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Terminal lucidity: when dying people wake up



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MANY years ago, I looked after a man who was dying at home from a lower body malignancy. He had had significant pain but, choosing not to travel over 1000 km to Brisbane for palliative radiotherapy, accepted an epidural and was being cared for at home by the local domiciliary nursing service and with me as his GP and neophyte palliative care doctor.

I knew him and his family well as I had interacted with them in various contexts as far back as my junior hospital-doctor days.

He was set up in a hospital bed in the living room of his home, and I visited him every day or so.

At the time, I was cutting down a large bougainvillea hedge which required multiple weekend trips to the local dump. After loading up my trailer, I would wash away the blood from the bougainvillea spikings, spruce myself up in a manner appropriate for a weekend home visit in the tropics, and head off to the patient’s house, which was, conveniently, about halfway to the dump.

When I was done with my home visit, I would change back into fresh gardening clothes in their bathroom and resume my journey. His family were amused, or perhaps bemused, by this ritual, but did not think it inappropriate.

As he approached the end of his life, one of the visits was quite remarkable. The man had been non-responsive for several days and we all knew that he did not have long to live. When I arrived, I joined a number of family members and the community nurse standing around the foot of the bed. Just in front of and facing away from him, another family member was regaling us with some long story or other.

Behind the talker’s back, the patient raised his right arm and, with his fingers on top and his thumb below, indicated to the rest of us that they were just yacking on and on. We all roared with laughter and his wife, thrilled, said that he had always had a great sense of humour.

In that moment he had been lucid – “marked by clearness of reasoning or expression” (*The New Shorter Oxford English Dictionary*). He was engaged within his family, and his final thoughts and communication were humorous.

It is important to be clear about our definitions. The literature on “paradoxical lucidity” describes a small number of dying patients with dementia, and some with other chronic conditions, who suddenly and unexpectedly become lucid, remembering forgotten family, events and other important matters. [Mashour and colleagues](https://www.sciencedirect.com/science/article/pii/S1552526019300950) speculated that this could be due to the cessation as a prelude to death of inhibitory pathological processes that were part of the underlying disease. However, these are uncommon events and [most patients dying with organic brain disease never regain the capacity for lucidity](https://www.theguardian.com/society/2021/feb/23/the-clouds-cleared-what-terminal-lucidity-teaches-us-about-life-death-and-dementia?CMP=Share_iOSApp_Other) that they had lost earlier in life or had never had.

Most of us in specialist hospital palliative care do not see paradoxical lucidity because we are not caring for large numbers of patients with long term organic brain disease, and also because it is infrequent. The life-ending illnesses of the bulk of our patients are characterised by a decline over a period of less than a year.

On the other hand, I understand “terminal lucidity” as describing what I have observed not infrequently in my patients: that some people at the end of their life emerge from a coma-like state to engage in meaningful discussions with family, friends and clinicians. We offer a number of reasons why this might be so when we explain to families what they are experiencing.

Many times, I have gone into a patient’s room to find them apparently and peacefully unconscious and surrounded by family who are interacting with one another. I might say, “Good Morning Mrs …!”, and their family are shocked to hear them say “Good Morning Doctor!” Mrs … had not been responding to words or touch, or during personal care, perhaps for several days.

At other times I have engaged in bedside conversations with the families of patients in the terminal phase and, as a common courtesy, asked the patients if they were listening. Not infrequently, I got a hand-squeeze, a nod or even a yes.

Unsurprisingly, when dying people don’t respond to gentle stimulation, we assume that they are obtunded as a consequence of a specific organic process that we are not trying to reverse. We don’t try to wake them up with unpleasant stimuli because that would be unkind and would not reflect the goals of palliative care.

My experience is that patients dying of renal or hepatic failure who become unconscious do not become lucid before they die. I think that this is because their increasing metabolic derangement progressively and irreversibly impairs the function of their brain. While their level of consciousness may fluctuate a little, they are deeply unconscious when they die.

Patients with brain tumours often decline slowly, and eventually stop eating and drinking. I warn families that some of these patients do actually experience a period of temporarily increased alertness. I explain that presumably this occurs because, as they become a bit dry, the swelling in and around their tumour decreases and activity is able to restart to some degree in those parts of the brain not damaged by the tumour, surgery or other anticancer treatments. Most patients don’t regain full lucidity.

Patients who are delirious may undergo a transition from hypo- to hyperactive delirium. However, while delirium is a fluctuating condition and many delirious patients do have some periods of lucidity, a greater alertness is not necessarily matched by thought content that could be described as “clearness of reasoning or expression”.

It is also most important not to forget that some people who have lost the motor skills necessary for most forms of communication may be able to fully understand and remain fully lucid, while they seem non-communicative. One of the most challenging tasks in palliative care is to support patients with diseases such as motor neurone disease who are commonly lucid until the end of their lives but face enormous difficulty having us understand their wishes and thoughts.

How is it that another of my patients dying at home could remain unresponsive while his son who worked on a trawler travelled for two days to be at his side, wake up when his son arrived, engage in a few hours of conversation before lapsing back into non-responsiveness, and die a few hours later?

How many times have nurses told us at morning handover that early the previous evening one of our patients who seemed stable and had been sleeping peacefully most of the time in our palliative care centre had roused themselves to an alertness not seen for ages and asked the nurses to summon their family for a meeting? After a period of conversation, the patient has gone back to sleep, and died later that night.

What is going on when patients wake up from seeming unconsciousness and connect with their family, friends, and/or health care workers?

First, we should not assume that someone who is non-responsive is comatose (if we take comatose as meaning that they are unable to wake up due to organic disease). Many dying people are greatly fatigued by their illness and have little of the energy necessary to stay engaged with those around them. Such people do sleep on and off, making it hard to know when they are simply being content just to listen. Nurses in particular do an excellent job of treating all their patients as though they can hear and understand what they are being told.

Others assume that the medications of palliative care – opioids, antiemetics, anticholinergics – make people unconscious as they approach death. However, most patients who are settled in a comfortable state do not require significant medication increases in the lead up to their death. They deteriorate due to the disruptive effects of their disease.

Our consciousness is a state that fluctuates across every day and throughout our life. Some of us, particularly older doctors and soldiers, will have experienced being so tired that we could not stay awake. And once asleep we could not be woken, apart from for a significant event such as a cardiac arrest or a battle, and sometimes even then. I think that some patients are in such a state.

Some dying people summon the energy to lift themselves from the bottom of a very deep well of fatigue, and rise, or perhaps sometimes struggle, up to the surface for a short time to fulfil social interactions that are important for them. But there is no predicting or planning that this will happen. Many patients no longer have the energy or strength, or, having accepted that they are dying, are content just to listen to the fading voices of their loved ones and to be still as they die.

After several years of palliative medicine, I realised that one of my tasks was to prepare patients and families for the unpredictability and variety in the journeys of people approaching death, and that we can aspire to certainty only in the continuity of care. Forewarned of the range of possibilities, patients and their families are better able to deal with whatever path unfolds for them. The chance opportunity of a few moments of lucidity, perhaps even with a joke as a finale, might best be accepted simply as an unexpected bonus.

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