

Conclusion

The challenge of being a compassionate presence for someone who is dying reaches new heights when that person is unresponsive and can no longer communicate. They cannot tell us how they feel emotionally, spiritually or physically, and while taking note of every alteration in demeanour and behaviour, family are often left wondering what each of these changes could mean. As Arnold Mindell suggests, we attempt to interpret the signals without knowing if what we assume is right and whether our actions are appropriate to the situation that confronts us.¹ I will illustrate this with a true story recounted by the recently deceased Ram Dass.

Ram Dass was a volunteer in a palliative care unit. Given his expertise and long involvement in compassionate care, he was the 'go to' person when challenging situations arose. On one occasion he was asked by nursing staff to work his magic on a man who was near to death. Despite this man's moribund state, he continued to make loud unintelligible sounds. Thinking he must be in pain, the nurses administered pain medication, but with no effect. They then increased his sedation, and again the noises continued. Out of desperation, they asked Ram Dass to help. He willingly obliged, but not knowing what to do he sat and observed the patient. After a short time he felt inspired to mimic the very same sounds made by the patient. In a matter of minutes, the patient stopped calling out, opened his eyes, and looking directly at Ram Dass, he said, 'Oh, you can see them too.' Following this, the man stopped calling out and died a short time later.

I wonder how each of us would have approached that or a similar situation. Most care providers are locked into a way of thinking called the biomedical model, where a medical cause is sought for any change – clinical or behavioural – and some form of treatment or intervention is prescribed. This approach works quite well when a person is able to verbalise their concerns and the effectiveness of treatment that may have been administered. It is, however, less reliable when the person is unresponsive, unable to communicate and where death is not only inevitable, but nigh.

Despite years of caring for unresponsive patients, I was often unsure of the cause and significance of symptoms such as restlessness, sighing respirations and groaning. When the normal approach of questioning and listening was no longer available, I sometimes prescribed treatment more in hope rather than any certainty of a good outcome. Generally, this approach had the desired effect, and while this eased both the family's and my concerns, I wondered if there may have been other 'powerful events' trying to happen that may have benefited from a less invasive approach. Knowing what I now know, I question how often restlessness in unresponsive patients is due to a non-physical cause such as an end-of-life dream or vision. In their book, *Doorways into Dying*, Ingrid Rose and Kay Ryan write:

In many cases the importance of experiences such as visions, confusion, delirium, dementia, transpersonal dreams, conflicts, altered states of consciousness and spiritual phenomena are minimized or explained [away] as being part of the dying brain. We don't quite know how to address these phenomena and so they tend to get pushed aside, [medicated] and often ignored.²

Neither I nor the authors are suggesting that the biomedical model should be abandoned in those nearing death. What we are saying is that a more holistic, person-centred approach be adopted – an approach where intuition and nuanced observations are adjudged as valuable as any clinical assessment and where

care of the psyche and the soul are given equal status to care of the body. In saying this, I am reassured by the words of British immunologist and Nobel Prize winner Sir Peter Medawar, who said:

There is a large and profoundly important scientific element in medicine, there is also an *indefinable artistry*, an *imaginative insight*, and medicine is born of a marriage between the two.³

According to Trisha Greenhalgh, Professor of Primary Health Care at University College Hospital, London,

We are most intuitive when doing our regular work and dealing with patients whom we know well. In unfamiliar situations, we resort to a more formal and rational approach based on explicit professional rules. The skill of the expert is to respond to the subtle cues that signal a need to shift between the two approaches.⁴

It has long been known that the biomedical or curative model of care is lacking when cure is an unlikely outcome.⁵ As far back as 1992, Michael Kearney alerted the palliative care community that they ran the risk of becoming mere 'symptomologists', forgoing the opportunity to explore a patient's experience of illness in a more holistic and intuitive way.⁶ Despite these warnings, many patients continue to be cared for in a manner that is reflected in the words of one patient who said:

It does seem bitterly sad that my fate, the fate of me, will be decided, indirectly, through the functioning of a fleshly envelope. I see the soul, thus entrapped, as being the great and ultimate casualty of cancer's mortal war.⁷

Caring for an unresponsive patient who is near to death asks more of a care provider than their clinical expertise and deductive skills. It also requires a willingness to listen to what their intuition is telling them and to integrate this in a balanced way with the principles that underlie evidence-based medicine.³ This move to holistic, person-centred care depends not so much on what you know about your craft, but how much you know about yourself. The ongoing journey of self-knowledge can open our mind to possibilities we may not have considered, allowing us to see challenges as opportunities and to learn and grow. This open-minded approach to palliative and aged care prepares one for patient experiences that are potentially transformative, but which run the risk of going unseen and unheard, of being misdiagnosed or mistreated. How easy it is to misinterpret a word, a sign or an experience if we are unable to open ourselves to the mystery of dying.

Midwifing the death of another calls us to be present and aware, to serve with our head, heart and hands and to learn from our teachers – those who are dying.

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Appendix 1

The Bispectral Index Monitor

The Bispectral Index monitor is a small bedside instrument distributed in Australia by Covidien Pty Ltd. It is a non-invasive and validated means of determining the effect of sedative and anaesthetic medication on a patient's level of awareness. BIS scores range from 100 to 0 (see table below). Scores between 40 and 60 are common with palliative sedation, coma, deep sleep, anaesthesia and in those who are unresponsive at the end of life. The monitor is connected to the patient's forehead and analyses electrical activity from the front of the brain. It converts this signal into a score called the Bispectral score. The score is calculated every 15 to 30 seconds and a continuous moving one-hour record appears on the monitor screen.



Pictures courtesy of Covidien Pty Ltd

BIS score	Level of awareness
100	Awake
80	Drowsy or light sedation
70	Mild sedation
60	Sedation equivalent to anaesthesia
40	Deep hypnotic state
0	Brain death

NB. The BIS measures level of awareness NOT consciousness. There is no measure of consciousness nor can it be detected by any form of instrumentation