

What to expect in the last days of life

Care of the dying



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Last days of Life

We understand there are many mixed feelings and emotions when we think about end of life. It is likely to be a difficult time when someone close to you is dying. You may have questions about what to expect in the last days of life, and how someone important to you will be cared for.

This booklet will aim to explain some of the changes that may happen in the last days of life and what help is available to you. You are encouraged to discuss any issues you are not sure about with the palliative care or healthcare team who are supporting you.

The approach that the healthcare team use will be individual to each person, and they will make sure that comfort is maximised. Teams and organisations work together across Somerset with the aim to provide high quality care.

Please speak to your healthcare team about what is available if someone is in hospital or a hospice. You may have open access visiting opportunities; it may be possible for visitors to stay if a private room is available. Visitors are usually informed where to get food or drinks and may be offered refreshments. Some hospitals or hospices may be able to support with parking rates, on-site accommodation, or relative's facilities.

If advance care plans are in place, ensure these are shared with the health and social care teams, so any end of life wishes can be supported where possible. More information about 'Planning Ahead' can be found here or on the Somerset End of Life Care website.



Where can I find help if I am at home?

If you need to find care and support at home there can be help available from your local NHS, social care, and hospice services. An assessment will be carried out and equipment can be issued to help make mobility and activities easier at home. Care can be arranged during the day and/or night; 24-hour care is not available at home unless arranged privately, which can be done through employing a carer, a micro provider or care agency that offers this service. You could consider employing an end of life doula or soul midwife to help you; for more information see the Somerset End of Life Care website. You may also want to consider what help friends, family, and neighbours can offer.

If you need advice you can contact:

- **GP surgeries**

These are normally open during working hours Monday to Friday. At weekends, evenings and night time call 111 or your local out of hours support.

If you need to contact 111, make sure you tell the call handler that you or the person you are calling about is known to be coming to the end of their life. If the person has a treatment escalation plan (TEP) which details whether the person is for resuscitation or not, it is important to let the call handler know.

- **District nursing services**

District nursing teams are essential in coordinating care and support at home. They can also apply for NHS funding for extra care or equipment. Please contact your GP surgery if you feel you need district nursing support.

Please see the back page of this booklet for relevant contact numbers.

Hospice 24-hour advice line

Hospice care focuses on delivering support to individuals with life-limiting illnesses. The hospice advice line is open for information 24 hours a day, 7 days a week to anyone with a palliative diagnosis, who has a Somerset GP.

Referrals for more formal hospice support are usually made via GP or hospital services. If a referral is accepted to the hospice, the person will be supported in their own home by a specialist palliative care nurse. Occasionally someone may need to be admitted to the hospice inpatient ward for complex symptom control or if their needs can no longer be met in their place of residence.



St Margaret's Hospice Care:
01823 333822 or 01935 709480



Dorothy House Hospice Care:
0345 0130 555



Weston Hospice care:
01934 423900

To find out which hospice covers your area please scan here (available on the somersexolcare.uk website).



Marie Curie

Marie Curie offers practical information and emotional support about living with a terminal illness, end of life and bereavement in Somerset. Hospice Care at Home provides overnight end of life care in people's homes, offering reassurance and respite for families and carers. Companions provide companionship, practical and emotional support in acute and community hospitals. For trusted information and community and bereavement support – there's the Marie Curie Information and Support Line: 01884 210351 (Monday – Friday, 8am – 6pm)

What will I expect to happen when someone is dying?

The dying process is different for every person. It may be unpredictable and take days or even weeks, but some changes are often seen, which can help us identify a person is dying.

Changes in communication

As a person is dying, they will spend more time sleeping and less time interested in what is going on around them. Gradually the person may naturally become unconscious. This can be hard to accept for loved ones, even when you know the person is dying. It is our understanding that hearing is one of the last senses to go. If you are with someone who has lost consciousness continue to talk to them and give comfort through your presence and familiar voice.

Reduced need for food and drink

When a person starts to die their body may no longer want or have the same need for food or drink. This is because they do not need as many calories as they did when their body was healthy.

At first, increased weakness may reduce appetite. As someone comes closer to dying, swallowing may become difficult. It is not unusual for people to go long periods without eating anything. You may be worried your loved one is hungry or dehydrated so you can help with offering a drink or small amounts of food. Let the person make food choices as they wish.

Speak to a healthcare professional for advice about specific recommended diets or if you have concerns about nutrition or hydration at the end of life.

The mouth and lips may look dry so can be kept moist by giving regular mouthcare such as a damp flannel or mouth sponges and lip balm.

Restlessness

Some people will experience a period of restlessness or agitation during their final days of life. The gentle touch or a comforting voice of a loved one can help. Medication may be given to reduce any agitation.

Changes in breathing

You may notice changes in the rate or pattern of breathing.

This is a natural part of the dying process. Occasionally breathing patterns can be altered by feelings of anxiety, so having someone to reassure can ease this feeling of breathlessness.

As a person has reduced energy, they may struggle to cough up normal secretions and this sometimes builds up in the chest or at the back of the throat causing a 'rattle' or gurgle noise. This may be distressing for loved ones, but it does not appear to distress the person who is dying. A change of position or medications may be used to help.

In the last hours of life, breathing may become very irregular with rapid, shallow breaths followed by long pauses. Sometimes a person will give several pants as their heart and lungs stop. Others may give a long exhale followed a few seconds later by what seems another intake of breath. This may be repeated for several minutes. This is all part of the natural dying process.

How can someone be made comfortable?

Knowing what provides pleasure to the person who is dying and how to provide this in the last days of life is important.

For example, being taken outside in a bed or chair to sleep in the sunshine, having people who are important visiting, or listening to favourite music, TV, or radio.

It is essential that the care team know what is important to the person who is dying. In hospital, support is available for people of all faiths and beliefs via the spiritual care team. They can provide spiritual, religious, or emotional support.

Hospital spiritual care centres can be used for peace and quiet reflection. Please speak to the ward staff to find out more about what is available. For people who have been referred to a hospice, they will be offered symptom management as well as care for their emotional, psychological, and spiritual needs. Hospices offer spiritual care for people from all faiths and beliefs both at home and in the hospice. Spiritual care for those at home can be provided via telephone call or by home visits. There is also a supportive care team to help with emotional and psychological needs pre and post bereavement.

Medication

Maintaining comfort and avoiding unnecessary treatment is a priority. Any medication given at the end of life supports an individual's symptoms. Medication given does not hasten death.

Medication may be used to control symptoms. Often medications that are no longer helping are stopped. Medications are used 'as required' in the right quantity to help any symptoms such as sickness, pain, shortness of breath, secretions in the throat and restlessness.



The dying person may be prescribed 'just in case' medication to help treat these symptoms. A nurse, doctor or paramedic emergency practitioner can administer these medicines and on occasion a family member may also be taught to administer; your healthcare team will discuss this training process with you if it is appropriate.

These drugs may not be required quickly, but can be difficult to get hold of at short notice or out of hours, hence why they are ordered in advance. Please keep them in a safe place out of the reach of children. When it is not possible to give medications by mouth these may be given by injection or by a syringe pump. The pump will deliver the medicine continuously and slowly over 24 hours through a cannula (a small plastic tube) that is placed under the skin.

You will have support from a nurse who will check the pump and replenish its contents. They will also ensure regular reviews of the dying person. You will be given more information if this is needed.

What will I expect to see when death happens?

Although dying is a natural process, those caring for the dying person may experience many different feelings as the person dies. It can feel very overwhelming.

As the person is dying their skin tone may change colour, become pale, go blue, blotchy and feel different. The person may become very cold and/ or hot as the body loses its ability to control its temperature. Facial expressions usually relax. There may be a loss of bodily fluids, such as urine or faeces, as the body's muscles relax. Breathing will stop. The heart will stop beating and the person cannot be woken. Eyes may remain partially open, and their mouth may fall open slightly as the jaw relaxes. Their body will eventually stiffen.

If you are present when the person dies, there is no rush to do anything. Take the time you need and if you feel able to, moving the person onto their back with only one pillow under their head would be helpful for the ongoing care of their body.

What happens after someone dies?

When the person has died, you will need to contact their healthcare team, most likely the district nurse or hospice specialist. After the death is verified, you can contact a funeral director.

What is the Somerset Medical Examiner Service?

The Somerset Medical Examiners Service is part of a national system for reviewing deaths that occur in hospital and in our community. The Medical Examiner is a senior doctor, who is independent and not involved in your loved one's care. The duty Medical Examiner will review the person's records alongside the doctor over-seeing their care to establish a cause of death prior to the issuing of the Medical Certificate of Cause of Death (MCCD).

Following this, the duty Medical Examiner or one of their trained Medical Examiner Officers, will contact you. This step will ensure the accuracy of the cause of death and highlight any cause for concern regarding care which has been provided.

This will give you the opportunity to discuss the care and treatment the person has received and share any feedback you may have. The Medical Examiner Officers are also able to answer any questions you may have on practical steps you need to follow in the days to come. In some cases, the Medical Examiner or the responsible doctor may need to speak to the Coroner before the MCCD can be issued and you will be informed if this is the case, but this is not a usual occurrence.

Once the MCCD has been issued you should make an appointment with the registrars office to register the person's death. From there you can begin to plan the funeral.

What do I do next?

It can be a very sad and distressing time when someone you have loved and/or cared for dies. It is natural and often helpful to express your feelings, whether they are of sadness or relief. There may not be anything that anyone can say to ease your feelings of distress at this time. You may wish to spend a little time saying your goodbyes.

The Somerset End of Life Care and Bereavement Support website provides information about what to do when someone dies, preserving the persons legacy and funeral planning information.

somerset.eolcare.uk

You may find it useful to look at this and prepare ahead if you have been told that someone close to you has only months, weeks or days left to live.

Who can support me when I am grieving?

There are bereavement support services available in Somerset, which you can find on the Somerset End of Life Care and Bereavement Support website. It also contains information on how to support children at this difficult time.

The healthcare team who has been supporting you and your loved one will give you more information about what is available. If the person died in hospital, the ward staff will give you written information about what to do next in the form of a bereavement pack.

We hope the information in this booklet is helpful in the coming days and weeks



Important Telephone Contacts

District Nurse Service (diverts to night hub overnight)

Bridgwater and North Sedgemoor
0300 1245 601

Taunton and West Somerset
0300 1245 606

South Somerset
0300 1245 600

Mendip
0300 1245 602



Scan here
for more
information

Night District Nursing Hub

0300 1245 609

St Margaret's Hospice Care Adviceline

01823333822 or 01935709480

Dorothy House Hospice Care Adviceline

0345 0130 555

Weston Hospice Care Adviceline

01934 423900

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