Techniques to Pass On: Technology and Euthanasia

Brian Martin[1]

Abstract

Proponents and opponents of euthanasia have argued passionately about whether it should be legalized. In Australia in the mid-1990s, following the world's first legal euthanasia deaths, Dr. Philip Nitschke initiated a different approach: a search for do-it-yourself technological means of dying with dignity. The Australian government has opposed this effort, especially through heavy censorship. The citizen efforts led by Nitschke have the potential to move the euthanasia issue from a debate about legalization to a struggle over technology.

Keywords

voluntary euthanasia, dying with dignity, technology, self-help, Exit International

1. Introduction

Euthanasia has a long history involving vehement debate (Dowbiggin, 2005). Present-day proponents argue, typically, that people have a right to die at a time and place of their own choosing. Instead of spending their final days in a hospital or nursing home with the prospect of pain, breathlessness, indignity, and loss of autonomy, many people prefer to die at home among friends and family, in a dignified way under their own control at a time of their own choosing. Proponents argue for legalization of voluntary euthanasia, with tight controls to ensure consent is freely given and is not distorted by mental illness.

Opponents argue that euthanasia should remain illegal, because it is too easy to slip down the road to involuntary euthanasia of people with dementia or other disabilities, as in the infamous Nazi euthanasia program that killed hundreds of thousands of people with intellectual and physical disabilities. Opponents point to the alternative of palliative care that can make dying comfortable and usually pain free.

The arguments for and against euthanasia and physician-assisted suicide have been examined and argued exhaustively (Yount, 2007). My aim here is different: to look at the role of technology within a particular niche of the euthanasia struggle, with Dr. Philip Nitschke and his organization, Exit International, the most prominent players. In most conflicts over euthanasia, technology is a backdrop to legal and ethics-based debates and campaigns. With Nitschke and Exit, technology has become a key means by which the campaign is carried forward and by which opponents have responded.

I start with a brief overview of the background to the current voluntary euthanasia debate, especially the role of technology. Then I describe Nitschke's role in turning to technology as a better road to voluntary euthanasia, followed by the subsequent tactics, mainly in Australia, over access to this road. I conclude with comments about the implications for understanding the role of citizen activism and technology.

2. Death and Technology

Only a few centuries ago, death usually was a natural process: The body succumbed to disease or accident and that was that. With the rise of modern industrialized medicine, especially in recent decades, dying and death are more commonly accompanied by technological interventions, including a wide range of drugs (chemotherapy, anticonvulsants, painkillers, and many others), operations, transfusions, resuscitation, defibrillators, respirators, and feeding tubes. A body that previously would have died can now be kept functioning for days, weeks, or even years, as in persistent vegetative states (Colby, 2006; Nuland, 1993).

Many aspects of advanced medical intervention are widely welcomed. For example, people can now recover from heart attacks and live many more years of productive life. However, high-technology medicine has created a new phenomenon: the extension of life in a medical environment, often in a hospital or nursing home under constant medical care, with reduced consciousness and a lower quality of life. Whereas people previously would die at home as disease progressed, now their life may be extended through medical interventions.

[1]University of Wollongong, Wollongong, New South Wales, Australia

Corresponding Author:
Brian Martin, Arts Faculty, University of Wollongong, Wollongong, New South Wales 2522, Australia
Email: bmartin@uow.edu.au

Some, seeing this happen to family or friends and fearing a similar outcome for themselves, see voluntary euthanasia as an alternative, as a way to achieve death with dignity.

Over the same period that technology has made possible the extended viability of bodily functions, some opportunities for easy death have been removed. In the 1950s, it was easy to commit suicide by overdosing on sleeping pills, especially barbiturates, and sometimes this happened accidentally. Marilyn Monroe was the most famous victim. Governments and pharmaceutical companies gradually removed such drugs from sale so it is now quite difficult to commit suicide by overdosing on over-the-counter medications of any sort.

Another factor in reducing deaths from attempted suicide is improvements in emergency response. Most people saved by swift and effective interventions have no intention of dying—for example, they might have suffered a heart attack but can recover and live many more years or decades. But emergency response also makes suicide more difficult.

Anyone desperate to die has plenty of choices, such as jumping from a building, leaping in front of a train, using a gun, or hanging. None of these methods is entirely reliable. People with limited mobility may have difficulty leaping in front of a train or even getting out of a window. All these methods can go wrong and lead to serious injuries, exacerbating the agony from which death is the desired release. Most importantly, these methods are distressing to others, including family, friends, and train drivers. They do not fulfill basic criteria for a peaceful death.

Death with dignity thus seems to be becoming less common for two convergent reasons: rapidly developing technology to extend life, but under the control of the medical system, and removal of easy, peaceful ways to end one's life.

One response has been voluntary euthanasia or physician-assisted suicide. Euthanasia can be classified in various ways, including covert and overt. When euthanasia is illegal, it may still occur covertly (Magnusson, 2002). Typically, a person with a terminal illness asks a doctor for assistance in dying, or hints at it, and the doctor increases administration of painkillers or other drugs with the knowledge that death is probably hastened. This can also be called "slow euthanasia." In many countries it is not prosecuted so long as the doctor primarily intended to ease suffering. In some cases the person is not sufficiently conscious or competent to express a wish to die, yet family members or the doctor judge their suffering to be so great as to justify hastening death.

In overt euthanasia, decisions and actions to end life are made openly. The individual or carers decide that death is the more humane option and proceed to end life, for example, by lethal injection. This option is the main focus in the huge ongoing debate over euthanasia.

In only a few parts of the world has euthanasia been legalized or officially tolerated. In the Netherlands, Belgium, and the states of Oregon and Washington, laws allow euthanasia under medical supervision in strictly defined circumstances.

In Switzerland, assisting suicide is not prosecuted; Switzerland is the only country in which foreigners can obtain suicide assistance legally.

In all these places, legal controls are strict. Nevertheless, critics argue that these laws open the door to abuse and that some euthanasia deaths do not satisfy the legal conditions.

3. Australia's Euthanasia Experiment

Australia, a country the size of continental United States with a population of 21 million—less than Texas—has six states and two territories. One of the territories is the Northern Territory, a huge area in the center and north of the country nearly twice the size of Texas but with a population of only 200,000, the majority of whom live in Darwin, a city on the northern coast in the tropics.

In 1996, the Northern Territory became the first place in the world where euthanasia was legal (Ryan & Kaye, 1996). The law was strict, applying only to terminally ill patients and requiring approval from two doctors and examination by a psychiatrist. The only doctor willing to take a lead in the process was Philip Nitschke, who had a long history as a dissident, for example, speaking out about the health risks from visiting U.S. nuclear warships.

Nitschke rigged up a computer-based system that ensured individuals had maximum control over their dying. With an intravenous line in place with a syringe driven by the computer, the dying person had to answer several questions posed on the computer screen before death-inducing chemicals were automatically injected into their veins. Once the system was set up, Nitschke could take a back seat and family and friends could be with the dying person, if desired.

The Australian federal parliament overruled the Northern Territory law 9 months after it took effect. Just four people had died using the provisions of the law (Kissane Street, & Nitschke, 1998). The federal parliament's action was in the face of popular support for voluntary euthanasia, with opinion polls showing more than 75% of Australians in favor.

4. The Exit Route

Nitschke was transformed by his experience with the Northern Territory law. He became disenchanted with the legal road to euthanasia after seeing how easy it was for a hostile government to reverse legal changes. He was also disillusioned by the lengthy, restrictive process required by the law. He saw individuals in extreme suffering who could not be helped because legal requirements could not be satisfied.

The Northern Territory experience spurred Nitschke to pursue a different path to euthanasia: technology. Rather than lobby to legalize a process still controlled by the medical profession, Nitschke—who had a background in experimental physics before becoming a doctor—began a search to find ways for people to have full control over their own deaths,

to peacefully die in dignity in a time and place of their own choosing (Nitschke & Stewart, 2005).

In Australia, it is legal to commit suicide but illegal to assist someone to kill himself or herself. Doctors routinely give painkilling drugs that hasten death and sometimes provide individuals with information and drugs for dying, but very few are willing to admit to this because of the possibility of being charged with murder (Syme, 2008). In this context, Nitschke wanted to find ways that people, mainly those with terminal illnesses with excessive suffering, could choose death without implicating others in the process.

Nitschke set up an organization, Exit International, to support this quest. Most members are elderly, with a personal interest in having a peaceful death. Members of Exit include retired engineers, chemists, and others with technical skills relevant to finding ways to die that satisfy several conditions: the technique allows a peaceful death, it is under the control of the person dying, and it is reasonably simple and cheap. Exit's efforts are part of a wider international quest to find or develop technology to assist deathing (Ogden, 2001).

One technique—the best discovered so far—is to go to Mexico, buy pentobarbital, a barbiturate commonly known by its trade name *Nembutal*, at a veterinary supply store, and take a suitable dose. The drug itself is cheap and the trip from Australia to Mexico not too expensive. The death is quick, easy, and reliable if instructions are followed.

An even more convenient option would be the capacity to produce pentobarbital in a home laboratory using commonly available chemicals and standard equipment. However, thus far Exit's efforts toward this goal have been unsuccessful.

Another technique involves what is called an "exit bag." In one version of this technique, a bag a bit larger than one's head is made according to detailed instructions, with a pull cord at the opening. A container of inert gas such as helium is purchased and a controlled-release nozzle fitted. Dying is achieved by opening the inert gas nozzle, inflating the bag, exhaling, pulling the bag down over one's head and taking a deep breath, which quickly causes unconsciousness followed by death minutes later. Care has to be taken, for example, not to make the bag too tight. This technique is cheap and the equipment is not overly complicated. However, the technique required is a bit tricky, especially for those who are very ill or disabled, which means it is not entirely reliable. More importantly, most people find it less appealing than Nembutal, feeling it is undignified to die with a bag over your head.

A more conventional approach is to ask your doctor for a prescription of barbiturates or some other drug that will assist in ending your life. However, some doctors are unsympathetic or afraid of being charged as an accomplice. Therefore, Nitschke recommends making the request for lethal drugs sound sincere. Instead of asking for 100 mg propoxyphene—which sounds suspiciously well-informed—it might be better to say "Could I have some of that pain reliever my friend said was so good? I think it started with a D." The doctor may then

provide Darvon—the U.S. trade name for propoxyphene. Obtaining tools for suicide by verbal techniques could be said to be a form of "human engineering," namely, using social techniques to achieve objectives, in this case objectives involving technology in the form of drugs.

Nitschke and other members of Exit are constantly searching for better information about use of these and other techniques. For example, rather than building the exit bag nozzle for themselves, people can now buy nozzles that fit commercially available helium canisters. When helium canisters became unavailable in Australia, Exit recommended nitrogen as an alternative.

The activities of Exit have attracted attention, mainly through media stories about members who have ended their lives, often with Nitschke's advice and assistance in obtaining materials. As Exit has developed its techniques and spread its message, euthanasia opponents in the Australian government have tried to hinder these activities. The result has been a sort of game or race, with each side trying to find means—technological or otherwise—to advance its goals.

5. A Sociotechnical Struggle

The Australian government's primary response was to pass a law against giving information about how to commit suicide using any electronic communications medium, including telephone and the Internet. This is the most draconian law in the world against providing information about how to kill oneself. For example, if you tell someone over the telephone how to tie a rope for hanging, in principle you could be prosecuted under the law. In practice, conversations like this are not the target of the law: It is aimed at Exit's activities.

Exit responded by hosting its Web site in the United States and putting its telephone help line in New Zealand and later relying on Skype for calls because it is hard to intercept. Cheap telecommunications make censorship of phone calls and Internet materials impractical. The main effect of the law, so far as telecommunications is concerned, is a symbolic assurance that the government is acting against Nitschke's activities.

Nitschke runs workshops giving information about end-of-life options (Fickling, 2004) throughout Australia and in New Zealand and Britain and initiated North American workshops in November 2009. After the passing of the Australian suicide-information censorship law, Exit's workshops in Australia are run in two parts. In the first part, a public meeting that anyone can attend, Nitschke gives general information. After this segment, anyone who wants to stay must become a member of Exit and sign a waiver form intended to protect Exit from prosecution. In the second part of the workshop, for members only, Nitschke can give more detailed information, for example, about purchasing Nembutal and constructing an exit bag.

Nitschke and his partner Fiona Stewart, a public health sociologist, wrote a book titled *The Peaceful Pill Handbook* giving detailed information about how to kill oneself (Nitschke

& Stewart, 2006). It is freely available in most countries but banned by the Australian government. However, it is easy to buy a copy on the Internet directly from Exit International, either in hard copy or an electronic version including photos and video clips. In practice, the Australian law is not enforced against individuals who buy copies, as long as they do not publicize their law breaking. The ban affects libraries and limits publicity in Australia. However, because the ban does not effectively block access to the book, it could be considered to be a form of symbolic politics by which the Australian government demonstrates that it is doing what it can against Nitschke.

In 2008, the Australian government announced it was planning to introduce mandatory filtering of the Internet. The official reason was to block access to child pornography. However, critics alleged that a side effect would be to block access to many other types of sites—including on euthanasia.

The proposal triggered a firestorm of opposition. Because the filtering was to be based on a list of Web addresses, critics said it would make little difference to the availability of child pornography, which is usually distributed via unpublished sites, peer-to-peer networks, or e-mail, sometimes encrypted. More insidiously, the sites to be blocked by the filter system were to remain secret, so members of the public would not know what was being censored.

Implementation of this filtering system would put Australia among a select group of countries with draconian Web censorship including Burma, China, Iran, and Saudi Arabia. Most Australian Internet service providers refused to participate in the government's planned trial. A range of anticensorship groups joined in campaigning, led by Electronic Frontiers Australia, whose membership jumped dramatically because of this issue. The Australian online activist group GetUp mounted a major campaign against mandatory filtering.

Internet filtering was a threat to Exit's operations, but because it was a threat to so many other Internet users, the antifiltering campaign mobilized a wide range of supporters. In effect, the government, by casting its censorship net—in this case also its Internet censorship—too widely, stimulated the creation of a massive opposition that served to defend Exit's Internet presence.

Another tool used by Exit members is civil disobedience. In 2002, 69-year-old Nancy Crick drank Nembutal and died. She was surrounded by 21 family members, friends, and supporters who could have been charged with assisting a suicide and been sentenced to life imprisonment under the laws of the state of Queensland. Crick's case was widely known through an Internet diary in which she wrote about her impending death. There was safety in numbers: none of the 21 was charged. Since then, Exit has set up a network called "Nancy's Friends" for advice, support, and ensuring no one need die alone (Nitschke & Stewart, 2005).

6. People's Research

Most research is done by professional scientists who studied science at university and usually were apprenticed to senior scientists through doctoral research. The variations from the standard professional model are unusual and hence worth noting.

In the 1980s and 1990s, after the emergence of AIDS, many activists studied the science concerning the disease. Many of them had little or no prior scientific training, yet they became so highly expert in technical aspects directly relating to AIDS that they could hold their own ground with leading experts in the field and make credible interventions concerning research priorities, treatment regimes, and the design of clinical trials of AIDS drugs. This was an example of nonscientists achieving in-depth understanding without becoming practicing scientists (Epstein, 1996).

In Japan, in the 1970s, local teams of citizens—supported by a few scientists—formed to investigate the cause of Minamata disease. They investigated the history of the disease, interviewed sufferers, and took measurements of plants and were able to identify the cause, mercury poisoning from industry, when large teams of scientists with plenty of money did not (Ui, 1977).

Since then, citizen investigators have tackled many problems, most commonly local environmental issues (Community Research Network, 2009). They are not professional scientists but often they have some scientific training, typically acquired through undergraduate study or practical experience. They tend to investigate locally significant issues ignored by professional scientists, sometimes because industry funding discourages research that might threaten industry interests.

In some fields such as astronomy and botany, there is a long tradition of amateur involvement in research. Lower cost technology and easy access to information is making it possible for amateurs to make discoveries (Ferris, 2003).

Exit's search for methods of peaceful death fits into this tradition of amateur and citizen research. Some Exit members are trained scientists, but not with specific expertise in end-of-life technologies. Exit's research is highly focused: It could be called *goal-directed*. It is not about knowledge for knowledge's sake.

Exit's research organization is analogous to that in many research laboratories. There is a research director—Nitschke, who actually does a lot of the research himself—and many investigators under his supervision. Rather than being held together by money and careers, like conventional science, Exit's research is driven by commitment to a common cause.

Exit's research, like other technological endeavors, contains both technical and social dimensions. It includes methods of access to existing technology, such as how to identify and purchase drugs such as Nembutal. It contains information on using technology, such as how much Nembutal is lethal and

what to expect when taking it. It contains information on constructing technology, such as putting together an exit bag. And it contains information about politics and law, such as how to avoid being charged with murder for assisting suicide.

7. Conclusion

Technology has played an ever increasing role in the euthanasia issue. Advances in medical technology have made it more likely that the final stages of life will be both extended and dependent on medical intervention in ways that are, for some, filled with physical and mental suffering. Parallel advances in palliative care have reduced the level of suffering for many, including by slow euthanasia under the supervision of medical professionals. At the same time, technological options for a peaceful death under one's own control are available but restricted by governments opposed to euthanasia.

In response to these dilemmas, a citizen-based self-help movement developed in Australia, resulting from Philip Nitschke's experiences with the short-lived period of legal euthanasia in the Northern Territory, leading to the creation of Exit International and the search for the peaceful pill, namely, a self-administered technological aid for dying with dignity.

The Australian federal parliament's intervention to overrule the Northern Territory euthanasia law inadvertently triggered Nitschke to pursue a self-help trajectory. This has led, curiously, to an escalating technology struggle between Exit and its government-supported opponents, involving the Australian government imposing increasingly stringent controls over information that Exit has circumvented by using the flexible features of telecommunications technology.

Australian government attempts to censor Exit may actually have the impact of spreading information about do-it-yourself euthanasia more widely. Exit's investigations have become ever more probing into ways of getting around harsh laws, especially censorship. This has led Exit increasingly away from the legal road espoused by most voluntary euthanasia organizations in Australia and other countries. Critics of the technology path raise concerns that removing legal or medical oversight of dying may increase the risk of mistakes and abuses and reduce the prospects for law reform (Syme, 2008; Werth, 2001).

Exit is searching for information about methods that use ordinary materials to enable a peaceful death. Given that a large majority of people in Australia and many other countries support voluntary euthanasia, Exit's findings will have a ready and expanding audience.

What is the future for euthanasia? For simplicity, it's convenient to describe three possible future paths. Path 1 is continuation of laws that ban euthanasia, so most instances remain covert, as at present. Path 2 is legalization—formal or tacit—following the examples of the Netherlands, Belgium, Oregon, Washington, and Switzerland. Path 3 is the spread of knowledge and skills for easy techniques for peaceful death. This is Exit's path.

Exit's approach sidesteps two types of controls: Path 1's legal controls and Path 2's medical controls. If the push for access to euthanasia is seen as a social movement (McInerney, 2000), then Exit may be serving as a "radical flank" (Haines, 1984): an approach seen as radical even by the mainstream movement. As such, it may provide a greater incentive for legalization or better provision of hospice. Or, in the spirit of self-help movements in various fields, including the open-access and open-source movements, the search for technological means to peaceful death may become the main path.

References

Colby, W. H. (2006). *Unplugged: Reclaiming our right to die in America*. New York: Amacom.

Community Research Network. (2009). Retrieved November 2, 2009, from http://www.loka.org/crn/index.htm

Dowbiggin, I. (2005). *A concise history of euthanasia: Life, death, god, and medicine*. Lanham, MD: Rowman & Littlefield.

Epstein, S. (1996). *Impure science: AIDS, activism, and the politics of knowledge*. Berkeley: University of California Press.

Ferris, T. (2003). *Seeing in the dark: How amateur astronomers are discovering the wonders of the universe*. New York: Simon & Schuster.

Fickling, D. (2004). A happy ending? *Lancet, 364*, 831.

Haines, H. H. (1984). Black radicalization and the funding of civil rights: 1957-1970. *Social Problems, 32*, 31-43.

Kissane, D. W., Street, A., & Nitschke, P. (1998). Seven deaths in Darwin: Case studies under the Rights of the Terminally Ill Act, Northern Territory, Australia. *Lancet, 352*, 1097-1102.

Magnusson, R. S. (2002). *Angels of death: Exploring the euthanasia underground*. Melbourne, Australia: Melbourne University Press.

McInerney, F. (2000). "Requested death": A new social movement. *Social Science & Medicine, 50*, 137-154.

Nitschke, P., & Stewart, F. (2005). *Killing me softly*. Melbourne, Australia: Penguin.

Nitschke, P., & Stewart, F. (2006). *The peaceful pill handbook.* Lake Tahoe, NV: Exit International.

Nuland, S. B. (1993). *How we die: Reflections on life's final chapter*. New York: Random House.

Ogden, R. D. (2001). Non-physician assisted suicide: The technological imperative of the deathing counterculture. *Death Studies, 25*, 387-401.

Ryan, C. J., & Kaye, M. (1996). Euthanasia in Australia: The Northern Territory Rights of the Terminally Ill Act. *New England Journal of Medicine, 334*, 326-328.

Syme, R. (2008). *A good death: An argument for voluntary euthanasia*. Melbourne, Australia: Melbourne University Press.

Ui, J. (1977). The interdisciplinary study of environmental problems. *Kogai: The Newsletter from Polluted Japan, 5*, 12-24.

Werth, Jr., J. L. (2001). Policy and psychosocial considerations associated with non-physician assisted suicide: A commentary on Ogden. *Death Studies, 25*, 403-411.

Yount, L. (2007). *Right to die and euthanasia* (2nd ed.). New York: Facts on File.

Bio

Brian Martin has a PhD in theoretical physics from Sydney University and is professor of social sciences at the University of Wollongong. He is the author of 12 books and hundreds of articles on scientific controversies, nonviolence, dissent, information issues, and other topics.