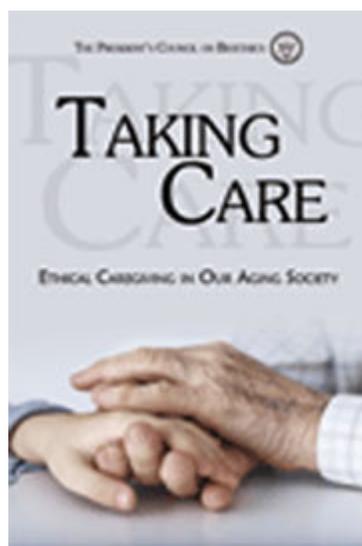


Carolyn Moynihan | Saturday, 19 November 2005

## Who cares? The crisis facing an ageing society

When the baby boom generation embraced birth control they forgot to ask who would support them and look after them in their old, old age.



Has there ever been a better time to grow old? Call it the luck of the baby boomers, or call it the fruit of their genius and hard work, but wealth, technology and medical advances seem to have combined to hand my generation the prospect of years of healthy and vigorous living stretching way beyond the retirement horizon of 65.

Our sheer numbers will change the face of societies around the world by mid-century. As a result of lower birth rates in recent decades, growth of the 65-plus age group will eclipse that of other groups. In America the population aged 45 to 64 is expected to grow modestly from 61 to 85 million – about 40 per cent, while the population 65 and over will more than double – from 34 to 79 million. Let the politician who dares, try to reduce state pensions!

Those figures, however, mask an acute vulnerability, since the fastest-growing group of older Americans will be those over 85, whose numbers will quadruple during the same period from 4 million to 18 million. In the words of a recent American report – [Taking Care: Ethical Caregiving in Our Aging Society](#) – we are on the threshold of a "mass geriatric society" in which the "price" many people pay for the gift of added years of healthier life is likely to be "a period of protracted debility, dementia, and dependence stacked up at the end before they eventually die". In view of the fact that this will touch every man, woman and child in the US – and every other Western country – it is astonishing that most of the media ignored the report when it was released a few weeks ago.

### A crisis of dependency



How are we responding to this looming crisis of dependency? In a typically technocratic and number-crunching way, says the *Taking Care* report, which comes from the President's Council on Bioethics – a United States advisory group – guided by its outgoing chairman, [Leon Kass](#), whose ethical sensitivity is evident in every page.

"Socially, we have preferred to place our hopes in programs that promote healthy aging and in scientific research seeking remedies for incapacitating diseases like Alzheimer's. In so far as we do approach the topic of long-term care, we worry mainly about numbers and logistics: How many will need it? Who will provide it? How will we pay for it? The ethical questions of what the young owe the old, what the old owe the young, and what we all owe each other do not get mentioned. Neither do the questions of social support for the caregivers or a good end of life for us all."

The mention of Alzheimer's is not accidental. Roughly half the people over 85 will suffer some degree of dementia. Today, an estimated 4.5 million Americans have Alzheimer's disease; by 2050 the figure could be as high as 16 million – leaving aside the question of prevention or a cure.

The identification of this syndrome from among various symptoms of senile dementia, and its increasing incidence due to the ageing of the population, has made it a symbol of the (terrifying) burdens of old age. The report therefore focuses on this illness as it reflects in detail on the looming crisis of caregiving and the ethical challenges it poses.

### **Crisis of caregiving**

Until now, family members – spouses, daughters and sometimes sons – have supplied the bulk of long-term care. We have done it in our family, nursing our mother at home before she died and now helping with care of my eldest sister who lives in a nursing home.

But this sort of thing will be more difficult in the future (I have no idea who would do this for me!). Families are smaller and there are fewer adult children to care for their aged parents. Many more old people are childless and alone – single-adult homes are already the most common type in the US. Increased family instability and greater geographic mobility have an impact, as does the pre-occupation of younger women with paid work.

Even institutional care is beset by problems. In my country, New Zealand, church-based trusts are selling their rest homes and hospital to investment companies, whose bottom line is profit. Nurses and geriatricians are becoming scarcer, while the wages and conditions offered nurse aides do not attract sufficient committed workers. These factors, combined with wider economic pressures, have the makings of a genuine crisis and demand "urgent social attention".

When society does turn its attention to the problem, however, it must be guided by basic ethical principles. *Taking Care* says it is necessary to steer between two rocks: "We need to prevent the worst kinds of betrayal and inhumanity towards the dependent elderly – such as relying on institutions that 'warehouse' elderly persons," promoting assisted suicide and embracing euthanasia.

But we must also "avert the danger of inter-generational conflict over scarce resources, meeting our obligations also to our children and grandchildren, sustaining other social goods, and avoiding a major new drag on the economy that would (among other things) weaken the economic capacity of working families to provide

care for their loved ones".

Put positively, this means "we need to encourage families and local communities to become responsible caregivers and to sustain one another in giving care, while recognising the role of the state in providing a safety net of decent care for those who lack adequate economic resources or a network of family support".

### The test of Alzheimer's disease



Whether a society manages to steer this middle course will depend very much on how it responds to the test of dementia, and, specifically, Alzheimer's. Loss of the power to act and communicate, to recognise and remember; total dependency and physical decay over, perhaps, many years – all this is a fearful threat to the modern mentality that sees personal autonomy as the highest ethical good and dependence as a fate worse than death.

Yet, as the report points out, the burden of the disease for the sufferer is greatest in the early stages when more awareness remains – "the more the disease progresses, the more the sadness resides with the family." Having to deal with dependent relatives may account for the greater part of our fear of dementia.

Personally, I have not found dementia such a dreadful thing. My mother became helpless through dementia of the stroke-related variety at the end of her 91st year and died after a mercifully short period of 2½ years. My eldest sister is now at a late stage of a decline that began with early-onset Parkinson's disease and has brought a related dementia.

We (another sister and I) were sad to see our mother fail, but her dementia had many communicative and even funny moments during the first year or so, and we were never tempted to think her personality had been destroyed. Something similar happens with my sister, who continues to recognise us and engage in limited repartee. I am sure this is related to the amount of time we spend with her. The greatest burden for us at present is seeing many other helpless people who seem to have no one of their own to spend time with them.

### Burdens and benefits

If our sister's condition is not unduly burdensome to us, however, perhaps it is to society. One of Dr Kass's own colleagues on the bioethics council would probably see it that way. In a personal statement appended to *Taking Care*, [Dr Janet Rowley](#), a geneticist from the University of Chicago, denounces the report as a "scary document" that would cost countless billions to implement and thus runs straight into the rock of stealing from the youngest generations to fund unwarranted care for "demented elderly individuals".

Dr Rowley's regards dementia as an inhuman state and her solution is assisted suicide. She is furious that bioethics council report has ruled it out: "The clear message of this report is, if you feel strongly about not living in a decerebrate state, you better kill yourself while you still have control over your fate!"

Ideally, she says, every individual would have a living will specifying the "level of medical care desired if mentally incapacitated" (typically, none). At the same time government guidelines would put limits on what could be offered to patients in various stages of dementia (very little).

If nothing else, Dr Rowley's vehement dissent serves to show why the rest of the report, with its calm, humane and thorough reasoning, is necessary. As we grapple with what exactly we owe the old in the evolving state of society, we should be clear about the ground rules:

- In the first place, we must continue to respect them as equal members of the human community and seek their well-being "here and now" – not by launching them into the hereafter. "We should always seek to benefit the life incapacitated persons still have, and never treat even the most diminished individuals as unworthy of our company and care."
- "No euthanasia, no assisted suicide." Besides the long-standing moral and legal prohibitions against the taking of an innocent life there is another reason: "one cannot think wholeheartedly about how best to care for the life the patient now has if ending his or her life becomes, for us, always an eligible treatment option".
- The goal of ethical caregiving in the clinical setting is not extend life as long as possible but to benefit the patient. Comfort care must always be given but feeding tubes, respirators, and other medical interventions may be omitted if they would not be effective or if they would add to the patient's burdens.

Some things will help us along this path and some will not. Living wills, by and large, will not, since "there are too many situations in which following orders is not the best way to give care". Advance proxy directives, on the other hand, are very helpful since they specify who should make crucial decisions on our behalf. Discussing options for care while one is still competent is also highly desirable. Social support is vital, and good policy in this area is so important that the report recommends a Presidential Commission on Aging, Dementia and Long-Term Care.

Above all we need a change of attitude. As Dr Kass wrote in a column in the *Washington Post*: "Against our confidence in mastery and control, we need to remember that old age and dying are not problems to be solved but human experiences that must be faced. In the years ahead, we will be judged as a people by our willingness to stand by one another, not only in the rare event of a natural disaster but also in the everyday care of those who gave us life and to whom we owe so much."

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