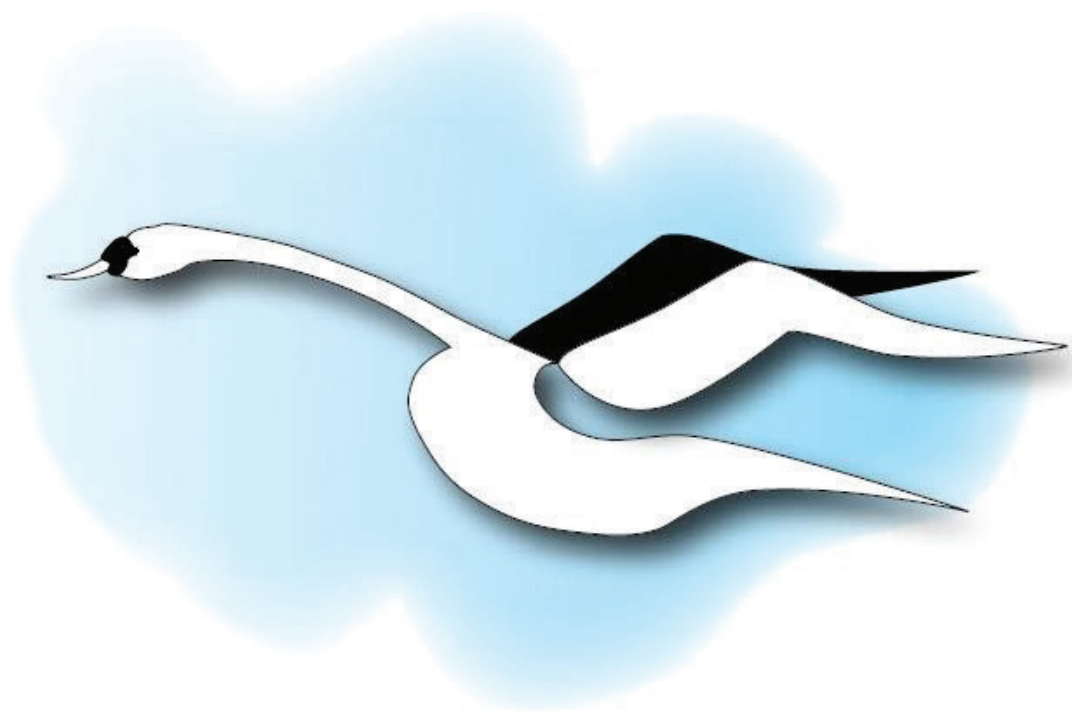


The End-of-Life Experience:

Care and support in the community

Adult Community Services - Supportive Care (Care Co-ordination)



To contact Care Co-ordination – our central
point of access – please call:

01902 443322

Introduction

We know that many patients and their families choose the home as the most preferred place of care, and increasingly, people are receiving care and dying at home, not in a hospital setting. It can be comforting for people to be at home as they can be surrounded by their loved ones, their own belongings and their own comforts. This booklet provides information for you and your family that may be helpful in understanding the experience of end-of-life care in the home. It contains an explanation of our community services, the range of care and support available to you and your family, information regarding the symptoms that may be experienced at the end of life and some answers to questions which are frequently asked at this difficult time, as outlined below:

What can I do to make someone more comfortable?

What happens when a person is dying?

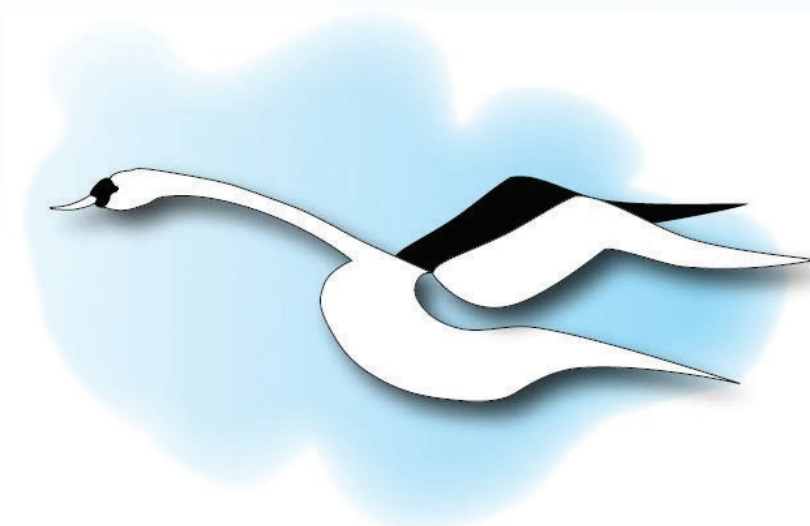
What happens after death?

Who is there to support me?

Can I change my mind?

Why is it important to communicate my wishes?

What is important to me?



To enable us to provide the best care and support possible to you and your family, we would like to offer you the opportunity to tell us what is important and matters to you and how we can best support you. There is space in the booklet to write down your thoughts and discuss these with the team. It may also help to write down any concerns or questions that the staff may be able to help you with or any feelings that you may wish to share.

What can happen when a person is dying?

Everyone's experience in the last days of life is different. Often, dying is very peaceful, however, it may be helpful to be aware of some common signs and symptoms which may indicate that a person is entering the last stages of life.

Sleepy

Variety of emotions

Difficulty swallowing

May lose interest in surroundings

Losing weight

Hands, feet, legs and arms may be cold to touch

**Faith, belief and religion
may become particularly important**

Lose control over their bladder and bowels

Confusion and disorientation

Not wanting to eat or drink

Breathing changes

It can be upsetting to watch someone you love experience these changes. This is a part of the natural dying process and does not necessarily mean they are uncomfortable or in distress. Nurses and Doctors caring for the person in the last days of life will do all they can to ensure the person is as comfortable as possible and cared for with dignity and respect.

Why might observations and medicines be stopped?

A person may have been taking some medicines for many months or years and these may need to be stopped or changed if they are no longer helpful. The doctors and nurses will discuss this with you. We may no longer be carrying out routine observations, for example blood pressure, blood glucose measurements or blood tests. These may no longer be of any benefit to the person and may cause unnecessary distress.

What symptoms might a person who is dying experience?

Changes in Breathing

This may be fast, it may slow down, become shallow or deep. Should this be experienced, there are simple measures to help, including opening a window, changing position or using a fan. The nurses can also administer a small dose of medication via injection to ease symptoms short term.

Chest Secretions

Everyone makes secretions (fluid) in their chest and throat. When someone is in the last days of life, the normal secretions that they have cannot be cleared. The breathing can sound noisy but is not normally distressing for the person. Changing the position of the person may help. Medications can also help to dry up some of the secretions and these can be given by injection.

Pain

Not everyone who is dying will experience pain. Even if the person has difficulty communicating, it is usually possible to tell if they are in discomfort. It is reassuring to know that there are several ways of relieving pain, this will be assessed on an individual basis. Medicine such as morphine can be useful and can be given by injection if needed. Medications will not be given until other alternatives have been explored such as repositioning.

Distress and Restlessness

As part of the natural dying process the person may become confused, distressed or restless. Sometimes hallucinations may occur. This can be difficult for the family and others to see. It can help to keep the environment calm and quiet and to gently reassure the person by holding their hand and talking to them. Medicines are available which can help relieve these symptoms. The doctors and nurses caring for the person will look for any other causes that may be contributing to the distress, and communicate this with loved ones.

Nausea and Vomiting

There are many possible reasons why patients might feel sick at the end of their life. The person may feel sick when they are moved, or certain smells may trigger sickness. Medicines can be prescribed to help relieve this symptom via an injection.

Bowels and Bladder

As the person's condition deteriorates, they may not be strong enough to use a toilet or commode. Often the bowels and bladder slow down and do not work as normal. Occasionally, due to muscle weakness the person may become incontinent. This will be assessed by the doctors and nurses with the aim of maintaining dignity and comfort. Catheters can be used for people who have signs of retaining urine, which can cause distress and restlessness.

How else can symptoms be managed?

Sometimes a syringe pump/ driver (a small portable pump) may be set up by your doctor or nurse. The syringe pump is used to deliver a constant dose of medicines usually over 24 hours and may contain more than one medicine at a time. A very small needle will be inserted just under the skin in the tummy or arm through which the medicines will be given.

A syringe pump means that the person can have the medicines they need and so will not need to have lots of individual injections. The medicines and their doses will be reviewed each day before the pump is refilled to make sure the person is receiving the best medicine for them at that time. The family or others will need to collect any medicines from a chemist from where they will be dispensed.



Which services may help to provide end-of-life care in the home?

When the preferred place to be is at home, Planned Care District Nurses will plan their visit schedule, individually to the patient needs. Everybody is different. The Royal Wolverhampton Community nurses are available 24 hours a day, 7 days a week. Our Trust has multiple services who collaborate to ensure quality care for our patients at the end of their life.



We also work very close with other services outside of The Royal Wolverhampton NHS Trust. These may include:



Can religious, spiritual or cultural communities be involved?

Often support comes from family and friends but sometimes it helps to talk to someone who is independent. You or your family may also wish to have any religious and spiritual needs supported by your own faith representative. Please make this clear, ensuring your wishes are known to those involved in your care.

What personalised care do we support and offer?

What matters most to you and your loved one is essential information to help ensure all the staff who are providing care can meet the needs of you and your family.

Some families and others may want to be involved in assisting the nurses with comfort and care.

Families may want to record familiar sounds for their loved one to listen to; children, grandchildren or family members who cannot be present either singing or talking to the person.

Playing favourite music may be soothing.

SWAN CARE: Sign, Words, Actions, Needs

In the community, we have designated SWAN Champions who are staff who volunteer their time in addition to their day-to-day roles to go above and beyond to deliver patient and family-focused care.

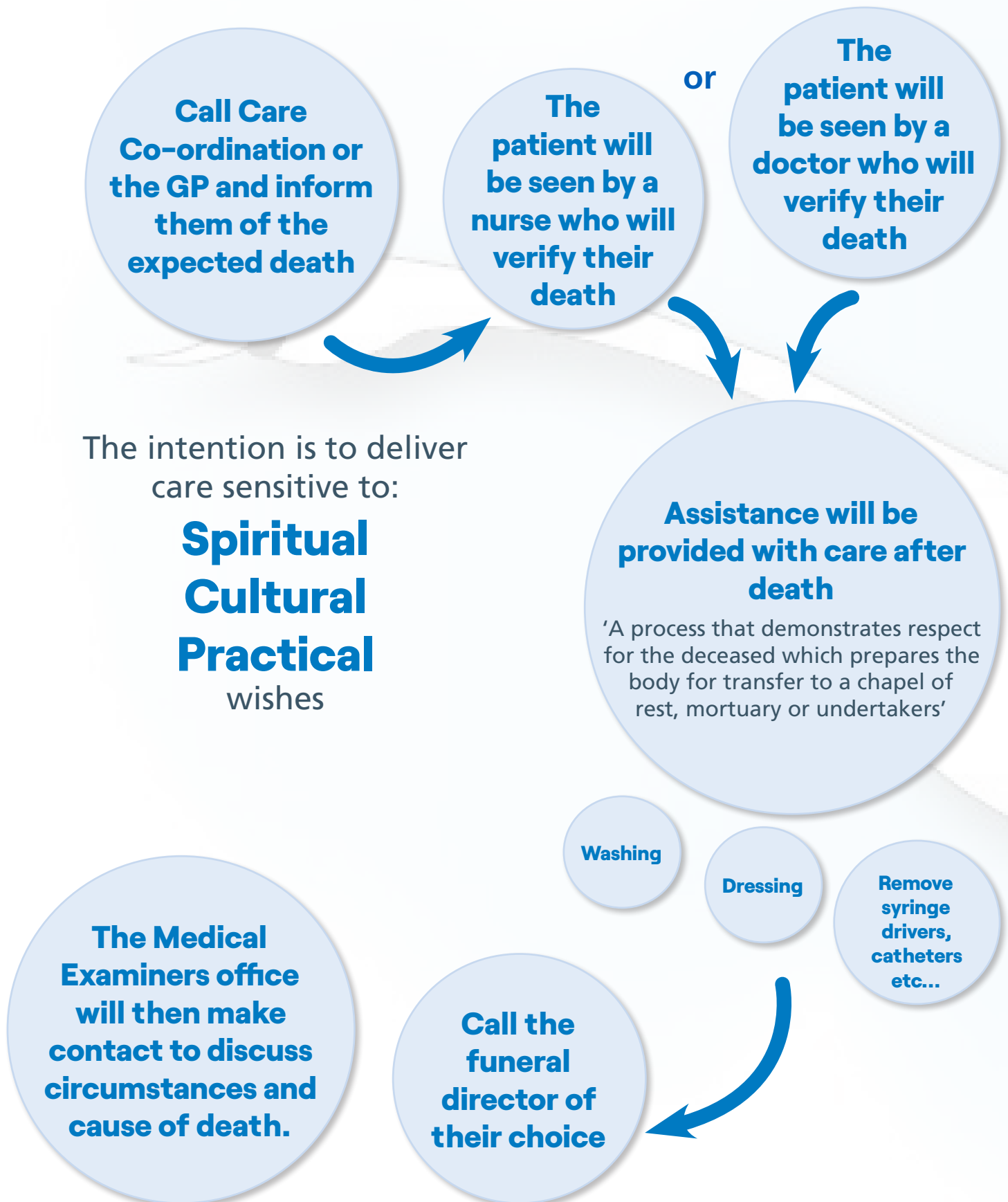
As part of our SWAN care, we offer memorable keepsakes for our patients and family members, including a notebook, a candle, a pen, a ring box and two knitted hearts.

We also offer or provide photograph images of the patient's hands, sentimental objects or pets...



What happens after death?

When someone dies, there are certain things that have to be done, but this often comes at an incredibly difficult time when people may feel least able to manage. We will continue to provide guidance, care and support.



Can organ and tissue donation be considered?

Every year, hundreds of lives are saved with the help of donated organs such as hearts and kidneys, but you may not realise that donated tissue such as skin, bone and heart valves can also save and dramatically improve the quality of life for many.

We rely on, and are very grateful for, the generosity of our donors and their families. Thanks to them we are able to provide skin, tendons, bone and other tissues to help enhance the lives of thousands of people. Many people can be considered for tissue donation for up to 24 hours after death.

All of the major religions of the UK support the principles of donation and transplantation. However, within each religion there are different schools of thought which means that views may differ. All the major religions accept that donation is an individual choice. The retrieval of tissue usually takes place in a mortuary, occasionally in an operating theatre, and rarely in a funeral home.

Funeral arrangements, the work of the pathologist and HM Coroners are not interrupted or compromised by the donation process.

Further information can be found regarding organ and tissue donation at:
www.organdonation.nhs.uk

Frequently asked questions

What happens if my relative gets better?

Occasionally a person's condition can improve. If a person gets better, the care they need will be reassessed by the doctors and nurses caring for them. The care and treatment will be discussed with you.

What do I tell the children?

Talking to children about a person approaching the end of life can be challenging and exactly what you tell them often depends on their age. Generally, it is best to be as honest as possible with children. This may be distressing but it can help children deal with things a little better after the death. You may wish to consider memory making with children which can be helpful in their grieving process.

Can the person hear and communicate with us even if they seem deeply asleep?

People vary. Some people communicate by squeezing hands until they are too weak to do so. Some may still be able to communicate a little. As their condition deteriorates further, they will be able to communicate less. Sense of hearing is a fairly strong sense, and it can be comforting for them to hear familiar voices from friends and family. It is unlikely that they will always be able to continue to communicate with you as their condition deteriorates.

What is on your mind?

How are you feeling?

This image shows a single sheet of white paper with horizontal blue or grey ruling lines. The lines are evenly spaced and run across the width of the page. There is no handwriting or other markings on the paper.

What is worrying you?

[illegible]

Do you have any questions?

[illegible]

What is on your mind?

How are you feeling?

[illegible]

What is worrying you?

Do you have any questions?

[illegible]

