Chapter 1

Awakening to Unconsciousness

Our normal waking consciousness, rational consciousness as we call it, is but one special type of consciousness, whilst all about it, parted from it by the filmiest of screens, there lie potential forms of consciousness entirely different

William James *(The Varieties of Religious Experiences)*[1]

Like many in my profession, I once believed unconscious patients, irrespective of the cause, were completely unaware of what was happening to them and around them. I imagined them to be in a coma-like state, oblivious to the outside world, disconnected from their sense of self and free of all the pain, angst and grief they may have endured beforehand. The possibility of them having any awareness of what was happening while they were manifestly unresponsive seemed as improbable as it was inconceivable. How wrong I was!

Following my move into palliative care, this naive understanding of unconsciousness was challenged when I observed a number of patients at the edge of death open their eyes and acknowledge those at the bedside with a smile, a gesture or a greeting. Families were shocked, puzzled or heartened by this transient return of consciousness, now variously described as terminal lucidity, paradoxical lucidity or lightening up.[2–4] These awakenings were so opportune I often wondered if they occurred in response to a cue from deep within the dying person's psyche or from an external stimulus like the voice or touch of someone they knew and loved. Such was the case with Tim, a young man dying from septicaemia complicating acute myeloblastic leukaemia. Tim had been unresponsive and at death's door for several days when, to everyone's surprise, he opened his eyes and smiled the moment his sister, having just arrived from the USA, entered the room. Equally remarkable was the time Pam roused from her unconscious state. She too had been unresponsive for days, but stirred after her daughter reminded her, 'Today is your birthday.' Pam opened her eyes and, upon learning family had come to visit, she asked to be taken to the room where they had gathered. There, she sipped champagne and partied before returning to bed some hours later. Both Tim and Pam became unresponsive and died shortly after their respective awakenings without regaining consciousness.

After witnessing many such incidents, I could only conclude unconscious patients had an inexplicable connection with the outside world. My medical training had not prepared me for such a paradox and my clinician's mind had, until then, blinded me to what was happening before my very eyes. I was a victim of outdated beliefs and, in the words of the poet William Blake, 'could only see things thro' narrow chinks of my cavern'. These unexpected awakenings shattered my preconceived view of unconsciousness and led me on a quest to discover more about this enigmatic state, which some writers, poets and philosophers appear to better appreciate and articulate than most clinicians or neuroscientists.

Consciousness, unconsciousness, awareness and wakefulness

One of the many concerns I have about the biomedical approach to end-of-life care is the tendency to medicalise, pathologise and depersonalise dying. This isolates doctors and nurses from the lived experience of dying patients, increases the likelihood of a patient's metaphorical language being

misunderstood, having end-of-life dreams and visions labelled and treated as delirium and seeing experiences such as Tim's and Pam's brushed aside without a second thought.

Problems also arise when unresponsive patients are labelled as unconscious although the latest evidence suggests they are in a state more akin to sleep. The words *unconscious* and *unconsciousness* are misleading and invariably give rise to a plethora of confusing thoughts and emotions that add to the escalating grief felt by those at the bedside. Invoking these words immediately medicalises a situation that is otherwise destined to be a time of connection, healing and reconciliation. Many involved in the care of the dying – doctors and nurses included – have a limited understanding of unconsciousness and few, if any, palliative and aged care services have formulated a consensus policy on unconsciousness and how it can be clearly, honestly and accurately articulated to those at the bedside. The messages given to next-of-kin concerning their relative's state of consciousness are, at best, confusing and, at worst, contradictory.[5] So it comes as no surprise to know that grieving relatives commonly express concern about the care their loved one receives and the untold suffering they imagine them to be experiencing. The helplessness and uncertainty felt by family, together with the unpredictable duration of unconsciousness, lead many to envisage unconsciousness as the cruellest way to die.

Our understanding of unconsciousness is bedevilled by the absence of a widely accepted definition of consciousness. Indeed, little, if anything, is known about the nature and origin of consciousness, a fact that led the Australian-born philosopher David Chalmers to once famously declare, 'We all know what consciousness is until we try to explain it.' What Chalmers is alluding to here is not the 'easy' question such as the neurophysiological changes responsible for hearing, vision, memory, et cetera, but the 'hard' question of 'what it *feels* like to be you in this moment'.[6] This feeling is not conducive to rational analysis; it is an experience that can only be *felt*. As tantalising as this exploration may be, I do not intend to go deeper into it this mystery, and will now turn my attention to two of the less complex aspects of consciousness relevant to the care of unresponsive dying patients, namely their level of awareness and their degree of wakefulness.[7]

Awareness is defined as the phenomenal perception of self and surroundings.[8] Put more simply, it is a combination of what we perceive from the outside world (via the senses) and what we feel on the inside (emotions). This form of awareness is called *connected consciousness* and is in stark contrast to *disconnected consciousness* where awareness is detached from the outside world and is preoccupied with the inner world of dreams, daydreams and paranormal experiences such as visions and out-of-body experiences. While those who are awake and aware can tell us what they perceive, how they feel and the dreams they may have experienced, there is no way of knowing what is happening or has happened in the mind of those who are unresponsive. We can, however, quantify their level of awareness by way of clinical indicators and/or processed electroencephalography such as the Bispectral Index or BIS monitor (see Appendix 1 for details).

Irrespective of the state of consciousness (see Table 1), the level of awareness in unresponsive patients varies depending on the clearness and vividness of what the person is experiencing.[9] This can be seen in Figure 1, where the Bispectral scores of 17 patients is seen to vary considerably in the last 24 hours of life.[10] The following analogy highlights the fact that consciousness is not an all or nothing affair.

> Think of waking conscious as a furnace burning brightly. If you are deeply asleep, the flame of consciousness (awareness) has died down to a low but persistent level. In rapid-eye-movement sleep, when you dream, the flame is jumping and burning

brightly, but erratically. In coma, it is a glowing ember. *With death, the flame is extinguished forever.*[11] (my words in italics).

Table 1. Examples of altered **s**tates of consciousness based on known or presumed cause

Physiological	Pharmacological	Pathological	Paranormal or Non-ordinary
Waking	Anaesthesia	Comatose states	Mystical experiences
REM sleep	Medically-induced coma	Minimally conscious state (MCS)	Near-death experience
Non-REM sleep	Recreational drugs	Locked-in syndrome	Out-of-body experience
Hypnogogic (falling asleep)		Persistent vegetative state*	End-of-life dreams and visions
Hypnopompic (waking up)		Chronic vegetative state*	Deathbed vision
Daydreaming or mind-wandering		Confusional states	Terminal lucidity
Meditation		Dementia	Paradoxical lucidity
Contemplation		Unresponsiveness associated with dying	

*Now referred to as Unresponsive Wakefulness Syndrome (UWS)

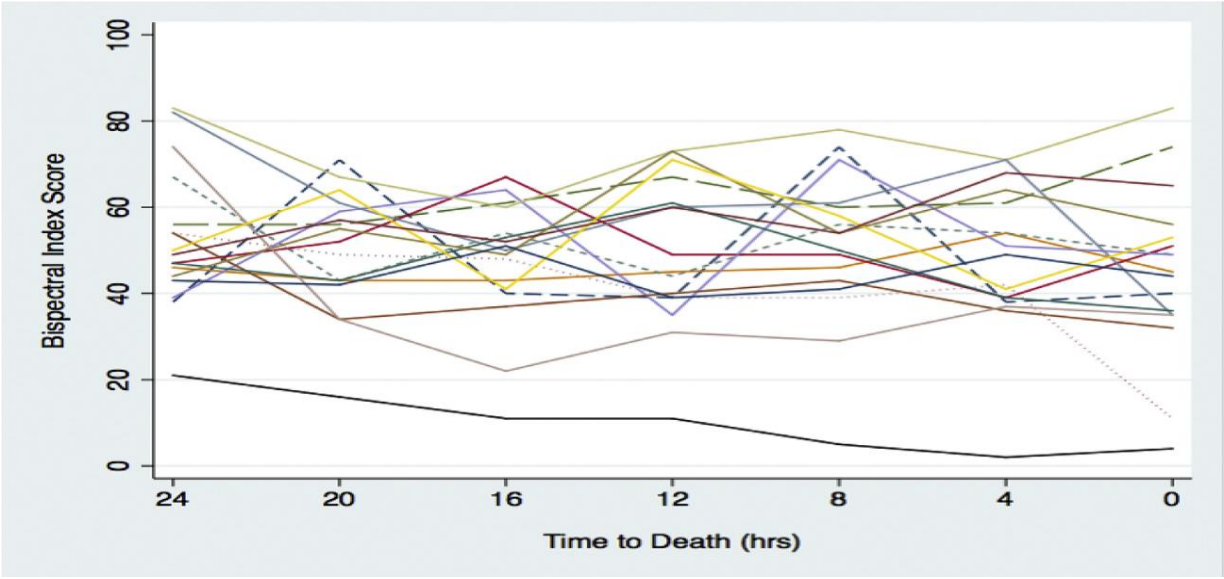

Figure 1. Four-hourly Bispectral Index Scores in 17 patients in the last 24 hours of life.
Zero (0) on the Time to Death scale does not coincide with death. It represents the time of the last four-hourly BIS reading prior to death.

Wakefulness describes the 'state of arousal or the potential to experience awareness'.[8] The level of wakefulness can be assessed by observation or quantitative scales such as the Richmond Agitation-Sedation scale (RASS) and is evidenced by eye opening, purposeful movements, groaning or other forms

of vocalisation. As there is a linear correlation between levels of awareness and wakefulness for most physiological and pharmacological states of consciousness (Figure 2), measures of responsiveness such as the RASS and the BIS monitor are useful ways of assessing either state quantitatively. The relationship between awareness and wakefulness is less clear in pathological states of consciousness such as vegetative states, the minimally conscious state and locked-in syndrome (LIS).

Due to the lack of research, it is hard to know where those who are dying and 'unconscious' fit into this scheme of things. If we believe they are comatose, we might conclude they have little or no awareness. If, on the other hand, we consider them to be in a state more akin to sleep, their level of awareness and wakefulness could be anywhere in the sleep spectrum as shown in Figure 2.

We know a person's level of awareness is largely determined by their state of consciousness, which in turn influences the clarity and vividness of experiences. Figure 2 also tells us the reverse is true. A good example of this is the dramatic change in Hazel's state of consciousness (see Introduction) – from unresponsive to seemingly wide awake – brought about by her deathbed vision. Changes in the level of awareness can also be affected by tactile and vocal stimulation. This has implications for family and care providers and for the environment we seek to create when someone is dying. More will be said about this in Chapter 6.

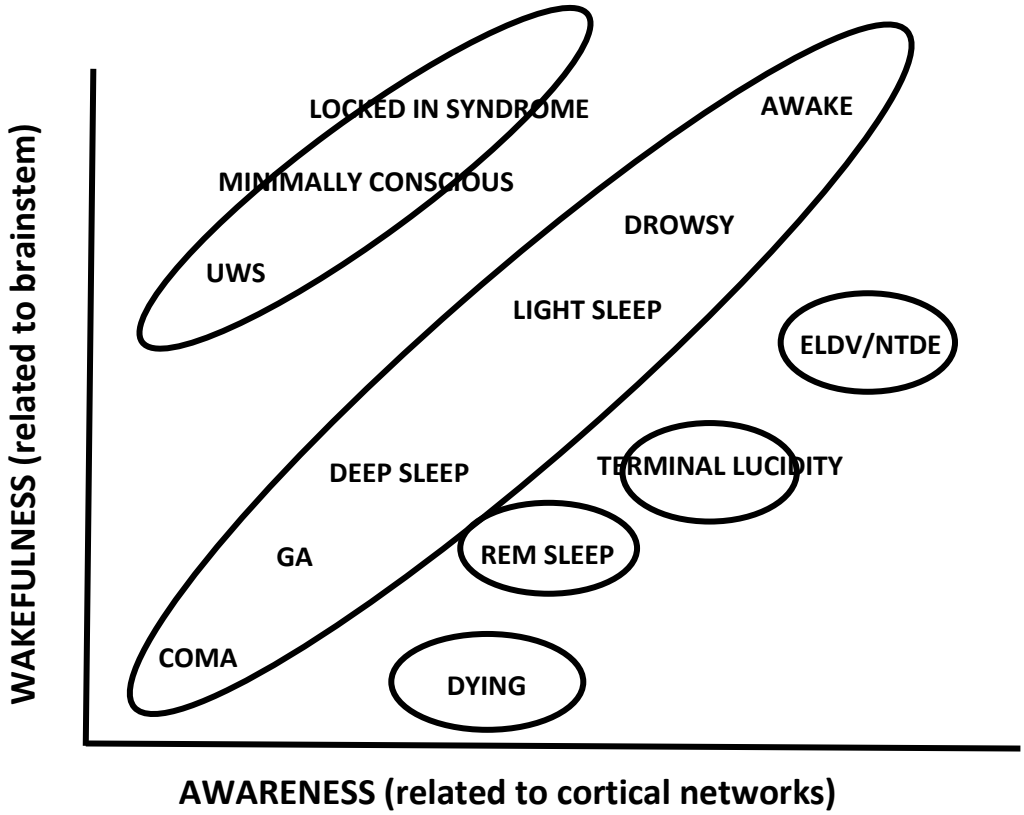

Figure 2. Relationship between wakefulness (level of consciousness) and awareness (content of consciousness)
The relationship is linear for most physiological and pharmacological states of consciousness. This relationship is less certain with pathological states of consciousness, near-to-death experiences and in those close to death. The representation of these latter states is a 'best guess' assessment.
This figure is adapted from Rady[12] and Di Perri.[8] (UWS = Unresponsive Wakefulness Syndrome, GA = General Anaesthesia, ELDV = End-of-life dream or vision, NTDE = Near-to-death experience).

In the clinical setting, a dying patient is said to be unconscious when they display no purposeful movements and do not respond to auditory or tactile stimuli. In other words, there are no signs of wakefulness. The mistake most people make is to assume this physical inertia or lack of wakefulness is accompanied by an absence of awareness when, in most cases, all that is lost is a person's capacity to respond/react to external stimuli and to their inner world of dreams and emotions, all of which amounts to the contents of their consciousness.[13] Studies have shown that a high percentage of so-called unconscious patients have some level of awareness of what is happening to them, around them or within them.[14,15] The following comment made by a young woman after awakening from an induced coma testifies to the level of awareness that is possible in those who demonstrate physical inertia: 'People would visit and talk to me. I heard what they were saying, and in my head I was talking back to them, but I wasn't actually talking.'[16]

The words unconscious and unconsciousness are so misleading there is much to gain by deleting them from the palliative and aged care vocabulary. Unresponsive is a more accurate description of the 'unconscious' state, but when speaking to relatives and friends of the dying, I am more inclined to say their relative is in a state not unlike sleep. They can relate to this narrative more so than unconsciousness and unresponsiveness and are less likely to be alarmed by fluctuations in consciousness and moments of lucidity provided they have been warned of these possibilities beforehand. Sleep is neither a euphemism for unconsciousness nor a way of softening the truth. It is a more accurate representation of the situation and, as we shall see later, it provides a framework to better explain most, if not all, end-of-life experiences.

Abandoning the word unconscious will not alter the anticipatory grief family experience as they wait for the inevitable. Meeting everyday people with everyday language, sitting comfortably with what we do not know and holding reverence for our own limitations go a long way to removing some of the greatest barriers to effective doctor-patient/family communications. Using the term 'sleep' to describe someone who is unconscious is a significant step forward in breaking down barriers we inadvertently create when we medicalise death. This step alone creates an environment where families may be more comfortable about asking questions and seeking clarifications. The way a family perceives the last hours or days of a loved one's life has a profound effect on their grief. Clear, compassionate and frequent communication during the unresponsive phase of a patient's illness can have a beneficial and long-lasting effect, thereby lessening the risk of protracted and complicated grief.

States of consciousness and contents of consciousness

It was William James who first alerted us, more than 100 years ago, to the many states of consciousness, with each possessing a different degree of awareness.[1] These different states of consciousness can be arbitrarily classified as physiological, pharmacological, pathological and paranormal or non-ordinary (Table 1). While each state is unique, the level of awareness and wakefulness is, as mentioned previously, related more to the clearness and vividness of its contents than the state itself.[8,9]

Sudden shifts in consciousness are common and are not confined to those who are comatose, unresponsive or in an altered state of consciousness. They manifest in the majority of healthy individuals as daydreaming and mind wandering, during which a person's mind suddenly and seamlessly moves from what they are doing or perceiving to one of meta-awareness – a state where the person becomes absorbed with usually imagined fantasies and interior monologues at the expense of all else.[17,18] This serendipitous, momentary experience of meta-awareness is beautifully illustrated in the following verse from the William Butler Yeats poem, *Vacillation.*

My fiftieth year had come and gone
I sat, a solitary man,
In a crowded London shop,
An open book an empty cup
On the marble table top.
While on the shop and street I gazed
My body of a sudden glazed;
And twenty minutes, more or less,
It seemed, so great my happiness,
That I was blessed and could bless.

The movement from awareness to meta-awareness and back to awareness is also prevalent amongst those burdened with an insurmountable challenge or existential crisis such as the confrontation with death. For this reason, we should not be surprised to find those nearing the end of life 'lost in thought'. These are times of healing and, unless there is some pressing business, this period of mind wandering should be allowed to run its full course, free of interruptions. I will say more about this in Chapter 4.

There is much we do not know or understand about consciousness, but we can be reasonably certain that unresponsiveness does not ipso facto mean a person is unaware.[13] This realisation has led one neuroscientist to say,

> It is possible that someone who fulfils the criteria of being unconscious might still, in another sense be conscious ... phenomenal consciousness [subjective experiences] does not necessarily include the ability to respond to stimuli or communicate with the environment.[15]

Despite my concern surrounding the use of the word unconscious, it is still commonly invoked by doctors and nurses when referring to those who are unresponsive at the end of life. The label 'coma' is occasionally mentioned, but it too is inaccurate especially if used in reference to a dying patient. Coma is a descriptive term given to a patient who is unconscious or unresponsive because of a head injury, stroke, drug overdose, et cetera. It is also used with patients who, for clinical reasons, have been placed in a medically-induced coma. The longer a person remains in a coma that is not medically induced, the chances of them emerging or surviving diminishes. If they do survive, the coma often morphs into an altered state of consciousness that is more persistent, such as a vegetative state, minimally conscious state or a locked-in syndrome.[19,20]

For many years I have avoided the word *unconscious* in the palliative care situation and prefer instead to use *unresponsive* or *deep sleep*. The words unresponsive and unresponsiveness acknowledge the absence of spontaneous purposeful movement and a lack of response to tactile and verbal stimulation, but do not exclude the possibility of awareness of what is happening in the outer world or how the person feels on the inside. In these situations, the lack of response or wakefulness may be due to the patient's moribund state and the medication they are receiving rather than a lack of awareness.

All associated with the care of an unresponsive patient should assume they have some level of awareness and will be comforted by hearing the voice or feeling the touch of someone they know and love. One young man who had been comatose for a month said on awakening:

> What made the big difference was my dear wife's presence. I could feel her hand in mine, our fingers intertwined. I knew it was her, though I could not figure out what she was doing in these strange worlds.[21]

Many comatose patients are not only trying to figure out what is happening to them but could, at times, be overwhelmed by a sense of helplessness from not knowing how to draw the attention of others to their predicament. Hearing the voice of relatives and care providers can make all the difference to their state of mind as well as their recovery. The therapeutic benefits of speaking to comatose patients was verified in a recent study that showed greater improvement in measures of arousal (wakefulness) and awareness in patients who were spoken to regularly by those well known to them.[22] This confirms what we have long suspected: a meaningful auditory connection has the potential to induce clinical improvement either on its own or by complementing medical/surgical interventions.

In the palliative, aged and dementia care situations, well-chosen words are unlikely to result in any clinical improvement. Together with tactile stimulation, however, they may bring a feeling of peace or evoke a brief period of lucidity in seemingly unresponsive subjects.[19] I will say more about this in a later chapter.