



East Kent **End of Life**

A guide for carers, when someone is nearing
the final stages of life

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Aim of this information pack

We understand that when you receive the news 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.

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 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.

The future

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 something special with the person you care for and there may also be important decisions to discuss or make.

Relationships

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.

Children

When there are children who will be affected by the news, there is no easy way to talk 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 feeling 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 (**0300 3020 110**) will be happy to provide you with copies and discuss this with you.

Planning

It can be useful to think about what information you'd like to know and talk to the person you care for about this. This allows the person you care for to make their own decisions to support friends and family with the emotional burden of arranging the funeral at an already difficult time. It is 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 for example 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** A legal document containing instructions as to what should be done with one's money and property after one's death.
- **Powers of attorney** The authority to act for another person in specified or all legal or financial matters.
- **Advance directive** A living will which gives durable power of attorney to a surrogate decision-maker, remaining in effect during the incompetency of the person making it.
- **Funeral plan** This allows the person you care for to make their own decisions about the day which supports your friends and family with the emotional burden of arranging the funeral at an already difficult time.

You may need to ask where important documents, such as life insurance and pension documents are kept, and consider online accounts, documents and passwords. You should also ensure that buildings insurers are contacted if a property is going to be unoccupied, perhaps due to a lengthy hospital stay or a placement in care. It is also important to let them know when the person you care for has died if the property will be unoccupied to ensure appropriate cover is in place. Plan ahead if possible, it will make you both feel more in control of the situation.

Difficult conversations

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, for example home or a care home?
- Saying goodbye to family and friends.
- What happens after they have died?
- Do they wish to consider whether organ donation is an option?

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.

Finances

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 and/or their 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 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).

You or the person you care for may be entitled to a benefit such as Personal Independence Payment,

Attendance Allowance or Carer's 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 or community nurse. If you are unsure how to access them, ask your local Carers' Support service or your GP.

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.

Your health and wellbeing

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 your own 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 manage your caring role.

You might consider 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.

It may be that you would find additional support through a counselling service which you can access without charge – your GP, hospice or local Carers' Support Service can provide more information.

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?

Telling people the news/keeping people updated, shopping – could a friend or neighbour help?

Time for yourself

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 rest or you may feel you need a longer break, a few hours, a day or even days.

Carers' Support services can discuss with you ways you may be able to achieve this.

Spiritual wellbeing

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 local faith Leader to visit.

Counsellors, social workers and nurses may also be able to offer support.

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. If the person you care for is in hospital, a hospice or care home those providing care will be able to offer information and support.

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
- Community
- Intermediate care team
- Pilgrims hospice doctor/nurse
- Social services case 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.

Towards the last few weeks of life the person you care for may receive care at home, in hospital, a hospice or care home. Those involved in their care will be able to discuss with you options around place of care and death, and will take into account any decisions already made by the person you care for.

If the person you care for is in hospital or a hospice and their condition is stable, the multi-professional team will talk with you and the person you care for about discharge. This may be to return home or to a care home, or from hospital to a hospice depending on a range of factors. If you are concerned, for example about how you would manage if the person you care for returns home, or feel uncomfortable about decisions around place of care and death, it is OK to say.

If end of life care is to be provided at home, in a care home, or in a hospice, the person you care for should be assessed for NHS continuing care. Continuing care is professional care given to meet the physical or mental health needs of adults with a disability, injury or illness over an extended period of time. NHS continuing healthcare means a package of care that is arranged and funded by the NHS and is free of charge to the person receiving the care. This is sometimes called 'fully-funded NHS care'.

Hospice

In east Kent hospice care is provided by Pilgrims Hospices. When the person you care for has complex needs, Pilgrims Hospice will work with your usual health and social care professionals to provide care and support for you, the person you care for and your family at home. The person you care for may be admitted to the hospice if your needs can't be met elsewhere. Hospice admissions are usually for a few days to a week or two but will depend on the person you care for's circumstances. Pilgrims Hospice is also available to provide advice and information to those professionals caring for the person you care for.

Care homes

Social Services can provide you with information about care homes and information on paying for care if NHS Continuing Healthcare is not in place. Details of how to contact social services is provided at the end of this booklet.

You could ask about the support the home will be able to provide to someone facing the end of their life and how they work in collaboration with other professionals, as care may involve the local hospital's palliative care team, the local hospice team, your GP and community nurses who can visit the care home.

Home

If care is to take place at home those involved in the discharge will ensure there is access to any equipment that may help the person you care for to manage and will discuss who will be involved in this care.

The last few weeks of life

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 for example, GP, community nurses and care workers.

The community nurse and/or hospice team may discuss with the person you care for whether increased support/more frequent visits are needed.

The last few days of life

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.

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 periods 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 community nurse.

They will be able to give them medication either by injection or through a syringe driver. A syringe driver is a small, portable pump that can be used to give a continuous dose of painkiller and other medicines through a syringe. It may be used if the person your caring for is being sick or unable to swallow. The doctor or nurse will let you know if the person you care for needs 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.

Changes in the last days of life

The following information describes what to expect in the person you care for in the last days of life :

Signs that a person may be dying

- The person's appetite is likely to be much reduced.
- They may no longer wish to eat or drink anything. This could be because they find the effort of eating or drinking to be too much. But it may also be because they have little or no need or desire for food or drink.
- Eventually, the person will stop eating and drinking, and will not be able to swallow tablets.

Should I be worried?

- If a person stops eating or drinking because of their reduced appetite, this may be hard to accept, but it is a normal part of the dying process.
- If they stop drinking, their mouth may look dry, but this does not always mean they are dehydrated.
- It is normal for all dying people eventually to stop eating and drinking.

Is there anything I can do to help?

- If the person is conscious and they want something to eat or drink, you can offer sips, provided they can still swallow. You can give some comfort to a person with a dry mouth by:
 - » offering a drink through a straw (or from a teaspoon or syringe).
 - » moistening the mouth with some gauze.
 - » placing ice chips in the mouth.
 - » applying lip balm.

Signs that a person may be dying

- The person's breathing may change.
- As a person's body becomes less active in the final stages of life, they need less oxygen, and their breathing may become shallower. There may be long pauses between their breaths.
- Sometimes the person's breathing may also make a noise, commonly known as 'death rattle'. This is likely to be because they are not able to re- absorb or swallow the normal fluids in their chest or throat, which can cause a rattling sound.
- In the very last moments of life, the person's breathing pattern may change. Breaths may become much slower and quieter before they stop altogether.

Should I be worried?

- A change in the breathing pattern is a normal part of the dying process. If the person is anxious, their breath rate may increase a little.
- The rattling sound may be upsetting to hear, but it does not seem to cause any distress to the dying person. It can be a bit like snoring – which affects those who hear it more than the person who is making the sound.

Is there anything I can do to help?

- If the person is anxious, sitting with them so that they know you are there may help to reduce their anxiety.
- Breathlessness can be frightening – a small fan and an open window can help.
- If the breathing is very rattly, it may be helpful to change the person's position so that they are on their side if they agree or do not seem too disturbed by being moved. You can ask to be shown the best way to move the person – ask about sliding sheets.
- The doctor or nurse may also suggest medication which may help to reduce the fluids in their chest and throat. This is not always needed, and it does not always make a difference.

Signs that a person may be dying

- The person may become much sleepier.
- The person is likely to spend more time sleeping, and will often be drowsy even when they are awake.
- Some people become completely unconscious for a period of time before they die – this could be short, or as long as several days.

Should I be worried?

- It is normal for a dying person to sleep more. They generally become less interested in what is going on around them, and have less energy to take part, but this does not necessarily mean they are no longer hearing what you say to them.

Is there anything I can do to help?

- It is important to remember that, even when the person is or appears to be sleeping or resting, they may still be able to hear you.
- Do not feel that you need to stop communicating with the person. You might want to carry on speaking quietly and calmly to them.
- You could also try letting them know you are there in other ways. For instance: holding their hand, reading to them, or playing their favourite music.

Signs that a person may be dying

- The person's skin may feel cold and change colour.
- The person's hands, feet, ears and nose may feel cold to the touch (this is due to reduced circulation). Occasionally, a person's hands or other parts of the body may swell a little.
- Their skin may also become mottled and blue or patchy and uneven in colour.

Should I be worried?

- These changes are all normal parts of the dying process. If the person's hands swell, please be assured that this is not usually painful. The swelling is not usually painful or uncomfortable.

Is there anything I can do to help?

- It may be comforting to put gloves or socks on the person.
- You do not need to warm them up – but doing so may help you to feel more comfortable.
- Gentle massage may help – the nurses may show you how.

Signs that a person may be dying

- The person may become more restless and agitated.
- This may happen in the last few days of life, though the person may become more peaceful again before they die.
- Sometimes they may appear confused and may not recognise familiar faces. They may hallucinate, and see or hear people or things that are not actually there – for instance, they may see pets or people who have died.

Should I be worried?

- Restlessness and agitation can be caused by many things. It may be manageable by quiet reassurance and the comfort of people like you who are close to the person, though it may still be distressing for you to see.
- Agitation could also be caused by physical problems, like constipation or difficulty passing urine – ask the doctor or nurse caring for the person of you are concerned about this.
- If the dying person does not recognise you, this may be distressing for you but it is not a sign that they feel differently about you.

Is there anything I can do to help?

- Simply sitting with the person may often help to calm them down. Keeping things as normal as possible may help comfort the person.
- You can also talk to the doctor or nurse, as they can check if there is any treatable reason for this or may be able to offer medication to help settle the person's anxiety.

- You can help by:
 - » Speaking clearly and audibly to the person.
 - » Telling/reminding them who you are (and being prepared to do so repeatedly).
 - » Keeping their surroundings calm with minimal changes in noise level.
 - » Trying not to correct them if they say something wrong, or insist on them getting things accurate, as this may be upsetting for you and them.

Signs that a person may be dying

- The person may lose control of their bladder or bowels.
- This happens because the muscles in these areas relax and don't work as they did.
- They may also have fewer bowel movements as they eat less, and their urine may get darker as they drink less.

Should I be worried?

- This may be distressing to see, and you may worry that the person may feel embarrassed.

Is there anything I can do to help?

- You can ask a nurse to help by showing you how to:
 - » Keep the person clean and comfortable.
 - » Protect the bed.
- You can also ask the nurse or doctor for equipment that may be able to help with this, such as incontinence pads or a catheter (a long thin tube that can be put into the person's bladder to drain urine).

Concerns and worries

Does the person I am caring for need medication? If so, which medication and how do I get hold of 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 can 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 medication if the person has difficulty swallowing or keeping it down.

The person has experienced some kind of physical change.

- Talk to the nurse or doctor looking after the person to find out what they think is happening.

The person feels sick or is vomiting

The doctor or nurse will be able to give some anti-sickness (or 'anti-emetic') medication. Sometimes these medications may have to be given as injections under the skin, often using a machine called a 'syringe driver'.

- Apply a cool, damp cloth to the person's forehead.
- Avoid strong smells, such as air freshener, aftershave/perfume, or smells from cooking.
- Give the person small portions of food rather than large meals.

Will the person's pain get worse as they get closer to dying?

- Not necessarily. You can look out for body language which may tell you if a person is in pain, such as wincing, flinching, clenching their teeth, and stiffening of the body or a scrunched-up forehead. The person may moan occasionally but this could be just an involuntary sound or caused by breathing rather than they are in pain.
- You can help by letting the doctor or nurse know as they will be able to check the person and give extra medication to help if needed. If the person had been taking pain killers, usually this will need to be continued. If they cannot swallow, they may need this to be given by injection, possibly using a syringe driver (or pump) described above.

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 (for example continence pads) showing you how to use this equipment
- 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.

The person seems distressed, or is experiencing difficult emotions: they may be feeling angry, scared, guilty.

- 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.

After death

If your loved one is in hospital, a hospice or care home, 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 you do not need to call an ambulance.

If the person you care for has died while your GP practice is open, you can contact them and inform them of the death. You may want to contact the community nurse to come to your home. **They are trained to verify the death, and will support you in making any immediate arrangements, such as the removal of any equipment in a timely manner.** However if a community nurse is unable to attend, the GP will visit.

If death occurs when your GP surgery is closed, you or a member of your family will need to contact the out of hours GP service and inform them of the death. A night community nurse will be able to visit and verify the death in the same way as the day community nurse.

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

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 five 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 community nurse will organise 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.

After death in hospital

If your relative passes away in hospital the signed death certificate will be available for collection from the relative support officer after three days. You will need to make an appointment with the relative support officer to collect the death certificate along with any belongings.

Tell Us Once

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.

Arranging the funeral

Most people use a funeral director, although you can also arrange a funeral yourself. Choose 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 costs when asked.

Some local councils run their own funeral services, for example 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.

 0345 606 0265 (Monday to Friday, 8am to 6pm)

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



National organisations

Carers UK

☎ 0808 808 7777

💻 www.carersuk.org

Carers Direct (NHS)

☎ 0300 123 1053

💻 www.nhs.uk/carersdirect

Age UK

☎ 0800 169 2081

💻 www.ageuk.org.uk

Citizens Advice

☎ www.citizensadvice.org.uk

Cruse bereavement care

☎ 0844 477 9400

💻 www.cruse.org.uk

Dying Matters

☎ 08000 21 44 66

💻 www.dyingmatters.org

UK Government

💻 www.gov.uk

Macmillan Cancer Support

☎ 0808 808 00 00

💻 www.macmillan.org.uk

Marie Curie

☎ 0800 090 2309

💻 www.mariecurie.org.uk



Local organisations

Carers' Support (east Kent)

Information, advice and support for Carers

☎ 0300 3020 110

💻 www.carers-supportcdt.org.uk
www.carers-ashford.org.uk

Crossroads Care Kent

Practical home based support for Carers

☎ 0345 956 701

💻 www.carerskm.org

Macmillan Volunteer Service

☎ 0845 095 800

The Macmillan Welfare Benefits Service (east Kent)

This service supports people with cancer and their families with a comprehensive, impartial Welfare Benefits Advice Service. The project covers the East Kent area, via Citizens Advice Bureau (CAB) offices in Canterbury, Herne Bay and Ashford. Services include income maximisation, appealing against benefit decisions, transport concessions, accessing charitable grants, housing costs and council tax discounts.

☎ 01227 762 122 💻 macmillanadmin@canterburycab.cabnet.org.uk

Kent Community Health Foundation NHS Trust (Customer care team)

☎ 0300 123 1807

💻 www.kentcht.nhs.uk

Pilgrims Hospices (Hospice care in east Kent)

☎ 01233 504 133 (24hr Advice Line)

💻 www.pilgrimshospices.org



Useful resources

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

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

Age UK

 Information, guides and factsheets

- » *Advice for Carers.*
- » *When someone dies – a step-by-step guide what to do.*
- » *Powers of attorney.*
- » *Wills and estate planning.*
- » *Bereavement.*

Carers UK

 Carers UK website

- » *Carers Rights Guide – looking after someone.*
- » *Assessments and the Care Act.*
- » *When Caring ends.*

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

 Macmillan website

- » *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

 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

 NHS website

- » *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.*

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

 NCPC website

- » *What to expect when someone important to you is dying, A guide for Carers, families and friends of dying people.*

We hope that this pack has been useful and provided you with helpful information and contacts.

We would be grateful if you would take a few moments to let us know what you think about the information in the pack.

Any feedback received will be used to help improve and update the information in the packs to be given to carers in future.

You can contact us by email or by post. Addresses for each of the NHS clinical commissioning groups in east Kent are given below.

NHS Ashford Clinical Commissioning Group

Inca House, Trinity Road
Ashford, Kent, TN25 4AB

 03000 424 815

 ashford.ccg@nhs.net

NHS Thanet Clinical Commissioning Group

Thanet District Council, Cecil
Street, Margate, Kent, CT9 1XZ

 03000 424 615

 thn@thanetccg.info

NHS Canterbury and Coastal Clinical Commissioning Group

Ground floor, Council building,
Canterbury, Kent, CT1 1YW

 03000 425 019

 c4.ccg@nhs.net

NHS South Kent Coast Clinical Commissioning Group

Dover Council Offices, White Cliffs
Business Park, Whitfield,
Dover, Kent CT16 3PJ

 03000 424 700

 southkentcoast.ccg@nhs.net

All comments will be treated with the strictest confidentiality. Thank you for taking the time to tell us your views on the Carer's Pack.

Produced in collaboration with:



NHS Ashford Clinical Commissioning Group, NHS Canterbury and Coastal Clinical Commissioning Group, NHS Thanet Clinical Commissioning Group, NHS South Kent Coast Clinical Commissioning Group, East Kent Hospitals University NHS Foundation Trust, Kent Community Health NHS Foundation Trust