

‘To allay fears of death we need to bring it back to life’

The over-medicalisation of death has pushed it to the back of minds. This needs to change, say experts

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CYCLE OF LIFE Making time to talk about death improves people's quality of life.

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As Covid-19 deaths fall in SA and the pandemic recedes, people are again pushing death to the margins of their lives. But greater support and compassion should be offered to the bereaved and those dying, and more community involvement with health and social care services is needed, say experts from an international commission on the value of death.

“The Covid-19 pandemic has seen many people die the ultimate medicalised death, often alone but for masked staff in hospitals and intensive care units, unable to communicate with their families, except digitally,” said commission co-chair Dr Libby Sallnow, a palliative medicine consultant at St Christopher’s Hospice in London.

“How people die has changed dramatically over the past 60 years, from a family event with occasional medical support to a medical event with limited family support. A fundamental rethink is needed in how we care for the dying, our expectations about death and the changes required in society to rebalance our relationship with death.”

The commission’s report, raising the alarm about the over-medicalisation of death and aggressive end-of-life treatments which fail to reduce suffering, was published in the [journal Lancet last week](#).

More than half of all deaths globally happen with no pain relief or palliative care, the researchers found.

Commission co-chair Dr Richard Smith, from the UK Health Alliance on Climate Change, said: “Dying is part of life, but has become invisible, and anxiety about death and dying appears to have increased.

“Our current systems have increased both undertreatment and overtreatment at the end of life, reduced dignity, increased suffering and enabled a poor use of resources. Healthcare services have become the custodians of death and a fundamental rebalance in society is needed to reimagine our relationship with death.”

The cycle of striving to avoid death at all costs, to the detriment of other priorities, including minimising suffering and spending time with loved ones, has perpetuated a widespread fear of death and made dying more invisible.

The report warns that “too many people worldwide are dying a bad death” when there are alternatives. It calls for a new vision of death and dying.

Cape Town doctor Martinique Stilwell, who is undergoing treatment for breast cancer, supports a new vision. “I am in a fortunate position to have provided humane, non-interventional palliative care to patients and, having done so, it has lessened the fear of my own death and allowed me to speak frankly to my oncologist about how to proceed should curative chemotherapy fail.”

The commission, composed of experts in health and social science, theology, philosophy, social care, economics, political science and community work, and patients and community activists, researched how societies worldwide care for the dying and perceive death for a report titled: *The Value of Death: bringing death back into life*.

It highlights “widespread inequalities that continue throughout life into death” between the privileged and those who struggle to get care and resources – for example, the glaring inequalities in SA – particularly in access to palliative care.

Commission member Mpho Tutu van Furth, wrote: “This commission has centred the story of the value of death in a relatively wealthy, mostly white and predominantly western perspective. What this means is that white, western and relatively wealthy is the norm to which every other experience must refer.

“Most people in the world do not have to wrestle with an over-medicalised death. They have minimal access to quality healthcare ... In the two contexts in which I lived longest, SA and the US, black people have never had to engage in a fight to die. Society and the medical world have considered black lives cheap.”

The commission found that over the past 60 years dying has shifted from the home and community settings into the hands of healthcare workers and institutions.

Before this doctors and technology were seldom involved, apart from acute disease and injury. “Today, the majority of deaths are from chronic disease,

with a high level of involvement from doctors ... the idea that death can be defeated is further fuelled by advances in science and technology,” according to the authors.

Sean O’Connor, the host of SA podcast *How to Die* and founder of one of the country’s first death cafes, located in Cape Town, said: “Death is seen as something that happens at the end of life, separate from life, and that is a fallacy.

“Death is part of life, is something we experience continually in the death of the people we love and our parents, in the deaths in our communities, in our own bodies ... in our planet. These reverberate. This report shines a very striking lens onto inequality in life and death.”

Critical conversations about death and dying between people, families and doctors often do not happen or “too often happen in times of crisis”, the report noted.

The late Dr Paul Kalanithi, author of the outstanding book *When Breath Becomes Air*, written as he was dying of cancer, wrote: “The physician’s duty is not to stave off death or return patients to their old lives, but to take into our arms a patient and family whose lives have disintegrated and work until they can stand back up and face, and make sense of, their own existence.”

The report’s authors hope to break down the taboo about death and dying and encourage conversations.

“People with serious illness have priorities besides simply prolonging their lives. Surveys find that their top concerns include avoiding suffering, strengthening relationships with family and friends, being mentally aware, not being a burden on others and achieving a sense that their life is complete,” wrote Dr Atul Gawande, author of another seminal book, *Being Mortal: Illness, Medicine and What Matters in the End*.

The report urges us “to bring death closer and put it at the centre of life”, said O’ Connor. “As terrifying as that might be, it is not terrifying once you accept that you are mortal. Life and death are like that infinity sign,

inextricably linked in a deep way ... because if we lose one, we lose the other.

“But pushing death further away from life, which is what science and technology have encouraged, makes us more fearful of it, less understanding of its value. Talking about death is not fatal, it is life affirming.”

The Value of Death: bringing death back into life

Key points of the report include:

Understanding dying as a relational and spiritual process rather than simply a physiological event;

Creating networks of care to lead support for people dying, caring and grieving;

Encouraging conversations and stories about death, dying and grief;

Providing clear information to people and families about the uncertainties and potential benefits, risks and harms of interventions in potentially life-limiting illness to enable more informed decisions;

Prioritising access to pain relief at the end of life worldwide; and

Recognising death as having value. “Without death, every birth would be a tragedy.”