
Shared vulnerability

the key to soulful and just end of life choices

*Sande Ramage*

**1: Shared vulnerability: the key to soulful and just life choices**

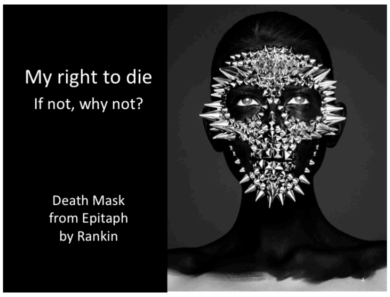
**2:** I used to love the story of Little Red Riding Hood. There was something deliciously appealing about getting dressed up in an elegant red cape and sauntering off into the world alone. Grandma turning into the wolf didn't bother me, perhaps because I was so absorbed in the elegance of my outfit.

**2a:** But there's no getting away from the fear and vulnerability that arises when we contemplate the deliberate ending of human life. Questions of identify, who am I? Does my life have meaning? Questions of power, if I don't fit the dominant, powerful group, will I have a place? Am I of worth if I am fragile, dependent and non productive? And what's more, like the story of Red Riding Hood, what if those closest to me decide to do me in?

If you're a health professional, another set of questions may loom that push at the commitments made at the beginning of your practice. Questions that now make you wonder who you are, what ethics you subscribe to and how change about the meaning of life can be accommodated within the professional life you have built.


when suffering overbalances meaning

**3:** Despite all these questions, I'm an avid supporter of the right to choose the time of our death when suffering overbalances meaning. I have no doubt that the law will change in Aotearoa New Zealand but I don't want the law to change as a result of frenzied political lobbying or debate that is really only a trading of position statements, only includes a limited expression of views and, in the process, minimises our various vulnerabilities.

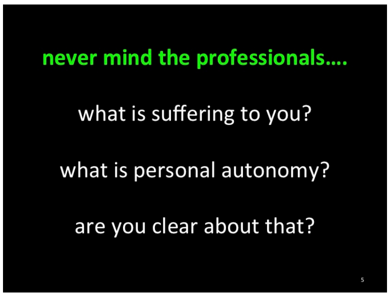


My right to die
If not, why not?

Death Mask
from Epitaph
by Rankin

**4:** Even whilst knowing the fragilities around this discussion, I still have a dream that sets out a rather broader scenario. My hope is that we are able to develop a philosophical, spiritual and legal framework within which people have a clear and protected right to die.  And if I don't have a right to die, I want to know why not.

Once that right is established, I think we must honour this choice as a valid and valued rite of passage with as much ritual, music, colour, art, poetry, song and community connection as any other, until one day, midwifing into death this way may be the preferred way to die.



never mind the professionals….

what is suffering to you?

what is personal autonomy?

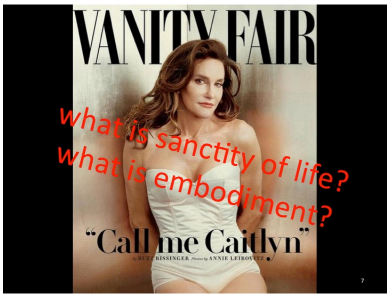
are you clear about that?

**5:** There's no doubt that we are on a journey that is much more than a change in legislation, much more than a rejigging of the Crimes Act. It is a change in our understanding of what it means to be human. What it means to live and die and whether we have a right to choose death. What autonomy means. What suffering means. None of these questions are an easy answer.

pilgrimage – connectedness - meaning

**6:** Under those circumstances we are reaching for what is called ultimate meaning and for me this indicates that we are on an important spiritual pilgrimage. By spiritual I mean the ways in which 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)

Some people bring the G word into it at that point, creating a theology, or thinking about God that endorses the sanctity of life argument. The idea that there is something so special about human life that we must never tamper with what is said to be God given.



what is sanctity of life?
what is embodiment?

**7:** But tamper we do. At the same time as the heartbreaking story of Lecretia Seales was gaining traction in the media Bruce Jenner was crying 'call me Caitlyn' as she graced the cover of Vanity Fair.

It's not as though being transgender is new or that the pain of embodiment is unknown to us. What's different is that what was once seen as God given, divinely ordained, untouchable, sacrosanct, is up for redefinition. And the intimate stories that illustrate this change are being featured in mainstream media, which our smartphones instantly connect us to.

There's no pretending it's not happening, or that God is in charge, instead, we are faced with being inextricably involved in the redefinition of what might be sacred or what matters most for a community.

'Caitlyn's beauty makes it problematic for a fat old queen like myself.' *Shelley Howard*

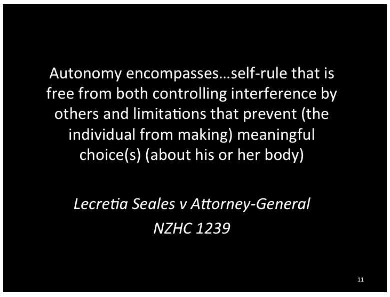
**8:** But whilst Caitlyn may have rocketed to celebrity Twitter status with a million followers in the fastest time ever, her story is just one amongst many stories of isolation, rejection and self-hatred. As Shelley Howard, a transgender woman who spent much of her life as a military male said, 'Caitlyn's beauty makes it problematic for a fat old queen like myself…' Issues of power, money and circumstance are always present in any human change.

What is sacred?

**9:** These varied stories can make us more aware of the diversity of humanity. Whilst that can be quite bewildering at times, it forces constant rethinking of sacred cows. What is central to our being, how we communicate that to one another and how we make decisions about what is right for ourselves and for our communities; the places in which we live and move as embodied creatures.


Thank you Lecretia and Matt

**10:** The story of painful embodiment was central as Lecretia Seales went public with her struggle for the choice to die on her own terms. Along with husband Matt, Lecretia captured the imagination and compassion of New Zealanders. It wasn't just her intelligence, wit, legal acumen or love of life that appealed, although those things mattered. Lecretia's story spoke to the fear and anxiety present in many. Not a fear of death necessarily but the fear that when we are no longer able to be who we understand ourselves to be that our decision-making, our autonomy will disappear at the very moment we need it most.


Autonomy encompasses…self-rule that is free from both controlling interference by others and limitations that prevent (the individual from making) meaningful choice(s) (about his or her body)

*Lecretia Seales v Attorney-General NZHC 1239*

**11:** Justice Collins noted in his judgement on Lecretia's application that autonomy is a concept open to debate. He referred to a biomedical approach to individual autonomy as encompassing…

> … self-rule that is free from both controlling interference by others and limitations that prevent (the individual from making) meaningful choice(s) (about his or her body). Lecretia Seales V Attorney-General NZHC 1239 at (71)


Can I be trusted to know what I want?

**12:** He also commented that Ms Seales' statement of her belief that she is not vulnerable must be respected. In other words, listen to what the person says and believe them. What she sought said Judge Collins 'is a rational and intellectually rigorous response to her circumstances.' (81)

For some of us a reasoned self-rule free from controlling interference sounds fine but for others, assisted suicide, or in my language, choosing when to die, is not a personal, individual choice. Euthanasia Free New Zealand says 'Assisted suicide and euthanasia involve society – The slogan, "It's my life, my choice" doesn't apply.' I find it hard to accept that to be honest.

**13:** ***End of Life Choices in VT 2013 Ad***
https://www.youtube.com/watch?v=FxPd2fHr3t0

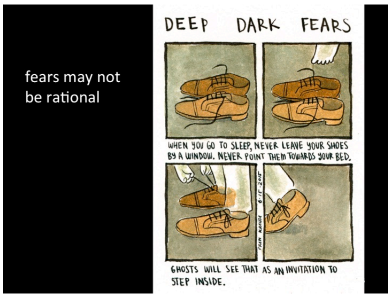
**14:** Despite the problems with slogans and language, we already know that 70-80% of Kiwis support the right to die but alongside that that there is strong organized opposition to this desire.

Justice Collins has now set out the law as he sees it and rejected Lecretia's application. However, he also fully acknowledged 'that the consequences of the law against assisting suicide as it currently stands' were extremely distressing for her and that she was suffering because that law didn't accommodate her right to dignity and personal autonomy. (192) That has to be of concern.

Whose conscience decides?

**15:** He also made it crystal clear that the complex legal, philosophical, moral and clinical issues raised by Ms Seales' proceedings can only be addressed by Parliament passing legislation to amend the effect of the Crimes Act.' (211)

Matt Vickers added that the law is 'paternalistic, overly-protective and rooted in the past.' Whilst he may well be right, many people are not reading and digesting the judgement but often responding out of feelings or perceptions.

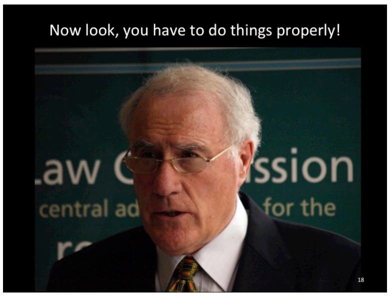


fears may not be rational

**16:** As John Roughan said in an article, written before Lecretia died, 'All I know is that I do not want her to take her own life, with or without assistance, and nor does the law but I don't know why.'

There's no point saying that there is nothing to be frightened of because there is. We all know that human beings can be dreadful to one another and that with the best will in the world, things can go wrong. When you're in the full throes of trying to get or obstruct a change in society, it can be tempting to push through, or manipulate other people's fears and objections so that your goal can be achieved. This one does exactly that.

**17**: ***Euthanasia and the vulnerable:***
https://www.youtube.com/watch?v=LCKHDxcSFsU



Now look, you have to do things properly!

**18:** Enter the incredibly resourceful Sir Geoffrey Palmer. Although happy to assist MPs draft a bill, he's quick to say that there will be serious difficulties if the government doesn't lend its weight and authority to supporting the process being done properly.

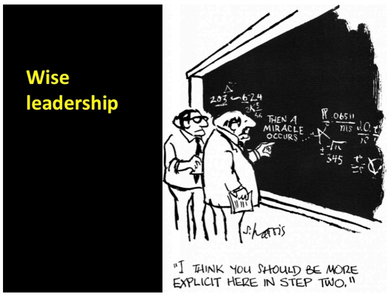
Drafting legislation, he says, needs to be treated dispassionately and analytically by people who know what they are doing. It's not a place for popular prejudices and opinion that is uninformed.

He reckons that the Law Commission ought to be asked to produce an issues paper. This would be an excellent start and could avoid what he sees as the real danger of things going wrong, 'because the process is not clear and no one is responsible for it.' (The Listener, 2015)

**19:** Whilst agreeing with him on the issues paper, I want to advocate for a broader process that doesn't just include lawyers and politicians. A process that is not held captive by the medical profession, theologians or activists for legislative change, fabulous and all as you are! I also think this conversation has to broaden out beyond terminal conditions of the medical kind and must not stay within the ambit of palliative care.

This exploration of the right to die is about all New Zealanders and about more than changing the legislation. It's about how we develop compassionate, safe practice that means something for everyone involved.

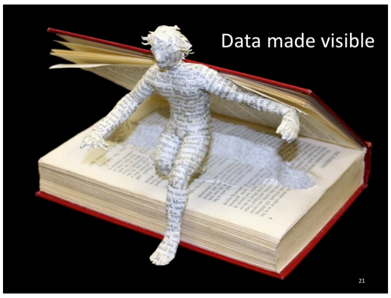
I've been thinking about some of the things that I think need to be considered as we walk down this path. Some of them may well come into a Law Commission process but others will need support in different ways.



**20: Wise leadership**

A trusted person or organisation needs to be a guiding force in the process. Leadership that will encourage positive focus on the issue, limit political game playing and foster a fearless exploration of the situation.

The leadership would seek to engage all interested people and groups in the process of working out what is best for our society around end of life choice. Riding the waves of change without trying to force the issue would be paramount, working with politicians, religious groups, academics, the media, and ordinary folk with the aim of fostering understanding and awareness.



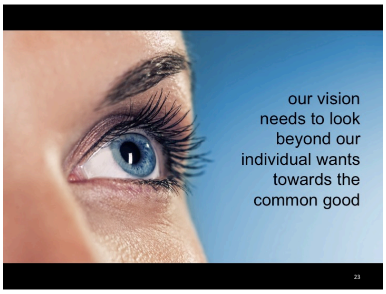
**21: Data made visible**

The Voluntary Euthanasia Society has been diligent in collecting academic literature that helps explain and rebut some objections. However, I think we also need literature from philosophy, theology, psychology and social science so that a broader discussion can unfold, particularly around what we mean by suffering, personal autonomy and community responsibility for the vulnerable.

let's avoid pitfalls

## 22: Analysis of practice

There have already been many years of assisted dying in some countries. We can learn from them a very practical level about what has worked. We also need to know and openly share what has been a problem, how issues have been worked through and what pitfalls await us. Let's be honest so that we are not accused of trying to hide difficulties.



our vision needs to look beyond our individual wants towards the common good

## 23: Develop a vision

To encourage constructive social change we need a vision around end of life choice that is based on some shared values. Even if assisted dying isn't for everyone, this vision needs to engage others, to be seen to be for the common good, offer clear community benefits like compassion, alleviation of suffering and perhaps development of thinking around autonomy.

listening and waiting

## 24: Listening

I work as a hospital chaplain and a central part of my work is being a professional listener, particularly when people are vulnerable about mortality. My job is to be gently curious at the right moments so that the story is able to emerge into the space between us. It takes time.

Being listened to is in short supply in life generally and it's no different in the health system. Despite best intentions, on average, doctors listen to patients for 23 seconds before they start interrupting to ask questions.

Under these circumstances it can be quite difficult to ever get to what actually matters for a person, given that our deepest fears and desires are often buried and we've lost the art form of being comfortable with death.

My experience and action research in the hospital shows that spirituality, what matters most, or what is of ultimate value is very hard to talk about for patients and clinical staff. This also includes talking about death and dying. We have avoided this like the plague and been willing recipients of the promises made by religion for eternal life and medicine for life as long as you get it should you be so lucky to last until the latest big find is on the market!

So whilst there may be a significant percentage of people saying they want assisted dying, this doesn't entirely stack up with the anxiety people experience around being frank about death. Neither do those figures recognise the enormous shift that medical professionals have to make in order to participate in assisted dying.

I think there needs to be more attention paid to the important skills of listening and waiting, the kind of listening that doesn't rush to take sides but that hears underlying motives, intentions and fears as we learn to develop our ultimate human values together.

Ways to do this may be to set up:

- user friendly hearings/conversations/social media events that enable ordinary folk to easily express their fears, hopes, beliefs and ideas – death cafes might well offer something here
- spacious conversations with all stakeholders including Hospice New Zealand, the New Zealand Medical Association, representatives of religious traditions so on so that there is the possibility of hearing what matters, what might be lost, what resources they have to offer rather than just focusing on what is objected to.


communicate for understanding

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**25: Communicate for understanding not necessarily persuasion**

- promote spacious conversation rather than debate
- offer clear, easily understandable information that lays out the pros and cons and doesn't just give one group's perspective
- have a clear, easily accessible glossary of terms that could form an agreed language about assisted dying – this glossary needs to include terms like autonomy and suffering
- ensure dissenting voices are invited to every table and enabled to speak.

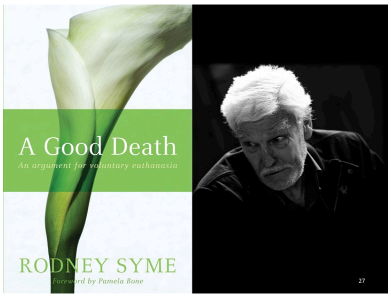

Fearless!

26

**26: Make a fearless inventory of reality**

One of the values of following other countries into this area is that they already have valuable experience that we can learn from. They've also already gone places many people fear to tread. Places like euthanasia for people with mental illness or assisted dying for children.

These situations are frightening for some. To ignore these fears or push through them, pretending the requests will not come in New Zealand is dishonest. Let's have those conversations in the open along with the ones about people wanting to end their lives because meaning is lost, even though they do not have a life threatening condition.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**27:** In my earlier presentation, *Voluntary Euthanasia: an unfamiliar pilgrimage*, I used the story of Helen to illustrate this. 80 years old, living alone and not prepared to enter a nursing home when she became frail and unable to enjoy her independent life. She did not have a terminal illness but, according to Dr Rodney Symes in his book, A Good Death, hers was a hopeless condition. In his words, ‘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.’

So what we mean by suffering and the value of that in our existence needs to be addressed. Once the church or religion would have been dominant in thinking this through. Whilst I think theologians from a wide variety of traditions have a valuable contribution to make from a long history of exploring this issue, in our increasingly secular New Zealand, we need a broader view.

### 28: Be creative with future plans

When a change in legislation is enacted, there will be a huge flurry of interest and then things will settle down to business as usual. A heightened focus on safety will emerge and there will be attempts to tie up every last possible loose end to prevent something going wrong.

What this could lead to is a secretive, clinical and utilitarian process that makes end of life choices a miserable option. That would be dreadful. Instead, what if we were to start working now on the creation of the most sensitive, safe, compassionate, empowering and life enhancing process in the world? the point would be to ensure that death stayed in our own hands.

What if some of the conversations we encouraged went a bit further and talked about the practicalities like who needs to be involved, what systems could be created for safe practice, how we can encourage a midwifing into death movement, and how all this will be incorporated into clinical practice without over professionalising it?

Those who tell the stories rule society - Plato

## 29: Making ordinary stories matter

Stories matter. We saw that with Caitlyn and Lecretia’s stories. Suddenly whole communities are transfixed. It’s the real life stories of people that engage us and let us make up our own minds without feeling as though we’re being told what to think or believe. It’s a creative form of community engagement.

When you’re at the peak of your powers with influence, status and money it’s easy to get heard. Think back to call me Caitlyn. However, when you start to wane a bit, getting heard becomes increasingly difficult.

But I reckon it’s the stories of ordinary Kiwis that we need alongside the legal capabilities of lawyers to help us through the next phase because I think these stories will matter a great deal to our community. We need to help them be told and you’ve already started this on the VES website.

What if we could hear and see more people like you telling us about why you do, or do not want assisted dying and what it means to you? What if your families were included in those stories, telling us how they want to gather to remember your life with you whilst you’re still alive and help you to the end as an act of love?

What if we could hear stories from people who struggle with it all, who are not so sure? How about stories from health professionals who sit every day with people who talk about their desire to die now? Then there are the stories of people who have already been prosecuted for helping others die.

I see this story telling unfolding a bit like StoryCorps does in the United States. In reality, StoryCorps is one huge oral history project that since 2003 has collected and archived more than 50,000 interviews from more than 80,000 participants.

I'm not suggesting that we aim for those numbers but I am advocating this process, adapted for our time and place, may be a way to encourage spacious conversation instead of rhetoric and debate.

There is potential to turn the story telling into an oral history or a research project that can encompass the ongoing narrative of assisted dying in Aotearoa. It may also contribute towards the safety and quality framework.

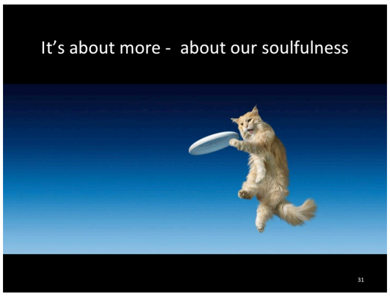
The fascinating thing is about StoryCorps is that it helps people talk about what matters to them and sometimes explore the conflicts between them. In the process it becomes an act of love, something I think we need to factor into our end of life choice conversations a bit more.

NO

**30: Finally**

For the Voluntary Euthanasia Society all this may seem like a backward step. You may think that messing around with listening to people, many of whom will never change their minds, is a futile exercise. You may believe that change is very near. You may be putting your faith in a politician who promises they can get a bill before parliament in the near future.

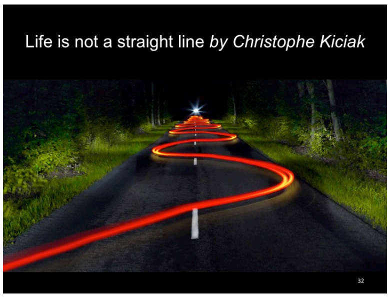
You may be right and there could be a perfect set of conditions around the corner, but I doubt it. I don't think this is going to be a quick process and I think there's value in that because as I keep saying, I think there's much more going on here around the assisted dying conversation than just getting a piece of legislation changed.



It's about more - about our soulfulness

**31:** This is about who we are, how we live and how we die, and how we might just get a bit better at that. This is about our soulfulness, that strange expression of our embodiment where the essence of us lives and breathes and has its being.

I believe that as activists for a change in this area, we have an obligation to do more than just focus on legislation. For to only make our case using statistics or legal and medical frameworks ignores the diversity of poetic, mythological and spiritual ways of understanding the human condition.


Life is not a straight line *by Christophe Kiciak*

**32:** I think we need to broaden our focus so that the tension of ideas around euthanasia are offered the most spacious conversation, before, during and after any change. Otherwise by forcing the issue we may be complicit in the kind of violence that opponents of the change are fearful of. That will help no-one.

However, to engage in spacious conversation means that you cannot predict or control the outcome and what's more, you have to be prepared to be changed by that encounter with another.

On the one hand that's scary. On the other, it might also mean that we are gifted with the creative energy of Kiwis who see things differently and have superb ideas to help build a constructive, compassionate vision for the future that we haven't yet thought of.


midwife me into death as a final act of love

**33:** When it's time for me to go, I hope we have managed to get to the point where I have the right to choose to die. I want no funeral, instead I want the people I love to come and be with me to listen to beautiful music, to sing, to read some of my words and those of others, to share our memories, to tell our stories one more time. And when it is time to help me die, to midwife me into death, not because they want to get rid of me but because I have chosen this and they do it as a final act of love.

**34:** You know, hardly anyone gets past the bit in Red Riding Hood where she's eaten up by the wolf. That's a shame because she comes back to life again.

But the entry into the beast, that which she feared most, the exploration of death, the longest dark night of the soul, was the only way that was going to happen. It is our shared vulnerability on this incredibly difficult journey that is the key to soulful and just end of life choices, the key for us to learn about midwifing into death. I advocate finding ways to do it with the people who disagree with us.