Chapter 3

Connected and Disconnected Consciousness

Therāvada Buddhist contemplatives report that when one gains access to the first dhyana [stage of advanced meditation], one experiences a naturally pure, unencumbered luminous state of consciousness which manifests when awareness is withdrawn from the physical senses and when the activities of the mind, such as discursive thoughts and images, have subsided. This happens naturally when one falls into dreamless sleep and in the last moments of one's life.

B. Alan Wallace *Fathoming the Mind*[1]

In a recent publication, Tricia O'Connor and her colleagues highlighted the vulnerability of patients at the end of life, particularly when they become unresponsive. Apart from the urgency to develop tools that better assess the needs of unresponsive patients, the authors also identified numerous challenges that stand in the way of delivering holistic care when patients no longer have a voice.[2]

Sudden death aside, most people who are dying pass through a phase of unresponsiveness prior to their death. This period of unresponsiveness generally lasts around 24 hours, but it can be as brief as minutes or as long as a week.[3] This is a very short time in the course of a person's illness, but the significance and intensity of the experience, not the duration, is what makes it so important. The quality of care given to the patient at this time and the manner in which information is communicated to those at the bedside is what lives on in the minds of those who grieve. Given this, the lack of research into the holistic care of these, and similarly compromised patients (e.g. the aged and those with dementia), is extraordinary. It remains one of the most pressing issues for palliative and aged care services.

According to O'Connor, a basic requirement for meeting the challenge is for palliative care to develop holistic, evidence-based protocols that address the needs of unresponsive patients and grieving families. As mentioned in an earlier Chapter, one of the major obstacles to achieving this goal is the absence of a consensus view within palliative care about what is meant by unconsciousness or unresponsiveness. Just as the management of pain improved dramatically with a deeper understanding of pain, the humane care of an unresponsive patient depends on a better grasp of consciousness and the lived experience of the unresponsive patient.

Much of what we currently know about unresponsive and comatose states has come from intensive care and anaesthetic units that are better equipped and skilled to monitor the neurophysiological and clinical changes associated with these states. While this type of research is at odds with the philosophy and practice of palliative and aged care, these holistic services can still contribute by appraising the scientific data in the light of what is observed at the bedside of those dying. In concert with this is the urgent need for palliative and aged care to develop and appraise assessment tools and protocols, advance holistic end-of-life care, evaluate the effects of palliative sedation and the needs of grieving families.[4]

What follows is an overview of what I have learnt about the experience of unresponsiveness and how this can be relevant to the care of dying patients as they move from wakefulness to unresponsiveness and ultimately to death.

Waking consciousness

Our normal waking consciousness hardly needs any introduction. It is what you and I know and experience daily. Essentially, it drifts between awareness of the outside world and our own inner world of memories, thoughts, emotions and fantasies. It creates our reality and contributes to the sense of self or 'I'. The experience is intensely personal and the reality we perceive or imagine is influenced greatly by our culture, the beliefs and values we live by as well as our state of mind.

One aspect of waking conscious you may not be aware of is stimulus-independent thought (SIT) or mind wandering, also known as daydreaming. SIT spares no one. It happens to us all and is characterised by a disengagement from the outside world while, at the same time, engaging thoughts or fantasies that arise out of the blue without any external precedent. This tendency to become absorbed with an internal train of thought is believed to occupy 50% of waking consciousness. We are most prone to it when involved in a monotonous or repetitive task, when relaxing or doing nothing in particular.[5,6] SIT is less frequent in those who practice mindfulness or are engaged in a task that is stimulating or requires focused attention. The thoughts or fantasies come uninvited, remain for an indefinite period of time and vanish, often without a trace. In the meantime, previous thoughts tend to dissolve and may be hard to retrieve. Common scenarios that you may relate to include opening the refrigerator door and wondering what you came for, or the need to read something a second time only because you cannot recall a word of what you have just read.

Mind wandering or daydreaming should not be regarded as wasted time. According to some researchers, '[it] provides a necessary break that allows the mind to return to a task with a refreshed capacity for dedicated processing.'[5] At other times it can result in remarkable insights, creative ideas and radical thinking,[7] examples of which include Einstein's theory of relativity, inventions such as the sewing machine, the discovery of the benzene ring, the poems of Coleridge, Wordsworth, Keats, Shelly and WB Yeats and numerous musical compositions by JS Bach and other well-known composers.

These unstructured, uninvited internal trains of thought are believed to arise from a poorly understood cortical network called the default mode network (DMN), named because the network is most active when the mind/brain is doing nothing in particular. The DMN has a special connection with another neural network called the external or executive control network (ECN), which is concerned with awareness of the external environment.[8] Apart from facilitating mind wandering, the DMN also suppresses the ECN. As a result those who have disengaged are not even aware their minds have wandered.[6]

The DMN becomes more active as patients become weaker and frailer. This results in frequent episodes of dozing, mind wandering and daydreaming, which are known to evoke dreams, visions, out-of-body experiences and deep mind states.[8] These episodes of 'drifting off' alarm grieving relatives who, almost invariably, attribute them to one or more of the medications, notably morphine or its equivalent. While this possibility must be considered, mind wandering is part and parcel of the aging and dying journey. For those confronting the reality of their own death, these escapes into the mind can bring much-needed respite from troublesome thoughts, and the process itself may bring healing. Michael Kearney alludes to this when he says

> … [these deep mind states] contain, often in the most unlikely and darkest corners and in the most unexpected disguises, exactly what is needed to deal with the particular question, challenge or life crisis that confronts us.[9]

The important message here for family and all involved in the care of the aged and those nearing the end of life is to understand that mind wandering and daydreaming are not abnormal or harmful. They bring a quiet calm into the dying person's day and are sometimes accompanied by profound insights, comforting dreams and personally relevant visions. We honour them by allowing these momentary lapses to run their course free of interruption. BIS scores during waking consciousness would normally be around 90–95, but drop to 70–80 with daydreaming or dozing.

Connected and disconnected consciousness

There comes a time when the aged and those who are dying spend more time asleep than awake. In the early phase of this transition, the person may rouse when spoken to or touched, and may even greet relatives and friends by name, or with a smile or a gesture. These moments of lucidity become less frequent as the descent into sleeping consciousness continues. Ultimately, unresponsiveness prevails except for when the patient is being turned or attended to by nursing staff. Although unresponsive patients are often described as being unconscious – having no awareness – the majority continue to have external or internally generated experiences that remain covert to family and care providers.[10,11]

In the earliest stages, the lived experience of the unresponsive patient is predominately informed by the senses, and this is interpreted by the discursive mind. The awareness required for this to take place is maintained by the executive control network located in the frontal cortex of the brain. This state is described as *connected consciousness* and the lived experiences of patients during this phase is not dissimilar to those described in Chapter 2, confirming they, like comatose patients, have a variable degree of connection with what is happening to and around them (Table 2).

Table 2. Characteristics of connected and disconnected consciousness

	Connected consciousness	Disconnected consciousness
Predominant neural network involved	External/executive control network (ECN)	Default mode network (DMN)
Content of consciousness determined by	Incoming sensory information: pain, auditory, tactile, etc.	Internally generated experiences: dreams, ELDVs, OBEs
Subjective experience	Yes	No
Awareness of external stimuli	Yes	No
Behavioural responsiveness	Variable	No, except with vivid ELDV
Bispectral scores	50–70	<50

Adapted from and compliments of Scheinin.[11]

As a patient's condition deteriorates and the discursive mind settles, awareness of the outside world diminishes and *disconnected consciousness* or internally generated experiences such as dreams, near-to-death experiences and out-of-body experiences (OBEs) are more likely to occur. This is a transitional time in which the dying person moves beyond a subjective experience mediated by the ECN and enters a transcendent level of consciousness that is endowed with transpersonal experiences and mediated by the DMN. With good palliation, this is a time when pain and suffering give way to healing that comes through stillness and the experience of transcendence. While reason is incapable of grasping transcendent realities, this transition is beautifully symbolised in Verse 15 of the Tao Te Ching, which states, 'The muddiest water clears as it is stilled and out of that stillness life arises.'[12]

This transition from connected to disconnected consciousness is not absolute or permanent. Evidence suggests a dying or frail patient drifts in and out of connected consciousness and that the frequency and duration of connected consciousness diminishes as death nears. This drifting between connected and disconnected consciousness (outer and inner awareness), as depicted schematically in Figure 3, offers a possible explanation for experiences of terminal lucidity as described in Chapters 1 and 6.

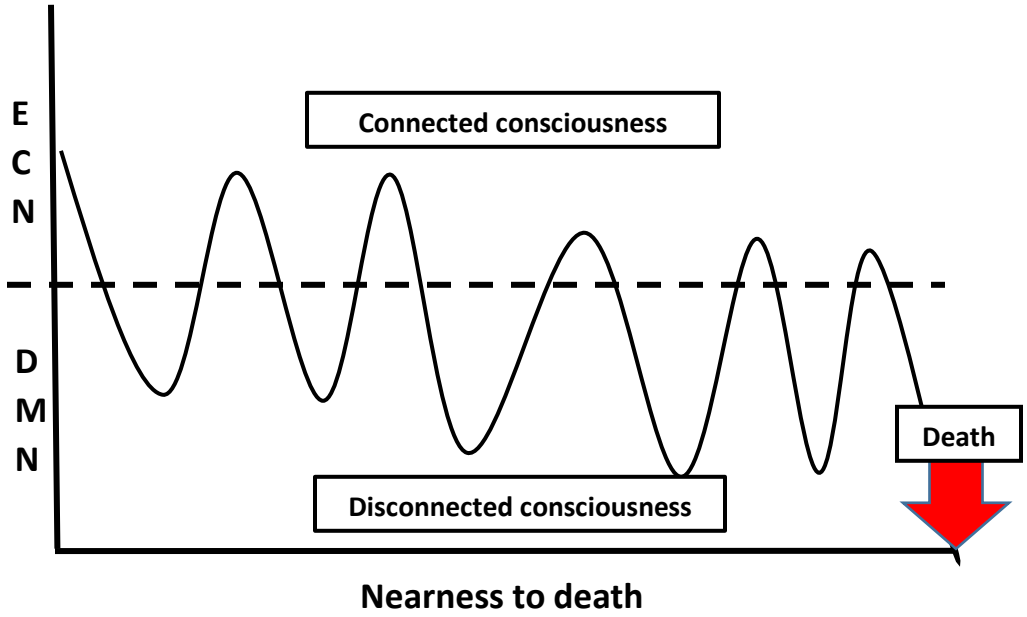

Figure 3: Schematic representation of transitions from connected to disconnected consciousness in relation to nearness to death (ECN=external control network; DMN=default mode network).

Covert consciousness

Covert consciousness is defined as a subjective experience that is not accompanied by external signs and is, therefore, not apparent to those at the bedside. While covert to the naked eye, positron emission tomography (PET) and functional magnetic imaging (fMRI) have confirmed the presence of covert consciousness in a significant number of patients with traumatic brain injury.[13–15] There is, however, little more than the occasional anecdotal report of covert consciousness in the palliative or aged care literature. The earliest published report appeared in 2001 and come from the first trial of BIS monitoring in the palliative care population.[16] The anecdotal findings, described below are a timely reminder that unresponsiveness does not automatically mean the person is unaware.

Figure 4 shows a one-hour BIS tracing of a young man who was dying of HIV/AIDS. He'd been unresponsive for 24 hours and was receiving palliative sedation to ensure he was pain free and comfortable. On the far left of the tracing BIS scores hover around 55–60, consistent with his unresponsive state. The first spike occurred just as his bedside phone rang and the second was in response to his mother's voice. The spike in the BIS suggest both sounds were perceived even though there were no changes in the patient's demeanour. The phone may have jarred him from a peaceful sleep (as it would anyone who is sleeping), but I would like to believe his mother's words touched him at a much deeper level.

Figure 4. Example of covert consciousness following auditory stimulation in an unresponsive patient.[16]

There is a long-held belief in palliative care that hearing is one of the last, if not the last, sense to go when someone is dying. This tenet was put to the test in a recently published study which compared reactions to auditory stimuli in responsive and unresponsive hospice patients with young healthy control subjects.[17] The authors noted the pattern of responses in some (but not all) actively dying hospice patients were similar to those of the young healthy controls and from this they concluded: 'Hearing may indeed be one of the last senses to lose function as humans die.'

What we do not know is whether a functioning auditory pathway and primary auditory cortex in unresponsive patients automatically means there is conscious awareness of what is said or happening. Perception and awareness are entirely different. Conscious awareness of any stimulus, be that auditory, tactile or pain, requires forward spread of activation beyond the primary sensory cortex.[18] In deep sleep, auditory stimulation only activates the primary auditory cortex because the cortical networks supporting subjective experience are disabled.[18] The effect of this is reflected in the authors' concluding remark: 'Unconscious states might not necessarily block the object of consciousness; rather, the observing subject may not be at home.' Although the authors of this last publication make no specific mention of dying, it is quite possible that palliative sedation and nearness to death (alone or together) contribute to the same form of disabling and lack of awareness.

Based on these studies, it is reasonable to assume that dying patients perceive and are aware of external stimuli (to a greater or lesser degree) in the early unresponsive stage. As the duration of unresponsiveness increases and the person's condition deteriorates, perceptual decoupling increases and with this, awareness of auditory and other external stimuli lessen or disappear altogether. This is accompanied by a corresponding increase in activity in the default mode network (disconnected consciousness), which favours dreams and visons over sensory experiences.

There is now evidence to suggest that familiar voices, familiar stories and emotionally charged words can lead to improved levels of arousal and awareness in patients with traumatic brain injury.[19,20] Whether the same occurs with unresponsive dying patients is unknown, but it is possible this form of sensory stimulation could induce periods of lucidity. Having said that, communicating with unresponsive patients is not done in the hope of inducing a lucid moment, but for the dying unresponsive patient to know they are not alone and that they are much loved.

The second example of covert consciousness involved an elderly hospice patient who had been unresponsive for several days. Apart from multiple co-morbidities, the patient had a gangrenous leg ulcer that required daily dressings. Although her demeanour remained unchanged throughout the procedure, an unaccountable spike in the BIS score was noted at the time of each dressing (Figure 5). As she was receiving a subcutaneous infusion of morphine and midazolam, breakthrough opioids had not been administered beforehand. In view of the spike in BIS scores, a decision was made to administer a breakthrough dose of morphine 30 minutes before future dressings. No further increases in the scores were subsequently noted.

Figure 5. Example of covert consciousness involving pain in an unresponsive patient.[16]

These anecdotal reports highlight the phenomenon of covert consciousness where auditory, tactile, painful or distressing stimuli and dream-like states may be experienced by unresponsive patients, unbeknown to those at the bedside. Although BIS-like monitoring may, at some future date, become an additional asset in the management of unresponsive patients, the pressing first step for palliative care services is the formulation of a standardised, widely accepted holistic approach to the care of the dying based on a better understanding of the lived experience of those unable to self-report. [2,21,22]