

Nearing the End of Life : A Guide for Relatives and Friends of the Dying (9)

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

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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.

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 takes 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 cafes 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 hospital 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.

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