

Life After Dementia

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I am afraid of developing [dementia](#), the most common form of which is [Alzheimer's disease](#). The possibilities are horrifying -- the ineluctable loss of memory and other cognitive functions; dependency on others to dress me, to feed me, to change my diapers; slipping into a fog, where I cannot recognize even people I love.

But is dementia inevitably a cruel, distorted end of a human life?

When I was younger, I thought so. I had no doubt that I would prefer death to living in a demented state; that I would want to take my own life; and that, if I missed the timing and could not act on my own, I would want someone else to do it for me. "Just shoot me," I said to my wife -- knowing, of course, that she would not and could not, but hoping that she would act swiftly as my health care proxy to have any kind of life support -- including food and water -- removed when I was no longer myself.

As I have become old (I am now 68), my thinking has changed. When the time comes, if the time comes, I may want to live -- even if I cannot engage in witty conversation; even with the need for someone to help me hobble on a walker to get out for a breath of air; even with the indignity of someone cleaning me after I mess my diapers.

What we expect and want for ourselves changes over time. That is the fundamental insight of developmental psychology. When I was a child, being a child seemed right. When I became a teenager, I fought against being a child. As a grown-up, my adolescence was an embarrassing memory. I am happy now not to be driven to succeed at the work, which largely and happily defined my existence as an adult. The low-stress life I am fortunate to have now feels right to me.

What will feel right when I am very old? Will I care if I can no longer analyze public policy? Will I be deeply distressed if I cannot write or teach? Will I suffer if I cannot tell a joke or have an informed conversation about politics, world events, and the fields of knowledge and activity that have been central to my life?

Or will a visit from someone I like make my day? Will my daughter and grandchildren (if I have them) be a source of constant interest? Will watching world events on the TV with only faint understanding be enough? And when the time comes, if it comes, will the feel of the sun on my

face be enough for me to want to live? Will a caring hand on my shoulder, the taste of French fries, the sound of jazz, the sight of a beautiful painting or sunset be enough? I do not know the answer.

I *do* know that dementia unfolds in stages. Although many people in the early and mid-stages are devastated by the growing loss of important abilities and develop mood or anxiety disorders, others have "full" lives that include the pleasures of friendships, love, and sex; the satisfaction of participation in social and communal activities; and even the discovery of new interests. In fact, some experts on dementia (see, for example, John Zeisel's book, "[I'm Still Here](#)") maintain that diminished cognitive functions result in the release of capabilities that have been suppressed by the very cognitive abilities that are now in decline -- particularly the willingness to take creative risks and the openness to human affection and intimacy.

There are, as we all know, people with dementia who become depressed, frightened or angry -- some so angry that they are abusive to people who try to care for them. There are some people with dementia who wonder why they are alive, or wish for death.

But there are also people with dementia who experience pleasure, who feel love, and who are at peace.

So, even though I still fear developing dementia, I no longer say with any sense of certainty, "Just shoot me."