Chapter 5

The Near-Death and Near-to-Death Experiences

Mystery defines rather than complicates the practice of palliative care

Tomasz Okon[1]

The near-death experience

In 1975, Raymond Moody's book *Life After Life*[2] lifted the lid on what we have all come to know as the near-death experience (NDE). Interest in the topic exceeded all expectations and in the years since the book's launch, 14 million copies have been sold worldwide. Because of the unprecedented response, the International Association for Near-Death Studies (IANDS) was established in 1977 to encourage research and afford an opportunity to those who experienced a NDE to share it with a credible organisation. IANDS also launched a website and has since built an extensive bank of factual information and resource material for anyone to access.[3]

The release of *Life After Life* went much further than introduce NDEs to the world. It came at a time when a serendipitous confluence of voices sought to bring death into the full light of day; where it could be spoken about openly and honestly and not remain that 'unmentionable thing'.[4] The voices included Elisabeth Kübler-Ross, Dame Cicely Saunders, Mother Teresa, Balfour Mount, Ram Dass, Frank Ostaseski, Joan Halifax, Stephen Levine and Sogyal Rinpoche. The pall surrounding death was removed in the 1960s and 1970s, and the subsequent years saw the coming of age of palliative care and the gradual introduction of a more holistic approach to the care of the dying.

Life After Life details the experience of 50 people who had a close brush with death or were successfully resuscitated after their heart had stopped. While no two descriptions were the same (as is true of all NDEs), one or more of the following phenomena were described by each of the subjects. The overall frequency of some of these experiences, shown in brackets, is taken from a later publication by Greyson and Stevenson.[5]

1. The ineffability of the experience.
2. Hearing the news of being pronounced dead.
3. A feeling of peace and quiet.
4. Noise such as buzzing, whistling or music (57%).
5. Sense of travelling down a dark tunnel (31%).
6. An out-of-body experience (75%).
7. The sense of a presence or seeing pre-deceased relatives (71%).
8. Appearance of a bright light (27%).
9. A life review (27%).
10. Arriving at a point of no return (57%).
11. A return to their body, either spontaneously or by choice.
12. A new perspective on life and death.

NDEs are reported to occur in 4–15% of the general population and are most commonly described by individuals who survive a life-threatening incident/accident, such as a motor vehicle accident, drowning

or cardiac arrest. When the risk of biological death is real, as with a cardiac arrest, the incidence is closer to 20%. NDEs occur across all age groups and their incidence is unrelated to gender, race or creed. Each NDE is unique in its phenomenology and most include three or more of the features listed above. The effect of the NDE on the experiencer is generally one of peace and equanimity, but a small percentage of NDEs have been described as distressing or frightening.[6]

As a way of categorising NDEs and distinguishing them from neurological or stress-related conditions, a NDE scale was constructed by Bruce Greyson.[7] This sets out a basic minimum requirement for an experience to qualify as an NDE. Some years later, the same author felt NDEs could also be grouped into four distinct types – cognitive, affective, paranormal and transcendental – with most experiences incorporating one or more of these characteristics.[8] The so-called full-blown experience, which includes all or most of the 12 phenomena listed, is relatively rare and is most commonly of a transcendental nature. This category of NDE often contain vivid and detailed descriptions and are frequently associated with remarkable recoveries from life-threatening illnesses.[9,10] Transcendental NDEs receive enormous publicity and raise the hopes of many about miraculous cures and life after death. These are contentious issues, and while there is no irrefutable evidence to support either, we are reminded by the palliative care physician and philosopher Tomasz Okon that death and near-death are embedded in mystery.[1] Emeritus Professor Ian Maddox was always quick to point out, *nothing* is black and white in palliative care.

Research discussed in Chapter 4 throws some light on the neurophysiological changes at near-death that could be responsible for NDEs, but why they occur in some but not all confronting a life-threatening situation is yet to be determined. There is some evidence to suggest the capacity of a person to dissociate from the real world when faced with a stressful or potentially dangerous situation may play a part.[11] This tendency to dissociate is not considered abnormal; rather, it is an adaptive response by normal people to acute stress or trauma experiences. The likelihood of a person experiencing a NDE may, therefore, have as much to do with their personality as it does with the incident that confronts them. Bruce Greyson, a psychiatrist and foremost authority on NDEs, says NDEs are a normal psychophysiological response to stress.[11]

The Coma Research Group based in Belgium suggests the classic NDE, 'Corresponds to internal awareness experienced in unresponsive conditions, thereby corresponding to an episode of disconnected consciousness.'[12] This state of disconnected consciousness is frequently described as meta-awareness – a form of awareness where one engages with the current content of consciousness (in life-threatening situations this may be a NDE) while at the same time being unaware of the external environment. It too is a form of dissociation, but uses neuroscientific jargon rather than psychological language to describe it. Out of interest, the Coma Research Group is reluctant to label NDEs as a dream on the basis that its recall, unlike that of a dream, does not fade.

Susan Blackmore, a distinguished psychologist with a long-standing research interest in NDEs takes a very different position to that of Greyson and the Coma Research group. She attributes a NDE to a series of neurophysiological changes in the brain associated with oxygen deprivation. Blackmore calls this the 'dying brain hypothesis'.[13,14] It is well known that certain features of an NDE can be reproduced under experimental conditions, but it is the reductionist nature of Blackmore's assertion that leads others to question her conclusion. Another feature that renders this theory unlikely is that NDEs associated with an imagined rather than a real threat of death are not associated with oxygen deprivation.

Finally, there are those who propose a metaphysical or paranormal explanation for NDEs – an explanation that is beyond our understanding and is therefore founded on belief rather than reason. Included in this group is Raymond Moody, and some who have written about their own NDE, the best known being Doctor Eben Alexander and Anita Moorjani.[9,10]

Stafford Betty, Professor of Religious Studies at California State University, is one of the most ardent proponents of a metaphysical theory and suggests that NDEs and other paranormal experiences present evidence of an afterlife.[15] This claim was possibly fuelled by Elisabeth Kübler-Ross, who in the forward to *Life After Life* wrote: 'This book will confirm what we have been taught for 2000 years – that there is life after death.' Initially, Moody did not accept or reject this claim, but he has since aligned himself with it and says: 'I am convinced that NDEers [sic] get a glimpse of the beyond, a brief passage into a whole other reality.'[16]

On the question of life after death, Susan Blackmore believes a NDE can be an illuminating and life changing experience, but vigorously resists the thought of it furnishing evidence for a 'life after life'.[14] In a review of parapsychological experiences, the Australian psychologist Harvey Irwin states: '[although] tantalizingly provocative for the notion of post-mortem survival … the viability of the survival hypothesis has yet to be established beyond reasonable doubt.'[17] Bruce Greyson, whose research into NDEs predates the release of *Life After Life*, brings an olive branch to this debate when he says:

> There is enough evidence to take seriously both a physiological mechanism for NDEs and continued functioning of the mind independent of the brain … there is no reason NDEs can't be *both* spiritual gifts *and* enabled by specific physiological events.[18]

In saying this, he invites us to keep an open mind on the question of life after death and to reflect more on the transition from life to death. The validity of NDEs is not questioned, but the ubiquitous question of whether they offer evidence for life after death has distracted many from their immediate benefits. Paramount among these are: a heightened appreciation of life, a reduced fear of death, a sense of personal renewal, increased tolerance and compassion, and a more reflective spiritual approach to life. The changes can be so dramatic that close family and friends often find it hard to adapt to the change.

The words of eminent psychologist Abraham Maslow, penned following his heart attack, remind us how the confrontation with death, with or without a NDE, can be transformational:

> The confrontation with death – and the reprieve from it – makes everything look so precious, so sacred, so beautiful that I feel more strongly than ever the impulse to love it, to embrace it, and to let myself be overwhelmed by it. My river has never looked so beautiful – Death, and its ever present possibility makes love, passionate love more possible (source Rollo May, *Love and Will*, 1969, p. 99).

Near-to-death experiences

As this manuscript is really about the experience of dying, I will now turn the discussion to the many and varied phenomena that occur in the months-days leading to death (*near-to-death* in distinction to *near-death* experiences). These phenomena have been variously labelled as deathbed visions, end-of-life dreams and visions, end-of-life experiences, near-to-death experience, deathbed phenomena and death-

related sensory experiences (to name a few). The title I prefer and will use throughout this chapter is the *near-to-death experience (NTDE)*. Kathleen Dowling Singh describes this holistically as '… the subtle signals or qualities that indicate the dying person has entered a significant and transforming field of experience.'[19] The important message she is conveying is that it is the dying that activates the potential for healing or transformation, most commonly by way of a dream or vision. How important then is it for all of us to honour and acknowledge the process of dying?

Although NTDEs have been described throughout history, it was not until the publication of *Deathbed Visions* in 1926 did they came to the attention of the wider community.[20] The author, Sir William Barrett, believed NTDEs offered strong evidence for life after death and while this was a strongly held belief within the spiritualist movement, to which Barrett belonged, it gained little traction in an increasing secular community. Initially, doctors paid little heed to these phenomena, and as medicine became increasingly medicalised, they were wrongly attributed to a delirium or hallucination brought on by any number of causes including medication, notably opioids.

As NTDEs are almost always accompanied by a sense of peace and equanimity, it was not the person's demeanour that led to the diagnosis of delirium or hallucination, but what they described. Such was the case with Trent, a young man burdened by constant pain from a very aggressive cancer. Despite radiotherapy and large doses of morphine, the pain persisted necessitating admission to hospital and increasing doses of morphine. Trent was a popular young man and his hospital room was often overflowing with visitors. One evening, his father joined others in the room, but as he went to sit on the only unoccupied chair, his son called out, 'Careful Dad; don't sit on my friend.' The father, looking at the empty chair asked, what friend? Trent calmly replied, 'He is a good friend; he's here to guide me.' Convinced his son was delirious and hallucinating from the effects of morphine, the father spoke to me and asked that the dose of medication be reduced. I suggested we return to the room and ask his son to say more about this 'friend'. Although mystified by what Trent shared, the father realised he was not delirious and took comfort from the peace his son was displaying.

The tendency for those nearing death to use symbolic language is not unusual. The image or the language used to describe the visions may at times seem bizarre, but the demeanour of the person is almost always one of peace, joy and serenity. This alone should be sufficient to reassure family that their loved one is being graced with a truly amazing gift, but as the following quote suggests, this is not always the case,

> … [When] we use metaphor or symbolism to communicate the essence of our experience, we run the risk of losing this essence in the translation; and might also lose our audience in the process.[21]

Nina was an elderly Italian matriarch admitted to the hospice for end-of-life care. The family had requested that Nina not be told she was dying even though her body language suggested she already knew. During one of my ward rounds, her daughter approached me and asked that her mother be given an injection to settle her down. She said Nina was agitated and was asking to leave the hospice. When I entered the room, Nina was sitting upright in bed, gesticulating and speaking in her native tongue. Her eyes were directed straight ahead as though looking at something or someone. What struck me was the smile that lit up her face. When asked to interpret what she was saying, the daughter translated her mother's words as follows, 'My bags are packed, my boat has come, I am going on a beautiful holiday and none of you can come with me.' I ushered the family outside and told them Nina was not delirious nor was she hallucinating. I explained that it was a NTDE and sharing it with the family was her way of

assuring them that she was not afraid of dying and all that remained were the good-byes. Nina died several days later, but not before she and her family said their goodbyes.

In an excellent review, Daniel Dugan says patients in the process of dying move from a literal to symbolic consciousness and that this is often reflected in their dreams and their efforts to communicate.[22] Such was the case with a man who continued to linger despite his desire to die. In a lucid moment he reported a dream in which he had to remove his dinner jacket, but despite all his efforts he could not loosen the last button.[23] This symbolic language is the means by which people who are dying communicate that for which there are no words. Knowledge of their illness and of approaching death not only comes from what they are told but also wells up from the deep unconscious by way of symbolism, dreams and visions.

In the words of the hospice volunteer and Natural Dreamwork practitioner, Mary Jo Heyen, 'The dream brings its own medicine, its own healing for the dreamer and they will know it. Even more, they will feel it.'[24] This becomes a problem if symbolic messages conveyed in a dream conflict with what others are saying. It also explains why patients like Nina know they are dying even when family ask for this news to be withheld or supplanted by a 'loving lie'. We should never assume that patients can be shielded from the truth. Their dreams and visions will reveal what others are reluctant to divulge. How sad it is for the dreamer when they cannot share these dreams only because their loved ones patently avoid the topic. In her memoir, Cory Taylor reminds us of the loneliness that invariably follows the avoidance of truth: 'For so many of us, death has become the unmentionable thing, a monstrous silence. But this is no help to the dying, who are probably lonelier now than ever.'[4]

My friend and colleague, Michael Kearney writes powerfully about what he calls, the underworld of consciousness where fears, hurts and painful memories are locked away in 'some enormous subterranean cavern', but where great inner resources also reside.[25] Dreams and visions are the gifts that reside in this subterranean cavern. What a blessing it is to have someone who not only asks a dying person about their dreams, but who also listens deeply as the person plumbs the depth of their soul. Without going into great detail, it appears from the writings of Jung, von Franz and Eldred that…

> The [psychological] unconscious attempts to bring consciousness to the issues inherent in dying, encouraging terminally ill individuals to realistically and directly confront their impending demise.[26]

The imagery the psychological unconscious invokes depends on a number of factors including the dying person's age and their acceptance of the situation.[22] The imagery is usually gentle and includes known pre-deceased relatives and modes of travel such as trains, planes, buses and boats. Sometimes, the imagery is starker. Steve, who would not confront the reality of his impending death had recurrent dreams of being stabbed from behind by a person he could not identify. While this may seem a brutal way of delivering the message, it resulted in Steve talking about his fear of death for the very first time. This in turn led to a remarkable transformation that saw him make peace with himself and his family who he had long abandoned and always blamed them for his problematic lifestyle.

The silence that previously surrounded near-to-death experiences is partly attributable to the medical profession's failure to comprehend the metaphorical and symbolic language used by those who are dying. Nurses, however, were not deaf to their patients' messages and must have uttered a combined sigh of relief when doctors finally started to take notice. Although there had been numerous earlier publications describing end-of-life experiences,[27–35] it was not until Doctor Christopher Kerr and his colleagues

published a review of dreams and visions of the dying in 2014 did the medical profession acknowledge the consequences of their entrenched way of thinking.[36] Of the 59 patients Kerr and his associates interviewed, 88% reported dreams/visions that most commonly involved pre-deceased relatives or friends. Visions of living relatives, people they could not identify or religious figures were also described, but they were the exception rather than the rule.

The figure of 88% is much higher than the 21% previously reported by Morita in a nationwide survey of Japanese families of deceased cancer patients.[37] Such a discrepancy is not uncommon and, as was the case here, it results from different methodologies employed rather than differences in culture or religion.

Childhood visions are somewhat different to those of adults and more commonly include living relatives, friends, teachers and even pets. While cognitive, emotional and transcendental qualities are frequent accompaniments of adult experiences, they are far less common in children.[38] Their visions are more down to earth and commonly depict travel.

As is the case with adults, the ability and willingness of a child to share their experience is dependent on their communication skills, the perceived receptivity of others and how they themselves perceive the experience. To the best of my knowledge, there are no formal studies of childhood NDEs or NTDEs, but there are numerous anecdotal reports[39–41] including those by Melvin Morse.[42,43] A recent case report of an end-of-life vision in a 15-year-old adolescent shows similar phenomenology and outcomes to those seen in the adult population, thus highlighting the need for greater awareness of metaphysical experiences within all age groups.[44]

While the vast majority of NDEs and NTDEs are associated with a sense of peace and equanimity, distressing or hellish experiences have been described in some 15% of cases. Some may be truly nightmarish; however, the majority are frightening because of how the 'patient' interprets the experience.[6] I recall only one instance of a frightening near-to-death experience. The patient was a woman admitted to the hospice for end-of-life care. She was extremely distressed and frightened by bizarre patterns and colours that would come (often accompanied by pain) and go. She was encouraged to stay with the vision and after some minutes she was asked, 'Is anyone there with you?' to which she replied, 'Yes, my aunt and her mother [both of whom had died] and they are telling me "It's okay".' Thereupon the pain resolved, the patient relaxed and fell into a deep restful sleep.[45]

In her book, *The Grace in Dying*, the late Kathleen Dowling Singh states, 'Dreams and waking experiences become clearer and more intense as death nears … [and] there is a growing awareness of the transpersonal realms and transpersonal levels of consciousness.'[46] The focus of awareness is no longer confined to the discursive mind, but shifts to archetypal imagery, which brings with it, intuitive knowing and deep meaning. Her final comments are so significant I will quote her words verbatim:

> It is often in symbolic, and metaphoric language – the language of depth – that those in the Near-to-Death Experience attempt to speak to us. When we take the time to understand these symbolic communications, everyone benefits in the act of understanding. The one who takes the time and energy to understand benefits by the wisdom gained. The one who is understood benefits by the connection understanding creates, which is, in itself, healing.[46]

As death approaches, the dying person's consciousness becomes more internally directed. Sleeping, musing, daydreaming and mind wandering become more frequent and dreams become imbued with archetypal images and symbolism. Language too, takes on a more metaphorical flavour and, as has been suggested more than once in this review, this symbolic language is often mistaken for a hallucination or delirium.

The dying person's connection to the outside world diminishes considerably in their final days and, apart from times of terminal lucidity, their awareness is mostly directed inwards. It is during this period of unresponsiveness that dreams become frequent and ultimately, by way of a deathbed vision, they beckon the dying person to surrender into *what is*. Provided the patient is pain free and comfortable, family and care providers can rest in the knowledge that the dying person's inner world is probably rich with symbolism and that they are more at peace than at any other time in their illness. While few of us may understand, we are called to trust that the one we love follows a trail that is foreign to the conscious mind, but unerringly familiar to the archetypal realm.

Terminal and paradoxical lucidity

Some of the most incredible recollections of grieving families are the times when their unresponsive dying loved one has an unexpected period of lucidity. These episodes of terminal lucidity,[47] also known as lightening up[48] or pre-mortem surge,[49] are extraordinary in their own right, but verge on the mysterious when they occur in patients with a long history of dementia, schizophrenia, strokes or other neuro-degenerative disorders. This 'unexpected, spontaneous, meaningful and relevant communication or connectedness in patients assumed to have permanently lost the capacity for coherent verbal or behavioural interaction' is most commonly referred to as paradoxical lucidity.[50–52]

With terminal lucidity, a previously unresponsive patient may utter a few words, deliver an important message, bid farewell or set their house in order. Some seek relief from pain, discomfort or thirst while others are content to look, listen and soak up the moment.[53,54] Paradoxical lucidity, on the other hand, is characterised by spontaneous, meaningful and relevant snippets of communication previously considered 'lost'. They may even remember names or recall events that were long forgotten.

One would expect these patients, especially those with pre-existing dementia, to be vague and confused on 'awakening', but no, they are deceptively sharp. The duration of terminal and paradoxical lucidity is usually brief, but can be as long as days and may be accompanied by a vision.[50] When all is said and done, the person eases back into a deep sleep and dies shortly after.[55,56]

Occasionally, the lucid moment may not seem so lucid. This was the case with one of my patients who woke and said, 'I'm climbing a steep mountain. When I get to the top, I have to do an appendix operation. I'm frightened because I've never done one before.' This woman was a doctor and, as is often the case, she resorted to metaphor to describe something that was beyond words – what dying was like for her. She shared little else other than a smile before lapsing back into her previous unresponsive state, and died some hours later.

Reporting on a series of six cases, Doctor Sandy MacLeod suggests the incidence of 'lightening up' or terminal lucidity is much less now than previously.[48] While he attributes this to the increasing use of palliative sedation, other factors such as profound weakness and a preoccupation with inner realities, such as dreams or visions, may also contribute to the decreasing frequency. As the vast majority of dying

patients prefer to be pain free in their last days, proportional doses of pain medication and sedation are prescribed to meet this request. In so doing, we ensure their comfort, but we may also deprive them and those at the bedside of a brief period of lucidity.

The same is undoubtedly true for the iconic deathbed vision that manifests in the final moments of life. While rarely seen today, one suspects from the writings of Barrett and others they were much more common prior to the palliative care era and the introduction of palliative sedation.[57,58]

Before you start questioning the place of pain relief and palliative sedation, I must point out that pain, more than anything else, prevents a person nearing death from entering into the deep peaceful sleep in which deathbed visions are known to occur. When used with discretion and in appropriate doses, palliative medication ensures, as best one can, that dying patients are free of physical suffering and are therefore more likely to have a transcendent experience. Except on rare occasions, those at the bedside will be oblivious to such experiences. I would like to think the surge of neurophysiological activity recorded in some patients at the moment of death may be the only evidence we have of their covert deathbed vision.