is no longer eating or drinking. We will cover this in more detail in Handout 2: Notes to accompany Nutrition and Hydration Power Point presentation.

These changes do not always indicate that the person is dying, and you need to be aware of potential reversible causes such as:
• hypercalcaemia (high level of calcium in the blood)
• infection
• the side effects of medicines.

You will need to carry out a holistic assessment and use an appropriate assessment tool such as the Supportive and Palliative Care Indicators Tool [SPICT] https://www.spict.org.uk/.

Care of the dying person (Slide 7)
When it is agreed that the person is actively dying, their care will be informed by their anticipatory care plans and involve discussion with the person their family and carers. The specific care needs in caring for a dying person includes:

• **Mouth care which is of utmost importance**
  ▪ If the person can swallow – give small amounts of water
  ▪ As death approaches increasing the frequency of giving water **but** in smaller amounts
  ▪ Use a piece of damp gauze in the persons mouth with crushed ice – water evaporates without the risk of choking.
  ▪ Ensure that the person is lying on their side
  ▪ Do **not** use lemon/glycerine swabs as they are extremely unpleasant tasting.
  ▪ Apply Vaseline to the person’s lips

This helps keep lips and oral mucosa clean, soft, moist and intact and prevents infection, decay and halitosis.

• **Regular turning**

It is important at this stage to turn the person as regularly-as possible - **even when a pressure relieving mattress is in place**. This is to counteract stiffness which may cause pain and discomfort.

• **Importance of being with the person**
It is important to note that the staff member who speaks to the dying person and their family and carer should be confident and experienced and have a good rapport with them. If you do not feel comfortable doing this, ask a colleague to help. However, you can still provide sensitive support to the person and their family.

The points below will help to guide you:

- Being with people who are dying is more than just providing physical care until the point of death. It is about enabling the dying person to express their thoughts, feelings, and fears. It is also important to be present even when family are sitting with the person to provide comfort and reassurance to the family.
- Even when families and carers know that they person is nearing the end of their life it can still be a shock when the person reaches the last days of their life. It’s important to speak to the person and their family and carers about what’s happening.
- Approach the conversation sensitively but try to avoid using euphemisms such as ‘going to a better place’. Using the word ‘dying’ where appropriate can avoid confusion.
- It is important not to make any specific predictions. It’s very difficult to predict how long a person is going to continue to live for and getting it wrong can be very distressing for their family and carers. It may help if you are able to say it maybe days or hours rather attempting to be accurate.

Peripheral shutdown – day/s to live (Slide 8)

In peripheral shutdown what you are seeing is the bodies attempt to continue to preserve life. The supply of oxygen and other nutrients are being directed to the vital organs of the heart, lungs and brain and no longer reaching the tissues in the body’s extremities such as the hands, feet and legs. During peripheral shutdown, the dying person may still have a day, or days, to live.

The noticeable changes are:

- **Bluish-cold look to the extremities** — mottling - is blotchy, red-purplish marbling of the skin. This usually occurs first on the feet, then travels up the legs and is caused by a lack of blood circulation when the heart is no longer able to pump blood effectively. Because of this, blood pressure drops, causing extremities to feel cool to the touch. The skin then starts to become discoloured. While it is very common it does not always happen before death.
- It is important to realise that the dying person will rarely feel cold and so should not be covered with too many blankets, as this could cause restlessness.
- **Cheyne-Stokes respiration**, or laboured breathing with gaps during which the dying person appears to hold his or her breath (a space of five to sixty seconds between breaths). This can be eased by gently raising the person on soft pillows.
- **Pinched nose** - and general changes in the face include sunken and hollow eyes, collapsed temples, cold and transparent ears.
- **Death rattle**, - caused by the build-up of mucous in the person’s throat or airways and they are no longer able to cough or clear their airways. It is often referred to as a ‘death rattle’, but this is not a medical term. Suctioning generally is not recommended because it
can increase secretions and discomfort. Turning or changing the way the person is sitting or lying down can help with this. It can be upsetting and worrying for family and carers to hear these noises. You should explain what is happening and reassure them that it is unlikely to be painful or distressing for the person him or herself.

Care at this stage will include: (Slide 9)

- Careful regular observation and recording of pain, breathing difficulties, and anxiety are required to achieve a peaceful, dignified death but avoid unnecessary interventions such as, blood pressure monitoring, excessive turning or blood sugar monitoring.
- Keep a light on in the room to help the person to remain orientated if they wake up.
- As sight and hearing fail – the dying person will only see what is near and hear what is spoken close to their ears. It can be helpful to explain this to families and carers and encourage and support them to continue to speak to the person.

To provide peace and comfort for the person keep outside noise to a minimum and play soothing music or sounds based on the person’s preferences. If the person is unable to hear or see, alternative sensory comforts may be used for example smell or touch. If the person has COVID 19 you should follow Health Protection Scotland Guidance https://www.hps.scot.nhs.uk/guidance/

Central Shutdown - Imminent dying – hour/s to live (Slide 10)

When death is imminent, the body weakens further.

Changes include:

- Breathing it is now no longer laboured, but shallow
- Less and less oxygen is delivered to the vital centres.
- The pulse is thin and thready.

The dying person is likely to have only an hour, or hours, to live. It is essential that staff notice the signs of this final stage and are careful to monitor the person’s pulse and breathing. They will be able to explain this to family and carers who can choose if they wish to be present at the death.

It is important to sit with and be present with the person and their family for comfort and reassurance – There are no special words needed. (Slide 11)

In the days and hours before death (Slide 12)

- In the days and hours before death the person may have a temporary surge of energy. A brief state of heightened consciousness caused by reduced oxygen and glucose or short burst of energy from neurones. As a result, the person may become restless and try to get out of bed or talk to/about family and friends who have died or other things. There is a risk that this may be misinterpreted as ‘Terminal Restlessness’ but it is not, and it will be important to respond appropriately to what they are saying or describing. Please also see Presentation and Handout 3: Notes to accompany Terminal Restlessness Power Point presentation.
After death (Slide 13)

- Even though you have been present during the dying process, the moment of death will be powerful. Each person will experience it differently. Here are the indications that death has occurred:
  - No breathing for a prolonged period of time.
  - No heartbeat.
  - Eyes are fixed and slightly open, with enlarged pupils.
  - Jaw relaxed, with the mouth slightly open.

- It is important to continue to respect the body of someone who has died - family and friends may want to sit with the body for a time. There is no need to rush things, and sitting with the body, praying or reminiscing may be comforting for them.

- Immediately after the heart stops beating, the body rapidly cools down until it reaches room temperature.

- It is important that you are aware that if you are moving the position of the body after the person dies you may hear a moaning or groaning sound which is caused by the body expelling air. For staff who have not previously experienced this it can be very frightening. Also, if the persons bowels or bladder were full at the time of death they will empty after death.

- The last offices or laying out the body is the procedures performed by staff to the body of a dead person shortly after death has been confirmed. They can vary between care setting such as care homes and hospitals as well as between cultures. You should familiarise yourself with the local procedures and individual cultural and religious requirements of the people you are caring for who may be dying.

Where the deceased was known or suspected to have been infected with COVID-19 please follow Health Protection Scotland Guidance relevant to your area of practice.
https://www.hps.scot.nhs.uk/guidance/