



生命提昇

2013年1月
(逢月初出版)
雙月刊

第十五期

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Nearing The End of Life:

A Guide for Relatives and Friends of the Dying



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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The Project on the "Life Enlightenment Hospital"

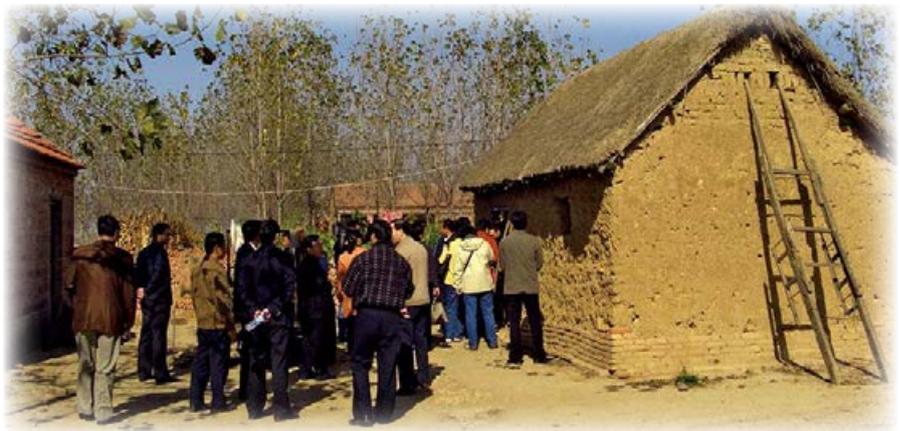
The notion and plan of the "Life Enlightenment Hospital" is a totally new, innovative and unique large project on medical services. The core of the project is initially to establish a full service private hospital with 260 beds. Besides the provisions of general medical care, it will also provide **an innovative integrated holistic caring service** that has never been provided by hospitals and other institutions before. This unique kind of **"end-of-life care"** will comprise of the following:



Currently, the services provided are very incomplete and fragmented, such that it makes the dying persons and their relatives to have suffered, especially from the **flaws and faults** that are caused by the present death and dying services. The scientific knowledge on brain cognition in advanced modern sciences has unveiled the fact that "human cognition" does not necessarily occur only in the human brain. There are some cardiac arrest patients who have suffered from their health problems and

had gone through the "Near-Death Experiences" (NDEs), as well as those who have revived from their deaths, due to various causes, and had also gone through the "Near-Death Experiences". These people could provide lots of relevant information in providing a clue that deceased persons could still have their "cognitive ability" even after "clinical death". **These empirical experiments, which have been conducted by world-renowned authoritative scientists with their reports published in scientific journals, have found to be strong proofs with solid scientific evidence.**

1. **Death Education, and knowledge on course of the after-death world** – to eliminate the patients' feeling of loss towards death and fear;
2. **Palliative care before death** – including care service for the dying persons' relatives and caregivers;
3. **An all-round "end-of-life care" and after-death services** – caring services for the dead at the crucial moments of death and dying, as well as the "guiding services for both the few hours, and (for navigating through the critical period) within 49 days, after death".



In fact, modern people have a very limited understanding on death.



Scientists have found that about 10-15% of those cardiac arrest patients who had been confirmed as "clinically dead" (that is, the cessations of breaths, heart beats and brain functions) could be revived by "cardiopulmonary resuscitation" (CPR) from death. Their "experiences of clinical death" could provide solid scientific evidence in proving that the human "consciousness and awareness" continue to exist during the "state of death".

In fact, the findings of at least five scientific researches conducted independently in England, USA and Holland have shown that about 10% of those patients who have later survived, after suffering from acute cardiac arrest and were confirmed as in the "state of clinical death", were found that they still had their "continuation of consciousness" during that time period.

This "continuation of consciousness" of a person never cease even during the "state of clinical death".

This discovery has a strong and significant meaning to it, which has confirmed the fact that it does not mean that nothing will remain after death, but instead, the "continuation of consciousness" of a person still continues to keep on functioning. In fact, these relevant researches and their findings had now been published in such renowned medical journals as "Resuscitation" and "The Lancet", where availed relevant research reports.

Dr. Sam Parnia, as Chairman of the "Horizon Research Foundation", an independent organization focused on research of the "mental states of human beings during terminal moments", has announced the launching of a large-scale research project during the "Symposium on Human Consciousness" held by the United Nations in September of 2008. This is a large-scale research experiment on the topic of "whether

there is the continuation of consciousness and awareness at the moment of death"? This research project would last for three years, and has been carried out by 25 physicians from nine different hospitals in both England and USA. This research project has sampled on researching 1,500 patients

who had survived cardiac arrest, which is led by Dr. Sam Parnia, the Honorary Senior Clinical Researcher at the University of Southampton, UK, together with **Dr. Peter Fenwick**, an authoritative Neuropsychiatrist.

The numerous research findings of the different experiments have confirmed that the "consciousness and cognitive ability" of human beings continue to exist even after death. Furthermore, it has also shown that the physical bodies still have not yet died completely after a few hours to a few days, and so special caring services for them are much needed. In fact, a related large-scale study of near-death experiences has already been launched. Therefore,

the palliative care services before death, the end-of-life care services, and the "guiding services after death" are clearly all extremely important for the dying persons. If the dying person has received the necessary **"Death Education"** while one is still alive, and has learned the necessary knowledge on the operations of the **"World After Death"**, they will definitely understand the importance of the "end-of-life care services". As a result, the society will have a huge demand for this kind of service. Unfortunately, there is still not a single institution that can provide such type of comprehensive services at the present moment. **Such a fault is, indeed, a great regret for all human beings, but, at the same time, it is actually a great business opportunity.** As such, in order to assist the dying persons to have real and civilized cares during their last journeys in life, the "Life Enlightenment Charity Foundation Limited" has proposed to establish this Special Project on the "Life Enlightenment Hospital".

"Life Enlightenment Charity Foundation" *

"Life Enlightenment Charity Foundation Limited" (herein known as the "Foundation") actively advocates the Special Project on the "Life Enlightenment Hospital", through playing the role of a **charity body**. Upon the completion of this Special Project, **the "Foundation" will re-invest all the amounts of profits gained from this operation for other charity projects**, so that this innovative

project of great potential can help to nurture numerous other charity projects and items, with its sustainable resources to be perpetually developing, without ever drying up. The "Foundation" anticipates that this Special Project of the "Life Enlightenment Hospital" would create great demands in Hong Kong, the Mainland, and even for the whole world,

due to **its innovativeness and uniqueness** (especially on the various integral components of the end-of-life care, education on death, as well as the continuity of the holistic integrated services). Hence, upon the completion of its structure and the launching of its operation in Hong

Kong, the "Life Enlightenment Hospital" will become a unique role model of its own, so that its mode of operations would then be further extended to the rest of China, and to the global market of the whole world in a "franchise manner".

It is estimated that the total investments for the first phase of development for the "Life Enlightenment Hospital" will require HK\$2.7 billion. As this Special Project will have new sources of income coming from its innovative services (such as the "end-of-life care"



services, etc.), therefore it is expected that the payback period for this project would be around seven years. Furthermore, the "Foundation" is exploring its feasibility on all sorts and styles of financing alternatives, which may take different formats of financial cooperation with **public and/or private organizations, and direct investments of individuals, as well as loans, subsidies, and/or donations.**



We strongly believe this Special Project on the "Life Enlightenment Hospital" can actually cater for the real needs of dying persons, and will really provide the real caring services for their last journeys in life while living in a civilized society, all of which will simultaneously create a whole new market. Therefore, this is, indeed, a project that is both of a charitable nature and of great commercial opportunities.

* "Life Enlightenment Charity Foundation Limited" is a **registered charity body in the Hong Kong Special Administration Region of China.** The general public can find evidence on the Hong Kong Special Administration Region Government website at URL: http://www.ird.gov.hk/chi/tax/ach_search.htm

No Restrictions on Any Religious Beliefs

Many people might have misunderstood that the all-rounded "end-of-life care services" during and after death – especially the "guiding services for both the few hours, and (for navigating through the critical

period) within 49 days, after death" – would let this Special Project on the "Life Enlightenment Hospital" to be restricted by and confined with the religious norms of "Tibetan Buddhism"? **The answer is totally negative, that is, there are absolutely no restrictions at all on any religious beliefs.** This is because the

"World After Death" is a kind of environment that exist in Nature, and its Law of Evolution is well beyond any religious norms. In this regard, the kind of spiritual guidance for all human beings, and even for all sentient beings, to select for the right paths, while protecting them from falling into dangerous pitfalls, when entering into the "World After Death" should be a kind of universal education and basic knowledge, and is thus not confined to any religions. As such, this Special Project on the "Life Enlightenment Hospital" is suitable for all human, and sentient, beings. Yet, on the other hand, this Special Project will not hinder anyone to conduct any kind of religious rituals and ceremonies. Indeed, it can be described as the best place of help and guidance, in terms of spiritual shelter and refuge, for all human, and sentient, beings. It is



also the best place of spiritual assistance in guiding one's spiritual "life" to be uplifted, and to become "enlightened" eventually and successfully. From the deepest of our hearts, we hereby sincerely wish and pray that such a **perfect kind of** "Life Enlightenment Hospital" would **soon be established !**

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Donation Form

“Life Enlightenment Charity Foundation Limited” is a registered charity in the Hong Kong Special Administrative Region government, and all donations will be exempted from tax under Inland Revenue Ordinance 88 of the HKSAR Government.

Please make a donation to the Life Enlightenment Charity Foundation Limited and help to carry out



Life and Death Education

**Various charitable activities,
Establishment of the “Life Enlightenment”
Hospital and its innovative services.**



We need your donations!

To make your donation, please complete this form and return it to: “Life Enlightenment Charity Foundation Limited”, at 4/F, Federal Centre, 77 Sheung On Street, Chaiwan, Hong Kong.

Title: _____ First name: _____ Surname: _____

Address: _____

Mobile number: _____ Office phone number: _____

Email address: _____ Fax number: _____

I would like to make a donation of HK\$ _____ for:

- All projects:
- Life and Death Education, Printing of “Life Enlightenment” Bi-monthly Magazine:
- “Life Enlightenment” Hospital Establishment Foundation:
- No need to express gratitude.

I prefer to make payment in:

- Cash:
- Cheque(s) (_____ Bank, Cheque number: _____):
- Directly deposit to the Foundation’s Bank account (Please fax the deposit slip to 3157 1144, dated: _____):
- AutoPay (Monthly AutoPay amount: _____, Receipt will be sent in April of each year. If you choose the AutoPay method, please contact us at 2558 3680 for registration.)

Please make payment by sending a crossed cheque, payable to “Life Enlightenment Charity Foundation Limited”, together with the filled-in form to 4/F, Federal Centre, 77 Sheung On Street, Chaiwan, Hong Kong; OR Deposit to the bank account of “Life Enlightenment Charity Foundation Limited” (Hong Kong Bank: 809-523715-292). After which, please send the deposit slip and the filled-in form to our address, or fax them to (852) 3157 1144. Receipt will be sent to you afterward. For phone enquiry, please call: 2558 3680.

Boundless Thanks, Boundless Blessings

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「生命提昇慈善基金會」的標誌

Logo of "Life Enlightenment Charity Foundation"



標誌的下方是一雙手，代表人類互相守望相助，以「**生命燃點生命**」。正在燃點的燭光，表示人類的智慧獲得啟迪，照耀著人類的社會及其文明，引向美好的將來。左右兩旁，分別有兩個人手攜手地往上提昇，表示著人類整體之「**生命、精神素質**」得以提昇，從而發揚人類的文明，促進世界社會之「**和諧共融**」。

The two hands at the bottom of the emblem represent the mutual care and support of all human beings through our motto of "**Life Lights Up Life**". The lamp of the lighting candle represents the enlightened human wisdom will be able to shine upon our human society and civilization, and thus will lead to a better and brighter future. On top of that, at the two sides, the two persons are united and are joining hands together for a higher elevation upward towards the sky. This symbolizes that the "quality of life and spirit" of the whole humankind would be further elevated so as to evolve our human civilization to higher levels of progression and elevation, towards a more universal "harmonious and accommodative" global community.