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How can I tell my patients they'll be fine in a nursing home? Our trust in the industry was misplaced

Ranjana Srivastava

There is one conversation in medicine that I hate having: telling patients they need residential care

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“What do you think, doctor? Does she have to go to a nursing home?”

“You can’t provide the care she requires,” I gently reply.

“Maybe we can muddle along somehow, by being together,” he pleads.

One can’t fail to appreciate his optimism and the urgency to remain at home with his wife of 60 years. This year she has sustained two strokes and two falls. Physically frail and psychologically fragile, she has accrued minimal gains with past rehabilitation, so the team has recommended residential care.

Most of my year is spent seeing cancer patients, but for some weeks I also work on the medical service looking after other elderly patients. Today my first job on our ward round is to explain

our decision to a despondent couple.

She doesn't want to go into a nursing home. He doesn't want her there. But unless (meagre) council help, (costly) paid care, and the (busy) adult children can come together to support their needs at home, the writing is on the wall.

Outsiders often assume that the worst part of my job must be telling cancer patients that they are terminally ill. They wonder how it feels to daily dim someone's hope, confront stunned relatives and preside over the inevitable decline of patients who have grown close over the years. What they don't necessarily see is the therapeutic relationship between oncologist and patient that allows trust, empathy and compassion to fill that difficult space and make the universal process of dying a little more dignified and a little less painful for many, though not all. Oncologists who work in close partnership with palliative care services have a valuable source to rely on when they are stuck knowing what to do or how to react.

When I express my regret at their decline, many of my patients console me that we all have to die some day. This wisdom is deeply moving and an undeniable attraction of being an oncologist. Over the years I have become unafraid of saying to people that they have a terminal illness. I can accomplish this with my ethics, integrity and confidence intact because together we can navigate the path.

But there is one conversation in medicine that I hate having and that I'd increasingly give anything to avoid: telling patients they need residential care. In my opinion, it is the conversation with the most far-reaching consequences in terms of initial shock, enduring trauma, guilt, pain and conflict. A geriatrician friend reminds me that no one says, "I want to grow old so I can go to a nursing home." This truth reveals itself in heartwrenching ways when a patient is placed.

In the past I could dissemble my ambivalence by telling patients that a nursing home was the place to meet their special needs, where trained staff, customised care, and appropriate food and activities would ensure their comfort and longevity.

The hospital narrative around nursing home placement long adhered to this familiar routine. Our tactful silence turned out to be our implicit support and, in turn, it silenced those who expressed concern.

Then the royal commission happened.

The worrying signs had been there for years, but it took a proper inquiry and courageous speakers to whip off the massive fig leaf protecting the systemic wrongdoings of the residential care industry. Suddenly the abject conditions of our most elderly and vulnerable citizens, their deprivations, pressure sores, measly meals, their hunger for hygiene, attention and comfort were laid bare for all to see. Just as we averted our eyes from one story, a more awful one came along, forcing us to confront the realisation that while the choice to send someone to residential care may have been unavoidable, our blanket trust in the industry was a serious misjudgment. Suddenly we woke up to the fact that the nearly half of residents who never receive a visitor miss out on more than a familiar face. They miss out on advocacy. We realised that some of the biggest names were responsible for the most egregious errors, and their apology seemed to contain more dismay at being caught than remorse.

With an ageing population, far-flung supports and people's own valid needs that prevent them from becoming carers, nursing homes will continue to be one solution for care. The royal commission findings have not reduced the number of patients awaiting placement, but they have already triggered more guilt and suffering for frail patients and their conflicted relatives

who are apprehensive to know if a particular nursing home is “good”. While many nursing homes must resent being tarnished by association, the honest answer seems to be, “You will have to live there to find out.”

When people ask me if the Australian public health system is any good, my answer is a resounding yes. When they ask me if cancer patients are well served in Australia, I can say yes, they have some of the best outcomes worldwide.

But when it comes to the treatment of aged-care residents, it's hard to say yes with confidence. One hopes that with a combination of better policy, stronger governance and greater respect for the consumer voice, cultural change will occur - but it will take a long time and we must hold the industry accountable, not losing sight of the fact that one day we will be in the place of our elders.

We have wrapped up a defeated exchange where I have told my patient all about the medical reasons she needs residential care and sidestepped many of the emotional reasons she doesn't want to go there. The conversation feels unfinished, and while not dishonest surely not one of our more distinguished moments. When we leave she is resigned and he has his head in his hands.

Moments later he joins me outside, his face crumpled with concern.

“Doctor, these days they hit people in nursing homes, don't they? That's unthinkable.”

I feel nauseated by the image. There was a time when I'd have dismissed it and counselled him to stop panicking, but now how can I? The widely publicised recordings of gratuitous violence against defenceless people are as unbearable as they are shameful. And the rejoinder I have is that it doesn't happen in all nursing homes, but it sounds so feeble that I can't bring myself to do it.

Instead, I take his hand” “I know it's hard, I'm sorry.”

He is smart enough to know that I haven't really confronted his question and gracious enough to let it go. We stand in silence and then it's time for me to move on and for him to go back inside and reassure her that the doctor thinks the nursing home will be just fine.

●. Ranjana Srivastava is an Australian oncologist, award-winning author and Fulbright scholar. Her latest book is called *A Better Death*

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