

Review calls for better care in our dying days

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A new paper from The Australian National University (ANU) highlighting failings with palliative care and how we are cared for when we die.

The paper is co-authored by Alan Bevan, 68, who was told his partner was dying by a palliative care specialist in the final eight hours of her life.

His partner, Sue McKeough, was diagnosed with Alzheimer's disease at 49 and died just over five years later in a nursing home with Alan by her side.

Mr Bevan says he felt he was the only one responsible for her care when she fell into a coma in the final weeks of her life.

"There were all sorts of problems associated with getting a palliative care specialist and finally I got someone only hours before she died," said Mr Bevan.

"Up to that point there were no specialists there. It seemed that it was just me caring for her.

"The issue was she had no specialist palliative care support in the nursing home. I didn't fully understand what was happening up until that point.

"I was just stretched emotionally, not knowing what was going on, or what sort of care she should have."

Mr Bevan was asked to join the report after ANU researchers came across his wife's story.

"I was so distressed by my inability to get appropriate palliative care," he said.

"The nursing home staff were bringing in food when she was in a coma.

"I can't convey how important it was to have someone who understood what was happening, who was able to tell me my partner was dying.

"She told me that Sue wasn't not going to last more than a week and it turned out she didn't last eight hours."

Mr Bevan's experience has helped inform a review of palliative care that is calling for involvement from patients in all decisions across the end-of-life care sector.

Lead author of the report, Dr. Brett Scholz, says how we are cared for in our final days needs a revamp—specifically by involving people who have lost loved ones.

"This review shows we are not meeting policy expectations about involving consumers in how we are cared for before we die and we are missing out on a lot of the benefits of patients' point of view," said Dr. Scholz from the ANU College of Health and Medicine.

"Death is an important part of life that everyone will go through and using that experience of knowing what it is like to have someone die in hospital or a nursing home could make that situation a little bit easier for others.

"It is never going to be a good experience, but if you have experiences

informing the kinds of treatments you offer, the services and what it looks like to die in a hospital you could make it more comfortable and easier for families who are grieving."

The review suggests patients and consumers should be part of all levels of decision-making processes that health services offer, as well as in delivering education, conducting research, and setting policy agendas.

"At the moment patient involvement is tokenistic and we are recommending real engagement from consumers," said Dr. Scholz.

"When someone we love is dying we look to doctors and think they know best but they are not the experts in our own lives."

Mr Bevan says he was shocked to discover how ill prepared institutions and medical professionals were around his partner's end of life care.

"I thought palliative care was something that would happen for people when they needed it," said Mr Bevan.

"I think that Sue should have had a [palliative care](#) specialist from when she was first diagnosed."

The paper is published in *Palliative Medicine*.

Provided by Australian National University

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