



# End-of-Life Matters

Information about death, dying and bereavement.

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# Welcome

The purpose of this booklet is to provide information about what your loved one might experience during the last hours and days of life, and what to do after a loved one dies.

There is also information about the grieving process and support for after death. Please talk with your healthcare provider about further information and any questions you may have.

## Last days and hours

*The dying process is unique to each person, however there are a few common changes that happen to almost everyone in the last hours or days of life.*

*Some of these changes may appear distressing, but they often have less impact on your loved one, and are normal parts of the process of dying.*

### Eating and drinking

Your loved one can be supported to eat and drink if they want to and are able to do so safely. However, at the end of life, your loved one will typically have less appetite as their body's need for food and drink reduces.

Having a dry mouth is common but this doesn't mean they're dehydrated. You can continue to care for them by moistening their mouth with a soft toothbrush or clean flannel and using lip balm.

Family and friends sometimes ask about having fluids through a drip if a loved one is unable to swallow. If the person is thought to be dying soon, fluids are unlikely to help them live longer or make them feel better, and it can cause other problems. Please do not hesitate to ask the healthcare team to talk you through this option.

Most medicines taken by mouth aren't needed when your loved one can no longer swallow. Some medicines like painkillers or treatments for specific health conditions can be given by single injections or through a small pump, called a syringe driver, which delivers medication under the skin. Your healthcare team will support with these conversations and decisions.

### Increased need for sleep

Your loved one is likely to spend more time sleeping and may be drowsy even when awake. They may drift in and out of consciousness, which is a natural change. It doesn't mean they can't hear you, and we would encourage you to talk to your loved ones as we believe they're likely to be comforted by familiar voices and sounds.

## Restlessness

In the last days and hours of life people can sometimes become restless, they may also appear confused and may hallucinate.

Talk to your healthcare team in person or by phone if your loved one is distressed and not settling. The team can review if there is a treatable reason for these problems. Simple things you can do often make a difference. You could:

- Sit with your loved one to help calm them
- Remind them who you are and do this often if you need to
- Keep their surroundings calm with minimal changes in noise levels
- Let them know the time of day
- Try not to correct them if they say something wrong

Your loved one may need medicines prescribed by the doctor or nurse to ease symptoms of restlessness, anxiety or confusion, helping them to be more peaceful. These medications may either be taken by mouth or injectable versions that a trained person can administer either as a single injection or via a syringe driver.

## Changes to skin

As a person approaches death, they may experience changes in skin colour and temperature. You may wish to alter bedding weight for comfort, but it's unlikely that temperature changes will distress your loved one.

## Changes in breathing

During the dying process there may be noticeable changes in breathing patterns, these changes occur naturally, often without distressing your loved one. Breathing may become more rapid and shallow or may slow down, and you may notice both at different times.

Towards the end of life, your loved one may only breathe periodically, with an intake of breath followed by no breath for several seconds. These pauses in breathing often get longer the closer a person is to dying until breathing stops completely.

At times there may be audible breath sounds which can be loud, gurgling, or wet. This is due to a pooling of saliva which your loved one is unable to clear by coughing, and they're unlikely to be aware of it. Changes in position may help to relieve this symptom and if required your healthcare team can discuss medications that may help.



# Practical considerations

*There are a number of things to consider when a loved one is dying. We have listed a number of key things to discuss with your loved ones.*

## Identify a funeral director

When a person has been recognised as dying, we ask their next of kin to identify a funeral director and inform the staff member caring for them. Knowledge of this in advance enables us to arrange the transition of care to the chosen funeral director smoothly when the person has died.

This is particularly important if your loved one is being cared for on the inpatient unit at the Hospice, as we do not have the facilities required on site that allow us to keep patients for more than a few hours after they have died.

## Organ and tissue donation

The gift of organ donation, such as kidney, heart, lung and liver, can only be made if a person dies in an intensive care unit. However, the gift of tissue donation, such as corneas, can potentially be made when someone dies in the Hospice, at home or in a care home. Retrieval of the tissue would need to occur within 24 hours of death, so if that is a wish, please alert the Hospice staff as soon as possible.

## Useful resources

- Dr Kathryn Mannix, Dying for Beginners: what happens when someone is dying:  
<https://youtu.be/ayMhA1pRLeY>
- Talking to others, including children, about dying:  
<https://www.stmichaels Hospice.org.uk/our-care/bereavement-services/>
- Tissue Donation:  
<https://www.nhs.uk/what-we-do/transplantation-services/tissue-and-eye-services/tissue-donation/become-a-donor/tissue-donation-after-death/>

# What to do when someone dies

*When a person dies it may be overwhelming, please be reassured that we'll guide you through the next steps.*

## Verification of death

When a death occurs a healthcare professional will need to confirm the person has died, this process is known as a verification of death.

## Who to call

**In the Hospice:** Use the call bell or come to find a member of the nursing team.

**At home:** Call the hub phone at **St. Michaels Hospice: 01256 848863**. We'll talk you through the next steps. If a member of the Hospice team is unable to visit, we'll either ask you to contact the GP/111 service or the community nursing service.

## Contacting a funeral director

Once the verification of death has occurred you'll need to contact your funeral director to arrange for your loved one to be transferred into their care. Funeral directors are available seven days a week.

## The death certificate

After a person dies a Medical Certificate of Cause of Death (MCCD) will be completed. This will be done by a doctor following consultation with the Medical Examiner's Office. The completed certificate will be sent electronically to the register office.

All deaths in England and Wales not investigated by a coroner must be independently reviewed by a Medical Examiner. Medical Examiners are senior doctors who are trained in the legal and clinical elements of the death certification processes. Their role is to provide independent scrutiny of the causes of death. It's normal practice, as part of this process, for the medical examiner's office to contact the nominated next of kin.

There are certain circumstances, which are defined by law, that require a person's death to be referred to the coroner. The coroner is a qualified doctor or lawyer, who's responsible for inquiring into the circumstances surrounding a death. If you've been told that the death has been referred to the coroner, a death certificate will not be issued until the coroner's enquiries are complete. The coroner's officer will be in touch with you directly and will guide you through all the process.

For more information about the Hampshire Coroner's Service please visit:

[www.hants.gov.uk/birthsdeathsandceremonies/coroners](http://www.hants.gov.uk/birthsdeathsandceremonies/coroners)

This website will provide information regarding who can register a death, what you'll need to take with you for the appointment, and what documents you'll receive following the appointment.

## Telling other institutions about the death

The Tell Us Once service lets you inform several different government departments of a death at the same time. This helps to avoid over-payment of benefits, pensions, and reduces the number of phone calls you need to make.

Please visit the Tell Us Once service here:

[www.gov.uk/after-a-death/organisations-you-need-to-contact-and-tell-us-once](http://www.gov.uk/after-a-death/organisations-you-need-to-contact-and-tell-us-once)

## Returning medical equipment and unused medicines

### Yellow label equipment

- Contact Hampshire equipment services by calling **01256 476800** to arrange for collection of equipment or visit:  
[www.hants.gov.uk/socialcareandhealth/adultsocialcare/equipment-adaptations](http://www.hants.gov.uk/socialcareandhealth/adultsocialcare/equipment-adaptations)

### St. Michaels Hospice equipment

- The St. Michael's Hospice Therapy team will contact you to arrange for equipment collection.

### Syringe drivers

- The St. Michaels Hospice at Home team or District Nursing service will contact you to arrange for equipment return.

### Sharps box

- The yellow bin will either be collected along with the syringe driver equipment, or you can arrange for it to be collected by the local council.

### Medicines

- Any medication can be returned to your local pharmacy. Unfortunately, St. Michael's Hospice are unable to receive these.

### Continence products

- Please discuss surplus continence products with your healthcare team. Unfortunately, St. Michael's Hospice are unable to receive these.
- Sealed packages of incontinence pads can be taken to any of our charity shops or our donation centre (RG24 8QL) to be sold.

## Coping with Grief

*Each person's grief is unique to them, but there are certain emotions that people can experience when they are grieving.*

Often the initial feelings are intense and can involve a longing to be reunited with your loved one. As well as significant emotional pain, you might have physical reactions, such as heart palpitations, tiredness, or dizziness.

It can seem like things are not "real", and it might be difficult to think about anything apart from the person who has died. It's not unusual to have trouble focusing or becoming forgetful.

The period after a funeral can be difficult, as it may feel like everyone else's lives have gone back to normal, and you're wondering how you'll move on.

In time, many people begin to accept what has happened. You might feel like you can get back to taking part in activities again and enjoying them. While you haven't forgotten your loved one, their death has become a more "accepted" part of your memory. Thinking about them isn't as distracting as it was in the beginning, and feelings of sadness and grief are not the only emotions you feel.

However, the length of time it takes to process these emotions is unique to everyone – it can take weeks, months, or years. There may be periods when intense grief re-emerges. This is common and can happen around significant events like birthdays, anniversaries, or at a stressful time.

## How to cope with grief

There are no 'one size fits all' solutions for how to cope with grief, but these coping strategies might help you manage your feelings and provide some comfort:

### **Spend time with people**

Tell your family and friends about your feelings and remind them that you need company. If your energy and motivation are low, suggest meeting at your home.

### **Give yourself time**

It's best not to make any significant decisions for a while, especially if they involve spending large amounts of money or making big life changes. Decisions that you make during this time can be influenced by your grief, and you might regret making them later.

### **Everything you're feeling is normal**

Sadness, sleeplessness, a sense of unreality, relief and even guilt are among the feelings you might experience when you're grieving. Don't be afraid of how you feel, and if any of your feelings or thoughts are troubling you there is support available to help you (please see Bereavement Support on page 6).

### **Don't be afraid to cry**

Crying is the body's way of reducing stress and is a very natural reaction. It doesn't matter whether it's days, weeks, months or years after someone has died, if you feel like crying allow it to happen.

### **You won't always feel like this**

Grief is an extremely difficult process, but it gets easier with time. It's common to have good and bad days, but in time the good days outweigh the bad. By staying active, and focusing on each day as it comes, things will get easier.

# Bereavement Support

*Coping with the death of a loved one is very difficult. It is important to be aware of the help and support that is available to you. Please see the options below:*

## **Speak with your GP**

### **St. Michael's Hospice Bereavement Services**

Our bereavement services are available to those that are coping with grief. We offer a range of services ranging from counselling, complementary therapy, spiritual support and various bereavement support groups. All the details of our current services will be included in our introductory letter sent to the next of kin six weeks post bereavement.

### **St. Michael's Hospice Family Support team**

Email: [family.support@stmichaelshospice.org.uk](mailto:family.support@stmichaelshospice.org.uk)

Phone: 01256 844744

Website: [www.stmichaelshospice.org.uk/our-care/bereavement-services](http://www.stmichaelshospice.org.uk/our-care/bereavement-services)



### **At a Loss**

A charity established in 2016, to help bereaved people find support and wellbeing:  
[www.ataloss.org](http://www.ataloss.org)

### **Good Grief Trust**

A national charity that has a comprehensive directory of bereavement support across the UK, listing specific services for people who have lost a child, partner, sibling, parent or friend: [www.thegoodgrieftrust.org](http://www.thegoodgrieftrust.org)

### **Samaritans**

Available 24 hours a day, 365 days a year: [www.samaritans.org](http://www.samaritans.org)

### **Cruse Bereavement Care**

A national charity offering face-to-face, telephone, email and website support:  
[www.cruse.org.uk](http://www.cruse.org.uk)

### **Widowed and Young (WAY)**

A UK charity that offers a peer-to-peer support network for anyone who's lost a partner before their 51st birthday – married or not, with or without children, inclusive of sexual orientation, gender, race and religion: [www.widowedandyoung.org.uk](http://www.widowedandyoung.org.uk)

### **Hope Again**

This is a cruse bereavement care website specifically for children and young adults:  
[www.hopeagain.org.uk](http://www.hopeagain.org.uk)

### **Simon Says**

A Hampshire based charity supporting children and young people up to the age of 18 years old who have a significant person in their life who has died or is dying:  
[www.simonsays.org.uk](http://www.simonsays.org.uk)

### **Winston's Wish**

Providing free digital bereavement information and support for children and young people across the UK who are grieving the death of someone important to them:  
[www.winstonswish.org](http://www.winstonswish.org)

## **Ways to remember**

*We understand that many friends and families of loved ones cared for by us feel inspired to give something back in their memory - helping us to continue providing quality care for others in North Hampshire.*

*There are many meaningful ways to honour your loved one while making a real difference to those with a life-limiting illness, facing the end of life or experiencing bereavement.*

*As a registered charity, we rely on donations and fundraising to help fund our services. Your generosity will help us provide specialist care and support for people in North Hampshire now and in the future.*

### **Make a one-off donation**

You can make a one-off donation online, over the phone, using our donation units located in the Hospice Reception and Family Room, or by sending a cheque to us, payable to St. Michael's Hospice (North Hampshire).

Did you know that Gift Aid provides an ideal opportunity to increase the value of your donation at no additional cost to you? If you are a UK taxpayer, Gift Aid means we can reclaim the tax you have paid from HMRC, helping your donation go further.

### **Donations in lieu of flowers**

If you prefer, you can ask friends and family to consider making a donation to St. Michael's Hospice instead of sending flowers. This can be arranged through the funeral directors.

### **Funeral and celebration of life collections**

You may want to collect on behalf of St. Michael's Hospice at your loved one's funeral or celebration of life service. As well as providing a collection box, we can also offer donation envelopes for you to give to friends and family. These envelopes are discreet and enable those that choose to give to also 'Gift Aid' their donation at no extra cost.

### **Much loved tribute pages**

Setting up an online tribute page is a wonderful way to remember a loved one. You can share photographs, stories, and memories of them with family and friends while raising vital funds for the Hospice. It's easy to set up; just visit our website and follow the simple steps. Donating in someone's memory is a fitting and beautiful tribute, and your page can become a permanent memorial to your loved one.

### **Memory tree**

Create a unique dedication by engraving your loved one's name on a leaf of our Memory Tree. This beautiful installation, made up of gold, silver and bronze leaves, is located in a calming and light area within the Hospice building. We also have a limited number of sunflowers at the base of the tree, with space for a more detailed dedication. You are welcome to visit the tree and take a quiet moment to reflect. Every donation will help us deliver the best care for our community.

### **Annual remembrance events**

We organise two remembrance events every year: Light up a Life in Winter and Summer Memories in the Summer. These events unite the community in remembrance and celebration of those no longer with us.

### **Gifts in Wills (Legacy Donations)**

No matter the size of your gift, please know that it will play a crucial role in our work, ensuring that everyone can access free end-of-life care when it's needed most.

If you choose to support St. Michael's Hospice in your Will, the following details can assist your solicitor:

St. Michael's Hospice (North Hampshire)

Basil de Ferranti House, Aldermaston Road, Basingstoke, RG24 9NB

Registered Charity Number 1002856

If you already have a Will in place but wish St. Michael's Hospice to benefit in some way, this can easily be added with a codicil – this is a way of making a change or addition to your existing Will without having to redraft the Will completely.

For more details about any of the Way to remember a loved one, please contact the Supporter Care team:

Email: [supportercare@stmichaelshospice.org.uk](mailto:supportercare@stmichaelshospice.org.uk)

Phone: 01256 848848





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