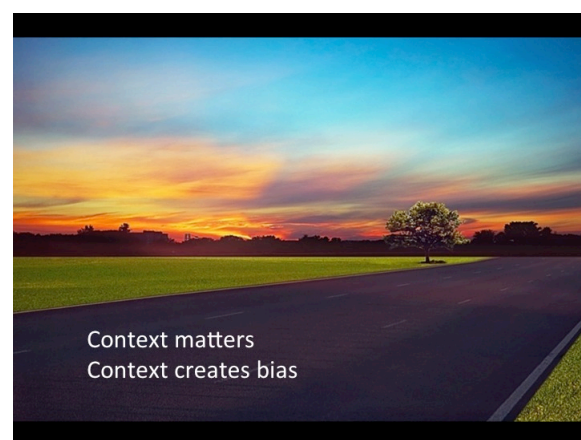


A small skull sits on my desk. It helps me remember that death is my beginning and my end and a tease along the way. Flicking me provocative glances early on then keeping her distance until now I see she's trying to be best friends, intent on a partnership because she is my destiny.

We all have a range of death experiences throughout our lives, whether actual or metaphorical. They are not mistakes or near misses although at a material level they may seem like that. Taken seriously they can help open the gates of wisdom to help us step down into meaning, rather than bob about on life's surface, subject to changing tides.



Meaning has always mattered to me, first through being adopted into a fundamentalist Baptist home and then through the lifelong project to find my way to faith beyond the construction of God first offered to me.

Meaning matters for me in my roles as Anglican priest and hospital chaplain, where I engage with death every day. Today, I draw from all that experience, although I do not speak on behalf of my employer, the ICHC, MidCentral Health that hosts me as a chaplain at Palmerston North hospital, or the Anglican Church. Notwithstanding that, my context matters.

Like many of you, I have borne a child and sat beside dying parents, one who had a protracted journey with varying forms of cancer and the other who contracted motor neurone disease in the latter stages of life.

As the conversation about end of life choices has developed it has resonated with my experience. I've noticed a similar instinctive response around the world as the issue vibrates and finds resonance in people's lives and so I imagine that it only a matter of time before end of life choice will eventually become one of the options in New Zealand.

As we move to that point there will be erudite arguments for or against, but I don't think arguing for a particular position is my task. Instead, I think it's to add to the spaciousness of the conversation from a contemporary spiritual perspective.



If death is our beginning and our end, then it is, at the very least, a conundrum that forces us to wonder. To wonder what constitutes a life, what ultimate values underpin that life and thread their way through it, and how we make meaning within that life for which we have ultimate responsibility.

As scientific knowledge has expanded, so too has our puzzling life span. This creates an illusion of eternity in real time, although there appears to be no considered meaning or purpose behind this achievement. You could say this is a convenient fiction that reinforces the act of extending life.



Immortality, the most excellent book by English philosopher, Stephen Cave presents what he calls the four stories that humans have created to avoid death. <sup>i</sup>

First there is the resurrection story, which religions have been quite keen on.

Second there is the soul story where just a bit of us lives on, often in a new form or a new environment. Living on through our grandchildren or the monuments we build is the third very popular legacy story.

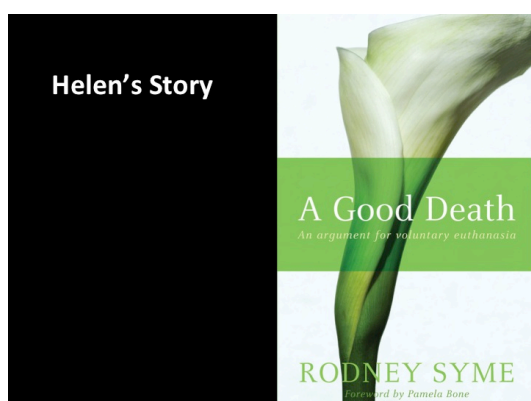
The final one is the staying alive story, which has much to do with the end of life choice conversation. In this story we attempt to stay alive in a variety of ways, through cramming vitamins and potions down our throats, swallowing and injecting a variety of drugs, having operations to cut out tumours or implant new parts and being resuscitated to ensure we keep breathing and well, staying alive.



In the end Cave concludes that none of the narratives can deliver, which leaves us in something of a fix. He advises an approach to mortality steeped in the wisdom traditions, something Colin Jamieson, a Methodist minister in Christchurch might agree with when he points out that 'many have had their

lives prolonged so that they can no longer live in ordinary communities but have to be accommodated in age care facilities.<sup>ii</sup>

This situation, that many of us want to avoid, seems to be one of the drivers for euthanasia conversations as some are left grasping for significant meaning about the continuation of our lives.



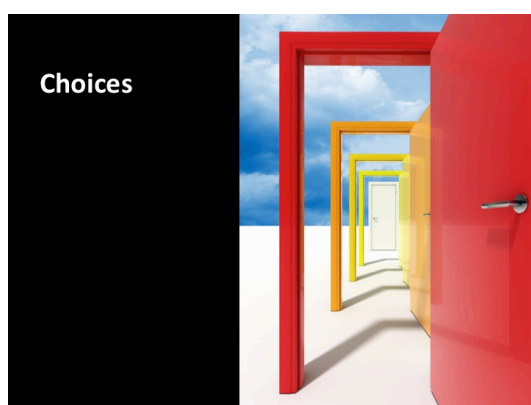
No surprises then that I was captivated by Helen's story, one recounted by Dr Rodney Symes, an Australian advocate for physician-assisted dying, in his book, *A Good Death: an argument for voluntary euthanasia*.<sup>iii</sup>

Helen was 80 years old, living alone in her own small home, where she enjoyed pottering about in her garden. She had given up golf and bridge, not because she was becoming frail but because she was losing her sight, which also meant her ability to enjoy television, film and the theatre was gone.

Although Helen had an attentive family her sense of value as a mother and grandmother was diminishing, as was her ability to cope with independent living, although she had excellent general health.

Despite her daughter's protestations, she felt she would be a burden and wasn't prepared to enter a nursing home. After much consideration, Helen eventually made the decision to self terminate, something she had to do alone for fear of implicating her friends and family.

Helen's death was not imminent. She did not have a terminal illness. She had, according to Symes, a hopeless condition. But ultimately, he says, 'it is not the illness, whether it is terminal or hopeless that matters but the nature of the suffering and whether it can be effectively relieved'.<sup>iv</sup>



Under Maryann Street's End of Life Choice Bill, this case seems to fit under Section 6 (1) (ii) where a qualifying person may receive medical assistance to end his or her life if he or she is mentally competent and has an irreversible physical or mental medical condition that, in the person's view,

renders his or her life unbearable.

A case like this shifts the conversation away from people experiencing unbearable physical suffering and imminent death within the constant care of medical professionals.

Under this section, a human being is assumed to be competent to understand their own suffering and the implications of that and, should they believe this is irreversible, make a decision to seek medically assisted death.

I understand that this is anathema to some but it resonates with me for I live alone; have done for many years and have come to understand the rhythm of that. At home, things are done the way I like them to be. My rituals enliven me, I have my familiar bits and pieces scattered about to help orient me to what matters. There are many cues in my home to help me make sense of my world.

Furthermore, my government has repetitively told me that being independent and taking care of everything myself is the way to be. This is the social and political context in which I live.

Like Helen, if I become frail and unable to live independently, I do not want to lose that sense of meaning and find myself infantilised by being forced into a community living situation, something I have run screaming from my whole life.

As I read Helen's story, I realised that I want the choice to self terminate when life no longer holds meaning for me. And I want that choice to be listened to as the choice of a thinking human being who has worked hard to figure out how to live with meaning. I do not want to be patronized by people with power of any kind; including medical professionals telling me I am depressed or unable to make my own decisions.

Unlike Helen, I hope I can ritualize the end of my life with my friends and family. To tell stories, to give thanks for my life, to drink a glass or two of beautiful bubbly, to read some of my words again, the ordering of which has given me such



joy, to bless the people I love and be blessed by them, and in a dignified way, acknowledge that it is done.

When I have been expected all my adult life to take responsibility for myself, it seems like the ultimate betrayal of a society, a glaring lack of compassion to have this final task of the greatest meaning taken from me.



But Helen's case and my desire to have the choice to do likewise is a bridge too far for some. The worry seems to revolve around the question of what will become of us if we embrace the ability of our community to self terminate?

Will we end up as monsters, devouring our own kind, adrift in the universe without moral code or compass, lacking even shreds of compassion for others and ourselves?

Colin Jamieson again. 'Euthanasia is about how and why we die; what processes should be prohibited or modified, but mainly it's about the value of compassion and the motives of the participants.'<sup>v</sup>

Nevertheless, major, existential community fears need to be listened to, sat with and explored. In particular, we need to address the overwhelming fear that we are not enough to competently, wisely and compassionately manage the creative life force that energises us for a time before it slowly starts to wane.

Once many might have appealed to an omnipotent, external God or a sacred text for guidance, but more often now the realisation is that we have to take responsibility for life and develop the faith in ourselves that we can do this with compassion, love, justice and mercy.

But can we listen to one another, respect autonomy and individual choices whilst living in the tension of a wider community? Are we up for it and what if we get it wrong? What will guide us?



Although we may have moved past an overarching religious meta-narrative or agreed reference point, our search for ultimate values and meaning continues. Contemporary expressions of spirituality, although they may sound unfamiliar, need to be taken into account to help illuminate this process.

A New Zealand definition:

Spirituality means different things to different people. It may include (a search for) one's ultimate beliefs and values; a sense of meaning and a purpose in life; a sense of connectedness; identity and awareness; and for some people, religion. It may be understood at an individual or population level. ([Egan, et al., 2011](#))<sup>vi</sup>

Or from the United States:

Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred ([Puchalski, et al., 2009](#)).<sup>vii</sup>

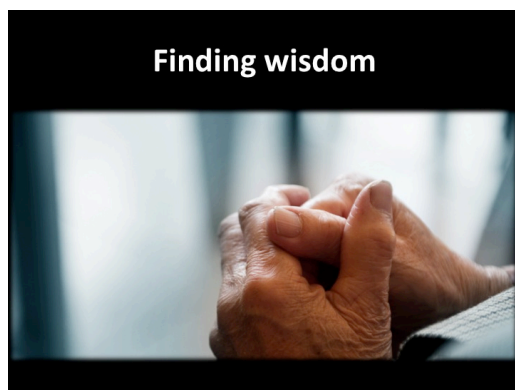
The remarkable thing about the growing body of contemporary spirituality definitions from around the world is that they all point to issues of relationship, meaning and connectedness.



Connectedness featured in a slightly different way in the New Zealand study 'I wouldn't want to become a nuisance under any circumstances,' which explored the reasons why some healthy older individuals support medical practices that hasten death. <sup>viii</sup>

When I first read this study, I became worried about the tragedy of society where the old and frail enter a side-stream, apparently without value. Meanwhile, young thrusters dominate the mainstream intent on building up assets and achievements within an economically driven framework.

Nothing should ever detract us from the need to keep developing a compassionate society so that all people whatever their race, creed, age, orientation, ability or otherwise are enabled to live lives of dignity. However, as read this paper alongside many other documents, watched videos and pondered, I began to wonder.

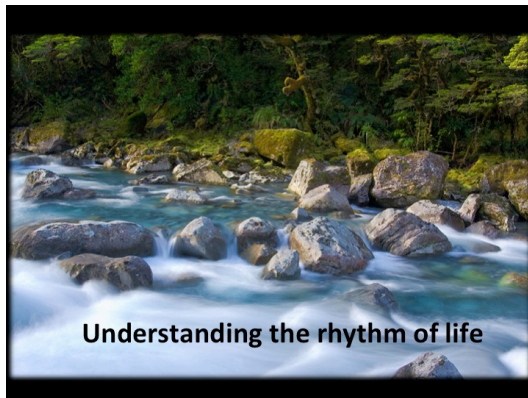


Erik Erikson was a psychologist who observed a [seven-stage process to the life cycle](#). He held that in the seventh stage from about 65 to death, the task required is to reflect on life. There is something of a balancing act between integrity and despair, with the significant question being whether we have lived a meaningful life. The major virtue to emerge out of this process is wisdom.

With this in mind I could see that the unwillingness to be a burden, expressed by so many older people in this and other studies, might have a depth of wisdom within it not able to be perceived by people in earlier stages of life.



For when the building up of resources and achievements is an over-riding preoccupation, extending life to accommodate even more achievements seems sacrosanct and rejecting it, somewhat profligate.

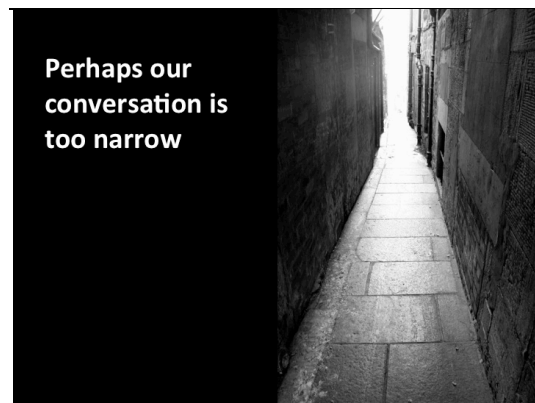


However, as this achievement phase slows, there comes a realisation that our tasks are almost complete, that time and circumstance can be seen for the imprisoning constructs that they are, and that we now sit beside the river rather than actively navigating it.

The river appears to flow much faster than we can cope with and we may be aware that to wade in it, to cross this river or to stand against its current, will likely take much more energy than we can conceive of ever having again.

This seems to me to be a wise understanding of the rhythm of life and offers the opportunity to cast a quizzical eye on the ways and means of the river traffic.

As I read Helen's story, it seemed that as her connections diminished along with her meaning making activities, not wanting to be a burden became a positive sacrificial movement that was no sacrifice at all. Perhaps instead it was a choice to let her life go into the stream of the greater good as she neared the completion stage of her life.



Perhaps our  
conversation is  
too narrow

It appeared to me then that the parameters of this conversation about euthanasia and end of life choices are a little narrow, having often been reduced to 'simplistic legalistic comparisons like 'physician-assisted suicide' versus 'natural death'. ix

The Medical Association, Hospice New Zealand, Advance Care Planning groups and others are resolutely opposed to any change in the status quo, believing that end of life choices have no place in palliative care, even although we know that palliative care and euthanasia continue to grow together in Belgium.

Positions are being taken and arguments marshaled as the goal of stopping the legislation or getting it enacted is pursued. Listening can be the casualty here. Not the listening for a gap in the argument so you can throw your best arrow kind, but the type of listening so familiar to chaplains that hears the heartbeat of human pilgrimage.



Listening to the heartbeat beyond our own

Whenever a change in society calls, a change that tears away at what we considered to be important, vital, absolute, it's never about a quick dash to the end. Instead, it's like a pilgrimage, a slow, painful journey with blisters, walking alongside people you'd rather not know and wish would shut up.

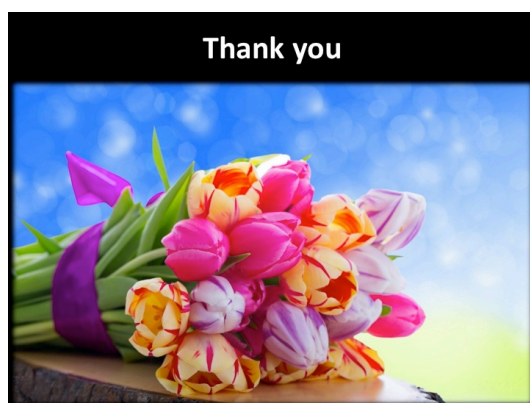
But the point of a pilgrimage is not really the physical, the walking, or the losing weight, or learning to sleep in horrid pilgrim hostels with dozens of people who snore. Rather, it's about deepening our human understanding of life beyond the superficial. Being open to hearing the heartbeat that throbs beyond our own.

I think this end of life choice journey that we're on is more than winning or losing a fight about a piece of legislation. It's more than some people getting their own way and others feeling aggrieved.

From my perspective, this is one of New Zealand's significant spiritual pilgrimages where we have to learn to listen deeply to each other. To listen to our motives, our intentions and our fears as we learn to develop our ultimate values.

These values will contribute to the core of what will sustain us as we move into a new phase of spirituality that has no central immovable line but must be fluid and flexible to accommodate diverse perspectives on what makes meaning.

This journey will stir up our unconscious, what lies deep within and between us. It will be painful, for we have to move past thinking that keeps us imprisoned by fears into a developing stream of consciousness, grounded in gratitude and compassion where the dignity of all people is paramount, even if the choices made by some are not what we might make.



Thank you once again for your invitation and for being a people willing to explore the yearning in human hearts. And thank you to [Maryan Street](#) and other politicians who have been prepared to put themselves on the line, always a place of deep personal cost.

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<sup>i</sup> Cave, Stephen. *Immortality: The quest to live forever and how it drives civilization*, Biteback Publishing, London, 2012.

<sup>ii</sup> Jamieson, Colin. *A Good Way to Go: considering mercy, self-determination and self termination*, Xlibris Corporation, 2013, p33.

iii Syme, Rodney. *A Good Death: an argument for voluntary euthanasia*, Melbourne University Press, Melbourne, 2008, p183.

iv Symes, Rodney, *A Good Death: An argument for voluntary euthanasia*, Melbourne, 2008, Melbourne University Press, p192-198.

v Jamieson, p33.

vi Egan R, MacLeod R, Jaye C, McGee R, Baxter J, Herbison P. (2011) What is spirituality? Evidence from New Zealand hospice study. *Mortality*, 2011; 16(4): 307-324.

vii Puchalski, Christina M., Ferrell, Betty, Virani, Rose, Otis-Green, Shirley, Baird, Pamela, Bull, Janet, . . . Sulmasy, Daniel. (2009). Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference. *Journal of Palliative Medicine*, 12(10), 885-904.

viii Malpass, P, Mitchell, K & Johnson, M, *I wouldn't want to become a nuisance under any circumstances ...* NZMJ 27 July 2012, Vol 125 No 1358, pp9-19

ix Carey, Lindsay B., Cohen, Jeffrey, Rumbold, Bruce. *Healthcare Chaplaincy and Euthanasia in Australia*, in 'Scottish Journal of Healthcare Chaplaincy, Vol 12, No 1. 2009, p11.