

# Final days of care

Information for family and friends

*because  
you matter*

**St Nicholas  
Hospice Care**

A Registered Charity No. 287773



**Need to talk?**

01284 766133

[stnicholashospicecare.org.uk](http://stnicholashospicecare.org.uk)

St Nicholas Hospice Care aims to provide comfort, dignity and emotional and spiritual support to people as they reach the end of their life and to their families.

This leaflet aims to answer some of the questions most frequently asked of our staff by family and friends of our patients.

However, every death is different and this leaflet can only give you broad guidance on what to expect. You may have some specific concerns or questions that our staff will help you with, but please remember that no-one can predict exactly what will happen.

Knowing someone close to you is dying is terribly upsetting, and at St Nicholas Hospice Care, we want to support you during this difficult time. Please ask a member of staff at any time if you have any questions, concerns or comments, and we will do our utmost to help.

We have tried to minimise the use of medical language in this leaflet, but if there are any words or phrases that you don't understand, please ask for an explanation.

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## Questions this leaflet may help with:

- Will they be in pain?
- How will they feel?
- What problems might they have?
- Will they have problems breathing?
- Will they still know I am here?
- Will they still be able to talk?
- Will they be able to eat and drink?
- What can I do to make them comfortable?



# What happens to people as they get closer to death?

## **Fatigue and loss of consciousness**

As an illness progresses, the body begins its natural course of slowing down. This varies from person to person and may take hours or a few days. The dying person may become very weak and sleepy and have difficulty staying awake. You may find you spend more time sitting quietly whilst they are asleep.

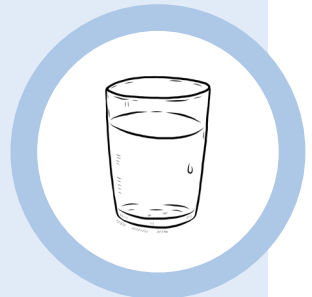
At the very end of life, people may be unable to respond, though they may move themselves from time to time. It is important that you still talk to them, even when they appear to be sound asleep. Towards the end they may still be able to hear you, as hearing is one of the last senses to go. It is important not to say anything in their room which you do not want them to hear.

## **Appetite and thirst**

You may have noticed a gradual decrease in their appetite, even with their favourite foods. We suggest that you do not try to force them to eat or drink as this may be difficult.

Pressure to eat will be frustrating for them and you.

If they are still awake, you can offer moistened 'foam sticks' and use lip balm to prevent lips cracking.



## Pain and discomfort

It is important to remember that most people die without pain.

When pain is a problem, St Nicholas Hospice Care staff will closely monitor the effectiveness of painkiller medications.

Signs of discomfort will be noted by the nurses and we also welcome your opinion. If a patient is not able to swallow tablets or syrups, our staff will ensure that the important medicines are given by other means, such as injection or by a syringe driver. A syringe driver is a small infusion pump which gradually administers the medication.

*Everything will be done to maintain a patient's comfort*

## Going to the toilet

Sometimes people are unable to control their bowel and bladder, which can become distressing and embarrassing. The nursing staff will do all they can to keep the patient as clean, dry and comfortable as possible. This may involve the use of pads or catheterisation.

You may notice the urine becoming darker and more concentrated, and decreasing in amount. This is because the patient is drinking less.

## Becoming muddled

People may become confused and disorientated for a number of reasons. If you notice they become muddled, please do speak to St Nicholas Hospice Care staff about this.

Your loved one may occasionally say things that do not make sense or are out of character, or may see things or people that are not there. You may notice them pulling at bed linen, their clothes or thin air. This behaviour can be upsetting to watch but does not always mean the person is distressed.

## Too hot or too cold

Sometimes a patient can become flushed and feel warm to the touch, or sometimes become cold. This can be due to the body's internal 'thermostat' not working very well.

Feet and hands may become cold to the touch and very sensitive, or you may notice their skin colour changing and feeling clammy. This is because of a decrease in circulation. Blankets can be used, but be careful that they do not become overheated as they may not be aware of feeling cold. If you think your loved one is cold, please let the nurses know.



When a patient is hot, fans or cool, wet flannels can be used. The doctors may also prescribe simple Paracetamol to help.

## Chesty coughs and noisy breathing

Sometimes fluid may collect in their lungs, making a person's breathing have a slight groaning or rattling noise. This can be very upsetting for people around, but thankfully, it is not uncomfortable for the dying person themselves.

A patient may need medication, repositioning or occasionally suction to try and ease the problem. It is not always possible to prevent the rattling sound, but we will still do all we can to maintain their comfort.

## Changes in breathing

You may notice that a patient's breathing becomes irregular, with long gaps in between breaths. There may also be times when they stop breathing for a few seconds and restart, building up to deep breaths. Changes in breathing often occur in unconscious or very drowsy people in the hours or days prior to death. It is a normal pre-death symptom.

## Emotions and feelings

Feelings can be very intense and difficult for a patient to bear. At other times, they may feel numb or disbelieving.

By allowing them to share the memories or feelings they are experiencing, you can offer support and comfort through this distressing time. Sometimes you may not feel up to offering that support. Please talk to a member of staff who will be happy to help.

When approaching the end of life it is often found that the dying person may review their life and talk about wanting to complete any unfinished business, such as:

- Resolving any problems with personal relationships
- Visiting certain places
- Sorting out personal belongings
- Giving gifts or special things away to family and friends
- Getting their Will and other financial affairs in order
- Seeing a religious or spiritual leader

As death becomes closer, the person may communicate less, be less aware of their surroundings and seem at peace. Just letting them know that you are there can be very comforting. Being cared for in this way enables people to feel that their lives have been worthwhile and that they will be remembered well.

It may be important to reassure them that it is alright to 'let go' and die when they are ready. This conversation can be one of the hardest things for you to do.



# The care we provide

Our doctors, nurses and other clinical staff focus their care and attention on the particular needs of patients and their families.

## **Religious and Spiritual Care**

Not everyone has a religious tradition. At St Nicholas Hospice Care, we recognise that people have differing spiritual and/or religious needs and we will try to accommodate these.

Spiritual issues may include values, a sense of meaning and purpose in life, beliefs, wishes and perhaps the need to make funeral plans. Our Chaplaincy team are available to discuss these issues with you and to support you at this difficult time.

## **Support for You**

If you need support or a listening ear during the final days of your loved one's life, St Nicholas Hospice Care is here to help. You can speak to our nurses, doctors, Chaplain or a member of the Family Support Team.

Please also feel free to sit in the Chapel or Bradbury Green if you need to take time away from their bedside.

Children are very welcome to visit patients at the Hospice. If you have any worries about explaining anything to your children, please talk to a member of staff.

## **Facilities**

Please use our Bradbury Green Bistro or the vending machines for meals, drinks and snacks.

You can also take 'time out' in the Family Room situated next to the Ward.

We also have a room available where families can stay overnight. Please speak to our nurses if you feel it would be helpful for you to use this room.

This leaflet is intended as a guide to be used alongside advice from the patient's GP, Hospice doctors and nurses, and other care professionals.



If you have any concerns or questions not covered by this leaflet, please speak to one of our nurses.

St Nicholas Hospice Care is a local charity which helps people live with long-term and life-limiting illnesses. Our patients, their family and carers are at the centre of everything we do. We will work with patients, their doctors and other carers to:

- Minimise any physical effects of the illness or its treatment
- Offer emotional and spiritual support
- Help with difficult decisions, planning or conversations about care at the end of life



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This leaflet is available in different formats upon request.  
Please contact the Marketing and Communications  
Department for further information on 01284 766133.

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