

SPECIAL CARE

Greater access and availability are needed when it comes to palliative care outside of our major cities.

STORY TERRI COWLEY

Rocky Varapodio clearly recalls the day doctors told him and his family that nothing more could be done for his ailing father Santo, aged 88. “We were at St Vincent’s [in Melbourne] when the decision was made that there wasn’t much more they could do for Dad and that we were going to move to palliative care,” Rocky says. “We knew that GV Hospice provided that service at home, so it was a pretty easy decision in the end. We knew he would prefer to be there than in a hospital setting.”

Santo’s wish to be at home at the end of life isn’t unusual – in fact, figures from peak body Palliative Care Australia (PCA) show up to 90% of people in this situation wish for the same. But for Santo and others from regional, rural and remote Australia, being at home means being back in your community, in the place where you have lived, with the chance to be surrounded by family, friends and familiarity in your last days, rather than hundreds – sometimes thousands – of kilometres away from everything you know and love. For Santo, a legend in the local transport and horticultural industries, it meant coming home the 190km to Shepparton, from a sterile institution in the bustling Victorian capital, to be near the orchards he had overseen for decades and his 2 children, 5 grandchildren and 4 great-grandchildren.

“The experience from that point on was incredible,” Rocky says. “They took care of most things, including getting a suitable bed for Dad. By the time we got back, it was all set up for him. The hospice team was in constant contact with us.”

Unfortunately, the experience of Santo and his family is far from universal. Camilla Rowland is the CEO of PCA and has been campaigning to put the issue of accessible and available palliative care for all Australians on government agendas and is currently building a public petition, available to sign on the organisation’s website.

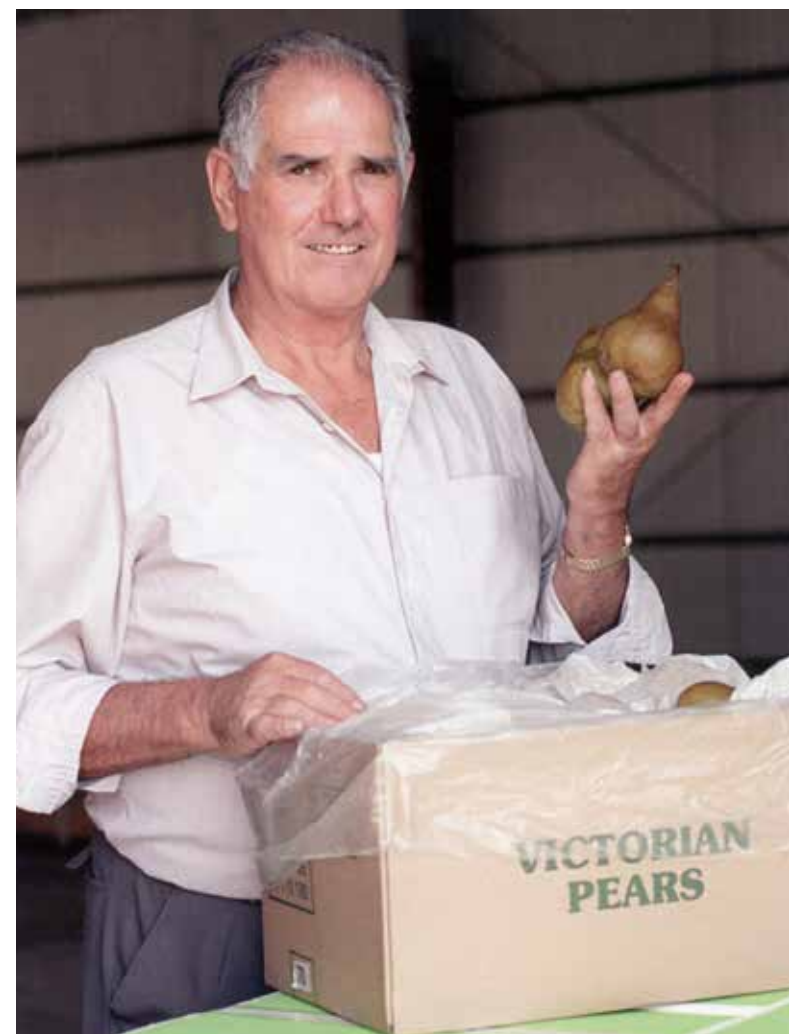
“Only 16% of all specialist palliative care doctors are located in rural, regional and remote communities,” Camilla says. “The pressure on carers is huge. Some of the distances you have to travel, and the costs are really significant. If you’re off a property, you have to think about the downtime needed to provide that additional support and care, particularly if it’s a family business or a small business.”

Camilla says the New Aged Care Act passed in November embeds palliative care as a human right (from July 1, 2025), meaning patients are entitled to care from staff that are trained in this specialty. “At the moment there is a postcode lottery,” Camilla says. “There are huge discrepancies between local health districts and after-hours service availability. Most people want to die at home. Services have to be designed to meet that right. We have to find the staff to do it. We have to think about workforce as well.”

Camilla says the personal consequences of not meeting these needs mean patients will miss out on symptom control and will face delays in accessing treatment. “We don’t want anybody to have a bad death,” she says. “It also impacts on family and can be highly distressing, resulting in family trauma.”

Susi Tegen is the chief executive of the National Rural Health Alliance, which has been highlighting the discrepancies between levels of healthcare in the cities, compared with the rest of Australia, for many years. But for her, the issue of palliative care is personal.

“I cared for my father at home on the farm [near Penola, SA],” Susi says. “It wasn’t easy, but I wanted to give him a quality of life for those final months, when he was suffering from cancer and Alzheimer’s. We really struggled but I just felt, ‘How can you not support your family?’ Just because people don’t live in the city, we should be able to come up with a model for all Australians to age and die with dignity. Rural people just want to be at home in their communities, with the sights and smells they’re used to.” >



CLOCKWISE FROM TOP: GV Hospice holds an annual memorial service to remember lost loved ones at Shepparton Art Museum; National Rural Health Alliance’s Susi Tegen; the late orchardist Santo Varapodio, who received appropriate palliative care in his last days.

Susi says palliative care medicine in rural Australia is in crisis. “We know that people in rural Australia die earlier, the further they live from major cities,” she says. “They die 12–16 years earlier, and part of that is because they have less opportunity to receive any healthcare. In terms of palliative care, they have even less opportunity than their urban counterparts.”

Susi says people living in the bush should not lose out when it comes to carving up healthcare budgets. “Despite only making up 30% of the population, the people that make up rural, regional and remote Australia contribute significantly to the Australian economy. They produce 2/3 of exports, about 50% of tourism and put 90% of the food on Australians’ tables. They are an economic powerhouse and they’re not receiving the care they should be getting. We really need to look at technology and our funding models, and we need flexibility. There are no 2 communities that are the same. Government expenditure on health is \$6.55 billion per year but there is an underspend in rural health that equates to \$848 less per person, on average. Put the money aside and let communities deal with it.”

All 3 universities in Sa – the University of South Australia (UniSA), Flinders University and the University of Adelaide, have partnered in a unique research project

to give rural South Australians in palliative care a voice. Researchers are exploring the end-of-life care experiences of people living in rural areas, with the aim of improving access and delivery of services.

UniSA researcher Shannen van der Kruk says the study is an important opportunity to understand the unique challenges faced by rural families accessing palliative care. “Palliative care is person- and family-centred care for someone with a life-limiting illness and aims to optimise their quality of life,” Shannen says. “It encompasses a range of emotional and physical supports, including pain relief, home-care assistance, grief support and counselling, and can be delivered by a wide range of health and community providers at any stage of illness. Yet people living in country or rural areas have less opportunity to receive specialist palliative care, which can significantly affect their quality of life. This is partly due to fewer medical professionals living and working in these areas, but other factors may also contribute.”

The study hopes to capture real-time behaviours, experiences, and key moments that shape how and why people living with a life-limiting illness and who need assistance, make decisions about palliative care. “The initial goal is to understand which palliative care supports are working well, the areas that need improvement, and >



On the campaign trail: CEO of Palliative Care Australia, Camilla Rowland.

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GV Hospice palliative care nurses (l-r) Jayme Bramley, Kim Martin, Annie Jorgensen and Erica Varapodio.

any potential gaps,” Shannen says. “We’re committed to finding ways to better support families at such a critical time.” The research team wants to talk with people living in rural areas who are facing a long-term, incurable illness – as well as their carers, and will be recruiting participants until approximately May 2025.

The health scientist moved from the Netherlands 5 years ago, where she experienced better access to palliative care when her grandfather died. “It’s really important that we share people’s stories,” Shannen says. “There is always the hope that we can actually make change and that the government is listening.”

Wendy Ross, the CEO of GV Hospice based in Shepparton, says a combination of State Government funding, grants, community support and income from an op shop, allows her organisation to offer free palliative care to the community 24 hours a day, 7 days a week. “The service started in 1989 because a couple of doctors recognised that people were dying in hospital that shouldn’t have had to,” Wendy says. “They preferred to die at home, if they had the proper support.” About 150 patients are in the care of the service at any one time and have access to a specially trained nurse – whether at the end of the phone or in person – and special equipment, as well as counselling for family members.

“The misconception is that we only deal with end of life, but we also deal with symptom management and referrals between services. People sometimes don’t want to be referred because they think people are giving up on them, but we discharge people all the time.”

Rocky Varapodio and his family cannot speak highly enough of the palliative care Santo received before he passed away of kidney failure last June. “It’s very comforting to know they’re there and they’ll come if you need them,” he says. “It was a very positive experience.

We were offered counselling and regular check-ins to see how we were travelling. On the night he did pass, they came to confirm it. They called the undertaker and did some of those things that need to be done right in the moment. The nice part about that is that they’ll do as much or as little as you want. Everyone grieves and handles that stuff in a different way. They’re very good at reading the play. What amazes me is that they do this every day, day in and day out, and they know what the outcome is going to be. I think you need to be a special kind of person.”

To learn more or to express interest in the SA study, email Shannen.vanderkruk@unisa.edu.au.

Disclaimer: story author Terri Cowley volunteers on the board of management of GV Hospice.