

Taking Others Into Account

Towards a positive vision of solidarity and support for our human condition

"The very existence of an offer of euthanasia will decisively change our ideas about old age, the coming of death, quality of life and what it means to take others into account...If euthanasia becomes an option, there is too great a risk that it will become an expectation aimed at special groups in society." *Danish National Centre for Ethics, 2023¹*

No man is an island,
Entire of itself,
Every man is a piece of the continent,
A part of the main.
If a clod be washed away by the sea,
Europe is the less.
As well as if a promontory were.
As well as if a manor of thy friend's
Or of thine own were:
Any man's death diminishes me,
Because I am involved in mankind *John Donne*

All autonomy is exercised in the embrace of others *Ed Pellegrino*

Care, competence and solidarity

The whole structure and impetus of medicine and healthcare is a recognition of our common shared vulnerabilities, strengths and solidarity in a fabric of mutual support. In general this is supported by an ethos of hope, competence, and supporting our fellow citizens from suffering and despair to the greatest extent possible. This urge has been described by the philosopher Martha Nussbaum in her *Fragility of Goodness* as forcing us to ask whether, almost paradoxically, we might not find in our tragic vulnerability to a world beyond our rational control the true source of human beauty and goodness².

A challenge to this solidarity arises from many sources, from emerging neoliberal discourses which seek to separate and prioritise the individual over the collective good, to prejudices against disability and ageing, to eugenic impulses which resurface periodically even in modern societies, such as involuntary sterilisation in Sweden and Canada up until the late 20th century. A particular focus of prejudice is associated with conditions affecting memory,

¹ Danish National Centre for Ethics. The Ethical Council's Opinion on Euthanasia. Copenhagen, 2023

² Nussbaum MC. The fragility of goodness: Luck and ethics in Greek tragedy and philosophy. Cambridge University Press; 2001

such as dementia, despite increasing knowledge of both quality of life but also of how best to engage and support those affected.

Lurid metaphors

Echoing the phraseology of the differently-abled referring to many of us as the 'presently able-bodied', Susan Sontag wrote that "Illness is the night-side of life, a more onerous citizenship...everyone who is born holds dual citizenship...Impossible to take up residence unprejudiced by the lurid metaphors with which it has been landscaped."³ Our challenge is to ensure that our journey of vulnerability, care and growth will not become painted with such lurid metaphors which would position some forms of living as "lebensunwürdig" or life not worth living, or pathways of nihilism and despair.

We can see just such lurid metaphors in the sentimentalisation of euthanasia prompted by poor care in fêted modern films. For physicians experienced in rehabilitation, for example, the euthanasia of the quadriplegic woman boxer by her coach at the ending of Clint Eastwood's film *Million Dollar Baby* arose at the end of an extraordinary catalogue of missed therapeutic opportunities. Her pressure sores, as well as an infected leg which led to amputation, were indicators of sub-standard care by modern standards, she clearly had a severe untreated depression and unresolved family strife, and no effort was made to provide a more domestic and personalized environment in her "care" facility. A similar scenario of inadequate care, support and interpretation leading to euthanasia was played out in the French film *Amour*, gaining many unthinking critical plaudits.

Undermining professional and societal solidarity

Such accounts also feature in media reports euthanasia/assisted suicide in cases of dementia, which unwittingly contain many of the elements of the malignant social pathology described by the pioneer of dementia care, Tom Kitwood⁴ - Disempowerment, Infantilization, Labelling, Stigmatization, Invalidation, Banishment, Objectification, Disparagement, Treachery – and which fail to recognize growth and support among those living with the condition and their care partners.

The impact on the social support framework was most notable in a recent case where a nursing home doctor in the Netherlands failed to recognize the refusal for euthanasia by a person living with dementia arising from a prior advance directive. We recognize that people change with the course of their illness, and failing to read these signals, the doctor sedated the

³ Sontag S. *Illness as metaphor and AIDS and its metaphors*. London, Macmillan; 2001

⁴ Kitwood TM. *Dementia reconsidered: The person comes first*. London, Open University Press, 1997

patient without her knowledge and consent, and had the family restrain her while she was euthanized. In terms of tolerance for this major breach of trust and solidarity, the profession and courts in the Netherlands sided with the doctor rather than the person who had been killed. It is this erosion of the caring and solidarity contract which is most corrosive in permitting assisted suicide and euthanasia.

Supporting control and agency in the face of illness

An often-heard refrain is that of control in the face of terminal illness, failing to recognise both the advances in recognition of consent for, and refusal of, treatment, advances in support and care, but also the degree to which our sense of control is always mediated by external factors. While autonomy is hugely important, as described by the pioneering ethicist, Ed Pellegrino, it is exercised in the embrace of others, and mediated by other principles such as justice, beneficence and non-maleficence on not only the person but also those around them, and impact on the social contract.

As described in a recent Irish paper on end-of life care⁵ operating solely from a primacy of choice logic negates the interdependencies in care relations and assumes that all patients are independent and autonomous, even at moments of high vulnerability; there is a danger that those in end-of-life care are framed as abstracted rational choosers, ignoring that they are relational, emotional, and embodied human beings. Choice logic may also lead to the prioritization of performance and control over compassion and care⁶, failing in the process to fully acknowledge the reality of bodily decline and the needs of caregivers.

An equal issue is that of dignity: perhaps direction here can be taken from the learnings and opening words of the constitution of the new Federal Republic of Germany: *Die Würde des Menschen ist unantastbar* – the dignity of the person is unassailable. It is aspects of the care and settings which may be undignified, rather than the person, and the the collective impulse of medicine over the millennia has been to work to improve knowledge, skills and attitudes of staff, and develop more appropriate care settings.

The negative impacts of assisted suicide in Canada, Oregon and the Netherlands both in practical terms and in the erosion of a positive supportive approach to care have been eloquently described to the committee by Dr Harvey Chochinov, among others. This raises

⁵ Lolich L, Lynch K. No Choice without Care: Palliative Care as a Relational Matter, the Case of Ireland. *Soundings: An Interdisciplinary Journal*. 2017;100(4):353-74.

⁶ Campling, P. 2015. Reforming the Culture of Healthcare: The Case for Intelligent Kindness. *BJPsych Bulletin* 39, no. 1, 1–5.

very serious concerns as eloquently expressed the Danish National Centre for Ethics. A deeply considered and researched position paper by senior ethicists in a liberal pluralist democracy which should give due pause for thought. This is echoed in the Position Paper of the Royal College of Physicians of Ireland, widely circulated among 14,000 specialists in Ireland and throughout the world through two iterations, raising concerns on impact of assisted suicide and euthanasia on principles and standards of care, suicide prevention, combatting discrimination, and failing to learn from past and present adverse experiences

The response to distress and pain is solidarity, compassion and care

Much of the impetus for seeking euthanasia/assisted suicide relates to a complex web of issues, including existential concerns over the future; fears that one's voice will not be heard; misperceptions of care paradigms; occult (and sometimes overt) prejudice against disability, age and dementia; denial of the resilience of the human spirit in the face of adversity; and a failure to contextualise autonomy as one component of our relational framework of care and support through life. Public and private discussion with regard to euthanasia/assisted suicide should be seen to represent concerns over adequacy of treatment and support as well as existential concerns relating to the future: these need to be proactively addressed.

To ask doctors to run counter to this by killing patients⁷ short-circuits and undermines our impetus to care, comfort and support and damages not only framework of care but also our shared humanity. Current and future patients need to be reassured that the response of the healthcare professions to distress and pain is one of solidarity, compassion and care, addressing the needs at a range of levels - biological, psychological, social and spiritual - while respecting wishes to the greatest extent possible. They should be reassured by not only the evidence that death is widely experienced as occurring with dignity within current paradigms⁸, but also by the existing and ongoing development of care paradigms, training and research to continually enlarge the framework within which the final period of our lives is spent.

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⁷ The Lancet. Preventing healers from becoming killers. Lancet. 2023 Nov 18;402(10415):1805. doi: 10.1016/S0140-6736(23)02501-1. Epub 2023 Nov 8. PMID: 37951224.

⁸ Chochinov HM, Hack T, Hassard T, Kristjanson LJ, McClement S, Harlos M. Dignity in the terminally ill: a cross-sectional, cohort study. Lancet. 2002 Dec 21-28;360(9350):2026-30.