

# Nearing the End of Life : A Guide for Relatives and Friends of the Dying (7)

By Sue Brayne  
and Dr Peter Fenwick

The Life Enlightenment Charity Foundation Limited hereby acknowledges the kind authorization, with a written permission, by the two authors to publish their following two publications in our English and Chinese bilingual magazine “Life Enlightenment” for a wider circulation to the general public, namely:

- (1) *Nearing the End of Life: A Guide for Relatives and Friends of the Dying*;
- (2) *End-of-Life Experiences: A Guide for Carers of the Dying*.

## Short Introduction of Both Authors

**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 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 the end-of-life care. Sue is also a psychotherapist, specializing in **trauma and bereavement work**, and is a trained **Further Education** teacher.

**Dr Peter Fenwick** BA (Cantab), MBBChir (Cantab), FRCPsych



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. Currently, he is the Honorary Clinical Consultant neurophysiologist at Broadmoor Hospital, and Honorary Senior Lecturer at the Institute of Psychiatry, University of Southampton, UK. He has a long standing interest in End-of-Life Experiences (ELEs), 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.



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

### Stopping Life-Prolonging 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 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 Pathway. However, **it may help you to know that this offers the most comfort for your relative, and support for 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 4.00 pm, 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

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