

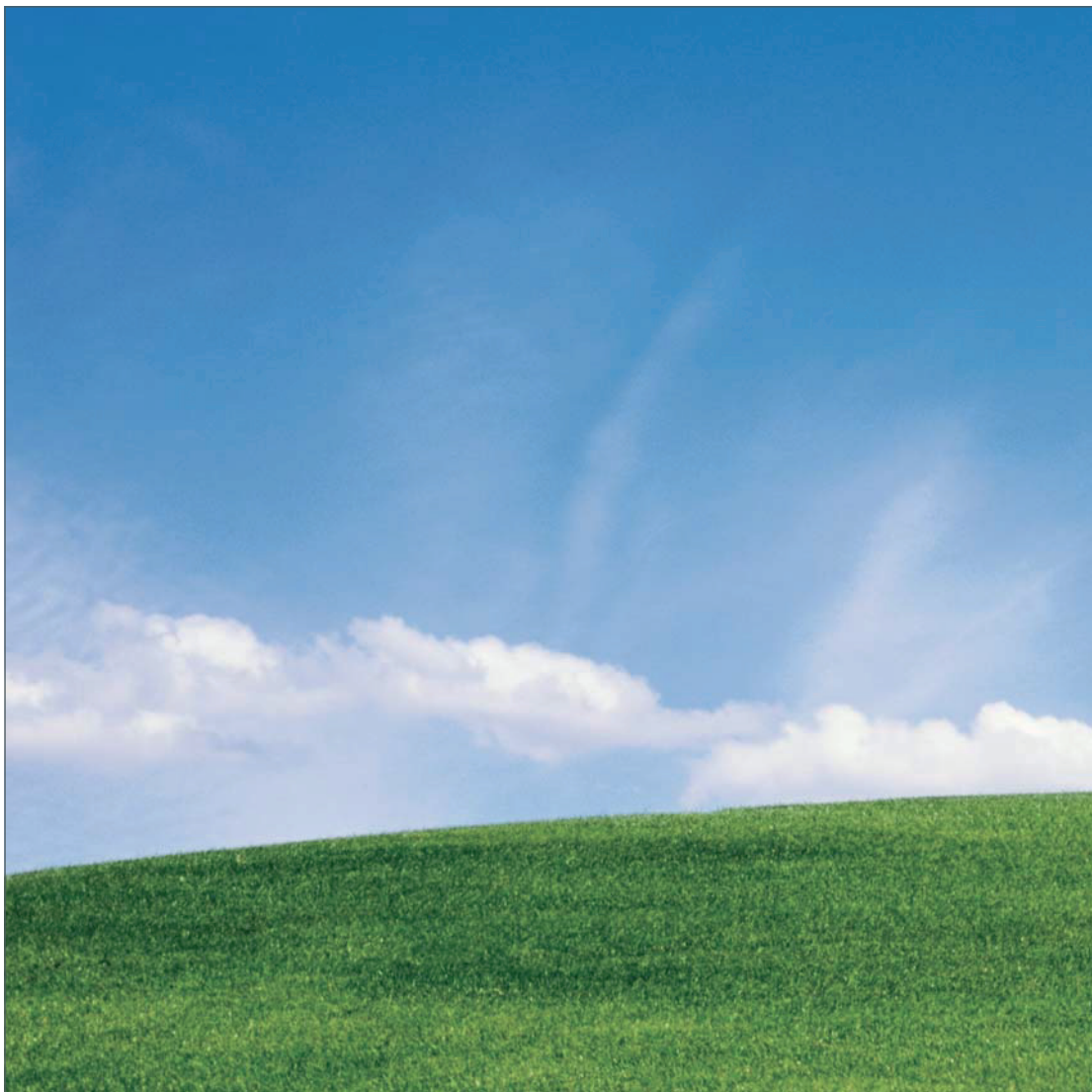


planning
a good
death



bbc.co.uk/health





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foreword

by Esther Rantzen

Death is often called the last taboo. For most of us, the thought of our own death or the death of someone we love is too painful to think about, talk about, or plan for. In any case, what's the point, since nobody can foresee how, when or where they will die? Why don't we just leave the whole thing to accident or fate?

There are good reasons to break the taboo and not only think about our death, but also discuss it with those closest to us, because there are important decisions we can make in advance. For example, we may have a clear idea about how we would like a funeral to be arranged. We might have views about whether we would prefer to die at home or in hospital. We would probably wish to have time to spend with family and friends and to say what needs to be said, and to have an assurance that our final hours will be pain-free and comfortable. We would probably also want to leave our affairs in good order, and be confident that our friends and family are left with good memories. We can try to talk about death and dying with our doctors and nurses, and find out about the different options for end-of-life treatment. So, tough as it may be to face the inevitability of our own death, it can be valuable and

There are, of course, no certainties ahead. No one can be guaranteed a good death. But following the suggestions in this booklet could increase our chances of dying as we would most wish, with privacy and dignity. The booklet describes some of the practical steps we can all take, and also looks at the emotional and spiritual aspects of our last days, the aim being to help us plan ahead.

There are other advantages in breaking the silence surrounding death which are less tangible, but just as real. When I interviewed terminally ill patients and their families and carers for the BBC Two programme *How to Have a Good Death*, I realised how much they valued the opportunity to share each other's thoughts and feelings at this most precious time. We hope reading this booklet, and using the blank pages for your own notes, will inspire you to have the same discussion with those closest to you. I have learned that no one can escape the pain of bereavement,

Esther Rantzen

practical|preparing for a good death

In a world where life-saving medical breakthroughs are often made and people can live for many years after a serious illness is diagnosed, it is easy to put off making important decisions about how we want to die, often until it is too late. A living will (see page 12) gives you the opportunity to influence your medical treatment at the end of your life. Just as important is a document or wish list that gives your family, friends and doctors detailed guidance on where and how you wish to live if you have a serious or terminal illness. You can write this wish list at any time in your life and update it whenever you want. Once written, though, it can provide vital information if you become unable to explain your wishes yourself – or it can simply provide reassurance, as you know that you have already made some decisions.

Some things you may wish to decide:

- Where you think you would like to be cared for if you are dying (hospital, nursing home, hospice, at home).

- Whether you would want to be told when you are close to death (assuming your doctors are able to predict this), and whether you want other people to know.
- Who should talk to any children, or other close family such as elderly parents, about your impending death if you are unable to do so.
- Who should look after your pets.
- How you want your final days to look and sound – what you would like in your room (flowers, pictures, radio, TV and so on).
- Who you would wish to visit you near the end.

Do I understand what's likely to happen to me as my life draws to a close and what support I might need? How do I find out more about my



“My friend Viv was dying of cancer. We all knew it but her family insisted that it was never mentioned. It was dreadful to keep up the pretence but we couldn't go against the family's wishes. I was in the room when a reflexologist, who was giving her a treatment, asked if she was frightened of the future. I'll always remember Viv nodding slowly, all the time looking into the therapist's eyes. That evening, Viv told her sister that she wanted to be reconciled with her father whom she had not seen for many years, and a couple of days later he came and spent the whole day with her. She died later that week and I've always felt grateful to the reflexologist for doing so simply what none of us dared to do.

Jackie,

Your notes

I have discussed my death and health care directive with friends Collin & Irene Storrie, Alan & Beth Bolton.

See my WEB Page:

www.zen26008.zen.co.uk/allpages/pages/my_funeral_wish.html

“66% of people have never discussed death with their loved one”

Taken from an ICM Research survey of 500 people for the BBC programme How to Have a Good Death, summer

practical|putting your affairs in order

This isn't just about having tidy files – it's also about leaving instructions on where everything is kept. This will save your family having to search through piles of papers to find the information they need, at a time of great stress. The instructions could include:

- ▣ details of your bank, building society, credit cards, pension, tax district and any other financial contacts
- ▣ telephone numbers and addresses of close (and distant) friends, family and colleagues
- ▣ where you keep documents such as your passport, house deeds, insurance, life and other policies, mortgage and hire purchase agreements, birth and marriage certificates, as well as items like car and house keys

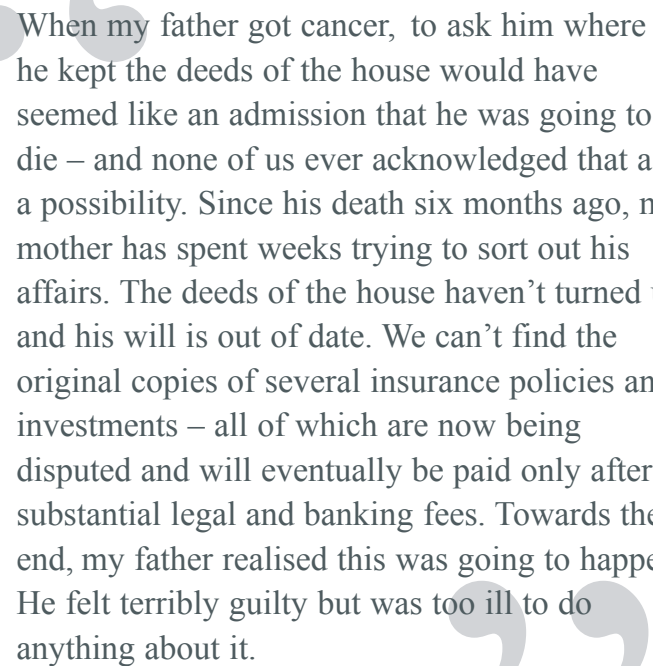
Age Concern has an eight-page form that you can use to note down this kind of information: 'Instructions for my next-of-kin and executors upon my death' (Information Sheet IS18 – see page 34 for contact details).

How easy is it for my next of kin to find my important documents if I become ill or die suddenly? How can I make it easier?



Your notes

My will is held by: _____
Digby Brown & Co, The Savoy Tower,
Renfrew Street Glasgow G2.



When my father got cancer, to ask him where he kept the deeds of the house would have seemed like an admission that he was going to die – and none of us ever acknowledged that as a possibility. Since his death six months ago, my mother has spent weeks trying to sort out his affairs. The deeds of the house haven't turned up and his will is out of date. We can't find the original copies of several insurance policies and investments – all of which are now being disputed and will eventually be paid only after substantial legal and banking fees. Towards the end, my father realised this was going to happen. He felt terribly guilty but was too ill to do anything about it.

Matthew, 40

practical|writing a will

Dying without leaving a will may cause problems for surviving relatives, often needing lawyers to sort them out. A do-it-yourself will form bought from a stationer's or via the Internet can be fine for straightforward situations, but bear in mind that a will is a technical and legal document and mistakes cannot be corrected after your death. The Law Society recommends that a will should be drawn up with face-to-face advice from a specialist solicitor who can point out the potential consequences of any bequest.

Start by making a list of all your possessions and the people or charities you want to provide for, including any property you may wish to divide in a certain way. A will can name guardians for any dependent children and record your wish to leave money or property in trust for children or grandchildren. You could also write a letter of wishes to the children's guardians or your heirs. Think, too, about arrangements for the care of pets or other responsibilities.

If you don't write a will, can you be sure that the people who are important to you will end up with a fair share of your savings and property?



Your notes

**My health directive and funeral wish's
can be seen on my WEB page:**

www.zen26008.zen.co.uk/allpages/pages/my_funeral_wish.html

practical|writing a living will

Anyone with a serious illness is always asked to give their consent before having medical treatment. You can also let your doctors know your wishes in advance, in case you become physically or mentally incapable of telling them in person. A document known as a living will (or advance directive) can specify treatment that you would wish to refuse always, or in certain circumstances. It can simply be the result of a discussion between doctor and patient, as long as the patient's wishes are written up in their notes. You can also nominate someone to speak to the doctor on your behalf if you are incapable of doing so yourself.

A living will is used most often to record a wish to refuse artificial life support, resuscitation or drugs such as antibiotics, even if this speeds up death. It cannot be used to request treatment, including any form of euthanasia.

In thinking about making a living will, you may want to consider such questions as:

- ▣ What if I become too sick to eat except through a tube?
- ▣ What if I can't talk or write or signal my thoughts?
- ▣ Who do I trust to make important treatment decisions for me?

Ideally, your wishes should be known and understood by your GP, your next-of-kin and your wider family as the instructions may not be followed unless there is widespread support for them.

Organisations such as Age Concern, Dignity in Dying and the Natural Death Centre offer advice on living wills (see page 34 for contact details).

Do I want to influence the medical treatment I'll receive if I become unconscious or unable to communicate my wishes?



I decided long ago that I didn't want to be kept alive artificially if it meant I would survive without being able to walk and talk. My gran took ten terrible years to die from dementia and would have gone peacefully and with dignity if the doctors had withheld antibiotics when she had pneumonia early on. I've also seen how a living will can help people to live without fear in their final weeks. My father believed strongly that it was morally wrong to refuse life-saving treatment, and raising the subject provoked very heated discussions. Now, though, my parents have both written a living will and are happy that I have. Our trust of each other has deepened and I think we all feel easier about the future.

Susan, palliative care nurse

Your notes

AS I have said in my health care directive
I do not wish to be resuscitated however
I have not discussed resuscitation
with medical staff.

See my WEB page:

www.zen26008.zen.co.uk/allpages/pages/my_funeral_wish.html

“ 56 of patients have not
discussed resuscitation with
medical staff ”

Taken from an ICM Research survey of 500 people for the
BBC programme How to Have a Good Death, summer

practical|thinking about the children

Hard as it is to think about, it is important to decide who you would like to look after your children if you die. Their other parent will often be the choice, but this may not always be possible or appropriate. Consider who you think would be able to offer love, warmth, stability, patience, continuing contact with friends and relatives, and the minimum of other changes to their life. Seek the agreement of your chosen guardian(s) and then write your wishes into your will. Think, too, about who you would like to tell your children that you are dying or have died, and make your wish known to those looking after you.

Children and young people are often excluded from conversations about death by adults seeking to protect them. Yet they may have questions about what is happening and what will happen in the future, both to the person who is dying and also to them. What will happen at the funeral and can they be involved? Who will look after them afterwards? Make time to reassure children and answer their questions, and find out if there is a local childhood bereavement service that could help (some are listed on pages 34–38).

Who would you want your children to grow up with if you were to die?



Your notes

I do not have any children

Jane's daughter, Ally, died of cancer. During her last few months of life her children lived with Jane, with whom they have always had a very close relationship. The children knew that their mum was dying and felt supported by Jane who always kept them informed of what was happening. They were able to go to their own schools and clubs and have friends home for tea. They all expected this to continue after Ally died. Their father, whom they hadn't seen for eight years, appeared at the funeral and insisted on taking them home with him immediately afterwards. They are 230 miles away from Jane, their friends, their schools, their toys and precious belongings and – importantly – their dad won't let them talk about their mother.

practical|planning a funeral

Arranging a funeral is a hard thing to do but it can also be therapeutic, helping you come to terms with the death of someone who has been close to you. It can also be stressful, though, especially if you have no idea what they would have wanted for their final send-off.

Have you thought about your own funeral – whether you would like to be buried or cremated, or where you would like to have your grave? Perhaps there is a place that is important to you, or somewhere your friends and relations would enjoy visiting. You could consider whether you want a religious service, what music you would like played and who should be invited. Or you might prefer one of the many non-religious services, celebrants and burial grounds, or a ‘do-it-yourself’ funeral. There are fewer regulations surrounding funerals and a much wider range of options than most people believe.

While it may feel strange at first, some people find that planning their funeral when they are able to research the subject brings a feeling of relief and a freedom to get on with their life. Whatever you decide, make sure you share your wishes with those who need to know.

Have I made plans for my funeral and shared them with family and friends?



Your notes

See: _____
www.zen26008.zen.co.uk/allpages/pages/my_funeral_wish.html

emotional|making peace

Many of us wish we had talked more to a parent, friend or colleague who has died, to have said “Thank you, you were so important” or “Don’t worry, it didn’t matter” – or to have heard the same from them. Sadly, important issues are often avoided when someone has a terminal illness, sometimes simply because it is too overwhelming even to start a conversation.

With a potentially terminal illness, people are often encouraged to focus on the positive. There’s a feeling that a conversation triggered by the fear of dying can be a big turn-off. On the other hand, having people trying to be cheerful all the time can make it difficult to express what it feels like to be dying. Perhaps instead of them saying “You’re going to be fine”, you might want them to ask “Are there some things that worry you?” Instead of being told “We’re going to beat this”, you may want to hear “We’ll be here for you, whatever happens.” We may need to encourage friends and family to feel comfortable with this change of emphasis.

However hard, it is also important to try not to be overcome by the intensity of the moment. Rather than saying “I just can’t talk about this”, try “I’m feeling a bit overwhelmed right now. Can we talk about this later tonight?”

Even harder is trying to heal a rift with someone. Some quarrels may go too deep to be overcome, and dying people don’t suddenly change character. If it feels too difficult to do on your own, it may be worth seeking the help of a counsellor, chaplain or other professional. It is now recognised that unfinished business can cause physical as well as emotional pain that can linger for years.

Could the prospect of dying help me to find the time and patience to talk more to family and friends, or even end a long-standing quarrel?



“Maxine Edgington was terminally ill with cancer when she joined a Rosetta Life project to co-write ‘We Laughed’ with singer Billy Bragg – and saw it get to number 11 in the charts in November 2005. The song was based on a photograph of Maxine and her 15-year-old daughter, taken shortly after she had been given six months to live. “I just wrote lots of things that had meaning to me and the experience somehow allowed me to release my innermost feelings. I realised that dying is not actually about me, it’s about those around me, their feelings, their needs, their ability to cope and their knowing that I love them. It’s about leaving nothing unsaid, preparing them for my departure but leaving happy memories of our last days together.”

Your notes

I have discussed the emotional and physical needs with my friends.

“80%” of people consider it important to talk about emotional as well as physical needs

Taken from an ICM Research survey of 500 people for the BBC programme How to Have a Good Death, summer

emotional|talking about dying

A 'bad' death might be defined as one where the dying person suffers a great deal of pain or other unpleasant, avoidable symptoms, or is prevented from being surrounded by their family. For all the health care funding spent on the last few weeks of life, many people suffer pain and loneliness while they are dying. Those who witness the bad death of a friend or relative often say they felt powerless to help. Doctors, too, may feel there is little they could have done.

A bad death is not likely to be intentional. It is usually the consequence of a series of decisions taken by doctors, normally in consultation with relatives and often the patient – and in the case of life support, for instance, frequently made in an emergency.

The way to have some influence is to find out the options for end-of-life care generally and the decisions that may have to be made during the final stages of a particular illness. Then comes the tricky bit: discussing your wishes frankly and in detail with your doctors, your family and, if there is one, the person you have nominated to represent your wishes. All of these people should support your choices.

Have I made my wishes clear to my family and doctors so that those who have to make decisions on my behalf can do so with confidence?



Your notes

~~I would want to be pain free even if this hastened my death.~~

See my WEB page:

www.zen26008.zen.co.uk/allpages/pages/my_funeral_wish.html

emotional|asking doctors for all the facts

Until recently, many doctors did not inform their patients when nothing more could be done to help them, believing that it was kindest to spare them the anguish of knowing they were dying. Today, things are different. The view is that people have a right to know everything their doctors know, that information can be a kind of medicine to patients as making decisions becomes part of the treatment. All the same, quite a number of doctors still withhold bad news unless the patient specifically asks to be told. Relatives, too, may often feel that this is for the best – for them it may be unbearable to have their loved one exposed to the knowledge that they are dying.

Everyone is different. Some of us want this knowledge and others don't, whether patient or relative. People may also change their mind about what they want during the course of an illness.

If you have been diagnosed with a serious illness and want to be informed as fully as possible, you may need to make it clear not just that this is your wish, but also that you can bear to hear bad news.

Would I want to know how serious my condition was?



Your notes

Yes I would wish to know how serious my condition was.

I've always been surprised by how reluctant patients' relatives are to discuss the option of discontinuing active treatment. But then when my own father was dying of cancer, I had to tell the surgeon that we did not want him to have a further operation. I knew he had no chance of recovery, and he'd always said he didn't want to go on living if he was disabled mentally or physically. Yet the conversation with the surgeon was one of the most difficult I've ever had.

He obviously believed it was his duty to carry on as if my father had a chance of recovery.

A part of me wanted to do the same, feeling that being realistic was betraying my father. I have never regretted the family's decision – though I'm also much more sympathetic to relatives in that situation.

John, 53, consultant physician

emotional|saying goodbye

Collections of letters from deceased family members, old photographs and narratives about the lives of parents or grandparents are often our dearest possessions. Such mementoes may have come about accidentally, but you may wish to create something to leave behind for your family and friends.

Something as simple as writing a letter to your family can help you stay connected to future generations. You might want to write about parts of your life that your family don't know about or feelings you find it too difficult to express face to face. You could think about writing a personal history, or leaving a 'memory box' containing items that have a special meaning for you.

These days, technology provides the opportunity to create other kinds of memories, such as audio recordings, videos and DVDs. Taking this a step further, many hospices organise creative workshops with artists, film-makers, poets, songwriters and musicians to help people to express their feelings and tell their story in order to complete their lives and prepare themselves to face what lies ahead.

Would I like to create something to leave behind for my family and friends?



Your notes

See my WEB pages: _____
www.jim-stewart.co.uk and _____
www.zen26008.zen.co.uk _____

“People ask me when is the right time to make a video. I always say now is the best time, not least because you will never again be as young as you are today,” says Josefine Speyer, psychotherapist and co-founder of the Natural Death Centre. Her husband, Nicholas, made a videotaped message in 1998, talking in a relaxed and humorous way about what was important in his life and passing on advice to his son and his friends. It was a half-hour exercise that proved extraordinarily moving at his memorial three years later after his sudden death in a car crash.”

emotional|being spiritual

For many people, there is a spiritual aspect to approaching death that may be beyond religion. Questions such as “Why is this happening to me?”, “What was my life about?”, “Who am I?” and “What is going to happen next?” go to the limit of our understanding and our ultimate spiritual concerns.

Such inner thoughts may be difficult to express. Yet there is evidence that many people with a terminal illness find it helpful and supportive to talk about spiritual concerns. Listening intently, even to jokes and throwaway lines, is the best way to engage in such conversation. Bear in mind, too, that there are different spiritual ‘languages’. For instance, a deeply religious person and a humanist may talk about things in quite different ways.

Silence itself may be one of the best ways of communicating spiritual concerns, whether it is by sharing silent contemplation or meditation, or just being with someone, holding their hand and perhaps holding their gaze.

How do I feel about spiritual matters and could I talk about them?



Your notes

- ✓ I have no belief in a after life
- ✓ I would not wish a religious funeral service
- ✓ see my WEB page. www.zen26008.zen.co.uk

check list|practical

I have:

Recorded all my personal information so that it is clear and comprehensible

Drawn up a legally binding will and had it checked by a solicitor

Considered writing a living will

Made arrangements for the future care of my children

Written down or told someone where I would like to be cared for if I am terminally ill and what I would like to have around me

check list|emotional

I have:

Talked to friends and relatives about what dying means

Agreed with family and friends what I want to know about a serious illness and what medical treatment I may wish to refuse

Thought seriously about the people with whom I have unfinished business

Talked to at least one of those people

Begun recording the memories of my life that will be there

further information and advice

Age Concern

Astral House, 1268 London Road,
London SW16 4ER

Tel: 0800 00 99 66

Web: www.ageconcern.org.uk

'Instructions for my next-of-kin and executors upon my death' (Information Sheet 18), available free or download from their website.

Association of Children's Hospices

First Floor, Canningford House,
38 Victoria Street, Bristol BS1 6BY

Tel: 0117 989 7820

Web: www.childhospice.org.uk

British Association for Counselling and Psychotherapy (BACP)

1 Regent Place, Rugby,
Warwickshire CV21 2SG

Tel: 0870 443 5252

Web: www.bacp.co.uk

Has lists of qualified psychotherapists
and counsellors.

British Humanist Association

1 Gower Street, London
WC1E 6HD

Tel: 020 7079 3580

Web: www.humanism.org.uk

For information about non-religious

Cardiff Humanists

Tel: 01443 229 278

Humanist Society of MidWales

Tel: 01654 702 883

Web: www.humanistweb.welshnet.co.uk

Humanist Society of Scotland

Tel: 0131 552 9046

Web: www.humanism-scotland.org.uk

Humanist Association of Northern Ireland

Tel: 028 9267 7264

Web: <http://nireland.humanists.net>

CancerBACUP

3 Bath Place, Rivington Street,
London EC2A 3JR

Tel: 020 7696 9003

Helpline: 0808 800 1234

Web: www.cancerbacup.org.uk

Cancer information and support service.

Child Bereavement Trust

Aston House, High Street, West
Wycombe, Bucks HP14 3AG

Tel: 01494 446648

Helpline: 0845 357 1000

Web: www.childbereavement.org.uk

Support for bereaved families.

Childhood Bereavement Network

8 Wakley Street, London EC1V 7QE

Tel: 020 7843 6309

Web: www.childhoodbereavementnetwork.org.uk

Support for bereaved children
and young people, their parents
and caregivers.

Cinnamon Trust

10 Market Square, Hayle, Cornwall
TR27 4HE

Tel: 01736 757900

Web: www.cinnamon.org.uk

Network of volunteers who provide dog-walking and fostering for pets while owners are in hospital.

Compassionate Friends

Tel: 08451 23 23 04

Web: www.tcf.org.uk

Support for bereaved parents and their families.

Cruse Bereavement Care

Cruse House, 126 Sheen Road,
Richmond TW9 1UR

Helpline: 0870 167 1677

Cymru/Wales: 029 2088 6913

Northern Ireland: 028 9079 2419

Web: www.crusebereavementcare.org.uk

Information and support for bereaved people.

Dignity in

(formerly the Voluntary Euthanasia Society)

13 Prince of Wales Terrace,

London W8 5PG

Tel: 0870 777 7868

Web: www.dignityindying.org.uk

Information on patients' rights in end-of-life medical treatment decisions. Produces a living will.

DPP: Developing Patient Partnerships

Tavistock House, Tavistock Square,
London WC1H 9JP

Tel: 020 7383 6803

Web: www.dpp.org.uk

Produces health education campaigns that help the public to manage their health and use services effectively.

Help the Aged

207–221 Pentonville Road,
London N1 9UZ

Tel: 020 7278 1114

Web: www.helptheaged.org.uk

Advice booklets include Planning for the End of Life and Bereavement.

HM Inspector of Anatomy

Department of Health, Room 630
Wellington House, 133–155 Waterloo
Road, London SE1 8UG

Tel: 020 7972 4551

Contact if you live in England, Wales or Scotland and wish to leave your

Hospice Information

Help the Hospices, Hospice House,
34–44 Britannia Street,

London WC1X 9JG

Tel: 0870 903 3903 or 020 7520 8232

Web: www.hospiceinformation.info

Enquiry service for hospice and palliative care.

The Law Society

Tel: 0870 606 2555

Web: www.lawsociety.org.uk

For a guide on writing a will and lists of specialist solicitors in your area.

Macmillan Cancer Relief

89 Albert Embankment,
London SE1 7UQ

Macmillan CancerLine: 0808 808

2020 Textphone: 0808 808 0121

Web: www.macmillan.org.uk

Information and emotional support for people living with cancer.

Natural Death Centre

6 Blackstock Mews, Blackstock Road,
London N4 2BT

Helpline: 0871 288 2098

Web: www.naturaldeath.org.uk

Support for those dying at home, and
help with family-organised and
environmentally friendly funerals.

Publishes The Natural Death
Handbook.

NHS Direct

Tel: 0845 4647 (24 hours)

Scotland: 0800 22 44 88

Web: www.nhsdirect.nhs.uk

Advice and information on any
health concern.

Rosetta Life

Hospice House, 33–44 Britannia
Street, London WC1X 9JG

Tel: 020 7520 8270

Web: www.rosettalive.org

Artist-led charity helping patients

Samaritans

Tel: 08457 90 90 90

Web: www.samaritans.org.uk

Sympathetic listening service for
despairing and suicidal people.

UK Transplant

Tel: 0845 60 60 400

Web: www.uktransplant.org.uk

How to register to become an organ
donor.

Winston's Wish

Clara Burgess Centre, Bayshell
Road, Cheltenham GL50 3AW

Tel: 0845 20 30 40 5

Web: www.winstonswish.org.uk

Support for bereaved children.

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2006.

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