

# Care for dying – we knew, we forgot, we’re back

New Zealand’s palliative care system is finally showing signs of renewal, with hospice leaders pushing for lasting change

## PALLIATIVE CARE

Kevin Norquay

After a decade of palliative care neglect in which New Zealand slumped by world standards, there is new hope the terminally ill may soon be suffering less.

An often hidden health service, palliative care improves the quality of life of patients and their whānau who are facing issues linked to a terminal illness.

It prevents and relieves suffering, manages pain and other symptoms, physical, mental or spiritual. It offers a support system to help patients live as actively as possible until death.

Without a broad national system it is not hard to picture an anxious rural mother dispensing painkillers to a terminally ill child, with help for them both hours away.

And the system has been headed for life support itself, with our quality of care ranking falling from third in the world in 2015, to 12th in 2021 and now 15th.

Somehow the final part of the health mantra “start well, stay well, get well, die well” has gone AWOL, even if palliative care is a valuable investment that keeps people out of hospitals.

Palliative care treats dying as a stage of life, not an administrative inconvenience, but in the modern world, money talks.

Hospice NZ chief executive Wayne Naylor has been lobbying, and Health Minister Simeon Brown has been listening, so the mood in the sector is more upbeat than it was six months ago.

There is still not enough funding to halt the slide, the fate of dying remains a topic society still doesn’t want to talk about, or place value on, there is a decline in carers, lack of training, and insufficient funding.

“We don’t talk about this, or we don’t talk about what might happen or what we might need when that time comes,” Naylor says. “Society puts death out on the margins because it’s seen as a medical failure, Naylor says.

“So that’s a challenge. It permeates right through, into the government, all the way through our health system.”

There is a need for better funding, training, a holistic approach to care, particularly paediatric care, so there are consistent, accessible, and well-funded palliative care services nationwide.

New Zealand has only two paediatric palliative care specialists: at Auckland’s Starship Hospital, and the Rei Kōtuku charity in Wellington, headed by Dr Amanda Evans.

It is a worse situation than in many



Wayne Naylor, Hospice NZ chief executive says society puts death out on the margins – it’s seen as a medical failure.



Wingatui trainers Terry and Debbie Kennedy visit late journalist Jamie Searle at the Otago Community Hospice.

developing countries, Evans says.

“In New Zealand, one child dies of a serious illness every day and 3000 annually are living who require palliative care [pain and symptom management] for long-term medical conditions,” she says.

“Those children who die outside of Auckland have no access to publicly funded specialist paediatric palliative care, meaning children living elsewhere are potentially dying in unnecessary pain and distress.

“We’re hopeful that, with a review of the status quo under way, this Government will make a once-in-a-generation change that will mean children and their families are fully supported on the most difficult journey of their lives.”

### Signs of progress at last

And things are at last moving that way. “There’s been a lot of work done to address it,” Naylor says, adding it was important successive Governments maintained the work, so that it was not constantly picked up and dropped.

“We’re talking to the Minister. We’ve been talking to other MPs, the opposition and coalition partners, to say this work



Family members caring for people with a life-limiting illness can turn to a Hospice, in this instance Nelson-Tasman.

needs to carry on,” Naylor says.

“If you’re in the Government or Opposition, you need to commit because it’s about people who are dying and making sure they get good care. We’ve come so far that we can’t just have a new Government stop it.”

Health New Zealand has a National Palliative Care Work Programme under way, aiming to develop nationally consistent approaches to paediatric and adult palliative care.

As well, there is the recently launched Hospice Service and Funding Review. Together they could rebuild a consistent, nationally funded system, though Naylor predicts improvements are at least a year or two away.

From 2001 to 2015, New Zealand built a sophisticated, holistic palliative care system, then stalled. Our slip in the world rankings was due to standing still, while other countries invested and improved.

“We’ve not been doing anything, and loads of countries have been doing a lot. So they all have national strategies, they have

national training programs,” Naylor says.

“Governments are investing in palliative care, and those countries have overtaken us because we’ve been doing nothing up until probably two years ago.

“We made huge leaps and we just stopped. And in a lot of cases, we’ve stood backwards, especially around education and training and engagement at the health agency level and with the government.”

Hospice services have taken a long, at times uncomfortable, look at what they have been doing, and and Health New Zealand is now undertaking a Hospice Service and Funding Review

There are high hopes we are about to escape the spiral of rising need as the population tilts toward older ages, combined with shrinking services, exhausted hospices and patchwork funding.

While it all sounds bureaucratic, the human cost is immense in terms of stress – the terminally ill and their families missing out, lives ending less well than they should. Hospice and palliative care workers had

to face increasing workloads, or implement cuts to services and face-to-face time that goes against their ideals.

“We save people, we cure people. And now I think society is realising that we do need to acknowledge that people die, and we need to plan for it, and then have a system that supports them,” Naylor says.

### Funding, training and care gaps

Hospices have been unable to keep up with rising demand – leaving some patients waiting, some families under strain, and some services contracting.

Rural areas miss out the most. Training has withered, children’s palliative care is “the biggest gap”, Naylor says, and families often face an unequal, postcode-dependent system.

South Island children must travel to the North, which is a poor option, Naylor believes. “We know parents and children want to be at home. So we need to do something, we need a different model,” he says. “There’s a great proposal that’s sitting

with Health NZ, and everyone’s waiting for it to come out.

“Then it has to be funded, and it’s not even large – it’s in the range of \$8 million a year for a national coordinated service of palliative care for children that are dying, or children living with life-threatening conditions.”

The current national review aims to guarantee a minimum level of care for every dying New Zealander.

Dr Catherine D’Souza, spokesperson for Australia and New Zealand Society of Palliative Medicine (ANZSPM), warns that urgent action is needed.

“The number of people dying is set to double within 30 years,” she said in a statement.

“If we don’t act now, already stretched health services will struggle even more – and risk falling apart.”

New Zealand has less than one-third of the recommended number of palliative care specialists per capita, and many are nearing retirement, according to the *New Zealand Medical Journal*.

Yet there is insufficient funding to train replacements.

Specialist services, such as hospices, remain deeply valued by communities, but are under severe financial pressure. Public financial support keeps them afloat.

The last comprehensive national palliative care strategy was written in 2001. A 2017 action plan was developed but never funded, and more recent health frameworks mention palliative care but fail to make it a policy priority.

Naylor says there is plenty to build on. The current national review aims to guarantee a minimum level of care for every dying New Zealander.

“We have one of the best hospice systems in the world, because we work all across the community, and we have the ability to bring people into an inpatient hospital if necessary,” he says.

“We have multi disciplinary teams. But the problem is, because we’ve been standing still for so long when it comes to palliative care, we’ve started to slip backwards.

“We need to do a better system reset and place palliative care as a key area focus for our health system, to make sure that when people are dying, they get the care they need, and their families are supported.

“It’s not complicated with systems and services there. We need better funding. We need better training programs.”

Every New Zealander deserves end of life care – it shouldn’t come down to luck, postcode, or charity.

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