Accepting understood risk: Choosing to live with dignity

Dr Julie Landvogt

Summary

At the heart of this submission are people living with dementia or other conditions which make it impossible for them to express a reliable view about their wishes. My suggestions could apply also to situations such as terminal illness, but my primary focus is on those who can no longer express a coherent view, but who when competent supported active euthanasia. It addresses therefore the call for written submissions to explore “How current medical practices and palliative care assist those managing their end of life” and offers some suggestions for further discussion about assisted dying.

I would be very happy to discuss the ideas and experiences in more detail in person.

“How current medical practices and palliative care assist those managing their end of life”

My mother’s final six years are described in an article published in The Age on March 30 2015. I have attached a copy as an Appendix, and it can be found here: http://www.theage.com.au/comment/what-makes-a-life-its-more-than-just-breathing-20150329-1m73aq Of course this is just one person’s story – but the response to the article suggests that the experience resonated with many, in both personal and professional capacities.

So what’s the problem?

Discussion in this area is often coloured by fear:

- Fear of what might be ahead, before any diagnosis or in the early stages;
- Fear that when one is in the situation, and unable to speak for oneself, one’s views may have changed;
- Fear of abuse of wishes by relatives, professionals or other interested parties - not necessarily due to greed for the possessions, but due to exhaustion, guilt, reluctance to bear the burden;
- Fear that one may be influenced to choose to die in order not to cause difficulty to others.

These fears make increase the difficulty of beginning discussion, and increase the likelihood that important issues will be missed.

Possible solutions

• Accept the notion of *understood risk*
• Develop protocols to encourage and guide discussion
  o Within families and close friends
  o Between professionals and the individual
  o Between the individual, their family/loved ones and professionals
• Establish panels of appropriate people to ratify, review and finally confirm the wishes of the individual

These ideas are elaborated on below.

Astride of the grave

My mother had an easy death - less than 24 hours, asleep for most of it, minor assistance with oxygen. From one moment to the next she was here and she was gone. She lived out – or rather, ceased to live – that old cliché “she drew her last breath”. It was only in the last hour or two we realised that this time it would finally be over.

For her, dying was easy. It was the living while waiting for death – seven years or more of moving closer to the end – that was unbearable and wrong, for Mum and for us.

My mother died in a nursing home. I have written about her condition; the piece published in *The Age* on 30/3/2015 is attached as an Appendix; or a link may be found
here: [http://www.theage.com.au/comment/what-makes-a-life-its-more-than-just-breathing-20150329-1m73aq](http://www.theage.com.au/comment/what-makes-a-life-its-more-than-just-breathing-20150329-1m73aq). Suffice it to say that the last six years of her life were everything that she would not have wanted. She was private – in a nursing home, everything about your body and your mind is recorded and discussed. She was a loner – in a nursing home, eating alone or choosing not to engage in bingo or sing-alongs are seen as signs of either failure or noncooperation.

What might the alternatives have been? Given her cognitive decline – short term memory loss, leading to difficulty in maintaining consistent eating and hygiene, let alone relatively minor things like medicines etc. (yes, they are minor, in the scheme of things), loss of language, loss of a sense of time and space – what might we have done?

- increase home care
- nursing home
- move her to live with us
- move us to live with her
- continue as is, with the risk of a fall or unsupervised accident

I have not described here why my sister and I decided as we did, although the detail of the sequence of experiences and consequent decisions demonstrates how difficult is the navigation of conflicting and complex information while in an emotional and uncertain state. We could not know what Mum’s deterioration would be like, nor how long it would take; none of us wanted to believe it was happening, and the “right” choices were far from clear.

But if I had known then what I know now, I would have argued that it would have been more in keeping with who she was and how she lived to let her stay at her home, to live or die with the consequences of a fall. Death is not the worst that can happen, and not every individual wishes to preserve life at all costs. But had that happened, I would not know what I know now, and so the family would have been left with a lifetime of guilt and regret.
When does dying begin? The writer Samuel Beckett said we are born astride of the grave; from the moment we take our first breath we move towards our last. We all live with that, which is to say that most of the time we ignore it. It’s when we, or our loved ones, develop progressive illnesses or conditions, that movement towards death becomes something more immediate. As a society and as individuals we must address the question of what it means to live with dignity in the presence of decline. The central issue is whether, and how, we should allow people the right to choose the time to make an end.

What makes a good death? Final speeches given in bed surrounded by loving family happen more in the breach than in the observance. So “a broader scope in end of life choices” seems a pretty good aim. What might that look like?

Mum’s was a good death – peaceful, short and painless. But she had more than six lousy years of living while waiting to die. The much overused journey motif applies; and the first challenge is deciding when we set forth. The destination is known and probably not really wished for; and the unknown is how long we take to get there and via what route we travel. We differ as individuals on how we want to live, where we want to live, how we construct our daily interactions. Why should the time of dying – years, months, days – be any different? To take another cliché and make it true – why is it so difficult to die as we have lived?

**Setting forth**

The key challenge of allowing broader choice during the final stages of life is that once the final stage is begun, it may not be possible to be sure that wishes once expressed still hold true. In Mum’s case, she became inconsistent and found it difficult to focus for a couple of years before she moved into the home – that is, eight or more years before her death. For many, degeneration doesn’t happen suddenly, from one day to the next; it’s a slide, and it’s hard for anyone to know that it is beginning. When we cleared Mum’s home, we found books about improving memory, exercises for mental control, reminder lists for everything. She knew she was declining, and for a long time she was determined to beat it. But once the slide to dementia is begun, it is too late for the
conversation. The problem is that when one is well it is too easy to postpone discussion, and in the early stages, when memory lapses and errors can be explained in terms of stress or “senior moments”, it can be too uncomfortable for children or friends or even partners to raise what is wished for and when as the worst approaches.

So in allowing people to choose the circumstances under which they would prefer to die than to live, we must accept what I call “understood risk”. We must accept the possibility that once in the decline of dementia or other conditions which make it difficult to convey coherent opinions, it is conceivable that the situation will be less unbearable than it seems. This is the risk that we take on if we make a plan that includes the circumstances under which we would like to be assisted to die. Having described situations which for us would be unacceptable, we must understand that if we can no longer communicate, the actions (assisted death) will be carried out as we outlined when of sound mind. We cannot have it both ways. It will not be compulsory to make plans for assisted death. It is a valid choice to make no plan.

However, we must not misunderstand the decision to do nothing as one which allows “nature to take its course”. I learned from the years with Mum that the system is set up to get in the way of nature – to preserve and lengthen life. This is all for good reason, and seems at the heart of the purpose of medicine. But our technology, our techniques, mean that we can now continue to breathe way beyond being anything like the person we once were. When doctors join the profession, they swear to do no harm. But in preserving life in all circumstances, this is precisely what they do.

The risk that one might feel differently when unable to communicate needs to be discussed, understood and accepted if a choice is made for an assisted death under certain circumstances. Such a choice is not for everyone. But the choice once made means it will be necessary to live with – die with - the consequences of decisions made when in better health. It's not perfect – but all of this must be balanced against the alternative.
- So this is an argument for early **planning**. Like any journey, we need to consider what we hope to get out of it and what we need to bring with us to make it more pleasant and even productive.

- Because our views might change with age and experience, there needs to be regular, structured review; less regular when young, unless circumstances change – more regular as the likely time draws nearer.

Challenges arise from different definitions of key terms: *palliative; dignity and purpose in living*; and to what extent and under what circumstances individual should have the right to have control and power over their futures.

So my argument is for **Panels** and **Protocols**.

**Panels**

I propose the establishment of panels to discuss, ratify and bear witness to the individual’s wishes, and to confirm that the conditions have been met when the time has come to carry them out.

**How would they operate?**

- Panels might consist of a lawyer, a doctor and a citizen – perhaps drawn from the list of professions entitled to sign affidavits.

- Two distinct panels would be needed before wishes could be carried out. One panel would approve the wishes, and the other would confirm that the time has come to carry them out. These should have no more than two people in common, and ideally the doctor on at least one panel should have known the dying person before their illness.

- Members of the panel may be paid for their services. While this would be a new cost, it would be less than maintaining people’s unwanted lives, as is the current state. Further, it would invite the development of a structure for accountability and training, and also a platform to continue to review and refine the processes and protocols.
- End-of-life wishes should be reviewed on a regular basis – perhaps every ten years under 60, every five years between 60 and 75, and annually or biennially after that. Of course if circumstances change (an illness or accident), review may be more frequent.

- It could be argued that where the individual did not seek change, there could be a simpler process similar to an affidavit or certification of a document. If change were wished for, ratification by a panel would be necessary. The counter argument is that – given the seriousness of the decisions – formal consideration should be compulsory.

**Why do we need panels and the resulting bureaucracy?**

Won’t advance care directives suffice? Do we really need more regulation and bureaucracy in our final hours and days? In my view advance care directives are necessary but not sufficient. They help when the individual remains mentally competent, and when the terminal illness has a clear outcome and timetable.

Conditions like dementia cannot be quietly assisted with an increase of medically legitimate morphine. I am proposing active intervention to ease into death, and that is a serious proposition. Regulation and accountability are needed; the existence of panels would keep the issue in public debate, ensure ongoing learning and discussion, and allow for review and analysis of the effects of the initiative on all involved – the individual, family, and professionals.

**How might this have worked for Mum?**

My mother expressed her views clearly throughout her life through informal conversation, and more explicitly after the death of my father in 1999 and as she visited friends in nursing homes or hospices. At that time – in her 70s, and before her illness took hold - she was able to be quite clear about aspects of dependence she found unacceptable – assistance with hygiene, restricted food, enforced community eating and entertainment.
By 2006 or so, three years before she entered the home, her illness and increasing deafness made clear communication and consistent responses more difficult. Yet her behaviour - refusal of assistance in personal matters (bathing, dressing, cooking) either from family or from paid help - was consistent with what she had always argued. So while she could no longer sustain an argument, on a fundamental level she made choices that were in line with her previously expressed wishes.

While we are a family comfortable with argument and debate, both on a personal and political level, discussions about her deteriorating condition and its effects were very difficult to conduct. Her brother, a GP, told us that her time for independent living would not be long; he pointed to such things as the empty fridge. My sister and I began to fill the fridge, and to suggest easy things for meals; we brought full meals and filled the fruit bowl. But she would eat 10 bananas one after the other; she ate sugar from the canister by the tablespoon. She began to lose her sense of time; she ate in the middle of the night or at 3.00 in the afternoon. Did that matter? Time is arbitrary – she had always been an insomniac and nocturnal, so does it really matter when meals are taken? Were we right to see this as a problem?

Hygiene was more difficult. I don't want to be explicit about these issues, but they are well known to those who work in the field. As shocking to us was arriving mid afternoon to find Mum in bed or still in a dressing gown – she who had always dressed with such care and elegance. The dressing gowns were grand enough, but the message was becoming clearer; things were awry.

Her brother told us to take her to a psychiatrist for treatment for depression. She refused. We asked him to intervene. He tried – and it is great comfort to me that before he died he told us we would never succeed in getting her to attend. She had been stubborn and determined all her life – why should that change now?

*Why should that change now?* This is a foundation question for this debate. Why should people be expected to give up the things that have been central to the way they live and who they are, just because they can no longer behave in a way that conforms to society's norms? Imagine it being acceptable to say: *I'm prepared to take the risk of a fall caused*
by my rug or slipping in the shower, of poor nutrition because I prefer chocolate, of ignoring the annual visit to the gastroenterologist. Imagine family members being able to say: We understand the risk you want to take on, and we can live with the possible consequences.

Protocols – guidelines and structures - for discussion would have helped her family and professionals to review her condition with her, and may have lessened the outrage she felt when these issues were raised. Protocols would have helped us to find the words to discuss impossible things. We could have put a printed version on the table between us and worked through it together; it would have had the seal of authority, instead of seemingly intrusive questions from daughters. The existence of protocols would have confirmed that this was a conversation we had to have.

Protocols: From conversation to formalisation

Visible, available, expected structures and protocols would help us move from informal conversations “I would hate to end up like this” to more formally expressed wishes. It’s one thing to visit a nursing home or ICU and be horrified, and quite another to express a clear wish for relatives and professionals to help to end life should such circumstances arise.

I propose two kinds of protocols – compulsory and optional. In all cases, protocols must be transparent to all participants; they must be circulated beforehand and visible throughout (for instance, in hard copy on the table) so that everyone knows how the conversation will be conducted. Protocols would guide panel discussion both between panel members and between the panel and the individual submitting the plan.

Compulsory protocols would dictate areas to be covered
  • during panel discussions
  • when professionals such as doctors, nurses, carers, lawyers and accountants meet with individuals who wish to set up end of life plans.
Optional protocols would be primarily for families. The intention would be to suggest both issues for consideration and ways of discussing them. Protocols could take the form of headings and questions, and/or could include scenarios to allow for different situations to be more fully imagined, and to invite therefore more nuanced discussion.

Areas could include (but not be limited to):

- Acceptable degrees of dependence. For instance, some people might prefer to continue to live at home and accept the possibility of falling and not being found
- Mental capacity
- Physical deterioration
- Pain and pain relief
- Unfinished business, from bucket lists to resolution of issues.
- Preferred frequency of review

How might this have worked for Mum?

It would have minimised the awkwardness that is inevitable when children (of whatever age) have to take responsibility for their parents. It would have given us markers to look for; it would have allowed space and structure to consider with her the implications of being frail and living alone. We had such conversations with doctors and health professionals such as occupational therapists from the local council. But these conversations were (understandably) all about ensuring safety, protecting and prolonging life. They did not allow for the choice of understood risk.

Finally

My plea is to allow, support and make space for the option of examining and reviewing how each of us wishes to live when death approaches. It is to give guidance to consider, to elaborate on, and to review, the circumstances in which living is no longer the preferred option and we wish to choose assisted death, active euthanasia.
Common to the idea of the panels and the protocols is the underlying principle that each of us must be able to make the choice to decide what for us constitutes a good life, what for us it means to live with dignity, and what we wish to do when the things that have made our lives fulfilling can never return.
"Dying with dignity" … the idea should be reframed. What about "living with dignity", and when that is no longer possible, it's time to make an end.

My mother is a Holocaust survivor; the stubbornness that helped her through the Warsaw Ghetto and two years hiding with her family in a single room serves her poorly now. She has lived in a nursing home for more than six years. In the early stages of decline she said she preferred to die than be dependent; in no circumstances were we to take her to a nursing home. In all physical matters she was intensely private; I never saw my parents do more than link arms. But when one can no longer manage daily life – bathing, toilet, eating in any kind of consistent fashion – and if assistance is rejected, whether by family or carers – what choices remain?

So move she did. A few months after, she declined food and liquid. It was the last real decision, the final assertion of personal control. She was put on a drip; refusal to consume is not permitted, and we were told that the alternative was psychiatric hospital. If I had known then what I know now, I would have done all in my power to remove the drip; at the time, all we wanted was to avoid the threat from the wet-behind-the-ears trainee psychiatrist that they would try shock treatment. (Behind each of these sentences is a full story; of well-meaning doctors who see only through the lens of their speciality; of overworked and underpaid staff; of the humiliation of being placed on a toilet until there is "action" or until staff can return from other residents; of people sitting in front of television all day with their only contact the carers putting food into their mouths or the nurses administering medicine; of singers entertaining a roomful of sleeping people, mouths agape ... ).

When the drip was removed, she no longer walked. She no longer spoke. For more than six years the only sounds we have heard are grunts and infrequent giggles; much more often, we hear shouts of "No No NO NO NO" and howls of rage.

Now 89, she can do nothing at all for herself. Her hands and feet are claws, curved with arthritis. Her teeth have fallen out, so her food is pureed to baby mash. She sits in a bucket chair; hearing aids have long been abandoned, and while she wears glasses, they serve little purpose; she has cataracts, but the surgery to remove them would be too dangerous. (Dangerous? What result do they fear?) So she cannot move, she cannot hear, she cannot see, and she does not speak.
I do not want to paint too harsh a picture. She can engage, at times, with anger or with smiles. When her grandchildren visit, she seems to know them and to respond; something of society’s norms of behaviour returns to her face when her sons-in-law regale her with events of the day or family stories. What is “response”? An eyebrow raises, eyes widen, perhaps almost a nod. But there is no comprehension; it’s as if she is pretending to be part of a party when she’s had too much to drink to hold a thought, and the music is too loud to hear. If we move beyond her line of vision, we are forgotten.

What makes a life? This is a woman who read the books of Simone de Beauvoir and Gabriel Garcia Marquez in her adopted language as soon as they came out. My parents supported theatre, ballet and cinema in their new country from the moment of their arrival in the late 1940s; it was partly a connection to the Europe they had left, and partly a commitment to encourage the fledgling developments here. She was elegant and beautiful, and being so was important to her. She enjoyed her food, vodka with friends, and a regular glass of liqueur before bed. She delighted in her grandchildren, and she offered her time for my toddlers so I could study. If she could see herself now, sitting in front of daytime television with a tea towel for a bib, hair awry, no jewellery or make-up, bits of breakfast still in crumbs on her chair, and more detail I can’t bear to write about, she would be disgusted; she would weep. We weep for her.

I have wondered how to distinguish selfish feelings from my feelings for my mum. My sister and I each visit twice a week; I can’t deny that I would relish being freed from the duty. Her accommodation is expensive; she is fortunate to be able to pay for this from her own funds, but I understand how much of a burden this can be for some families, and for the state. This is why most discussion of euthanasia deals only with those who can still voice a decision; who can be confirmed by doctors to be able to speak for themselves. The agony of those with terminal conditions, if not terminal illness, is no less. The law must find a way to acknowledge wishes previously expressed, to allow people the choice of death rather than lengthy deterioration.

Rather than having to act while still well enough to make decisions, it should be possible to describe the conditions under which life would become, for each individual, unbearable. That this is fraught with ethical challenges makes it no different from many 21st century issues. It is not a reason to turn away.

My mother's cognitive decline means she can no longer speak for herself, so I must speak for her. Many years ago one of her doctors said that she has no quality of life; but our medicine, our aged care facilities, our constant monitoring, have been able to maintain her so that she continues to breathe. Nothing remains to her of what signified in life; she thrived on intellectual and cultural engagement, on a community of friends and conversation, on dressing well, on being part of a wider family to whom she felt an intense commitment, perhaps as a result of the war experience. Events in Israel over the last year would have made her physically ill; her heart would be with Israel, but also with the victims on both sides. The radio would have been constantly on, the television on 24-hour news; every update would have mattered.

There is more to life than breathing. When the things that we live for are denied us, never to return, we should be able to be assisted to depart. Last week The Age reported that 86-year-old Dorothy Hookey, a member of pro-euthanasia group Exit International, took her own life. For those like her, who are terminally ill but able to act, ways can be found, and ways are found. For those unable to act for themselves, the law must lead the way; it must provide guidelines to protect, while allowing structures to release.

Dr Julie Landvogt is an education consultant and former teacher.

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What makes a life? It's more than just breathing

It's impossible to contemplate what life would be like for someone who has been so mentally strong and gone through so much but all there is left is breathing. Having watched over my father as he drew his last breath and seen the change in his physical body as if the stress of dying just dissipated into nothing, I can't help thinking that those who go mentally but remain alive physically are somehow trapped in between worlds yearning for release while those who are left behind watch on in agony not able to help them.

Surely it's time to have a mature conversation about this?

I still don't understand why abortion is legal yet assistance with passing isn't. The abortion life has no choice to live or die yet this is legal. I am pro choice but pro choice for all. Great article.

Strictly speaking, abortion is not legal in NSW. However, I endorse your "pro-choice" for all stand.

It's a difficult situation. But if someone refuses food once, does that mean they want to die? Is it up to us to decide if their physical difficulties make their life not worth living?

We are supposed to live in a democracy. Voluntary euthanasia has the support of 83% of the population. The 83% wish it to be available for themselves and are not forcing anything onto the remaining 17%. If they wish to die in horrible pain or as a vegetable hooked up to a machine that goes ping then they have every right to. It is an abuse of democracy that our political masters are so cruel as to force people to continue living when they have no wish to do so. Suicide is not illegal so why should getting someone to help you do something that is perfectly legal be itself illegal. That is just illogical.
What makes a life? It’s more than just breathing

"Polls are said to show 80% of citizens support voluntary euthanasia. How long will big-party politicians go on ignoring us?"

Izaak | Bundoora March 30, 2015, 9:36AM

"We need to make a clear distinction between the decision of a seriously depressed person to end their life because of a perception of hopelessness and the decision of a rational person to end their life because their quality of life has permanently sunk to an intolerable level. One is suicide, the other is not."

Protect Pink | March 30, 2015, 10:21AM

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