
Bioethics Outlook

Plunkett Centre for Ethics

A joint centre of Australian Catholic University and St Vincent's Health Australia (Sydney)

Volume 26, No 4

December, 2015

‘Voluntary’ euthanasia: why it will be a way station.

Bernadette Tobin

Recently, on the ABC's programme, Q&A, the case for legalizing euthanasia was canvassed by a panel which included Andrew Denton. In any such discussion, it's a good idea to start by being precise about what it is that *is* illegal before we consider whether a change in the law would be, all things considered, desirable.

Not the relief of pain and other distressing symptoms at the end of life such as breathlessness or constipation or incontinence or depression or anxiety. Relieving them is perfectly legal. Relieving them is good palliative care, even when that relief happens to hasten death. No, we are talking about a doctor *intentionally* bringing about a patient's death, either by assisting that person to commit suicide or by (say) administering a medication in a dose sufficient to bring about the person's death.

'Assistance in suicide' is a clear enough term for the former. Until recently, 'euthanasia' was the conventional term for the latter. But it was never more than a term meant to persuade us that a good death is one that is deliberately brought about by a doctor, which of course was always nonsense. After all, the person who dies in his sleep dies a good death!

In this issue

Dr Garry Niewkamp, an emergency physician, reviews some of the best literature on the subjective experience of suffering.

Bernadette Tobin argues that, were euthanasia to be legalized, the pressure to extend it from voluntary to non-voluntary would be immediate and irresistible. She also reports briefly on the Annual Plunkett Lecture given by Justin Oakley of the Monash Bioethics Centre.

Language matters

The old term was ‘mercy killing’. That at least was an honest description, even though we know that motives other than mercy can be at work here. And at work even in the most loving of families. For accompanying a relative in the trajectory towards death is almost always a challenging, as well as sad, time for the family. Which is one reason why a member of the family sometimes asks the doctor to ‘hurry things up’. The family member, rather than the person who is dying, is suffering.

But today, no one will use even the expression mercy killing. ‘Aid in dying’ is the latest term, which seems to have replaced yesterday’s ‘dying with dignity’. And of course there is strategy in the deployment of these fudges. Support for euthanasia hinges on how it’s described; the clearer the language the less support there is for its legalization.

So, should we support a change in the law to permit doctors to give assistance to a person who wishes to commit suicide? Should we support a change in the law to permit doctors intentionally, deliberately, to administer a medication in a dose sufficient to bring about a person’s death? Let me explain one reason why I think we should not.

Fairness in access to this ‘benefit’

If bringing about a person’s death, either by assisting him to commit suicide or by administering a medication in a dose

sufficient to achieve that end, is a ‘benefit’, why should that ‘benefit’ be available *only to those who can seek it*? Why should it not be available to anyone who is in pain, discomfort, constipated, incontinent, depressed, anxious, etc? Think of all those who might ‘benefit’ from it but who are not able to request it. Those with advanced Alzheimer’s who never expressed such a wish and certainly cannot do so now. And some infants. Surely it would be ‘unfair’ to deny these people the ‘benefit’ that we will make available to those who are able to request it? Surely it would be unfair to make the availability of this ‘benefit’ dependent on its being requested?

Here’s the rub. The ‘safer’ we try to make the protections against abuse of assistance in suicide and euthanasia (requiring that two doctors rather than one certify that the person is ‘terminally ill’, requiring that two psychiatrists rather than one certify that the person is of sound mind, requiring a ‘cooling off’ period of two weeks rather than one between the request and its fulfilment, etc), the more ‘unfair’ will be the law we will have enacted.

Pressure to widen access

That is why any legalizing of euthanasia when it is voluntary will be unstable. Because as soon as ‘voluntary euthanasia’ is in place, there will be pressure to relax the obstacles to the availability of this ‘benefit’. The voluntary will be a station on the way to the non-voluntary.

That, I think, is a powerful reason why we should not go down this route.

Objection and reply

A response to this claim about the ‘logic’ of legalizing euthanasia when it is voluntary might be as follows: Has this actually happened? Is there any jurisdiction in which euthanasia when non-voluntary has been legalized? Otherwise, is this not simply a variant of the well-known ‘slippery slope’ objection to legalizing euthanasia when voluntary?

However, a concrete example of the pressure to expand access to this ‘benefit’ in circumstances when the person concerned could not seek it is found in the Groningen Protocol for Euthanasia in Newborns. This Protocol includes guidance on the conditions under which a doctor may deliberately bring about the death of a very young child. That is a straightforward case of non-voluntary euthanasia.

As for its legality: The Protocol was drafted by doctors at the University Hospital of Groningen in 2004 and subsequently authorized as a national guideline by the Dutch Association for Paediatric Care. Though it has not been ‘written into law’, there has in fact never been a prosecution of a doctor who acts in accordance with this Protocol.

What needs doing?

Of course, there is much for us to do to improve the way people die in Australia today. Three things in particular:

We need to improve medical knowledge and know how with respect to the relief of pain and other symptoms.

We need to ensure that all doctors are knowledgeable about and competent in providing that relief, and that they are not frightened by the known side effects of so doing.

And we need to ensure that all Australians have access to such competent care. As I say, there is much for us to do, as everyone who has witnessed even one bad death instinctively knows.

But let us not, out of well-meaning but misguided compassion, permit doctors deliberately to bring about the death of their patients. No good will come of it.

Conclusion

Some of us think that there is an in-principle ethical objection to a doctor deliberately killing his patient, whatever the motive. We think that there is an in-principle objection to a doctor deliberately helping his patient to commit suicide. Whether or not you share that view, you should think seriously about the logic of so-called ‘voluntary euthanasia’. For it will be only a way station.

Pathographies: Suffering and the patient's perspective

Garry Niewkamp

I work in a busy emergency department north of Sydney. Anyone working in healthcare for any prolonged period of time is faced with burn out and the prospect of compassion fatigue. Suffering, because familiar and commonplace in this setting, can seem ordinary and untroubling. It is very easy to slide into a comfortable professionalism that helps to distance the practitioner from what is actually being felt by the patient. With this in mind, one of the ways I draw attention to this danger, when educating junior doctors, is by focussing on patients' accounts of their illness. An increasing body of literature helps here. In what follows, I show what I set before junior doctors, to draw their attention to some alternative perspectives on illness in the hope that it will have more general interest.

In her essay, *Illness as Metaphor* Susan Sontag describes illness as

"the night-side of life, a more onerous citizenship. Everyone who is born", she writes, "holds dual citizenship in the kingdom of the well, and in the kingdom of the sick. Although we all prefer to use

the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place".¹

And, some time later, Christopher Hitchens describes the summoning of emergency services and being taken to hospital as

"a very gentle and firm deportation, taking me from the country of the well across the stark frontier that marks off the land of the malady".²

The metaphor of sickness as a place is a useful one. It marks out illness as a territory that at some stage we all must navigate. And, if I can extend the metaphor, both Sontag and Hitchens contribute to our understanding of that territory by writing their own travelogues.

Pathographies are that subsection of biographies that provide us with an individual's account of their travels in the

¹ Sontag, S. *Illness as Metaphor*. Toronto: Collins Publishers, 1988

² Hitchens, Christopher. *Mortality*. Sydney: Allen & Unwin, 2012

land of malady, a country where doctors and nurses might appropriately be described as travel guides. In committing their experiences to writing, these authors have much to teach us about the subjective experience of illness. It is in the telling that suffering is made evident. It is very easy during a busy shift in an emergency department, when one is overwhelmed by the constant distraction of vital sign, diagnostic workups, patient flows, four-hour deadlines, the 'cholecystitis in bed 13' and the 'overdose in bed 16' to lose sight of the person. Dipping into this body of writing from time to time can remind us that, while we have much to teach patients about their illnesses, they have much to teach us about their experiences..

Truth-telling

In *A Very Easy Death*, her account of her mother's final illness, Simone de Beauvoir recounts how she and her sister are concerned about what her mother is being told about her illness. Her mother has bowel cancer and has been told simply that she has peritonitis. De Beauvoir's sister questions the treating professor.

'But what shall we say to Maman when the disease starts again, in another place?'

'Don't worry about that', says the Professor. 'We shall find something to say. We always do.'

And the patient always believes it.³

The daughters go along with the deceit, but it comes at a cost. '*The betrayal was beginning*' was how de Beauvoir describes her ambivalence and collusion. And so it was. For they had sacrificed truth for a fiction.

This beautiful vignette is a snapshot of a moment in time, a moment that captures beautifully the tension that can often be at play when important ethical principles seem to be in conflict. Mindful that '*Maman had dreaded cancer all her life*', de Beauvoir did not want to add to her pain by making her mother confront the truth of her condition. She saw the unfolding events as a race:

'between torture and death ... And even if death were to win, all this odious deception! Maman thought that we were with her, next to her; but we were already placing ourselves on the far side of her history. An evil all-knowing spirit, I could see behind the scenes, while she was struggling, far, far away, in human loneliness. Her desperate eagerness to get well, her patience, her courage - it was all deceived. She would not be paid for any of her suffering at all. I saw her face again: 'Since it is good for me.' Despairingly I suffered a

³ De Beauvoir, Simone. *A Very Easy Death*. New York: Pantheon Books, 1965 Page 45

*transgression that was mine
without my being responsible for it
and one that I would never
expiate.*⁴

This snapshot in time is now many decades past. Today, when we reflect on whether or not to deliver bad news, we tend to err on the side of truth-telling. De Beauvoir would endorse this practice.

Depression

Les Murray is one of Australia's greatest poets. He is most insightful when he shares with his readers the struggle he has had with depression. It is hard on a ward round to get a sense of the havoc that depression can cause. We are told that the "overdose in bed 3" is waiting for mental health review. So we shuffle on to the next bed. Les Murray wants to draw us back and to remind us of the pain that is often hidden.⁵ He describes his own pain in the introduction to a book of essays and poems called *Killing the Black Dog*.

He writes:

*'Every day though, sometimes
more than once a day, sometimes
all day, a coppery taste in my
mouth, which I termed intense
insipidity, heralded a session of
helpless, bottomless misery in
which I would lie curled in a foetal
position on the sofa with tears*

⁴ p 58

⁵ Murray, Les. *Killing the Black Dog*, Sydney: The Federation Press, 1997

*leaking from my eyes, my brain
boiling with a confusion of stuff
not worth calling thought or
imagery: it was more like shredded
mental kelp marinated in pure
pain.*⁶

In the poem *Corniche* Les Murray describes the early morning struggle with the black dog in such raw detail that it becomes difficult even to imagine that every day as we manage patients with depression it is *this* disease as described by Murray that we are confronting. Therein lies the value of pathographies.⁷

*"It was the victim-sickness.
Adrenalin howling in my head/
The black dog was my brain. Come
to drown me in my breath/
was energy's black hole,
depression, compère of the
predawn show/
when, returned from a pee, you
stew and welter in your death."*⁸

Hope and surviving the odds

Susan Sontag's son, David Rieff, has written an unflinching portrait of his

⁷ Murray, Les. *The Best 100 Poems of Les Murray*. Collingwood, 2012, p 6

mother's final illness.⁹ Having endured disfiguring surgery for breast cancer, Sontag became energized by the idea of what science could offer. Her friend puts her in contact with a Parisian oncologist who has an interest in immunotherapy as an adjunct to chemotherapy. The friend, armed with histo-pathology slides from Memorial Sloan Kettering, makes the trip to Paris to seek the advice of Dr Israel. He examines the slides and writes to Sontag, saying:

*'I do not think your case is hopeless.'*¹⁰

Sontag's son notes: '

*That sentence was the turning point for my mother. It gave her the strength to continue, and she would subsequently attribute her survival largely to Dr Israel's care.'*¹¹

Rieff describes this encounter between his mother and the science of Dr Israel as

*'a marriage of magical thinking and reason.'*¹²

In essence though, Rieff's account of his mother's illness teaches us about surviving against the odds and the value of hope.

Helen Garner also reflects on hope.¹³ She calls one of her books *The Spare Room* in a reference to the room in her house that she prepares for her friend, Nicola.¹⁴ Nicola is coming to visit for three weeks to receive treatment she believes will cure her cancer. Almost immediately Garner questions her decision to allow the visit.

*'Death was in my house. Its rules pushed new life away with terrible force.'*¹⁵

Like Sontag, Garner has faith in science and gently encourages her friend in the direction of palliative care services. But Nicola seeks hope in an Institute which specialises in alternative treatments for cancer. She embarks on a course of treatments consisting of large infusions of vitamin C and regular coffee enemas. Despite being surrounded by Garner's '*blackest, most glowering scepticism*'¹⁶, Nicola finds solace. She returns from the clinic one afternoon in high spirits. A '*real doctor*' had seen her at the clinic. "*How could you tell*"? questions Garner.

'Oh...just by looking. He said that the increased pain is definitely being caused by the treatments jazzing the cancer up. I listened and nodded," wrote Garner "and smiled because she was pleased. But I wondered what he had really said to her, and in what language,

⁹ Rieff, David. *Swimming in a Sea of Death*. New York: Simon & Schuster, 2008

¹⁰ p 32

¹¹ p 32

¹² p 32

¹³ Garner, Helen. *The Spare Room*. Melbourne: Text Publishing, 2008

¹⁵ p 80

¹⁶ p 92

*for jazzing up sounded like one of her own expressions, drawn from the same posh, old-fashioned lexicon as carry on, crash hot, my divine niece and some mad little hotel in South Yarra.*¹⁷

So what are we to make of hope? What can these very different accounts of hope teach us about the provision of care? Does it matter that a practitioner at the cutting edge of immunotherapy provided Sontag with hope, while a practitioner at the alternative end of the spectrum provided Nicola with hope? What differentiates hope in these scenarios?

In the *Nicomachean Ethics*, Aristotle describes virtue as being situated midway between two vices (though admittedly he did not think of hope as a virtue: that comes later with Christianity). At one end of the spectrum is despair, and the phenomenon at the other end might best be described as presumption.

Another way of looking at hope is by reflecting on the person who inspires hope. What differentiates Dr Israel from the practitioner at the Institute? I am tempted to argue that Dr Israel aims at truth, and that Sontag's hope is not based on a deception. On the other hand Nicola's hope is tainted by falsehood, and so at the very least, this difference invites differing moral assessments. A problem with this analysis is that the practitioners at

Nicola's Institute (despite our - and Garner's - scepticism) believe they are standing on firm scientific ground and so think they are aiming at the truth. Inevitably we find ourselves having to reflect on the nature of evidence and on those good habits of mind that enable it to be a more efficient instrument of knowledge. These 'intellectual virtues' include benevolence, humility, therapeutic parsimony and' importantly, honesty. Dr Israel has them; the other practitioner does not. Those who pay attention to the importance of the exercise of intellectual virtues will try to ensure both that their beliefs align with evidence and that they themselves do not fall prey to self-interest.

W;t

Another account of illness worth reflecting on is found in the the Pulitzer prize winning play *W;t* by Margaret Edson.¹⁸ The main character Vivian Bearing PhD, who studied under the great E.M. Ashford and is a scholar of Donne's Holy Sonnets, suffers from advanced metastatic ovarian cancer. These two aspects of her life, the sublime and the lethal, weave their way throughout the course of the play and provide the audience, through the insights of the main character, with valuable reflections on life and death. In one scene Ashford talks with her pupil, Vivian who has submitted an

¹⁷ p 116

¹⁸ Edson, Margaret. *W;t A Play*. New York: Faber & Faber, 1999

essay on Donne but without the attention that Ashford believes the subject matter requires.

'This is Metaphysical Poetry not The Modern Novel' argues Ashford¹⁹. She questions her pupil about punctuation.²⁰

'Do you think the punctuation of the last line of the sonnet is merely an insignificant detail?' "The meaning of the entire sonnet is compromised", she argues, "because it is sacrificed to hysterical punctuation:

And Death-capital D- shall be no more-semicolons!

Death-capital D-comma-thou shalt die-exclamation point!

If you go for this sort of thing, I suggest you take up Shakespeare.

Gardner's edition of the Holy Sonnets returns to the Westmoreland manuscript source of 1610 - not for sentimental reasons, I assure you, but because Helen Gardner is a scholar: It reads:

And death shall be no more, comma, death though shalt die. (As she recites this line, she makes a little gesture at the comma.)

Nothing but a breath -a comma- separates life from life everlasting.

It is simple really. With the original punctuation restored, death is no longer something to act out on stage, with exclamation points. It's a comma, a pause.

This way, the uncompromising way, one learns something from this poem, wouldn't you say? Life, death. Soul, God. Past, present. Not insuperable barriers, not semicolons, just a comma.'

Vivian responds in much the same way as we might respond.

'Life, death ... I see, It's a metaphysical conceit. It's wit! I'll go back to the library and rewrite the paper.'

She has of course, missed the point. She is corrected by Ashford.

'It is not wit Miss Bearing. It is truth.'

It is just a whisper's breath that separates us all from the hereafter. Just a comma, as Ashford would say. It is within the space of that comma that our professional careers play out. The great E. M. Ashford has something to teach us about uncompromising professionalism and about the truth at which our practice aims. In an emergency department we can easily identify with Bearing in her endeavour simply to rewrite the paper and move to the next thing. It is Ashford who reminds us to focus on the detail, which inevitably requires a focussing, a slowing down. The slowing down will permit us to

¹⁹ p 13

²⁰ p 4

better see the patient's suffering when it might not otherwise be obvious.

Mortality

Christopher Hitchens' account of his final illness is given expression not only in his words but also in its form. His writing is meditative, unsparingly honest and beautifully composed. As the end draws near, the completed chapters give way to brief observations written in the form of anecdotes and epigrams. At one point he writes,

*'A Bout de Souffle.... Seberg / Belmondo. Funny how one uses 'breathless' or 'out of breath' so casually. At Logan [airport]-can't breathe! Next stop terminal.'*²¹

And so it is. Hitchens the uncompromising atheist writes as though he wants to reassure his loyal followers that in the face of death he will not capitulate and 'fall into the hands of God'. He is, until the very end, authentically Christopher Hitchens. There is honesty and truth in his account. He writes:

'I have come to know that feeling ... the sensation and conviction that the pain will never go away and that the wait for the next fix is unjustly long. Then a sudden fit of breathlessness, followed by some pointless coughing and then -if it's a lousy day- by more expectoration

*than I can handle. Pints of old saliva, occasionally mucus, and what the hell do I need heartburn for at this exact moment? It's not as if I've eaten anything: a tube delivers all my nourishment. All of this, and the childish resentment that goes with it, constitutes a weakening. So does the amazing weight loss that the tube seems unable to combat. I have now lost almost a third of my body mass since the cancer was diagnosed: It may not kill me, but the atrophy of the muscle makes it harder to take even the simple exercises without which I'll become more enfeebled still.'*²²

The suffering behind the words is all too obvious. The power of narrative and language creates an affective response in me, the doctor, which is not always felt in the practical necessities that are part of the everyday bustle in a busy emergency department. I doubt that the suffering Hitchens describes would be obvious to me in the patients I see, as I flit from bed to bed, jotting down my own clinical accounts in the patient's electronic medical record.

Pathographies have a way of pulling us up, and reminding us to focus on the things that are really important in healthcare: on the one hand the patient in his or her suffering, on the other truth, honesty and authenticity in our professionalism. ∞

²¹p 87

²²p 70

Surgical Report Cards: a desirable development ?

Report of the Annual Plunkett Lecture for 2016

Dr Justin Oakley of the Centre for Human Bioethics at Monash University gave this year's Annual Plunkett Lecture at St Vincent's Hospital in Sydney. The principal response was given by Dr Anthony Grabs, the Vascular Surgeon and Head of Surgery at St Vincent's. Dr Oakley argued the surgical profession in Australia should adopt the policy of supporting the provision 'report cards' on the practices of individual surgeons.²³ He outlined three reasons for his view that this would be a desirable development in the relationship between the profession and the community.

Better informed patients

First, surgeon report cards enable patients to make better informed decisions about surgery.

More accountable practitioners

Second, report cards help surgeons meet their responsibilities with respect to professional accountability.

Improved safety and quality of care

Third, there is evidence that surgeon report cards improve the safety and quality of patient care overall.²⁴

Each of these arguments was expanded upon the night, by Drs Oakley and Grabs and members of the audience.

In relation to the first, it was noted that it is now over twenty years since Australia's High Court pointed out that, whereas the contemporary standards of the profession do determine what constitutes proper practice with respect to how a procedure is done, those standards do not determine what constitutes proper practice with respect to the giving of information and advice.

The giving of information and advice is an objective matter, independent of whatever the contemporary standards might happen to be. (One only needs to conjure up an imaginary country in which the profession agrees that, for one reason or another, it is unwise to give too much detail to prospective patients themselves and safer to talk only to family, to see this point. Indeed, cultural habits in some parts of the world would tend to support such widespread if not universal reliance on the 'therapeutic privilege'.)

It is pleasing to see that this 'Australian' view is progressively being recognized and adopted around the world.

In addition, we are beginning to see the emergence of a better description of what it is for a potential patient to be properly informed. For years it has been asserted that

²³ Oakley, J. Surgeon Report Cards, Clinical Realities, and the Quality of Patient Care. *Monash Bioethics Review*, 28, 3, 2009, 21.1-21.6

²⁴ Clarke, S and Oakley, J. eds. *Informed Consent and Clinician Accountability: the Ethics of Report*

Cards on Surgeon Performance, Cambridge. Cambridge University Press. 2007

the patient must be 'fully' informed, but that was always an unreasonable ask. Now it is increasingly said that the potential patient must be 'adequately' informed.²⁵ Oakley's point is that to be adequately informed, patients are entitled to know the risks of surgery, and the risks of surgery in a given case depend in part upon which surgeon is performing the operation. Indeed, this kind of information can help the potential patient understand what he or she is consenting to.

The second issue, the responsibilities of surgeons with respect to professional accountability, was not much addressed on the night. But a case can be made out to the effect that, because the community grants to the surgical profession a monopoly on the provision of a certain kind of expert help, the profession has a responsibility to earn the continued faith of the community. Report cards constitute a way the profession, and the individuals who make it up, can demonstrate to the community that surgical care is being provided to the requisite level of competence, that surgeons themselves are worthy of the trust invested in them.

There was much discussion about whether this innovation would improve safety and quality in patient care. Not surprisingly it was debated whether report cards have that effect. Prior to their introduction in Pennsylvania and New York State, it was feared that they would make surgeons more risk-averse, encouraging them to avoid operating on high-risk patients, and that they would lead to the 'outmigration' of patients to locations without report cards. Oakley cited evidence which certainly seemed to show that the existence of individual report cards

²⁵ See, for example, NSW Ministry of Health. *Using Resuscitation Plans in End of Life Decisions*, September 2014

had not led to a decrease in the number of high-risk patients coming for coronary artery surgery, and that a feared outmigration to states without report cards had not taken place. He accepted that one has to be careful about how to understand patterns of mortality after surgery after the introduction of report cards. But he claimed that the feared ill consequences of the introduction of such transparency did not seem to have happened.

As Oakley pointed out, a crucial factor in the success of any surgeon report card scheme is the involvement and support of the surgical profession itself. In particular, he argued, it is important that we do not create incentives for better-informed surgeons to act in more risk-averse ways, and that we therefore foster confidence amongst surgeons in the risk-adjustment procedure used in processing data on raw mortality rates.

For these reasons, it was invigorating to hear the Vascular Surgeon Dr Anthony Grabs debate these issues with Dr Oakley. Their discussion brought both the theoretical and the practical considerations into a fruitful dialogue.²⁶

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A quarterly bulletin of the Plunkett Centre for Ethics

The Plunkett Centre is a centre of Australian Catholic University
and St Vincent's Health Australia, Sydney

www.acu.edu.au/plunkettcentre/

Telephone: +61 2 8382 2869 Fax: +61 2 9361 0975
Email: plunkett@plunkett.acu.edu.au

Subscriptions: \$99 Institutions; \$55 Individuals;
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²⁶ The video of their conversation will soon be uploaded to the web:
http://www.acu.edu.au/about_acu/faculties,_institutes_and_centres/centres/plunkett_centre_for_ethics