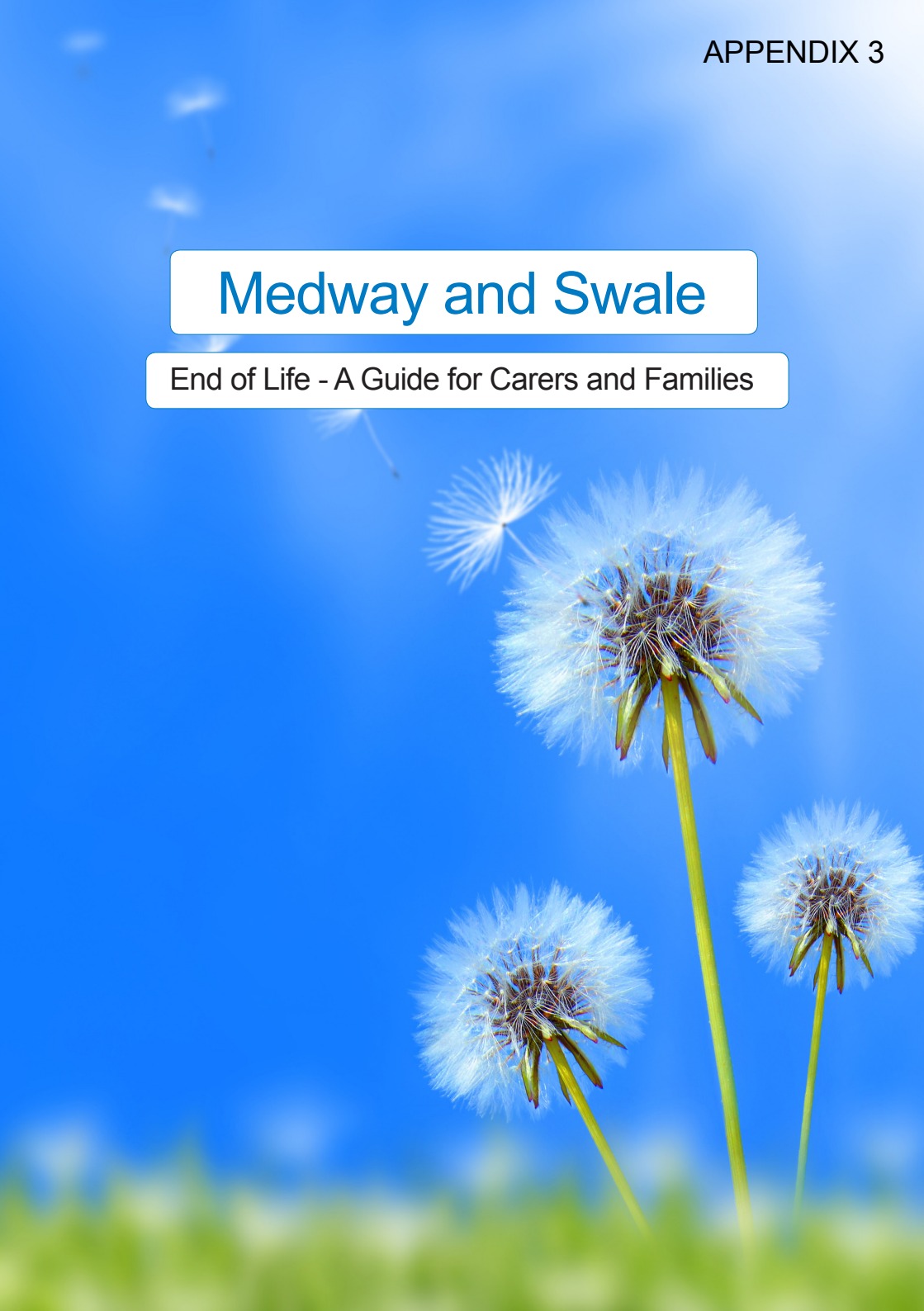


Medway and Swale

End of Life - A Guide for Carers and Families



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Dealing with the news

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 for 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.

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 you may find 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, however you may find it difficult to talk to those closest to you who will also be dealing with their own emotions. If this is the case help and support is available from a range of sources, including those involved in the care of the person you care for.

Your local carers' support service (see p28) 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.

This booklet contains information and sources of support that may be helpful at this difficult time.

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 will be happy to provide you with details and discuss this with you.

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:

- Saying goodbye to family and friends.
- Personal care and who will help with this?
- A written advance care plan - An opportunity to document future wishes with regard to care, for example;
 - Where would they like to be cared for?
 - If needed, discuss religious beliefs
 - Where would they like to die?
 - 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.

The advance care plan and the discussions related to it represent the wishes of the person you care for. With this knowledge and understanding, the document will give you the power to carry out the wishes of the person you care for.

Planning for the future

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

You might want to plan and do something special with the person you care for, to focus on the quality of life. There may also be important decisions to discuss or make.

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 building 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. This ensures appropriate cover remains in place. Plan ahead if possible, it will make you both feel more in control of the situation.

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 them 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 them 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 or 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 all legal and financial, health and/or welfare matters.
- **Advance directive** A living will which gives power to a surrogate decision-maker to refuse treatment, remaining in effect during any period the person lacks capacity.
- **Funeral plan** This allows the person you care for to make their own decisions about their funeral. This supports you, the family and friends, with the emotional burden of arranging the funeral at an already difficult time.

Notes:

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 carer 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 carer support service can provide you with information about entitlements to financial support and access to specialist advisors to help you apply.

You may also need help with practical costs like transport, equipment, 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 carer support service.

You might find the person you care for needs equipment such as a special mattress/bed and 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.

Your health and wellbeing

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

It might 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.

Your local carers' support service may be able to provide 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 or 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 carer support service can provide more information.

Time for yourself

You may feel alone, tired or 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. You may feel you need a longer break, a few hours, a day or even days.

Your local carers' support service can discuss with you ways you may be able to achieve this.



Spiritual wellbeing

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

You 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 or counsellor about your feelings. They can provide support to the person who is dying and you.



Approaching the end

The following pages contain information about what to expect towards the final stages of life. They discuss the stages of dying, and of 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, how to prepare yourself, and to think about any questions you may wish to ask.

Those involved in the care might include:

- GP
- Community nurses
- Hospice doctor/nurse
- Social services care manager
- 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 a hospital, in a hospice or in a care home. Those involved in their care will be able to discuss with you options around place of care and death, taking into account and revisiting decisions 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 arrangements for discharge will be discussed with you and the person you care for. This may involve returning home, transferring to a care home, or moving from hospital to a hospice depending on a range of factors. If you are concerned or feel uncomfortable about how you would manage if the person you care for returns home, it is OK to say.

If end of life care is to be provided at home or in a care home, the person you care for should be assessed for NHS Continuing Healthcare. This is a package of care funded solely by the NHS for individuals outside of hospital who have ongoing healthcare needs. If you would like more information regarding NHS Continuing Healthcare please speak with a health care professional or the Special Assessment and Placements Team (p29).

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 the patients' GP and other services in the community to care for them at home. You might also find having the patient at home easier. You can work to the patients' routine, instead of fitting in around the routine of the 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 palliative care hospice team, a GP, community and specialist teams who can visit the care home.

Hospice

In Medway and Swale, hospice care is provided by Wisdom Hospice. When the person you care for has complex needs, Wisdom Hospice will provide care and support for you, the person you care for and your family at home. They will work together with your GP and other community services offering guidance and support. If needed, the person you care for may be admitted to the hospice. These admissions are usually for a week or two but will depend on the person's needs.

The last few weeks of life

More regular reviews and visits might be required in the last few weeks of life, and other professionals may be involved, such as healthcare professionals, a GP and care workers.

The physical and emotional wellbeing 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 'anticipatory' medication may be prescribed for use by a health care professional in an emergency. This will avoid any delay in symptoms being relieved and managed.

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.

In most cases they will gradually become very weak and have very little energy

- They may have a reduced or no appetite for food or fluids
- They may even be unaware of their sudden moods or actions
- They may seem less aware of their family and surroundings
- Moving around will be difficult. They may spend most or all of their time in bed as they feel sleepier.

Do not be afraid to ask any health care professional if you have any concerns for the patient you are caring for.

Nearing death

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. This can 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 help control symptoms by delivering a steady flow of liquid medication through a continuous injection under the skin. It may be used if the person you are caring for is being sick or unable to swallow. The doctor or nurse will let you know if a syringe driver is needed.

When death is very close (within minutes or hours), the skin can become pale and moist and slightly cool. The breathing pattern will change with sometimes long pauses between breaths, until it finally stops altogether.



Changes in the last few days of life

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

Eating and Drinking

The person will stop eating and drinking, and will not be able to swallow tablets.

Should I be worried?

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

Breathing

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The person's breathing may change, there may be long pauses between their breaths and they may also make noises. This is likely to be because they are not able to re-absorb or swallow the normal fluids in their chest or throat, this can cause a rattling sound. Breaths may become less regular before they stop altogether.

Should I be worried?

A change in the breathing pattern is a normal part of the dying process. The rattling sound may be upsetting to hear but it does not 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?

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, if they do not seem too disturbed by being moved. Sitting with them so that they know you are there may help and be of comfort to you both.

If you have any concerns please contact the community nurse.

Increased Sleepiness

Some people become completely unconscious for a period of time before they die – this could be a short period, 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?

You could try letting them know you are there in other ways. For instance: holding their hand, reading to them, or playing their favourite music.



Changes You May See

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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.

Is there anything I can do to help?

You do not need to warm them up – but doing so may help you to feel more comfortable. A soft blanket or bed socks may bring some comfort.



Restlessness

The person may become more restless. 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. This may happen in the last few days of life, though the person may become more peaceful again before they die.

Should I be worried?

Restlessness 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.

Is there anything I can do to help?

Simply sitting with and reassuring the person may often help to calm them. 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 them.

Continence

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The person may lose control of their bladder or bowels, as 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 reduce and get darker as they drink less.

Should I be worried?

This is a normal part of the dying process, it 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.
- The community nurse may be able to help with this by providing continence pads or a catheter (a long thin tube that can be put into the person's bladder to drain urine).

As a carer this is a stressful and difficult journey in your life. Please read "Your health and wellbeing" on page 9 and you may find support reading "Spiritual wellbeing" on page 12.

After death

If your loved one dies 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. Take your time and you do not need to call an ambulance.**
- You need to contact the community nurse to come to your home. They will support you in making any immediate arrangements, such as verifying the death, organ donation and the removal of any equipment in a timely manner.
- When you are ready, an undertaker will need to be contacted. You will be able to organise the funeral arrangements according to the person's wishes, as you may have read in the "Planning" section on page 7.

Notes:

Registering the death

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

- Make an appointment to get a medical cause of death certificate from the GP or hospice/ hospital doctor. You'll need this to register the death.
- Make an appointment to register the death within five days in the district where it occurred. The registrar will give you the documents you need to arrange a funeral.

A death needs to be registered in the district where it occurred. A death in Medway Maritime Hospital or any other place within the Medway Council area will need to be registered at Medway Register Office in Rochester.

If someone dies anywhere else in Kent, the death can be registered at any of the registration offices in Kent, other than Medway.

If it is not possible to visit the register office where the death occurred you could visit your local register office and make a statement called a declaration which would then be sent to the relevant office.

It is advisable to purchase additional copies of the death certificate as they will be needed by the deceased's bank, building society, insurers etc.

We normally recommend around 6 copies, depending on the number of institutions that need to be informed as photocopies can not be used. Each certificate is a certified copy of the entry in the death register and costs £4 at the time of registration or £7 to £10 at a later date (Price correct as of July 2017).

To book an appointment to register at Medway, call 01634 338998. To register anywhere else in Kent call 03000 415 151.

The community 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.

Who can register the death?

A death can be registered by:

- a relative
- someone present at the death
- a senior administrator from the hospital
- the person making decisions about the funeral arrangements
- occupier of the house where the death occurred

N.B. Being an executor of the Will does not in itself, qualify someone to register a death.

What you need to do:

Take the medical certificate showing the cause of death (signed by a doctor) with you. It is also useful, but not essential, to take the person's NHS medical card together with proof of names and address such as :

- birth certificate
- council tax bill
- driving licence
- marriage or civil partnership certificate
- passport
- proof of address (e.g. utility bill)

Do not worry if these documents are not available as the registrar can still register the death without them.

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
- Society of Allied and Independent Funeral Directors

These organisations have codes of practice – they must give you costs when asked.

The British Humanist Association can also help with non-religious funerals, you can discuss this option further with your funeral director.

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.

Contact the department for Work and Pensions (DWP) who will cancel all DWP benefits, as well as help to establish if you are eligible for help towards costs and advise you on your eligibility for other benefits. There is a time limit for claiming bereavement benefits and a funeral grant so it is important to contact them as soon as possible.

The Bereavement Service Helpline can also provide information about this and other benefits you may be entitled to.

 **0345 606 0265 (Choose option 2)**


Local organisations



Medway

Carers' FIRST

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

Funding 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

Funding 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 based at the hospice. The service includes an inpatient unit, bereavement support, advice and psychosocial 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, 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 carers in future.

You can contact us by email or by post. Addresses for Medway and Swale NHS clinical commissioning groups are 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 Carer's guide.

Produced in collaboration with:



With special thanks to East Kent CCGs for sharing their resources.

Lead by:

NHS Medway Clinical Commissioning Group
NHS Swale Clinical Commissioning Group