

Our patient advice and liaison service (PALS) can help patients, families and carers with questions, comments or concerns about NHS services. If you need advice about our services, facilities or staff, or would like to make a comment, please contact PALS at:

## Service Experience Team

Sussex Community NHS Trust  
FREEPOST (BR117)

Elm Grove, Brighton BN2 3EW

Telephone: 01273 242292

Email: [sc-tr.serviceexperience@nhs.net](mailto:sc-tr.serviceexperience@nhs.net)

Website: [www.sussexcommunity.nhs.uk/pals](http://www.sussexcommunity.nhs.uk/pals)

## Other formats

Please ask any member of the team caring for you if you need this information in large print, Braille, easy read, audio tape or email or if you need help to understand this information in a language that is not English.

This booklet is endorsed by the Palliative Care Partnership (PCP) a joint partnership with Martlets and Sussex Community NHS Trust. We would like to thank everyone who was involved especially carers and those recently bereaved whose contribution played a crucial part in shaping this booklet.

If you have any comments you would like to make about this booklet, please contact the PCP at:

The Martlets Hospice, Wayfield Avenue, Hove BN3 7LW

Tel: 01273 964164

[www.sussexcommunity.nhs.uk](http://www.sussexcommunity.nhs.uk) [www.themartlets.org.uk](http://www.themartlets.org.uk)



## Preparing to Say Goodbye

What to expect when someone is dying  
Information for families and carers

### The Palliative Care Partnership

Sussex Community   
NHS Trust

  
Martlets  
Care, compassion and support  


# Introduction

The death of someone we know is one of the most stressful events that we will ever experience; particularly if the person dying is someone we love.

This booklet has been written to help you make sense of what may happen as someone nears the end of their life. It may help to read it with another family member or friend – or if the time is not right for you at the moment, keep it for future reference.

The booklet aims to describe some of the physical and emotional changes that you may notice when someone is close to death, so that you can be better prepared and therefore better able to cope.

In compiling this booklet we are grateful to the many people who have shared with us their experiences of caring for close family members or friends who have died at home. What they said has helped us write this booklet from the carer's perspective. Each of their experiences was unique; however, there were common themes that may be of benefit to others who find themselves in a similar situation.

This can be an anxious time for everyone involved and it is important that you have help with any thoughts and feelings which concern you.

Your district nurse, general practitioner or specialist nurse are there to support you and will be ready to talk about any concerns you may have.

When someone is dying they may become very weak and tired and sleep for long periods of time. They may become less interested in what is going on around them.

Everything becomes more of an effort and they may become too tired to hold a conversation. Concentration and memory require a lot of mental energy. You may find yourself needing to repeat news or information, or notice that their thinking has become confused or muddled.

There may be physical changes:

- **Skin** – Feet and hands may feel cool to the touch and the colour of their skin may change. This is due to changes in blood circulation and you may first notice this happening around lips and finger nails as they take on a bluish tinge or appear bruised.
- **Breathing** – You may notice a change in breathing patterns. Often people will breathe shallowly and rapidly for a while, followed by a long pause where they seem to stop breathing. This can last for up to a minute or so, then the process starts again. Their breath may also sound noisy as there is no longer energy to cough up the natural secretions of saliva and mucous which lie at the back of the throat. This is sometimes called the 'death rattle' and may sound frightening to you, but it is unlikely to distress the person who is dying. It does not mean they are in pain, neither does it mean they are 'struggling for breath'. Often most noise is heard when they are breathing out. Sometimes changing their position may help and medication can be given.

# Physical changes

- **Eating and drinking** – It can be very hard to accept that someone no longer needs to eat or drink, since it reinforces the realisation that they are not going to get better. However, as death approaches, it is quite likely that they may be less interested in food and drink, and will probably stop eating completely, since their body no longer needs nourishment. If they are still able to swallow and want to eat, it may help to offer small tastes or sips of their favourite foods and drinks. Very small ice chips, or an ice lolly to suck can help to keep their mouth moist. Try not to worry or insist if they don't want to do this, as at this stage food and drink are not necessary.

- **Mouth care** – You may notice that their mouth becomes very dry and swallowing is often difficult or impossible. Moistening the mouth frequently can help to keep it comfortable. You can use either sponge sticks (supplied by your district nurse) moistened with fresh water, which you can place gently in and around the mouth or, if you have one, use a very soft baby's toothbrush to clean teeth, gums, and tongue. Putting a little Vaseline or lip salve on the lips can help to prevent them cracking and keep them comfortable.

- **Bowels and bladder** – You may notice that urine is not passed very often and when it is the colour is much darker than usual. Also they may become unable to control their bowels and bladder. Your district nurse will supply pads and advise you on how to maintain comfort and dignity. If they haven't passed urine for several hours and this seems to be making them restless and uncomfortable, the district nurse may put a tube into the bladder (called a catheter) to enable the urine to pass and make them more comfortable.

- **Restlessness** – You may notice that they become more restless. They may make repetitive movements of the hands, for example, plucking or pulling at the bed covers or moving their body. Try not to feel as if you have to stop these movements – often talking calmly and quietly, stroking them gently or playing soft music can be soothing and relaxing. The doctor or district nurse can help too by adjusting their medication, so that they can become more calm and relaxed.

- **General care and comfort** – Perhaps the most important aspect of any care at this time is to keep the dying person comfortable. Sometimes this means letting go of old routines, and often carers say that they do not feel they can do much. Trust your intuition and your knowledge of the person you are caring for; if you are uncertain about anything just ask your district nurse. If you want to help the nurses, tell them, and don't feel you have to leave the room when they visit.

# Emotional and spiritual changes

## You may notice:

- **Withdrawal** – People may seem more confused or disorientated, particularly if they are sleeping for long periods. You may need to limit the number of visitors, or ask them to stay for a shorter time. You may wish to talk to the person you are caring for about who they would like to see and be with over this precious time. Eventually they may become too exhausted to take in what is going on around them. As hearing is often the last sense to be lost, even when someone appears deeply asleep, continue to talk to them naturally. Never assume they can't hear, and remember it can be comforting to hear familiar sounds and voices. Talk as you would if they were awake and say all the things you want to say.
- **Visions** – Some people close to death appear to be having conversations with relatives or friends who have already died. Don't be alarmed by this as it is very common. It helps to accept what they say without contradiction.
- **Saying goodbye** – It is important you feel able to say everything you want to say, and let the person know they are loved and will be remembered. You may want to get into bed and lie with them and hold them close. Some people want to recount stories and memories and remember shared experiences; others need to say precious words such as "I love you" or "thank you" or "sorry". Tears are normal and a natural part of saying goodbye and letting go. Allowing someone close to you to 'let go' when they need to is one of the greatest gifts you may ever give them.

- **Personal rituals** – Some people wish to create an atmosphere in the room that reflects the life and personality of the person who is dying. Lighting candles, playing favourite music, reading poetry or prayers can all be ways of doing this, although you may have other rituals of your own. These are an important part of the choices and freedom you have in helping them to stay and die in the comfort of their home. You also may wish to think about any special clothes or significant possessions they might want with them now and also what they may want to be taken with them after their death. Some people have very clear wishes about this.
- **Religious or spiritual needs** – If the person who is dying has a faith and wishes to have certain practices observed during the final days of life and after death, please tell your district nurse and GP, so that everyone is aware of their wishes and can support you in carrying these out. Your own parish priest, minister or faith leader may be another source of support and comfort.

# The moment of death

As the dying person finally lets go, their breathing will stop completely, and their heart will stop beating. Their skin colour will change very quickly and drain from their face and their eyes will lose their light and remain in a soft stare if they are open. Their jaw will relax, their lips part and their mouth may fall open. It is also quite common for people to open their bladder and bowels as they die.

Sometimes people die at the very moment you have left the room after sitting with them for some time. This can leave you with feelings of guilt and sadness. If this happens, try to remember that all the care you have given them before they died has helped them die knowing you loved and cared for them.

Even though you have been expecting this moment and have prepared yourself as much as you can, it can still come as a shock. You may feel a variety of emotions; many people experience a sense of calm and deep peace. It is not an emergency and you do not need to do anything straight away. There is no need to call for an ambulance. If you can, it is helpful to write down and remember the time of death. You may want to spend some quiet time sitting, talking, holding hands, or whatever feels right to you. Don't feel rushed. It can be a comfort to see someone at peace, especially if the preceding days have been difficult. If you have a religious faith, prayers or meditation may be natural for you now.

# Following a death at home

When you feel ready and have had the time you need to be with the person who has died, please contact your doctor and the district nurse. Your district nurse will then visit to confirm that the person has died and to remove any syringe drivers or catheters. If there are any religious practices you wish to observe in caring for the body, tell the nurses. You may want to help the nurses with any final care that is needed.

Your doctor will tell you whether a visit is necessary in order to be able to write the death certificate. You will then be able to contact the funeral director you have decided to use. Some people want to do this as soon as possible as they wish the body to be taken out of the house straight away, others prefer to take their time. All funeral directors offer a 24-hour service, but if death has occurred at night you may choose to wait until the morning. Funeral directors will be able to answer any questions you may have and advise and support you through the immediate practicalities.

## Finally

We recognise that your experience of caring for a person who is dying will be unique. This booklet is only meant as a guide to help you and your family through what can be a difficult and challenging time – physically, emotionally and spiritually. At times you may feel overwhelmed or daunted by what you are facing – this is only natural and understandable and we urge you to be gentle on yourself and remember that you too need care and support.

# Useful organisations

If there is anything in this booklet you do not understand or which has upset or concerned you, please talk it over with your district nurse, doctor, or specialist nurse. We have also included a number of other organisations which offer support and advice.

## Useful telephone numbers and addresses:

### Age UK Brighton & Hove

29-31 Prestonville Road, Brighton BN1 3TJ

**Local office Tel:** 01273 720603

**Email:** info@ageuk-bh.org.uk

[www.ageuk.org.uk/brightonandhove](http://www.ageuk.org.uk/brightonandhove)

### Age UK

Tavis House, 1-6 Tavistock Square, London WC1H 9NA

**Tel:** 0800 169 6565

[www.ageuk.org.uk](http://www.ageuk.org.uk)

Age UK offers support to anyone over 50 in the UK. They provide day care and an information service. They campaign on issues like age discrimination and pensions, and work to influence public opinion and government policy about older people.

### Brighton & Hove Citizens Advice Bureau (CAB)

1 Tisbury Road, Hove BN3 4AH

**Advice line:** 01273 223951

[www.citizensadvice.org.uk/brightonhovecab.htm](http://www.citizensadvice.org.uk/brightonhovecab.htm)

Call advice line for times of drop in sessions. They provide a general advice service to help clients with any type of legal problem and also a specialist advice service for specific complex legal enquiries. They can offer advice on form filling, if you are housebound.

### Brighton & Hove Register Office

The Register Office, Brighton Town Hall, Bartholomew's, Brighton BN1 1JA

**Tel:** 01273 292016

[www.brighton-hove.gov.uk](http://www.brighton-hove.gov.uk)

**Open:** Mon - Fri 9.30am - 4.30pm (Wed 10am - 5pm)

To register a death. A death should be registered within five days. If you would prefer to make an appointment or would like further information call the number above.

### Carers Centre for Brighton & Hove

18 Bedford Place, Brighton BN1 2PT

**Tel:** 01273 746222

**Email:** info@thecarerscentre.org

[www.thecarerscentre.org](http://www.thecarerscentre.org)

The Young Carers Project at the centre provides support to carers between 5 - 18 years. Mon - Fri 9am - 4pm.

They provide emotional support, listening and understanding to enable carers to identify their problems and help improve their situation. Also practical bereavement support, advocacy and information, and they campaign to raise awareness of carers' issues.

### Compassionate Friends

14 New King Street, Deptford, London SE8 3HS

**Helpline:** 0845 123 2304

10am - 4pm and 9pm - 10pm, 7 days a week

**Tel:** 0845 120 3785

**Email:** info@tcf.org.uk

[www.tcf.org.uk](http://www.tcf.org.uk)

A nationwide organisation of bereaved parents offering friendship and understanding to bereaved parents after the

death of a son or daughter, from any cause. Personal, group support and support for bereaved siblings and grandparents.

### **CRUSE Bereavement Care**

Cruse House, PO Box 800, Richmond, Surrey TW9 1RG

**Tel:** 0208 939 9530

**Bereavement support:** 0844 477 9400

[www.cruse.org.uk](http://www.cruse.org.uk)

**Brighton branch:** 01273 234007

Office hours are 9am - 12pm Mon, Tues, Thurs and Fri.

**Email:** [brighton@cruseeastsussex.org.uk](mailto:brighton@cruseeastsussex.org.uk)

[www.cruseeastsussex.org.uk](http://www.cruseeastsussex.org.uk)

Cruse offer bereavement support by providing counselling, advice, information on practical problems and social contact. They provide a range of leaflets, books and a newsletter for members.

### **Lesbian and Gay Bereavement Project**

London Friend 86 Caledonian Road, London N1 9DN

**Tel:** 0207 833 1675 (general enquiries) 9am - 5pm

**Helpline Tel:** 0207 403 5969 Tues 7.30pm - 9.30pm

There is no website address at present.

This is a nationwide service offering counselling, advice and information.

### **National Association of Funeral Directors**

618 Warwick Road, Solihull, West Midlands B91 1AA

**Tel:** 0845 230 1343

[www.nafd.org.uk](http://www.nafd.org.uk)

They can provide you with a recommended list of funeral directors, costs etc.

### **The Natural Death Centre**

In The Hill House, Watley Lane, Twyford, Winchester  
SO21 1QX

**Tel:** 01962 712690

[www.naturaldeath.org.uk](http://www.naturaldeath.org.uk)

A charitable project which runs discussion groups, workshops and counselling. They provide details on inexpensive 'green' family-organised funerals, in woodland burial grounds.

### **The Samaritans**

Dubarry House, Newtown Road (Nr Hove Park Villas), Hove  
BN3 6AE

**Tel:** 01273 772277

**National number:** 08457 90 90 90

**Email:** [jo@samaritans.org](mailto:jo@samaritans.org)

[www.samaritans.org](http://www.samaritans.org)

The Samaritans is a telephone helpline, which is run by volunteers 24 hours a day, 365 days a year. They offer confidential emotional support. Most local branches have rooms available for person-to-person contact.

### **Bereavement Support for Children:**

#### **Brighton & Hove Bereavement Support**

The Chapel Royal, 164 North Street, Brighton BN1 1EA

**Tel:** 01273 772210

**Email:** [info@brightonandhovebereavementsupport.co.uk](mailto:info@brightonandhovebereavementsupport.co.uk)

[www.brightonandhovebereavementsupport.co.uk](http://www.brightonandhovebereavementsupport.co.uk)

Offering individual bereavement support.

## **CRUSE Bereavement Care's Youth Involvement Project**

**Freephone helpline:** 0808 808 1677 Mon - Fri, 9.30am - 5pm  
[www.rd4u.org.uk](http://www.rd4u.org.uk) (website for young people)

## **Winston's Wish**

3rd Floor, Cheltenham House, Clarence Street, Cheltenham,  
Gloucestershire GL50 3JR

**Tel:** 01242 515157 (general enquiries)

**Helpline:** 08452 03 04 05

**Email:** [info@winstonswish.org.uk](mailto:info@winstonswish.org.uk)

[www.winstonswish.org.uk](http://www.winstonswish.org.uk)

For grieving children and their families. They offer guidance,  
information and support.

## **Child Bereavement UK**

Clare Charity Centre, Wycombe Road, Saunderton,  
Buckinghamshire HP14 4BF

**Tel:** 01494 568900

**Email:** [support@childbereavementuk.org](mailto:support@childbereavementuk.org)

[www.childbereavement.org.uk](http://www.childbereavement.org.uk)

They offer support to bereaved families, information and  
resources.

## **About Martlets**

Martlets Hospice in Hove provides end of life care services  
to adults with terminal illness including cancer. Facilities  
include an 18 bed inpatient unit, a Hospice at Home service,  
community services and a patient and family support team.

Less than a third of its funding is from the government. It has  
to raise £8,000 a day to care for patients and their families.

**Tel:** 01273 273400

[www.themartlets.org.uk](http://www.themartlets.org.uk)

We are the main provider of community NHS healthcare  
across West Sussex and Brighton & Hove.

Our expert teams provide essential medical, nursing and  
therapeutic care to over 8,000 adults, children and families a  
day. From our health visitors looking after new born babies to  
our community practitioners (nurses and therapists) caring for  
the frail elderly, we look after some of the most vulnerable  
people in our communities.

For further information about the trust, visit our website  
**[www.sussexcommunity.nhs.uk](http://www.sussexcommunity.nhs.uk)**

For further information about the services we provide visit  
**[www.sussexcommunity.nhs.uk/services](http://www.sussexcommunity.nhs.uk/services)**

## **Join us as an NHS foundation trust member**

Are you interested in having your say on local services  
provided by the trust?

Well, why not join us as a member. It's FREE and you decide  
how involved you want to become. You could:

- Receive our newsletter with latest information about  
the trust.
- Be part of a focus group to drive service change and  
improvement.
- Or look to become a governor.

For further information and to join, visit our website  
**[www.sussexcommunity.nhs.uk/ft](http://www.sussexcommunity.nhs.uk/ft)**