Why can’t we die at home any more?

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Australia’s “death-denying” culture is hampering hospitals across the country, according to a new report on how and where people spend the last phase of life.

It found a quarter of all public hospital beds are occupied by patients who are predominantly elderly, in their final year of life, and often receiving high-intensity care without clear benefits.

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In Australia’s “cure-based” system, treatment is frequently at odds with patients’ known preferences.

The report was prepared by the Violet Initiative, a national not-for-profit organisation that for the past 25 years has helped people navigate this final stage.

While 70 per cent want to die at home, with emotional and medical support [https://www.afr.com/wealth/personal-finance/why-you-need-to-prepare-for-the-day-nobody-wants-to-talk-about-20220725-p5b4cr], less than 15 per cent achieve this. The report says the associated costs add an annual $4 billion burden to the health and aged care systems.
It found that dying in hospital is the least preferred place to die, yet one in two Australians die there, spending an average of 33 days in hospital across four admissions in their final year.

This helps to explain why 11 per cent of the federal health budget is now being spent on 1 per cent of the population who die in that year.

The last stage of life is not truly a clinical issue, it's a social issue, says Kate Carnell, chair of the Violet Initiative. **Simon Schluter**

"This is happening at a time when our public health systems are in crisis, with hospitals overwhelmed and dealing with bed blocks, elective surgery delays, emergency department overcrowding, and ambulance ramping," says Kate Carnell, chair of the Violet Initiative.

"The cost of our cure-based health system will escalate because our population is ageing, and the number of frail people is set to double within 15 years.

"Although the medicalisation of dying is not good health care or good social care, governments don't want to touch it and pass it from department to department.

“We think part of the solution is to accept that the last stage of life is not truly a clinical issue. It is a social issue. It’s about having a proper conversation and a proper plan. [https://www.afr.com/companies/healthcare-and-fitness/how-to-go-out-the-way-you-want-to-20120329-j386w]

“People should be able to fund the plan out of their health care packages. They can get a nurse, but getting an appropriately qualified person to help the family put together a plan is not covered.”

In its mission is to transform the last stage of life, Violet has helped 18,000 people navigate these most personal moments.

People find themselves on a conveyor belt from home to hospital, often ending on life support in ICU, says Professor Ken Hillman from the UNSW.

Called “Too little, too late: the experience of the last stage of life across Australia” the report reviews national and global evidence and calls for action from federal and state governments.

In the forward, Ken Hillman, professor of intensive care at UNSW, writes that hospitalisation is the fall-back position for people in the last stage of life.

“They are subject to a conveyor belt from home to hospital, often ending on life support in an intensive care unit.”

Just as there has been a shift in birthing, with soon-to-be parents now reclaiming the process, so the last stage of life needs to be reclaimed too.

Professor Imogen Mitchell, chairman of the Violet Initiative’s clinical committee and an ICU specialist, writes that our “death-denying culture” denies the need to plan for a high-quality death.

“Changing the current dogma is going to be hard, and we need to think beyond palliative care as being the whole solution.”

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