The acute care conveyor belt: a personal experience

This wasn't "end of life"; this was his life.

Perhaps the best comment I read at the time of the big 2015 bacon scare was "So what *are* we allowed to die of?". Every stage of life has now become medicalised, not just birth and death. The fact that there is even a conveniently euphemistic acronym for the end of life, "EOL", rather than the words themselves, is symptomatic of how removed we are as a profession from the reality that despite our very best efforts, life has only one ultimate outcome. But Hillman and colleagues' description of the "acute care conveyor belt"[1] eloquently describes the path that I impotently watched my father travel.

At 86, he was extremely well — still golfing and travelling, dining out and never missing the latest films. There was the usual raft of preventive medications to control his sugar and lipid levels, his gastric acid and his blood pressure. There was even an indolent carcinoma that created some inconvenient symptoms requiring increasingly regular trips to hospital for antibiotics and a first-name relationship with the local ambos.

This wasn't "end of life". This *was* his life — each day just like every day before presenting its own unique challenges and pleasures. That he would die sometime in the next while, he knew and accepted. What mattered was today and whether health and weather would align to get him to the golf course.

For my father, the conveyor belt started with one of his trips to hospital. Acute renal failure was unexplained but managed well and resolving. After transfer to a ward pending discharge home and community nursing, he suffered a massive stroke. Had this occurred at home on an early Saturday morning, it is unlikely he would have survived. But it occurred in a hospital ward, where he was surrounded by people with the skills and knowledge to keep him alive. And they did. And they transferred him to intensive care.

When I was a medical student, it was pretty unusual for anyone over 75 to get to intensive care. These days, it's pretty unusual if they don't. It seems that my father has the constitution of an ox. Even off his barrage of meds because of the renal failure mystery, his heart doesn't miss a beat: perfect systolic rhythm; his saturation hovers around 100%, breathing on his own with just nasal prongs; and his blood pressure is excellent. Only his brain is refusing to cooperate, big time — bilateral infarcts, seizures and midline shift.

The nephrologists, the neurologists, the intensivists and the gastroenterologist have all had their say. In intensive care, no one uses the "D" word. In medicine, dying equals defeat. I couldn't be clearer with the team about what my father wanted. This is not a case of "the failure of people to have stated their wishes regarding EOL care".[1] We had had this conversation many times, especially since the cancer diagnosis.

"We know he is dying. Why can't we talk about it?"

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They tell us that if he does survive, he will need high-dependency care. I ask the team about their palliation plan. They are shocked and refuse to engage. I am shocked that they refuse to engage, despite their determination to move him back to the ward. We all know this is just another euphemism for palliation, for covert euthanasia. We know he is dying. Why can't we talk about it?

Ironically, the person most comfortable discussing the topic is the youngest resident, a graduate of one of our newer medical schools. She's not recommending euthanasia, but at least she is willing to acknowledge our agony of indecision and our horror at the idea of "comfort feeding": a euphemism for starvation and dehydration.[2]

In intensive care, visiting is limited. Visitors are forced to wrap themselves in cloying yellow plastic that makes the sweat run down your back and arms despite the air conditioning. On the weekend, staff are casual, comforting and relaxed, and we hold vigil by his bedside for extended periods. I am terrified to leave in case he dies alone. But come Monday, the rules snap back into place: two visitors only, visiting hours only, meaning long hours when he has no family by his side.

I want to take him home. I am told not to get ahead of myself, but I know just how good the local palliative care team is. My mother died at home in her own bed surrounded by almost everyone she loved. But she died of cancer. It's OK to die of cancer; the system supports you. They give you painkillers and personal care and don't pretend they can do anything more. The palliative care nurses live by the tenet "medicine at this time has nothing more to offer" — but good nursing care certainly has more to offer.

There will be no more rapid response teams in my father's care. We have made that quite clear. But unless his body declares a ceasefire, he will remain hostage to the acute hospital system until the conveyor belt chugs him into a high-dependency nursing home bed possibly far away, with a percutaneous endoscopic gastrostomy tube and incontinence pads. Some days the golf may even be on the TV droning in the background.

There are no more holes-in-one or beers with his mates at the 19th in my dad's future. A more humane system would help him off the conveyor belt and onto the fairway in the sky. Thank you, Drs Hillman, Rubenfeld and Braithwaite, for daring to start this essential conversation.

Postscript

Dad finally died 10 days after his stroke. He never regained consciousness. We were able to be with him right to the end. The medical and palliative care that he received was exemplary, but this does not negate the need for a robust discussion about the role of euthanasia at the end of life and the ethical ambiguity of current means of palliation. ■

References are available online at www.mja.com.au.

1 Hillman KM, Rubenfeld GD, Braithwaite J. Time to shut down the acute care conveyor belt? *Med J Aust* 2015; 203: 429-430. https://www.mja.com.au/journal/2015/203/11/time-shut-down-acute-care-conveyor-belt

2 Kitzinger C, Kitzinger J. Withdrawing artificial nutrition and hydration from minimally conscious and vegetative patients: family perspectives. *J Med Ethics* 2015; 41: 157-160. ■