

## Chapter 5: Eldercare

### 01 – “TOO YOUNG FOR YOU” (ME, THAT IS)

Some visual events really happen while you're seated at your PC, maybe in a cluttered apartment, at a bank of three of them. Your landline phone is on the Titches sofa, and your mom, recovered from heart surgery a year earlier, is reclining. You answer the phone and talk to a young lawyer about all of your libertarian theories, and finally stop.

Okay, I will now switch to the first person. She asks me who it was, and I say a lawyer friend whom I will visit after the Y2K holiday, in January. She asks how old he is, and I say, truthfully, about 30. She says that's too young for me. Now, I don't really have an opinion about him physically anyway; he's unremarkable (and not in the movie picture). But she says that's too young even for "friendship." At the time, I'm something like 57. Then she talks about "real life."

This has happened a couple other times in my own community. Recently, I shared a video from MSN about bedbug battles, and noted the attractiveness of the local actor (a mature adult, to say the least, at about 25), and got at least one comment, "he's too young for both of us."

I remember another moment at a gay pride event in 1999, when someone active in fighting "Don't Ask, Don't Tell" appeared at the GLIL pavilion. He had suddenly gained a lot of weight in the stomach area. It's possible (remembering the incident in retrospect) this was due to protease inhibitors. I did say something to him about this. A month later, back in Minnesota, I got an angry email from him, decrying lookism and saying "what a way to greet someone."

### 02 – GETTING OLD: THE BASICS

Senescence is the destiny of every one of us who lives long enough. Providing for one's needs at end of life is rapidly becoming a big issue, especially as life expectancy increases.

Every one of us will age. That's the result of entropy, according to physicists. Reproductive life and consciousness may be nature's antidote to entropy, throughout the Universe. No one notices the gradual "autumn" after biological solstice in the twenties. No one can get into a time machine and experience his or her body at 21 decades later.

Analysis, functional decomposition, is in order here. As people age, they face two issues. One is less income, from being less able to work, or sometimes just because employers wrongly believe they are unable to work. The other is health, not just more medical care, but the greater likelihood of needing caregiving services, or custodial care. This whole process affects women more than men because they tend to live a few years longer.

There are three ways our society provides this care, and we tend to both combine and confuse them.

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One is that people save for their own retirement (maybe including a spouse's). That can include payments of pensions or annuities, or simply accumulating enough savings to earn investment income. That's the mechanism that libertarians like. But the actuarial models for sustaining the (private, "Wall Street") investments that support pensions, especially for public employees, have come under criticism and need real reform, particularly to take into account changing demographics, as we will see.

A second is that younger or extended family members support them and take care of them, physically and/or financially.

A third is that government safety nets take care of them.

The Religious Right is sometimes critical of the idea of the safety net, saying that it lets adult children off the hook for remaining loyal not to just their parents but to their entire families. But the notion is deceptive, because what seems like a safety net is partly really individual savings.

Social Security retirement benefits by and large are related to the FICA taxes one (or one's spouse) paid, as if they were like "annuity premiums." (Actually, it's a "layered" formula with several "tiers.") It's true that because of longevity, fewer workers and the economy that the FICA taxes are no longer adequate to fund promised benefits forever. But private insurance companies providing life annuities and pension plans have the same problems.

Some of FICA is a "tax." For example, in the beginning, elders who had not contributed received benefits. If you don't have 40 covered quarters you get nothing for your "tax." And if the shortfall were met by increasing the wage base, it would become a "tax" to the extent that the extra taxes would not necessarily provide higher benefit levels for those who paid them. It also provides some disability pre-retirement insurance.

Since some of the Social Security Trust Fund has been spent on other government projects and covered with double-entry IOUs, it could be said that, if the country is really broke, some of the Social Security benefits even for current retirees (maybe up to a third) could be means tested and forfeited for those with enough other income or even assets.

If Social Security benefits were completely means tested, then FICA would also resemble a true tax.

There was a Supreme Court opinion way back in 1960, *Flemming v. Nestor*, which said that Social Security beneficiaries do not individually have a legal claim to future benefits based on the tax they paid, however FICA may look like an annuity premium. That means that Congress can take them away or means test them, possibly to get through a runaway financial crisis, or to deal with the "demographic winter" problem. As a purely legal note, it's important to note that the Treasury still may have to pay Social Security for what it has borrowed (that is, the Social Security Trust Fund is a "bond holder" and may have legal priority), so in practice there is less danger of sudden cutoff in a debt ceiling crisis than most liberals claim. There may exist questions about whether the Trust Fund has the same "standing" as an international creditor. Social Security still must always make payments then as Congress has

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previously directed. But Congress can make sudden changes and reduce or even eliminate benefits for some people.

Most politicians say that they will protect benefits “as is” for current retirees and are mainly concerned about providing a dependable, partially or totally privatized “ownership” scheme for younger workers. But a few say that there is no moral reason why even wealthy seniors today should continue collecting it, if the US is “broke” and borrowing up to 40% of its budget. This came up during the debt ceiling debate in 2011, when there was a real threat that the government would stop paying bills it already owed, including benefits to existing Social Security recipients. Some bloggers (including me) urged the government to publish exact numbers per beneficiary on what their FICA (and their employers’ and spouses’) contributions covered actuarially, and pay only that; others talked about lopping off the top “tiers” in the benefits formulas.

Some European countries (especially Sweden) have worked on converting their “social security” systems into “notional defined contribution” systems, where retirees do own their benefits but where they can be scaled back automatically as longevity increases. This idea could indeed “save Social Security” in the United States but it would come at the expense of the less well off.

And complicating all of this is that not only are employers pulling back on “defined benefit” pension plans (and sometimes failing to honor existing ones – with the worst cases including municipalities who had taken their workers out of the Social Security system altogether), but until a few years ago, they had counted on winnowing out workers in their 50s with “early retirement,” not only encouraging a premature start of Social Security benefits, but also applying “Social Security offsets” against their own pension payments. There’s still another mean wrinkle: Social Security applies “annual earnings limit” tests against early beneficiaries to make sure they have “really retired” – a nebulous idea at best. (If someone starts Social Security at age 62, he or she will lose out because of reduced benefits if the life span is 78 or longer.)

The discussion of Social Security prompts a mention of the debt ceiling crisis, which erupted in 2011 and threatened to do the same in early 2013. Actually, as I just noted, the immediate threat to current Social Security recipients is probably less than many doomsayers predict (including myself in the past). But the overall threat to economic stability and to assets is serious, maybe grave. Many people, for one reason or another, could get “stiffed” and have to turn to each other for support. There is an element of our governing culture (some radical House Republicans) that wants to see a “purification” or “revolution” that would throw people back into old established social structures (able to defend themselves and families with firearms in a survivalist culture). It’s important here for another reason. One reviewer of my book *Do Ask, Do Tell* on Amazon was quite critical of claims by me that libertarianism “would advocate the use of the established political power structure to deconstruct itself,” p. 325. Indeed, that seems to be what some people in Congress are trying to do with the debt ceiling matter. (That is, if you think of the Tea Party as “libertarian” -- or is it just super-partisan and quasi-faith-based, willing to drive debate into the world of K-street lobbyists as much as any political group?) Be careful what you wish for.

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There was a point early in the summer of 2011 when House Speaker John Boehner (and I believe U.S. Senator Rand Paul of Kentucky) suggested that “better off” seniors give up Social Security benefits immediately because “we don’t have the money” (false). I did not think this was funny. Yes, one could make a case and say, well, if I had become a life insurance agent or tax preparer, I wouldn’t “need” my benefit. I find it extremely offensive to “give up my life as I know it” (because of a “broken promise” for a life-long benefit I thought I had “paid for”) to sell services that “take care of other people’s families” when I didn’t have one. I’m jumping ahead for a moment to record a knee jerk reaction.

There’s not much question that a growing elderly population means that, by and large, adult children will have to take care of their parents (or sometimes other relatives) to the extent that parents don’t take care of themselves, and to the extent that the safety net falls short. And, yes, as adults live longer, their adult kids will have more “burden” to support, and in middle and upper classes there are also fewer adult children to help support their parents.

So much for retirement income. Let’s move to medical costs. Again, the debt ceiling debate could force sudden changes, maybe.

Medicare is also partly funded by collected “Medicare taxes” so in some sense it really does mimic a “health savings account.” (Some claim that only about 25% of Part B benefits are paid for previously by recipients, the new Part D, even with the doughnut hole, is even less “personally” funded. Medicare is much less “self-funded” than is Social Security.) But the real problems with runaway Medicare costs have to do with economic mechanisms. There needs to be completely automated record keeping and prescription information (doctors shouldn’t have to request paper records and lists of meds from family members; HIPAA could take care of this). There needs to be tort reform and the end of gratuitous tests. There need to be age and circumstance-related guidelines as to end-of-life care.

Still, the controversial problem comes down, as already suggested, to the obligation that adult children have to care for their parents.

That issue is generally first seen in terms of providing custodial care at the end of life. Medicare generally does not pay for custodial care (except for a little bit of hospice); it only pays for skilled nursing care, where the patient is expected to get better. So patients are left with self-pay (from savings), or long-term care insurance (which can be difficult to claim), or, after spending down assets (or if the individual has no assets), state Medicaid (which has federal participation). And the federal government and states have strict “look back period” rules regarding giving away assets to heirs “viatically” in order to qualify for Medicaid. It is true that some states have experimented with “partnership” LTC plans to relieve some of the giveback rules.

The Obama administration maintains that the Patient Protection and Affordable Care Act of 2010 (“Obamacare”), for all its controversy (contributing to the 2013 debt ceiling cliffhanger) and initial difficulties at implementation, will strengthen Medicare and care for seniors as well as for the general population. This is an evolving issue. In any case, it seems to do little or nothing about custodial care.

### **03 - FILIAL RESPONSIBILITY**

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But there are more sinister problems. First, up to 28 states have “**filial responsibility laws.**” These allow states to go after adult children to force them to support indigent parents (presumably not ever in a position to give away assets at all), and sometimes siblings or even grandparents (assuming they are still indigent if receiving Social Security). In some cases, these can be interpreted as allowing states to go after adult children for Medicaid nursing home bills, if the state determines that there are adult children able to pay. Laws give judges discretion in deciding which among adult children should pay, but the childless could obviously be targeted. As states become more stressed to balance their budgets by recession, some may be more inclined to enforce them. Some states have time limits (5 years in Virginia), and Pennsylvania recently (in 2005) took the provocative step of moving filial responsibility from the welfare code to the family code. Virginia’s law (20-88) has this link: <http://leg1.state.va.us/cgi-bin/legp504.exe?000+cod+20-88>.

These laws have been enforced so far in at most scattered fashion. But there was a complicated case (of John Pittas) in Pennsylvania, reported in the media (to the press establishment’s shock) in May 2012. I had never heard a reporter mention the term “filial responsibility law” on the airwaves until it (on CNN) woke me up in a remote High Sierra California motel room one morning just as I turned the TV on, well before breakfast. The question can certainly challenge modern perceptions of “family responsibility” (like in the 1998 movie *One True Thing*) and turn them upside-down. In the soap opera *Days of our Lives*, in 2012, the gay college-age character Will Horton got a female character pregnant to prove to his father that he is “a man.” Now he faces responsibility to raise the baby (which could derail college). But my point is he could face responsibility for his parents anyway. He could be “better off” with children after all.

The methods of delivery of care lead us into sensitive territory. Everyone dreads nursing homes, but better assisted living centers offer much more privacy and varied activities. A really good concept is the CCRC, or continuing care retirement community, where the senior buys a condo or pays an entrance fee and lives independently until he or she needs assisted living. The individual is then able to move into an assisted living facility within the same community.

But social workers are increasingly encouraging keeping seniors at home and bringing services to them. A whole industry of home health care has developed, which is more expensive than either nursing homes or assisted living, if at a strictly hourly rate for 24 x 7 (except for the “live in” exception).

What is controversial is the extent to which adult children give unpaid care themselves, giving up their own jobs or lives to take over responsibility that they sometimes rightly feel was “dumped into their laps,” especially if the parents cannot afford to hire care (filial responsibility) on their own, or resist care from outside the family, which often happens in practice.

It’s interesting to recall how this was handled a couple generations ago. Until the 1950s and 190s, at least, unmarried adults (especially women) tended to “stay home” and be “chosen” to look after their folks, all relatives. On the other hand, most of the time, when old people got very sick, they didn’t live long. Not much could be done, so periods of intense caregiving were often short. Sometimes unmarried

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adults inherited more for taking care of their parents, and the funds tended to go toward taking care of them.

A modern individualist would say that's a "**family slave**" situation and view this as second-class citizenship or station in life. But filial responsibility can be particularly challenging for an adult (especially a male) who did not have his own family.

Typically, the law requires that the adult child make sure that the adult parent is adequately cared for and not neglected. If the parent has adequate savings or insurance, then of course this may be used; so it's not the same thing as being responsible for a financially dependent minor child. Although, some people are saying that people with Alzheimer's disease or even purely vascular dementia often act like "children," forcing adult children to parent their parents – a notion I find offensive.

Frequently, the adult child arranges with an elder attorney to get various powers of attorney to manage the parent's affairs. It may be advisable to build a living trust. In some states, forms of conservatorship or guardianship are possible, but typically are not done. The adult child may have considerable legal authority under the POA, which raises a question in reverse. The parent is in a position of being told what to do for his or her own good and losing independence, but the adult child and other caregivers may be stricter than necessary because of fear or legal liability. It shows how easy it is to lose one's independence because of medical or cognition problems and how these problems are seen as potentially affecting others.

The adult child also can be exposed to risks and perils due to uncertainty about how sensitive matters are perceived. Anyone suspecting him of abusing his POA, or neglect or of financial comingling can bring in Adult Protective Services in their locality or state. Some states actually publish guidelines that view "lack of affection" (or loss of it) as "abusive"! Generally, the adult child must not behave in a manner that could interfere with the care provided by others hired to actually do it. For example, now the adult child cannot jeopardize the reputations of other caregivers online, or even leave the impression that he might do so in the future, or a hostile workplace situation could emerge.

That can be tricky, because caregiving experience triggers so many complex and varied emotions. That's particularly the case if the adult child lives in the same residence as the parent but needs to bring in home health care anyway. (It's a little less tense if the adult child owns the house rather than the parent, and having his own marriage or relationship can work both ways; but gay couples have taken care of a parent successfully in their homes). One problem will occur if the adult child resists showing affection or allowing the parent to "depend" on him (or her) "physically." The hired caregivers might feel slighted or that such work is "beneath" the adult child, triggering old-fashioned social tensions. The adult child may (as in my case) say that he doesn't want to allow a non-intact parent to monopolize him if he doesn't have an adult relationship of his own; he may resist being drawn into the world of "protecting" others through social posturing when he was humiliated by the competitive parameters of the straight world earlier in life; he may resent that a parent becomes assigned to him as his "purpose in life" because he had failed competitively earlier. But if a hired caregiver heard this explanation, it could come across as contempt.

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In fact, the experience of medicine and eldercare in the past 15 years is that the effort to give quality care (which is very labor intensive) pays off in considerably longer lifespans, so in an economic and ethical sense, it is creating real issues. Seniors with moderate dementia and circulatory disability may need continual prompting and cuing for nutrition and hygiene. They are more likely to do what is “right” if they believe that the caregivers really love them and “join in” with them at their level of reality rather than that “objective reality” of the family caregiver. (Psychologists call this “forced intimacy” and it always poses ethical problems.) So the adult child, particularly if monopolized away from his own life, is in a position of losing sovereignty himself over his own right to consent to those with whom he will share emotion and intimacy, long considered a basic right in the modern world (but not necessarily before).

The entire caregiving industry is stretched by the explosion of need, but most of all home health, where there are still some battles going on about overtime and where in the future requirements for health coverage will become an issue. (The Supreme Court made an important ruling in 2007 that maintained the exemption for normal overtime rules for live-ins and certain independent contractors.) The heavy employment of immigrants in these positions is likely to add to pressure on families to care for their own (and play into the political debate on immigration).

Because of longevity, **smaller** families face the prospect of having to provide personal care for disabled elders for long periods of a decade or more, and this circumstance will occur much more frequently than in the past. This is not about lack of love or cowardice; it is about wanting to anticipate “involuntary” responsibility and plan ahead for it. We have gotten accustomed to thinking that “family responsibility” starts with conception, an act of choice; but in practice it often happens anyway. (How many people have raised siblings, or siblings’ kids after a family tragedy – the *Raising Helen* scenario dramatized by Hollywood several times.) Family responsibility becomes something more fundamental, and may be demanded of any of us, just as military service used to be for men (and could still be again). It provides purpose and structure and reminds one of what it is like to be really needed.

All of this leads down into existential traps. I know about grace and forgiveness, and yet I perceive sacrifice as what the word means: for a foreseeable time period, it makes someone less, to meet someone else’s needs, or to meet a larger community need. Sometimes it’s fatal. Perhaps it’s better if someone is gone forever, even in the hereafter, so people understand its potential finality – at least in the world we can access now. Perhaps terrorists want us to get that. But then, another question comes up, how “important” was that which I was asked to “give up”? If it’s my self-created fame (which now becomes a liability or risk factor, as it could attract harm to the parent), one could say, why would anyone want to listen to me anyway until I had real “family responsibility.” Why didn’t I think enough of my biological essence to want to have kids, anyway? Shouldn’t wealth and influence go to those who will take and measure up to the intergenerational risks?

The incidents involving “upward affiliation” that I started this chapter with (and covered in Chapter 2) become relevant. The most damning observation seems to be something like this: I had always assumed it was virtuous expressive behavior to identify good and “not so good.” Now I understand “the knowledge of good and evil” problem. I have presumed that allowing someone “non intact” to depend

on me doesn't represent an accomplishment, because it seems to be supporting "unworthiness." The job is all right, within limits, but the actual emotional bond is not. Yet, what good is one's work, broadcast to the world, if it doesn't help someone who really needs it?

This leads to one more step. I would feel an emotional bond for someone "dependent" only if I felt connected biologically and socially to something more important and permanent than me, as well as connected just through individual works or "projects."

#### **04 - ODYSSEY INTO ELDERCARE STARTS ON THE WHITE PHONE**

The chronology of my mother's final years and of my journey – odyssey – into eldercare will certainly help set up an understanding of how my views changed.

Go back to my father's final days. On the first Saturday of 1985, I had spent a day around Atlanta (on a long weekend from Dallas), and flown home. When Mother picked me up at (then) National Airport, she told me she had just taken him to the hospital coughing up blood.

My father had metastasized prostate cancer, and would pass away in just four weeks during the early hours of New Year's Day, 1986. The last time I saw him alive was in a hospital bed in Arlington, after a resident, having just poked through a wrist artery, had said, "you're blood gasses don't look too good." During the three weeks at home, I was told he stayed in my bedroom because the prostate cancer had caused reactivation of his latent boyhood tuberculosis (he had been born in 1903). My father was active and "productive" up to the last four weeks of his life, with dizziness the only warning. He had undergone surgery for an aortic aneurysm at age 74, and recovered quickly. He could not stand the idea of becoming dependent, despite his stable and well-tested marriage. He always did what he wanted, like me.

I went back to Dallas and work in a couple days, and scheduled a trip to come home for New Years, because I had a systems implementation New Year's Day. I got the call from Mother at 3 AM January 1, and came back Jan. 2 on a flight I had already reserved. I was back to work Jan. 6. (I actually still supported the implementation at work New Year's Day.) The memorial service and burial (and reception) all happened on a Sunday afternoon. At the reception, there was a sense of moving on. I even got a sympathy card from the young woman I had once dated before "coming out" a second time.

I had returned to the DC area by 1991, and lived in my own high-rise apartment, while Mother stayed in "The House" which became a Drogheda. Friday mornings I went over and left laundry, and had dinner there Friday nights after work, for about eight years. But in June 1991, while on a trip to see her sister Eppie in Oberlin, she fainted while getting out of bed and broke an ankle. She was 79 then. They put her in "special care" and found nothing specifically wrong. I drove the "tunnel highway" (the good old PA Turnpike, which has been losing its tunnels) out to Ohio and brought her back. Aunt Eppie came back and stayed and looked after her a couple weeks.

During the mid 1990s I had an indirect sneak preview of how (other people's) family responsibility can creep into your life. When I moved back to the DC area in 1988, I rented and then sold my condo in

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Dallas to a woman under an unqualified FHA assumption, for some loss as the market had tanked then during the late '80s "oil bust" and savings and loan scandal. I had not realized or thought about the risk of doing this. The Tuesday after Christmas in 1994, I found a letter from the mortgage company in the bottom of my mailbox (the post office hadn't bothered to make me sign for it). During the week between Christmas and New Year's I found that lawyers can be busy. I made some of her payments, and then tried to foreclose, when she declared Chapter 13 bankruptcy. It turned out well, as by 1999 I had been paid back with interest. But this episode had given me fair warning as to how one can become responsible for "other people's problems."

All was well until a Friday afternoon in April 1996, when Mother broke her right hip on a fall on the front porch while cleaning kitchen windows. I had driven home to my apartment that lunch hour to tend to a matter related to my planned book, but I had not stopped by the house. She crawled to the bedroom and called for help. I got a call at work at 3:30 PM. I went to an SLDN reception that evening, seeing her before and after surgery. In the aftermath, she had some heart rhythm abnormalities, and an intern was concerned that I did not know her medical condition (as to possible recurrence of a 1980 breast cancer) better. A rumor that the fracture had been pathological turned out to be wrong.

Eppie came back again and stayed and Mother recovered quickly. In May 1997 (a year later), she had an artificial hip joint put in. She had some more heart symptoms after surgery, but these quickly resolved on their own. Maybe the doctors let her off the hook then, and me, too. This time we hired a live-in caregiver for about eight weeks while she healed. I remember that I had to co-sign the payment guarantee for the home health agency.

By July, Mother was almost healed, and I felt comfortable about my intended move to Minnesota after the publication of my book, to avoid the "conflict of interest."

In the fall of 1998, I started getting phone calls from her concerned about health. I would feel uneasy if I called and there was no answer. If I was on the road, I would check for messages on my machine from pay phones; I had just gotten a cell phone, but it was clunky and hard to use. Nevertheless, my life went on as normal (really, still one of its best periods, despite my own three-week interruption in January 1998 from my own accidental hip fracture, with a quick recovery and then the usual game playing by health insurance companies) until Sunday, February 28, 1999. I had called the house early Sunday evening and gotten no answer, and gone to a Libertarian Party event. When I got back, around 10:20 PM CST, I got a call from her friend Cecilia about a heart attack that evening. "You should know," she said.

Mother stayed in Arlington Hospital a few days and was treated with anticoagulants, and sent home. I came home for a week toward the end of March. I met her cardiologist. There didn't seem to be a lot to do other than for her to take "rat poison" to thin her blood. She would get herself to monthly blood tests to monitor that notorious INR level.

I made reservations for a trip to Europe toward the end of May. On Tuesday, May 5, I returned to my office desk from a class in object oriented-programming to see the "UFO" message light blinking red, and received another message from Cecilia that late the evening before, she had been taken to the

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hospital again after calling Cecilia and complaining about chest pains in bed. Cecilia had a key and went over there whenever Mother called.

I was in repeated phone calls with her cardiologist that week, who first just wanted to do an angioplasty to relieve severe angina; then they decided that her aorta was too stiff, and by Saturday had decided to do a triple bypass. The second-hand story is that they “ganged up” on her and confronted her on Saturday afternoon. At age 85, she was considered to have a 90% chance of survival. Monday morning, they got her up at 5 AM, cracked her open “like a lobster” by 7, and were done by noon. They said “take Sal Hepatica by 7, feel fine by 9”; my father believed that back in the 1950s.

I did not return for the surgery. I’ll get back to that in a moment. On Monday, as I returned to my Minneapolis apartment during the lunch hour (it being only a Skyway day jaunt from the office) the white phone rang and it was indeed her surgeon, who informed me that the five-hour procedure had gone well; the only problem had been to clean up the excess bleeding. It’s quite an experience for the patient: you’re denied water for about 12 hours, and they get you up at 5 AM, shower you, and then knock you out. As I hinted already, I had one bout of surgery myself in early 1998, after a fall in a convenience store and a serious acetabular fracture. I recovered quickly and was back to work in three weeks; Mother did not come out to see me until I had recovered and thrown out the crutches.

In ICU after surgery Mother was, in fact, incoherent over the phone for a couple days, but on Saturday they suddenly sent her to a skilled nursing facility or SNF – “still” a nursing home.

The following Tuesday afternoon, I left Minneapolis on the Northwest-KLM “party plane” for Amsterdam, and did my prepaid nine-day trip. I was indeed distracted. In Bayeux, France, (probably in the museum with the Tapestry), I lost my rental car key and had to have the car replaced in Caen – which in theory could have exposed me to liability for the car had anything happened. (Hotel keys in Europe are so big that they cause other keys to fall out of pockets.) I “met someone” in the Connection Disco in Berlin, with its downstairs exhibit making light of the Holocaust. I visited the site of Auschwitz in Krakow, Poland. I wandered the streets of Dresden. I did all of this in nine days.

Shortly after I got back, Mother was discharged from the nursing home, and I arranged 24-hour live-in care by phone. In about twelve weeks, she was well enough to be by herself again.

Now we come to the hard part. Why didn’t I go back immediately? Let’s say first, I did go back for about a week in early June, after Mother had returned home. And I did hear that she had been mistreated in the “skilled” nursing home. One night, a nurse’s aide refused to help her go to the bathroom, after surgeon had ordered that she not get up on her own for some time until the sternal stapling healed. Fortunately, she wasn’t injured. But Cecilia registered a vigorous complaint with the state ombudsman. I shudder to think of the complications had the surgical wound unraveled.

While I was home in June, I did get an earful of pressure (from a friend of Mother) to get my employer to transfer me back to Arlington. I did not give in to it. As explained in previous chapters, we had agreed I would not work in Arlington again over the “conflict of interest” problem over my public involvement and book on the “gays in the military” issue (discussed in Chapter 3). Moving back, in my

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case, meant “sacrifice,” the loss of the job. I won’t indulge in speculation as to whether I could have picked up a quick Y2K mainframe job, but having to stay home in Arlington would have been a big problem, as most of those jobs involved travel and living in corporate apartments. (You can certainly make a case that I should have “sacrificed” enough to use unpaid family leave, as mandated by the 1993 Family and Medical Leave Act [FMLA], as well as vacation, so that she could avoid any contact with nursing homes at all.) So here I was, facing a certain self-created irony, a personally dangerous situation that tracked back not only to the “don’t ask, don’t tell” problem itself but that reached back to earlier eras (when there was a mandatory draft), when gender nonconformity had been viewed just in “moral terms,” as a way to evade shared responsibility and risk. And we could make a moral argument: I keep my life intact, whereas a “live-in” has no life of her own at all. She gets to live in a nice house for a while, as my mother once said. This was the best she could do; she can’t run out into the street and scream “I’m free!” like a friend of mine does in a controversial video. Later, a family friend would refer to the live-in aide (pre 9/11) as “illegal,” but I’m pretty sure that both of the live-ins we hired had green cards. In any case, it was the home health agencies who were probably legally accountable, although that’s a tricky matter legally if the hiring family “suspects.”

But, in this case, the old adage “it gets better” applied. By August, she was doing well, when I visited her again on a weekend trip that included a stop to look at West Virginia strip mining and mountaintop removal.

In fact, she flew to Minneapolis and spent two weeks in my one-bedroom apartment in downtown Minneapolis for Christmas and the Y2K New Year, when I did have to work. She slept on the living room couch. She was her old self. That’s what led to the conversation that opens this chapter, about someone’s being “too young for me” even at adult age 29.

When I was home in April 2000, I visited a Sunrise assisted living facility myself, to see if a placement like that was appropriate. At the time, a small two-bedroom apartment in one would have cost \$3600 a month. I didn’t yet understand that other kinds of facilities, called CCRC’s (like the Goodwin House), where you live independently as long as possible before using assisted living services, were a more appropriate idea to check out. Mother had actually looked at a pricey high-rise in Arlington called the Jefferson as early as 1991, shortly after recovering from her ankle fracture. Maybe she didn’t go anywhere with it because I seemed to be so preoccupied with work and overtime.

Mother, well after open-heart surgery, even went on a cruise in early 2002, I think. But she was living alone in a big house with basement stairs and particularly steep attic stairs. Nevertheless, I decided to return to the DC area in late August 2003 and live with her after a lease ran out in Minnesota.

It may have been premature, as far as her needs went, to come back. She still did very well for at least four more years. During that time, there would be four hospitalizations for internal bleeding related to Coumadin. Nevertheless, the cardiologists, monitoring her for an official diagnosis of aortic stenosis (based on a shrinking “aperture measurement”) and congestive heart failure, kept the medication the same. She took about eight pills and at the time was able to handle her own medication

(with pill boxes) and her own finances (although the latter was all strictly by hand, the old-fashioned way).

### 05 – PRODIGAL SON

One could say there was a bit of a winding down in her life. After I came back, she would never be farther away from home than Ohio, where she went several times, to see Eppie, who eventually had to move into assisted living there. I usually drove her to BWI for Southwest Airlines, but in 2006 I drove her out, flew back, then returned to drive her home. She had a large old Chevrolet Celebrity, and I had my Escort.

It was apparent that there was some strain in our relationship. She really did live for “family” as a collective experience. It wasn’t so much about my being gay (although as far back as 1990 she had once said she had hoped I would meet a “nice girl”) as it was my separation from the fellowship of others, and the possibility that **my attention-getting could attract harm to others in the family or community**. Ostracism happened, in her experience, because a community or family was threatened with loss of sustenance. This belief is something she had been concerned about with respect to my 1997 book (a copy of which she had kept “hidden away” in a closet, as in Josh Groban’s song). She once said that I wasn’t careful about “my family,” an irony indeed in my mind because I had not married or had children or done anything to form a new family limb that would be really “mine.” Yet she really didn’t understand that through the Internet and Web I was still getting public exposure (through search engines, especially, in the era that led into Facebook) that I could not have achieved in earlier days when people had to “compete” to “get published.” She did not know how to use a home computer, and probably wasn’t capable of learning at this point. I had a large Dell desktop and high speed Comcast in the basement – I paid for it, buying it right after I returned – and she really didn’t get what was going on. Her concerns about family reputation came from old-fashioned notions. Before I went down to a gay rights dinner in Richmond in 2005 she worried about my appearing on television and asked if I would keep a “low profile.” (Earlier she had said that I should never again mention “William and Mary”!) Nonsense, I was on the Web. The whole rest of my life was invested in my story (if I didn’t want to become a huckster, which Mother really wouldn’t have wanted if she had grasped all of this). Yet, in the post 9-11 world with the sudden “walking in” to family responsibility, and with a rising crime rate during the agonizing Bush years, I felt that the notion of “**protecting**” other people (from external “jealous hostility”) in a family (or school, as in the subbing) had been “imposed” on me; I had never experienced it before. (One can ponder how this has escalated, as with the flash mob problems, including those in Britain recently.)

Mother was a finicky housekeeper (taking care of house didn’t leave her time to “accomplish” other things in the sense that I am accustomed to thinking), spending hours on dusting and on caring for every square inch of the house, as if we could suddenly have to extend radical hospitality in an unforeseeable emergency. It was touch-and-go to keep her away from my stuff in the basement. Placement of old furniture from my apartment in my bedroom was an issue because she could trip over it – but why does she need to come into my room? See where this was headed? She was always asking about my whereabouts late at night (clubs, sometimes); in my 60s, I felt like a child and a bit of shame

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about living with my mother. True, I had never paid rent since coming back, and that “Wesley Mooch” element was weighing on my thinking. I converted my IRA from my last job at ING to a faster kind that would allow me to simulate income, in case the attention I was getting from the Web forced me to get an apartment. As a result, I paid more taxes than I should have.

In the late summer of 2007, things started to change. She fell in a nearby parking lot while out shopping by herself. The medics let her drive home, and she started acting more dependent, as she felt weaker and had much more back pain after the fall. (“I’m down in the back.”) But again, very slowly, she got better again. In retrospect, I think the fall could have been caused by a very small stroke.

For about 20 months or so, my own life receded more into twilight. I worked very little. I was “afraid” to leave her alone for periods of more than a few hours. A few years before, when I had been substitute teaching, she had not been very concerned about my comings and goings, but now she often complained about my “staying out late” some weekend nights (yes, the discos). Before, I had often left in the late afternoon on a weekend for a movie and full night out, and now I waited until about 9:30 so as not to leave her alone to possible falls for more than a few hours. She would sometimes pester me about the basement, when she was able to step down the stairs very slowly.

In December 2008, she had a third hospitalization for internal bleeding, and in March, a fourth. By then, I had started doing the pill boxes. She was still driving and doing some errands herself, but sometimes getting lost, as when going to a friend’s house or to Eastern Star. But she never had trouble finding her way to the First Baptist Church of the City of Washington DC in town (near Dupont Circle ironically), which I had “grown up in,” or finding her way back from it alone. After the fourth bleeding incident, they finally stopped the Coumadin, and switched to Plavix (no more blood tests).

In the meantime, I was starting to get criticisms from people that I was personally inattentive, as to matters like her choice of clothing in the morning (there was even a discussion of her bra [related to mastectomy], an intimate matter way out of my element). Because of my own adult “choices” (or lack of them) I had never “tended” to anyone’s more adaptive or intimate needs this way in my life. (I would have had to court women, marry and have children first myself, I thought, or else become a “family slave.”) I found myself the subject of inappropriate comparisons to others.

In April of 2009, sometime after she had come home from the most recent hospitalization, I did start to confer with an eldercare lawyer. I had official powers of attorney documents drawn up. We discussed setting up a living trust, which might have to be done soon if she were developing dementia; we followed through shortly. I would have a lot of “authority” with a POA document and responsibility for a trust. In Virginia (and most states), it’s possible to set up formal conservatorship or guardianship, but I did not want to do this. I wanted to keep things informal. I wanted her sense of continuity with her whole life to remain intact, and as time went by, it always did.

On Friday morning, May 22, 2009 she woke up complaining she felt “upside down.” For the third time in six months, I called on emergency services. This time, it was determined, after a couple of targeted MRI’s, that she indeed had a stroke. She was released Monday, Memorial Day, into rehab – another “skilled nursing facility” – this time, the Jefferson, now operated by Sunrise. She stayed there

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for the 20 days allowed by Medicare, with her “residence” comprising half a room, marked off by a partition, from another stroke patient. Nevertheless, I brought a closet-full of her clothes over, and she had lots of visitors, and there were lots of activities, including one sing-along concert. It struck me that concert musicians or pianists could make some of their living playing in assisted living facilities or nursing homes (while maintaining a little psychological distance).

She was discharged with a diagnosis of extreme frailty (due to progressive congestive heart failure) and (mild) “dementia.” It was probably more related to vascular problems and heart failure than to an Alzheimer’s process. She did have short-term memory problems according to accepted neurological “quizzes,” but she never had problems recognizing family members or close friends or remembering the basic course of earlier portions of her life, including her 45 years of marriage and her being brought up in Ohio and coming to Washington to work in the 1930s, and could relate to old family pictures. Indeed, her desire to stay in “The House” was anchored by the previous (only) 45-year marriage, which had lived through what might have been a serious challenge back in the ‘60s (because of what happened to me). I was told (by at least two nurses) she should not be left alone again, and that I had to have coverage anytime I went out. Mishaps (particularly with people on memory-related meds) could lead to questions from Adult Protective Services or to legal consequences. Some of this “advice” may have been dubious; it is common now for physicians to order medication for even milder symptoms to prevent them from progressing, and every case is different in some ways from what is said in the literature. Extreme frailty may have been a more valid reason not to leave her alone. The Virginia Statute (link <http://leg1.state.va.us/cgi-bin/legp504.exe?000+cod+18.2-369>), 18.2-369, is somewhat vague (in the final analysis) of a few matters like whether a “responsible person” must have become so voluntarily, and seems to have some “outs.”

The Jefferson recommended an agency to provide home health services, and the attorney had contact with another agency. I decided to work with two agencies in order to be sure of backup.

For a while, Mother got a little better, and I actually used the services intermittently, except for some scheduled help with bathing. I tried twice to set up respite visits to Ohio for her to see her sister, but medical issues related to decline with age kept coming up. In October 2009, she had another lumpectomy on the advice of her surgeon, after which the decline seemed to accelerate. One caregiver criticized me for not “taking charge” of medical providers – in this case, a surgeon who could have been motivated financially to provide unnecessary surgery given her age. Again – I resent being expected to manipulate people into doing what they should do anyway – I did not choose to be “in charge” of “protecting” anyone. We had already seen this with the SNF stay after her coronary bypass surgery.

In November, I scheduled help every day Monday-Friday, and after the latest cardiology tests, called Capital Hospice, which agreed she could qualify. So we had intermittent visits from hospice nurses and a social worker (and even a minister) during her last 13 months. The norm for acceptance into hospice is a life expectancy of six months or less, but many patients with home care from Medicare-supported hospice live longer than expected.

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We had oxygen service (simple compression canisters) after March, and by September she was on it 24x7. (No one smoked; my father had given up the habit after his “mild heart attack” and my William and Mary expulsion, in early 1962.) She also needed a wheelchair by then to go from room to room – including the bathroom at night. I would buy nutritional supplements, like Ensure, as she lost weight. The medication was a balance between controlling fluid in the lungs and dropping blood pressure.

Her course was up and down, with only a gradual trend down. Scheduled help, however, enabled me to get out more reliably. **For about 19 months, I could not comfortably leave the house for a significant time without making sure that help was there – I longed for old freedoms.** In April 2010, I started working as a Census taker, and about that time we pre-scheduled day help seven days a week. In late September, her decline was severe enough that we had help 24 x 7, until she was taken to Capital Hospice on December 10. I was actually at a “don’t ask, don’t tell” rally downtown.

I certainly have a personal perspective on this, which from an individualistic or “selfish” perch is disturbing. Why did I not show more “affection”? I can’t deal with emotion being demanded of me from situations I did not create. I had already experienced this with the substitute teaching. At a certain level, I had to deal with right and wrong on my own. But I also began to see the importance of social connection, that at an individual locus, there was a certain “Heisenberg” quality to morality: you really couldn’t count on people to do everything they had promised or contracted to do, because at a certain point it becomes impossible. It’s the bigger picture – the family and community, and its ability to sustain itself – that matters.

It could be said that I was lucky enough to hire caregivers (with her funds built up by my father’s consistent and conservative family savings and investment practices – lots of utility stocks for openers) for hands-on, close-up and intimate family work that I should have been doing. One caregiver even said that “loving” the patient was part of the job! The caregivers may well be underpaid, which gets into another big political and potentially legal issue that is starting to surface as the demand for eldercare grows. There is a legal controversy in many states over the mandatory payment of overtime to caregivers (at time and a half), although the Supreme Court, in a Long Island NY case, ruled in 2007 that this could not apply to live-ins. One could argue, for example, that I could become responsible for their kids, or that, as a response to growing demand for eldercare, people will be pressured into forming new familial relationships outside of traditional marriage to get some economy of scale with both child care and eldercare. It puts a whole new spin on family responsibility as being much more than a matter of following through on one’s own sexual “choices” (to have children or not). Remember how the movies (*Raising Helen* or *Saving Sarah Cain*, or the television series *Summerland*) depict the problem of suddenly having to raise a sibling’s children after a tragedy. Turning this around, I am in touch with the idea that if responsibility is demanded of me, I need the lineage to go with it. People would implore me to “take charge” and be able to manipulate the medical establishment to “protect” her, behavior that, as I have noted, is psychologically alien to me, having not gone the path of (heterosexually) marrying and having children.

In broad retrospect, it seems to me that I entered a final endgame in managing her caregiving about eighteen months before her passing. In late 2009, after an echocardiogram that showed extreme

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narrowing, we conferred with Capital Hospice, and used their services at home under Medicare (there must be an expectation that the normal course of illness would leave less than six months to live, but in practice this is very unpredictable). I learned a lot about elder medicine (including the Part D doughnut hole), but I never learned to administer injections myself.

My mother had always wanted to stay in her “Drogheda” home, site of her nearly half-century-long marriage, as long as possible, till the end. To live in a small apartment in an assisted living facility (we showed her the Emeritus in November 2009 – the amount of physical downsizing in square footage of private living space was rather shocking) would have been a tremendous resignation, not just a downsizing. Emeritus told me that the Alzheimer’s unit (which my mother would not need) was 70% female, because women live longer than men. (One matter that surfaced was the requirement to take a TB test. I was concerned about that, but we never did it – she might well have been exposed to my father in 1986. I explored this issue with the local Health Department and never got much of an answer. Conceivably, someday, it could become an issue even for bringing caregivers into the home. I also wondered what complications I would face if bedbugs ever somehow got into our home.) At the end, when she went to Capital Hospice, she was taken out of her beloved home for the last time, never to see it again.

Our “society” probably cannot “afford” to indulge everyone in their last years the way my mother was; this becomes a matter of “family,” and willingness of others to “feel” for kin in a preferential manner. In earlier generations, unmarried or childless family members tended to accept the idea that they would be the ones to take care of their parents, as part of belonging to something that transcends themselves – an idea that’s essential for a society to sustain itself – but in practice, critically or terminally ill elders did not live nearly as long as they do today, because not as much could be done to keep them alive, let alone have some quality. This is a paradox; longer lives for elders are making us rethink our values with respect to how we can sustain our way of life – especially the moral ideal that human life, as opposed to all other animal life, must be revered for its own sake as much as possible. In the past ten years, adult children have been stunned by the amount of sacrifice involved for their parents – again, not a result of behavioral “choice”; this includes both the “childless” and the “sandwich generation.” The explosion of Alzheimer’s disease will only make the caregiver “burden” grow rapidly. It’s important to understand that eldercare responsibility has become controversial in recent years in a way that it could not be when medicine was less able to help people to live as long.

The hospice social worker repeatedly suggested the idea of a live-in. I could have moved from my own boyhood room to the basement. (Or possibly moved to a senior apartment myself half way to Fredericksburg.) I did not think we should “take advantage” of someone and keep them 24x7 so I could “have a life.” That sounded immoral.

Emotionally, I found all of this very unsettling. I, in my 60s, had become a never married man winding up living with his mother. It was not OK with me to look at it that way. I even experienced an existential argument with one weekly caregiver, who said rhetorically “she’s not your mother.” But I could not allow someone to monopolize my life, unless I had entered into an arrangement which extended me forward. Suddenly, it had become unacceptable to have never married and had children.

## 06 - LANDING

The last time Mother could understand me was that Friday night at Capital Hospice. Some music played into the bedside speakers. Oddly, it was one of my favorite pieces, the finale of the *Symphony #2* of Robert Schumann. Saturday, I went on an already arranged train trip to New York to a concert by Timo Andres (more Schumann, as well as his own music actually based on Schumann), and came right back. She never regained consciousness when I was there, and passed away Tuesday at around noon. It got a cell phone call back at the house.

There was a graveside service in one week, and a wonderful memorial service at the First Baptist Church of the City of Washington, DC on a Sunday afternoon in mid-January. Yes, I did address “don’t ask, don’t tell” in my own remarks. The music included the Schumann, the last music she had ever heard.

The day before her passing, I had received a call from Census about a kind of extension of the job I had performed earlier in 2010. A confidentiality oath (and normal business confidentiality anyway) prevents me from going into details. But I can say the transition to a new life was sudden. I would spend the first week of January in Charlotte, NC in training, immersed so suddenly I could hardly grasp what had just happened. And I have one general remark about the interviewing I did. Some families I visited certainly experienced life within the family unit much more “intimately” (in a psychological sense) than I did, and my presence probably was a bit disquieting for both sides.

## 07 – POSTSCRIPT PRINTING

Notorious “right-wing” pastor Pat Robertson in Virginia Beach raised some eyebrows recently with his remarks to the effect that it might be forgivable for someone to divorce a spouse with Alzheimer’s disease, because the tragic disease is a kind of death.

I could take offense at the remark. Milder dementia is not death, and one could wonder if someone would leave an aging spouse because of lower attractiveness due to what Dr. Phil calls “tissue death,” or diseases affecting sexual body image like breast and prostate cancer (and testicular cancer, which occurs at younger ages).

To look back, I could compare my eldercare experience with that of being an AIDS buddy (Chapter 2). It’s not the same. Originally, full-blown AIDS patients had little time to live but had not enjoyed prolonged active lives until the 1990’s. Now, people often live “productively” for decades after HIV diagnosis, because the medications have become that effective. AIDS has become manageable in many cases, and not necessarily a sign of decline. Alzheimer’s and other diseases usually associated with aging play out differently. In our culture, they represent a last chapter of life. With the nation facing the possibility of 15 million cases of Alzheimer’s by 2020, there is plenty of incentive to develop drugs and other mitigating and preventive strategies. It’s possible to show moderate clinical plaques in an MRI but still have few symptoms that affect daily life, but an MRI can be a sign that medication (however expensive) should be started.

But Robertson missed a chance to support his own belief system. The “problem” with a lifestyle like mine (with all the emphasis on fantasy and upward affiliation, larger than just homosexuality itself), is that it does not prepare someone to integrate the self into a community and take care of others when called upon to do so – something any society that places a high value on human life must sometimes do. (The moral underpinnings on the debates about abortion and euthanasia – even the Terry Schiavo case – are similar.) Anyone could be expected to take care of others but not everyone will be. That uncertainty – meaning “life is not fair” – lies beneath the need for religious faith, especially notions like grace and forgiveness, as well as personal compassion, sometimes called “the hidden resource.” It seems as though Robertson is caving in and walking away from compassion himself. And there was a further wrinkle in my case. I had drawn attention to myself with self-publishing, and all the sudden people wanted me to take care of them. Interesting!

I will face the issue of managing the risk of my own future need for long-term care. Insurance companies offer “single-premium” plans, with limited monthly benefits for custodial care, normally when at least two daily life activities are compromised. (But the standard of negligence for an adult child could be less.) This could be predicated on intrusive interviewing and medical exams and monitoring (maybe even Holter monitoring) by the insurance company. Am I morally obliged to subject myself to this because I had no children who could “take care of me”?

I still believe that in elder medicine, sometimes “less is more.” I would prefer to address quality of years, with activity, than quantity, with life-extending treatments like chemotherapy or even (as for prostate cancer, sometimes), castration, leading to down time, misery, and even humiliation.

But this whole experience reinforced “one true thing” from boyhood (as had the substitute teaching): People expected personal attentiveness from me as a sign of my values. They saw it as primal, not the result of marriage or women. I had dropped it like a fumbled ground ball, way back when.

### **08 – AND EVEN MORE CONCLUSIONS**

As I’ve noted, I felt a certain shame in the way I lived during the 88 months “at home” after I returned to look after mother. It would have been all right had the care taken place in a home that I had set up, under a relationship that I had also established. I felt a bit like a parasite. And I had lost a lot of freedom. In part, I was a sixty-something living with his mother.

I did resent “emotion” and “attentiveness” and even protective combativeness being expected of me when I had never “signed up for it” by marrying and having children. On the other hand, having my own children would have made all of this make sense psychologically, because then I would have had “my family.” In fact, I recall a conversation, around 2006 or so, when Mother said she wondered if I had much regard for “my” (“your”) family, when I hadn’t procreated one. I wondered she had gotten wind of the online attention I was getting. I was indeed constantly afraid that someone would make a flame and I would have to take everything down. That never quite happened. I survived. (There’s a saying: “I became a celebrity so I could never get fired.”)

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In fact, having a family is a natural result of becoming attentive to “the real needs of other people.” It doesn’t cause it. So my problem is that I had dropped attentiveness and gone my separate way early in life because “social combat” had proved too shameful. After years of relatively prosperous “urban exile,” much of it (pre-Internet) lived as a double-life, I was needed after all.

Medicine, by offering screening and invasive treatments that greatly increase longevity, has indeed (perhaps unintentionally) brought back some of the old-fashioned patriarchal values of family cohesion familiar to the past. Because we value human life and are (supposed to) love family preferentially, people are challenged to sacrifice so that others may live longer (or so that the public dole need be used less). At some point, we have to work out a series of new expectations. The filial responsibility laws on the books in many states are bound to grab attention in coming years.

It is certainly a mistake to believe that “personal responsibility” is only about honoring promises and “contracts” that one “chooses” to make. Or perhaps it’s a mistake to think that ethics and character are just about “personal responsibility” in that narrow sense. It seems, that both legally and morally, one has certain family responsibility and some duties to community regardless of choice, and that some of this becomes very personal (not just financial) in nature. The scope of that responsibility changes as society and technology change. In the past we had a military draft. Today, we practically have to conscript adult children into eldercare if we want people to live longer. As a corollary, we find a lot more can be done for the disabled than in the past (when I was growing up), but only if ordinary people will rally to support the efforts socially. And we’re finding that we have to expect more personal attentiveness from people if we wish to ease growing social tensions and sustain our freedoms. Some of that attentiveness may mean, as a policy matter, that we can no longer afford to shut off a third of our adults from the prospect of having and raising children. All of this has profound implications for how we view the “purpose” of marriage and family, which is increasing becoming a “result” rather than just a “cause.” I certainly learned my own lesson in “demographic winter.”

I do have my own spin on the “equality” debate. Ironically, it has turned out for me at least, the real issue for “equality” matters as much, or even more, for those who try to live “standing alone” as those who marry (for the “1000” benefits), even in a same-sex scenario. As previous generations knew, under different circumstances perhaps, people will always have to meet the needs of others, way beyond what happens in an economic market system. The practical reality is, if you don’t create your own family (and hopefully have fully equal rights), you’re likely to be called on to make sacrifices for those who do, to serve as part of their “insurance policy.” That’s just part of the “entropy” of any community. You will feel like “second class.” You will face assignment, expropriation (to support the heterosexual passions of others), even “purification.” I remember that sometimes well-meaning people would ask me if I would feel proud of my mother’s reaching 100 (she reached 97). They “missed the point.” I could not support the doomed efforts to keep anyone alive forever, even my own mother. (There is recent research that says parts of the body and even brain can live for hours after the pronouncement of death, which is a chilling thought, as I saw my own mother for the last time in the funeral home maybe three hours after her passing.) If I really had to support Mother’s (or anyone else’s) immortality, that would destroy me. I could not just do what everyone wanted and jump on demand.

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Yet, the living arrangements, as I had returned to my mother's home, certainly tended to undermine respect for me from others.

Dr. Mehmet Oz one time told Oprah Winfrey that he doesn't like to do radical heart surgery on an elderly person that isn't in a relationship, where he or she loves someone who loves him or her back. I thought love was supposed to be unconditional, not reciprocal.

The final "landing" left me relatively well off, although not forever. Ten more years of productive life would be OK. I can't see the "morality" in expecting heroic or unusually invasive procedures (like transplants) for me, after age 75 or 80 or so. I can't see going through what my mother did. Technology, however, is making many life-extending procedures less invasive, and I can certainly see how I could deal with some of them. I still want to be a "good guy" and not part of the Medicare problem. But the real way to become "good" is accepting a little of the paradox of the "Rich Young Ruler" Gospel parable. I sometimes do ponder the "physics" of all this. No, there is no way to "time travel" and wake up with my body as it was at age 18. I really missed a lot before I knew that "it" was gone.

I am in the trust-owned "Drogheda" house, which is more than I "need," but it's not that easy to sell and move on, and continue my media projects at the same time. Do I have a moral obligation to keep the house ready to shelter others in case of disaster – a good question, looking ahead. I cannot step into the life of another family just to prove something, yet if one presents itself from the blue, that could prove a real test. Again, this gets back to the equality debate.

As for my own religious beliefs, watching my mother's passing did make me revisit how I see things. I was impressed with the fact that she had a last supper, a last good day, and months before, a last day where she was free on her own. We would reverse the time arrow and walk back through her life (as a relativistic thought experiment only). I also had to ponder my own attitude toward other generations, and how I carry on after I'm gone, and my previous indifference to the idea of having children. I think that our consciousness carries on in a sense where we "know" a lot more, especially about our deepest intentions and the intentions and thoughts of others around us – but we cannot "experience," unless we are born again (possibly reincarnated, maybe even on other planets). I talked about the Rosicrucians in the third chapter of the first book.

I can see how some people could say that I shouldn't be spending time writing or on media, but should be involved in sheltering and providing for other people – the intrinsic "poor" – even if from a socially "inferior" position. That probably could have been required. It wasn't, but I see the point. I can only say that I still have an ego (despite my balding legs). I want to see my music produced, a novel out, and a film about all of this. After that, things won't be the same. If I didn't have my own separate creative world, well, I'd have to interact with people and "love" them on their terms, not mine. As I've noted, that's only possible if I think everyone else will (and they won't). So I need my own space. Of course, you have to like your customer enough for it to matter that he listens to what you have to say.



