



Medway and Swale

End of Life - A Guide for Patients

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Dealing with the news

The aim of this guide is to address some of the concerns you may experience on hearing the news that you are nearing the final stages of life.

It covers issues such as choosing where to be looked after, sorting out unfinished business and getting financial help. It also offers guidance on who can help and what to expect in the last few days of life. Being prepared for what may happen can make the situation a little easier to cope with.

Throughout your journey you will hear about different forms of care.

Palliative care is the supportive care you and your family receive which helps people with an advanced, progressive, incurable illness to live as well as possible until they die.

End of life care is the care you receive in the last few weeks of life. Both include managing pain and other symptoms and providing psychological, social, spiritual and practical support. (*National Council for Palliative Care 2006, cited in DOH 2008*).



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 talk to your family and friends about dying. There may be things you want them 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.

My wishes before I die:

My wishes after I die:

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 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.

Specialist information is available to help you choose how and what to tell them. Your local carers' support service (p16) will be happy to provide you with details and discuss this with you.

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, that your symptoms are well controlled, and 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'. Locally this is called an '**Advance Care Plan - My Wishes**'. This is a record of your plans, wishes, preferences and priorities for your care in the future. This form is to be held by you and is for you to record your thoughts in a way that can be shown to the health and social care professionals you may meet if you become ill and are unable to make your wishes known. Your GP and community nursing staff can ensure your information is also recorded on an electronic system called '**My Wishes**'. This is a register for end of life patients, which ensures your wishes are accessible by your GP, the hospital, paramedics, the hospice, community and other specialist nurses.

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

Important things to consider are: Putting your 'house' in order, seeking legal advice on your Will, pensions, Powers of Attorney for finance and/or welfare. Think about your funeral and whether or not you wish to consider organ donation.

Healthcare professionals may also discuss resuscitation with you. DNACPR (Do Not Attempt Cardiopulmonary resuscitation) is a legal document that allows a natural death but does not withhold any treatment.

If you have any questions about recording your wishes or making changes, contact your local GP or community nurse.

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 the local carer's support team. 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 health and social care professionals. They can assess your needs and help coordinate your care providing help with:

- Skin care
- Issues with continence
- Equipment
- Symptoms
- Practical advice
- Referring you to specialist services i.e. dietician and occupational therapy or physiotherapy.

Adult social care

Adult social care helps people to live as independently as possible by providing coordinated person centred services. This can include home care with personal and practical support, equipment and adaptations to assist daily living, meals or residential and nursing support. Services provided are wide ranging so anyone can request a needs assessment.

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 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 possible.



Spiritual wellbeing

Towards the end of life, people often become more aware of religious/spiritual beliefs or feelings.

You may find yourself questioning your beliefs or taking comfort in them.

Whether or not you or your family or carer have religious or spiritual beliefs you may find it helpful to talk to a faith leader or counsellor about your feelings. They can provide support to you, your family and carer.



Preferred place of care

Towards the last few weeks of your life you may receive care at home, in hospital, 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 professionals that care for you will talk to you and your family about discharge. This might involve returning home or to a care home, or from hospital to a hospice, depending on your needs. If you have concerns about the decision, for example about your place of care and death, it is OK to say so.

If end of life care is to be provided at home or in a care home, you should be assessed for NHS Continuing Healthcare funding. This is a package of care that is arranged and funded by the NHS. This is sometimes called 'fully-funded NHS care'. If you would like more information regarding NHS Continuing Healthcare please speak with a health care professional or contact the Specialist Assessment and Placements Team (SAPT) directly, using the contact details on page 17.

Home

Many people choose to die at home, where they feel safe and comfortable. The surroundings are familiar and they can be with friends and family. A community nursing or hospice team will work with your GP and other services in the community to care for you at home. Your carers might also find you being at home easier. They can work to your routine, instead of fitting in around the routine of a hospital or hospice. If you or your family have any concerns, talk to your GP or community nursing team, they will provide help and support.

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 are provided at the end of this booklet.

You could ask about the support the care home will be able to provide to someone facing the end of their life and how they work in collaboration with other professionals. Care may involve the hospice palliative care team, a GP, community nursing and other specialist teams who can visit the care home.

Hospice

In Medway and Swale hospice care is provided by Wisdom Hospice. If you have complex needs, Wisdom Hospice will provide care and support for you and your family at home. They will work together with your GP and the community nursing and other specialist teams, offering guidance and support as part of your care. You may be admitted to the hospice, these admissions are usually for a week or two but will depend on your needs.

The last few weeks of life

In the last few weeks you may require more regular reviews and visits. People, such as healthcare professionals, GP and care workers may become involved.

As you become less well your physical and mental wellbeing changes. You may experience more symptoms which will vary according to the type of illness you have. Your medicines may be reviewed or stopped by your GP or specialist nurse.

If you have symptoms such as pain, nausea or breathlessness, medication may be prescribed to you for use in an emergency. This will avoid any delay in relieving and managing your symptoms.

Do not be afraid to ask any healthcare professional if you have any concerns.

The last few days of life

Everyone'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.

- You will gradually become weak and have very little energy.
- Moving around will become more difficult and you may spend most or all of your time in bed as you feel sleepier.
- You may not want to eat or drink.

Do not be afraid to ask any healthcare professional if you have any worries or questions.

Nearing death

For most people, dying is peaceful. Usually you will slip slowly into unconsciousness.

If you have pain or other symptoms, the community nurse can give you medication by injection and/or through a syringe driver. Your doctor or nurse will let you know if you need a syringe driver. A syringe driver is a small, portable pump that can help control symptoms by delivering a steady flow of liquid medication through a continuous injection under the skin. You may use one if you're being sick or you can't swallow.

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




Local Organisations




Medway

Carers' FIRST

Provides information, advice and support for Carers

 0300 303 1555


 www.carersfirst.org.uk

 info@carersfirst.org.uk

Medway Community Healthcare CIC

Provides a wide range of community healthcare services for Medway residents, from community nurses to therapy 24/7


 01634 891 900 (MCH OneCall)

 www.medwaycommunityhealthcare.nhs.uk

Medway Council

Funds the care of those people already a resident in Medway who are assessed as needing care, and who are eligible for public financial support.

 01634 334 466

 03000 419 191 (out of hours - emergencies only)


 www.mymedway.org


 accessandinfo@medway.gov.uk

Swale

Carers' Support

Information, advice and support for Carers


 01233 664 393

 www.carers-ashford.org.uk

 admin@carers-ashford.org.uk

Virgin Care Coordination Centre


Provides a wide range of community healthcare services for Swale residents, from community nurses to therapy 24/7


 0300 123 4450


 www.virgincare.co.uk

Kent County Council

Funds the care of those people already a resident in Swale who are assessed as needing care, and who are eligible for public financial support.

 03000 416 161 (Mon-Fri, 9am-5pm)

 03000 419 191 (Out of hours for emergencies only)

 www.kent.gov.uk/social-care-and-health

Local Organisations




Medway and Swale

Wisdom Hospice

Our specialist palliative care service is based at the hospice. The service includes an inpatient unit, bereavement support, advice and psycho-social and family support to patients and family, also providing community palliative care at home as well as in hospice.


 01634 830 456

 www.medwaycommunity.nhs.uk/our-services/palliative-care

 www.fowh.org.uk

MedOCC (Medway on Call Care)

Medway and Swale out of hours GP services, for urgent care problems when surgeries are closed.

 01634 792 098 (My Wishes palliative care line)

Cruse Bereavement

Advice and support for people struggling to deal with bereavement

Medway

 01622 671 011

 maidstone@cruse.org.uk

Swale


 01622 884 444

 eastkentwithswale@cruse.org.uk

Specialist Assessment and Placements Team (SAPT)

SAPT are responsible for ensuring the delivery of NHS Continuing Healthcare for the local population.

01634 335 045


 nkccg.placements@nhs.net




National Organisations




Age UK


 0800 169 2081

Alzheimer's Society Association


 www.alzheimers.org.uk


Cruse Bereavement Care

 0808 808 1677


 www.cruse.org.uk (national)
www.hopeagain.org.uk (children and young people)


Dying Matters

 08000 21 44 66


 www.dyingmatters.org

Macmillan Cancer Support

 0808 808 00 00

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

Marie Curie

 0800 090 2309

 www.mariecurie.org.uk/nurses


National Council for Palliative Care

 www.ncpc.org.uk

NHS Choices

 www.nhs.uk

Tissue and Organ donation

 0300 123 2323


 www.organdonation.nhs.uk



We hope that this guide 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 this guide.

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

You can contact us by email or by post. Addresses for each of the NHS Clinical Commissioning Groups involved are given below.

NHS Medway Clinical
Commissioning Group
50 Pembroke Court,
Chatham Maritime, Kent,
ME4 4EL
 01634 335 020
 Medway.ccg@nhs.net

NHS Swale Clinical
Commissioning Group
Bramblefield Clinic, Grovehurst
Road, Kemsley, Kent, ME10 2ST
 03000 425 100
 Swale.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 Patients guide.

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Lead by:

NHS Medway Clinical Commissioning Group
NHS Swale Clinical Commissioning Group