Hospital care for the old and dying

The dying of my father

A call by Craig Newnes in *The Psychologist, 1994,* for clinical psychologists to 'make public what is common knowledge' blew not only the lid, but a breath of hope. A single case illustrates the need to ensure that trained common sense and imagination (psychological resources) are directed to prevent the suffering that can be caused or continued by medical technology, talking and therapies.

To illustrate this, contrast the dying of my father recently, aged 94, with the simple cost-free measures that should have prevented or at least mitigated the humiliation and despair of his last weeks in hospital.

My father was a brilliant polymath whose career even after retirement was full of achievement and happiness until shingles at age 87 resulted (unnecessarily) in a crippled arm and chronic pain - he finished his last book typing not just single-handed but one-fingered. When he was 91 the family managed to relieve neighbours' anxieties for their safety by arranging that renewal of his driving licence required a medical examination. My father ('man-like' said the accident-repairman) then said he no longer wished to live. He grew feeble in movement, and more autocratic, and at night, if he fell, I sometimes had to call the police to help me lift him up. He never hurt himself in a fall, although once he broke a window by falling through it. His constitution remained forty years younger and his brain remained alert, and the nurses who during his last two years came each morning to help him were charmed by him. His last public speech was at age 93, when he was videotaped talking on Australian water-supply and part of his talk was included in a government video on the subject. ("I could say what I liked, and nobody could contradict me," he said afterwards. "They're all dead.") But he was very weary, and spent most of the day asleep or dreaming, and a good deal of the night wanting company. He often said he wanted to die, because of the unrelievable chronic pain. Two days before he had the fall that took him to hospital, he gave two great-grandsons a model marine engine of his father's dated 1887, and showed them how to make it go and how to fix it if it stopped.

I tell you all this, so that a picture of a real person carries through now to what happened to him as a patient.

My father was having respite care for a week at a special accommodation hostel, where he was a favourite with the nurses and ladies. He was to be Assessed for a nursing home, since he now needed more physical care than they could give. But the day before the Assessment, he fell down again. They sent him off, chirpy and alert, in an ambulance, in case of a fracture.

He was sent to an acute ward of a big public hospital where he had veteran's rights. As a daughter, I had no say whatsoever over what happened next. The role of a psychologist should have been to have prevented or stopped it.

It was soon clear that he had no injury from the fall, but the hospital said they would keep him temporarily for observation then place him in a small private hospital for quiet care while I found a nursing home for him. However, the rules are that nobody can go on the waiting list for a nursing home until they have an Official Assessment as needing nursing care. But when the geriatrician made his weekly round of the public hospital, my father would be overlooked, and it would be postponed to 'next week'. When the Assessment was made, it had ten errors of fact in it, due to paying no attention to the medical notes that had come with my father to the ward. The errors in the Assessment would have misled the nursing home as to the sort of care that was needed, and so they had to be corrected the next week - more time lost. The social worker never had time to contact a private hospital, due to too many meetings, and yet she was reluctant to let me arrange the transfer. So he stayed most inappropriately in the acute ward till he died.

My father suffered for four weeks from completely unnecessary things. The staff were caring, friendly, and did the best they knew. But they treated him like a young feller of 70, not a very weary old man of 94 who wanted only to rest and be left alone. So he would not get bedsores, he had to be chivvied and up and dressed and sitting up and pushed around to physio and other paramedics and more tests .. "They stripped me naked, and would not say why." They called him 'Ron' and chivvied him when he was sad. He winced, but tried to be polite. (I remember the old folk in our family who died at home after years of dignified bedridden - how did our womenfolk keep their old relatives' skin intact?).

His medical record had specified medication, medical regime and counter-indications, and I had told the ward staff too. His record showed that, as with many old people, the stronger sort of psychotropic drugs tried for his chronic pain had made him confused and hallucinating, and he had innocuous over-the-counter sleeping tablets at night. In the hospital, to keep him quiet at night, they gave those same psychotropic drugs again. He became confused and stuporous and upset again. So then they took him off again and he had severe withdrawal symptoms of almost manic non-stop talking, which amused the staff as he told them for twenty four hours about life in the old days, the paddle-steamers, the war, the land question, the bushfires ... He spoke to me on the phone - a speech exactly like the thousands of eloquent and fluent speeches he used to make - but it was about how he, the head of an organisation, was being thwarted and impeded by person or persons unknown, against his consent, with all information withheld from him, despite the kindly treatment of the nurses about whom he could not speak more highly and who should not be blamed for the difficulties under which he

was now placed. The nurse interrupted to tell him he was speaking to his daughter, and he gave a short speech about her being awarded a doctorate in Medical Engineering.

As an educational psychologist, I had learnt early that education begins in the school lavatory. Caring for the old, it is cleanness that can make the difference between dignity and abandonment of self-respect. The staff paid no attention to my father's medical notes or to the bowel medication brought with him. So first he stuffed up, and then they dosed him, and then he had diarrhoea. So they stuffed him up ... and the cycle recurred.

(Meanwhile I was now going around nursing homes - and observing the contrasts even among the 'best' ones, between the places where grey people sat in semicircles on plastic chairs and were gently put back if they stood up, and the rare places where 'our aim is fun, not cure'. But the trouble was, the old folk had such fun they never died, to shorten the waiting list.)

I took my father home for one of his traditional "Puffing Billy Days", when great-grandchildren and local children flocked to ride round our backyard on one of the model steam-engines my father made when he was 75. He sat and watched and dozed and watched. But it took three of us to care for him, and even the daily nurse could not cope, so he had to go back to the hospital next morning. He asked me to stop the car and run a hose from the exhaust into the window for him.

He developed symptoms of pneumonia, and for a day they were worried, but then they reported proudly that he was responding well to antibiotics. He was miserable.

He was talking to me on the phone the day following, and suddenly cried loudly and repeatedly for help to the toilet - he was on the laxative roundabout again at the time - and then he began, a grown man of demonstrated life-long courage, to whimper. "I'm messing myself! Oh, Oh, I'm messing myself!" Nobody was answering. I told him to hang up, and I rang the ward to report that he needed help. "Oh, no, he's quite alright, I can see him, he's just holding the phone," said the nurse.

The next day I when I came in, he lay in bed incontinent. "He isn't aware of whether he's dirty or not. We just come round every hour, and if he's dirty after that, we clean him up at the next hour." I took him out in the garden in the wheelchair by the fishpond. He only spoke a few words. He was in black despair. My father had given up. We sat there. I took him back. I cried as soon as I was out the door.

Next day the doctor rang. "He is in distress. We don't know if it's a bowel block or what. I'm giving him morphia. We'll let you know how he is." I could not get in until the evening. He had died fifteen minutes before.

Later, we collected his belongings in a plastic bag. It did not include the photograph of my mother, nor various little gifts and cards he had been given. We were told they had probably been cleaned up when his cubicle was disinfected.

What, then, is the role of a clinical psychologist here? To train all the staff on how to put the most important things for the patient ahead of the rituals and the tests and even the meetings - important as the meetings are for the staff's needs. For example:
1. To take seriously the records the patient brings, and what the relatives say, rather than take the very common tinge-of-pride attitude of 'starting diagnosis from scratch' and ignoring the past. Put both old record and new findings together.
2. To ensure that the hospital records are correct, and facts are checked. So often notes are made carelessly, with the note-taker's own ideas of what has happened, rather than listening to what did. On my father's notes, the primary diagnosis was dementia. He had a CAT scan - no doubt it showed that my father was functioning with less than he had, but he had always had more than most people, and in everyday life he had most of his wits about him most of the time. 'They' put on their record that he had had a major stroke that disabled his arm - ignoring the history of shingles and the gradual crippling and herpetic neuralgia that followed. He had no disabling stroke.
3. I put this requirement highly. To have at each bed a photograph of the old person when they were in their youth, so that young staff can always see in that old person, that shell, what they really were, and respond to that image, of another human being like themselves, inside the shell they see.
4. To improve ways of caring for the very old and weary, so that they can rest in bed if they want to, even if it does 'shorten their days'. There's nothing I like myself more sometimes than a 'good lie down' - and I am petrified that in my old age I could be kept sitting up bored and weary and uncomfortable and chilly all day.
5. To put a high priority on the dignity of the old person - and that means far more attention to bowels than to clever tests to help train medical students.
6. Let the patient set the relationship. First-name calling between people of roughly the same age can establish friendliness, but when young staff first-name the elderly before given permission, it can increase the effect of declaring 'second childhood' and the lower status of the patient.
7. Always assume awareness somewhere. Underestimating patients is so easy and can push them into the state they are supposed to be. I have learnt from experience and observation always to behave as if a person even in a coma can hear, and to give physical contact to the dying even if they are supposed to be unconscious. Weariness, despair and drug effects are not the same as dementia. Few old people know or care what day it is anyway. With their friends and relatives old people can often still show a life that staff may not see when they have put a patient at a physical disadvantage. Even the demented have a person suffering within.
8. To ensure that all staff, including social workers, put the organizing paperwork before the meetings among themselves. Our nice girl was incommunicado in too many meetings, while paperwork and phone calls that would have taken five minutes should have had priority, to really help patients and families. A good deal of her busy time

(and ours) was therefore wasted in her answering calls that were just repeating the same unfulfilled requests.
9. I was surprised by how often nursing staff in nursing homes as well as in hospitals objected to old people having personal reminders of their lives with them, because 'they're a nuisance to the cleaners'. If they do have photographs and cards, often they are put on the wall behind the bed where the patient cannot see them. Yet the happiest people I saw in the nursing homes were those who did have mementos of their lives around them, to remind them who they still were. When Everyman dies, he can take nothing with him, he is stripped of all (except, some say, Good Deeds) - but why should he be stripped while he is still alive?
10. To ensure that grieving relatives receive all the personal belongings of the patient, and that they are not the perks of some cleaner.

There are other functions of the psychologist in hospitals that include the welfare of the nurses, cleaners, social workers, medical staff, students, visitors, administrators, and others, so they too feel cared for and can enjoy their work and their responsibility and use their own commonsense and imagination. This, too, means attending to the small 'horse-shoe-nails' that lose battles and cause deaths, as often more useful than arranging small groups talking.