

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



Sue Brayne
and Dr Peter Fenwick

IN ASSOCIATION WITH
THE CLINICAL NEUROSCIENCE DIVISION
UNIVERSITY OF SOUTHAMPTON

First published in Great Britain in 2008
Copyrights © 2008 by Sue Brayne and Dr Peter Fenwick



GRATEFUL THANKS TO PETER AND JULIET
KINDERSLEY AND THE SHEEPDROVE TRUST FOR
THEIR GENEROUS GRANT WHICH SUPPORTED THE
PRODUCTION ON THIS BROCHURE.

WE WOULD ASK THAT IF YOU WANT TO QUOTE
FROM THE BROCHURE, YOU RESPECT COPYRIGHT BY
REFERENCING THE AUTHORS.

*To order more copies of this brochure, or to order
Nearing the End of Life: A Guide for Relatives and Friends of the Dying,
please email: Sue@braynework.com*

Dr Peter Fenwick: Peter_Fenwick@btinternet.com

Or both brochures can be ordered through
www.d-word.co.uk

CONTENTS

INTRODUCTION TO
END-OF-LIFE-EXPERIENCES (ELEs) 6

A SHORT HISTORY OF ELEs 8

SO, WHAT ARE ELEs? 10

1. *Transpersonal* 10

2. *Final Meaning ELEs* 11

HOW DO YOU KNOW ELEs ARE NOT
JUST DRUG-INDUCED HALLUCINA-
TIONS OR DEMENTIA? 13

WHY ARE ELEs IMPORTANT
TO THE DYING PROCESS? 15

WHAT TO SAY, AND HOW TO SAY IT 17

IS THERE ONE RIGHT TIME
TO TALK ABOUT DEATH? 19

IMPORTANCE OF GOOD
COMMUNICATION SKILLS 21

USE OF GOOD QUESTIONS 24

Direct question 24

Indirect question 24

Leading questions 25

Short Statements 25

I DON'T THINK I COULD DO
SOMETHING LIKE THIS 26

HOW DO I HELP SOMEONE COME TO
TERMS WITH UNFINISHED BUSINESS 27

BEING A BENEVOLENT WITNESS 28

MY COLLEAGUES WILL THINK
I'M MAD! 29

IN SUMMARY 30

REFERENCES 31

INTRODUCTION TO END-OF-LIFE- EXPERIENCES (ELEs)

Welcome to this educational guide to End-of-Life-Experiences (ELEs).

Nursing home carers and hospice workers often say they feel ill-prepared to deal with existential issues, or difficult questions about death and dying, that may arise during the last few weeks and days of a person's life.

We hope this guide will provide support for you in end-of-life care, as well as helping you gain a better understanding of the dying process.

What it's not intended to do is dictate, predict or determine how death 'should be', nor does it wish to romanticise the end of life in any way.

Death is a singularly personal experience, coloured by the person's own life experiences, beliefs and culture.

In addition, many of the dying find death

frightening to contemplate, and may deny that their life is drawing to a close.

So, it is essential to respect the person's individual needs, and be aware of the danger of imposing on them your own beliefs about death and dying.

Nevertheless, the dying process may be recognised by certain behaviour and language which differ from the ordinary.

Learning to recognise these things can help both the carer and the dying to ease the passage towards death.

When a patient is severely ill, he is often treated like a person with no right to an opinion. It is often someone else who makes the decision if and when and where a patient should be hospitalised. It would take so little to remember that the sick person too has feelings, wishes, and opinions, and has – most important of all – the right to be heard.

ELIZABETH KUBLER ROSS

A SHORT HISTORY OF ELEs

Death is both emotionally and intellectually challenging, and will always carry with it a certain mystery.

None of us truly knows what happens after death, irrespective of our religious or spiritual beliefs.

However, we do know that ELEs have been experienced by the dying for thousands of years, and that they are reported in many different cultures and religious practices.

There is now an increased acceptance within the scientific and medical arenas that these experiences are more diverse and subtle than deathbed visions as traditionally reported, and that they are not at all unusual.

Following from ELE studies conducted by the authors with palliative care nurses and doctors, hospice workers and nursing home carers, Dr Peter Fenwick (of Kings College Institute of Psychiatry, and the Department of Neuropsychiatry, Southampton University) recently received over 700 emails in response to an appearance on national television in the UK speaking about ELEs.

These contained personal accounts of ELEs during the dying

process of relatives and friends, and provided unequivocal confirmation that ELEs occur widely, and need to be taken seriously.

Many responders spoke of how this was the first time they had admitted to their experience, and how they had previously feared ridicule or even dismissal.

The dying would like us to relate to them as people who are living, compassionately accepting their vulnerability and suffering while still seeing them as whole.

CHRISTINE LONGAKER



SO, WHAT ARE ELEs?

We suggest that there are two categories of ELEs: Transpersonal and Final Meaning.

1. TRANSPERSONAL ELEs

Transpersonal ELEs possess an other-worldly quality that not only seems to predict approaching death, but can often calm and soothe the manner of dying. However, they cannot easily be linked to the pathological process of dying.

Since ELEs are multicultural, individuals sometimes report seeing a religious figure associated with their own belief. For example, a Christian may see Christ or Mary, or a Hindu may see Vishnu.

One of the most famous illustrations of an ELE can be found on the Giotto frescoes in the San Francesco church which surround the tomb of St Francis of Assisi in Umbria.

One of the frescoes shows St Frances on his deathbed being visited by a choir of angels. Another shows a dying monk elsewhere in Italy, aware that St Francis is dying, calling out to him, ‘Wait for me St Francis, I am coming, I am coming’.

Transpersonal ELEs can include for example:

- Visions involving deceased family members or religious figures who come to help the dying through their dying process.

- Being able to transit to and from other realities, often involving love and light.
- Coincidences which are experienced by someone emotionally close to the dying person but physically distant. The person might for example report that the dying came to them at the moment of death, often to say they were OK, sometimes across great distances and often at the precise moment of the person's death.
- Other 'strange' or transcendent phenomena occurring at, or around the time of death such as a change in room temperature, clocks stopping synchronistically, and the witnessing of vapours, mists and shapes around the body. These shapes can be accompanied by feelings of love, light and reassurance, which may stay with the person who witnesses it for many years.
- Cats, dogs and birds can behave strangely. Some carers feel a 'presence' in the room for a short period of time after death has occurred. Often carers describe this as a warm, loving atmosphere. Other find it more troubling.

2. FINAL MEANING ELES

Final Meaning ELEs are profoundly significant in the sense that they appear to prompt the dying person to settle unfinished business in life before death.

Doing this can relieve existential discomfort and allows the person to enter into spiritual readiness as death approaches.

Final Meaning ELEs can include, for example:

- A sudden desire to become reconciled with estranged family members or to put personal and family affairs in order.
- Previously confused, semi-conscious or unconscious individuals might experience unexpected lucid moments that enable them to rally enough to say farewell to those around them.
- Unconscious or dying people may appear to possess the capacity to wait for the arrival – or departure – of relatives before they die.
- Profound waking or sleeping dreams which help the individual to come to terms with what may have happened during their life, perhaps in part to prepare them for their death.

SPIRITUAL QUALITIES OF ELEs

Transpersonal and Final Meaning ELEs appear to possess spiritual qualities, such as a sense of meaning and purpose, hope, connectedness and belief.

Both carers and the dying frequently describe these experiences in compassionate and reassuring terms such as calming, soothing, greeting, comforting, beautiful, readying, quieting.

In most cases ELEs are seen to ease spiritual suffering and distress, and therefore ease the passage of death.

They also appear to be in marked contrast to the anxiety and distress caused by drug induced-hallucinations.

HOW DO YOU KNOW ELEs ARE NOT JUST DRUG-INDUCED HALLUCINATIONS OR DEMENTIA?

Once you know about ELEs, the difference between genuine ELEs and drug-induced hallucinations is usually fairly clear.

People who experience drug induced hallucinations describe them as annoying rather than particularly frightening.

These hallucinations can include seeing animals walking around on the floor, children running in and out of the room, devils or dragons dancing in the light, insects moving in wall-paper, or mistaking something on the carpet for a pattern.

Carers tell of patients and residents ‘plucking’ at the air, and shivering. Hallucinations like this can often be controlled by a change of medication.

In contrast, Transpersonal and Final Meaning ELEs usually arise in clear consciousness and seem to be powerful subjective experiences with profound personal meaning for those who experience them, as well as for relatives and carers.

Both categories of ELEs help to ease the person's manner of parting, as well as often providing comfort for distressed relatives.

A palliative care nurse explained how she perceives the difference:

[With drug-induced hallucinations] you see people going down to pick up things they can see crawling and that can happen over a couple of years. But ...when you get a sense of this real inner peace, it feels more spiritual than hallucinations do. It's a different thing altogether.

Therefore, it is important to bear in mind that when a dying person appears to be incoherent, he or she may be in the process of coming to terms with a powerful subjective experience within their confusion.

It is down to the carer to be sensitive to this, and not to dismiss it out of hand.

WHY ARE ELEs IMPORTANT TO THE DYING PROCESS?

Research suggests that Transpersonal and Final Meaning ELEs can act as predictors for impending death.

When a person engages in ‘Granny-visiting’ talk, such as speaking of seeing dead relatives, or friends from childhood, religious figures, or animals they once owned, or they experience other-worldly people, it can be an indication that death is nearing, possibly within days or weeks.

Similarly, when a patient or elderly resident expresses the need to put their affairs in order, or becomes unexpectedly lucid for a few hours, or a few days, it can also signify the approach of death.

Learning to recognise ‘the language and behaviour of dying’, you can become alert to the needs of the patient.

Perhaps they want to tell you something they have never spoken about before. Perhaps they want someone to sit with them as their time approaches. Perhaps they want to say goodbye to family, but are too ill or frightened to express that.

You can help the people you care for by being open with them, allowing them to talk about their fears.

Or you can take the practical approach of helping them to fulfil any last wishes.

Alternatively, if they wish, you may be able to arrange for someone to come and sit with the person during their last hours and days.

*It's the strange dream, it's Granny visiting.
It's the transition that once 'Granny' has
visited, or whatever, I know then they are
almost certainly going to be peaceful as they
let go of this physical world, and they have got
this peace to look forward to what's next.*

PALLIATIVE CARE NURSE



WHAT TO SAY, AND HOW TO SAY IT

It's understandable that those working with the dying might fear causing upset by saying the wrong thing.

At the best of times, death is a difficult subject to talk about, unless of course the person has come to terms with the end of his or her life.

So, when you know or suspect someone is frightened of dying, how do you broach the subject?

There is no rigid formula to this.

Everyone needs to be treated individually, which means exercising sensitivity, and being open and courageous in exploring the best approach.

Sometimes people make it easy for us.

They may, for example, report an ELE, which can allow you to engage with them about their readiness to die.

If this happens, it is important for you to listen to them without judgment. This is their dying process, and it is not for you to question or belittle their experience.

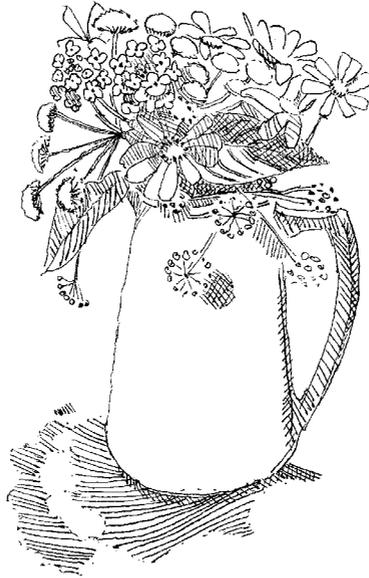
Encourage them to describe what or who they have seen, and

ask them questions. Normalising the experience helps the person to become more receptive to their dying process.

So be interested and curious, rather than incredulous or dismissive.

He was going unconscious. When I looked at him, he was looking fixedly at something in front of him. A smile of recognition spread slowly over his face, as if he was greeting someone. Then he relaxed peacefully and died.

DR PETER FENWICK



IS THERE ONE RIGHT TIME TO TALK ABOUT DEATH?

The short answer is no.

It may have been playing on someone's mind for a long time, and suddenly out of the blue - for instance, as you are helping them to wash - they may start talking about it, or ask you questions about your own beliefs. Or it may be late at night when they can't sleep, or early in the morning when they first awake.

Alternatively, they may vacillate between wanting to talk about it, and then denying their death.

Again, it's imperative to stay with the person's process, and to respect what they can, or cannot deal with in any given moment. Unless we have approached actual death ourselves, none of us knows from our own experience what it is like to go through the dying process or how we will deal with it when our turn comes.

The best policy is to treat others as you would like to be treated yourself, with respect and dignity.

For some people, talking about death is more complex and alarming, especially if they have unfinished business playing on their mind.

They may express a desire to talk, but not know how to go about it. This is when good communication skills are vital.

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 remains tightly compartmentalised and mutually inaccessible. That merging is what I mean by the spirituality of death.

L. STAFFORD BETTY

IMPORTANCE OF GOOD COMMUNICATION SKILLS

Some people want to talk about their death, but are confused about what they believe or think.

Therefore, patients might use ‘tester’ questions such as *‘What do you believe will happen to you after death?’* Or, *‘Do you have a religious belief?’*

This can feel as if you have been put on the spot. But, responses from carers consistently confirm that truth is the best policy.

By sharing what you believe, you can help the person to discover what is true for them. This can provide immense comfort for what is to come.

However, to share your beliefs is very different from evangelising. Evangelising means forcing your beliefs on to someone. Sharing is being open about what you believe, but also being willing to listen to other viewpoints.

So, it’s important that you communicate clearly and honestly, without judgement. At the heart of good communication lies a willingness to listen. This may seem obvious, but it is

surprising how few people know how to listen well.

The simple act of listening actively and well is one of the greatest gifts we can give a fellow human being.

It sends the signal that:

*You matter, and what you think
and feel matters too.*

This is never more important than when you are with someone who is approaching death.

Here are a few golden rules for active listening:

- Engaged body language. Look the person in the eye. Be alert and attentive to what they are telling you, and how they are telling you. Listen to their tone of voice; 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?
- Put your own thoughts aside. It's easy for your attention to be hijacked by your own thoughts, such as the row you had with your daughter this morning, the shopping to be done, the washing machine breaking down, or your being tired and wanting to go home. So, it's about training yourself to be fully present and attentive.
- Use open questions, such as *How*, *When*, *Where*, *Who*, *What*, and (although be a bit more careful with this one, as it can sometimes sound intrusive), *Why*.

Open questions give the message that you are interested, and encourage the person to tell their story. Closed questions such as *Do you? Will you? Can you?* prompt yes/no answers which often closes communication.

You just need to listen. I'm asked a lot about my own beliefs. People want to know and I think that's part of the sharing. I'm happy to talk about my beliefs to patients if they ask. And sometimes this leads patients on to talk about the afterlife and things like that. So that's how they test the water a bit.

PALLIATIVE CARE NURSE



USE OF GOOD QUESTIONS

Good questions can help you to reach out to the person, as well as making it easier for them to talk to you.

Direct question:

Sometimes a direct question such as (closed):

‘Are you frightened of dying?’

Or (open):

‘What are your fears about dying?’

can help the person to talk about their attitude towards death. But this may be too challenging for others. The way you use questions depends on your relationship with your patient, and their willingness to engage with you.

Indirect question:

A more gentle approach is to use an indirect question such as:

‘Is there anything you want to talk to me about?’

Or:

‘Is there anything preying on your mind that you would like to tell me about?’

This provides the person with the choice to either say yes, or no. Providing choice is empowering. The person may decline initially, but knows the door is open if he or she wants 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 also can ask leading questions to gently find out how they are feeling such as:

‘If you become really ill, would you like someone to come and say prayers with you?’

Or:

‘If you were to become ill, who would you like me to call?’

This again provides the person with the opportunity to think and prepare for what he or she would like when their time comes.

Short Statements:

Short statements can also provide comfort, such as, *‘If there ever comes a time when you wanted to talk about something or you felt frightened, please know you can always do that’*. This gives the person permission to talk in his or her own time, without expectation.

Some patients throw out these little emergency flares – help! They will say something – and when that happens I want us not to ignore it, as I believe sometimes a lot of us do. It’s much easier to deal with the pain and the vomiting than to deal with the ‘help’.

CONSULTANT ONCOLOGIST

I DON'T THINK I COULD DO SOMETHING LIKE THIS

That's OK too.

Knowing your limitations is an act of courage in itself. If you feel you don't want to talk about death and dying because it makes you uncomfortable, or you feel the person does not want to talk to you, then speak to your colleagues about it.

They may provide you with important information about the person which could help you to approach him or her in a different way. Or it may be better for someone else from the team to open up the conversation.

The most important thing is for you to feel at ease when talking to someone about their dying process.

So, when in doubt, don't!

Seek help and advice instead, at the same time as making sure your colleagues know the person may want to talk to someone they trust.

HOW DO I HELP SOMEONE COME TO TERMS WITH UNFINISHED BUSINESS?

If someone asks for help to find resolution for something that's bothering them, ask them what they need in order to do this.

They may want to contact a relative, or write a letter. (They may even ask you to write their letter). They may want to speak to a pastoral carer, or unburden themselves to you.

It is vital that these final requests are taken seriously. They not only help the person to prepare spiritually for their death, but also ease the process of dying.

So, talk with your team to make sure requests are registered, and acted upon. Tell the person that this is happening, and keep them informed of progress.

It is our task to make the end, the parting from human beings, when it comes, as pleasant as possible...

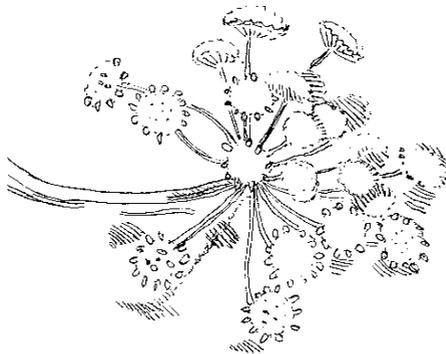
NORBERT ELIAS

BEING A BENEVOLENT WITNESS

Becoming a benevolent witness is a privilege, and respecting confidentially is immensely important.

However, listening to people's stories can be a burden. This is where supervision and team leadership are important.

Make sure you feel supported, and make use of that support, particularly if you feel emotionally affected by what you have heard.



MY COLLEAGUES WILL THINK I'M MAD!

Unfortunately, in some situations there is still a taboo around 'strange' things that happen when someone dies. Not everyone you work with may be receptive to the existence of ELEs. Sometimes you might meet with reserve and possibly even ridicule.

However, it is important to challenge this taboo. Those who are dying deserve the finest possible end-of-life care. Sharing what you know, and how you dealt with difficult questions, can help form best practice within your team.



IN SUMMARY

- Be alert to ‘Granny visiting’ ELE language. A change in language or behaviour can indicate that death is nearing and that this person may require additional attention and care.
- Respect what people tell you about their dying process, or any ELEs they may be having. The dying process is an intensely personal journey and very real to that person.
- Trust yourself. You know if you are comfortable talking about death and dying. If not, and if you think someone in your care would like to talk about what is happening to them, make sure you tell your team.
- If someone asks you about your beliefs, be truthful. But remember that none of us knows what happens after death.
- Some of what you hear may cause you discomfort, or challenge your personal or spiritual beliefs. If so, it is best to withdraw and seek advice and help from colleagues about who might be best to talk with that person and listen to them.
- If you become distressed by what you hear, make use of team support and supervision.

Finally - as authors of this guide, we hope this information has given you a little more confidence in dealing with difficult

questions or 'strange' situations that you may encounter as part of your end-of-life care-work.

We wish you well with the essential work you do with those in your care as they move into their final phase of life.

When they tell that they're seeing things, I feel they will go soon. So they need understanding and support.

NURSING HOME CARER



REFERENCES

- Betty, L. Stafford, (2006) “Are They Hallucinations or are They Real? The Spirituality of Deathbed and Near-Death Visions”, in *Omega*, Vol 53 (1-2) 37-49,
- Brayne, S., Farnham, C., Fenwick, P., (2006) “An Understanding of the Occurrence of Deathbed Phenomena and its Effect on Palliative Care Clinicians”, in *American Journal of Hospice and Palliative Care*, Jan/Feb issue
- Brayne, S., Lovelace, H., Fenwick, P., (2008) “End-of-life experiences and the dying process in a Gloucestershire nursing home as reported by nurses and care assistants”, in *American Journal of Hospice and Palliative Care* (in press)
- Elias, N. (1985) *The Loneliness of the Dying*, Oxford: Basil Blackwell
- Fenwick, P., Lovelace, H., Brayne, S., (2007) ‘End-of-life experiences and implications for palliative care’, in *International Journal of Environmental Studies*, Vol 24: issue 3
- Kubler Ross, E, (1970) *On Death and Dying*, London: Tavistock/Routledge
- Longaker, C, (1997) *Facing Death and Finding Hope*, New York: Doubleday

NEARING THE END OF LIFE:

A Guide for Relative and Friends of the Dying

Sue Brayne, Dr Peter Fenwick

To order copies, please go to www.d-word.co.uk

Sue Brayne MA, Post Grad Dip Couns, PGCE

Sue Brayne originally qualified as a State Registered Nurse. She went onto 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 ELEs. She has several academic papers published on End-of-Life Experiences and provides educational workshops for carers on the 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 into End-of-Life Experiences and their importance for the dying and the bereaved.

Available now

Peter Fenwick and Elizabeth Fenwick THE ART OF DYING A Journey to Elsewhere

Continuum Books, 2008
www.continuumbooks.com
www.horizonresearch.org

Announcing forthcoming publication of

Sue Brayne THE D-WORD Talking about Death and Dying

Continuum Books, January 2010
www.continuumbooks.com
www.d-word.co.uk