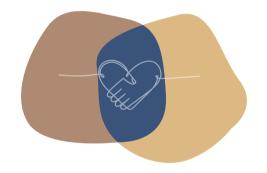


The Dying Process

For Patients, Family Members & Carers



The Dying Process

The moment of death is usually peaceful. If you have never seen anyone die, you may be nervous or fearful of what might happen. This booklet will help you to understand, anticipate and respond to some of the changes you may notice.





Caring for a person during the last few weeks and days of life can be stressful and demanding. You may have many different feelings and emotions.

Family members and close friends are often concerned that death will be a painful experience for the person. However, the time before death is generally peaceful. There is a gentle slowing down that may take several days. The body starts to "let go" of life. If restlessness does occur, it can be treated.

Not all the changes discussed in this booklet will occur with every person and they do not happen in any particular order. Sometimes these changes appear a few hours before death, sometimes a few days. These physical changes are part of the normal, natural process of the person's body gradually slowing down.

Apart from the changes described here, you may notice other changes that worry you. If you have any questions, you can discuss these with the Hospice Team. Please ask for help at any time.



You can bring great benefit to the person you are caring for simply by sitting with them, holding their hand and speaking in a calm and reassuring manner. Even when the person does not respond, they can probably hear you. Don't underestimate the value of these simple things. Sitting and being present with the person can be more important than doing things for them.

CHANGES YOU MAY NOTICE AND WHAT YOU CAN DO TO HELP

Not wanting to eat or drink

The person's appetite may decrease, and they may have little desire to eat or drink. This concerns many families and friends, however it is a natural process and is not painful for the person. Sips of water or a moist mouth swab may help them. You can ask the nurses to show you how to help with mouth care if you wish. Attempting to feed someone who is not hungry or unable to swallow may make them distressed.

'A moist mouth may keep the person comfortable.'

Sleep and alertness

Changes happening in the person's body mean that they may spend a lot of time asleep or they may be drowsy and difficult to wake up. It is best to talk to the person when they seem most alert and allow them to sleep when they want to. There is no need to shake the person or to speak loudly. Speak softly and say the things that are important to you, while allowing the person to rest.

'Allow the person to sleep when they want to sleep.'



Temperature

The body's temperature may change. At one time, the person's hands, feet and legs may be increasingly cool to the touch, and at others, the person may be hot and clammy. Sometimes parts of the person's body become blotchy and darker in colour. This is due to blood circulation slowing down and is a normal part of the dying process. If the person feels cold or complains of being cold, use light blankets to keep them warm. Too many bedclothes or an electric blanket may make them hot and restless. If the person is feeling warm, a fan to circulate the air and cool damp facecloths on the forehead can help them feel more comfortable.

Incontinence

The amount of urine produced reduces as the person drinks less. The urine may become darker in colour. Many family members are concerned that the person will lose control of their bladder and bowels. This does not happen to everyone, but if it does, there are pads and special absorbent sheets to enhance comfort and hygiene. The Public Health Nurse or Hospice Team will advise you about what is needed.

'There are no silly questions. Please ask if you are not sure about anything.'

Breathing

Breathing patterns may change. Sometimes the breathing may be fast, and at other times there may be long gaps between breaths. Breathing may be shallow or noisy. This is not a sign that a person is distressed or breathless.

'Changes to breathing sounds and patterns are natural and not usually a sign of distress.'

Secretions

As coughing and swallowing reflexes slow down, saliva and mucus may collect in the back of the person's throat, causing a gurgling, bubbling or other noise. This noise can worry family members but does not usually cause distress to the person. The person will not choke or drown from secretions. Medications can also be given to slow down the production of saliva and mucus.



If you are worried about your relative's symptoms, please speak to your GP, Public Health Nurse or Hospice Team

Restlessness

Due to the decrease in blood circulation to the brain and other changes happening in the body, the person may become restless or agitated. To help the person feel calm, speak in a quiet natural way, lightly rub the person's hand or softly play music that the person likes. If many people want to be present in the room, make sure there are not too many people talking or asking questions. Let a member of the Hospice Team know if the person becomes restless or agitated. Medications can be given to ensure that your relative is not distressed.

Pain

Not everyone has pain. Some people will have a small amount of pain that is easily managed by repositioning them in bed and giving paracetamol. Although we try to ensure that people have no pain, some people have a level of pain that is not always possible to resolve.

The Hospice Team is able to assess someone's pain even when the person is not able to talk. Medications will be given as needed to ease any pain so that the person who is dying is as comfortable as possible.

'The Hospice Team can help manage restlessness and pain.'

Syringe Driver

If the person is unable to swallow their medications, a pump called a syringe driver will be used to give the medications through a needle placed under the skin. The Hospice Team will review the person every 1 or 2 days and will make changes to the medications if necessary. They will discuss these changes with you. There is more information in the syringe driver leaflet, which the nurse will give you.

'A syringe driver, also known as a "pump", is helpful in managing symptoms. It can be used for a longer period of time for some people. It is not only used in the last days of the person's life.'

HOW WILL YOU KNOW THAT DEATH HAS OCCURRED?

- Breathing stops, the chest does not rise and fall.
- No heartbeat or pulse can be felt.
- The person cannot be woken up.
- Eyelids may remain half-open and sometimes the person's mouth may also be open after the last breath has been taken.
- **Pupils are fixed.** This means that they do not change in response to light.

WHAT SHOULD YOU DO?

• The only people you need to ring are:

- The patient's GP (or DDoc out of hours)
- The Hospice Team
- Your Funeral Director
- You don't have to contact anyone immediately unless you want to.
- If the person dies during the night, you can wait until morning to make these calls if you wish.
- It is important that you do everything in your own time.
- Telephone a relative or friend if you want them to be with you.



PHONE THE HOSPICE FOR ADVICE

If you are worried and would like advice on what to do next, phone St. Francis Hospice. You do not need to ring any emergency services.

St. Francis Hospice Raheny 01-8327535

St. Francis Hospice Blanchardstown 01 8294000

It is important to know that if a 999 or 112 emergency call is made, that the ambulance crew is obliged to attempt resuscitation unless an authorised and recent documented Do Not Attempt Resuscitation order is in place. The ambulance crew may need to contact the Coroner. This is because the main purpose of the 999 or 112 service is as an Emergency Response service.

When a decision has been made to focus on comfort and dignity, then it may be more appropriate to make contact with the hospice as a first option rather than the emergency services.

WHAT TO DO WHEN SOMEBODY DIES AT HOME

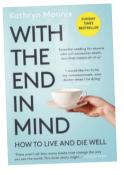
The person's body can stay at home, especially if you would like friends and relatives to come and say their goodbyes.

It is a good idea to turn off or remove sources of heat such as radiators, electric blankets and hot water bottles. It is also important to straighten the person because their limbs will stiffen, and if you can, replace dentures if they were removed.

You can sponge away any perspiration or body fluids that worry you. It is not necessary to bathe the person completely unless you want to. When you are ready, contact the funeral director, who will remove the person's body and guide you through the funeral arrangements.



WOULD YOU LIKE TO FIND OUT MORE ABOUT WHAT TO EXPECT?



Kathyrn Mannix, a palliative care doctor, has published a very helpful book:

With the End in Mind: How to Live and Die Well, 2019, HarperCollins. ISBN13 9780008210915

She also recorded a short video with the BBC that clearly and gently explains the normal dying process.

www.bbc.co.uk/ideas/videos/dying-is-not-as-bad-as-you-think/p062m0xt



The Gladiolus

represents hope, strength, integrity and remembrance.



