

A soft-focus photograph of a field of pink cosmos flowers. The flowers are in various stages of bloom, with some fully open and others as buds. The background is a bright, hazy sky, creating a gentle, warm atmosphere. The text is overlaid on the image in white boxes with blue borders.

East Kent **End of Life**

A guide for patients, nearing
the final stages of life

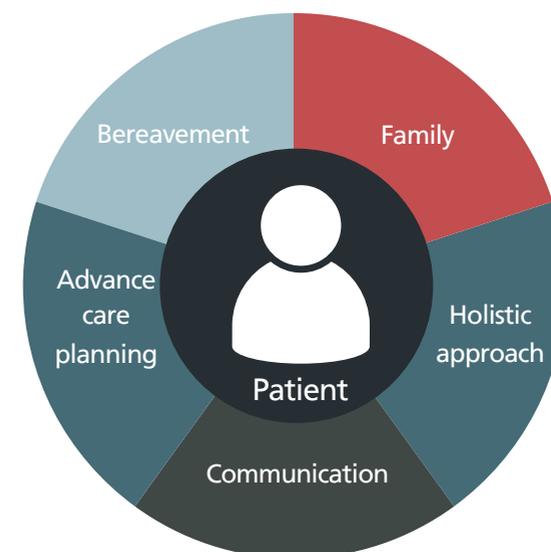
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What is End-of-Life care?

End-of-Life care is care that helps people with an advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative needs of both the patient and their family to be identified and met throughout the last phase of life and into bereavement

It includes managing pain and other symptoms and providing psychological, social, spiritual and practical support. (*National Council for Palliative Care 2006, cited in DOH 2008*).



Aim of this information pack

The aim of this information pack is to address some of the concerns you may experience throughout your journey.

It covers issues such as choosing where to be looked after, sorting out unfinished business and getting financial help, as well as offering guidance on who can help if you are being cared for at home and what to expect in the last few days of life.

During your last few weeks, you may experience a number of emotional and physical changes and symptoms. Even though these changes and symptoms are normal, they can be upsetting for both you and the people around you. Being prepared for what may happen can make the situation a little easier to cope with.

Talking about dying

Talking about dying won't bring it any closer but may help you make the most of the time you have left. It is important to be brave and talk to your family and/or friends about dying. There may be things you want your family and friends to know, for example your wishes about your funeral.

Professionals involved in your care may ask you how you wish to be supported, what is important to you, where you want to be cared for as things change and even the types of care and/or treatment you might want to avoid.

Things to consider

Talk about your care and support by making decisions now about things that will affect you in the future. These 'advanced decisions' help doctors and nurses understand things such as whether or not you want to be treated if you stop breathing. This process is called resuscitation. Making an advanced decision is also a way of telling doctors how long you want to be treated for if you can't make decisions for yourself. It means your family and friends know what you want.

Make a will which tells your family what to do when you die. Appointing a solicitor will help with legal issues such as creating a Power of Attorney.

Think about your funeral.

Do you wish to consider if organ donation is an option?

Who will look after you?

This will vary depending on your medical condition, your needs and the care you require. The following professionals may be involved:

- Hospital consultant
- GP
- Community nursing team
- Intermediate care team/ therapists
- Pilgrim's hospice specialist doctor/nurse
- Social services case manager
- Other specialist services, for example dietician, speech and language therapist
- Carers: social/health care workers.

Contact numbers

You will be given contact numbers of all the professionals looking after you. This will also include numbers for out of hours, bank holidays and weekends.

Wishes and preferences

Where you are cared for and die usually depends on what you want, what help you have from family and friends and what services you require. Wherever you are, it is important that you get the care you need and that your symptoms are well controlled. If you want to stay at home, it is important that you and your family have as much support as possible. You may hear doctors and nurses talk about your 'End-of-Life care plan'. This deals with your specific needs for food, drink, symptom control, emotional support and social support. You will be involved in, and supported through, any decisions about your care.

You can change your mind at any time about your preferred place of care or death. This will be discussed at an early stage and/or whenever you want to talk about it.

Five things to do before I die:

Five things I want to be remembered for:

Practical support

Caring can be hard work, both physically and emotionally, so it's important that you and your family have as much support as possible. It's not always easy to ask for help as people often feel they should be able to cope on their own. If a family member is caring for you and needs more support for themselves they can contact Carer's Support. They may also find it useful to read the carer pack which is available from the Carer's Support service. Your GP, though, has overall responsibility for your care. There are many health and social care professionals who can help you with practical support.

Community nurses

They work closely with GPs and can assess your needs and help coordinate your care with other health and social professionals by monitoring and treating any difficult symptoms you may have. They provide a range of nursing care interventions e.g. administering medication. Community nurses may arrange for you to have equipment to help with skin integrity or continence issues and can help with showing your family and carers how to move you and take care of your personal needs.

They may be able to arrange for social services to assess whether or not you are entitled to help with tasks such as washing and personal care. Community nurses often work with palliative care nurses to help give you and your family the support you need to allow you to remain at home. Community specialist palliative care teams provide care that improves the quality of life for people who are coping with life-limiting progressive illnesses, including cancer, and their families. You may be referred to a palliative care team if you need specialist support or care, for example if you have troublesome symptoms that need controlling.

Physiotherapists

They can help you to move around by working with you and showing you simple exercises. They can also give practical advice to help with pain relief and breathing problems.

Occupational therapists

They can help you maintain your independence and quality of life. They can assess whether you need specialist equipment that will help you remain at home for as long as you want, such as a hospital bed, special mattress or chair cushion.



Preferred place of care

Towards the last few weeks of your life you may receive care at home, in hospital or in a hospice or care home. Those involved in your care will talk to you about your options regarding your place of care and death, and will take into account any previous decisions you have already made.

If you are in hospital or a hospice and your condition is stable, the multi-professional team will talk to you and your family about your discharge. This may be so that you can 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 at home, or if you feel uncomfortable about any of the decisions around place of care and death, it is OK to say so.

If end of life care is to be provided at home, in a care home or in a hospice, you should be assessed for NHS Continuing Healthcare. This is professional care given to meet the physical and/or mental health needs of adults with a disability, injury or illness over an extended period of time. NHS Continuing Healthcare is a package of care arranged and funded by the NHS and free to the person receiving it.

Hospice

When you have complex needs, Pilgrims Hospices will work with your usual health and social care professionals to provide care and support for you and your family at home. You 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 your circumstances. Pilgrims are also available to provide advice and information to those professionals caring for you.

Care homes

You could ask about the support the home offers someone facing the end of their life and how they work alongside other professionals. Care may involve the local hospital's palliative care team, the local hospice team, your GP and community nurses who can visit you in the care home.

Social Services can provide you with information about care homes and paying for your care if NHS Continuing Health Care is not in place. They will carry out an assessment of your care needs and provide advice and guidance on looking for a suitable care home if that appears the best way to meet your care needs. Individual homes on their website. Details of how to contact social services is provided at the end of this booklet.

Home

If you want to be cared for at home, it is beneficial to have a nurse assessment to support you and those close to you. This will help in making sure you have the right support, care and treatment at home. This may include medication, access to any equipment and advising you on what services are available to you.

The last few weeks of life

The physical changes and symptoms will vary with the type of illness you have. As you become more ill your medicines may be reviewed or stopped by your GP or nurse. If you 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 relieving and managing your symptoms.

You may require more regular reviews and other professionals may become involved, such as your GP, community nurses and carers.

The community nurse and/or hospice team may increase their support and visit you more frequently.



The last few days of life

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

- Usually you will gradually become weak and have very little energy.
- Moving around will be difficult and you may need help getting from your bed to a chair. You may need to spend most or all of the day in bed as you feel sleepier.
- You may have a reduced appetite for food – or none at all.
- You may begin to withdraw from your family and your surroundings.

Nearing death

For many people, dying is very peaceful. Sometimes, though, death can happen quickly and the changes may be distressing for your family and/or relatives to see. The community nurse will be available to offer reassurance and support. You'll usually slip slowly into unconsciousness and find that it's difficult to wake up. Some people have phases where they are awake and can talk and then slip back into unconsciousness.

If you have pain or other symptoms, the community nurse can give you medication by injection and/or through a syringe driver. A syringe driver is a small, portable pump that can be used to give you a continuous dose of your painkiller and other medicines through a syringe. You may use one if you're being sick or you can't swallow. Your doctor or nurse will let you know if you need a syringe driver.

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

These medications do not slow down or hasten death, they ensure you are comfortable and pain-free.

After death

When someone is being cared for at home at the end of their life, there are a few things that might be helpful to know. Most importantly, your relatives do not need to do anything immediately after your death. They may want to stay with you for a little while. They can take their time and do not need to call an ambulance. If you die while your GP practice is open, your family can contact the surgery and inform your GP of the death. Or they may want to ask the community nurse to come to your home.

Community nurse are trained to verify the death and prevent any delay in you being collected by an undertaker. If your death occurs 'out of hours', your family will need to contact the out of hours GP service to tell them about the death. A night community nurse will be able to visit in the same way as the day community nurse.

Further information is available in the carers' pack.



National Organisations

Age UK

0800 169 6565

Alzheimer's Society Association

www.alzheimers.org.uk

Carers UK

0808 808 7777

www.carersuk.org

Cruse bereavement care

0844 477 9400

www.cruse.org.uk

Dying Matters

08000 21 44 66

www.dyingmatters.org

Government services

www.gov.uk

Macmillan Cancer Support

0808 808 00 00

www.macmillan.org.uk/information-and-support

Marie Curie

0800 090 2309

www.mariecurie.org.uk/nurses

NHS Direct

111

www.nhs.uk

NHS Choices

www.nhs.uk



Local Organisations

Carers Support: Canterbury, Dover and Thanet

01304 364 637

www.carers-supportcdt.org.uk

Crossroads

www.crossroadsk.org

Dying matters

www.dyingmatters.org

Pilgrims Hospices/ Hospice care in East Kent

01233 504 133

www.pilgrimshospices.org

Kent Community Health Foundation NHS Trust (Customer care team)

0300 123 1807

www.kentcht.nhs.uk

National Council for Palliative Care

www.ncpc.org.uk

Social Services

03000 41 61 61

www.kent.gov.uk/careandsupport

social.services@kent.gov.uk

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



References/resources

Carers' Support

 www.carers-supportcdt.org.uk

Department of Health

 *End-of-Life Care Strategy - Promoting High-Quality Care for Adults at the End Of Life. (2008)*

Dying matters

 www.dyingmatters.org

Kent Community Health Foundation NHS Trust

 www.kentcht.nhs.uk

Macmillan Cancer Support

 A booklet for people in the final stages of life, and their carers. *Macmillan Cancer Support, September 2015*

National Council for Palliative Care

 www.ncpc.org.uk

 National Council for Palliative Care, Hospice UK, Sue Ryder: "What to expect when someone important to you is dying", A guide for carers, families and friends of dying people. *Grey, A, March 2015*

 National Institute for Health and Care Excellence (NICE) Care of dying adults in the last days of life (NG31) *December 2015*

Pilgrims Hospices (hospice care in East Kent)

 www.pilgrimshospices.org

Plan my decisions

free and simple website to help plan ahead for future treatment and care

 plan.mydecisions.org.uk



Patient information leaflets

Available from your Community Nursing Team (Kent Community Health NHS Foundation Trust)

- Cardiopulmonary resuscitation.
- What happens when someone is dying. *(Available on the Kent Community NHS Foundation Trust Public website)*
- T34 syringe pump at home.
- Marie Curie home support.
- What happens and what to do when someone has died.
- Anticipatory care medication, called 'Just in Case' box.
- NHS Continuing Healthcare and NHS-funded Nursing Care, Department of Health *(This is document is available at www.gov.uk)*

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