Chapter 6

A Guide for Companioning a Dying Person who is Unresponsive

Most dying people need assistance to experience fully the powerful events trying to happen. Without assistance, altered states confuse and baffle us. We misinterpret the signals of an altered state, believing they are signs of pain, drugs or disease.

Arnold Mindell, *Coma*[1]

The words of Arnold Mindell may resonate with those who have journeyed with a relative or friend during their final days. It is such a surreal time words rarely convey how we feel and silence becomes the only form of communication that does justice to the sorrow we hold in our heart. We are overwhelmed by waves of emotions including sadness, fear, uncertainty, wonder and awe that stem from a deep sense of impending loss. We know the end is drawing near, but not knowing when this may happen is as taxing as the knowledge of its inevitability. While our heart is the chalice holding all this unrest, our mind remains vigilant to what is or may be happening. We notice the minutest change in our loved one's appearance; the rhythm and sound of their breathing, the furrowing of their brow, a teardrop in the corner of an eye, the coldness and colour of their skin, the faintest twitch of their hand as it is held in yours, and we wonder what any or all of this means. We look into the eyes of the doctors and nurses and try to unravel what messages they hold. We search for words that may bring solace to the one we love, while all the time wondering if it is time to let go and say good-bye. We do not want to be left with things unsaid, but is it too late or could the words be as painful to hear as they are to say? If only we knew what to say and do and what to expect.

While all this is happening within you, the dying person's connection with the outside world gradually diminishes while awareness of their inner world of dreams, visions and disembodied experiences expands. This transition from outer to inner awareness is shown diagrammatically in Figure 7 and while its accuracy cannot be guaranteed, it is drawn from the experience of comatose patients who live to tell their story (see Chapter 2).

In the early unresponsive phase, comatose or dying patients are constantly trying to make sense of their world. This is hard at the best of times, but it is made harder by the gradual waning and distortion of sensory experiences. This was highlighted in Chapter 2 when one recovering comatose patient reported dreams of Alaska when ice packs were placed around her neck, while another dreamt of trains when he heard the sound of trolleys being pushed around the ICU floor. Prolonged sensory deprivation can lead to confusion, disorientation and delirium even in those who are conscious, thus emphasising the importance of orientating and communicating with unresponsive patients, particularly when we believe or suspect they can hear and appreciate touch.

Apart from this change in sensory appreciation, the discursive mind gradually falls silent, further facilitating the transition from an outer to an inner reality.[2] Based on published research and my own clinical experience, it appears sedation and analgesia have less effect on the inner reality of dreams and visions than it does on the appreciation of sound and touch. Although the descent into deep sleep may

be quicker in those receiving palliative medication, research has shown their survival time to be the same or little different to those who are medication-free.[3]

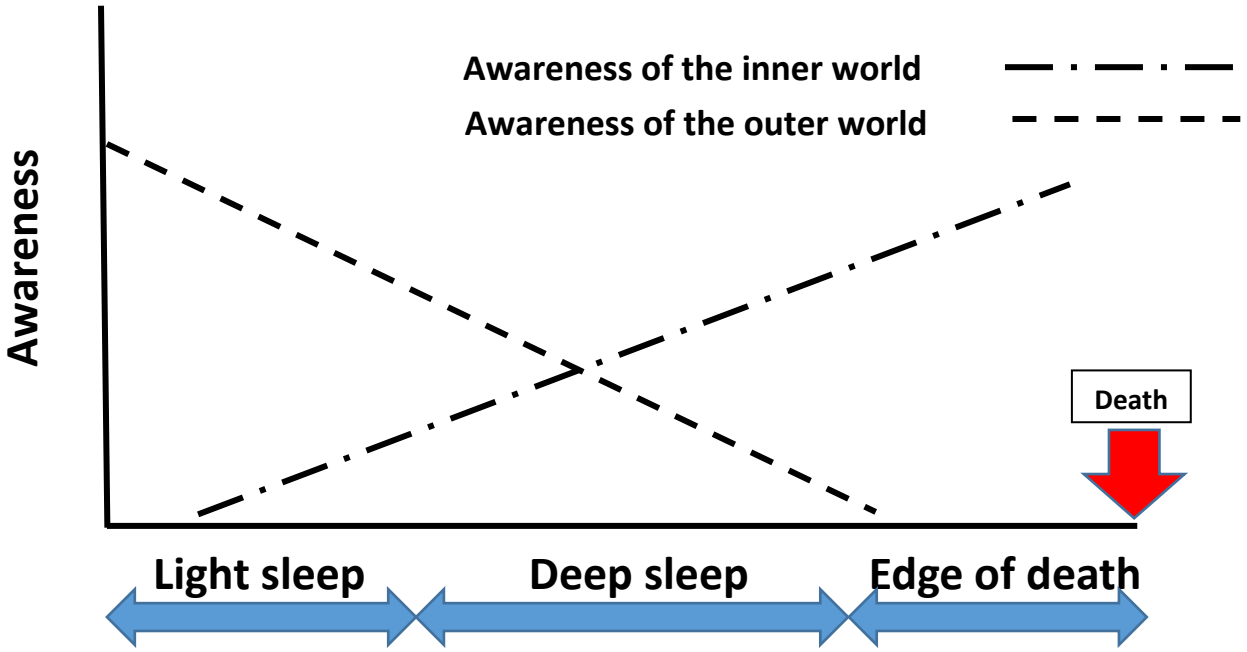

Figure 7: Alterations in awareness in dying patients as they journey from unresponsiveness to death.

These varied experiences of consciousness have led many to suggest that it is not so much a loss of consciousness that occurs with dying, but rather an expansion of consciousness. As paradoxical as this may seem, an expansion of consciousness at near-death is espoused in Buddhist and secular teachings[4–6] and by many who have had a near-death experience. This belief led Ram Dass to liken dying to taking off a tight shoe!

A possible explanation for this expansion of consciousness was put forward by Dean Radin, Associate Professor of Transpersonal Psychology at the Californian Institute of Integral Studies and Chief Researcher at the Institute of Noetic Sciences. In a talk titled *Mind and Matter,* Doctor Radin suggests that the somewhat clunky rational brain becomes more like a quantum computer as it starts to fail, giving it the capacity to experience phenomena outside of time and space.[7] As unbelievable as this may seem, it has the backing of some impressive scientists including Roger Penrose, a 1990 Nobel Laureate in Physics.[8] Consciousness is one, if not the greatest, of all mysteries. It is physically undetectable, cannot be measured and can only be experienced. Ironically, our experience of consciousness is enhanced around death and this very fact led Stanislav Grof and Joan Halifax to view the process of dying as an adventure in consciousness rather than the ultimate biological disaster.[9] Such was the mindset of one of my patients who said: 'I've read a lot about this dying business . I'm only going to do it once so I want to be wide awake when it happens.'

In an effort to better understand the lived experience of dying patients, I will now describe a hypothetical journey from unresponsiveness through to death. As speculative as this may be, it represents a best fit

model based on our current understanding and research. It advances a roadmap for family and care providers who seek to better understand what may be happening in the mind of a person who is unresponsive and how to relate to that person in a meaningful and humane way. It also informs and empowers care providers as they seek to give credible answers to questions commonly posed by grieving families. One such question is: 'How long does the period of unresponsiveness last?' Although studies have shown the mean duration to be approximately 1–3 days, it can be as short as hours or longer than a week.[3,10] Quoting numbers, however, does little to appease a family's concern and may indeed compound it if their loved one dies before or later than the predicted time. As Bruce Rumbold of La Trobe University has often stated, families do not necessarily look for answers, but the opportunity to express their concern and know that it has been heard.

My hesitation in proposing this model rests with the knowledge that nothing is certain or predictable about dying and that every patient will die their own death. Not every unresponsive patient will progress as I describe, but some knowledge of how dying unfolds, what unresponsive patients may experience and how we can best journey with them is much better than the helplessness that comes from not knowing. I firmly believe the holistic care of those who have no voice will improve as we learn more about the lived experience of dying. My hope is that others will build on this tentative beginning.

How to be present to someone who is unresponsive and nearing death

Light sleep: Except for the earliest stage of the light sleep phase, the unresponsive person may not, or infrequently responds to tactile or auditory stimulation. Reports however from anaesthetised patients and those who survive a period of coma suggest they can hear and may appreciate some of what is being said, especially if the person speaking to them is intimately related and what is being said is affirming or personally relevant.

Start by introducing yourself in a manner known best to you. Use short sentences and choose words that are clear and uncomplicated. Follow each message or piece of information with silence, allowing time for the 'sleeping' person to decipher what has been said. If what you are attempting to convey is important, do not hesitate to repeat the message. All this helps with orientation and allays confusion that may arise from hearing your voice. Touch adds to the reassurance and helps to maintain a connection during periods of silence. Remember to speak to and not about the person dying. Encourage family and friends to do likewise and ensure all discussion about the dying person's condition are avoided while in their presence.

Seek to create a healing environment by keeping 'white noise' to a minimum. Ensure mobile phones are turned off as a sudden sharp ring can be disturbing and disorientating for someone sleeping. Familiar forms of sensory stimulation may, however, be beneficial. Relatives are encouraged to use their imagination and knowledge of the person's preferences when deciding upon music, readings and rituals. One family made a recording of the surf and played this in the background as their surfer son lay dying, while another produced a soundtrack of steam train whistles and played it to their father when he was unresponsive. He was an ex-steam train driver!

Restlessness is a not uncommon in those who are unresponsive and is more likely throughout the 'light sleep' phase. Although the causes are many and varied, the standard practice is, first and foremost, to exclude pain. In the absence of pain and other sources of discomfort or if the restlessness does not

improve despite medication, an underlying psycho–spiritual–existential cause or a vivid dream should be considered. In such a situation, intuition can be as important as any clinical assessment, so do not be backward in coming forward with comforting words for your dying loved one or suggestions that may guide nurses and doctors in their care. The needs of the one dying go well beyond the care of their body. Their heart and spirit can, if we are not mindful, be the greatest casualty of the dying process.[11] Families play a very important role here, not only in care planning but also by lovingly informing their loved one, verbally and tactilely, that they are not alone.

Deep sleep: The dying person's appreciation of verbal and tactile stimuli (connected consciousness) will diminish over time, but this is matched by an inner life that becomes increasingly vivid and engaging. Unless there are reasons to believe otherwise, I encourage family to follow the practices just described, but with a greater emphasis on silence and tactile connection. If the person appears peaceful, they are probably pain free and in a deep sleep that may or may not be punctuated by dreams and visions. As this sleep is both restful and healing, it is preferable to leave them be and not disturb them. Sit silently and wait until there's a noticeable change. This may come in the form of a sound, the minutest movement or a change in their breathing pattern. When this happens, identify yourself and say what you have observed or heard. For example, 'It's [your name]. I've been sitting by your side and have only now noticed you are frowning.' This is referred to as the process-oriented or patient-directed approach to the care of unresponsive patients. It involves identifying any change and relaying this back to the one dying. According to Ingrid Rose and Kay Ryan, the authors of *Doorways into Dying,*[12] this helps to create a an equally beneficial connection based on awareness. The authors refer to this as *Deep Democracy;* a way of supporting all experiences in an honourable and respectful way. You may deepen this connection by validating the dying person and by telling them how much they are loved.

This is also a good time for each family member to spend some time alone with their dying loved one to share their deepest feelings and fondest memories. It is not only a powerfully healing experience but also ensures there are no regrets for not having done so.

The edge of death: The onset of this terminal stage is generally heralded by an alteration in the pattern of breathing, coldness of the peripheries and a mottled bluish discolouration of the fingers and toes. More important, however, is a deep knowingness that the end is near

Laboured or sighing respirations and Cheyne-Stokes breathing are two of the more frequent accompaniments of dying. The former is sometimes associated with gurgling noises, often described as the 'death rattles'. While extremely distressing to those at the bedside, the person dying is so close to death they have no awareness of the struggle their body is engaged in, nor do they experience any of the distress that you imagine. If coughing occurs, this is a reflex action and not a conscious response. Cheyne-Stokes breathing is recognised by a speeding up, followed by a slowing down and then a cessation of respirations lasting many seconds before the cycle starts over again. This pattern of breathing can persist for hours or longer and, like sighing respirations and death rattles it is not distressing for the person dying.

There are times when nurses may seek to turn an unresponsive patient, even when they appear comfortable. This is done to prevent lung congestion and to ensure they do not experience covert discomfort from lying in the one position for an extended period. During sleep, we're subconsciously aware of any bodily discomfort and will adjust our position without any knowledge of having done so. As those nearing death do not have the strength to turn, nurses reposition them, knowing that restlessness

and pain might otherwise ensue. Experience has taught us that a small dose of palliative medication given beforehand ensures there is no discomfort during or following the repositioning.

As Figure 7 suggests, awareness of one's outer world falls away and the dying person is increasingly consumed by their inner world of dreams, visions and disembodied experiences. They are now in very deep sleep with no awareness of what is happening to them or around them. It is a time when inner experiences and intuitive wisdom arise unimpeded by the now silent discursive mind.[13] The person dying is now free of their tortured body and the distressing thoughts and emotions that might otherwise engulf their mind. It is a time of healing, and just as we would not wake a person from a deep sleep, we honour this time with our silence and our reverence. We avoid drawing our loved one out of their peaceful world by limiting noise, maintaining relative silence and by opening ourselves to our own pain. It is a good time for silent prayer and meditation, or you may prefer to read passages and poems or play the person's favourite music. Hand-holding and gentle touch are good ways of maintaining a loving connection, as is sitting in silence.

Families often feel the imminence of death before they are alerted to it by clinical staff. There may be contradictory feelings of sadness and relief knowing your loved one's suffering is coming to an end. As painful as it may be, you are encouraged to open yourself to the experience rather than resist. During this time love and joy may arrive to suffuse your heart and temporarily dilute the sorrow within. The death of someone you love will test you in unexpected ways. Be compassionate with yourself and with others, knowing you and they are doing their very best under extremely difficult circumstances. We each navigate grief in our own unique way. If you feel overwhelmed, seek a friend or soul mate who will listen compassionately as your pour out your pain.

Terminal lucidity and deathbed visions: Sometimes, those nearing death have a lucid moment when they awaken and share a few words or simply smile. This may occur out of the blue or in response to something that was said or done. If you are blessed with such a happening, treasure the moment for it is a gift beyond measure. This unexpected awakening does not mean death is some way off. The very name, *terminal lucidity* indicates death is near.

Rarer still is the iconic deathbed vision, similar to that of Hazels described in the Introduction. The person dying seemingly comes to life and frequently extends their arms as if to embrace the person(s) they alone can see. After a short time, they lay back, close their eyes, and their breathing stops shortly after. This too is a gift; a rare and precious moment that will stay with you forever. Recollecting the words of Joseph Campbell, 'The way is known. Although we travel alone, the road is marked'. Deathbed visions and all near-to-death experiences are there to direct those as they make the transition from life to death.

The person is now nearing the end of their life's journey. They have disengaged from the 'manifest' world and have melted into a progressively primal flow, which Buddhists call *The Essential Nature of the Mind*[5] or the clear light of death. One of our tasks is to ensure they are not distracted from this process of letting go. Silence is called for, but rituals and some of the practices mentioned earlier may be adopted in softer tones. Outbursts of grief are best reserved for later, but if they cannot be contained, the release is best done outside of the dying person's room. To know they are loved makes the dying person's journey easier to complete as it is an acknowledgment that they will not be forgotten. Such affirmations are best done earlier rather than later and repeated as often as seems necessary, even in those final moments. Granting them permission to let go is tough love, but when done with feeling by a close family member, preferably the next-of-kin, it helps in unimaginable ways.

Some family members choose to say something like, ‘go towards the light’ or ‘your mother will be there to meet you’. You can also express permission in a symbolic way that would resonate with the person dying. For example, if they are a keen surfer, say something like, ‘the perfect wave is coming, catch it and ride it all the way to shore’. For a jogger, you could say, ‘you are nearing the finishing line. You have run a good race and can now rest.’

Death is recognisable by the absence of respirations and a sense that the person is no longer there. It is a surreal moment. You may wish to have someone confirm that death has occurred, but there is no immediate rush to do so. Honour the moment with your own stillness and by absorbing all the emotions that accompany the death. Say your goodbyes in whatever way is right for you, partake of any rituals you may have planned and stay at the bedside for as long (or short) as you desire. If the death has occurred at home, notify the care providers, but only when you are ready.