



How to talk about and plan for the end of life



Everything you ever wanted
to know about death and dying
but were too afraid to ask...

Introduction

With improvements in medicine and increased life expectancy, people often don't experience bereavement until quite late in life.

In previous generations, death was recognised as part of the life cycle from a much earlier age, and it was acknowledged and dealt with far more openly than it often is today. People would gather in front rooms to pay their respects at an open coffin, drink a toast and reminisce about the deceased friend or relative.

Most people now die in hospital and go straight from there to the funeral directors. Death has become increasingly hidden from everyday life and talking about it has become more of a taboo.

At Pilgrims we've found that providing time and space to talk about death helps to reduce people's fears and anxieties. Planning for the end of your life before you need to helps to ensure you get the care you want and can help avoid unnecessary hospital admissions and treatment.

We hope this short guide will help you to start that 'big conversation', help you to feel more comfortable when thinking about death and dying, and plan for the end of life that is right for you.

Pilgrims Education and Training Department.

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Before Death

Starting the conversation...

Talking about what you want to happen when you die is not easy, but talking about death **before** you need to, ensures that everyone knows what to expect when the time comes, no matter how far away that may be.

Talking ahead of time can ensure that you get the care and medication that you want in the setting of your choice. What's more, if your wishes are clear, it saves your family and friends the stress of making difficult decisions for you when you are ill or after your death.

Conversation may come up naturally or you may need to guide it, there are no right or wrong ways.

Pilgrims Hospices Education Team hold regular **Time to Talk** events for the general public in East Kent. These events range from poetry evenings and lectures to film nights and Death Cafes and all aim to open up the conversation around death and grief. To find out more call 01227 812 616 or go to www.pilgrimshospices.org/timetotalk

Age UK have a guide available to help these discussions:

www.ageuk.org.uk/information-advice/health-wellbeing/relationships-family/end-of-life-issues/talking-death-dying

Tel: 0800 678 1602, 8am-7pm, every day of the year.

Death Cafes are an informal way to air your feelings around death over coffee and cake. It is not a bereavement or counselling session, just somewhere to talk about a subject we often avoid. As it can be hard to find people to talk to about dying and grief, a Death café brings together people who want to talk. Find your nearest Death Café at www.deathcafe.com or call Pilgrims Hospices which runs Death Cafes throughout East Kent, 01227 812616.

Dying Matters is a group of organisations which aim to help people talk more openly about dying, death and bereavement and to make plans for the end of life. Go to www.dyingmatters.org to find out more. Their website has lots of useful resources to help you start those difficult conversations.

GraveTalk is a café space, organised by Church of England churches, where people can talk about death and dying. GraveTalk cards are used as conversation starters for small groups of three or four people around a café-style table. To find out more go to www.churchofenglandfunerals.org/gravetalk

Independent Age have a helpful range of documents available to assist you with planning ahead, they include how to talk to your family, where to get support and funeral plans.

www.independentage.org/information/future-planning/planning-for-end-of-life

www.independentage.org/information/personal-life/difficult-conversations

Helpline: 0800 319 6789

Silver Line is a free, confidential helpline providing information, friendship and advice for older people. It is open 24 hours/day, every day of the year.

www.thesilverline.org.uk

Tel: 0800 470 8090

Writing a will

A will allows your friends and family to carry out your wishes. This can include what you would like to happen at your funeral and who you would like to inherit your money, property (and possessions). For more information go to: www.gov.uk/make-will

You can write a will using a will writing service, this can be done face to face, online or by post. A will writing service can be cheaper than using a solicitor. For further information about will writing services, please visit: Institute of Professional Will writers www.ipw.org.uk/public Tel: 0345 257 2570.

Did you know... you can buy simple will writing kits from stationery shops such as W.H. Smiths, and online.

Alternatively, any of the law firms listed below will help you write a will either for a fee or for an optional charitable donation during Free Will writing month if you are over 55.

Free Wills have also created a will planner that you can download and use to take to your free will appointment or to your solicitor.

www.freewillsmoth.org.uk/
www.freewillsmoth.org.uk/wp-content/uploads/2017/03/Free-Wills-Month-Will-Planner.pdf

Ashford Area

- Girlings Solicitors: 01233 664711
- Mowll & Mowll Solicitors: 01304 873344
- Whitehead Monckton: 01580 765722

Canterbury Area

- Boys and Maughan: 01227 207000
- Direction Law: 01227 764141
- Girlings Solicitors: 01227 768374 / 367355
- Whitehead Monckton: 01227 643250

Thanet Area

- Boys and Maughan: 01843 868861 / 842356 / 234000 / 595990
- Prospero: 01843 869042
- Robinson Allfree: 01843 592361 / 865261

Your digital legacy

Everyone who has online accounts should document what sites they use and what they would like to happen to them when they die. The Digital Legacy Association has lots of advice on how to do this.

www.digitallegacyassociation.org/for-the-public

Tel: 01525 630349

Recording your wishes/planning ahead

An Advance Statement is a general statement of anything that is important to you in relation to your health or wellbeing.

You can add:

- information about the care you would prefer, your current conditions, medicines and what makes you feel better, information about your lifestyle.
- Who you would like to visit you.
- What independence, privacy and dignity mean to you.
- Information on your religious or spiritual beliefs .
- Foods you like and dislike, your allergies and intolerances.

Advanced Statements are free and you can record them in any way that suits you. Compassion in Dying can support you to write yours.

www.compassionindying.org.uk

www.nhs.uk/conditions/end-of-life-care/advance-statement

An Advance Decision (sometimes known as an advance decision to refuse treatment, an ADRT, or a living will) is a decision you can make now to refuse a specific type of treatment at some time in the future.

An Advance Decision lets your family, carers and healthcare professionals know your wishes about refusing treatment if you are unable to make or communicate those decisions yourself.

Advance Decisions are free and there is no set form for making one.

You can make your own using the free website: www.mydecisions.org.uk

Compassion in Dying also provide free forms online :

www.compassionindying.org.uk/library/advance-decision-pack

0800 999 2434 (Monday – Friday, 9am-5pm), info@compassionindying.org.uk

There is also more information here:

www.nhs.uk/conditions/end-of-life-care/advance-decision-to-refuse-treatment

www.ageuk.org.uk/globalassets/age-uk/documents/factsheets/fs72_advance_decisions_advance_statements_and_living_wills_fcs.pdf

If you make an Advance Decision you can contact Compassion in Dying to request a Notice of Advance Decision card to keep in your wallet or purse.

You **DO NOT** need a solicitor to make an Advance Statement, Advance Decision, DNAR or Lasting Power of Attorney

A Lasting power of attorney (LPA) is a legal document that lets you (the ‘donor’) appoint one or more people (known as ‘attorneys’) to help you make decisions on your behalf, either about your health and welfare or your property and affairs.

This gives you more control over what happens to you if you have an accident or an illness and can't make your own decisions. An LPA has to be registered with the Office of the Public Guardian to be valid. For more information on how to set up an LPA, contact the Office of the Public Guardian for a form – see details below.

www.gov.uk/power-of-attorney

Office of the Public Guardian, customerservices@publicguardian.gov.uk

Tel: 0300 456 0300

An Advance Statement, Advance Decision or Lasting Power of Attorney will only be consulted if you lack mental capacity.

What is mental capacity?

Someone would be deemed as lacking capacity because of an illness or disability, such as a mental health problem, dementia, or a learning disability, or if they cannot do one or more of the following four things:

- Understand information given to them about a particular decision;
- Retain that information long enough to be able to make the decision;
- Weigh up the information available to make the decision;
- Communicate their decision.

Do not attempt resuscitation (DNAR) forms

A DNAR form is a document which is issued and signed by a doctor which tells medical teams not to attempt cardiopulmonary resuscitation (CPR) on someone. CPR is an attempt to restart a person's heart and/or breathing. CPR success rates vary, depending upon how well the patient is before their heart/breathing stopped and how quickly they are treated. Most patients do not survive CPR. This form is available from your doctor who will be able to help you complete it and discuss the issues with you.

If you make an Advance Statement, Advance Decision, DNAR or Lasting Power of Attorney it is important that people involved in your medical care know about it, here are some ideas to ensure you get what you want:

- Give photocopies to your GP to be kept on file.
- Give photocopies to anyone involved in your care.
- Order a bottle from the Lions Club International as part of their free 'Message in a bottle' scheme to keep a copy of your Advance Statement or Advanced Decision in the fridge. Paramedics know to look for the Lions symbol when entering your home. To order call 0845 833 9502.

Organ donation

Deciding what you would like to do with your body after you have died can be an emotional decision, the Human Tissue Authority (HTA) has guidelines on the donation of your body to science or a medical school:

www.hta.gov.uk/donating-your-body

Tel: 020 7269 1900

Monday to Friday 9am - 5pm

The HTA also provides information on organ donation:
www.hta.gov.uk/guidance-public/deceased-organ-donation

You can register with the NHS to become an organ donor:
www.organdonation.nhs.uk

Tel: 0300 123 23 23

From Spring 2020 all adults will be considered to be an organ donor unless they opt out.

Again, it is wise to tell family and friends what you have decided so that your wishes are clear.

End of life doulas

An End of life doula is trained to support a person with a terminal diagnosis. They are non-medical but work in the person's home, hospices, hospitals and care homes to preserve identity, wellbeing and dignity.

Doulas are available at any stage of a life-limiting illness and can also provide support for friends and family after a bereavement.

Doulas can:

- Guide people through End Of Life decisions;
- Offer practical and emotional support to the patient and their loved ones;
- Be an advocate when wishes need to be upheld;
- Help to give family and carers a break;
- Be a companion to the patient;
- Provide practical support including: walking the dog, doing housework, preparing meals, making tea, running errands;
- Support bereaved families and friends.

To contact a Doula you can follow the link below and fill in the form or simply call the number: 07887 840663

www.eol-doula.uk/get-doula-support

After Death

First calls

If your loved one is in a hospital, hospice or care home, staff will usually talk you through what happens next; it is ok to ask questions.

If your loved one died at home and the death was unexpected, or they had not seen a doctor in the last month, call 999 immediately.

The Bereavement Advice Centre has a comprehensive guide on what to do when someone dies, organised by place of death (i.e. home/hospital/when abroad etc).

www.bereavementadvice.org/topics/what-to-do-when-someone-dies/

Tel: 0800 634 9494, Monday to Friday, 9am-5pm.

If the death was expected, call the deceased's doctor or palliative care nurse, they are trained to verify the death and will support you in making any immediate arrangements, it is worth noting that if a nurse is unavailable to attend, a GP will visit.

If the death occurred out of hours you can call the out of hours GP service and inform them of the death, usually a night palliative care nurse will visit.

You do not need to do anything immediately and you can stay with the body for a while (please see the section about Care of the dead. You can contact an undertaker if you plan to use one.

You may want to start by phoning close friends and family. Often the next step is phoning a funeral director or celebrant to make arrangements if you choose to use them.

For more information on what to do if someone dies at home:

- www.ageuk.org.uk/information-advice/money-legal/legal-issues/what-to-do-when-someone-dies
Tel: 0800 055 6112, 8am-7pm all year
- www.goodfuneralguide.co.uk/do-it-all-yourself

How to register a death

Death must be certified by a doctor who will give the family a medical certificate stating the cause of death. This then needs to be taken to the Local Council's Registrar's office to register the death. You must register a death within five days in the UK. By registering a death you are agreeing to take responsibility for making funeral arrangements.

You may want to obtain multiple copies of the of the Death Certificate as anyone who deals with the deceased's assets will need these.

www.gov.uk/register-offices

Burial or cremation?

Once someone has died, a choice between burial or cremation needs to be made quite quickly. If the deceased has made their wishes clear in advance this is very helpful.

Two doctors will have to sign a second certificate if cremation is the desired option. The crematorium or funeral director will be able to help if you are not sure what forms you need.

For more information, see Funeral directors and funeral planning.

Care of the dead

Some people choose to keep their loved one at home after they have died, this could be for religious reasons or you could just prefer to have your loved one with you for a little longer. The general guidance advises that a body should be kept in a completely unheated, dark room with all of the windows closed, it is recommended that you contact a funeral director who will be able to give you advice.

Sometimes you may want to take part in caring for the body, typically this involves washing the body and any personal care that is necessary, usually a nurse will do this but you should always feel free to ask if you want to help.

Personal care should be carried out within two to four hours of the person dying to preserve their appearance, condition and dignity. Personal care usually involves the following:

- Laying the deceased flat on their back and straightening their arms and legs if possible.
- Leave one pillow under the head as this helps to keep the mouth closed.
- Supporting the chin with a rolled up flannel.
- Closing the eyes
- Brushing their hair into their preferred style.
- Applying makeup
- Clean and dress the deceased appropriately.

Further Information can be found here:

www.kingston.gov.uk/info/200136/funerals_cremations_and_cemeteries/338/carrying_out_the_arrangements_yourself_when_someone_has_died/3

www.goodfuneralguide.co.uk/do-it-all-yourself

It is possible to bring a body home with you from a Hospice, Care home or Hospital. This process is easier if you are using a funeral director, but you can do it yourself, discuss this with the healthcare providers before end of life if possible.

Funeral directors and funeral planning

Commonly, people use the services of a funeral director, although you can do it yourself, or you may like to carry out some of the duties yourself, and appoint a funeral director for others. It is possible to buy a coffin online, transport the body yourself in your family car or van: it is also possible to have the body at home before a service or you can transport the body from the place of death to a direct cremation.

There are many options, and many decisions to be made. If you make and share plans in advance, it makes planning a funeral and decision making in the midst of grief much easier. The following organisations can all help answer your questions and talk you through the various options.

It is recommended that you choose a funeral director who is a member of one of the below:

- The National Association of Funeral Directors, www.nafd.org.uk
Tel: 0121 711 1343
- The National Federation of Funeral Directors, www.nffd.co.uk
- The Society of Allied and Independent Funeral Directors, www.saif.org.uk

Tel: 0345 230 677 or 01279 726 777

You can find a traditional funeral director near you by visiting Google.com or by searching by your postcode on:

www.funeralzone.co.uk/funeral-directors

A good guide on essential questions to ask your funeral director can be found here: www.naturaldeath.org.uk/index.php?page=free-downloads

The British Humanist Association can help you with non-religious funerals:

www.humanism.org.uk/ceremonies

Tel: 020 7324 3060

Affordable/alternative funerals:

With the rising cost of funerals, many people are looking to less traditional options. Direct cremations and so-called 'DIY funerals' are both more affordable options. You do not need to be buried in a coffin, you could opt for a shroud or wicker basket. However, each choice comes with a set of rules that need to be followed, for example, some crematoriums won't accommodate a shroud. It is worth remembering that by-laws need to be followed at burial sites. If you know where you would like to be laid to rest or cremated, it is worth contacting them to find out what they are willing to accommodate.

www.hollysfunerals.co.uk

Tel: 01580 389 184

www.purecremation.co.uk

Tel: 0800 182 2162

www.simplekentfunerals.co.uk

Tel: 07806 613 297

www.simplicity.co.uk

Tel: 0800 484 0260

Financial advice on funerals

www.macmillan.org.uk/information-and-support/organising/benefits-and-financial-support

Financial issues can cause worry when someone becomes ill. You may be able to claim benefits to help you in your situation. You may also be able to get financial assistance from other organisations.

Tel: 0808 808 00 00, 7 days a week, 8am-8pm.

www.citizensadvice.org.uk/family/death-and-wills

Adviceline: 03444 111 444

www.ageuk.org.uk/information-advice/money-legal

Tel: 0800 678 1602, Open 8am-7pm, every day of the year.

Direct cremation: this is a simple, dignified option in which your loved one is cremated without a funeral service or ceremony. Sometimes known as an unattended cremation.

www.funeralguide.co.uk/direct-cremation

www.everplans.com/articles/5-things-you-need-to-know-about-direct-cremation

Eco Funerals: are environmentally sustainable funerals, such as eco-friendly burials in an established woodland or natural setting - with low-key memorial options made of wood rather than the more traditional headstone and using eco-friendly coffins or shrouds.

www.goodfuneralguide.co.uk/what-is-a-green-funeral

www.naturaldeath.org.uk/index.php?page=cremation

Helpline: 01962 712 690

www.treehugger.com/htgg/how-to-go-green-funerals.html

www.naturaldeath.org.uk/index.php?page=natural-burial-grounds

www.Kentnaturalburials.co.uk

Eco Coffins:

www.ecoffins.co.uk

Tel: 01795 830688

www.abbeycoffins.co.uk

Tel: 01297 34449

Shrouds:

www.naturaldeath.org.uk/index.php?page=coffins-and-urns-2

www.bellacouche.com

Tel: 01647 441405

Tell us once

Tell us once can be used to inform most government departments in one go over the phone or online.

The registrar will give you a unique reference number to use the Tell us once service.

www.gov.uk/after-a-death/organisations-you-need-to-contact-and-tell-us-once

Bereavement services

If your friend or relative died in a hospice you will usually be offered free bereavement support. Otherwise, support is often available free of charge from local charities.

If you feel that you need some support, the NHS website has a search function that allows you to look for services in your local area.

www.nhs.uk/Service-Search/Bereavement-support/LocationSearch/314

The Bereavement Trust

This is a national freephone helpline, operating every evening of the year from 6-10pm without exception.

www.bereavement-trust.org.uk

Tel: 0800 435 455

Cruse offers free face-to-face, telephone, email and website support, often they can travel to you.

www.cruse.org.uk

Tel: 0808 8081677

Monday to Friday: 9.30am - 5pm excluding bank holidays

Good Grief Trust

Everyone at The Good Grief Trust has lost someone they love, so they want to help you find the support you need as quickly as possible. You will find stories from others who have had a similar loss and targeted local and national support.

www.thegoodgrieftrust.org

Holding On Letting Go

Are a Kent-based charity that helps children aged 6-16, and their families, to cope with the death of someone close to them.

www.holdingonlettinggo.org.uk

Tel: 03445 611 511

All calls are free, confidential and unlimited.

Stepping Stones bereavement service

Stepping Stones Bereavement Support Group is a new service for the people of East Kent which offers support for adults who have had a bereavement.

The support service is available to anyone who is grieving irrespective of time, cause or relationship.

The group is run by a team of trained volunteers through a partnership between Pilgrims Hospices in East Kent and South Kent CRUSE Bereavement Care. There is no requirement to have had any previous contact with Pilgrims Services.

The informal, social format of this group provides a welcoming and confidential space for you to share with others in similar situations.

The support group meets every month in a comfortable lounge area in local Pilgrims Therapy Centres and is free of charge.

New people can join the group at any point and gain support for up to six months.

- **Pilgrims Hospice Ashford,**
Hythe Road, Willesborough, Ashford TN24 0NE
The first Friday of every month, 5-6.30pm
- **Pilgrims Hospice Canterbury,**
56 London Road, Canterbury CT2 8JA
The first Saturday of every month, 3-4.30pm
- **Pilgrims Hospice Thanet (Margate),**
Ramsgate Road, Margate CT9 4AD
The last Friday of every month, 4-5.30pm

There is free parking at each site, go to the reception area and someone will greet you.

Please call 01233 504 127 in advance to let the team know to expect you, do leave a message if this number is unattended.

If you would like more information on this service please call 01233 504 127 or email Steppingstones@pilgrimshospices.org

Winston's Wish is the UK's childhood bereavement charity. It supports children and their families after the death of a parent or sibling.

www.winstonswish.org

Tel: 08088 020021



Pilgrims Hospices

Ann Robertson Centre
55 London Road
Canterbury
CT2 8HQ

01227 812 616

education@pilgrimshospices.org

pilgrimshospices.org/bigconversation



From love comes beauty