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Healthcare rationing in Australia:

Should the young be favoured over the elderly?

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One of the most memorable lines in rock history is “I hope I die before I get old” from The Who’s 1965 hit *My Generation*. When sneered in Pete Townshend’s distinctively frustrated stutter, these words were symbolic of an attitude that marked many in his generation and from which Western culture is yet to recover.ⁱ But how old is ‘old’? Sandra David, for some years a Sister of Charity, educator and missionary, in whose memory this annual lecture is given, was only 57 when she died. This does not seem old to me, yet Janet Roebuck, in her classic study of the evolution of the idea of old age, puts it around 50.ⁱⁱ Many countries have adopted 65 as the statutory retirement age, a point first chosen by Bismarck for the cynical reason that most working class men were dead by then and so would not draw the pension. Catholic clergy and religious seem to go much longer: you are only old after 75 in the clergy, and nuns and popes can go forever...

We begin with the address given by Bishop Anthony Fisher – the Bishop of Parramatta – as the Sandra David Oration. It is followed by a sketch of the ‘Liverpool Care Pathway’ which has recently been phased out in the United Kingdom.

A more objective definition starts with the natural or 'species-typical' life-span, "the life-span of most of us in the absence of specific mortal diseases and fatal accidents".ⁱⁱⁱ There comes a stage beyond which most people would think they had had *a fair innings* and would not feel cheated were they to die sooner rather than later; nor would others judge their death as premature. (This is not to say that they are *ready* to die or that others will not *grieve* their passing.) Just when that is will be a part-biological, part-environmental, part-cultural matter: *Psalms 90* suggests 'threescore years and ten or four for those who are strong'. The last quarter or so of life up to (and beyond) the typical life-span is 'old age'. Once people have entered that phase of life they may engage in different projects, be honoured as 'elders' or warrant assistance of various sorts (pensions and superannuation, transport concessions, appropriate housing, spiritual care...). Healthcare obviously comes in here, and the specialty of geriatric medicine focuses on this phase of life and its particular challenges.

But should we spend so much on healthcare for the elderly, or would it be better, as some now suggest, to move some or all those resources to younger persons?

Australian Context

First, the context in which this question is asked: in 2011-12 Australia spent \$140.2 billion on healthcare, amounting to 9.5% of GDP, up from 8.4% only a decade before. Recurrent expenditure on health is now around \$6,000 per person, of which governments cover 70%.^{iv} The Australian government will continue to increase its expenditure on healthcare as our population grows and ages and as advances in healthcare technology and expectations also accelerate.^v In 2002 13% of the Australian population were aged over 65; by 2051 this is expected to

have more than doubled to 27%. The proportion aged 85 and over will have jumped from 1.4% to 9% over the same period.^{vi} Older people utilise healthcare resources to a much greater extent than younger people; though they account for about a sixth of the general population they utilize more than a third of hospital admissions and around half the hospital bed days.^{vii}

Calling it 'the intergenerational fairness agenda', some commentators now openly ask whether younger people should be expected to fund this.^{viii} In *The Pinch: How the Baby Boomers Took Their Children's Future - and Why They Should Give It Back* David Willetts argues that the over-65s are a burden on the young and that their expectations of endless pensions, health and aged care must be curtailed.^{ix} Daniel Knowles declared in the *Spectator* that "the baby-boomer generation is the most cosseted, untouchable, powerful generation in our history", that they "are living far longer than was envisaged" and costing too much, and that younger people cannot be expected to keep them in the style to which they are accustomed. The elderly should pay their 'fair share' themselves and draw less upon the public purse.^x

Allocating healthcare on the basis of age – what I call hereafter *age rationing* – is the policy of excluding persons over a certain age from certain treatments, scaling back care as they get older or preferring the young when there is competition for some intervention. In many countries older people already have less medical contact than their condition warrants and 'ageism' in healthcare has been well documented.^{xi} South Australian researchers, Julie Luker and Karen Sommers, found that though functional recovery after treatment is similar for older and younger stroke patients, older ones were much less likely to receive

appropriate provision in the Australian hospital studied. The authors concluded that age is probably a barrier to receiving optimal care after stroke in Australia.^{xii}

The Australian General Practice Network says there is “substantial anecdotal evidence” that many patients in aged care facilities do not receive timely and appropriate GP and PHC services, and that this suboptimal care leads to avoidable hospitalisations. They cite Catholic Health Australia research that found most aged care providers faced an “ongoing struggle” to secure GP services, with many resorting to inappropriate transfers to emergency departments and patient care being compromised at times.^{xiii} The Australian and New Zealand Society for Geriatric Medicine has made similar findings and noted that where GPs services *are* available to those in residential care it is often only from older gentlemen practitioners.^{xiv} Other studies have at least tentatively suggested that there is systemic or occasional, direct or indirect, conscious or unconscious, age rationing in various areas of healthcare in Australia, as overseas.^{xv}

The clinical case for and against age rationing

The clinical rationale for age rationing is that older people receive little or no benefit or are less likely than younger people to benefit from particular treatments; age is thought to be a useful rule of thumb both for appropriateness of an intervention (even were resources unlimited) and for sorting according to capacity to benefit (where resources are finite).

The problem with this is that age is at best a very rough guide to prognosis: it is the multiple diseases and physiological impairments that commonly accompany old age which affect average outcomes from

some medical interventions, not age itself. Because individuals vary enormously in their rate of biological ageing it would therefore seem more logical to use the relevant physiological impairments as the clinical basis for rationing rather than the surrogate of age.

Though counterintuitive, the elderly often respond better than the young to certain treatments and a medical ‘stitch in time’ for the elderly can save ‘nine’ down the track, thereby saving resources overall. Dialysis patients over 65 have a better survival rate than those between 55 and 64; renal transplants are as successful in the elderly as in younger people. There is likewise little difference between younger and older recipients of many cardiac interventions. Geriatrician John Grimley-Evans says denying the elderly treatments on the grounds of supposedly ‘poor prognosis’ is often a case of ‘aggravated ageing’.^{xvi} Surveying the evidence John Young concludes that age rationing is “unsustainable” on clinical grounds.^{xvii}

The fair innings case for age rationing

Nonetheless, many people think that *ceteris paribus* the younger person should get the ICU bed or heart-for-transplant, for ethical rather than clinical reasons.^{xviii} Australian philosopher Peter Singer argues that since healthcare rationing is inevitable we should use a rational basis for doing it: “life-years saved” would be one such rational basis; even better would be quality of life years saved; either way, putting scarce healthcare resources into the young will yield longer and greater benefits.^{xix} Yet the Australian population is wary of such utilitarian reasoning. Nord et al suggest “that QALY

maximization receives very limited support when the consequence of the maximizing strategy is a perceived loss of equity^{.xx} In other places I and others have argued that QALYs do not withstand clinical and philosophical scrutiny as a basis of healthcare allocation.^{xxi}

The classic ethical cases for age rationing were elaborated by Daniel Callahan and Norman Daniels.^{xxii} Both began with the notion of the fair innings or “a life long enough to experience those opportunities that life typically affords people^{”.}^{xxiii} For individuals to seek more than a natural life-span, especially at the expense of other important goods, might represent a lack of *prudence* or *fortitude* with respect to sickness and death, and a kind of *intemperance* with respect to healthcare. St Basil the Great counselled Christians to avoid treatment that “requires such undue thought or effort or expenditure as to make our whole life revolve around solicitude for the flesh.”^{xxiv} Different temperaments, commitments and life-plans mean people prioritise life and health differently, but there comes a point where seeking more may be both vain and in vain.

What’s more, expecting others to foot the bill for one’s aspiration to endless earthly life and health might represent an unreasonable preference for self and disregard for others and the common good.^{xxv} Healthcare systems may aspire to give everyone a good chance of a reasonable length of life in reasonable health. But faced with competing demands they must taper off provision to those who’ve already had this in favour of those who have not. Last year Callahan claimed the voracious appetite of the elderly for healthcare was making them a *hazard* to the young.^{xxvi} “A good society ought to help young people

become old people, but is under no obligation to help the old become indefinitely older.”^{xxvii}

There are, however, a number of problems with the fair innings rationale for age rationing. What length of life might one *reasonably* expect and what health opportunities up till then?^{xxviii} Is it unreasonable for someone in Swaziland to aspire to more than the 31.9 years ‘typically afforded’ in that region? As technology and economy improve so does life expectancy, and we rightly rejoice that more people enjoy a longer period of old age, in better average health, than was common in the past.

Nor is it clear that prudence would counsel skewing healthcare entitlements towards one’s early years, as the fair innings theorists assert. Many older people do in fact want healthcare such as resuscitation despite their children and health professionals thinking otherwise; what older people judge as adequate ‘quality of life’ is also different.^{xxix} A 2007 study in *Nursing Ethics* found people over 60 feared younger people categorizing them as ‘old’ because this means ‘low priority’ for healthcare.^{xxx} Even if people behind a ‘veil of ignorance’ would prefer age rationing, those who actually suffer the burden of such a policy are better placed to assess its reasonableness.^{xxxi}

A fairness case *against* age rationing

What justice requires

Fair innings accounts commonly assume that justice requires that people get the same amount of resources such as healthcare.^{xxxii} But every parent understands that larger and

older children need more food; every doctor understands that sicker people need more healthcare. If healthcare is intended for the sick as such, then *prima facie* the just way to allocate it will be *to the sick*, and first *to the sickest*; no wonder that the elderly receive much of this attention. No-one complains that children chew up a 'disproportionate' share of education resources: that is precisely whom they are for!

Healthcare has traditionally expressed and been governed by Hippocratic and Judeo-Christian ideals of valuing people equally; it has therefore been allocated on the basis of need – as far as possible, addressing equal needs equally and different needs differently.^{xxxiii} To adopt different principles that deprive the elderly of healthcare could reflect and would generate further bias against an already vulnerable group.^{xxxiv} Those who live 'too long' would be seen and treated as burdens; sensitivity to their needs would be dulled.^{xxxv} Justice demands better.

What medicine requires

Furthermore, healthcare is not just a 'resource' like a mineral to be distributed by the free market or government. The doctor-patient relationship concerns a profound human service not well captured by consumer language or resource allocation concepts. Age rationing tends to homogenize 'the elderly' in the eyes of carers as a demographic rather than several individuals, indeed as a swarm of voracious but unworthy consumers of a resource which must be guarded from them.^{xxxvi} Healthcare would be radically affected were professionals expected to assess who has had their 'fair share' of life-

span or opportunities before 'wasting' any more attention on them.^{xxxvii}

It should also be recognized that the rescue imperative of traditional medicine – which can be criticized for encouraging healthcare profligacy – has also been very fruitful both in assisting particular patients and in advancing medicine itself. Geriatric medicine and healthcare more generally would not advance were the elderly or very sick abandoned.^{xxxviii}

What the elderly deserve

Furthermore, the elderly are the ones who, on average, have made the greatest contribution to the health system as taxpayers, as well many other areas of society, in the reasonable expectation that their needs would be accommodated in due course. To deny them healthcare could amount to unjust enrichment, even theft, by the young.

One way societies that treat the elderly less well than they might in other spheres still demonstrate that they value older people is by providing dignified health and aged care. Such care expresses fundamental values such as equal respect for persons, the sanctity of life and the rescue imperative, concern for the weak and suffering, and reverence for elders. As the costs of health and other care of the elderly continue to rise, there will be a pressure to scapegoat, abandon, even kill, the elderly as a cost-cutting measure.^{xxxix} There are good reasons to resist that pressure now by a strong insistence that age not be a criterion of healthcare distribution.^{xl}

What healthcare need implies

A satisfactory resolution of healthcare allocation dilemmas begins by offering some

account of the place of life and health in a human story and what is needed to promote those goods; of personal responsibility for health and healthcare; of the traditions, norms and virtues of healthcare practice; of the responsibilities of all societies to provide for the needs of their members in healthcare; of the capacities and proper goals of our particular society; and of the scope and limits of the right to healthcare.^{xli} This will suggest that patients, health professionals and health services should give priority to people's most important needs over less important ones, and to those with more important needs over those with less important ones.

On this needs-based account of healthcare allocation, priority should be given *ceteris paribus* to the patient:

- whose need is more urgent
- who is more likely to benefit from the treatment or likely to gain the greater or longer benefit from it
- who is likely to gain the same benefit from less of the treatment or need the treatment for a shorter time or less frequently
- who is likely to suffer the lesser burden from the treatment or likely to suffer the greater harm without it or has fewer or no real alternatives to the treatment.

What Christian faith inspires

Justice, on this account, supports healthcare allocation according to need but not age.^{xlii} But the distribution of healthcare is not only about justice, narrowly construed. Healthcare systems also tell a story of the kind of people we are and wish to be. Care for the elderly reveals the quality of intergenerational relationships, attitudes to ageing and the elderly themselves, filial affection, gratitude

and duty. Their inclusion suggests we value life and health, above all persons, even if they are frail, vulnerable, sick or suffering.^{xliii} Age rationing suggests a very different narrative.

Christians tell the story of the Good Samaritan by themselves engaging in healing with neighbourly compassion and generosity. We cannot imagine the Good Samaritan assessing whether the man beaten and left for dead had already had a typical life-span or sufficient life opportunities, or doing a QALY and cost-benefit analysis before deciding whether he was worth investing care in. That we don't know whether the victim in the original story was young or old highlights that age is irrelevant to such a corporal work of mercy.^{xliiv}

In *Evangelium Vitæ* Bld John Paul II wrote of the 'intolerable' neglect that some of the elderly, handicapped and dying experience. He exhorted us "to preserve, or to re-establish where it has been lost, a sort of covenant between generations", a relationship of acceptance, solidarity, closeness and service.^{xlv} This would suggest a preferential option *for the elderly* in healthcare rather than rationing against them.

Conclusion

The elderly are not a problem, market or budget: they are real individuals, our own people, ancestors, eventually our selves. Healthcare is largely *for them*, not something we have to keep *from them*. Of course we need principles of fairness here and virtues like medical temperance. But to wish we were dead before we are old, or that the old were dead before they burden us, is no anthem for a good society.

References

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Care of the dying patient: lessons from an English approach

Bernadette Tobin

In July this year, the UK government announced that it would phase out an approach to the care of the dying – called the ‘Liverpool Care Pathway for the Dying Patient’ - after an independent review found that the Pathway had been wrongly interpreted by some doctors and nurses and that, as a result, some patients had been badly cared for in the last days of their lives.¹ Since this approach to care of the dying in hospitals has been widely recommended and adopted in Australia, its phasing out in England is of significance for Australian doctors and nurses caring for dying people and their families.

The Liverpool Care Pathway for the Dying Patient (LCP) was a model of care that was intended for use by doctors and nurses working in hospitals - to help them to provide the best care for the dying patient.² It arose out of the recognition that few people die in hospices or even at home, that very many die in hospitals whose main aim is to get people better, to cure them of illness or at least to improve their state of health. In that hospital context, it is very difficult both for doctors and for relatives to admit that a patient is dying and might need care appropriate to dying.

Developed by the specialist palliative care team at Royal Liverpool and Boardgreen University Hospital and the Marie Curie Palliative Care Institute at the University of Liverpool in England, the Liverpool Care

Pathway was intended as a ‘framework’ to support good care in the last days and hours of a person’s life, a framework to guide treatment and care so as to ensure that all the individual person’s needs - physical, social, spiritual and psychological - would be met as he or she died.

Key elements of end-of-life care

In developing this ‘pathway’, the team of palliative care and hospice specialists had identified ten elements of care they regarded as necessary for achieving good care for the dying patient: (1) *Recognition that the patient is dying*; (2) *Communication with the patient (where possible) and always with families and loved ones*; (3) *Spiritual care*; (4) *Anticipatory prescribing for symptoms of pain, respiratory tract secretions, agitation, nausea and vomiting, dyspnoea*; (5) *Review of clinical interventions that is oriented to the patient’s best interests*; (6) *Hydration review, including the need for commencement or cessation*; (7) *Nutritional review, including commencement or cessation*; (8) *Full discussion of the care plan with the patient and relative or carer*; (9) *Regular reassessment of the patient*; and (10) *Dignified and respectful care after death*.

Main features of the LCP

The Liverpool Care Pathway was recommended for consideration by clinicians when a patient had no reversible condition and the treating team considered that he or she was in the last days or hours of life. What it advised was, in summary, as follows.

¹ ‘More care, less pathway’: A Review of the Liverpool Care Pathway. <https://www.gov.uk/.../review-of-liverpool-care-pathway-for-dying-patient>, 15 July 2013. Accessed 15th September 2013.

² The Liverpool Care Pathway for the Dying. <http://www.sii-mcpil.org.uk/lcp.aspx>. Accessed 15th September 2013

When it is determined that the patient is dying, all treatment is to be reviewed, some interventions are to be continued, some discontinued, others initiated. A referral to a specialist palliative care service, or the seeking of a second opinion, is to be considered. At all time, good, clear, comprehensive communication is essential and all decisions leading to a change in treatment are to be communicated to the patient (where possible and appropriate) and always to the relatives and carers. Acknowledging that the patient is dying and making the decision to use the LCP to support care in the last hours or days of life are similarly to be discussed by the clinical team, with the patient where possible and appropriate, and (again) always with the relatives and carers. Consensus is to be aimed at, and reached, between the care team and those close to the patient. If disagreement does arise, then the clinical team is to involve an independent person, to seek advice from another senior professional, and if necessary to use a local mediation service. And the LCP is not to replace decision-making at the end of life but to support decision-making so that it is focussed on improving the way the person died. Decisions made with this goal in mind are to be regularly reviewed (at least every four hours) and in accordance with any change in the patient's condition – for instance, in circumstances in which the patient appeared to have an improved level of consciousness, functional ability, oral intake, mobility, or ability to perform self-care – and if any concerns were expressed regarding the treatment plan by the patient, the relative, the carer or a healthcare worker. At all times, the results of assessments are to be communicated to the patient where possible and appropriate and always to the relative and carer.

These procedural features of the LCP are recognizable as good principles of palliative care, in accordance with those found in the Catholic tradition.

Even good protocols can be misused

Concerns about the LCP had been expressed over some years. Opinion within the English Catholic community had been divided. Some Catholic doctors urged the healthcare authorities to withdraw it. Indeed, this time last year the Catholic Archbishop of Southwark, Peter Smith, called for an inquiry into the LCP. Other Catholics defended its merits *where it was used properly*. Ultimately, the Government set up an independent review, chaired by Baroness Julia Newberger, charged with the task of examining the experience of patients and families in the use of the LCP and making recommendations about what should be done to restore community confidence in end-of-life care in England, particularly in hospitals.

Of course, the treatment and care which patients receive in hospital is only partly determined by the *contents* of the protocols which guide doctors and nurses. (It is mostly determined by the knowledge, experience, dedication to the well-being of the patient which characterize the good doctor!) There is always scope for the contents of 'pathways' and guidelines to be misunderstood and used inappropriately.

Sometimes the guidance itself can be improved in order to reduce scope for misunderstanding. Sometimes, however, the guidance is so misunderstood it is judged necessary to withdraw it: this was the view reached by the Review Panel. In this regard, and as David Albert Jones, the Director of the Anscombe Bioethics Centre, Research Fellow at Blackfriars Hall, Oxford, Visiting Professor at St Mary's University College, Twickenham, and a member of the National Reference Group of the Liverpool Care Pathway pointed out, a number of pressures could always have subverted the proper implementation of the LCP.³ In his view, these included:

3

<http://www.bioethics.org.uk/images/user/CommentonLCPbyDirectorofABC.pdf>, accessed 14th September 2013

- *the subjective character of judgments about how soon someone is going to die, and the lack of explicit evidence-based criteria for this judgment in the case of the imminently dying;*
- *the fact that the LCP may be initiated by people who are not senior clinicians, or are not familiar with the individual patient's case, or who have not consulted with palliative care physicians;*
- *the influence of managerial pressures to reduce bed occupancy or meet targets of one kind or another;*
- *reluctance to face the problems of continuing care of certain difficult patients;*
- *the 'euthanasiast' outlook of some clinicians;*
- *the possibility of doctors or nurses regarding the LCP as a set of "tick boxes" (which is part of a larger cultural problem in the health service);*
- *that rather than assessing, and regularly re-assessing, the needs of the patient, fluids might be withdrawn automatically where they could have been useful in (for example) alleviating thirst: in some cases patients have been deprived even of sips of water or of the moistening of their dry mouth;*
- *other organizational and staffing procedures or constraints that may prevent an essential step or dimension of the LCP from being properly applied; and*
- *lack of discussion with patients (if they are competent) and relatives or carers.*

'More care, less pathway'

Amongst the findings (and recommendations) of Baroness Neuberger's Review, the following stood out:

- The term 'pathway' was clearly misunderstood: chosen to describe a very broad range of initiatives to provide care in the dying phase, it emerged that some doctors and nurses were treating the LCP as a set of instructions and prescriptions, that some relatives and carers thought it represented a decision on the part of clinicians, in effect, to kill the dying patient. So the Review recommended that the term 'pathway' should be abandoned and replaced with 'plan'.

- Given that there is no precise way of telling accurately when a patient is in the last days of life, placing patients on the LCP can lead to considerable distress in relatives and carers when the patient does not die within hours, or recovers. So the Review recommended that doctors and nurses communicate more honestly about these clinical uncertainties.

- Relatives and carers sometimes visited a patient only to discover that without any forewarning there had been a dramatic change in treatment. Sometimes the patient was excessively or unnecessarily sedated. So the Review recommended that every patient determined to be dying should have a clearly identified senior responsible clinician accountable for his or her care in 'out of hours' periods, and that unless it is urgent and clearly in the patient's best interests a decision to withdraw or not to start a life-prolonging treatment should be taken in the cool light of day by the senior responsible doctor in consultation with the healthcare team.

- There is misunderstanding and uncertainty over whether deciding to implement the LCP is a treatment decision requiring consent (or requiring a decision to be taken in the patient's best interests if he or she lacks capacity). The review recommended that documentation should make clear when there is a need for consent and when there is a need for explanation.

- Contrary to requirements stated in the LCP, some relatives and carers did not feel

that they were involved in discussions about the care plan or even offered a chance to be involved.

- Most of the submissions that were critical of the LCP made reference to hydration and nutrition. Judging from those submissions, the advice found in the LCP was often not being followed, and the Review recommended that the LCP's advice that patients should be supported with hydration and nutrition should be made clearer.

- The Review heard that, if a patient became more agitated or in greater pain as he or she died, he or she often became peaceful because the right drugs were given at the right time and in the right dose. But there were complaints that opiate pain killers and tranquillisers were being used inappropriately as soon as the LCP was initiated.

- Some people thought that implementing the LCP was a way of deliberately hastening a person's death, and the Review found that view understandable given what they heard about poor communication between clinicians, patients, relatives and carers about what was happening during the dying process.

Recommendation of the Review

The Review's main recommendation was: *'Use of the Liverpool Care Pathway should be replaced within the next six to twelve months by an end-of-life care plan for each patient, backed by condition-specific good practice guidance.'*

That recommendation embodies an ambitious goal. Indeed, if the problems identified by the Review Panel were not problems with the Liverpool Care Pathway *itself* but problems associated with its *implementation*, the question is raised whether, as some have suggested, doing away with the LCP was a matter of 'throwing the baby out with the bathwater'.

Conclusion

There are lessons to be learned for the care of the dying in Australian hospitals from the development of the Liverpool Care Pathway, its (often poor) implementation in hospitals in England, the controversy which subsequently arose about it, the Review and its recommendation that it be phased out and replaced with something different. An obvious lesson is that no protocol or guide or pathway dictates its own implementation, and that even the best protocol will be ineffectual in ensuring good care if it is not implemented by professionals who are well trained, well-resourced and dedicated to improving the way people die in hospitals. In this regard, Australian Catholic hospitals, public and private, ought to aim at being both 'thought' leaders and practice leaders. Thought leaders about when it is appropriate to discontinue medical procedures⁴; about the use of clinically-assisted nutrition and hydration in the imminently dying person⁵; about the use of pain relief and sedatives in circumstances in which their use may reduce lucidity and even shorten life⁶; and in general about avoiding both over-treatment and under-treatment of the person who is approaching the end of life. In addition, Catholic health care services should surely be distinguished in their care of people with special needs: the Review of the Liverpool Care Pathway found unmistakable evidence of unjust discrimination against one such group: old people!

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⁴ *Code of Ethical Standards for Catholic Health and Aged Care Services in Australia*, 5.9

⁵ *Code, op cit.* 5.12

⁶ *Code, op cit.* 5.20