Legislative reform OR technological innovation

Real end of life choice in the Peaceful Pill Debate

Philip Nitschke  MBBS, PhD
Director - Exit International

Email: contact@exitinternational.net
Phone: +61 407189 339

Abstract
This address examines two competing strategies, both aimed at providing choice at the end of life. The first is the path through legislation and law reform. This is compared and contrasted with the strategy of technological innovation. It is argued that the fundamental differences between these approaches and the dearth of middle ground make them awkward bedfellows indeed.

In this paper, I raise the bigger question of what these divergent approaches mean for the future of the global end of life choices debate. On the one hand is a growing cohort of elderly folk who will never be terminally, yet who wish to have control at the end, irrespective of their health status. On the other are one-eyed proponents who believe that only the terminally ill should qualify under the legislative model. With powerful members of the World Federation of Right to Die Societies not only failing to acknowledge the schism, but acting as luddites in the face of scientifically-driven technological innovation, reconciliation and co-existence under the one banner is looking distinctly remote.

Introduction
In this talk I will trace the divide that has developed in the Right to Die movement over the past decade. As the title suggests, I see two streams; firstly the provision of end of life choice through legislative change and secondly the break-throughs of DIY found in technological innovation. My question is can these two paradigms coexist or are they increasingly uncomfortable bedfellows?

In my experience of over a decade and a half working in the right to die movement, I am increasingly of the opinion that the approaches are mutually exclusive. No amount of small talk or semantic sophistry is enough to paper over this divide. One key question that now exists is what the future looks like, especially umbrella organisations such as the World Federation of Right to Die societies who have chosen one path over the other.

The Schism
Let me briefly outline the different strategies to which I refer. The provision of end of life choice through legislative change is a well-trodden route. Through political lobbying and campaigns, it is hoped that politicians become convinced of the need for law reform. Such legislation then allows
medical physicians to provide lawful assistance to terminally ill patients in order for them to die. This approach has had some success in several countries. In Australia over 15 years ago, I worked with precisely legislation of this kind and so I have seen it provide the terminally ill with some control over the timing and manner of their death.

The second approach grounded in technology is what I have called it the DIY Peaceful Pill strategy. What do I intend with this grandiose title? By this I mean the development, through technological innovation, of the means by which any rational adult (over a certain age), can peacefully and reliably end their life themselves at a time of their choosing. As with all aspects of scientific endeavour, things are still evolving, but there are options available now that can provide conditional but universal access to a peaceful and reliable death.

The question that I am addressing today, and one that I would argue is of fundamental importance to the World Federation (and this gathering), is how compatible are these two alternative strategies?

The Role of Technology – Lessons from Darwin 1996

On the 22nd Sept 1996 I was legally able to give a lethal injection to a dying patient of mine. Bob Dent was dying of advanced prostate cancer and was suffering a great deal. Three months earlier the Northern Territory of Australia had passed the Rights of the Terminally Ill Act (ROTI). This Act gave physicians like myself the option of providing a legal lethal voluntary injection to a dying patient like Bob, if and when he requested it.

Giving a lethal injection is a relatively simple process. First, you fill a syringe with the drug sodium pentobarbital, and secondly you inject the drug intravenously. This produces death through respiratory failure. For nine months in Darwin (where I am from), this act was lawful. But in saying that I lawfully able to kill patients in this manner, I never actually gave anyone an injection. There are several reasons for this.

Firstly, why was it left to me, as the treating doctor, to control this process at all? With the right technology in place the person wanting to die could do it themselves. A DIY approach would leave no margin for error. There could be no accusations of the evil doctor putting down a helpless moribund patient – another Harold Shipman acting under cover of this new ROTI Act. Secondly, I strongly believe that it is not the role of doctors to occupy centre stage in the final stages of life. The special place of sitting or lying next to the patient should be the domain of those closest to the person, regardless of how well-liked the family doctor might be. Finally, and I dare anyone of you to question otherwise, why should it be the doctor who is made to feel like the executioner? I am no murderer and my involvement in the right to die movement did not mean my own ethical and moral boundaries somehow didn’t matter anymore.

In thinking how to resolve these three dilemmas I turned early to technology for a solution. Drawing on the earlier Thanatron of Dr Kevorkian, I conceived and then constructed (with others) the Deliverance machine. The laptop computer would present a lucid patient with a series of questions the last of which asked “In 15 seconds you will be given a lethal injection . . . press ‘Yes’ to
proceed.” The doctor was no longer centre stage. The four of my patients who used this machine were able to die surrounded by those who loved them.

Although it was a sensible development that made an extremely difficult job easier for both patient and doctor, those critical of the new legislation denounced the Machine, describing it as an Orwellian development. At hysterical pitch they said, that the ROTI Act made it possible for computers, not doctors, to ultimately decide who would live and die!

As the fight to overturn the Northern Territory law intensified through 1996 – ’97, I was surprised to find that some people supportive of the ROTI legislation found the Machine repugnant. Most disappointing among these was the conservative politician Marshall Perron, who had been the architect of the ROTI legislation in the first place. The technophobia of Mr Perron manifested itself in a belief that the Deliverance machine had damaged the face of the right-to-die movement, and his legacy in particular. When he gave his keynote address to the 1996 World Federation of Right to Die Societies conference in Melbourne Australia, shortly after Bob Dent had used the Deliverance Machine, Mr Perron ignored both the Machine and my role in Bob’s death. For the first time I saw evidence that a divide in the movement had begun.

**Broadening out the Right to Die Criteria (National Review)**

When retired French academic Lisette Nigot contacted me in 1998 and told me she was well, but wanted to die in four years, “before I turn 80”, I was not supportive. By this time, the ROTI legislation had come and gone, and assisting a suicide was once again a serious crime in Australia. More importantly, Lisette didn’t fit the conventional medical criteria of who should be helped. As a doctor at this time I still believed in the medical model. I still believed that it was doctors (if anyone) who should be assisting in the deaths of those suffering with serious illness. I reserved the right to make this medical judgement. As an intelligent woman of strong will – what one might term an ‘intellectual’ - Lisette challenged me over and over. “What gives you the right”, she said, “to judge
me, and my reasons for wanting a peaceful death”. She quickly pointed out that what she wanted was knowledge, knowledge about the best way to peacefully and reliably kill herself. My censure she could do without.

After many months of contact, I finally agreed to support Lisette in her plans of how and when she would die. Importantly, my position had shifted. I found myself unable to tell Lisette that only the terminally ill were entitled to a peaceful and reliable assisted death. Following much soul-searching, I concluded that if you were an adult, capable of reason and insight, you should have the option of a peaceful death.

In a 2001 interview with National Review I outlined this change in my thinking when I answered the question put to me by infamous pro-life journalist Kathryn Lopez: “Do you see any restrictions that should be placed on euthanasia generally?”

My answer:

It’s my position is that if we believe that there is a right to life, then we must accept that people have a right to dispose of that life whenever they want. (In the same way as the right to freedom of religion has implicit the right to be an atheist, and the right to freedom of speech involves the right to remain silent). I do not believe that telling people they have a right to life while denying them the means, manner, or information necessary for them to give this life away has any ethical consistency. So all people qualify, not just those with the training, knowledge or resources to find out how to “give away” their life. And someone needs to provide this knowledge, training, or recourse necessary to anyone who wants it.

Just as the Deliverance Machine had done years earlier, these comments upset many in the Right to Die movement. Those who believed that the only way forward was through legislative change argued that that we should only provide help for those who are medically assessed as terminally ill or suffering from an untreatable illness. To do otherwise would be to give support to our opponents’ argument of the inevitable ‘slippery slope’ and this would make it that much harder for the Right to Die movement to achieve the desired legislative goal.
Restriction through Legislation

At this point it is worth stepping back and asking why it is that the law has any role to play in this issue at all. Like many other moral and ethical issues in society, there is a range of views about the ‘correct’ behaviour that one should adopt. Lobbyists of all persuasions fight tooth and nail to have their particular view prevail in the legislative processes. Once sanctioned by a country’s Parliament the issue at stake is subject to a recognised means of control. Abortion is the most obvious case in point.

If women could safely self-abort there would be little role for the law and legislation would be almost irrelevant. As things currently stand, doctors are required. This makes control through legislation possible. In doing so, the Church has been able to join the debate and is now widely accepted as a legitimate stakeholder. The development of RU246 sent shivers through the spines of the prohibitionists. For the first time it looked, for a while at least, as though Abortion could become a case of women ‘doing it for themselves’. In the assisted suicide debate there is an enticing parallel.

If a person wanting to die could access the drugs or equipment they need for a peaceful death, and the necessary know-how to go with it, any legislation (read mandated control process) would be called into question. Why would a seriously ill adult of sound mind subject themself under assisted suicide legislation to the rigors of medical and psychiatric assessment just to ensure their passing was peaceful? Imagine, if instead, they had possession of a bottle of Nembutal in the cupboard. At the right time, they would simply go to the cupboard. The four people I guided through the difficult assessment process for the Territory ROTI Act each made this point to me – “Why”, they said. “do I need a psychiatric examination? I just wish I had Nembutal at home.” Why, indeed!

De-medicalising Death

As a physician I am one of the first to admit that the profession of which I am a member has a long and illustrious history of advances that have changed the face of humanity. Inventions such as penicillin and organ transplantation spring to mind. However, the dying process is not simply another disease. Nor is it a state that always needs medical management and control, especially at the very end. Ask any sociologist and they will quickly point out the flipside of medicine’s predominance and that is its tendency to colonise areas of human experience where in the light of day it simply does not belong.

Where the end of life choices debate is concerned, the legislative approach places the medical profession, unquestioning, in a pivotal role. All legislative solutions set guidelines, or pre-requisites that a patient will need to meet before being eligible to use these laws. These conditions, often referred to as ‘safeguards’, need to be met. Assessment is always carried out by doctors who take on this gate-keeping function.

Yet the problem with this is that there is an assumption that the criteria that need to be satisfied are medical in character. For example, there is pain that needs to be managed through medication and so on. This allows the medical profession to place itself in a position of control of the process. In my
mind, one needs to be wary about allowing the medical profession to assume a place of importance in the dying process. Ask any sociologist working in this field – the Canadian Russell Ogden for example – and he will tell you that dying is equally a cultural and social process as well as a physiological occurrence. I find the idea that I review and judge the availability and means of a peaceful death to those around me, while maintaining my own personal supply of Nembutal, particularly offensive.

My point is that dying may or may not be accompanied by medical intervention, but it is not mandatory. Death, itself, is not automatically medical and caution is required. The rub here, of course, is that to acknowledge this is to jeopardise the entire legislative paradigm which so depends upon medicine’s sanction in order to operate.

Technological Breakthrough – the Role of a Peaceful Pill (Huib Drion)

In 2002, I travelled to The Hague to visit the late Dutch Supreme Court Judge Mr Huib Drion at his home. I had read of Mr Drion’s support for a pill - available to all over a certain age, that would provide a reliable and peaceful death. Judge Drion outlined his plans for a two-step ‘Drion Pill’. In particular he envisaged two components that would need to be consumed within a certain time for death to take place. In conversation, I suggested that the existing barbiturate Nembutal (sodium pentobarbital) came very close to an ideal ‘Peaceful Pill’. I argued that this drug was readily available, had an extremely long shelf-life, was easily taken by mouth (or could be injected), and could be consumed by all but the sickest of people, thereby giving them control over the timing of their death.

Of great concern to Judge Drion, was the need to move away from the concept of medical assessment and the idea that only those who were terminally ill should have access to lawful assistance. Mr Drion argued that age should be the ONLY criteria. Everyone, he said, over the age of 65 should have access to the pill. Lisette Nigot would most certainly have agreed. Legislation, in any
of the forms proposed, would never assist her. Yet for Lisette, and for a growing number of people like her who simply want control over their final fateful decision, law reform will never be for them. The answer for these people can only ever be through technological innovation; and one’s own Peaceful Pill.

The Face of the Future of the Right to Die Movement

Once upon a time I, too, believed a dual approach was possible but how does one reconcile two seemingly incompatible strategies? As I have outlined, the legislative approach depends on the wisdom of politicians to pass the requisite laws. Once enacted, it is down to the medical profession to restrict and control access in accord with the statutory guidelines. On the other hand, the DIY Peaceful Pill strategy has little regard for either the medical profession nor the legislative process. By definition, the legislative approach restricts access, whereas the Peaceful Pill approach provides (conditional) universal access.

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It is not surprising that those who travel the road of legislative reform see the development of Judge Drion’s universal Peaceful Pill as dangerous and irresponsible. It upsets me to say but this now appears to be the position adopted by most of the World Federation committee members. Indeed some office bearers of this Federation, have been publicly critical of the approach that Exit International advocates. At home in Australia, the South Australian Voluntary Euthanasia Society (SAVES) routinely distances themselves from me personally with a front-page banner on their website and publications. And, most recently, this year we see the long term president of one Australian society, a member organisation of the WF, being the target of a neo-military coup and being forced from office precisely because of his long term support for the Peaceful Pill strategy.
This public denunciation of the technological agenda of Exit as “irresponsible” has serious consequences for our organisation. It was in part due to criticism of the publication of The Peaceful Pill Handbook from within the Australian Right to Die movement that led to its unprecedented banning by the Australian government. Our book is the only book banned in Australia in the past 35 years. More recently we now have had to deal with the unilateral decision this month by the global megopoly PayPal to suspend sales of the Handbook and freeze funds in our account (several thousands of dollars). PayPal are now claiming that this book breaches their “community guidelines”; agreeing it would seem with many in the Right to Die movement.

PayPal freeze Exit Account – May 2012

My Way or the Highway ...

At the core of this current ideological battleground lies a deep-seated antagonism on the part of those wedded to the byway of legislative reform. While fear of the potential of technology in end-of-life choices might make you feel justified, it is nothing short of counterproductive for the longer term. Just as the infamous ‘General Ludd’ led the rioters in smashing the mechanised weaving looms in the early 19th Century, so the new Presidents (and other WF office bearers) are wreaking havoc in ensuring the right to die movement will never again be the broad church to which it once aspired.

Criticism of Drion’s universal Pill model is as old as they are tired. Technology has not and will not disrupt the goal of legislative reform. To suggest as much requires proof and there is none. Nor is it any longer acceptable to blame technologists like myself for un-nerving politicians who are contemplating legislation. As we have seen time and time again, law-makers can do this themselves with only a little help from the Church. This polarizing does no one any good. More precisely, it is harmful to the technological agenda for change.
The Future of Technological Innovation in the Right to Die Debate

There are three main areas of research that Exit International is currently pursuing.

Nembutal is still the most sought-after option for a peaceful and reliable death. As such it is a priority to ensure that those who desire it, have access to the best quality pentobarbital sodium. The emergence of China as a major supplier of the drug in the past 18 months has changed the face of Exit research. The synthesis of the drug has become less important, as testing – both composition and purity – and the reliable storage of the powder - have become research priorities. Mobile testing of the drug using portable automated assay equipment will begin in Australia and New Zealand later this year. Plans are well in place to bring the process to Europe and North America in 2013-14. People who have their own product, with confirmed purity of greater than 95% and stored correctly so that potency is maintained for up to 20 years, will have little or no interest in legislative reform.

The inert gases are the second key focus for Exit. Systems for storing 500 litres of the most useful gas Nitrogen (which is undetectable at autopsy) and delivering it on request at the optimum flow rate of 20 litres/ min are currently being rolled out under the Max Dog Brewing label. Other countries will follow.

Also nearing completion are two useful supplementary devices. The first is a monitor that attaches to the inside of the plastic Exit Bag, and reassures the user, by way of a red/green LED, that the oxygen content in the bag is <8% and that deep inspiration will be effective. The second is a cardiac monitor that is worn by the person wanting to die which will send a text message to a pre-appointed mobile phone number after death has occurred. This will alleviate the worry by some elderly folk that they may not be found for days or weeks after death.
Finally, Exit is developing systems that address one particular area of concern regarding the self-administration of one’s own Peaceful Pill. Although almost everyone can self-administer Nembutal, at even the most extreme stages of an illness, developing incapacity is an ever-present concern. For those worried about failing ability, an updated and increasingly sophisticated Deliverance Machine, that can be activated by eye movement and voice is nearing completion.

Originally commissioned by patients with high quadriplegia in Australia and ‘Locked in Syndrome’ in the UK, this machine will allow control and a peaceful lawful death for patients whose paralysis is near complete.

**Conclusion**

In closing, I remain deeply concerned of the schism that has developed within the right-to-die movement and the systematic demonization of technologists such as myself. Of the two strategies outlined, technological innovation and the development of the Peaceful Pill already has the ability to deliver wide-ranging choice to the largest number of people. In contrast, legislative reform continues to move at glacial pace having little to offer the seriously ill and elderly who, in most countries, realise they have no time to wait.

Looking at the question of whether the two approaches can co-exist, I think it is increasingly clear that there are too many fundamental differences in the two strategies to see any hope of this. To advocate legislative change as *the* answer, one *must* denounce the universal Peaceful Pill strategy as dangerous and irresponsible. That half of the current World Federation Board office bearers have publicly done so leaves little space for optimism. What I remain most concerned about is the political sabotage of the technological agenda by the constant denunciation of the proponents as being “dangerous and irresponsible”. Tunnel vision is never a virtue.

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