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to say before we die

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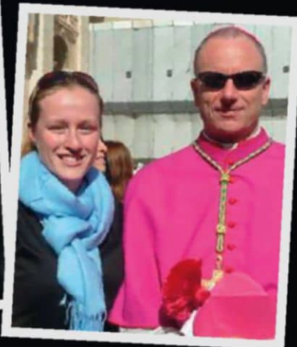
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EXCLUSIVE

ALTAR EGOS

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BY PETE MCKENZIE



A joyful end

Death is the natural disaster that awaits us all, says a US palliative care specialist advocating for a peaceful, rather than prolonged, end to life. **BY SARAH CATHERALL**

Is it possible to feel well while you're dying? It might sound like an oxymoron, but Ira Byock, an American palliative care doctor and hospice advocate, has come across thousands of patients in his four-decade career who feel the best they've ever felt as they're coming to the end of their lives. They may not feel physically well, as such, but instead, Byock talks about a gentle decline, when a person slowly "dissolves", and as they do, they often experience gratitude, love and joy. In what he calls an ideal death, they are honoured and celebrated by their friends, family and community, and their dignity is valued.

There are some key ingredients to dying well, though, and Byock talked about his observations at a Hospice New Zealand conference in early November, where he was the keynote speaker. Good palliative care and not-for-profit hospice care are at the heart of it, as well as a medical team who focus on making a dying person comfortable, connected – in some cases reconnected – with their loved ones, and even "joyous" rather than being kept alive at all costs.

On a windy Wellington day in late spring, Byock – emeritus professor of medicine at Geisel School of Medicine at Dartmouth College, New Hampshire – shared his insights on dying well and dying badly before a packed auditorium of palliative care doctors and nurses, academics, health workers and death doulas. He has published three books: *Dying Well: The Prospect for Growth at the End of Life*, *The Four Things that Matter Most*, and *The Best Care Possible*, and co-written two others on this area.

Byock is a passionate speaker who, in 2014, founded the Providence Institute for Human Caring in Southern California, which has as its goal the provision of "whole-person" healthcare for frail elders, seriously ill and dying patients and their families.

Known for his care as a doctor and his patient advocacy, he told the conference terminally ill patients should be treated according to their personal values and priorities, "because health and illness are personal, not just medical".

"Death is the natural disaster that awaits us all, ourselves and our family," he said. "Dying is hard but there is much we can do to ease people's suffering and help them to leave this life in gentle and dignified ways. Unfortunately, modern medicine, as it has become more technically sophisticated and evidence-based, has been fixated on fighting or forestalling that."

In a good death, a person completes and releases the parts of life that are no longer important to them. "They more dissolve out of life as they become less dense, complex, and corporeal, and more ethereal as they leave this life."

He read out a letter he wrote to a friend, Pano, who was terminally ill with colon cancer. Pano wrote back that he had overcome the shock and fear of dying. "I am in the timeless time before the end ... There is quiet, joyous anticipation and curiosity, gratitude for the days that remain, love all around. I am fortunate."

Byock shared the stories and photos of another late friend, Herb, an academic oncologist who, while he was dying, renewed his marriage vows, farewelled family and friends and co-workers, and enjoyed one of his favourite activities – gin and oysters with family and friends – a

week before his death.

Ideally, that's the scenario Byock would like to see: making the last days and weeks joyous and memorable for a dying person who gets the chance to say farewell in a way that those left behind will never forget.

THE DYING LIGHT

Byock trained in emergency and family medicine and planned to have a cradle-to-grave career as a family doctor in a rural practice. But from the late 1970s, while working as a medical intern in Fresno, California, he became concerned that the dying were often relegated to hospital rooms and wards away from those who were well. They appeared to be neglected, when caring for the dying seemed to be a basic human right.

The hospice movement was just beginning and palliative care didn't exist as a formal medical specialty in the US. Byock founded a fledgling hospice programme at the medical centre he worked at where he also kept coming across patients who told him they felt well even though they were closing in on their final breaths.

Byock told the *Listener* in an interview, "I began to think: 'Is it possible to feel well in the midst of knowing that you're dying, feeling physically lousy, being sad, knowing that you're leaving people you love?'"

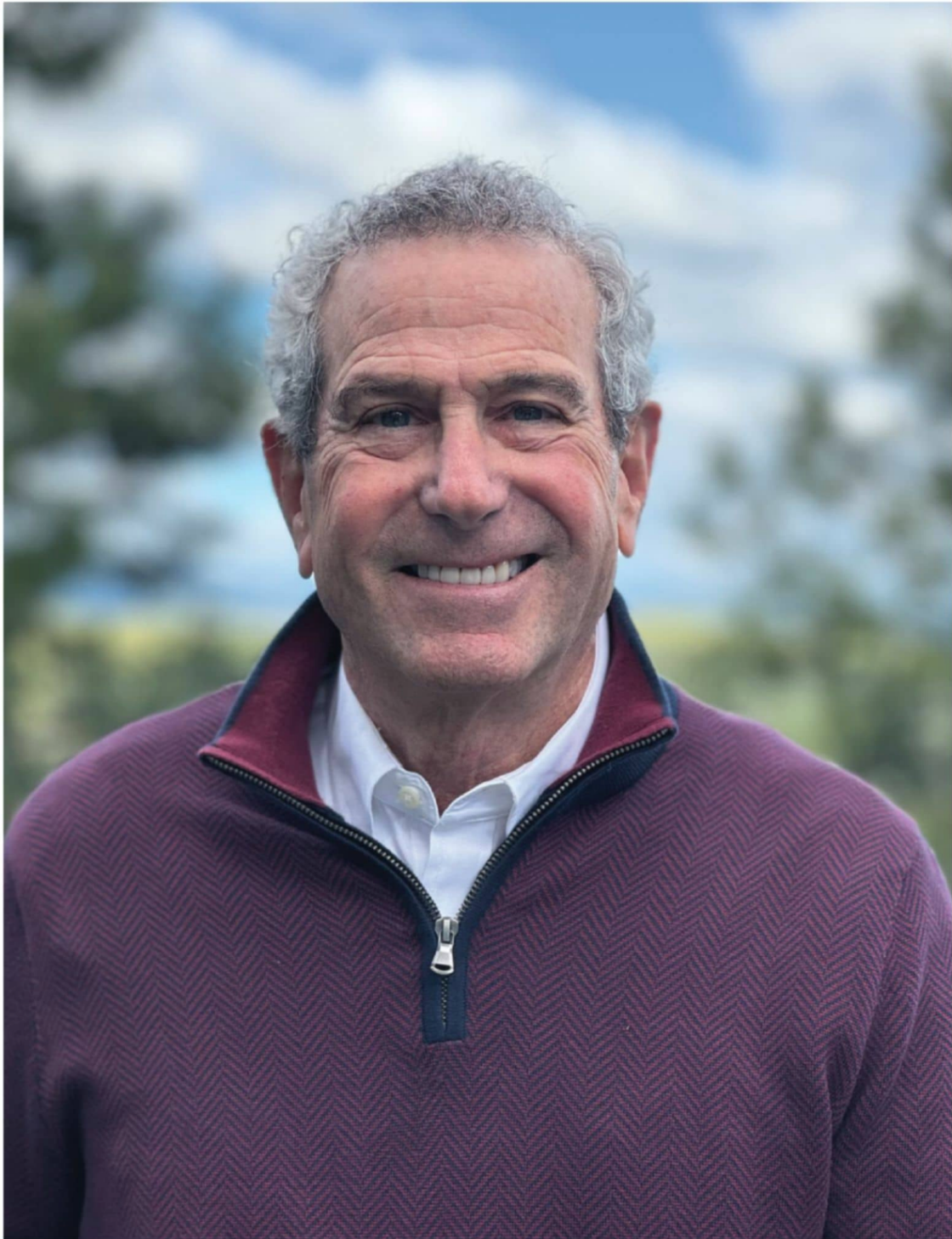
"Sometimes, I'd see a family who'd come back to the hospital after their mother had died. And they'd say, 'You know, when we heard Mum was seriously ill, it was the worst news we could have imagined. But doctor, this last month has been the best time we've ever had together as a family.'"

Only about 100 doctors were then working in hospice care across the US, and mainstream doctors thought Byock and his colleagues were "nuts". He wrote papers about the ethics of caring for the terminally



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Ira Byock: Caring for his terminally ill father was a turning point in his thinking.



Dying well

ill and how to do so well, and co-created a clinical assessment tool for medical staff to gauge quality of life in a seriously ill patient, rather than just physiological suffering. The Missoula-Vitas Quality of Life Index is still used in palliative care in the US.

A turning point for Byock was caring for his father, Sy, who was terminally ill with pancreatic cancer. They had not had a perfect father-son relationship but they made peace with one another. "I told him how much I loved him and how proud I was to be his son. The months during which Dad was ill and dying were awful. But in some ways, they were also wonderful."

He shows a photo of Sy making eye contact with his granddaughter, Lila, Byock's daughter. "Look, they are both ecstatic. My father's eyes radiate joy. I've seen this joy in the eyes of dying people or heard it in their laughter. It's almost always when they are with their families."

Byock's first book, *Dying Well*, came afterwards. Published in 1997 and used as a resource by palliative care and hospice doctors, it is full of patients' and family stories, and Byock's observations that a patient can have personal growth and connect with families and friends – and enemies – before they die.

At the time, he says, many Americans were dying in hospital, often alone. When he talked to patients about what was important to them, some of his colleagues "would look at me like I had three heads: 'How are you talking about wellbeing when somebody has advanced cancer or heart failure?'"

"But the medical profession needs to better understand the human experience and stretch our imagination to acknowledge that people can be well even during this period of physical decline, sometimes even while they're experiencing severe physical discomfort."

While palliative and hospice care has grown since then, he still calls for formal legislative changes, such as a safe dying act – where a person is supported and ushered out of life with the same holistic care and respect as when they are ushered in. He says more than half of people in the US die without any hospice care; a third of those who get hospice care have it for a week or less.

In New Zealand, only about a third

of those who are terminally ill or dying receive hospice care. Hospice New Zealand chief executive Wayne Naylor says others miss out because of funding, workforce challenges or access issues. "Hospices are unable to reach everyone in need, and there is also a fear and misunderstanding of what hospice care is and who can benefit."

Byock often avoids the word "dying" and talks instead of "a decline". Choosing his words very carefully, he also argues



Wayne Naylor: Access is an issue for hospice care in New Zealand.

that the hospice movement is a "wellness movement". Hospice NZ is a conscientious objector to assisted dying and Byock is also opposed to what he calls "lethal injections" or "dying by suicide".

Our Ministry of Health has just completed its review of the End of Life Choice Act, which came into effect three years ago. But any significant changes will need to go through the legislative process. The Act Party has already lodged a member's

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bill to extend eligibility for assisted dying. Nearly 2500 people have applied for a doctor-assisted death since the act took effect in November 2021, and by September, 970 people had died this way. At present, access is based on having a prognosis of less than six months left to live.

Byock says 11 of the 52 US states have legalised assisted dying. But he argues it should not be allowed until healthcare is universal – it could otherwise be seen as the best option for someone who is terminally ill. "My view is not a judgment on a person who wishes to end their life. My reluctance is that as a society we are not offering people the best care we can offer them."

THE WALL OF MORTALITY

He says when the medical profession tries to keep someone alive at all costs, it can bring immeasurable suffering. "We fight to keep people alive and we push against diseases like heart failure and cancer. I've treated so many people throughout my career, and in fighting disease that's what doctors do. But while we have prolonged life for many people, we have yet to make even one person immortal. At some point, as you're pushing against the disease, you're pushing the patient who is between you

and the immovable wall of mortality. And the more you fight, the more that person suffers.

"I've witnessed many people suffer as they were dying who, in the absence of medical interventions they'd chosen, such as breathing tubes for respiratory failure, dialysis for kidney failure, or antibiotics for pneumonia, would have been able to die gently, with only basic symptom management.

"Nature gives us gentle ways to leave this life. Our heart starts to slow down, we get less oxygen to our brain, or our liver starts to fail, and the natural toxins, many of which sedate us and anaesthetise us, start to build in our blood.

"But because we love our parents and our siblings, we don't want to see this person we love die. So we move heaven and earth to try to keep people from dying."

The Four Things That Matter Most: A Book About Living, was first published two decades ago. Again, it is based on his work: 15 years in emergency medicine and more



than 25 years in palliative care. There are just four things – 11 words – he argues that someone at the end of their life can and should say. They are “please forgive me, I forgive you, thank you and I love you”.

For those who think his theory is all a bit Zen, he writes that he has lost count of the number of people he has met who wished they had said some of these words before it was too late. Sometimes, someone dies in an accident: another reason not to put off what might need to be said.

Saying “I’m sorry” and asking to be forgiven are some of the toughest words to say. “Thank you” is something we don’t say enough: “Working with people who are dying has taught me that the people who are supposed to know how much they’re appreciated often don’t.”

CAREFUL WHAT YOU WISH FOR

Longevity is the new health movement and Byock approves of those who are trying to live healthy lives: enduring saunas and

cold plunges, or following an intermittent fasting regime, abstaining from alcohol or taking a bucketload of vitamins.

However, he says, “It’s wonderful to extend life and to particularly extend a healthy life. But there is an element of denial in wanting to live forever. People don’t actually want to live forever when you talk to them. They want to be healthy forever.

“We’re extending life through good medical care. But we haven’t fixed diseases such as dementia, which is progressive brain failure. We haven’t fixed arthritis. We haven’t fixed heart failure. By extending life we may



A consequence of our preoccupation with healthy lifestyles is that when we fall ill, we think we’re at fault.

Te Omanga Hospice in Lower Hutt. Misconceptions about hospices and hospice care are an issue, says Naylor.

be asking for something that we don’t fully understand and want.”

People used to die quickly from problems with the heart, liver, lung, kidneys or infections. Chronic illness evolved in the 20th century, protracting the last phase of life.

In a revealing comment in *The Four Things That Matter Most*, Byock writes that people struggling with chronic conditions are often embarrassed or ashamed about being sick.

“An unintended consequence of our preoccupation with exercise, diet and healthy lifestyles is that when we become ill, we think we’re somehow at fault. If we learn someone has cancer, we think, ‘Well, she is a smoker.’ We explain away other people’s misfortune in a futile attempt to protect ourselves from our own fragility and mortality.” ■

HOSPICE NEW ZEALAND