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# Bioethics Outlook

## Plunkett Centre for Ethics

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## Demoralization:

**Its influence on the will to live or the wish to hasten death**

**David Kissane**

In this lecture, I want to give you an account of over 25 years scholarship on the clinical predicament that creates the motive of giving up, the wish to hasten death, a state of mind we call demoralization. This research has been about improving palliative care, enhancing quality of life, promoting an adaptive adjustment to dying.

Over 56 years ago when I started training in medicine, the tradition of Catholic healthcare was very strong. Its importance undoubtedly lay in its ethic: a feminine ethic, the ethic of care modelled by the Sisters of Charity, who adopted the role of the Good Samaritan and saw the face of Christ, the face of God in the sick and the suffering. What a wonderful heritage they gave us! And the Charities were like the Mercy Nuns & Little Company of Mary, and other Christian services like Hammond Care and Silverchain – all women at the bedside of the sick.

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### In this issue

**We offer a written version of the Annual Plunkett Lecture, delivered by Professor David Kissane on Wednesday 20<sup>th</sup> November.**

**We also offer a note about the recently-published collection of essays by Dr Norelle Lickiss.**

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Pope Saint John Paul II is another source of context, with his emphasis on the dignity of each person. His early exposure to Nazi culture and crimes was highly influential. His contributions to the Second Vatican Council's documents on religious freedom, and *Gaudium et Spes*, were pertinent, and the 14 encyclicals he wrote across his papacy culminate in his *Gospel of Life* ... the value and inviolability of human life. Alternatively, you could take a secular viewpoint, for example the ACU philosopher, Raimond Gaita (*Of Romulus, My Father* fame) wrote about *Our Common Humanity*. But I choose a Catholic perspective here, the dignity of each person as a fundamental human principle. Against this background, the healthcare I see today is greatly challenged by an economic politic of care. The marketplace makes use of a buyer and seller, with an insurer or health department inserted between the patient and provider. Life expectancy grows, the aged increase greatly and the percentage of GDP spent on health rises inexorably. This challenges the ethic of care, with a principle of futility emerging as society asks what we can afford. A quick word on definitions: *Acceptance of dying* develops in the frail elderly; a normal and helpful pathway. The wish to die using *suicide* is a pathological state of mind about giving up on life.

Now, I had the opportunity to study Philip Nitschke's medical records and those in the Darwin Coroner's office in 1997 and publish case accounts with Nitschke [in the Lancet in 1998](#). These accounts revealed poor medical care (e.g. no radiotherapy for bone secondaries), failure of the safety or gatekeeping roles and the emergence of pointlessness (alongside depression) as a key symptom.

The psychologist Susan Folkman developed the [original Lazarus and Folkman model](#) of coping, wherein emotion-focused or problem-focused coping were the two major categories taught in 101 Psychology Classes in the 1980s. I heard her lecture in 1998, where she described studying the caregivers of men dying from AIDS in San Francisco in the 1990s. She became intrigued by what sustained their resilience in the face of many deaths, and came to appreciate what they gained from caregiving. It was a source of fulfilment, the opposite of demoralization. Susan realised that she had overlooked meaning-based coping in her original thesis; it is a third and vitally important human mode of coping with adversity, by finding meaning. Psychiatry had neglected meaning-based coping, the absence of which causes pointlessness. As with the Lancet publication, "pointlessness" was a prominent symptom calling out to be studied.

Against this background, I want to now introduce the construct of demoralization, for demoralization can be met in a patient, a family member, a clinician, a ward and a health care team or institution. [Demoralization is a mental state of low morale and poor coping](#), characterised by feeling trapped in a predicament or stressful event, where the further development of hopelessness, pointlessness, sense of failure and resultant isolation can lead to suicidal thinking. We did studies showing that it was a more powerful mediator of suicide

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than depression, in fact about three times more powerful, and in 2022, a systematic review confirmed this reality across 18 studies.

In *The Death of Ivan Ilyich*, Tolstoy wrote, “At one moment a gleam of hope, the next a raging sea of despair, and always pain, always misery and pain, over and over again. All this lonely misery was terrible.” Tolstoy described Ilyich as trapped by his progressive illness, struggling and writhing in a “black sack” from which there was no escape, aware that every moment, “he was drawing nearer and nearer to what terrified him.”

Let me help you to see the difference between demoralization and depression. The depressed are sad, downcast. We say their low mood is pervasive across the day. They lose interest and pleasure. In contrast, the demoralized can laugh and smile in the here and now. They lack hope and don't see the point in the future. They could be drug users, refugees, prisoners in jail, adolescents, they cope poorly. One could be a harbinger of the other; so they can be comorbid. Yet also quite distinct.

Such non-caring attitudes to life have had many names through the centuries. [Acedia](#) was an old church term for a slothful laziness. So, demoralization is an old concept that our studies have reactivated. Frankl saw it in concentration camps; Engel described it in the medically ill who gave up on life; it was seen in asylums holding the mentally ill. We created this model for how people became demoralized. Externally, they met a stressful experience, an illness like cancer that was deemed inoperable, a predicament they felt powerless to change, they felt trapped. For some they felt a failure, life started to lose value and purpose. In their internal world, a sense of existential threat could bring on feelings of helplessness, meaninglessness and despair. In some cultures, shame became intense. Normally in such predicaments, we would draw on background hope, religious belief, a generalised sense of meaning about life, and this resilient or religious coping would sustain us. Without it, the pointlessness of life could lead to a desire to die.

Of course, morale exists across a spectrum, a continuum. If you failed an exam as a student, you might drop your confidence. If you became unemployed in your youth, doubt and despondency might develop and lower your self-esteem more. If you were sent to jail, a deeper despair could develop. Clearly, the more severe end of this spectrum of morale is pathological; but losing a sporting event might not be.

Let me ever so briefly touch on the neuroanatomy. The limbic circuits regulate our emotional life. From the frontal cortex, messages pass deeply to the amygdala where sadness or anger are activated via serotonergic and noradrenergic pathways. But the seat of hope is the nucleus accumbens. Our wants, hopes and goals are planned for in the nucleus accumbens as it talks to our frontal lobes, this time making greater use of dopamine circuits. So, there is a physiology behind all of this, neurocircuits guiding what we think and feel. A hope system is very crucial.

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Now let me take a case example of a patient with head and neck cancer. He was ashamed of his disfigurement and became isolated, perceiving his life to become pointless and lack meaning. He could share a joke, laugh, yet apart from his children, he stopped seeing older friends.

So, pointlessness emerged as an important symptom, yet not something I had been taught about in psychiatry. The idea of developing and validating measures to study it empirically arrived. I was also curious about rational suicide, and went on a sabbatical to the Hastings Centre, where Dan Callaghan had written [The Troubled Dream of Life](#).

Rational suicide. Captain Oates was the philosopher's example of an altruistic suicide in Scott's expedition to the south pole. His frostbite turned to gangrene; he was slowing the expedition's return to base. His epitaph spoke of his courage. But was he also demoralized?

So, I published this article in the *Hastings Center Report* in 2004, arguing that an altered *appreciation* of the worth & value of the future may be darkened by a negative worldview when depressed or demoralized. This word "appreciation" is part of Grisso and Appelbaum's structured assessment of decision making in their [MacArthur Competence Assessment Tool](#) for treatment decisions (1998). Having a disordered relationship to the future impacts on decisions made in the present. Restated, if you have decided that your life is pointless & meaningless, can you make a competent decision regarding physician-assisted suicide if demoralized? [I believe not!](#)

There has been only one systematic review of the prevalence of lack of capacity in decision making, with 35 studies in a psychiatric setting and 23 among the medically ill. Among psychiatric cases, 45 per cent lacked capacity, as in depression or psychosis. Among the medically ill, impaired autonomous decision making occurred in 34 per cent, a difference that was not statistically significant. These are vulnerable patients that our law ought to protect. Autonomy was much discussed by Australian legislators, who perceived granting this freedom to be more important than protecting the vulnerable.

Before leaving autonomy, let me pay tribute to Professor George Mendz, who led the publication of [this paper on agency](#). Agency involves the exercise of freedom in self-governance, to achieve competent control and unencumbered intentionality as we initiate actions in our lives. Yet controlling influences are invariably significant in human decisions and can act as a tipping point for any judgement. Making explicit any such ambivalent tensions around a judgement is key to the clinical appraisal. Agency is examined by exploring judgement, insight, and cognition, while excluding altered perceptions and delusions that mar reality. Is the judgement of a person supportive of *autonomy-conferring* self-governance or is the judgement resultant from *autonomy-undermining* governance? Mental states of depression, demoralization, existential distress, psychosis, & the influence of family dysfunction may interfere with agency and impede autonomy. This seems clear.

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Returning then to my empirical work, we validated and published the [Demoralization Scale](#) in 2004, and revised it in 2015 as the [DS-II](#), a psychometrically stronger scale. It has been translated into over 20 languages, used in 100s of studies, and its use continues to grow each year.

You can see here in a community sample, looking at the DS scores in the middle column, that very isolated people have high demoralization mean scores, and very connected people have low levels of demoralization. Similarly, looking at the middle column with mean values for health status, you see that people with excellent health have low demoralization scores, those with poor health have high scores.

Whereas the Demoralization Scale is used in observational and interventional studies to show dimensional change in demoralization levels, we have also validated the [demoralization interview](#) to make a categorical diagnosis of a pathological state. In such an interview, people would reply "yes" or "no" to the presence of 14 symptoms, and if six or more symptoms are present, our studies have shown that the diagnosis of demoralization can be made.

In 2021, a psychiatry registrar, Lucy Gan did [a meta-analysis](#) for me reviewing 52 studies involving nearly 12,000 patients and showed a prevalence of demoralization of between 24 and 35 percent in settings of cancer, medical illness, mental illness, refugees, in other words, many stressful predicaments that would challenge coping. It is quite a common state of mind.

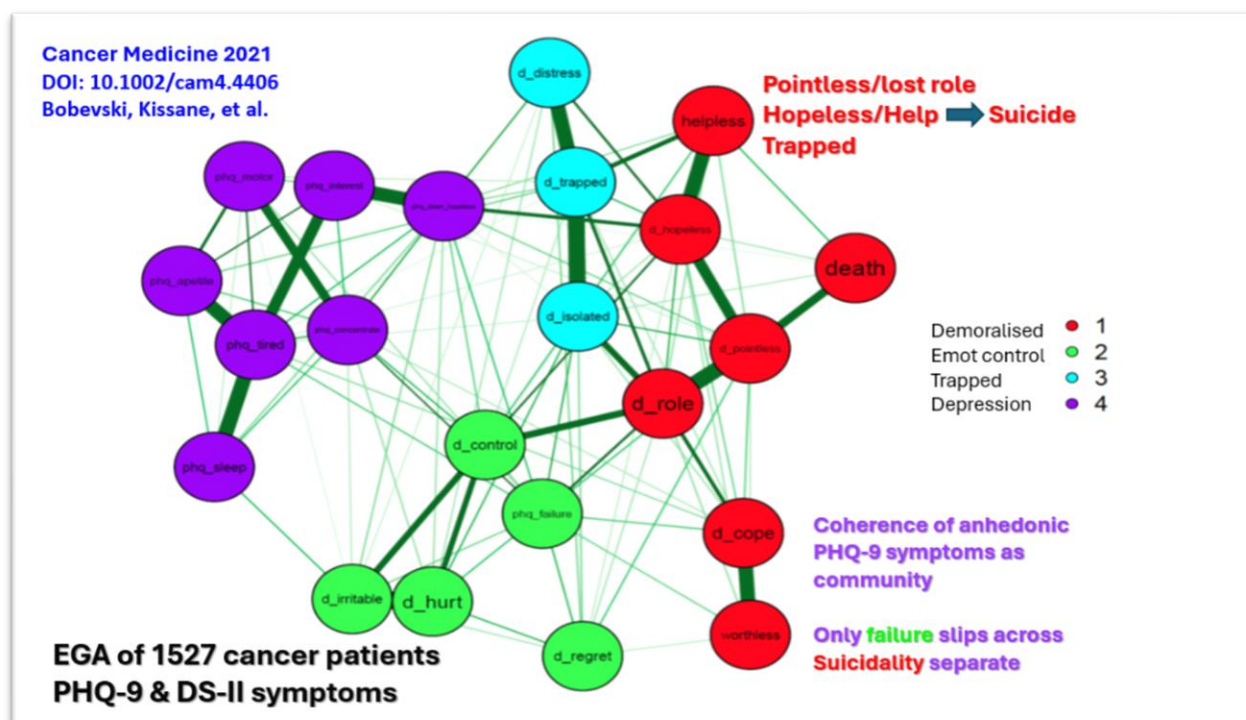
The predictors of demoralization include being single, socially isolated or poorly supported, being female and living with medical or mental illnesses. In contrast, being employed, religious, active and creative such that life is fulfilling nurtures resilience and counters demoralization.

My colleague from Hamburg in Germany, Sigrun Vehling showed very elegantly that when you control for anxiety or depressive disorders, in the right-hand column of this table, demoralization has a threefold risk of suicidal thinking developing, whereas depression misses statistical significance. Suicidal thinking as a consequence of demoralization is therefore a major clinical concern.

If I return to this model of the relationship between distress and the development of a wish to die, the key mediators are loss of meaning or value to life, loss of self-esteem or dignity, loss of hope and shame. Mediators make it happen; moderators are risk or protective factors. So, religion, resilience and support are protective, while poor symptom control (whether frailty, physical or mental symptoms) are risk factors. Depressive symptoms are moderators more so than mediators.

Our recent studies are called psychometric network studies that have looked at the associations between symptoms to better understand how one symptom influences another

within a network. The computer generates a graph where each symptom is placed as a coloured node, the four colours seen [here](#) reflecting the four groupings or clusters that symptoms congregate together.



The red symptoms are “depressive” ones, the pale green “hope and meaning” the purple “entrapment and discouragement”, the blue “coping and non-specific distress”. The green lines between symptoms reflect the strength of association, or what a statistician might call a partialized correlation coefficient that controls for every other association in the network – the thicker and darker the green line, the stronger the association; the paler or weaker the green line, the less significant is the association of one symptom to another. At the bottom in the pale green is death wishes, closely associated with loss of hope, purpose and meaning in life. This network is based on an [Italian cohort of 450 medically ill patients](#).

The next network is derived from [over 1500 German cancer patients](#). Again, four clusters, replicating the prior network. The computer has coloured the “depressive” symptoms purple this time, the “demoralized” symptoms red, “entrapment” blue and “non-specific emotions” have been assigned green. Depression is distinctly different to demoralization. This study confirmed again that pointlessness and hopelessness are most strongly associated with death wishes. Using Bayesian probabilities, we let this network go through 10,000 chance iterations to reach a stable pattern to the network. The empirical evidence here is extremely strong. Pointlessness and hopelessness as symptoms are the closest relatives of developing a wish to die.

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In these studies, we have looked at relationships between 22 symptoms, a sizeable number. But our bedside clinicians look for a simplified model to work with every day. So here, in this slide, we took six demoralization symptoms, and added anxiety, depression, confusion and the wish to die, just 10 symptoms to be monitored. We call it our [Psycho-existential Symptom Assessment Scale](#) (PeSAS) for palliative care. A patient is asked to rate each symptom between 0 and 10 for how distressing they are. And if you follow these symptoms clinically over a couple of weeks, you observe the improvement that can be produced as hopelessness, pointlessness and the wish to die improve with good clinical care.

In this table, I show the prevalences of these symptoms, in the middle column for when they are severe, and in the right-hand column for when they are moderate in intensity. So, if we take hopelessness, you see that 13.1 percent report this to be severe ( $\geq 8/10$ ), while another 22.7 percent report hopelessness as moderate; overall about one third suffer from it in the palliative care setting. Similarly, for pointlessness, 9.5 percent severe, 17.4 percent moderate; overall, over one quarter are suffering in this manner. Finally, look at the wish to die: 7.6 percent severe, 9.4 percent moderate; overall 17 percent becoming suicidal in this way.

Here is a network of these 10 symptoms in an Australian cohort of over 1200 palliative care patients. The wish to die sits on your left, with strong green lines showing how strongly associated hopelessness and pointlessness are to this wish to die. In contrast, depression has a much fainter association. Now demoralization is a contagious state, and in several studies, we see that around 40 percent of family caregivers become demoralized during palliative care. Clinicians can also become demoralized, interfering with the caring role and creating an urge to eliminate human suffering. Nurses in a tea room might comment, for example, on how smelly a bed sore is, how miserable a patient seems, how harsh a medical treatment has become. Burnout is one form of demoralization, which can surely interfere with the concept of physician as healer.

The management of demoralization differs from the treatment of depression which usually needs antidepressants, while demoralization is very treatable with counselling. In New York, [William Breitbart's group](#) adopted the principles of Viktor Frankl's logotherapy to generate meaning and overcome demoralization. The creativity of a person's life, their narrative, the many sources of meaning to bolster up a strong generalised meaning to a person's life, these overcome demoralization.

In Toronto, Gary [Rodin's group](#) combined good physical symptom management with identifying meaning in relationships and life in general. The effect size measured was small for depression, yet moderate for demoralization when death anxiety was high.

In Melbourne, Carrie Lethborg and I used a [6-session MaP therapy](#) – promoting Meaning and Purpose – with goal setting, intentionality and discernment of choices to add meaning to a

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person's life over the last 6 to 12 months that they lived. Biography programs run by palliative care volunteers review the value and beauty of a person's life and can also do much good. Psilocybin-assisted psychotherapies are very trendy and [in this study by Ross and colleagues](#), demoralization was one key measure that improved. In this graph, you see how demoralization reduces under the influence of a psilocybin-assisted psychotherapy.

Demoralization is an example of existential despair, and this table illustrates how we train clinicians in palliative care to counter the vulnerability expressed in many forms on your left, with the resilience that comes with a virtuous life on the right. Promoting hope, courage, meaning and purpose in life is central to human flourishing and fulfilment. This is how we overcome demoralization.

Let me return to euthanasia and physician-assisted suicide. The demoralized will seek this medical aid in dying unless the demoralization is recognised and treated. States across Australia differ in whether people can choose to take the injection or medication by mouth. In Victoria, where injection is restricted to those who can't swallow, only 15 percent receive injections. In Western Australia, 82 percent choose the injection, like Canada (99 percent), and 10 percent of these are being given by nurses. But it is not something that many medical practitioners want involvement with. In Victoria, only 208 practitioners were involved over a four-year period, a tiny fraction of those 30,000 practitioners registered in the State. General practitioners are drawn into involvement.

In Victoria, we did a [study of 141 patients](#) who expressed some interest in VAD. The reasons were:

- Wanting control/autonomy – 68%
- Actual suffering – 57%
- Fear of future suffering – 51%
- Feeling isolated or a burden – 22%

When you examine the suffering, 43 percent lies in the psycho-existential sphere; only 30 percent physical in nature. So if palliative care is to improve its delivery, it needs to build clinical skills to counter psycho-existential distress, and this is demoralization.

Now when you follow these patients who expressed an interest in VAD, over half died naturally, with palliative care assisting them. Just over one third chose VAD. Palliative care is challenged to accompany these patients, supporting and treating them. There are three paths that people follow. First, people committed to VAD all along; only 80 percent of whom access palliative care. Second, people who accept palliative care, whose interest in VAD is fleeting. Once they feel connected to the palliative care service, they stick to it and die naturally.

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The third group is the ambivalent one, where a person may struggle over how they will die. Some want VAD as a back-up plan. The palliative care team needs to walk alongside these patients, being always open to help as best they can.

There are lots of dangers for palliative care in this journey that we call accompaniment. There have been many studies showing that clinicians can miss the diagnosis of depression or demoralization. They fail to adequately treat the psycho-existential distress. Some clinicians won't ask why a person is interested in exploring VAD - they simply refer to the navigator. VAD can distract physicians from quality care, such that the physician gives up because the patient asked for a VAD referral.

We are challenged to sustain the quality of palliative care delivery. It takes a comprehensive multidisciplinary model of care to do a good job. A medical model of care, focused on pharmacology, often does a lesser job. With government funding over the past three years, I ran 72 workshops at 17 palliative care services across each State and Territory to train 650 clinicians to screen for and recognise demoralization. But there is still much work to do.

To conclude, I have given you an overview of 25 years scholarship in studying, better recognising and treating demoralization, this common state of mind that limits our coping. It is a metaphor for the challenge that is presented to palliative medicine today.

While societies choose euthanasia or physician-assisted suicide as their response to the fear of dying so prominent in our communities, I believe this research into demoralization is an example of hope, of quality clinical care, of striving to do better. I think that John Hubert Plunkett would have been on the side of palliative care, and see some triumph in our efforts to affirm the dignity of human life.

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*This is the edited text of the 2024 Plunkett Lecture. The Plunkett Centre for Ethics is located at St Vincent's Hospital, Darlinghurst, and is named after John Hubert Plunkett (1802-1869), the first Catholic Solicitor General and Attorney General of New South Wales.*

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# Taking an attitude to dying

*On the kindness of strangers and other essays:*

*Musings on medicine as a human science*

Norelle Lickiss attended the 24<sup>th</sup> Annual Plunkett Lecture, on line, in 2022. On that occasion, Xavier Symons examined whether hospitality was possible in the 21<sup>st</sup> century hospital and, if so, what shape it might take. Dr Lickiss' reaction was to do her *own* thinking on the subject: thus 'On Hospitality and Medicine: a Note'. That seven page note addressed a variety of themes, the most striking of which is the idea that, by the act of seeking assistance from the doctor, the patient opens the door to the 'holy ground which is within'. That is, the *patient* offers hospitality to the *doctor*.

Norelle Lickiss, now 90, is one of the great Australian medical doctors. She held various positions, in various hospitals, in various part of Australia and overseas before she retired to Tasmania where, with the help of Anita Hansen, she has now published a collection of the talks she has given over last 70 years.

In his foreword, Professor Arthur Conigrave recalls the impression Dr Lickiss made on him when he was a junior medical officer training in Endocrinology.

Norelle Lickiss was then setting up a palliative care service at Royal Prince Alfred Hospital in Sydney. It was mainly for cancer patients. Conigrave was struck by Lickiss' decision (one that seemed to go against medical training) to treat a patient who had advanced cancer and who had developed an associated disorder of calcium metabolism *not* with agents that would correct the abnormal calcium concentration *but* rather with agents that suppressed the distressing physical responses arising from it. It was a decision which 'prioritized the dying patient's lived experience'.

As Dr Conigrave says, the essays in this collection explain the thinking that underpinned Dr Lickiss' decisions. The collection, called *On the Kindness of Strangers: Musing on Medicine as a Human Science*, is intended for reading of a 'dipping in and out' kind. It brings together papers most of which have previously been published previously without, as it happens, 'updating' their turns of phrase.

Dr Lickiss is enormously well read. Her reading of philosophers, anthropologists, sociologists, as well as of medical educators who have gone before her, informs her thinking about how best to care for (and not just to treat) fellow human beings who are dying.

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Her ambivalent relationship with some religious traditions – Judaism fares better than do some other traditions - does not prevent her from recognizing the life of the spirit in those for whom she cares. She has the deepest reverence for the ‘spiritual privacy’ of each patient, a reverence which she thinks is threatened not only by the digital world and by tele-consultation and tele-therapy but also by ‘some fine people confident in their grasp of the true and the good’.

Let me cite just one of Norelle’s claims. In an essay on medical education given to the Australian College of Education in 1973, she says:

*‘It is an axiom that, at the very least, a doctor’s education should fit him to meet the real health needs of the society in which he practices as well as to be a leader within society and a contributor to the total store of human knowledge. Further if medical practice is to play an adequate role in the face of increasing awareness of the social dimensions of health problems, the doctor should be competent not only as a clinician in varying contexts but also as an analyst of social change, as a contribution to the shaping of health-related social policies as an informed social critic.’*

Written over 50 years ago, that claim could well stand as the starting point for an evaluation of today’s medical education programmes.

I am privileged not only to count Norelle Lickiss as a friend but also to have learnt so much from her in my time as Honorary Consultant to the Sydney Institute of Palliative Medicine which she set up at Royal Prince Alfred Hospital.

It gives me pleasure to recommend this collection of her [papers](#) to anyone who wants to think seriously about ‘the last things’.

**Dr Bernadette Tobin**

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