

YOUR HEALTH

COPING WITH DYING



The doctors and nurses will have explained to you there has been a change in your relative or friend's condition. They believe the person is now dying and is likely to be in the last hours or days of their life. We understand this is a very difficult time for you and it may be hard to remember everything you have been told.

The aim of this leaflet is to help remind you of some of the things you have been told and to answer other questions you may have thought of. We will ask you for your contact details, and what you would like to hear about, because keeping you updated is very important to us.

Our Aims

We will continue to give your loved one care that meets their needs and keeps them as comfortable as possible. We will involve them (and their family and carers if they so wish) in how we plan their care.

To do this we will:

- Keep family or carers informed about the patient's current condition as often as required
- Continue to assess the patient regularly and note these assessments in their care record
- Make sure that symptoms such as pain, nausea, agitation, shortness of breath are managed
- Help them take in food and fluids by mouth for as long as possible

- Deal with physical needs such as bowel care, mouth care, passing urine, pressure area care and personal care whenever required
- Continue to assess and review the effectiveness of their medication

Communication

The plan of care will be reviewed and changed if your loved one's condition deteriorates or improves.

It is very important for everyone involved to be clear about the plan of care so that you understand why decisions are being made. Please tell us what is important to both you and your loved one. You are free to ask questions at any time.

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Medication and treatment

Regular medication that is not helpful at this time may be stopped and new medicines may be prescribed to keep your loved one comfortable. Medicines for symptom control will be given only when needed to help relieve the symptom they are experiencing. If your loved one is no longer able to take medication by mouth, it may be given by injection or by a syringe pump.

It is unlikely we will continue with tests such as blood tests and blood pressure monitoring as they are no longer helpful in ensuring the patient is comfortable.

What is cardiopulmonary resuscitation (CPR)?

When someone's heart and breathing stops, this is called cardiorespiratory arrest. It is sometimes possible to try to restart their heart and breathing with emergency treatment called cardiopulmonary resuscitation or CPR.

A person's heart and breathing stops working as part of the natural process of dying. If someone is already very seriously ill and near the end of their life, there is almost always no benefit in trying to resuscitate them when this happens.

This is particularly true when patients have other things wrong with them that mean they do not have long to live.

In these cases, trying to re-start the heart and breathing can do more harm than good by prolonging their pain or suffering, and can be undignified for someone at the end of their life.

Deciding whether to attempt CPR is a clinical decision made by the most senior doctor in charge of the patient's care. However, we always involve the patient and family or carers in the decision-making process where this is possible.

If it is decided that CPR will not be attempted, what then?

We will continue to give the best possible care. There will be a note in the health records that your loved one is "not for cardiopulmonary resuscitation". This is called a "do-not-attempt-resuscitation" or DNACPR decision. If there are plans to transfer the patient home at the end of life, a document will go with them that makes sure other health professionals who visit them are aware of the DNACPR decision.

What about other treatment?

A DNACPR decision is about CPR only and your relative will receive all the other treatment and care appropriate at this time.

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The Dying Process

This is different for every person, but there are common changes that may take place. Knowing about these may help you to cope during this time.

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Reduced Need for Food & Drink

It's normal for someone who is dying to lose interest in food and drink and have less need to eat and drink. This can be a sign they are not going to get better, but people can lose weight even when their appetite is fairly normal. This can be because the body can no longer use the food to build itself up.

Someone's appetite may get smaller as the body seems to recognise it can no longer cope with food. It can be hard to accept that someone has stopped eating and drinking, even when we know they are dying.

We will help them to eat and drink by mouth for as long as possible. It's normal for people who are dying from advanced cancer and other illnesses to eventually stop drinking and to stop feeling thirsty. As the body weakens it needs less fluid.

It is important to remember it is the illness which is making the body fail, not a lack of fluid. If someone is very weak and is given fluid by mouth it may go down the 'wrong way' (into the lungs) and make them cough and splutter.

It is important to look after the mouth at this time to make sure it remains moist and comfortable. The nurses will explain how this is done and may ask if you would like to help.

Some people like to have their favourite drink frozen or to suck on flavoured ice chips: ask the nursing staff for assistance with this.

If the patient cannot take fluids safely by mouth, we may consider giving them fluids via a drip into a vein or under the skin. This can be a difficult clinical decision, as the risks will often outweigh any benefits at this stage.

If we start to give them fluids by drip this will be closely monitored to make sure there are no side effects.

In the last days or hours of life, giving drips can cause problems by overloading the body with fluid at a time when it cannot handle it efficiently. This can lead to swelling of the arms or legs or worsening breathlessness.

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Changes in breathing

When death is approaching, the breathing pattern may change. Sometimes there are long pauses between breaths or the breathing may become fast and shallow.

Occasionally a “bubbly” noise may develop as a result of a build-up of fluid that the person can no longer cough up but this does not cause distress.

Medication or a change of position may help but will often have only limited success. We try to avoid suction as it can be more distressing. If a person is breathing through their mouth, moistening the lips and tongue and applying lip salve will help.

Withdrawing from the world

A person who is reaching the end of their life may spend more time sleeping and eventually become unconscious. This is part of the natural process and they may remain in this state for a surprisingly long time, in some cases, many days.

Even if the person doesn't appear to know you are there, keep communicating and touching as they may still be aware of your presence which can be a great comfort to them.

Appearance

Skin can change in colour and become clammy or slightly cold. The eyes may stay open and seem to stare which can indicate death is getting near.

The heart struggles to pump properly which can result in swelling of the arms and legs. Urine may become darker in colour and decrease in amount.

The person may also become incontinent and need a catheter or incontinence pads to prevent their skin becoming sore.

Comfort

The staff will aim to keep your loved one comfortable so please feel free to discuss any preferences they may have, such as their position in bed.

Spiritual care

We embrace both religious and non-religious perspectives on life. We support anyone who wishes to explore personal thoughts and feelings that have arisen as a result of past and recent experiences.

Please ask a member of the team if the patient would like to see a chaplain or faith community leader. Your needs are also important, so please tell us of anything that can be done to help and support you at this time.

Organ and tissue donation

St Helena supports both organ and tissue donation and some patients may be suitable as donors. If you have any questions about donation, please ask a member of the team.

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Infection Control

We request that all visitors wash their hands with the alcohol gel situated at the main entrance to the Hospice to prevent the spread of infection.

Staying with your loved one

We can help you if you want to stay at the Hospice, so please talk to the nurse in charge. There is no restriction on visiting and we encourage children and pets to visit. We will try to accommodate the patient and family together in a side room where possible, although if the patient does not want to move then we will check if you can stay with them in a bay.

Care after Death

We believe it is a privilege to care for a patient at the end of their life, and after death.

Total care after death demonstrates our respect for the patient and is focussed on maintaining dignity and privacy. If the patient has any religious or cultural wishes about what happens after death, please let us know.

If you would like to be involved in the final care of the patient, or to dress them in particular items of clothing, please tell the nursing staff.

Once the final care has been completed you can take their belongings if you would like to. If you don't want to be involved in the final care, you can spend some time with your loved one before packing their belongings.

Once you are ready to leave, you will be given a leaflet entitled 'Guidance and Support' which will inform you of what happens next.

www.sthelenahospice.org.uk

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