



# Coping with dying

Information for patients, families and carers



## Coping with dying

In order to reduce the anxiety which often comes from the unknown, this leaflet describes some typical changes that are often seen during the process of dying. It tries to anticipate questions that you may want to ask and hopefully it will encourage you to seek further help and information.

The recognition and diagnosis of dying is always complex irrespective of previous diagnosis or history. Uncertainty is an integral part of dying. There are times when a patient who is thought to be dying lives longer than expected and vice versa.



## Changes that may occur towards death

The dying process is unique to each person, but changes which are common when a person is dying include:

- ♥ reduced need for food and drink
- ♥ withdrawing from the world
- ♥ changes in breathing
- ♥ becoming increasingly fatigued/sleepy/unroutable
- ♥ their skin may change colour and become slightly blue and pale. It may also feel moist and slightly cool prior to death. This is normal and due to changes in their blood circulation. Most people slip into unconsciousness and die peacefully, comfortably and quietly in their sleep.

## Reduced need for food and drink

The dying patient will be supported to eat and drink for as long as they are able to do so safely. However, there will come a time when food and drink are neither wanted nor needed. This can be very distressing for family members as food and drink are closely associated with caring for a loved one.

Try not to be discouraged if there is little response when offering food or drink to your loved one – this may be due to their weakness and/or complete lack of appetite and does not mean a lack of appreciation of you.

If your loved one is too weak or sleepy/asleep to manage fluids, nursing staff will provide regular mouth care to soothe and moisten the mouth. They will show the family how to do this if they wish. Patients are reviewed on an individual basis as to whether it would be in their best interest to have artificial hydration (fluid through a drip/tube under the skin) or fed through an existing tube.

If the patient is unable to swallow it might be appropriate to give medication to control symptoms by a small pump (syringe driver). This should be discussed with patient and/or family. Medication is given at the lowest possible dose to control symptoms without any side effects and minimise any unwanted sedation.

## **Withdrawing from the world**

'Withdrawing from the world' is a gradual process. The person will spend more time sleeping and will often be drowsy when awake.

This apparent lack of interest in their surroundings is part of a natural process which may even be accompanied by feelings of tranquillity. It is certainly not a snub to loved ones.

Eventually the person may lapse into unconsciousness and may remain in this state for a surprisingly long time (in some cases many days) although for others it is shorter.

## **Changes in breathing**

People who suffer from breathlessness are often concerned that they will die fighting for their breath. Yet towards the end of life, as the body becomes less active, the demand for oxygen is reduced to a minimum.

Occasionally in the last hours of life there can be a noisy rattle to the breathing. This is due to a build up of mucous in the chest, which the person is no longer able to cough up. Medication may be used to reduce this and change of position may also help.

These measures may have limited success. However, whilst this noisy breathing is upsetting to carers, it generally does not appear to distress the dying person. When death is very close (within minutes or hours) the breathing pattern may change again. Sometimes there are long pauses between breaths, or the abdominal (tummy) muscles will take over the work - the abdomen rises and falls instead of the chest.

If breathing appears laboured, remember that although this can be very hard to observe, for the person dying there is usually no distress. If you feel that your loved one is distressed do let a staff member know so they can review comfort and medication. If there are any signs of unsettledness or discomfort then medication for comfort will be started or adjusted.



### **Spiritual and religious needs**

You should be asked if you or your relative/friend has a religious tradition or belief, and you may want to consider specific support now, at the time of death or after death.

Not everyone who dies follows a formal religious tradition, and you may want to explore any values, beliefs, wishes or desires that you have at this time.

If you wish to discuss any aspects please let a member of staff know and they will be pleased to help you.

## **Personalised care framework for last days of life**

Every patient has a plan of care when they are both at home or in Saint Francis Hospice, this plan of care is reviewed and updated regularly. When a patient's condition deteriorates, if care is provided at home, District Nurses and GPs may discuss the commencement of a personalised care plan for last days of life. If the patient's condition deteriorates, and care is being provided in Saint Francis Hospice, and the medical and nursing staff believe they are dying the Hospice use a personalised care framework to ensure that no care needs are overlooked.

The plan ensures that the patient and their families receive the best possible consistent care and support during the last days of life. It is also used to ensure staff are aware of a patient's wishes for care (if possible) and family's wishes for care and to ensure good communication.

The patient will be assessed regularly by staff to ensure their comfort and dignity needs are maintained at all times. They will be observed for both verbal and non-verbal signs of discomfort or pain and comfort measures taken such as repositioning or giving medication. The personalised plan of care will be reviewed daily to ensure appropriate care. However, if you are concerned about your loved one please do not hesitate to alert nursing staff.

Saint Francis Hospice provides high standards of care for all patients. This is most important during the last days of life. We hope that this leaflet helps you understand the process of dying, and a little about the care that we give and may prompt you to ask questions. The team are willing to talk to you at any time. Whatever your question please be assured that it will be dealt with sensitively and confidentially.

### **Who do I contact if my loved one dies at home**

When a loved one dies at home a GP needs to be contacted to verify death. If out of hours you will need to call 111. **It is important to let them know that you are reporting an expected death.** Once a GP has attended, you can contact a funeral director (many offer a 24 hour service) to collect your loved one and take them to their chapel of rest. On the next working day you will need to contact the registered GP who will provide you with the medical certificate of cause of death.



## About Saint Francis Hospice

Saint Francis Hospice provides care 24 hours a day, 7 days a week to local people affected by life-limiting illnesses. As a registered charity, we rely on the financial support of our community to keep providing world class care free of charge to individuals and their families. Every year, we provide treatment, care and support to more than 4,000 local people affected by a life-limiting illness.

## Confidentiality

At Saint Francis Hospice we are committed to upholding your rights to confidentiality and protecting your privacy. We will treat your information with respect. Keep it secure and comply with the requirements of the Data Protection Act 2018 including GDPR. Our privacy notice is available on request or by visiting our website [www.sfh.org.uk](http://www.sfh.org.uk)

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