



# Coping with dying

Information leaflet



## Coping with dying

When your loved one is approaching the last days of life, you may feel frightened, alone and uncertain as if the ground beneath you has suddenly collapsed. We are trained to provide you with outstanding individualised person-centred care and to help you and your loved ones find clarity, comfort and peace. Uncertainty is an integral part of dying and we hope this leaflet will help guide and support you.

## Changes that may occur towards death

Your loved one is an individual and the dying process is unique to each person. Changes which are common when a person is dying may include:

- ♥ Withdrawing from the world and becoming increasingly sleepy, fatigued and unrousable
- ♥ Reduced need for food and drink
- ♥ Restlessness, agitation or confusion
- ♥ Changes in breathing
- ♥ Skin changes
- ♥ Spiritual and religious needs
- ♥ Saying goodbye



## Withdrawing from the world

Withdrawing from the world is a gradual process. The person will spend more time sleeping and will be more often drowsy than awake. Extreme tiredness may make it hard for your loved one to sustain a conversation.

This apparent lack of interest in their surroundings is part of a natural process which may even be accompanied by feelings of tranquillity. Do not take this personally, it is a natural part of the dying process.

Eventually your loved one may lapse into unconsciousness. The sense of hearing is the last sense that remains. Assume your loved one can hear you and continue speaking to them in your own natural way even if your loved one doesn't seem to respond.

## Reduced need for food and drink

The dying individual 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 people close to the individual 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. The dying person will be 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 person is unable to swallow, it would be in their best interest to give medication by a small pump called a syringe pump, this is to ensure symptoms are well managed.

## Restlessness, agitation or confusion

Shortly before death some people become restless, agitated and confused. You may observe your loved one repeating tasks or movements such as “picking” at sheets or tossing and turning in bed. Agitation may be severe, causing the person to sit up or try to get out of bed. This is known as terminal restlessness or agitation, and it often occurs within the last few days of life. It affects nearly half of all people who are dying. If

you ask your loved one what is the matter, they will probably not be able to tell you or whatever is said will have no real meaning. This can be very difficult to see, so it is important for you to remember that this is a result of disease and what is happening in their body.

If there are any signs of restlessness or agitation, medication can be given to alleviate this. Please speak to a member of staff of any concerns you have (including District Nurses).

### **Changes in breathing**

Toward the end of life, as the body becomes less active, the demand for oxygen is reduced to a minimum.

As the last hours of life approaches you may hear rattling or bubbly sounds. Sometimes these sounds are quite loud. This happens because saliva/mucous settles or pools in the back of the throat and upper airways. This occurs because your loved one has become weaker, and it has become increasingly difficult for them to fully clear these normal secretions.

Keep in mind that these noises can be more frightening and distressing to you than they are to your loved one. You may also observe changes in the breathing patterns. Sometimes a person will breathe rapidly alternating with periods of no breathing (called apnoea).

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 discomfort, medication can be given to alleviate this.

### **Skin changes and changes in body temperature**

Due to the bodies' changes in circulation and ability to maintain natural body temperature, your loved one may go back and forth between being hot and clammy to being cool and dry. They may also develop coolness in the hands, arms, legs and feet. At the same time, the lower part of the body may become darker and look blotchy or mottled.

### **Spiritual and religious needs**

We are aware that not everyone follows a formal religious tradition, and you may want to explore any values, beliefs, wishes or desires that you have at this time.

Please share with the hospice staff (or District Nurse if at home) if there are any aspects or needs that we can help support you and your loved one with.



### **Saying goodbye**

Stay focused on giving one of the greatest gifts possible to your loved one, the security of knowing that you will be all right and that your loved one has your permission and encouragement to let go.

Say good-bye, knowing that your loved one and you may both need to hear this.

Don't be afraid to cry, tears are a natural part of the experience, they express your love. Don't try to hide them.

As a loved one or friend, it is important to look after yourself too. Make sure you remember to take breaks to eat, drink and rest. All Saint Francis Hospice staff are here to support you at this difficult time.

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

Every individual has a plan of care when they are either at home or in Saint Francis Hospice, this plan of care is reviewed and updated regularly. When an individual'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 individual'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 individual and their loved ones receive the best possible consistent care and support during the last days of life. It is also used to ensure staff are aware of an individual's wishes for care (if possible) and their loved one's wishes for care and to ensure good communication.

Your loved one 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.



**The Dignity Flower is used on the Hospice Ward when the End of Life Personalised Care Framework is in place for an individual. This is to maintain confidentiality and dignity to the individual and their loved ones at the same time ensuring all members of the Ward team are aware and can pre-empt care needs accordingly.**

Saint Francis Hospice provides high standards of care for all individuals. 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 your loved ones registered GP and the next steps will be explained to you at this stage.



## About Saint Francis Hospice

Saint Francis Hospice, rated outstanding by the CQC, is an expert in providing care for people in our community with palliative and end of life care needs.

We provide support and care for any person from any faith or cultural background diagnosed with a serious life-limiting illness and living in Havering, Barking and Dagenham, Redbridge, Brentwood or parts of West Essex. Saint Francis Hospice has been offering expert, compassionate advice and support for over 40 years.

## 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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