

The Politics of Dying: Does the End of Life have to be Hell?

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Average lifespan almost doubled during the last century, while the rate at which we age remained the same, resulting in dramatic changes in the nature of old age and death. The last few years of life before death are increasingly consumed by chronic disease, disability, dementia and extreme aging. We argue that this bleak fate is not inevitable, but rather the consequence of our past social and medical culture, and therefore can and should be changed.

Is it inevitable that dying and the last few years of life are horrors? Does it have to be this way? It is tempting to think that aging and chronic death from old age are 'natural', while acute death of the young is somehow unnatural. However, the exact opposite is the case. Significant aging and degenerative disease are rare in wild animals, and were uncommon in humans up until two hundred years ago. Why? Because they died comparatively young, before they had time to age significantly. The average human lifespan was about 30 years before 1800, but since then has been increasing at about 2 years per decade in the UK. So that current life expectancy is about 80 in the UK, and should reach 100 years by the end of the century. Only in the unnatural conditions of modern society and medicine can the exotic diseases and deaths of old age flourish.

Death is certainly not what it was. Life in the past was once described as "nasty, brutish and short", but this would be a better description of Death throughout most of history. The very shortness of life tended to mean that death too was short. People died either as children or in their prime, so aging and the aged were rare. The most common causes of death were infections, violence or starvation. On the whole, death was rapid: people were fully alive one day, and fully dead the next (or at least the next month). There was relatively little grey area between life and death.

During the 20th century the average lifespan in the world almost doubled, and people in developed countries now tend to die old and slowly from degenerative diseases brought on by aging. Until recently it was thought that humans had a maximum lifespan that we would hit at some point as death from disease was eliminated. Many limits have been suggested, but each has been exceeded in practice. Average lifespan has been increasing at the staggering rate of about 2 years per decade (or 5 hours per day) for the last 100 years. And there is no sign of this slowing down, even in the countries of highest life expectancy (*Science* vol 296, p 1029). This suggests that there is no maximum human life span, or at least not one we are likely to hit soon.

That is the good news.

Unfortunately this dramatic increase in *longevity* has been accompanied by no discernable change in the rate of *aging*. People appear to age now at the same rate as they did two hundred years ago. But they live longer, and so they age longer and to a greater extent before they die. Consequently the increase in lifespan has not been matched by an equivalent extension of healthy life: increasingly, the additional years of life we gain are associated with bodily degeneration which translates into years spent with disability, disease and dementia. Between 1981 and 2001, life expectancy in the UK increased by 4 years, but healthy life increased by only 2 years, with the other 2 years being spent in ill-health [Office of National Statistics]. One cause of this is that the linear increase in lifespan is colliding with a roughly exponential increase in degenerative disease with age. For example, your chances of having Alzheimer's disease doubles every five years that you live beyond 65 years. One alarming result is that about 25% of people in the UK currently get dementia before they die. And if current trends persist this figure is likely to rise to 50% by 2050, simply because we are living longer [Dementia UK report]. Thus one half of the UK population currently under the age of 40 years may get dementia before they die, unless we take dramatic action now.

Are we taking action to deal with these trends? No – just the opposite: we are creating the conditions for such a social disaster.

The vast majority of people in the developed world (and increasingly in the developing world) die from degenerative diseases, such as cancer and heart disease. These diseases are caused by age, and dying from them is slow and is becoming slower, so that the processes of death and aging are merging into one. Death is currently preceded by up to 10 years of chronic ill health in the UK, and this figure is rising. Few people survive until death without significant physical and/or mental disabilities, extending over years. Death is no longer an event, it has become a long, drawn-out process. The fact that death is slower entails great challenges for ourselves, our societies and our health and care services.

Even in the absence of disease, old people progressively accumulate disabilities, including loss of sight, loss of hearing, and loss of mobility due to osteoporosis, arthritis, fractures, and declining muscle strength. And even in the absence of disability, aging brings decline in physical and mental capacities. Sight, hearing, taste and smell are dulled in everyone, and reaction times slow. Memory, IQ and linguistic ability decline; creative thinking falls off; mental productivity wanes; motivation and initiative fade away. While depression, anxiety and social isolation all increase with age.

None of this is good news, and there is no point pretending otherwise: it is one of the worst horrors of the human condition.

How did we get into this mess?

Our fear of death led us to prioritise *quantity* of life over the *quality* of life. Medicine has been oriented towards the postponement of death, no matter what the quality of life that remains. 'Life at any cost' has been the war cry as society attacked mortality and the acute causes of death without a parallel attack on morbidity. Huge resources are devoted to preventing infectious diseases, stroke and heart attacks in the elderly, which are arguably the least worst ways to die. Yet the consequence of these resource decisions are that people die by more protracted means, suffering years of dependency, isolation and poor quality of life. We now have the means to extend life beyond what is sensible - finding ourselves without the social, medical and political means to cope with and prevent degenerative ageing and the myriad chronic maladies associated with it. By attacking death at the end of life, we have allowed death-within-life to grow, so that the end of life is no longer worth living.

The suppressed dread of death has allowed our society to sleepwalk into a situation where people face real horrors at the end of life, simply because we cannot face dealing with the issue of how people should exit life. The ways in which we deal with degenerative ageing and those affected by extended years of illness add to the invisibility and lack of understanding of these issues. Extended, degenerative dying has generally been banished to hospitals, care homes and hospices. In hospital, doctors are bound to keep people alive at any costs, and the issue of how to care best for those with Alzheimer's, dementia and declining quality of life is inappropriately kept in a medical context, rather than being the subject of an extended social-political debate.

Medicine and medical research has had an unbalanced focus on mortality (i.e. death rates) rather than morbidity (i.e. years spent in illness). According to the 2003 World Health Report Global Burden of Disease, the relative contributions of different diseases to years lived with disability in the aged were: dementia (11%), stroke (9%), cardiovascular disease (5%) and all forms of cancer (2%). The proportion of research papers (since 2002) devoted to these chronic diseases reveals a starkly different ordering of priorities: cancer 23%, cardiovascular disease 18%, stroke 3% and dementia 1%. Thirty times as much money is spent on cancer research in the UK as on dementia research, yet dementia contributes 5 times more years lived with disease than cancer. Given these relative resource priorities, it is no surprise that

cancer deaths are declining while the prevalence of dementia is climbing rapidly. It is no longer sensible to leave these resource decisions to charities and medical research boards. Society as a whole needs to have an informed debate about difficult questions, such as: should we be reducing heart disease and cancer death rates, so that average lifespan increases towards 100 years, if that results in 80% of us being cognitively impaired.

We as a global society have been remarkably successful at taming acute forms of death. Yet many acute forms of death have been converted to chronic disease or disability. Heart attacks have become heart failure; stroke has become vascular dementia; diabetes, AIDS, even some cancers have been converted from acute causes of death to chronic disabilities. All of these are great medical advances, but they have a downside: the conversion of acute (rapid) to chronic (drawn-out) death. There is a crucial economic aspect to this, as the creation of longer-living but sick patients have an up-side for the pharmaceutical companies. Drug companies obviously do not set out to promote chronic disease – rather it is the modern economics of drug development that by a market-led process favours drugs that prolong disease over drugs that cure disease. Curing diseases does not pay - because you lose your patient, whereas converting an acute disease into a chronic disease pays very handsomely indeed – because you convert a short-term patient into and long-term consumer of your drugs. Development of a successful drug is thought to cost about \$500 million. So the business plan for a miracle drug is unlikely to leave the drawing board if the patient only needs to take one pill to be cured. All the main blockbuster (i.e. economically successful) drugs, such Zantac, Viagra, and anti-retroviral drugs for AIDS, are blockbusters partly because the patient is not cured.

Patients, medics and funding agencies have, understandably, been more concerned to prevent early death than to prevent degenerative disease. Yet the long drawn-out death of ill and often demented people is much, much harder and more costly for the individual concerned, their family, and society. So another strand of the over-due public debate about degenerative ageing has to be about care and its consequences for individuals, families and societies. Depression, anxiety and social isolation all increase with age, which place increasing burdens on carers and relatives. Frail elderly people often want to continue to live at home in the communities where they have a social life and networks. Yet there is relatively little effective care in the community for those with degenerative aging. And finding a care home is often difficult, hampered by the lack of places, information, and support for relatives and friends acting on behalf of the elderly person. Public discussion about the type, location and provision for this type of infrastructure is urgently required. Caring for the elderly ill has too often been an individual problem, dealt with on a case-by-case basis between family and the medical service; it needs to become a publicly acknowledged and more socialised process. Hospices provide an excellent model for palliative care of the old and dying, but because of economic constraints their services are currently restricted to those with incurable cancer who are acutely dying (i.e. the last week or two of life). Hospice services need to be more widely available in the community (i.e. for those at home with a range of diseases).

What are the consequences for society of these social attitudes to death, and the existing medico-pharmaceutical system? These consequences are far-reaching, impacting on the ways that people must plan for their old age, how societies deal with care for the modern elderly, and for the ways in which the new old are to be taken seriously by politicians and government policy. This brings us to the third consequence of degenerative ageing, namely the political dimensions. How is it that the plight of the very old has been ignored for so long? In part this has to be because they are more or less invisible as voters, as a pressure group, and as a political constituency. The very old suffer from a triple burden of invisibility - the general invisibility of the old, the invisibility of the ill, and the invisibility of the non-working. In a society obsessed with the young, with the fit, and with work and play, the very old are simply invisible to public opinion, the media and political debate. The few valiant advocates for the very old who are actively involved in taking these issues to the public face an uphill struggle to make themselves heard. Given that one quarter of the UK population currently get dementia before they die, with this figure forecast to rise to 50%, the issue is not a 'minority'

one – it will affect every one of us directly and indirectly. It is as significant an issue as personal pensions, and hence should engage the political will of governments, employers and ordinary individuals.

The new old

Our concept of old age is also increasingly outdated. A century ago the average lifespan in the UK was 50 years, and anyone reaching 60 years, and thus becoming 'old', had relatively few years to live. Now the average lifespan is about 80 years, so people are old for longer, old age is more heterogeneous, and the average old person is more aged. In many ways, the average person between 60-80 years old is much better off now than previously, because of economics, medicine and technology. But for a variety of reasons the 'new old', those over 80 years, are in a poor way.

People aged 80 years and over now constitute nearly 5% of the UK population, and are the fastest growing fraction of the population. Yet they have by far the worst health, and are probably the most poorly served by the state and society. It is tempting to think that their dire circumstances are a natural consequence of aging, but we should recognise that in part their present problems were created by society extending life without making parallel efforts to reduce aging and the diseases of aging. Again, it is tempting to think that the very old should be left alone, because they are going to die soon anyway, or because they are no longer contributing to society, or because there is nothing we can do about it. Would we accept such lame excuses in relation to any other fraction of the population? We owe the very old at least as much respect and attention as the very young, if only because that is where we and almost everyone we know are headed.

A century ago there were around 100 centenarians in the UK. But now there are almost 10,000 people alive in the UK today over the age of 100. And by 2050, the government's Actuaries Department predicts there will be astonishing 250,000 centenarians in the UK. This sounds like a good thing. However, according to a recent MRC survey, the quality of life of these oldest old is appalling, for example 80% have moderate to severe cognitive deficits.

How is it that the plight of the very old has been ignored for so long? In part this has to be because they are more or less invisible. The very old suffer from a triple burden of invisibility: the general invisibility of the old, the invisibility of the ill, and the invisibility of the non-working. In a society obsessed with the young, with the fit, and with work and play, the very old are simply invisible to the media, locked away as they appear to be in the home and 'homes'. And the very old make little noise: they are not shouting and demonstrating, and hardly seem to engage with society. So perhaps they are fine? Well, no, actually most of them are not: most of them are seriously ill, or disabled, or depressed, or demented. With the prospect of further ageing and degeneration among the elderly population, there is an urgent need to rethink and arguably, reorient social, medical and political priorities.

Ten recommendations for a better end to life

1. *Manage the compression of morbidity.* Mortality is the amount of death, while morbidity is the amount of disease and disability. The morbidity gap is the gap between average lifespan and healthy lifespan, and corresponds to the average number of years we live with chronic disease or disability. Hence the morbidity gap should be a central statistic in our society, as strategically important as GDP or inflation. Governments should commit to managing the compression of morbidity, i.e. reducing the number of years we live with disease or disability. Currently it is no-one's job to compress morbidity. Hospitals, health authorities, Governments and the World Health Organisation do not seek to compress the morbidity gap. There is still considerable uncertainty and argument as to whether morbidity is increasing (expanding) or decreasing (compressing) as average lifespan increases, and the answer may well vary from

country to country, and on how we define disease and disability. Current evidence in the UK indicates the morbidity gap is growing, but medics and governments seem happy to think it an inevitable consequence of an aging population, rather than a consequence of their past prioritization of preventing mortality rather than morbidity. Whether morbidity is increasing or not, we must now actively seek to reduce it in the future, i.e. we must actively manage the compression of morbidity.

2. *Fund medical research in proportion to the contribution of a disease to morbidity not mortality.* Governments must now act to compress morbidity by increasing funding of research into aging and diseases and disabilities of aging by several orders of magnitude. That may sound economically impractical. In fact it is likely to be fiscally neutral in the short-to-medium term and fiscally beneficial in the long term. Governments could stop their own funding of research on cancer and heart disease – this will not stop such research because it is currently mainly funded by charities. That money could be redirected to research on aging and those diseases of aging with most impact on morbidity (e.g. dementia, stroke, osteoporosis). By decreasing research on the main causes of death in the aged, the increase in life expectancy could be slowed, hence reducing the expected increase in the morbidity of the aged (e.g. due to dementia). And by redirecting research funding onto morbidity of the aged, we could additionally reduce the massive health costs associated with that morbidity (most health care costs are spent on the last years of life). Reducing morbidity at the expense of mortality has obvious economic benefits in terms of both health and pension costs. And those economic gains could be reinvested in aging research, until we have compressed morbidity at the end of life sufficiently to rebalance morbidity and mortality. When, in the future, the morbidity gap has been sufficiently compressed, then we can begin again to reinvest in preventing mortality and extending life, because then that extended life might be worth living.

3. *Take aging seriously.* Research and research funding needs to be redirected to aging and quality of life, rather than aimed simply at preventing death. We have spent two hundred years battling death, without seriously trying to change the rate of aging. Government and private sector spending on aging research is miniscule compared to spending on medicine. In part this may be because we believed that aging was natural and immutable. However, as argued above, aging is in fact unnatural, and research on lower animals has shown that the rate of aging can be slowed. It used to be thought that aging resulted from a fixed biological programme. But most scientist now accept that aging results from an accumulation of biochemical errors, which in principle are amenable to correction or prevention. All that is required is the political will and a few decades of research. But we need to urgently change our priorities by putting billions of pounds, rather than millions, into aging. The Medical Research Council (MRC), which has presided over the expansion of chronic disease in the UK, shown be broken up, and a new Research Council for Aging created, along the lines of the National Institute for Aging, which was a success in the USA. Aging research has had a bad press because it has been associated with the frivolous pursuit of immortality. But aging research and gerontology are not about immortality, but rather about making life bearable at the end of life.

4. *Create a realistic public route to drug discovery, clinical trials, patenting.* We have to develop alternative routes to drug development for therapies that don't make economic sense for the pharmaceutical and biotech industries to pursue. The NHS is the main market for drugs in the UK, and that NHS drugs bill is huge. However, the NHS, medics and the Government do not determine which drugs and treatments are developed. Rather this is determined by the market, because drug development is privatised in this country and elsewhere. The market and drugs industry, as it is currently structured, is efficient at producing certain types of treatment but not others. The NHS, Universities, Government Research Institutes and Charities in the UK have an immense expertise and potential for drug development. There are alternative routes to drug development within this public sector, but they are small and under-funded. They need to be massively expanded, so that the drugs that are actually needed are developed, rather than the drugs that the Pharmaceutical

industry wants us to have. However, we also need to produce economic and other incentives for the private sector to cure diseases and slow aging. One of the obstacles to drug and other medical treatment development is the patent system and intellectual property laws. This system does not allow treatments to be developed co-operatively within the public sector or between the public and private sector. And it discourages treatments that take a long time to develop and verify, which is particularly relevant for aging and the diseases of aging. We need to shake up the patenting system, so that it delivers what we want, not what it can.

5. Replace clinical targets for mortality rates with targets for reducing aging/morbidity rates.

The current UK government has an obsession with health targets, but many of those targets relate to reducing causes of death, such as heart disease and cancer. The recent policy green paper from the UK Conservative party repeats the same mistake in spades, making the top health targets of the probable next government: reducing mortality rates from cancer, heart disease and respiratory. However, hitting these targets is likely to decrease the health of the nation rather than increase it, unless aging and the maladies of aging are targeted at the same time.

6. Give people the death they want. Legalise assisted suicide, voluntary euthanasia and other forms of assisted dying, within a tight regulatory framework. These are not general solutions to the general problem, but they are specific solutions for specific individuals in specific situations. And those difficult situations are becoming much more common as a result of society's previous choices. It is untenable for society to create the conditions for a degenerative very-old age, and then claim there is no exit strategy for the individuals concerned other than to continue degenerating. Obviously there is a quick-and-painless alternative exit strategy, and it is inhumane not to offer that alternative to those who desperately want and need it. In those countries, such as the Netherlands, that do offer this alternative, it is only used in 1-2% of deaths, and it does not lead to the end of civilisation. Also we need to empower advance directives (i.e. living wills), so that people get the deaths they want. And most people want to die at home, but end up in 'homes' or hospital. We need a 'home death' or 'real death' movement, equivalent to the 'home birth' movement, to empower people at a time when they feel most powerless. Death needs to be de-medicalised as far as humanely possible, at least for those who want it that way.

7. Grant higher political priority and visibility to issues concerned with the quality of the end of life. This might involve giving higher status and priority to palliative care and end of life issues within medicine and care services. It is likely that more and better-funded hospices would be required, yet the public debate around how to provide these, how they are to be funded, managed and serve their users has still not been held. Hospices ought to be as ubiquitous and well-funded as maternity hospitals. In order to keep standards of care high and in the public eye, a system to monitor care homes could engage broad sectors of society, especially when people realise that they might be future users. We need to think about whether the state has a higher order of responsibility for the care of those over the age of 80 years (the new old) than for those over 60/65 years, especially when dementia and family fragmentation are increasingly prevalent.

8. Create enabling technologies for the very old. Think creatively about how to enable a higher quality of life for the old and very old. For instance, appropriately designed gadgets and information technologies built into the world around the old could extend their social networking, create artificial communities and permit a greater political presence. Companion technologies could also aid memory, face recognition and ameliorate cognitive deficits. Intelligent domestic robots could allow old people to live independently in their homes for longer. Intelligent wheel chairs integrated with power-assisted movement of limbs could facilitate physical mobility of the aged, if they were integrated into the design of houses and communities. The design of cities, buildings (especially community-based facilities), and streetscapes should take into account the ways in which the elderly and extremely old can move around and participate in society. Designers, manufacturers and architects can also

consult widely with the elderly and their carers more systematically in order to ensure the most appropriate technologies, materials and designs.

9. *Make the old less invisible and enable more realistic expectations of death and end-of-life.* Many people have unrealistic expectations about death and end-of-life. So they want to stay alive at any cost to their quality of life. And in consequence a half of a lifetime's health expenditure is spent on the last year of life, in an increasing fruitless, medicalisation of death. To change our relationship with age and death, children should be educated about end-of-life issues, through the school curriculum, student programmes and community activities. Care homes and hospices need to be brought closer to the communities they serve, through education programmes, visits, and other means. The old need to be reintegrated into society and communities in ways that are beneficial to all. In particular we should be enabling the younger old to help the older old, and more generally participate in the voluntary sector and other social roles.

10. *Change our concept of death.* Our concept of death, inherited from history and film, is either of violent death or of a fevered soul wracked by delirium fading into the night and expiring with a final, faint breath. This might have been the average death two hundred or four thousand years ago, but the reality now is very different. Death is no longer an *event*, it is a long drawn-out *process*. Because our concept of death is out-of-date, we still believe it is crucial to prevent death at any cost, whereas in many cases, death comes as a welcome release from the years of suffering at the end of life. That doesn't mean that assisted dying is the only solution to the problem -- far from it -- the solution is obviously to improve the quality of life at the end of life, by reducing the aging, disease, disability and social isolation of modern old age.

Biography

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