# Chapter 2

# The Patient's Experience of Unresponsiveness

*What better reason for truth seeking could there be than honesty about how little we really know?*

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When a dying patient becomes unresponsive, they cannot tell us how they feel or what they are experiencing. On these occasions, assessment of pain and overall comfort – something that is normally determined by what 'the patient says it is' – relies on the experience, expertise and judgment of doctors and nurses. There are a number of assessment tools that assist care providers in this quest, but research has shown they all lack the refinement and subtlety required to adequately assess what are primarily human experiences.[1,2] For this reason, assessment tools of any kind should be considered complementary rather than a substitute for the instinct of care providers and the nuanced sense of the immediate family.

A holistic approach is more appropriate and more reliable, but it too has its limitations. As with the biomedical approach, it tells us nothing about the subjective experience of patients. For this, we must rely on and learn from the recollections of those who survive a period of unresponsiveness or coma and live to tell their story. Although their experience is uniquely personal, the path they tread is, according to the transpersonal psychologist and Dharma practitioner Kathleen Dowling Singh, '… ingrained into the human psyche … no matter in what painful place we may find ourselves, the way is known. Although we travel alone, the road is marked.'[3] If only for this reason, the words of comatose patients as well as those who have a near-death experience need to be heard, for they are the authentic *explorers of consciousness* and offer first-hand insights into the nature of this pre-determined path and the experience of unresponsiveness. They not only describe the journey but also inform us on how best to communicate with those who partake of it.

In one of the earliest studies, an intensive care nurse interviewed 100 patients who had been in a coma and subsequently regained consciousness.[4,5] Most were men in their 50s who had been admitted following a cardiac event. Although 25% of the group had no memory of the time they were comatose, the remaining 75% recalled instances when they knew what was happening to them and around them. Many also described vivid dreams, near-death and out-of-body experience. Others recalled times when they were fearful and unable to make sense of what was happening. They could understand what was being said by those at the bedside and, while they were unable to respond in a perceptible way, their emotional reaction was as emphatic as it was indiscernible. One cardiac arrest patient vividly remembered the panic he felt on hearing a paramedic say, 'We are losing him,' while another spoke of his distress on being described by a hospital worker as a 'zonked-out patient'.

A young doctor who was in a month-long coma following a simple operation that 'went wrong' likened his experience to being 'conscious while unconscious'. He described the experience as follows:

> The voices – thoughtful, questioning and worried – came from nowhere. I could not see the people who were talking so intensely, but I realised they were discussing how to treat a desperately ill patient … I became gradually aware that the invalid was me. I was lying seemingly insensate, in a coma. Although paralysed, dumb, unseeing and

> apparently deaf to the world, I took in a lot of what was going on around me – and remember it vividly.[6]

We now know unconsciousness is not a loss of consciousness, but an alternate state of consciousness. Many so-called unconscious or comatose patients have piecemeal recollections of what happened to them, what was said and by whom and the emotions that were elicited. The aforementioned doctor summarised his experience as follows:

> It was a bewildering, alien sensation of things being done to me by forces I could not see … if the nurses had not warned my apparently deaf ears of what they were going to do, I think I would have been scared indeed.[6]

In another study carried out by two Australian nurses, five patients requiring intubation and sedation to the point of unconsciousness were interviewed four days after their discharge from the intensive care unit (ICU).[7] Although unresponsive throughout their ICU stay, all had vivid memories of their experience, including feelings of helplessness, an inability to communicate, loss of control and loneliness. Wild dreams and hallucinations were not uncommon and the authors believed these to be the psyche's desperate attempt to make sense of what was happening to them. One of the subjects had a recurrent dream of trains travelling around the unit. Upon regaining consciousness, he realised the sound came from the movement of trolleys over the ICU floors. Comatose or unresponsive patients are prone to confusion and disorientation, which leads one to wonder how much of this is caused or exacerbated by having no one to orientate them to what is happening.

The same study answered this question by highlighting the comfort, reassurance and security patients derived from the presence, voice and touch of close family and friends. The loneliness, physical and emotional isolation they experienced was offset by the quality of a human presence and the capacity of that person to be 'present' to them. This assessment is borne out by the experience of Claire Wineland, a young girl with cystic fibrosis who was put into a medically induced coma for two weeks after she became desperately unwell with septicaemia. The following excerpts taken from her account of the experience give a remarkable insight into what it is like to be in a coma and how the mind attempts to make sense of what is taking place.[8]

> If I liked the people talking and felt safe, it would affect what was going on in my head. Every time it was my mum, my dad or people I loved, it [felt] beautiful and comfortable. When it was people I barely knew, it was strange and I felt kind of lost.
>
> I have never been to Alaska nor shown any interest in it, but for some reason whenever I went to sleep I kept dreaming of Alaska. It was so beautiful. I remember just sitting there and staring at the most beautiful scenery ever for hours and hours. It was freezing cold, but I didn't care (Claire subsequently realised the Alaskan dreams were the mind's way of interpreting the actions of nurses who frequently placed ice packs around her).

A further glimpse into the experience of unresponsive patients comes from a study that looked at the subjective experience of healthy volunteers while they were sedated to the point of unresponsiveness.[9] In this study, 40 subjects were allocated to one of four groups with each group receiving one of the following sedative or anaesthetic agents: dexmedetomidine, propofol, sevoflurane or xenon. The dose of

each agent was increased incrementally until the subjects no longer responded to the verbal command of 'open your eyes'. At that point, the drug was discontinued and interviews conducted 5 and 30 minutes after the subject awoke. Almost 60% of those studied recalled sensorimotor, cognitive and affective experiences as well as complex dream-like states, including out-of-body experiences. The nature, frequency and spectrum of experiences were similar with all four drugs. The average Bispectral Index Score (BIS) for all subjects during this time was 55–70, depending on the agent used. The scores were similar to that found in a study of unresponsive palliative care patients,[2] suggesting they and others close to death, irrespective of cause, may have a similar experience.

These and other studies make it very clear that unconsciousness is a misleading term. It is not a state where nothing is happening in the mind of the persons concerned. Indeed, it is well known that with alternate states of consciousness, some brain functions are enhanced while others are diminished.[9] Unresponsiveness in dying patients is no exception.

**The psychological unconscious**

In all the studies I have cited, cognitive, affective and dream-like states are more commonly recalled than somatic complaints such as pain and breathlessness. The infrequent reports of pain could, of course, be attributed to the expertise of the treating physicians and the effectiveness of the medications prescribed. If so, one could rightly conclude that analgesics and sedatives used to ensure comfort are not so effective in placating the psyche.

In his book, *Mortally Wounded*, Doctor Michael Kearney offers an explanation as to why this may be so. He suggests that relief of pain frees the psyche from its preoccupation with physical suffering and allows it to embark on an unstructured journey of the mind, such as daydreaming, dreaming and mind wandering.[10] These adventures of the mind are not without purpose and it is now widely believed that healing and the emotional preparation for death often take place in these disconnected states of consciousness.[11,12] Such was the case with Laura, who had been hospitalised with symptoms related to disseminated malignancy. Laura rarely spoke about her cancer or that she was dying. One morning, she appeared much brighter than usual and somewhat excitedly told her daughter about a premonition that Tony, her husband, would come tonight.' Tony had died suddenly some months before. They first met at a dance and went dancing every Saturday night of their married life. When her daughter asked what they would do, Laura replied, 'I think we will go dancing.' Laura died that very night.

In his book, *A Place of Healing,* Michael Kearney describes the ancient Asklepian practice of dream incubation in which the sick found healing, 'In the deep aspects of the psyche rather [than] in the luminous consciousness of the surface mind.'[13] The rational, logical mind is unable to deal with death or the fear of death and leaves all the heavy lifting to the psyche, most of which is done during times of sleep, daydreaming or in the unresponsive phase immediately before death. We have long abandoned the rituals and practices of Asklepian healing, but daydreams and nocturnal dreams are a potential source of healing in those who are dying. As with Asklepian healing, these unstructured journeys of the mind are facilitated by creating a healing space around the person dying.

Daydreaming and nocturnal dreams centre heavily on the dreamers' current concerns and have a remarkable capacity for bringing into consciousness that which needs to be addressed.[14] The Natural Dreamwork Practitioner and Hospice volunteer Mary Jo Heyen reminds us that dream analysis is not only impossible in those close to death but also unnecessary as the dream brings its own healing.[11]

End-of-life dreams, visions and other near-to-death experiences offer irrefutable evidence in support of their healing potential. We are, however, left to ponder why these transcendent experiences occur when they do. This *enlightenment at gunpoint* led Kathleen Dowling Singh to suggest:

> The matrices for transcendent transpersonal experiences exist in the unconscious as a normal constituent of the human personality…and it's the inner certainty that one is dying that may be the locus for this psycho-spiritual stage of *Surrender*.[15]

Even if there is a semblance of truth in what Kathleen Dowling Singh says, how important it is for families and care providers to be honest and authentic in their dealings with those who are dying. It is only by acknowledging the truth that patients can ultimately surrender to it.

The belief that psycho-spiritual healing can take place even in those who are unresponsive is shared by many, including Arnold Mindell, the author of the ground-breaking book *Coma,* who says, 'Powerful, dramatic and meaningful events [are] trying to unfold themselves in comatose states.'[16] Based on years of experience of working with comatose patients, Arnold Mindell has developed a Jungian-based therapy called process-orientated psychology (POP) that helps those at the bedside connect with and support people who are comatose or nearing death and also those living with dementia. Those interested in this technique can read more in *Doorways into Dying;* a book written by two of Mindell's protégées.[17]

There is now little doubt that subjective experiences can and do occur during unresponsive states that are pharmacologically or medically induced. Our lack of understanding of the lived experience of unresponsive patients means that care providers operate in the dark and all decisions concerning management are based on clinical assessments, instincts and the experience and expertise of the doctors and nurses. While there is no way of knowing what is going on in the mind of the unresponsive patient, a better understanding of consciousness and how a patient experiences alterations in consciousness may further guide doctors and nurses in their choices and how they communicate their decisions to those at the bedside.