



End-of-life specialists are usually waiting in the wings of our lives, but the widespread death and bereavement wrought by the coronavirus pandemic has propelled them to centre stage, writes **Claire Keeton**

# Dealing with dying

“**S**ing *Naninina* at my funeral. It will take me straight to heaven!” said nine-year-old Limile Tsodo, who was buried recently in a windy cemetery following kidney failure.

Effervescent in life, Limile talked about death more naturally than most adults do, or ever will.

“He prepared us for the worst. He was ready to go,” says his grandmother, Buyiswa Jack, describing the big-hearted child from Khayelitsha, Cape Town, as the apple of their eye. “A few days before his passing, he was asking his best friend how he will feel when he’s gone.”

Talking about death is not about lessening the immeasurable grief of losing those we love, but it can mitigate the shock. Talking about death can shine light on who and what matters in our lives before it is too late.

Limile’s acceptance of dying softened the shock for his devoted family. However, he had time to reflect on his mortality, unlike many Covid patients.

Men and women in ICU do not always have enough warning, even breath, to say goodbye, which makes these hospital deaths particularly traumatic for the bereaved and their health-care teams.

“You can have a sudden deterioration. One minute someone is sitting up talking and five minutes later they have died.

“There is a huge grief in not being able to say goodbye. Sometimes the admission is the last time you see a person though some hospitals are allowing a last visit,” says Dr Liz Gwyther, professor of palliative medicine at UCT.

Since Covid swept the planet, death is no longer the uninvited guest at the door, waiting politely for old age most days, or nights. Since March the grim reaper was breaking down doors, leaving heartbroken families and friends behind.

Palliative care specialists like Gwyther are experienced at preparing people for death. She says: “I ask: ‘Is there anything that makes you fearful? What keeps you awake in the middle of the night? If you were to die, then ...’”

Yet most of us still think this “won’t happen to me” and are unwilling to open up this conversation – not realising what benefits it can bring if we do.

“It is not like we sit down and have ‘The Talk’ about death with those closest to us. It is 10,000 steps,” says spiritual counsellor and palliative care practitioner Christine Nachmann. “The first step is going inside

ourselves, and inching up closer to that edge.”

Exploring the space where life and death intersect, Capetonian Sean O’Connor has hosted a pandemic podcast series called *How To Die*, in which he interviews a “range of people who dance on the edge of life”.

An end-of-life counsellor, a cemetery director, funeral consultant, tombstone maker, traditional healer and sheik are among those he interviews about what death can teach us.

“Talking about death gives us perspective on what’s important in life and our relationships,” he says. “The tombstone maker was a complete stranger and in 45 minutes we reached consensus that love matters most.”

The men also laughed together, particularly when the second-generation tombstone maker would say “... if I die ...”.

Gallows humour gives relief to those in the funeral business; remember the ground-breaking television series *Six Feet Under*?

Around the world the “death movement” is gaining momentum, challenging the medicalisation of death and its removal from our lives. Increasingly people are being trained as “death doulas or midwives” to offer end-of-life care with dignity and compassion in SA.

But the taboo around talking about death still holds, says O’Connor, who is also a death midwife and who helped found Death Café in Cape Town, one of more than 12,000 to be launched in the world.

At a Death Café, strangers and friends can talk about their experiences and fears of death and pain and grief, or anything else they want to. On these occasions, death is on the table along with tea, coffee and cake.

Often it is easier for strangers to talk about dying than people who love each other, as my friend Gail Kirchmann discovered when she was diagnosed with acute myeloid leukaemia at 48 years old in 2017.

Without intravenous chemotherapy treatment she would die within three months, she was told. Even with treatment, only 27% of patients are alive five years later.

Once she was in remission, Kirchmann began to engage with the fact that she would probably die. “I did not want to, but the idea of death did not frighten me. My thoughts focused on the practicalities of it,” she says.

“I didn’t want my children to be dealing with grief and trying to think what to do. I enjoyed the task. I reflected on my life and how I would like it remembered. I wrote a letter to my family.

**If a patient has the courage to ask if they are going to die, we should have the courage to answer**

Dr Liz Gwyther, professor of palliative medicine at UCT

## In Numbers

45,000: The number of people who have died from Covid-19 in SA would almost fill Newlands Stadium in Cape Town

## Death folder check list

Will or living will, life insurance policy, bank account details, birth certificate, property deeds, car papers, account and device passwords, list of social media accounts, loan documents, copies of keys and funeral consultant (if you have one) are among the key items

**Covid has brought something back about death that has been true for most of human existence. Death can come for us at any time**

Christine Nachmann, spiritual counsellor and palliative care specialist

“Here is where it got difficult. I wanted to talk about what I had decided, and why. Almost everyone else did not. Those closest to me were the most reluctant ...

“I can’t tell you how isolated I felt. This was important to me and everyone dodged the conversation. Eventually, I managed to talk about it with my daughter, who was 22 at the time.”

Now Kirchmann visits people with acute myeloid leukaemia in the haematology ward where she spent months, switching to a video call under pandemic restrictions.

“It is useful for patients to have someone to talk to who has personal experience of what they are going through. My friend, Barbara Thatcher, said to me: ‘Ultimately, we die alone, but being with someone in the in-between moments is everything.’”

Covid has made this harder than ever. After providing years of end-of-life care to people in their homes, Nachmann has had to reach out remotely.

“Never before have I not held somebody’s hand. Never before have I not sat at the bedside,” says Nachmann.

There are so many deaths, says Gwyther, whose colleague had to deal with 14 doctors who died in Durban in a single week. “They do not have time to grieve for someone and another person dies. This is exhausting and emotionally overwhelming.”

The hospitals have been like war zones – with deceased patients wrapped up and taken away day after day – yet the rest of society is trying to live as normal a life as possible.

A tsunami of suffering will follow the pandemic, says Gwyther – adding to the mental health distress triggered or exacerbated by it.

Many South Africans such as traditional healer Gogo Masechaba, 50, have already lived through two waves of burials every weekend in their lifetime. A teenage activist in the ‘80s, she was burying friends killed by apartheid security forces and then again, in the early 2000s, family and friends who died of Aids before life-saving antiretrovirals were available.

With Covid, that pain is back. “Almost every day I get a call from my mother that another member of the family or neighbour has died,” she says.

Formerly in the corporate world and government, Masechaba responded to her calling in 2006. Now, in a scented healing room filled with precious stones, feathers, bones, dream-catchers, cloths and candles, she provides a bridge between the living and their ancestors who have moved beyond this world.

“Death is an unwanted visitor and we do not invite

that,” she says, explaining that talking about death is not common. “We place a lot of emphasis on how you live your life and the rite of passage when you die.

“You are never left alone, grief can never be done alone, and that is why Covid is so traumatic on a collective scale. Not being able to do the rites communally is creating more trauma which will be felt for a long time.”

People dying in isolation away from those they love is particularly traumatic, confirms Mary Ryan, founder of the Soul Carers Network in SA, which gives dying people and their loved ones emotional and spiritual support. She has trained 25 members in Cape Town and along the coast.

“The choice of where and how we want to die has been taken away with Covid,” says theologian and home carer Ryan, with long silvery hair and a gentle touch. “The fallout is going to be huge.”

“I spend a lot of time getting to know a person and help them make peace with the messy bits of life and forgive themselves and others. This lifts some of their anxiety.”

“Before Covid, we could connect to a caring community and get comfort. With Covid, I think we need to create small circles of care and healing, friendship circles, neighbourhood circles.”

Never before have the skills and experience of the end-of-life and spiritual counsellors, funeral consultants, hospice carers, palliative care specialists and healers been needed by as broad a cross-section of people as now.

“The demand for palliative care knowledge and skills has suddenly exploded,” says Gwyther, whose course numbers doubled this quarter to more than 20.

Usually, end-of-life specialists are waiting in the wings of our lives, but Covid has propelled them to centre stage.

Death is expected, like the weather, to be predictable, but Covid has “pulled out this false bottom”, says Nachmann.

Limile knew his time was running out, facing life and death head-on from the time he could talk with his family and the Red Cross Children’s Memorial Hospital team.

He knew what his blood pressure readings meant, he wanted to join in doctors’ ward rounds, he wangled visitors into giving him treats and, as a DJ on the hospital radio station, he lifted the spirits of other young patients and was not scared to tell the truth.

“If a patient has the courage to ask if they are going to die,” says Gwyther, “we should have the courage to answer.”