

Aged care royal commission hears many suffering painful deaths, facilities ill-equipped for dying

BY ELIZABETH BYRNE

UPDATED SUN 15 DEC 2019, 1:42 PM AEDT



PHOTO The aged care royal commission has heard some people are suffering needlessly painful deaths.

PIXABAY: SABINEVANERP

Dying is an interesting business.

Most of us probably hope to just drop, quickly, out like a light.

But that scenario is one of the least likely, as became clear during last week's Royal Commission into Aged Care Quality and Safety hearings in Canberra.

At the heart of the issue is the matter of directives given by people for their care when they are no longer able to communicate.

It's called an Advance Care Directive, and these days you can download a form and list your wishes.

But as the Royal Commission heard, it is the details that are important.

They can impact not the inevitability of death, but the manner in which the process of death unfolds.

Daughter says aged care facility was 'not equipped' for dying

One argument made by some at the Royal Commission hearings was that many aged care homes are not set up for dying.

Kate Davis said this was brought home to her when her mother Noeline Taylor was diagnosed with a brain tumour.

Her choice was not to have radical treatment.

But Ms Davis said the staff appeared unable to grasp that her mother was passing away.

 An aged care worker pushing a woman in a wheelchair.

PHOTO The aged care royal commission heard from palliative care nurses about how best to manage the dying process.

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She said that at that stage her mother was no longer eating and rarely conscious, but despite this staff would suggest getting her up for a shower.

"We would have the people responsible for personal care leaving a cup of tea and a biscuit on Mum's bedside table," she said.

"She hadn't been out of her bed for weeks."

She said the staff would often become upset themselves over her mother's condition.

"It was like they were a bit shocked she was dying," she said.

"I feel like the facility was not equipped at all."

The situation became distressing, particularly one evening when Mrs Taylor was left moaning in pain for three hours, without pain relief, because the only registered nurse had been left to cover several aged care homes.

Finally, Mrs Taylor was moved to a hospice, where her daughter says she was comforted and treated with dignity in her final days.

People deserve care that matches their symptoms: palliative care nurse

Palliative care expert Nikki Johnston from Canberra's Clare Holland House told the royal commission Mrs Taylor's experience is not unusual.

 Nikki sits in a chair smiling.

PHOTO Palliative care expert Nikki Johnston from Canberra's Clare Holland House says dying does not have to be painful.

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"We are living longer but not living better," she said.

She told the story of one of her patients, a 105-year-old woman who broke her hip.

"[She] was picked up in the ambulance, went to the hospital and because her advance care plan said 'not for resuscitation', they didn't even get her out of the ambulance, and they sent her back to the nursing home with no pain relief," she said.

Another palliative care nurse practitioner, Peter Jenkin, who works for the South Australian group Resthaven, told the hearing people should be able to get the care that meets their symptoms.

Those symptoms can include everything from breathlessness to incontinence, trouble swallowing and, of course, pain.

In his evidence, Mr Jenkin told of how it was a tricky business even when people had a clear Advance Care Directive.

"[Say] someone has an advance care directive that says 'I really don't want to be resuscitated if I was not able to recognise my family, or looked like I was dying, I don't want any life-prolonging treatment.'"

"The person may be looking like they have a chest infection."

"Does it mean that maybe they're willing to take antibiotics by mouth, but wouldn't want to take the next step which is intravenous, which usually means a hospital presentation?"

This became a problem for Ms Davis whose mother had chosen no medical interventions on her Advance Care Directive.

"Towards the end, there were plenty of interventions that were required for Mum to be comfortable," she said.

Having signed the Advance Care Directive, the dying woman was forced to give permission each time one of these interventions was made, including the use of catheters and bowel cleansing, procedures that do not prolong life but ease pain before death.

Ms Davis says she had assumed 'medical intervention' meant something invasive rather than something that would simply make her mother more comfortable.

'What is going on?' Commissioner asks why so many suffer

When the person has dementia, which is a large proportion of people in aged care, the problems are magnified, especially when it comes to pain.

But Mr Jenkin told the hearing there are many tools available to help in assessing dementia patients and no excuse for not caring for them properly.


 Peter sits in a chair smiling.

PHOTO Palliative care nurse practitioner, Peter Jenkin, spoke at the royal commission into aged care.

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"Sadly there are still people out there who think that they don't feel pain the same, which is just plainly ridiculous and there's no evidence to suggest that at all."

It was commissioner Lynelle Briggs who raised the real elephant in the room, asking the pair why the evidence kept showing people had been left in serious pain and not given relief by medical professionals.

"What's going on?" she asked.

"I would have thought this was core business."

Ms Johnston agreed, saying opioids were a good option for people who were dying and in need of pain relief because they don't interact with other medicine.

"I think there's an opioid phobia out there," she said.

"I think there's regulation that stops people from prescribing opioid medicine."

She has called for changes in the law which would recognise the clinical needs, particularly for aged care residents.

In many senses, it is a terrifying subject, but those working in palliative care carry an unexpected air of optimism.

Ms Johnston's advice if you're making an Advance Care Directive, is to start with what you love most, and put that at the top of your list.

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