

What to expect when someone is dying at home

Information for families, friends and carers:

This leaflet is aimed to help you understand what to expect in the final days and weeks of someone's life which may be helpful during this difficult time. We understand it can be difficult to take this information in, so it can be useful to have this to read in your own time or share with those who were not part of the conversations with the healthcare team. The last days of someone's life are precious and often remembered in detail by those who live on.

We welcome you to ask questions to the team caring for your loved one or express any fear or worries you may have. Remember, SinglePoint is available by phone 24/7 to listen to and answer your questions.

Recognising when someone is in the last days of life

Everybody is individual and each person's experience of the last days of life will be different, which can make it difficult to predict what will happen or how quickly changes will occur. Some people will die very quickly with little warning, whilst others will steadily deteriorate over a period of time. Rarely, there will be some people who are believed to be dying who improve and stabilise.

There are some general signs that occur when someone may be approaching the last days of life such as:

- The person will have reduced appetite and poor oral intake. They may struggle to swallow foods, fluids and medications
- The person will become weaker and will spend more time in bed. Even getting to the toilet may become too difficult
- They may become confused and disorientated, or lose interest in their surroundings
- The person will spend more time asleep, only waking for short periods, and eventually will become unconscious. This is part of the dying process, rather than being caused by medications

Care planning for someone approaching the end of their life

People who are thought to be in the last days of life will have an individualised approach to their care. The main priority is for the person to have a peaceful and comfortable death. Your health care team will discuss some important things with you including the wishes of the person who is thought to be dying and the views of the people identified as important to them.

Advance care planning

Your healthcare team will discuss where your loved one would like to have their end of life care, including whether they would like to die at home. They will discuss anticipatory

medications with you, which are injectable medications that are used to help your loved one's symptoms if they are unable to swallow other medications. Sometimes a 'syringe pump' (a small pump that delivers continuous medication over a 24 hour period) is used to help control symptoms e.g pain. Syringe pumps are renewed every 24 hours by a registered nurse. They will also discuss a Do Not Attempt Resuscitation document with you. All of these documents should be kept in your loved one's yellow folder.

The community palliative care team

Your loved one will be supported by the community palliative care team which is made up of their GP, community nurses and St Helena multidisciplinary team.

If your loved one has chosen to die at home, their GP has overall responsibility for their care. It is important for the GP to see the person either face to face or virtually within 28 days prior to their death, as without this, the case may be referred to the coroner.

The community nursing team can support the person with pressure relieving equipment, dress wounds, advice about continence issues and give injectable medications to manage the person's symptoms.

Specialist palliative care is provided by St Helena, which includes SinglePoint, a 24 hour telephone advice service available for families to call with any questions or concerns. You may also be visited by one/some of the hospice in the home multidisciplinary team depending on your loved one's needs.

Food and drink

As the person becomes weaker their need and desire for food and drink gradually decreases. This is a normal process but can be difficult emotionally for families and carers, and hard to accept. Softer and easier to swallow foods such as ice lollies or ice cream

may be better tolerated, but eventually the person will stop eating and drinking altogether.

We do not often give fluids artificially through a 'drip' when people are in the last days of life, as it does not normally help symptoms or prolong life.

We would recommend you purchase a baby's toothbrush and use water (or flavour of the person's preference) to help moisten their mouth to help with dryness and provide comfort. Oral thrush is a common problem towards end of life, your doctor or nurse can organise for a medication to treat/reduce this.

Changes to medications

There are some medications that can help symptoms and will be continued for as long as possible. Other medications may no longer be helpful, or may cause unwanted side effects, in which case they will be stopped. When the dying person becomes too weak to swallow we would only give medications which are most important by a type of injection which goes just underneath the skin. There are either given as one off 'stat' doses to control symptoms or if the medication is required more frequently, they may be put into a syringe pump.

Equipment

As the person becomes less well, their mobility will reduce and eventually be cared for in bed. The community palliative care team can speak to you about having equipment in the home to help with this such as a hospital bed, commode and slide sheets.

Care support

Some families will want to look after their loved one themselves, but if support is needed, it may be helpful to have carers come into your home to provide additional support. This may be provided by Essex social care (which is means tested), NHS

continuing health care, St Helena virtual ward or Farleigh Hospice for those who live in Mid Essex or you may choose to fund this privately. You can speak to the community palliative care team about what care support is right for your loved one.

Religious and spiritual needs

The thought of death can be frightening or bring up certain emotions. If the dying person, or those important to them, have a particular religious or spiritual need, or if you just want someone to talk to, speak to a member of the community palliative care team.

What physical changes might happen when someone is dying?

For most people dying is very peaceful. There may be certain changes that occur when the person is in the last days of life. You may find some of these changes distressing but knowing what to expect may reassure you that these are normal at this stage.

Skin changes

In the last days and hours of life a dying person's hands, feet and skin may feel cold and look pale. The skin may become mottled blue or uneven in colour and is sometimes sensitive to touch. This is caused by poor blood circulation, a normal process when someone is dying. The kidneys become less able to process bodily fluids, so certain parts of the body such as hands and feet become 'puffy' in appearance.

Continence changes

The person may lose control of their bladder and/or bowels. This happens because the muscles in the areas relax, the person may require continence pads or a catheter (a tube that goes into the bladder and drains urine into a bag). Sometimes it can be useful to use a urine bottle, these can be purchased in some shops or online. Often, the person's

urine can look dark in colour as their kidneys start to shut down.

Agitation

It is not unusual for the dying person to become confused or muddled, but sometimes a dying person becomes restless or agitated. This is usually caused by chemical changes in the body, but the healthcare team may also want to rule out other possible causes such as constipation or difficulty passing urine. If a dying person is unable to pass urine, a catheter may be necessary. If no cause is found, they may give some sedative medication to help the person relax. Sometimes quiet reassurance and the presence of people who are important to that person can provide some relief to the person.

Breathing changes

When the person is in the last hours of life, their breathing pattern may change. The breathing may become faster or more shallow. Sometimes, the breathing can sound bubbly due to a build up of saliva/mucus when the person is no longer able to cough or swallow. This can often be helped by changing the person's position or by giving medications, but sometimes this cannot be resolved. For those listening, you may find this distressing, however this does not normally cause any distress to the dying person themselves. You may notice gaps in breathing that get longer as time goes on. In the last few minutes the person's face muscles may relax, including their jaw and their colour may go pale. Breathing will eventually stop but is often difficult to identify the exact moment of death. Be prepared there may be one or two gasps after what appeared to be the last breath.

What can you do to help?

You may wish to be involved in aspects of your loved one's care. For example, you

might want to moisten the person's mouth regularly with a baby's toothbrush or if they would like, massage their hands to help them relax. Comfort can be provided by talking or reading to the person, smell familiar scents or play their music, listen to the radio or television programmes they like. Sometimes families feel that the person would simply want peace and quiet.

Simply sitting with the person who is dying can help keep them calm. Remember that although they may not be able to respond, a dying person will still be able to hear you and know you are there.

If you are worried anytime about any aspects of care, or feel the dying person is distressed in anyway, or if you just want some reassurance, please contact SinglePoint.

Some people may not feel that they are able to be present at this time. There is no expectation or judgement to be made if this is the case. You must look after yourself and do what is right for you.

When your loved one has died.

This is a deeply emotional moment, even when death has been expected for a while. People feel and react in different ways. You might experience shock, sadness, anger, loneliness, or a sense of relief. There is no 'normal' way to react, don't feel pressure from yourself or others to act in a certain way.

When you think the person has died, and when you are ready, the next step is to contact SinglePoint and we will arrange for a doctor or nurse to visit your loved one to undertake verification. There is no rush at this time, and sometimes it can take several hours for the doctor or nurse to visit. You may want to take this time to call other family members,

discuss which undertaker you are going to choose, or just be with your loved one.

You will be asked whether the person will be buried or cremated, as there are additional forms that the doctor must complete if someone is cremated.

Occasionally if the cause of death is not clear, we may need to involve the coroner, which can delay the doctor issuing the death certificate.

From here the undertaker will then help guide you through the funeral planning process.

If you have any questions raised from reading this leaflet, please call SinglePoint on our 24 hour contact number 01206 890 360.

