**East Kent**

End of Life: a guide for Carers, when someone is nearing the final stages of life

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NHS Thanet Clinical Commissioning Group, NHS South Kent Coast Clinical Commissioning Group,

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Carer Name:

**Carer Information Pack**

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Aim of this information pack

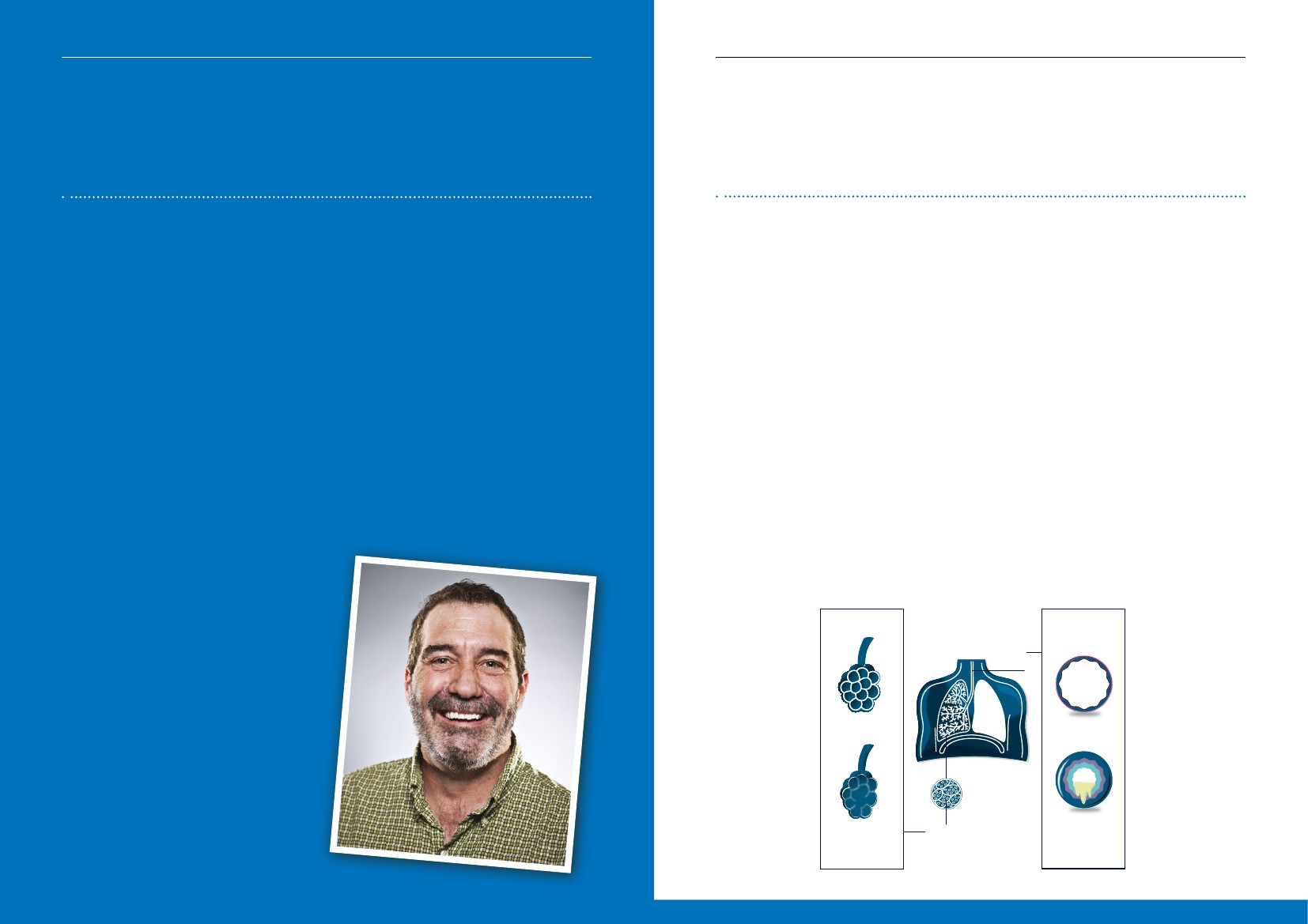
We understand that when you receive the news that someone you care for is nearing the final stages of life, you will have a range of feelings and concerns, for the person you care for and yourself.

It is important to consider your own needs and wellbeing alongside those of the person you care for. You may have questions around what will happen or what to do when the time comes, or be unsure about support available to you and the person you care for.

The aim of this pack is to provide you with information and sources of support that may be helpful at this difficult time.

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Need a new picture



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Dealing with the news

Hearing the news that someone you care for is nearing the end of their life can be difficult and distressing. You may feel overwhelmed and experience feelings of shock and disbelief. The person you care for will also be experiencing their own emotions, which can be difficult to manage these alongside your own feelings.

You may be frightened about what the future holds, feel tearful, depressed or angry that the person you care for is dying and be unsure of how to cope with all the feelings and emotions you have.

Friends and family can be a huge support at this time. But, you may also find it difficult to talk to those closest to you who will also be dealing with their own emotions.

Help and support is available from a range of sources, including those involved in the care of the person you care for.

Carers’ Support services can give you information about help and support. This may include information to read, putting you in touch with services that can provide practical support, emotional support/counselling or just being there to support you.

You may feel uncertain about the future and have questions about what will happen and how much time you have with the person you care for. You might also be thinking about what will happen after the person you care for has died.

It can be hard for doctors and nurses to predict how long someone will live. If they have made suggestions, it’s important to remember these are just estimates; the person you care for may live longer, or unfortunately in some cases for a shorter period of time.

You might want to plan and do some nice things with the person you care for and there may also be important decisions to discuss or make.

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The Future

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Relationships

When there are children who will be affected by the news, there is no easy way to talk to about the fact that someone is reaching the end of their life.

Children are often aware of things happening around them and may sense that something is wrong even if no one tells them what is happening. This may result in them becoming frightened and fearful, or that they are to blame in some way so it is important they receive lots of reassurance at this time.

There is specialist information available to help you choose how and what to tell them, your local Carers Support service will be happy to provide you with copies and discuss this with you.

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Relationships can change with the news that someone is going to die, and people can react in unexpected ways which sometimes do not reflect their true feelings.

Working through this can be challenging and it is important to try to keep your relationships as normal as possible.

If you normally talk about things together, try to continue to do this. Try not to worry about saying the wrong thing. Equally, if you normally argue a lot, don’t feel you must try to change this.

If you don’t know what to say, a hug or holding hands can be a comfort.

If there are times when you do not get on well, having short breaks from each other can help.

Remember everyone will be dealing with powerful emotions, and may need help and support to deal with them.

Closeness/discussion vs arguments – example from Macmillan

Children

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Although it may be difficult and upsetting, it is important to have conversations with the person you care for and possibly other family members about their choices, such as:

-Personal care and who will help with this?

-Advance Care Planning

-Where they would like to die?

-Saying goodbye to family and friends

-What happens after they have died?

The person you care for may make choices that you are uncomfortable with. It is important to talk to someone about how you feel and any worries you have.

Balancing your own feelings against those of the person you care for and other family members is difficult. Remember, your feelings matter too.

Your local Carers’ Support service can help you to think about how to manage these difficult conversations.

Difficult Conversations

It can be useful to think about what information you’d like to know and talk to the person you care for about this. Usually, doctors or nurses will be happy to talk things through with relatives. It is also helpful to talk to the person you care for about their wishes such as:

– if there is any treatment they do not want to receive

- where they would prefer to be cared for and wish to die

- what their preferences are after death e.g. burial/cremation

- if there are any other matters that are important to them.

You may want to think about whether the person you care for has, or needs to put in place:

* A will
* Powers of Attorney
* Advance Directive
* Funeral Plan

You may need to ask where important documents, such as life insurance and pension documents are kept. Plan ahead if possible, it will make you both feel more in control of the situation.

Planning

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You or the person you care for may be entitled to a benefit such as Personal Independence Payment, Attendance Allowance or Carers Allowance. Or, a discount/exemption or service such as free parking via a Blue Badge, or Council Tax discount.

Your local Carers’ Support service can provide you with information about entitlements to financial support and access to specialist advisors to help you apply.

You might find the person you care for needs equipment such as special mattresses/beds, aids to bathe or move around safely. These can be organised by an Occupational Therapist. If you are unsure how to access them, ask your local Carers’ Support service.

You may also need help with practical things like transport, managing washing if you do not have a machine, or even clothing if the person you care for has lost a significant amount of weight. Charitable grants are sometimes available, ask your local Carers’ Support service.

You might need to think about how the situation will affect your finances or those of close relatives.

If you and/or the person you care for work, it is important to discuss your situation with your employer as soon as possible.

You will need to determine what your contractual entitlements are around pay and leave. You may be able to negotiate flexible working arrangements/leave to help you manage your situation or need to help organise matters for the person you care for.

Your local Carers’ Support service will be able to advise you about Carers’ rights in the workplace and discuss your situation with you.

You, or the person you care for may also be eligible for some financial support, either directly (in the form of a benefit or payment) or indirectly (as a discount or service).

**Finances**

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It is easy to forget your own health and wellbeing when you are caring for someone. Whilst caring often brings a sense of comfort/satisfaction knowing you have done your best to ensure the person you care for is well looked after, caring can have an impact on own your physical and mental health.

It can be difficult to have a good night’s sleep, and you may develop physical injuries such as back strain as a result of moving/lifting someone.

**Remember** the better your own health and wellbeing, the better you will be able to cope.

It is important to eat and drink regularly, take time to rest and have a break when you can.

Have you considered a meal delivery service to save time cooking, or asking friends or family to help with tasks such as shopping, ironing or perhaps walking the dog?

Help and support is also available through Carers’ Support services. This may be someone to help with practical tasks, such as meal preparation or housework, or to be with the person you care for while you have some rest/take a break. This support is often free.

Image of a notepad in a format someone could write on

Who can help?

People often say “is there anything we can do?” and it can be hard to think about what others may be able to do, or ask for help. Don’t feel you need to manage everything yourself. It is important to have time with the person you care for, and for yourself.

Why not make a list of things others could help with?

My List ………

*e.g. Telling people the news/keeping people updated – perhaps a family member could do this for you?*

*Shopping – could a friend or neighbour help?*

Your Health and Wellbeing

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Spiritual Wellbeing

Time for yourself

Towards the end of life, those who are terminally ill and those close to them often become more aware of religious/spiritual beliefs/feelings.

You and/or the person you care for may find yourselves questioning your beliefs or taking comfort in them.

Whether or not you or the person you care for have religious or spiritual beliefs you may find it helpful to talk to a Faith Leader about your feelings. They can provide support to the person who is dying and you.

The Hospice and Hospital have Chaplains, or you can ask for a Faith Leader to visit.

Counsellors, Social Workers and nurses may also be able to offer support.

You may feel alone, tired/worn out and that you have no time to yourself. This can sometimes lead to feelings of anger/resentment and subsequently guilt for feeling this way.

These feelings do not mean that you care any less about the person you are supporting, just that you need to take some time for yourself. Sometimes this might be half an hour to soak in the bath, or have a quick snooze or you may feel you need a longer break, a few hours, a day or even days.

Carers’ Support services can talk with you about ways you may be able to achieve this.

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Approaching the end

The following pages contain information about what to expect towards the final stages of life, the stages of dying and caring for someone who is dying at home.

This information can be difficult to read, but may also help you know what to expect, to prepare and think about any questions you may wish to ask.

Those involved in the care of your loved one might include:

-GP

-District nurse/Community Matron

-Intermediate Care Team

-Pilgrim’s Hospice Doctor/Nurse

-Care Manager

-Other specialist services e.g. dietician, speech and language therapist

-Care Workers

It’s ok to ask questions, and your local Carers’ Support services are available for support also.

The physical changes and symptoms that occur vary with the type of illness a person has. As the person you care for becomes more ill, medicines may be reviewed or stopped by a GP or nurse.

If they have symptoms such as pain, nausea or breathlessness, the GP or Hospice may prescribe “Just in Case” medication to be in your home for use in an emergency. This will avoid any delay in symptoms being relieved and managed.

More regular reviews might be required and other professionals may be involved e.g. GP, District Nurses and Care Workers.

The District Nurse and/or Hospice team may discuss with the person you care for whether increased support/more frequent visits are needed.

**The last few weeks of life.**

**The last few days of life.**

**Nearing Death**

For some people dying is very peaceful. They may slip slowly into unconsciousness and find that it is difficult to wake up. Some people have phases where they are awake, can talk and then slip back into unconsciousness. Others may experience some pain, difficulty with breathing or become agitated. These symptoms can usually be managed with medication.

The aim of giving any medication is to keep the person you care for comfortable and settled. These medications do not slow down or hasten death, they ensure the person is comfortable. If you feel the person you care for is uncomfortable, distressed or in pain contact the District Nurse. They will be able to give them medication either by injection or through a syringe driver.

When death is very close (within minutes or hours), the skin can become pale and moist and slightly cool prior to death. The breathing pattern will change with sometimes long pauses between breaths until it finally stops altogether. At the same time some people become more agitated as death approaches and may need a change in medication in the syringe driver to relieve these symptoms.

Each person’s experience of the last few days of life will be different and it can be difficult to predict what will happen or how quickly the changes will occur.

Usually they will gradually become very weak and have very little energy.

Moving around will be difficult and they may need help getting from the bed to a chair. They may need to spend most or all their time in bed as they feel sleepier.

They may have a reduced or no appetite for food.

They may begin to withdraw from their family and surroundings.

In the first few days after someone has died you will need to:

-Get a medical certificate from the GP or hospice/ hospital Doctor. You’ll need this to register the death.

-Register the death within 5 days at your local Registrar’s Office (some Libraries offer this service). You will be given the documents you need to arrange a funeral.

To book an appointment call 03000 415151 or visit www.kent.gov.uk

The district nurse will arrange for any equipment to be collected and offer you information about bereavement support, if you wish.

A family member or friend may be able to help you to inform those who need to know that the person you care for has died.

If the person you care for had a solicitor they should also be informed.

It is important not to feel you need to do everything immediately, you can take some time to work through managing the funeral and the person’s affairs.

If your loved one is in hospital or a hospice, staff should talk you through what will happen next. If they do not it’s ok to ask.

If the person you care for is at home when they die it might be helpful to know the following:

Most importantly, you do not need to do anything immediately. You may want to stay with them for a little while. You can take your time and do not need to call an ambulance.

If the person you care for has died while their GP practice is open, you can contact them and inform them of the death. Or, you may want to contact the District Nurse to come to your home. They are trained to verify the death, remove any equipment e.g. catheter and syringe driver and can prevent any delay in the body of the person you care for being moved to the undertaker. However if a District Nurse is unable to attend, the GP will visit.

When you are ready, an undertaker will need to be contacted to collect the body, you might want to ask a family member or friend to help you to organise this.

**After death**

Most people use a Funeral Director, although you can also arrange a funeral yourself. Chose a Funeral Director who is a member of one of the following:

National Association of Funeral Directors

National Federation of Funeral Directors

Society of Allied and Independent Funeral Directors

These organisations have codes of practice – they must give you a price list when asked.

Some local councils run their own funeral services, e.g. non- religious burials. The British Humanist Association can also help with non-religious funerals.

You may be worried about funeral costs, or be unsure about ways in which funerals are paid for. If you are on a low income, you may be eligible for a Funeral Payment, the amount depends on your circumstances.

The Bereavement Service Helpline can also provide information about this and other benefits you may be entitled to Telephone – 0345 606 0265 (Monday to Friday, 8am to 6pm)

Carers’ Support services can provide you with help and information.

**Arranging the Funeral**

The Tell Us Once service can be used to report a death to most government departments in one go, rather than having to make lots of different calls.

When you register a death ask your local registrar who will give you a unique reference number to access the Tell Us Once service online or by phone.

You will need certain information about the person who has died and if you are not the person’s Next of Kin/Executor, you will need permission from the person who is and be able to provide their contact details.

Tell Us Once will notify the following

HM Revenue and Customs (HMRC) – To deal with tax and cancel benefits

Department of Work and Pensions (DWP) – to cancel benefits

Driver and Vehicle Licensing Agency (DVLA) – to cancel a driving licence.

Passport Office – to cancel a passport.

**Tell Us Once**

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What to expect when someone important to you is dying, NCPC, 2015

|  |  |
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| **What are you concerned about?** | **How can I help?**  **Who else can help?** |
| The person seems distressed, or is experiencing difficult emotions: they may be feeling angry, scared, guilty or confused | -A Chaplain or spiritual care co-ordinator is trained to help people who are experiencing such feelings. They can provide support for the person who is dying and those who are important to them, whether or not they hold a religious belief.  -If the person does have religious beliefs, they can also receive a visit from their local faith leader.  -A Counsellor, social worker or psychologist, as well as a nurse, may also be able to offer support. |
| Where else can I turn for help? | - The GP or nurse will know local services.  -Your local hospice or palliative care team can advise on all aspects of care in the last days of life.  -There are also lots of services that provide support for carers, often run by charities. |

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| --- | --- |
| **What are you concerned about?** | **How can I help?**  **Who else can help?** |
| Does the person I am caring for need medication? If so, which medication, and how do I get it? | -Your GP can give information about this, and prescribe it. If the person is in hospital or a hospice, the doctor looking after them will discuss medication with you.  -The Pharmacist can also give information about different medications.  -The person’s doctor can also suggest using alternative ways of giving the medicine if the person has difficulty swallowing or keeping it down. |
| How can I make the person more comfortable? | The Nurse or doctor can give you advice about this.  They can also help by:  - Arranging an assessment of what equipment the person needs  - providing equipment for physical care (e.g. mouth care sticks)  -Talk to an occupational therapist about what equipment the person needs.  - A physiotherapist or occupational therapist can also help with the person’s breathing and movement |

**Carers Services**

Carers UK – Tel 0808 808 7777

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

Carers Direct (NHS) 0300 123 1053

[www.nhs.uk/carersdirect](http://www.nhs.uk/carersdirect)

**Other Support:**

Age UK – Tel 0800 169 2081

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

Citizens Advice [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

Cruse bereavement care – Tel 0844 477 9400 [www.cruse.org.uk](http://www.cruse.org.uk)

Dying Matters **–**Tel - 08000 21 44 66 [www.dyingmatters.org](http://www.dyingmatters.org)

Gov.uk [www.gov.uk](http://www.gov.uk)

Macmillan Cancer Support: 0808 808 00 00

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

Marie Curie 0800 090 2309

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

**Carers Services**

Carers’ Support (East Kent) – information, advice and support for Carers - Tel 0300 3020 110

[www.carers-supportcdt.org](http://www.carers-supportcdt.org)

[www.carers-ashford.org.uk](http://www.carers-ashford.org.uk)

Crossroads Care Kent – Tel 0845 900 3735

Macmillan Volunteer Service – Tel 08450 95800

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

**Other Support:**

**Kent Community Health Foundation NHS Trust (Customer Care Team)**

Tel 0300 123 1807

[www.kentcht.nhs.uk](http://www.kentcht.nhs.uk)

**Pilgrims Hospices (Hospice care in East Kent)** Tel01233 504133 (24hr Advice Line)

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

**Local Organisations**

**Age UK** <http://www.ageuk.org.uk/publications/age-uk-information-guides-and-factsheets/>

AgeUKIG13 Advice for Carers

AgeUKIG03 When someone dies – A Step-by-step guide what to do

AgeUKIG21 Powers of Attorney

AgeUKIG31 Wills and estate planning

AgeUKIG32 Bereavement

**Carers UK** [www.carersuk.org](http://www.carersuk.org)

Carers Rights Guide – looking after someone

Assessments and the Care Act

When Caring ends

**Dying Matters** <http://www.dyingmatters.org/page/dying-matters-leaflets>

One Last Thing – Information to help those close to someone who is elderly or ill

Remember When We – Starting the conversation if someone close to you is dying

Thinking of You – What to say is someone you know is dying

Talking to children about dying – Information to help you help children understand death

Putting your house in order – Five things you can plan for end of life

Myth busting – getting the facts right about death and dying

**Macmillan** <http://be.macmillan.org.uk>

End of Life: a guide A booklet for people in the final stages of life and their carers. (Also available on CD)

Looking after someone with cancer

**Marie Curie** <https://www.mariecurie.org.uk/help/being-there/end-of-life-preparation>

End of Life: a guide A booklet for people in the final stages of life and their Carers

**NHS**

<http://www.nhs.uk/Planners/end-of-life-care/Pages/End-of-life-care.aspx>

End of Life care: Information about what to expect in the final stages of life, includes a useful section about talking to children about dying

**Pilgrim’s Hospice** <http://www.pilgrimshospices.org/about-pilgrims-hospices/publications-and-leaflet-directory/>

Facing loss

Supporting you when someone is dying

What to do after someone has died

**National Council for Palliative Care** <http://www.ncpc.org.uk/freedownloads>

What to expect when someone important to you is dying A guide for carers, families and friends of dying people

Below is a list of some resources that you may find useful to read. Most are available online, but if you would like a paper copy please ask your local Carers’ Support service, they will be happy to source a copy for you. Links to resources available online can also be found at [www.carers-supportcdt.org.uk](http://www.carers-supportcdt.org.uk)

Please Note – this list is not exhaustive and all web links were correct at time of publication.

Useful Resources



Change image