

NEARING THE END OF LIFE

A GUIDE FOR RELATIVES
AND FRIENDS OF THE DYING



We never face death until
Death unequivocally faces us
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A teacher in life and in death



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Contents

INTRODUCTION	5
WHAT THE GUIDE DOESN'T DO	6
FEAR OF DEATH.....	7
DEATH AS A “MEDICAL FAILURE”	8
WHAT DO PEOPLE NEED AS THEY NEAR THE END OF LIFE ?.....	9
HOW TO TALK ABOUT DEATH AND DYING	11
HOW TO LISTEN WELL	13
Life reviews.....	15
THE DYING PROCESS.....	16
END-OF-LIFE EXPERIENCES	18
End-of-life experience or drug-induced hallucination?.....	20
What should I do if my relative is having – or not having - an end-of-life experience?	21
What happens if my relative or friend has dementia?	22
WHAT SHOULD I DO IF I CAN'T BE THERE?.....	24
BEING THERE AT THE END	25
The use of gentle touch	25
Choosing the moment to go	27

WHAT HAPPENS PHYSICALLY WHEN SOMEONE DIES?..... 29

WHEN DEATH HAPPENS 32

WHAT YOU CAN EXPECT TO FEEL IMMEDIATELY AFTER.... 34

THINGS RELATIVES MIGHT NEED TO THINK ABOUT..... 36

 Stopping life-extending treatment 36

 The family 37

 Locations 38

 Practicalities to consider 40

 At the bedside of someone reaching the end of life..... 41

SUGGESTION FOR FRIENDS 43

 What to do: 43

 What not to do: 44

SUMMARY 44

 And finally... 45

SUGGESTED READING 47

WHERE TO FIND HELP AND ADVICE..... 47

INTRODUCTION

Death is not usually a time of wonderful experiences. But it is frequently a time for healing experiences.

Dr Sherwin Nuland

Welcome to *Nearing the End: a Guide for Relatives and Friends of the Dying*. We hope it will provide support and direction for you during the difficult times when someone you love and care for is dying.

Death is an emotive subject. In our modern culture most of us have little direct or personal experience of it. As a result, we can often be ignorant or afraid of death and dying. Rather than accepting it as part of our life experience, we can find ourselves running away.

This Guide – which draws on our research into end-of-life experiences – looks at the physical, emotional and spiritual progression of the dying process, and the impact this can have on you as relatives and friends, especially if you have never been with a dying person before. (Spirituality, within this context, is concerned with the search for meaning, purpose and hope).

How we respond to death depends on the nature of our relationship to the dying person. For instance, we will react quite differently to the death of a child than to the death of an elderly relative. We may be affected by the death of a close friend more than a close relative. We may grieve more acutely over the death of one parent than the other.

Knowing what to expect can lessen any dread of what you may see and experience, and can help you to play a positive and supporting role when someone close to you approaches the end of their life.

The questions this Guide will try to answer:

- Why is there so much fear of death?
- What do dying people need?

- What is the best way to support someone – spiritually and emotionally – who is dying?
- What should you do if you need to stop life-extending treatment?
- Should you be there at the end?
- What happens as the person enters their final phase?
- What happens at the moment of death?
- How can you support yourself – before, during and immediately afterwards?

The Guide also contains practical information on the importance of good listening skills, and how to recognise and respond to what is happening as the dying person approaches death. In addition, at the back of the brochure there is a helpful ‘what you may need to think about’ section for relatives, and there are suggestions for friends.

Being with a dying person is profoundly meaningful. However, it can also throw you into turmoil and take you on a journey deep into your self, which often changes your perception of life.

As with any voyage, it is wise to be well prepared.

WHAT THE GUIDE DOESN'T DO

This Guide does not address sudden death, death from suicide, questions of where it is best to die, bereavement issues, funeral planning or the ethical implications of euthanasia.

Nor does it consider what might happen to people after death, or whether there is any form of afterlife.

Moreover, the Guide does not wish to romanticise death, or determine how death ‘should be’. Death is an intensely personal experience, influenced by every individual’s belief system and personal history. Their dying process will happen in its own time and in its own way.

FEAR OF DEATH

'Death is hard work. Death is in control of the process. I cannot influence its course. All I can do is wait. I was given my life. I had to live it, and now I am giving it back'.

(Edelgard Clavey, died January 2004:

Taken from *Noch Mal Leben Vor Dem Tod*, 2007)

It's a sad fact these days that most people in the West learn about death second-hand – usually from reading novels or watching films. But, no matter how evocatively death is portrayed on film or in fiction, it is completely different when you experience the real thing.

Until the mid 20th Century, most people died at home, with their family and community around them. Death was an accepted part of everyday life, and old age was relatively rare.

Since then, our Western relationship with death has changed greatly. We live much longer, and most of us will die in a hospital, in a hospice or in residential care rather than at home with our family. This means that remarkably few of us have been present at the moment of someone's death. As a result, there is fear and sometimes even horror just at the thought of seeing a dead body.

Many of us therefore not only view death and dying with dread, but are unprepared to deal with issues that confront us when someone we love starts to die. We don't know what to expect or how to react, or how to provide the support our dying relative or friend really needs.

This is especially true when people die in institutions. It's easy to become enmeshed in medical and clinical processes and practices, where emphasis is placed on life-extending treatment and on our own desire for our relative or friend to recover, rather than on what the dying person really needs.

DEATH AS A “MEDICAL FAILURE”

Dying cannot be made good or well-managed if there is no recognition of dying
Professor Allan Kellehear

In our Western science-based culture, a doctor's task is seen above all as saving and preserving life. Death, as a consequence, is often regarded as a medical failure.

Thus the dying process can become something of a game of pretence, instead of a meaningful spiritual progression where everyone concerned can face the truth and grow together.

Even hospices can find it awkward to draw attention to death and dying. References to death are usually tucked away on the back of brochures or not mentioned at all. The language surrounding end-of-life care is more often about pain control, medication and prolonging life than about the reality that the patient is going to die.

So, rather than having the time to prepare for death, it is not uncommon for instance, for a terminally-ill person to be receiving life-preserving medical treatment such as chemotherapy until their final moments.

Failure to name the ‘D’ word can be distressing for everyone.

Relatives may know the person is dying, but are fearful of making things worse by talking about it. The dying person may be afraid of discussing it for fear of upsetting relatives.

Therefore death becomes the ‘elephant in the room’. Everyone knows it is there, but pretends it is not.

WHAT DO PEOPLE NEED AS THEY NEAR THE END OF LIFE ?

'When you are facing the end, everything that's not real is stripped away. You're the most real you'll ever be, more real than you have ever been before.'

Walter Schels and Beate Lakotta,
authors of *Noch Mal Leben Vor Dem Tod*, 2007

Of course, the dying need appropriate physical pain control. But they also have what might be termed soul needs – to feel heard, cared-for, connected and emotionally safe. They want to be understood and accepted like anyone else.

Some people are fortunate in being able to approach their dying process at peace with themselves and with those they love. But that's not always the case. People can be frightened, confused, unable to express what they're feeling or what they need.

- They may be afraid to die.
- They may feel they're a burden to you, to their family or society.
- They may be raging at the thought of being cheated of life.
- They may feel lost and alone, and desperate for someone to ask how they truly feel.
- They may feel angry and let down by God.
- They may be clinging onto hope for a miracle cure.
- They feel as if they have wasted their life and be grieving missed opportunities.
- They may be desperate to die.
- They may want to make contact with ex-partners or estranged family or friends.

- They may want to confess to things that have happened in the past, or to ask for forgiveness. This can be painful and upsetting for relatives, but it can also be powerfully healing.
- They may also become irrationally angry, blaming and resentful towards you, or the medical and nursing staff, or the world at large.
- They may be missing relatives and friends who are unable to be with them.

If your relative or friend is becoming anxious or upset and you feel unable to deal with this, do talk to the nursing staff. The person may not be able to tell you exactly what's going on for them. Indeed, they may find it difficult to understand themselves. But they may be willing to talk to a nurse, pastoral carer, volunteer visitor, or particular friend

Do your best to be there for the person who is dying, in any way that you can, but make sure you take care of yourself too. You may feel okay about being alone with the dying person. You may want and need company. But be aware that some close family members may find the thought of sitting with their dying relative too upsetting.

Saying goodbye in person is an important process for everyone. With gentle encouragement and support, anxious or frightened relatives can often overcome their alarm and find comfort in having done so.



HOW TO TALK ABOUT DEATH AND DYING

When the end is near, most people tend to want a bottom-line, no-nonsense handling of the situation. However, I have seen families in complete denial of the impending death who refuse to participate in anything that sounds like concluding affairs. “No Dad, you are going to pull through this. We don’t want to hear about wills or insurance papers.” And the family turns its back on the dying person’s very real need to settle accounts.

Megory Anderson,
Author of Sacred Dying

Those who are dying usually know what is happening to them.

Nevertheless, when a dying person believes relatives and friends can’t cope with the truth, it can be hard for them to talk about what they’re experiencing, or ask for what they want or need. This can leave the person feeling isolated and lonely, not knowing how to reach out or say goodbye.

So, how can a meaningful conversation happen?

Those who are dying sometimes help indirectly by throwing out ‘tester questions’ to check if you are willing to engage with them.

They might, for example, ask you ‘What do you think happens to you after you die?’ They might ask if you think there is life after death. They may ask, ‘Do you think God really exists?’

On the other hand, you yourself may want to broach the subject of death with your relative or friend, but don’t quite know how, especially if death has never been mentioned before.

One of the easiest ways of opening up the subject is to ask your relative or friend who they would like you to contact if they became very seriously ill. This conveys that you know they may not recover and are willing to

talk about it. It also gives them the space to decide whether or not to respond.

If you don't feel quite ready to have this kind of conversation and you're in a hospital, hospice or care home setting, talk with the nursing staff so they can offer appropriate support.

'Heiner's friends clearly didn't want him to be sad and were trying to take his mind off things. They watched football with him just like they used to do: they bought beers, cigarettes, had a bit of a party in the room. Some of them even said "Get well soon", as they were leaving: "Hope you're soon back on track, mate"!

"But no-one asked me how I was feeling. They don't get it? I'm going to die".

(Taken from Noch Mal Leben Vor Den Tod, 2007)



HOW TO LISTEN WELL

The most important gift you can give to a dying person is to listen.

Here are a few golden rules of good listening which can help you open up communication:

Be respectful: None of us truly knows what is going to happen after death, whatever our religious or spiritual beliefs. So it's important not to force our viewpoint onto the person. This is their dying experience. It's our job to bear witness, and not to judge.

Be honest: Often in difficult situations we tend to search for the 'right' or clever thing to say. Or we deny what's happening, or make a joke of it. While such reactions are very understandable – humour has an important place too, even in death – dying is a profound process that just needs us to be there, and perhaps hold a hand. The act of sharing ourselves openly and honestly can be very liberating and soothing for the dying person.

Engaged body language. Don't be afraid to look your relative or friend in the eye. Be alert and attentive to what they are telling you, and the way they are saying it. Listen to their tone of voice and be aware of changes to their facial colour; their willingness to engage with you; their willingness to meet your eyes.

Is what they are saying really what they mean? Are they asking you something with their body language that they are not expressing with words? If so, invite them to tell you what they really want to say.

Try to put your own thoughts aside. It's easy for your attention to be emotionally hijacked by thoughts about this person, your fear about them dying, or perhaps by something else that is happening in your life which is preoccupying you or causing you distress.

You may also feel embarrassed by this kind of emotional intimacy, or fearful of seeing your relative or friend cry or become helpless and vulnerable. Breathe slowly to calm yourself.

Ground yourself by feeling your feet firmly on the floor. This will help you to be present and accepting of what is happening.

Use open questions: such as How, When, Where, Who, What, and Why (although be a little careful with Why, as it can sometimes sound accusatory or intrusive). Open questions give the message that you are paying attention, and will encourage your relative or friend to talk frankly.

Using direct questions: Asking ‘Are you frightened of dying?’ or ‘What are your fears about dying?’ provides an opportunity for honest communication. However, it can take courage to put such questions to someone for whom you care deeply.

Using indirect questions: A softer approach can be to use an indirect question such as ‘I wonder whether there’s anything you want to talk to me about?’ or ‘Perhaps there’s something bothering you which you want to tell me about?’ or ‘What can I do to help you at the moment?’ This gives your relative or friend the choice to respond, or to say no. Providing choice is empowering. They may decline initially, but will know the door is open if they want to talk about it later. Indirect, exploring questions give the signal that you are safe to talk to, and that you care.

Leading questions: You can also gently ask leading questions to find out how they are feeling, such as, ‘If you become really ill, would you like me to sit with you?’ or ‘If you become ill, what medical care would you like?’ or ‘Have you ever thought about what you want to do with your belongings?’ or ‘Have you thought about what kind of service you would like at your funeral?’ Again, this provides the dying person with the choice to respond or not.

Using short statements: These can also provide comfort. You might say ‘If there ever comes a time when you want to talk about something or you feel frightened, please do tell me’. This gives your relative or friend permission to talk in his or her own time, without expectation.

It’s okay to cry: Crying is a natural response to emotionally charged situations. Being brave enough to express your grief can have a powerful

healing effect on your relationship, as well as giving your relative or friend permission to grieve for the life he or she is leaving behind.

DON'T FEEL YOU HAVE TO TALK ALL THE TIME. Just being there quietly at the bedside is important, and can often be surprisingly peaceful.

Life Reviews

Many people who are approaching death find Life-Reviews help them validate what has happened during their life-time. Going through old letters and photograph albums with them can be particularly healing.

Some set themselves clear objectives to complete and they may need help to accomplish this. Others may begin to question their religious or spiritual beliefs. Or they may find solace in old or new faith.



THE DYING PROCESS

There are certain signs that indicate when illness or old age has tipped into a preparation for death.

- **Physical changes:** These changes are part of the ageing process. The skin can become paper-thin and pale, with dark liver spots appearing on hands, feet and face. Hair can also thin and the person may shrink in stature. Teeth can discolour or develop dark stains.
- **Their external world begins to diminish** – until the dying person no longer wants to leave the house or their bed.
- **Increased sleep:** The person begins to sleep for long periods. This can be distressing for relatives, but it's important to understand that physical exertion for someone approaching death is exhausting, and for the moment, all effort is being put into staying alive. Nearer the end, they may increasingly drift in and out of consciousness.
- **Appetite reduces:** The body knows it no longer needs fuel to keep it going, and those who are dying often lose their desire to eat or drink. They can begin to lose weight, sometimes quite rapidly. It's important not to force food or drink onto someone who no longer wants it. But do take guidance from the nursing staff.
- **Change of language:** The person may start to talk about 'leaving', 'flying', 'going home', 'being taken home', 'being collected', 'going on holiday' or making some kind of journey. They may also begin to express heart-felt gratitude to their carers and to their family as a preparation to say their farewells.
- **Special requests:** They may want something special such as to visit a particular site, or be surrounded by their favourite flower, or to hear certain music, or to have family photographs near, or to make contact with someone who has been important in their lives.

Josefine's Story

My father urged my mother to eat, but she didn't want to. She told him, "I don't have to work anymore". He accepted this, because trying to feed a dying person is like watering a dying plant.

She mostly slept. But every so often she became agitated, distressed, and very anxious which made it difficult for her to breathe despite having oxygen. It felt as if her anxiety attacks were like going into labour – and they were painful birth contractions.

We sat her up. My Dad looked into her eyes and told her: "You are my angel, you always will be my angel!"

She weakly smiled at him, and then she calmed and lay back on her pillow.

Eventually she could no longer speak, but she conveyed to us she wanted to look out of the window at the trees and parkland which surrounded the hospital.

We moved her bed to the window, and she found the will and energy to sit on the edge of her bed for several minutes, looking out at the parkland.

Then she settled back into her bed peacefully. The next evening she died with my father, my sister and me sitting by her bed, him gently bending over her, telling us how they had first met.



END-OF-LIFE EXPERIENCES

The male patient asked us to stand one on each side of him because he wanted to thank us for looking after him. He then looked over my shoulder towards the window and said, “Hang on, I will be with you in a minute, I just want to thank these nurses for looking after me”. The patient repeated himself a couple of times, then he died.

Peter Fenwick and Elizabeth Fenwick
authors of the Art of Dying, 2008

Towards the end of life, the dividing line between the outer world and inner world can be very thin. For example, we know now from research how, when they are nearing death, people are often called by an almost organic process to confront and resolve unfinished issues from their past, particularly with family members.

It is also not uncommon in the weeks or days before death for a dying person to speak of being ‘visited’ by dead relatives, friends, groups of children, religious figures, or even favourite pets. They will say these apparitions have come to “collect” them or help them let go.

The person may also talk about moving in and out of ‘reality’, and describe other-worldly realms. They may speak of embarking on a journey, or may suddenly stare at a point in the room or turn towards the window and experience a sense of amazement, joy or wonder.

Even when semi-conscious and unable to communicate to those sitting with them, it may appear that they are reaching out to take hold of something, and then feeling it between their fingers as if puzzled. They may also appear to be thinking deeply, as if they are being ‘shown’ information that they may not have considered before. The dying, and those who witness these end-of-life experiences, usually describe them with loving, reassuring words such as calming, soothing, greeting, comforting, beautiful, readying.

It is not known how many dying people have such visions and experiences. But research does suggest that they happen in all cultures and religions, occurring generally within weeks, days or hours of death.

However, it is probable that many end-of-life experiences are not reported, because either the dying person is afraid of appearing confused or distressed, or believes he or she will be given medication to stop them happening.

Carers may keep quiet about them because they feel it is not professional to talk about such things. Or they simply do not have the time to sit with the dying, and therefore miss them.

Relatives may not speak about such experiences to staff or to family and friends for fear of ridicule or disbelief.

Nevertheless, our research suggests that end-of-life visions and dreams hold profound meaning for the dying, and help them come to terms with their dying process.

Whether dying persons are telling us of the glimpse of the next world or conversing with people we can't see, we should consider ourselves immensely blessed when it happens.

If we don't make the mistake of assuming they are 'confused' we are likely to feel some of the excitement they convey.

For we are witnessing the momentary merging of two worlds that at all other times remain tightly compartmentalised and mutually inaccessible.

That merging is what I mean by the spirituality of death.

L. Stamford Betty,
taken from 'Are They Hallucinations or are They Real?'
Omega, 2006

End-of-life experience or drug-induced hallucination?

The difference between genuine end-of-life experiences and drug-induced hallucinations is clear to nursing staff and to patients.

People who have drug-induced hallucinations will describe such things as the wallpaper moving, the carpet undulating, insects crawling up walls, strange animals walking around on the floor, or devils or dragons dancing in the light.

They may ‘pluck’ at their sheets or at the air, and shiver. These hallucinations are generally experienced as annoying rather than frightening, and doctors can control them with medication.

In contrast, people who have end-of-life-experiences seem to be calmed and soothed by them. They appear to help the person to let go of the physical world and overcome their fear of dying.



What should I do if my relative is having – or not having – an end-of-life experience?

These End-of-Life Experiences are real to those who have them. Listen to them without judgment or dismissal. It is important to remember that this is something they are actually experiencing, and that it is not for us to say whether it is authentic or imagined.

It is crucial that the dying person's reality is supported. Practice your listening skills (pages 12-13) to help your relative or friend know you really care about what is happening to them, and that you are willing to hear about it.

Tell them how much it means to you to know they are being reassured, even if you are unable to share their visions.

Put any disbelief or prejudices aside, and truly listen. Help them by asking questions such as 'What does he/she look like? How many have come to see you?' 'What does it feel like, or look like?'

If your relative or friend is not having this kind of end-of-life experience, that doesn't mean they are having a 'bad death'.

We don't and can't completely know what goes on in the mind of a dying person, or what they may be experiencing while asleep, confused, or in a coma. Reaching out a caring hand is very reassuring, as well as quietly saying loving words of farewell.

It is also important to know that some people become distressed by seeing end-of-life visions. If this is happening, tell the nursing staff, and they will provide medication to help relax and soothe the person.

What happens if my relative or friend has dementia?

Judith's Story

When my mother was suffering from the terrors of Alzheimer's, rarely being "in this world", she recovered sufficiently to have a day of complete clarity with me, when we were able to say all we needed to say.

On the final day, just before she died, she murmured something which meant she was making a reconciliation with my dear husband, which in turn, allowed me to move forward.



Dementia or severe cognitive impairment is a growing issue in the elderly. More than 100,000 people die with dementia in England and Wales each year. Research suggests the overall prevalence of dementia in those over the age of 65 is about 5%.

The impact dementia has on the dying process can be confusing and alarming. It can be difficult, and sometimes impossible, to reach the person, or understand what they are saying or what they may want.

However, we have come across many reports of those with severe dementia suddenly becoming lucid enough to say farewell to those around them, or talk coherently about seeing dead relatives.

So don't dismiss everything they say as disjointed ramblings. And be available in case this person does return to clarity and wants to make a final connection.

Mark's Story

I was present with my fiancée at the bedside of my future mother-in-law. Hers was not an easy death. She seemed to find it hard to let go because she was crying out and sounding very confused. But for me, the experience was strangely gentle, and also rather prosaic.

Eventually, we noticed her breathing had altered. We called the nurse into the room, and she confirmed that she was dying. We held her hands, and I could feel the warmth and the life ebbing out of her body from her limbs upwards, until the final breaths about 15 minutes later.

She had always been very private about her fears around dying. But hers was, despite the distress of her final days, as good a death for her as we could reasonably have hoped for. This was the first time I had been at the bedside of someone as they die, and I'm very glad I was there.



WHAT SHOULD I DO IF I CAN'T BE THERE?

When it's not possible to spend time with the dying person, you can still feel connected to them.

Memories of someone who is dying or has died are often bitter-sweet. Reminiscences become part of who you are. It's important to find something that helps you achieve a sense of completion.

You might, for instance, want to create a special space where you can light a candle and say prayers – or whatever you need to do – to say goodbye.

Perhaps write them a letter expressing the things you wanted to say but never did. If they have already died, you might want to burn the letter ceremonially or bury it.

Maybe you need to go into nature to say your farewells, or to buy a special tree or flower and plant it in their memory.

Funerals are of course central to the grieving process. They allow us to share our grief and to take part in an established social and personal ritual of saying goodbye, surrounded by others who also knew and loved the person.

If you find you are struggling with your grief, or holding onto unresolved feelings for this person, do consider talking to a bereavement counsellor.



BEING THERE AT THE END

Accompanying someone to the point of death is a remarkable experience. Nonetheless, you may find the anticipation emotionally and mentally exhausting. At times you may fervently wish for it to be over. And then you can feel guilty for thinking like this. But it is a normal and understandable response to a very stressful situation.

Remember: Hearing may be present until the end, so never assume the person is unable to hear you.

- Talk as if they can hear you, even if they appear to be unconscious or restless.
- If possible lower lighting until it is soft, or light candles, making sure they burn in a safe place. Try to keep bright sunlight away from their face and eyes.
- You can create a peaceful, soothing atmosphere by playing a favourite piece of music or songs softly in the background.
- You might wish quietly to read a favourite poem, or a spiritual passage or religious text that means something to them.
- Strong physical contact can be painful or invasive. It is best to sit beside the bed and gently hold their hand.
- If appropriate arrange for end-of-life prayers to be said by a chaplain, vicar or priest, or by other faith ministers

The Use of Gentle Touch

Gentle touch can provide comfort for the dying, and help communication on a deeper level. Even when a person is unconscious or semi-conscious,

they might be able to respond with faint pressure from their thumb, or for example twitch a toe.

A light massage using aromatherapy oils such as rose, geranium or lavender can soothe and reduce discomfort and distress. Those who are dying can also find gentle hand and foot massage relaxing and calming.

Claire's Story

My friend was awe-inspiring in how she put all her affairs in order and planned her own funeral arrangements. We sang songs and we laughed until the end came.

The biggest lesson for me was that although she appeared deeply unconscious – she hadn't spoken or stirred for a number of hours – she could still hear.

A nurse came in to check on her, and loudly said to me 'She is on her way now. She can't hear you and is in no pain.' At which my friend opened her mouth and loudly said ' I can and I am'! Her final words. She never opened her eyes or spoke again.

So I think it very important to be aware that a dying person may well keep their hearing even when it may appear they have lost all senses.

When she was declared dead the nurse lit candles and scattered petals on her pillow and made her look beautiful.

One of her requests to me had been to always make sure that she smelled sweet throughout the dying process, so I had given her French perfume, and over the last few days had dabbed this on her wasted body.

She had a desire to eat chocolate, so chocolate was bought and she ate as much as she wanted.

I believe she found tremendous support and strength in having someone with her who had the same spiritual outlook as herself. She knew that I could and did cope.

CHOOSING THE MOMENT TO GO

You get times when people suddenly seem to perk up just before they die. They seem to get better – enough sometimes to say goodbye to a relative. It's really strange. It's like an extra energy that they've got just prior to them dying. They become coherent – and then they seem to just go. It's almost like they know – and they are waiting for someone to come. Sometimes they will just hang on until the person gets there. The person can just walk into the room and they go. It's like they wait for the time to be right for them. It's strange, but it happens a lot.

Nursing home carer

More than we realise, people appear to choose the moment to die. They seem to know who is strong enough to face the moment with them, and to protect those who aren't.

It is not unusual for someone to hang on to life against medical odds until a relative or friend arrives at their bedside, or until a special anniversary or birthday. As mentioned before, a person who is confused, semi-conscious or unconscious may become lucid enough to be able to say a final goodbye before dying.

Some relatives may feel compelled to visit the dying person in the middle of the night, or experience being 'called' back to the bedside, for example, from a coffee break, just in time to be with them as they die.

In contrast, some people seem to make a deliberate choice to die alone. We have collected many stories of the dying who appear to wait until everyone has left the room – even for the shortest time – before they die.

We have also heard accounts of the dying seeming to choose to die with only particular people in the room.

It can be difficult when someone dies just as you have taken a break from being with them for many hours or even days. You may feel hurt that they haven't 'chosen' to be with you at the moment of death. Or you feel guilty for believing you have let the person down by missing the crucial moment.

It may help to know that sometimes a person needs emotional freedom to die in peace on their own, or, perhaps because emotions are running high, they choose to die in the presence of other relatives or friends who are more able to cope with it.

Jane's Story

When I was with my father while he was dying, I had been there most of the night. In the early morning having checked with the nurses I went to have some breakfast and as soon as I got there they phoned and he had died.

The same thing happened with my uncle. I was with my aunt with him while he was dying and we went to get some lunch, and he died.

I felt there was something here about some people being able to die at a time when they weren't being 'held back' by the people they loved.

Mind you I did feel cheated when after all that being with I missed the actual departure and I know my aunt still some 12 years later has a lot of regret about not actually being present when her husband died.

Regarding this it was very important to me to do some ritual about actually saying good bye. He (my father) did not want any funeral or such like but I really needed to do something to acknowledge his life and his going.

So I took his ashes out to sea and scattered them from the boat - he had been a naval man. There was then a sense of completion about his going.

I know for my aunt, who was 74 when my uncle died, she had never seen a dead body before so I took her to see him and this was very important for her having missed the actual death.

I think the ritual of the funeral was extremely important for her. She kept some of his ashes and still has them with her.

WHAT HAPPENS PHYSICALLY WHEN SOMEONE DIES?

It is impossible to predict when death will actually happen. People can hover between life and death for a long time, and it is easy to miss the final moment.

There are certain signs which indicate the person is preparing for death.

- **Congestion in the lungs:** The person's breath becomes laboured and 'gurgling', which can sound alarming. However, this is quite normal and caused by secretions pooling in the back of the throat.
- **Yawning:** Even when unconscious or semi-conscious, the person may often yawn. This is a natural response to draw more oxygen into the body.
- **Coldness in the limbs:** Sometimes the person's hands, arms, feet and legs become cold, with the skin colour changing to a pallid yellow as blood circulation slows down. However, this many not happen until right at the end.
- **Tea-coloured urine:** The lack of fluid intake and kidneys beginning to shut down means the person's urine will become concentrated and tea-coloured. It may also have a pungent smell, or cease altogether.
- **Incontinence:** As the muscles of the body cease to function, there may be a loss of bladder and bowel control. With patients who are unconscious, nursing staff will insert a catheter.
- **Agitation and restlessness:** Dying people who are confused or semi-conscious can become quite distressed. They may also cry out. Nursing staff will often give medication such as morphine to calm them down.

- **Dark bruising:** As the body system slows down, blood may coagulate, or pool, particularly at the base of the spine, with patches which look like dark purple bruising.
- **Smell:** The shutting down of the dying person's system and the changes of the metabolism from the breath and skin and body fluids, create a distinctive acetone odour. Be aware that this will happen, and that it may at first be uncomfortable for you.
- **No longer responding:** The person can no longer speak even when awake, and will take rasping breaths through an open mouth. This can sound like loud snoring which can be very disconcerting to listen to. It also makes their mouth dry. You can help to ease this by gently wiping mouth and lips with a damp cloth.
- **Breathing pattern change:** The person can alternate between loud rasping breaths to quiet breathing. Towards the end, the dying will often breathe only periodically, with an intake of breath followed by no breath for several seconds, and then a further intake. This is known as Cheyne–Stokes breathing. This can be upsetting to witness as the person seems to have ceased breathing only to start again.
- **When death happens, it happens very quickly. There is no doubt about what is taking place.** Sometimes the person will give several outward pants as their heart and lungs stop. Others may give a long out-breath followed quite a few seconds later by what seems another intake of breath. This may be repeated for several minutes, which can be alarming if you are not ready for it. However, this is only the lungs expelling air.

Other indicators are very clear:

- There will be no pulse.
- Skin colour rapidly drains to a sallow yellow.
- Facial expression changes, or loosens. You may not feel you 'recognise' the person anymore. Some people look remarkably at peace.
- There is a sense of no-one being 'home'.

David's Story

As I watched the death of my partner, his 'consciousness' appeared to lift out of his body steadily over a period of days – with the process appearing to accelerate in the last few hours of his life.

It started with his feet, moving upwards. His head and upper body were the last areas to appear animated by his 'life force' before his consciousness finally separated from his physical shell.

I sat with my partner's body for some hours after the moment of physical death.

I felt as if my vigil was supporting the departure of his spirit, and it also gave me an opportunity to let go and begin my grieving process.



WHEN DEATH HAPPENS

Denise's Story

I knew that my father was going to die that day and decided to leave him alone with my mother.

I had no problem leaving him as he had told me he was 'ready to go', wasn't frightened and very calm. We spent a lot of time talking while I nursed him, and without actually saying it, we had said our goodbyes.

I wandered around until I just felt that he had died, returning home to find he had indeed died 20 minutes before. I felt mixed emotions of relief, as he was no longer suffering and fearful.

I had not seen a dead body before. I stood nervously, with my back to the wall, at a distance, plucking up the courage to approach.

It was then I felt the pressure of hands on my shoulders and a voice whispering in my ear 'I'm OK'. This was followed by the overwhelming sensation of a very strong force moving far away with immense speed.

I knew it was my father. Any fear I had I felt melted away. It gave me the strength to deal with the duties associated with death. Much later I realised this experience had removed my fear of dying.

In medical terms the dying process is viewed as a biological closing down of the body's systems. It is difficult to know during this process when the person's consciousness dies. However, the moment of death can be experienced in many ways. It can be an intensely spiritual encounter. Alternatively, it may feel rather prosaic. The essence of the person has gone, leaving behind a body that can seem like an empty envelope.

You may feel grief. You may feel numb. You may feel relief. It may feel like an anti-climax – especially in a hospital or institution, where nursing staff may be coming in and out to deal with necessary practicalities.

If it's what you want, staff may also leave you alone for a while with the body – and that can be both reassuring and sometimes unexpectedly peaceful.

Sometimes, those present report less immediately physical experiences.

Carers and relatives may talk of seeing vapours leaving or hovering over the body. Others have described loving light filling the room or a sudden change in room temperature. Or there may be a heaviness in the air which takes time to clear. Or there may be other strange phenomena.

Relatives and friends who were not there may experience 'seeing' or sensing the dead person and knowing the exact time of death before they are officially informed. These 'visitations' are usually comforting and reassuring, and never forgotten.



WHAT YOU CAN EXPECT TO FEEL IMMEDIATELY AFTER

It's not unusual after someone has died, especially when you were present at the time, to feel disconnected from people, places or things. It can feel as if you are in a dream, or looking at life through frosted glass. This can be especially difficult when you are thrown into the intensity of making funeral arrangements.

It can be hard to explain how you are feeling, especially to those who have never witnessed a death. But feeling strange or disconnected from reality is understandable when we have watched someone die. Life will never be the same again. It can't be when we have witnessed something as profound as this.

You may feel you don't know what to do with yourself. You can find yourself aimlessly wandering around, feeling lost and alone and deeply questioning everything in your life.

Over the following weeks and months, for some there may be emotional and spiritual rawness that throws up feelings of anger as well as grief. For others, it can be truly liberating. We only really know what we need to deal with as we go through our grieving process.

Sue's Story

When my mother died I experienced something 'leave' with her last breath. It was for me quite a spiritual encounter. For several days after I also felt something intangible but very real leave me. Yet at the same time I experienced a sense of my mother's essence settling into me. It

felt uncomfortable and disconcerting, and it was a couple of weeks before I felt 'me' again. In the longer term, I realised I had absorbed something of my mother's spirit, and that continues to live within me.

It was different with my father who died seven years later. At the moment of his death it felt to me more like a switching off than something actually leaving his body. I then realised that the moment of death happens in different ways.

The feelings I subsequently experienced were the same when my mother died, only sharply intensified. It was hard to accept I no longer had parents. Even though I have a family of my own, I felt alone and as if I was no longer attached to anything - made more poignant when clearing the home they had shared for over thirty-five years. Much of this ended up in plastic bins bags with a charity shop. I think that was the saddest part - and the awareness that this will happen to me too one day.



THINGS RELATIVES MIGHT NEED TO THINK ABOUT...

Stopping Life-Extending Treatment

Many people make it known that they would not wish to be resuscitated or to receive life-prolonging treatment if their quality of life was to suffer due to a debilitating illness. For other patients, when it is clear to the medical team that treatment is not helping their condition, and that they are beginning to die, the doctors will decide to begin to stop, or withdraw these treatments.

In the case of an emergency admission to hospital, for example after a major stroke or heart attack, you may feel it necessary to inform medical staff about the wishes of your relative. However, it is important to understand that any decision to stop life-extending treatment is jointly made with doctors, and no pressure will be put on you for this to happen. The doctors will usually try to understand your thoughts, but they are not asking for your permission to withdraw life-prolonging treatments.

It can be very upsetting to be involved in such discussions on behalf of a relative who is unable to make their wishes known for themselves. So, take your time to talk through any concerns you may have with medical staff, and also with other relatives.

Once a decision to withdraw life-prolonging treatment has been reached, your relative may be placed on an End-of-Life Care Pathway, and it will be clearly stated in their medical notes.

When initiating an End-of-Life Care Pathway, doctors and nurses focus on making the person as comfortable as possible. Fluids may be stopped and the person will receive only essential medication for the relief of distressing symptoms (pain-relief, anti-sickness drugs, etc.), and nursing care such as regular mouth-care, washing and turning. Nursing staff may also insert a catheter into the bladder and give medication to ease the secretions in the back of the throat when the person is no longer able to cough.

It is difficult to gauge how long someone may take to die. For those sitting with the dying it can often feel like a very long time. You may also at times feel distressed – and even guilty – about your relative being on an End-of-Life Care Pathway. However, it may help you to know that this offers the most comfort for your relative, and support for you and your family.

The Family

The death of a close relative is a critical time for families. Although it usually falls to the immediate next of kin to provide support and care, the dying process can bring about a togetherness within the extended family unit that usually only happens on anniversaries and holidays. This togetherness can be – although sad – a wonderful shared experience for all concerned.

Sally's Story

I had never seen a dead person. Mum was to be my first and I was uncertain how it would happen, what it would be like and how I would know when she was dead. All four of us sat together round Mum's bed, taking turns to hold her hand and chatting quietly, all individually trying to prepare ourselves for losing this important person in our lives. Around 4.00pm, Mum's breathing became very laboured, stopped once or twice and then finally, an hour or so later, she stopped breathing altogether and died. It was an incredibly emotional moment. My younger sister and I wept loudly, my older sister left the room in tears to be alone, and my brother stood silently at the end of Mum's bed, just staring at her body in disbelief. I shall never forget it. It was an honour and privilege to be there and share that experience with my family.

Having said that, death – especially of the second parent – can bring back into focus family feuds and other unresolved issues which may have lain dormant for years. This may be a good time to resolve past hurts and grievances. However, do be aware that emotions will be running high, and tempers can fray.

Family members can react differently. For example:

- Some will have had a warm relationship with the dying person. Others may be harbouring dislike, grudges or anger.
- Some will freely embrace what is happening. Others may want to deny that the person is dying.
- Some will be happy to stop life-extending treatment. Others may not want this.
- Some may feel horrified or even sickened by the person's deterioration, and find it difficult to sit with them.
- Relatives who live at a distance may feel guilty for not being there. Others may avoid contact due to family conflict.
- Relatives who care for the dying person may feel their own life is on hold, and become angry and resentful with the rest of the family for not pulling their weight.
- Sibling rivalry may surface and divide loyalties, causing further resentments and disputes.
- Some may be holding on to secrets that no-one else knows, and be finding this distressing.

So, be prepared for this to be an intense time which needs patience and understanding, and a willingness to communicate openly and truthfully with the rest of the family.

Locations

At home

Many people prefer to die at home surrounded by familiar belongings, and where friends can come and go. If you and your dying relative want this to happen, talk through the practicalities with your GP and District Nurse to see if this is feasible.

As main carer you are more in control of what is happening to your dying relative than, for example, in hospital. Your GP and District Nurse will be your main source of medical support, or Macmillan Nurses if your relative is dying of a terminal illness. With their help you may need to arrange with your local Health Authority for special equipment such as an air mattress, special bed and lifting equipment to be supplied

Although rewarding, caring for someone at home can be physically and emotionally demanding. You need to think about your own needs. So it is important to find extra help to give you support, and time for breaks and sleep.

Hospices

Many hospices are run by charitable trusts dedicated to helping those with terminal illness. Due to the nature of their work, hospices provide a range of services and support for relatives of the dying, or those nearing the end of their life.

Most hospices are short-stay. They work towards stabilising terminally-ill patients to enable them to spend quality time at home before being readmitted, if required, for the final weeks or days. Often hospices have special rooms set aside for relatives to rest or to stay overnight.

Nursing Homes

Nursing homes, which are either privately owned or run by the National Health Service, cater for long-term elderly residents who are no longer able to cope on their own. However, family members can feel guilty for putting their relative into a nursing home, especially when the person has been fiercely independent. Consequently visits may become emotionally demanding and stressful for both resident and relative.

Nursing Home staff usually encourage regular visits from relatives, and are eager to consult relatives on continuing treatment and care of the elderly person, especially when the resident's health is failing. They do not usually provide rooms for relatives to stay overnight, but are normally happy for you to spend as much time as possible with the person who is dying.

Hospitals:

More than half of us die in hospitals. Hospitals are bustling, busy, noisy places which deal in helping people to get well. There are minimal facilities for relatives who spend extended periods of time with a dying person. You may be lucky enough for your relative to be put into a side-room. Insist on this if you can. Otherwise, your relative will be put in the main part of the ward, which can add to an already distressing situation.

Essentially, hospital may be the best place for your relative or friend to die, especially if they require specialised nursing care. Consequently it is important not to feel guilty if, for example, the dying person cannot be taken home. Usually you will be allowed to visit or remain at the bedside for as long as you wish.

Practicalities to consider

Here are a few suggestions to help you cope, whether your dying relative is in a hospice, nursing home or hospital.

- First of all, be prepared to cancel your life! When someone is dying you will probably find it impossible to do or to think of anything else apart from being with them or preparing for their death. And when you are not with them you will be on red alert every time the telephone goes.
- You may feel as if you are walking around in a bubble, unable to relate in your usual way to 'normal' life. Everyday conversations may seem trivial and irrelevant. You may find loud, busy or noisy places like supermarkets or restaurants hard to handle.
- Explain clearly to your children and other family members what you are going through. Additional stresses and strains can feel hard to bear. Tempers can easily fray.
- Get someone to stock up the fridge and larder with ready-made meals and soups. You probably won't feel like cooking when you come home. But do make sure you have something hot and nourishing to eat every day. You need your health and strength.

- Tell friends what is happening. People are amazing when they know they can be of support and help. It is comforting to have family friends sitting with the dying person. So, do offer friends the opportunity to come and say their farewells. Some will gladly do this. Others may not, preferring to remember the dying person as they were.
- Make sure you have plenty of credits for your mobile telephone, and remember to charge it regularly. You will find yourself making and taking lots of calls from family and friends. In a hospital, this usually has to be done in an echoing corridor with trolleys and people clattering and rattling by.
- If required, make sure you have plenty of change for the car park. Some machines only take coins. Be very careful when you are driving, as you will be preoccupied with what's going on.

At the bedside of someone reaching the end of life

It can be alarming to see the person you love attached to a syringe-driver, monitors and a respirator. It can be hard too to be with someone who is semi-conscious, in physical or emotional distress, and who may be moaning or crying out. You may yourself feel very anxious and helpless. You may also feel overwhelmed, vulnerable and lonely, especially when nursing staff are busy with other patients.

- Make sure you take plenty of breaks. It can be hard to find a private place when things get tough, but there are often quiet rooms in hospices, and hospital chapels are usually open round the clock.
- You may feel guilty when you go home knowing you might never see the person again. That's normal. Just make sure when you leave you say your goodbyes. These farewells can mount up as the days go by.
- Most hospitals, nursing homes and hospices will not provide food for relatives. Sandwiches, especially from hospital vending-machines can

be pretty dismal, and to keep your strength up you will need more than just snack food. So do consider bringing in your own food. Hospital cafés can be closed at weekends, and local cafes may be closed on Sundays.

- Staff are usually happy to give you coffee and tea as you sit by the bedside. But it might be an idea to bring in a thermos so you can have a drink at any time. Drinking plenty of fluids is very important, particularly as hospitals and hospices can be dry, hot environments.
- If you are in an open hospital ward, don't hesitate to pull the curtain round to get some privacy. Let the nursing staff know that's what you want to do.
- Bring in a comfortable pillow and blanket - especially if you are staying overnight. Hospital chairs have upright backs and are extremely uncomfortable after a couple of hours. If your relative is in a hospital side-room, you may be able to bring in a bed roll so you can sleep on the floor. **But check with the nursing staff first.**
- Don't be afraid to knock on the hospital Chaplain's door. They can also arrange for a priest, rabbi or ministers from other religions and denominations to come and talk to you, or to say end of life prayers with you and your dying relative or friend. They will often come in the evening, if appropriate, to say prayers with the dying person even when you may not be there.
- Let the nursing staff get on with their job of providing nursing care. It is usually best to leave the room when they are washing and making the dying person comfortable. But don't be afraid to ask staff to provide extra mouth-care or turning, or to inform them when your relative becomes distressed.
- Above all, don't be hard on yourself. This is a very difficult and challenging time. Phone calls and visits quickly become part of your daily life, and the process can seem grindingly endless. But remember that in comparison to the dying person's life-span, their dying process is a short, precious time for you, and for them.

SUGGESTION FOR FRIENDS

It is important for you to be able to say your goodbyes to your dying friend. Even so, for some families it can be difficult to accept friends being present during the dying process. Other families will be delighted and relieved to have you there. You may need to feel your way through this.

Providing the right kind of support to relatives of the dying is important, as well as being non-judgmental about how relatives and other friends may be emotionally affected by what is happening. It's little acts of kindness that count, and will be remembered.

What to do:

- Check with the family if it's okay to say your goodbyes in person. You may want to do this on your own, or while family members are present. Just let them know what you would prefer.
- If you are able to, offer to sit with your dying friend. This can be very comforting for families. Be sure you feel able to provide this support, as being with someone who is dying can be hard emotional work.
- Send regular short texts or emails to relatives, without expectation of an answer. It is comforting for the family to know you are thinking of them.
- Offer to baby-sit, cook meals for the family, or to fetch and carry youngsters to and from school. You may be needed to take other relatives to seeing the dying person.
- Don't take offence if you are not wanted! The offer of unconditional help is often enough.

What not to do:

- Don't send Get Well cards when you know someone is dying. It can be very upsetting for relatives to read them.
- Don't expect relatives to spend hours on the phone talking to you. They will have enough to do caring for their dying relative.
- Don't expect relatives to engage in conversations that do not revolve around the dying person, or the care they are getting.
- Don't ask questions of a dying person who is too ill to respond. It can be stressful for them to try to communicate with you.
- Don't be falsely jolly. Be sensitive and be yourself.

SUMMARY

It's okay to be afraid of facing the death of your relative or friend. But the gift of being prepared to face it with them is priceless.

- Remember that hearing often continues to the end.
- Remember just how awkward many people, and even medical professionals, still are with death.
- You may have to make difficult decisions about life-extending treatments.
- Try as far as possible to make sure that the dying person is cared for in a quiet and loving environment.
- Be aware that death can bring up unresolved family issues that may have lain dormant for a long time.
- Be willing to be open and receptive to your relative or friend wanting to talk about their dying process. If you feel you cannot do this, do talk to carers who can support you.

- Listen to what your friend or relative wants or needs, and try to ensure that those needs are met.
- Listen to what the dying person is describing during the last weeks and days of life, and be supportive to whatever is happening for them. It is their dying process.
- Help to create a sacred space as they enter their dying process – perhaps with gentle massage, or lighting candles, or playing beautiful music.
- If appropriate, be open to being there at the end, knowing this can be one of life’s most enriching experiences.
- You may – or may not – experience strange phenomena around the time of death.
- After being with someone who has died, be aware that you may feel strangely disconnected from reality for a period of time, and that you may find yourself asking questions about your own life.
- If at any time, and especially after several months, you feel caught up with grief and unable to move forward, do seek help from a professional counsellor.

And Finally...

We hope this Guide may help you to face the challenges of being with relatives or friends as they journey from life into death.

It is never an easy time, and there is always much to reflect upon. But, being present at the time of death can be a profoundly rich and moving experience, on many levels.

We wish you well with whatever you are dealing with, and hope you find peaceful acceptance within this extraordinary adventure.

THE ART OF DYING

Peter Fenwick and
Elizabeth Fenwick

Continuum Books 2008



THE D-WORD: Talking About Dying

Sue Brayne

Continuum Books 2010

www.d-word.co.uk

www.continuumbooks.com

END-OF-LIFE EXPERIENCES: A GUIDE FOR CARERS OF THE DYING

To order copies of this brochure, or to find out about workshops for carers, relatives and friends of the dying, please contact:

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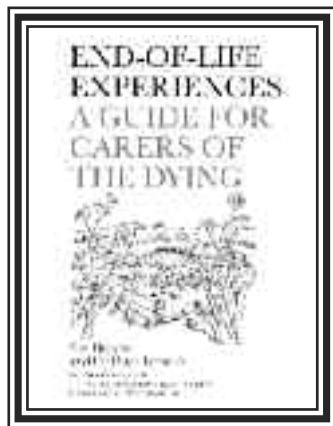
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WHERE TO FIND HELP AND ADVICE

Age Concern Head Office

Tel: 0800 00 99 66 – open 7 days a week

Website: www.ageconcern.org.uk/AgeConcern/contactus.asp

Citizen's Advice

Contact your local branch

Clinical Nurse Specialists – palliative care

Contact your local hospice for details

Cruse Bereavement Head Office

0208 9404818

Macmillan Nurses

Contact your local hospice or GP for details

Palliative Care Teams

Contact your local hospital or Health Care Authority for details

The Natural Death Centre

Helpline: 0871 288 2098

Website: www.naturaldeath.org.uk

The Samaritans

Contact your local branch

Sue Brayne

workshops for carers, relatives and friends of the dying experience and the spiritual aspects of end-of-life care.

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Sue Brayne MA, Post Grad Dip Couns, PGCE

Sue Brayne originally qualified as a State Registered Nurse. She went on to train as a Life, Death, and Transition Facilitator with the Elizabeth Kubler-Ross Foundation. After completing an MA in the Rhetoric and Rituals of Death in 2001, Sue began working with Dr Peter Fenwick as a Honorary Researcher into end-of-life experiences. She has several academic papers published on end-of-life experiences and provides educational workshops for carers, relatives and friends on the dying experience and spiritual aspects of end-of-life care. Sue is also a psychotherapist, specialising in trauma and bereavement work, and is a trained Further Education teacher.

Dr Peter Fenwick

Dr Peter Fenwick is a Fellow of the Royal College of Psychiatrists and has worked mainly in the field of neuropsychiatry and epilepsy. He has held Consultant posts at St Thomas's Hospital, the Westminster Hospital and for many years at the Maudsley Hospital and Kings College Institute of Psychiatry, the Radcliffe Infirmary in Oxford, and now at the Department of Neuropsychiatry at Southampton University. He has a long standing interest in End-of-Life Experiences, as well as in Near-Death Experiences (NDEs), and featured in the first UK documentary film shown on NDEs in 1987. He is now leading a multi-disciplinary project, researching End-of-Life Experiences and their importance for the dying and the bereaved.