

The End Game

The end of life places profound responsibilities on the elderly.

John Hardwig

From: *Forum for Applied Research and Public Policy* (Winter 2000), 60-65.

To be old is to face the end of life. This is not to say that young people never die. Nor that the old have nothing else to do, no valuable contribution still to make. But after old age comes death. That's simply a biological fact. It will remain a fact regardless of the medical technologies we develop, social programs we institute, and changes we make in our attitudes about aging and the aged.

There is a strong taboo in our culture against talking about the end of life, perhaps especially with the elderly. There is even a taboo against talking with a dying person about this central feature of her experience, even when it's obvious to everyone that she is dying.

But the elderly know. For some, the body fails before the mind. They feel the approach of death in their joints, their ears and eyes, their lungs, their bowels. Each year, the body performs more poorly than it did the year before. When the body starts to fail, we live with the specter of becoming frail, immobile, eventually debilitated and unable to care for ourselves; and then of death. For others, the mind fails before the body. When the mind starts to fail, we have more senior moments, and the grace we try to muster on those occasions does not hide the premonition they contain. We become more forgetful, increasingly confused, and more disoriented. Then, too, we live with the specter of dementia, of being unable to care for ourselves, and of death.

Even the elderly who are in excellent mental and physical health live in the face of death. For they know this will not last. It cannot last. Probably it will not last much longer. We ought not to pretend otherwise. To face the end of life is not, then, the same as actively dying. It is not even necessarily to carry a terminal diagnosis. Even when there is no terminal illness in sight, one is lurking around the corner. Thus was it ever; thus shall it ever be. So, when we talk about the responsibilities of the elderly, we are talking about the responsibilities of those facing the end of life.

Our New Way to Die

And yet, our medical technology is changing old age and death. The end of life used to come both earlier and much more quickly. When people commonly died of infections, the span between the onset of a terminal illness and death was often a matter of days, a few weeks at most. Moreover, anyone who became bed-ridden for any length of time would often develop pneumonia, and since pneumonia could not be effectively treated, the bed-ridden died. Under such conditions, few lived to be as old as many now do. People aged, became old much earlier, then usually died fairly quickly. This was accepted; not much could be done.

The progress of medicine changed all that. In large part, the change has come since World War II, with the development of effective antibiotics and the respirator. Today, we die of chronic illnesses rather than infections. As a result, the noted geriatrician Dr. Joanne Lynn reports that the average American now knows three years in advance what she will die of. Since much is known about most terminal illnesses, a lot is also known about what those three years will be like. Moreover, Dr. Lynn reports, the average American male is debilitated for 5 years before he dies, the average female for 8 years before she dies. Today, the elderly live a long time in the face of death.

Those of us who are not yet old will quite likely live even longer facing our demise. There is no reason to believe that medical progress will now halt in its tracks. We can expect to have even better treatments for a wide range of killer diseases. Those diseases that we cannot defeat, we will be better able to treat and, thus, to slow. These better treatments for terminal conditions will mean that most of us will live even longer facing death. Most of us will live longer than is common today, decline more slowly, and face even longer periods of disability and debility; and our dying processes will be much more prolonged than it was for previous generations.

If such a long dying seems grim, remember that it's medical progress that brings this new death. It is precisely because our medicine is so successful in treating so many diseases that we live so long and die so slowly. We are all happy to have this medicine available. I know I am. It brings us longer, healthier lives. But there is a dark side to this medical progress; it also saddles us with years of chronic illness and debility and a long, slow dying process. We shall have to learn **C** both as a society and individually **C** how to deal with a long, slow demise.

Society's Burden

This new kind of death brings very different problems from those of a quick death. For all of recorded history, the predominant fear has been that death might catch us unawares, carrying us off so quickly that we would not have time to make preparations. The Anglican Common Book of Prayer used to include the plea, **A**and from a sudden death deliver us, O Lord.[@] Now, many Americans believe that dying quickly is the way to go **C** **A**she never knew what hit her.[@] But our problem will most often be how to live in the face of death for years and years. My own mother, 90 years old and wheelchair-bound in a nursing home, said to me over and over, **A**I'm ready to die. I've been ready for years. Why does this have to take so long?[@] For her, and for an increasing number of Americans, the problem is no longer that death comes too soon and too quickly. Too often, death comes too late and too slowly.

The slow decline toward death brings serious burdens to the elderly and dying, as my mother's anguished cry attests. But this new extended old age and prolonged dying also brings burdens to families, friends, and society at large.

One of the first problems is how to pay for the care that the elderly and dying will need. A nursing home in the San Francisco Bay Area now costs \$5000 to \$7000 a month. Any medical care and medications that might be needed is on top of that. Over six or eight or 10 years, those

monthly payments add up. Many of the elderly do not have the \$500,000 to \$1 million saved for end-of-life care. Many could not have saved that much. And things look even worse for the future. In all likelihood, we will one day require even more care than the elderly now do. When individuals or families cannot cover the cost, society will have to, for we cannot just let old people die in their apartments. And yet the amount of money society has set aside to cover such expenses is steadily declining.

Perhaps even more important than the financial question of how to deal with protracted death, however, is the moral one. For regardless of how undesirable a sudden and premature death might be, it is morally much simpler to handle than a slow dying. Faced with the threat of an unexpected and early death, we do what we can to extend life. We do so almost automatically and without soul-searching. And when we fail, however grieved we may be over the death itself, there is moral solace in knowing we did what we could. When the overwhelming majority of deaths were premature and nothing much could be done to prolong the life of the dying, we could adopt a very simple moral maxim **C** save lives! Whenever possible, prolong life! As long as possible! That was simple, clear, easy to follow, and ethically compelling.

Now, we face the excruciating moral issue of when to stop trying to save a life. We could prolong the life of this person if we choose and we must decide how far to go with the effort. We must also ask, whose interests will shape the decision to stop the effort? The moral burden of this choice is weighty, often excruciating, and it falls on someone **C** the patient, the family, or a professional caregiver. Our society and most of us individually will have to come to terms with a whole series of profound moral dilemmas raised by deaths that are too slow and too late.

Now, the elderly undoubtedly have responsibilities resulting from an all-out attempt to prolong their lives. For example, the elderly may well have a responsibility not to use their political power to secure a disproportionate share of social resources for themselves, at the expense of the young. But for any individual old person, the responsibility to look after the interests of society is relatively unimportant; we can normally presume that society is able to take care of itself.

Familial Burdens

The families and loved ones of the elderly are less able to look out for themselves. We must, then, also consider the burdens to family and loved ones brought on by our new way of dying. Perhaps most important are the human burdens of actually providing hands-on care for a seriously ill or debilitated family member. Many families are struggling with the problems of trying to provide round-the-clock care for an elderly relative. Often, such care leaves the caregiver exhausted, with no friends, no life of her own. This caregiving can go on for decades. The burdens of such care often undermine even the health of the caregiver.

We must also recognize the familial financial burdens of old age, debilitation, and a slow dying. Many families struggle with the problem of how to pay for the medical and nursing care that a prolonged end of life presents to families. Thousands and thousands of families are bankrupted every year by medical costs and these are most often associated with the end of life.¹

Is it worth that cost to postpone a death in the family? Is that always the right thing to do?

It may sound callous and vulgar to mention money in the context of providing care for an elderly family member, especially when life itself is on the line. But on the personal and familial level, the human costs of having to pay for health care can be enormous. For the vast majority, there is more than just money at stake. For example, consider the example of a single, 55-year old woman who cared for her 87-year old mother during the mother's three-year struggle with terminal congestive heart failure. Besides three years of complete exhaustion, the care of her mother cost this woman her job, her career, her home, and all of her savings.

A career change at age 55 is difficult at best; she is unlikely to find another job nearly as remunerative or interesting. Even if she manages to start a new career, she no longer has enough working years left to recoup her savings. The end of her mother's life will profoundly alter the rest of her own life. Even her health care may well be affected, since affordable health insurance these days often comes only with a good job. It was not, of course, a question of saving her mother's life, except very temporarily. Her friends and family knew that her mother's congestive heart failure was terminal. It was only a matter of time. And so it was.

Individual and Collective Responsibility

Our society could **C** for a while longer at least **C** lift the weight of this responsibility from families like this one. We could develop a comprehensive plan to care for those who cannot take care of themselves, including the aged, the chronically ill, and the dying. We could, but it looks like we won't. In fact, we are moving in precisely the opposite direction.

In the United States, the burdens that families and loved ones bear when there is chronic illness, debility, or protracted death are steadily being increased by the cost-containment measures designed by insurers **C** mainly employers and the government. Health care costs in this country continue to grow much faster than our economy, giving rise to a very real need on the part of employers and government organizations to try to contain escalating health care costs.

One common strategy in the campaign to control these costs is to force families to provide more of the daily caregiving and to require patients and their families to pay more of the costs of health care. Thus, health insurance covers less of the cost of chronic illness. Patients are also discharged from health care facilities **A**quicker and sicker,[®] as the saying goes. They then go home **C** still unable to care for themselves **C** where they have to be cared for, almost always by the women in the family.

Now, any society must decide whether to bear the burdens of the unfortunate collectively or individually. Health insurance, social security and retirement funds, and welfare plans are all devices that allow us to bear responsibility collectively. Under a system of collective responsibility, those who are fortunate enough not to have family members who become seriously ill or who cannot care for themselves subsidize those who are not so lucky, and we all insure ourselves against having huge burdens fall upon us or our loved ones.

Accordingly, we could decide to tax ourselves to provide collectively for the needs of not just the medical care of people who can't care for themselves. That's what Canada is trying to do, and apparently no one there is impoverished by an illness in the family. Contrast the United States, where tens of thousands of families are impoverished every year by the cost of medical treatment.

The emphasis in the United States today is on individual responsibility. The popular idea in our country is that each person should be responsible for himself, and families should take care of their own without looking for much help from the rest of us. This approach may well reduce our taxes. But that is not the end of the matter. A social decision not to bear responsibility collectively does not mean that responsibilities simply evaporate. Rather, it increases our individual responsibilities, sometimes dramatically. If we choose not to provide collectively for those in need, we must protect and provide for our loved ones individually, at a time when we ourselves may also be in need.

As we reshape our social context, we also redefine our personal responsibilities. A renewed emphasis on individual responsibility means that many more of us will have to make very difficult individual choices at the end of our lives, if we are to protect our families and loved ones. Each of us must live and die in the social context we create together. Either we will bear responsibilities for our elderly collectively or we will have to face these responsibilities individually—often through personal caregiving, which can mean the loss of all assets, the sacrifice of careers, and, sometimes, the sacrifice of health. If we do not provide collectively, many of us will also face excruciating individual moral decisions when we ourselves become old. If I am not mistaken, the search for a responsible end of life could even require decisions to lay down our own lives. We may regrettably find ourselves in situations in which there is simply no responsible way to go on, as all options impose too great a burden on our loved ones.²

Responsible Aging and Dying

All developments and choices that will dramatically affect the lives of others, especially family and loved ones, raise serious moral questions. So, our new way of dying, combined with our penchant for individual responsibility, requires troubling ethical choices: How much can I ask my family and loved ones to do to support me during the final years of my life? How many years can I ask them to sacrifice because I would like to avoid institutional care or to live a little longer? Can I seriously compromise their futures and even their children's futures just because I want to live a little while longer or in the style I enjoy? What will be my responsibilities to my loved ones as I near the end of my life?

These are deeply disturbing questions—questions we all would rather avoid. So far, we have largely avoided such questions by just shutting them out of our minds and our family conversations. But this ostrich posture stands a fair chance of making matters much worse for those who have to take care of us and support us at the end of our lives. There is no easy moral solution, no comfortable and safe moral ground.

Now, I do not deny that the families and friends of those facing the end of life have

responsibilities, too. They have a responsibility to help us in this time of need. Perhaps they even owe us for help we gave them earlier in life. But there must be limits to their responsibilities, if the other members of our families are to be given an equal chance to live their own lives, achieve their own goals, and satisfy their desires. There must also be limits if families are to do what's best for all members of the family, not just what's best for the members who happen to be elderly. There must be limits if family members have other responsibilities, to partners or children or careers. The caring capacity of families must not be exceeded or completely swallowed up in the care of a family member who is facing the end of life. Longer life or the opportunity to live at home must not become an altar on which all other goals and values of the family are sacrificed. So, though families and loved ones also have responsibilities to the elderly, this does not eliminate the need to think about the responsibilities of those who are facing the end of life.

Many old people do think about the burdens on family that their old age and debility may bring. It is a common refrain among old people that they hope not to live so long that they become a burden to their loved ones. But fewer have considered what steps this hope might require of them. Most of us will not be able to avoid such questions **C** for we do not die alone. Our deaths are not simply our own, affecting no one but ourselves.

Professional ethicists may be appalled at the very suggestion that people have responsibilities at the end of life. Bioethicists, for example, focus almost exclusively on the kind of death the patient wants for herself. That, in fact, is their concept of a good death. But life is not about just doing what you want; often it's not even primarily about what you want. Neither is death.

One can live responsibly or irresponsibly. Accordingly, one can age responsibly or irresponsibly. One can respond to illness, disability, debility, or harbingers of dementia responsibly or irresponsibly. And one can die responsibly or irresponsibly. Most of us will face choices at the end of life and our choices may be either responsible or irresponsible. In aging and dying as in the rest of life, a self-centered life is wrong. It is irresponsible and wrong to make our choices thinking only about what we want for ourselves, without duly weighing the ramifications of our choices on the lives of others **C** especially on the lives of those who are close to us, for we have a special obligation to try to protect them.

As we age and then begin dying, we will have to figure out how we can protect the lives of our loved ones from the tragedies that our old age and death could bring upon them. If we are to keep the endings of our own lives from seriously compromising the lives of our partners and children, it will be up to us to make very difficult choices. Most of us will have to decide for ourselves how we will structure the end of our lives, trying to balance what we want for ourselves with our responsibilities to use our choices to protect the well-being of our loved ones.

Gauging Your Responsibilities

Having said all this, we come to the really serious question: how can I determine the extent of my responsibilities to family and friends? Exactly what are my responsibilities to my loved ones as I age, approach debility or dementia, and then die? How can I protect their lives from being

seriously damaged by my old age and death?

To my mind, these are the right questions we will all need to ask. But I will not even attempt to provide answers here. To begin with, the questions are too new. We have not devoted enough careful thought to them. The very idea of a responsible death is really quite foreign to us. Besides, I have no moral authority to define for others what their responsibilities are at the end of life. I also believe answers to these questions will be very contextual, shaped by many nuances of particular families. The responsibilities of an old person to her family will be shaped by their dreams, hopes, fears, and aspirations; by the history of the family, including who has made sacrifices for whom; and by the patterns of interaction that have characterized the common life of this family. I don't know nearly enough about any family except my own to be able to define the responsibilities of the elderly to the rest of the family.

The List

Having only questions to raise, not answers to offer, I leave you with a thoughtful, impressive list of responsibilities of those facing the end of life. It was drawn up by members of a seniors-organization that I was invited to address a couple of years ago.³

As I was preparing my talk for the organization, I decided I would break the taboo against talking with seniors about the end of life. Instead, I told the group that there are important responsibilities of others C particularly family members C to the aged, the infirm, the ill, and the dying, but that I wanted them to tell me what they thought were the responsibilities of those facing the end of life.

The group came up with a remarkable list. We had only 45 minutes for our discussion, so we could not spend much time talking about each proposed responsibility. But all items on the list were at least briefly discussed. Not everyone present agreed with every item, but there was considerable consensus about many items. And there were regular comments like, **AI=d better start doing that.@**

At the end of our brief discussion, one women came up to me and said, **AMy husband passed away three weeks ago. I just want you to know how comforting and helpful this discussion has been to me.@**

Some items among the responsibilities these seniors formulated are controversial. Still, each item represents the deeply held conviction of someone who is thoughtfully facing the end of life. Each is worthy of serious consideration. This list of responsibilities strikes me as an excellent starting point for moral discussion of our responsibilities at the end of life. I offer it as such:

Talk with your family about death.

Die in a way that will leave your family in the best position.⁴

Make a will.

- # Discuss death and dying while you are well. Renew this discussion periodically.
- # Don't live so long that your loved ones will wish you were dead.⁵
- # Don't insist on personal care. Don't ever say, "Never put me in a nursing home." If you've already said it, retract it and apologize.
- # Review the life you have shared, set things right, and ask for forgiveness from your loved ones.
- # Make a living will.
- # Don't leave to others decisions that will cause guilt.
- # Teach your spouse and inform your children about your finances.
- # Do things to minimize disagreements and conflicts among your survivors.
- # If you decide on suicide, be considerate of those who will find your body.
- # Put all your assets in both names, or else clearly separate them. Review this item periodically.
- # Write an obituary and make funeral and burial plans. Address the issue of donation of your body.
- # Talk with your loved ones about what they will do after you're dead and about how their lives will be without you. This will give them permission to go on to full lives after you're dead.
- # Teach household responsibilities to insure that your spouse has competencies he or she will need when you are dead.⁶
- # Help your spouse achieve enough independence and enough of a life of his or her own to live happily without you.
- # Tell your story. It will help you accomplish the other items on the list.

John Hardwig is a professor and head of the department of Philosophy at the University of Tennessee in Knoxville.⁷

John R. Hardwig
University of Tennessee
Professor & Department Head
Philosophy
801 McClung Tower & Plaza
Knoxville, TN 37996-0480

PH: Philosophy Department 974-3255
FAX: A @ 974-3509
email: jhardwig@utk.edu

1. See Kenneth E. Covinski et al., "The Impact of Serious Illness on Patients= Families," *Journal of the American Medical Association*, 272 (1994), pp. 1839-44.
2. See John Hardwig, *Is There a Duty to Die? And Other Essays in Bioethics* (New York, NY: Routledge, 2000).
3. This list was formulated by the Institute for Continued Learning, in Johnson City, TN, on November 5, 1998. The Institute for Continued Learning is a group of seniors who meet regularly to participate in educational events and programs. All are retired. The youngest member of the group is 55 years old. Most are in their 70s.
4. A discussion followed about whether there is a responsibility to commit suicide. Some Institute members think there is.
5. A discussion followed about a comment one member had heard from a friend: "I wish my mother had died while I still loved her."
6. In discussion, many felt the husband should cook, clean, and do the wash for a couple of months while the wife pays the bills, gets the car serviced, and takes care of the house and yard.
7. Material in this paper has been drawn from Hardwig, *Is There A Duty to Die? And Other Essays in Bioethics*.