

I Want to Burden My Loved Ones

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From: "Things that Count"
Intercollegiate Studies Institute, Inc.
Wilmington, Delaware
1999

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Recently I was a speaker and panel member at a small educational workshop on "advance directives" sponsored by the ethics committee of our local hospital. The workshop was an opportunity to provide information about, and discuss the relative merits of, living wills and health care powers of attorney as different ways of trying to deal in advance with medical decisions that might have to be made for us after we have become incompetent. This is not the first such workshop for me, and I suppose it may not be the last. And I was struck, as I have been before, with the recurrence of a certain theme.

Many people come to such a workshop already quite knowledgeable about the topic to be discussed. They come less for information than for the opportunity to talk. Some earnestly desire the chance to converse about a troubling issue; a few just want to express themselves. In either case, however, it is remarkable how often they may say something like the following: "I'm afraid that if my children have to make decisions about my care, they won't be able to handle the pressure. They'll just argue with each other, and they'll feel guilty, wondering whether they're really doing what I would want. I don't want to be a burden to them, and I will do whatever I can in advance to see that I'm not." And after someone has spoken words to this effect, there will be a chorus of assent from others who, evidently, share the speaker's view.

Now, of course, we can in many ways understand and appreciate such a perspective. None of us wishes to imagine his children arguing together about who really knows best how he should be treated (or not treated). We hate to think that our children's last thoughts of us would be interwoven with anger at each other, guilt for their uncertainty about how best to care for us, or even (perhaps) a secret wish that we'd get on with the dying and relieve them of this burden.

Nonetheless, as the workshop wore on, I found myself giving it only a part of my attention, because I couldn't help musing on this recurring theme. Understandable as it surely is in many respects, there is, I am convinced, something wrong with it. I don't know how to make the point other than a little too crassly—other than by saying that I want to be a burden to my loved ones. But, rightly understood, I think I do.

The first thought that occurred to me in my musings was not, I admit, the noblest: I have sweated in the hot sun teaching four children to catch and hit a ball, to swing a tennis racket and shoot a free throw. I have built blocks and played games I detest with and for my children. I have watched countless basketball games made up largely of bad passes, traveling violations, and shots that missed both rim and backboard. I have sat through years of piano recitals, band concerts, school programs—often on very busy nights or very hot, humid evenings in the late spring. I have stood in a steamy bathroom in the middle of the night with the hot shower

running, trying to help a child with croup breathe more easily. I have run beside a bicycle, ready to catch a child who might fall while learning to ride. (This is, by the way, very hard!) I have spent hours finding perfectly decent (cheap) clothing in stores, only to have these choices rejected as somehow not exactly what we had in mind. I have used evenings to type in final form long stories—far longer than necessary—that my children have written in response to school assignments. I have had to fight for the right to eat at Burger King rather than McDonald's. Why should I not be a bit of a burden to these children in my dying?

This was not, I have already granted, the noblest thought, but it was the first. And, of course, it overlooks a great deal—above all, that I have taken great joy in these children and have not really resented much in the litany of burdens recited above. But still, there is here a serious point to be considered. Is this not in large measure what it means to belong to a family: to burden each other—and to find, almost miraculously, that others are willing, even happy, to carry such burdens? Families would not have the significance they do for us if they did not, in fact, give us a claim upon each other. At least in this sphere of life we do not come together as autonomous individuals freely contracting with each other. We simply find ourselves thrown together and asked to share the burdens of life while learning to care for each other. We may often resent such claims on our time and energies. We did not, after all, consent to them. (Or, at least, if we want to speak of consent, it will have to be something like that old staple of social contract theorists, tacit consent.)

It is, therefore, understandable that we sometimes chafe under these burdens. If, however, we also go on to reject them, we cease to live in the kind of moral community that deserves to be called a family. Here more than in any other sphere of life we are presented with unwanted and unexpected interruptions to our plans and projects. I do not like such interruptions any more than the next person; indeed, a little less, I rather suspect. But it is still true that morality consists in large part in learning to deal with the unwanted and unexpected interruptions to our plans. I have tried, subject to my limits and weaknesses, to teach that lesson to my children. Perhaps I will teach it best when I am a burden to them in my dying.

This was my first thought. It led to a second. Perhaps it is a good thing, lest we be tempted to injustice, that the dying burden the living. Some years ago Robert Burt wrote a book about medical decision-making for incompetent patients. The book's title was *Taking Care of Strangers*. Burt's point, which carried a *double entendre*, was essentially this: Patients who are unable to make decisions for themselves are often in a state (e.g., severely demented, comatose) in which they become strangers to us. They make us uneasy, and we react with ambivalence. And to say of such a patient, "I'll take care of him," may be a statement freighted with ambivalence. Burt worries that, no matter how devoted our care, our uneasiness with a loved one who has become a stranger to us may prompt us to do less than we ought to sustain his life. (Nor, we should note, are physicians immune to such uneasiness.) It is, therefore, essential that we structure the medical decision-making situation in such a way that conversation is forced among the doctor, the medical caregivers, the patient's family, and perhaps still others, such as pastor, priest, or rabbi. Advance directives, designed to eliminate the need for such extended conversation—lest it should burden loved ones—are, from this perspective, somewhat problematic. They may not force us to deal with our own ambivalence in "taking care of" a loved one who is now a burdensome stranger.

This does not mean that advance directives are entirely a bad idea. It does suggest, however, that a health care power of attorney—in which we simply name a proxy to make decisions in the event of our incompetence—is better than a living will in which we attempt to state the kinds of treatment we would or would not desire under a variety of medical circumstances. At this point in my life, for example, I would surely turn over to my wife my power of attorney. In doing so I simply announce to medical caregivers: “Here is the person with whom you must converse when the day comes that you cannot talk with me about my medical care.” I myself do not particularly like even the recently fashionable attempts to combine the two forms of advance directives by naming a proxy *and* giving that proxy as much detail as possible about what we would want done. That move—though, again, it will be seen as an attempt to avoid burdening the loved one who must make such decisions—may not, in any case, accomplish our aim. It commits us to an endless, futile search to determine what a now-incompetent person would wish. Still more important, it is one last-ditch attempt to bypass the interdependence of human life, by which we simply do and should constitute a burden to those who love us.

I hope, therefore, that I will have the good sense to empower my wife, while she is able, to make such decisions for me—though I know full well that we do not always agree about what is the best care in end-of-life circumstances. That disagreement doesn’t bother me at all. As long as she avoids the futile question, “What would he have wanted?” and contents herself with the (difficult enough) question, “What is best for him now?” I will have no quarrel with her. Moreover, this approach is, I think, less likely to encourage her to make the moral mistake of asking, “Is his life a benefit to him (i.e., a life worth living)?” and more likely to encourage her to ask, “What can we do to benefit the life he still has?” No doubt this will be a burden to her. No doubt she will bear the burden better than I would. No doubt it will be only the last in a long history of burdens she has borne for me. But then, mystery and continuous miracle that it is, she loves me. And because she does, I must of course be a burden to her.