# A CFP's Personal Experience with End of Life Planning

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### By Frank Patzke

Frank Patzke talks about his personal experience with end of life issues and the importance of planning for these issues before the crisis occurs.

Certified Financial Planners (CFPs) are familiar with the five traditional facets of planning: retirement, estate, insurance, tax and investment planning. Providing these services to our clients is the foundation of our industry. Recent events in my personal life, however, made me conclude I have overlooked, or possibly avoided, an important facet of my professional services. I call it the sixth segment of planning—end of life planning. This is the story of how I came to discover the importance of this sixth segment. Some of what happened in my life may strike a familiar note for you.

I am constantly advising my clients to take a long-term view when it comes to the future needs of their parents and other family members. Plans that take into account a broad array of possibilities should be made as early as possible. The problem typically lies in asking the right questions and examining all the potential issues. Even after a plan to meet contingencies is in place, clients should regularly revisit it as their circumstances are almost certain to change and require readjustment. Just a few years down the road, the client's needs may be remarkably different.

This planning is a bit like building your first home. No matter how carefully you

and the general contractor plan, there will always be details that you overlook, items that you forget to include. The windows may not big enough, there may be a shortage of closet space or not enough bathrooms. Ongoing construction dust may be the biggest problem in the first year, but the permanent thorn in your side will be the three dogs next door that bark all day. Even though you know you probably won't get everything exactly right, you try to anticipate as many possibilities as you can.

Similarly, while we may try to anticipate every contingency associated with end of life planning, there are going to be many issues that even the most exact planning will overlook. We may strongly urge our clients not to procrastinate just because the end of life planning task appears daunting. The great danger in delay is not completing critical living issue discussions and planning sessions while family members are able to express their intent. If the mental capacity for these discussions is lost or diminished, everything becomes enormously more difficult.

Most people in their 60s and 70s defer thinking, much less planning, for the end of their lives. It is an uncomfortable topic to think about, and a difficult one for younger family members to raise with their parents. As a planner, your efforts to gather family members together for such a discussion are likely to meet apathy or resistance. They know it is an important preventive step in

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their overall health care, but if they are feeling all right, it can be put off until next month, next year, or some later date. Although the topic is unpleasant, the consequences of failing to confront end of life issues can be serious. We must work to address these issues with our clients and in our own families.

### Hard to Anticipate Everything

My mother is a widow of 30 years. I am her only child. My CFP training helped me recognize the late-life issues that would eventually arise if my mother lived long enough. In anticipation, I did some traditional estate planning. She had a current will, a trust, powers of attorney, long-term care insurance and other necessary documents to protect her and preserve her intentions. I thought I had done a thorough job of preparing for her later years. I had ensured her continued comfort and financial well-being, her wishes for dispersing any remaining assets on her death and her final disposition. All the necessary forms and filings completed, I was comfortable in the knowledge I had attended to all foreseeable events.

But I was wrong.

Despite all my preparation, the emotional trauma that arose once my mother reached her end of life years caught me unprepared. Her affairs were in better shape than the affairs of most people, but that provided little comfort when we came to an unexpected abyss. It was wider and deeper than I ever imagined, and I suspect there may yet be other obstacles we have not yet faced.

Nothing prepares us for all the decisions we face when relatives or friends are unable to take care of themselves. A common mistake—not knowing enough about the myriad residences and care options available—can lead to a host of problems. How many of us ever go inside these facilities until we need their services? We have no idea what they are like inside. Are they cheerful or gloomy? How does the staff treat residents? What kind of care is available? What do they smell like? That last item is unlikely to be near the top of anyone's list of considerations, but I can tell you it is important to someone who will live there permanently. The way a facility looks, feels and smells is a big part of its psychological impact on a new resident. Unless you visit these places before you need one, you have no idea what—or who—may be behind those doors.

In my mother's case, I felt comfortable because I knew the place she was moving to was a nice place.

Initially, she didn't need much medical help. In addition, there was an adjoining facility just down the hall should the time come when she would become incapacitated or need more skilled nursing help. This was important because it meant she would not have to move to another location. What I hadn't done was to visit the skilled nursing residence. I assumed it was similar to her residence in the original facility, but it wasn't. Neither my mother nor I knew what it was like behind those doors. When we had to move her there, I was taken aback. The sights and sounds were completely different; much less like someone's home and more like an impersonal hospital ward, but without the gowns, hovering nurses, footboard charts and suspended televisions. The double room had a single shared closet, a small dresser, nightstand and table lamp for each person and a single bathroom without a bathtub or shower. The final touch was the curtain between beds to simulate privacy when drawn. I felt I had let my mother down by moving her there. Despite having her financial and "well" residency affairs planned and seemingly well-taken care of, I was unprepared for the psychological and emotional change by that short move down the hall.

One of my first visits provided a startling example of the dissonance I encountered. My mom and I were trying to have a conversation in a sitting area, but another resident sitting at a table in the nearby dining area was babbling and screaming incoherently. It was unnerving for me, but I noticed the staff simply went about their business, oblivious to the clamor. I later learned this was not a lack of care or concern, merely acceptance of a common daily event. Obviously, if you work in such an environment, you quickly learn to distinguish between the everyday commotion and more critical calls for help. The experience, however, triggered an immediate emotional response in me. I felt badly for my mom and wondered how she must have felt. The discomfort made me feel a sense of guilt and remorse for the decision to move her there.

#### **Family Pressures**

While the overwhelming majority of Americans still lack a formal estate plan, increased media coverage in recent years has no doubt heightened awareness of the problems attendant to not having one. People are, at least, talking more about it. Sadly, most of their conversations are taking place in a generational vacuum. Parents talk to each other but do not include their children in the conversations, so they are unaware

of the problems that arise between generations. Family members need to talk to one another about end of life issues, such as a living will and a health care power of attorney. Parents must tell their children what their priorities and wishes are should they live to suffer diminished capacity. They should discuss the environment and activities they will want to be a part of. They must discuss reasonable expectations about living arrangements in light of cost and financial ability. Children will experience guilt and stress if they are forced to make these decisions for their parents without any background regarding their parents' wishes.

It is interesting that although we see new senior housing popping up all around us, we have no idea what these facilities are like inside or what life is like for the residents. Unless you have previously visited different facilities with your parents, you will have no idea what will be in their best interest, what they would like best and what is most important to them. Even deceptively simple decisions can become complicated, such as whether they prefer bright, sunny living quarters for long hours of reading or playing cards with other residents, or a cooler, darker environment for watching TV and reading. There are also broad cost variances to consider. Without planning, you are likely to face severe time constraints while making a score of decisions that will dictate how your parents spend the final years of their lives and whether they will be in an environment they would have chosen for themselves. Senior residence design is continuously changing, adding new, expanded activities, and lifestyles choices. If your last visit was a few years ago, there are likely new offerings that you or your family members have not considered.

Another huge issue is whether the residence accepts Medicaid. Many do not, which can lead to the gut-wrenching experience of having to move your parents or family member somewhere that may be less desireable. Parents and their children should discuss this and other relevant issues before any health issues arise. They should write down topics for consideration, just as in estate planning, visit and compare residences and project costs. There is significant planning in all of this.

In families with more than one child, there may be divergent opinions about what to do and how to fund the plan. Some children may want to apply their parents' assets towards seeing them live as comfortably and with as much dignity for as long as possible, as long as it is the parents' money paying for it. Children are likely to have their own financial obligations.

Some feel they should help out when their parents' assets are exhausted; others may not wish to take on financial responsibility for their parents' care. Our legal system will not address many of these issues unless they are planned.

What made events much worse in my case was eventually having to go through the experience all over—twice—with my mother's two older sisters. Their end of life situations are more complicated and time-consuming because I was unable to convince either of them to plan while they were still competent to make their own decisions, as I had my mother years before. As the physical and mental health of my two aunts deteriorated, I learned some valuable lessons.

# My Older Aunt: Unaware and Unconcerned

After a long period of slowly declining health, my older aunt (now 91) worsened quickly. One day, we found her lying motionless on the kitchen floor of her home. We thought she might have passed away but the paramedics we called revived her. It turned out she had no major physical impediments; she simply had stopped taking care of herself and had become dehydrated. After a few days in the emergency room and a few more in a traditional hospital room, she was moved into a separate facility for people without serious medical problems but still requiring some medical care.

She remained there while her physical condition improved and she regained strength. It was clear, however, she would never again take care of herself. From a financial perspective, we were fortunate that her condition still required medical attention because Medicare covered most of her expenses for the three months she remained there. Depending on the circumstances, 90 to 100 days is the maximum time Medicare will pay for hospitalization.

Since she was obviously incapable of going home and taking care of herself, the next step was to move her to a care facility for patients with dementia. Ultimately, she would move into a home specializing in care for Alzheimer patients.

I had to find an attorney experienced in geriatric care and elder law issues. The attorney collected personal data on my aunt from me and her doctors. A court-appointed *guardian ad litem*, an advocate who protects the rights of people unable to make their own decisions, visited my aunt to make an independent assessment of her condition. This ensured we were

accurately representing her need for special care. My attorney, the *guardian ad litem* and I met with a judge to confirm my aunt's needs and my appointment as her guardian.

Becoming a dependent relative's guardian is the first step down a long and twisting back road. There are a host of documents to attend to, including changing the title of anything in the relative's name. In my aunt's case, we opened a new checking account that reads, "W. O'Donnell, estate for disabled person, Frank Patzke, Guardian." That turned out to be the easy part. Getting other things switched was more problematic. Many companies seemingly have no clue how to deal with the title transfer of a living person's assets to a court-appointed guardian. Whenever I mentioned that I was a court-appointed guardian for my aunt's estate, they would ask for my aunt's death certificate. To this day, almost 15 months later, I have not been able to have my Aunt's monthly pension fund payments deposited into the guardianship checking account. I doubt the company issuing the pension check will ever get it straightened out. For now, I simply let them direct deposit the checks into her old account and every few months, transfer the money into the guardianship account.

An interesting aside to this is that some years ago, my two unmarried aunts decided between themselves that they would put both of their personal checking accounts (and for that matter, all of their assets) into joint tenancy. They figured if something happened to one of them, the other would take care of the finances. What they did not expect is that they might both become incapacitated at the same time, which is not uncommon for people of a similar age. So even if the pension company knew how to switch the automatic payments into the guardianship account, I still could not have closed my aunt's old checking account because her joint tenant sister was also declining, and though not as far gone as my older aunt, she was fighting the family's efforts to help her.

This illustrates how well-intentioned efforts by family members to provide for each other through joint tenancy agreements can backfire and trigger negative ramifications. I encounter a similar situation in my practice where a parent in her 60s or 70s names her son or daughter as a joint tenant or executor. Never revisiting this decision, when that parent reaches 90, her child may be in his 70s with his own disabilities or impaired judgment.

Once appointed guardian for my older aunt, I faced an avalanche of accumulated financial, tax

and healthcare-related statements, some unopened, bills unpaid. There were hundreds of statements from Social Security, Medicare, independent insurers, doctors, technicians and pharmacies. I didn't know who any of these people were and since my aunt was unable to communicate anything to me about them, I was right at square one. I did not even know who her private insurance carrier was. She had worked for the Federal Reserve Bank of Chicago and had excellent health insurance, but during her illness, the bank changed carriers. My aunt's declining condition left her unaware of the change; her healthcare providers were therefore also in the dark, and continued to send invoices to her old insurance carrier. Naturally, their bills were rejected, since my aunt was no longer insured there. Her doctors and hospitals did not know she had a new carrier; they assumed she simply no longer had coverage. I had to sift through two years of bills submitted by her providers to the wrong carrier.

It was an enormous snarl to untangle. Just getting all the doctors, hospitals, pharmacies and labs to resubmit their bills to another carrier was a major headache. In addition, the carrier did not accept invoices more than two years old, so some of the bills were too old to be resubmitted and the benefits were lost. It was difficult trying to determine the exact time when things first went awry, more time trying to recreate what happened afterward, and more time trying to fix it.

# My Younger Aunt: Aware but Resistant

My younger aunt is 87. Dealing with her condition was altogether different, and made dealing with my older aunt's condition seem almost easy by comparison. Her mental faculties had not worsened to the extent of my first aunt. Although our family could see she was rapidly going downhill and needed help with everyday living, she resisted and wanted to remain in her home. That resistance became a major impediment to helping her get the care she needed.

Finally, we had to seek professional guidance. We found a helpful woman working at a senior advocate center. She told us that before I could be appointed guardian, my younger aunt would have to undergo a series of tests—a geriatric assessment—to see whether she could make her own decisions. The assessment, a battery of tests which took place over several weeks conducted by various professionals, was a

combination of emotional, psychological, physical and mental evaluations. The tests were costly but legally necessary to confirm that her deteriorating condition could not be corrected through treatment or medication. After collecting all this data, the plan was to take my aunt to a meeting with her doctor and a social worker, present her with the evaluation, and let her know she was in trouble and needed care. But my aunt was suspicious and reluctant to leave the house. My cousin and I had to make up stories about where we were going every time we had to get her somewhere. She would sit in the various offices, perplexed, asking nonstop questions we didn't know how to answer.

While people in this condition tend to be disoriented and not sure of what is happening, they evidently have some "sixth sense" that tells them that whatever is happening is not what they want. Frightened like little children, they devise defensive ploys to fool those around them. For example, if a doctor or social worker asks them a question intended to identify a lack of acuity, such as "Who is the president," they try to hide their lack of awareness by changing the subject.

We agreed my younger aunt needed a guardian. But this time, we had to devise a strategy to convince her it was right for her. While the doctor, social worker, my cousin and I sat in one room planning how to tell her, in just a few minutes, she had left the adjoining room. We later found her wandering around the hallways.

The immediate problem now became what to do with my aunt while I went through the guardianship application. The doctor decided to help us by having her admitted to a special geriatric ward attached to the hospital. Amid this, something rather humorous happened. It took the doctor half a dozen phone calls to get through to the adjoining hospital; he spent another 10 minutes or so trying to navigate the automated answering system. He was pushing buttons, cursing, and getting more impatient by the minute. It was quite a show, and I exchanged a discreet "welcome to the club" grin with my cousin. Finally, the doctor connected with a live person, who told him my aunt could not be admitted because there were no beds available. I dreaded the thought of taking my aunt back home, not knowing how we would ever get her out of her house again. Then the doctor made some more calls and found another hospital with a bed available; unfortunately it was 30 miles away. We learned that not all hospitals have the specialized geriatric wards needed in a case like this. He arranged an appointment for us and we raced across town to get there, where they promptly seated us in a cramped room where we waited over three hours for admission! Meanwhile, my aunt's anxiety level rose higher by the minute. She was pelting us with questions. "Why are we here? When can we leave? Where's my purse? Whose glasses are those?" It went on like that for three hours.

Finally, a staff member interviewed us but said since our doctor had no association with the hospital, my aunt would have to undergo another evaluation by a staff doctor. They admitted her, but scheduled the evaluation for the next morning. When we left her there, we had to sneak out the back door. It was a terrible feeling. In addition, they could only keep her for three days—there was no reprieve—we would immediately have to find another, more permanent facility to accept her.

The next day, my attorney was able to secure temporary guardianship status for me while the longer process of full guardianship unfolded. Meanwhile, we were on the phone, desperately looking for someone to accept my aunt. Because of her physical and mental condition, she now required Alzheimer care. Location, costs and ambiance all had to be addressed. Once we found the one we felt best suited her, we had to find a way to traverse the 30 miles from the hospital to the home. They advised us an ambulance was the best way to take her there. Even that was not simple. We learned only private ambulance services take a patient up to her room; public services would merely drop her off at the building entrance. It was just one more unexpected and time-consuming obstacle.

I am not yet appointed my younger aunt's permanent guardian. Until that happens, I can't even change her address so the post office can do something as simple as deliver her mail to my home. Unlike my older aunt, who needed greater medical care, my younger aunt is not incapable of taking care of herself. But because she has no real physical problems, she cannot live in a medical facility. Unless I have her power of attorney or until I become her guardian, I cannot get her specialized care, and without that authority, no one will accept her.

My younger aunt was not suffering from any major physical disabilities, so it was more difficult to evaluate her condition which prolonged my guardianship appointment. My older aunt was unaware of anything going on around her and so had no preferences or objections to what happened to her or where she lived. My younger aunt, however, was a different story. She fought our efforts to help her. This is agonizing for family members. You want to do what is right, but feel you are dragging a defenseless woman from one member of the medical community to another. Meanwhile, against her wishes, you must foreclose on her home and force her to move.

### The Family Equation

Volunteering to take responsibility can be a thankless experience. The time and effort you invest goes largely unnoticed by nonparticipating family members. Depending on the extent of decline, the relative in question likely will either be unaware of your help or resent your efforts and regard them as intrusive and unnecessary. Saddled with a continuing search for documents and data, you do all the dirty work that no one wants to do, including cleaning up their home, sorting through mail, deciphering finances and moving a loved one into a facility. Your relationships with other family members may also take a hit. In my case, there are many cousins whose attitudes range from indifference to lip service. Only one has stepped forward and become involved.

On the other hand, there is some personal reward in all of this. You help loved ones when they are least able to help themselves. This is especially heartwarming when the person has never married and has no children. Choosing the family member best able to make the hard decisions can be problematic. Who will accept the responsibility for the time, expense, and aggravation, not to mention the potential resentment of the family member?

Another monkey wrench in the machinery can be the personal frustration the guardian may experience. I now find myself inwardly frustrated with my cousins for letting me take on all this alone. I chose the responsibility willingly. But I now realize I may have misjudged my ability to handle the job. I also wonder about the fairness of my relatives benefiting from my efforts while they do not have to deal with the attendant problems; they can remain benevolently indifferent. They also avoid the emotional strain and may all inherit a few extra dollars if I do my job efficiently.

While my profession gives me an advantage on the end of life learning curve, I continue to face unforeseen problems dealing with the different circumstances of my three relatives. As difficult as it has been for me over the past 18 months, I can hardly imagine how someone without my planning background or lacking my aunt's financial resources might deal with this. Planning's sixth segment—end of life planning—based on my continuing personal experience, is as important and necessary as any other facet of our professional services.

I like the idea of having clients keep a diary, binder or some organized record of their medical history, insurance, will, trusts, late life wishes and related information. In my experience, hardly anyone does this. I can't begin to tell you what a difference it would have made with my aunts. I could have saved incalculable time, money, frustration and family agitation.

I think advisors have an opportunity to provide the professional oversight needed to plan, organize and maintain such a history. While we associate all this with aging, younger family members also become incapacitated because of injuries or accidents. Because their life expectancy is much longer than a senior, it may be even more critical for younger people to plan for end of life issues or living with incapacity. I believe an ideal plan would be *multigenerational* in nature, involving family members of more than one or two generations. I recommend bringing my clients and their parents and/or children together to discuss their end of life plans. It is only through candid exchange that we can gain comfort in knowing we are carrying out our loved one's wishes.

Of course, a big problem for advisors is how to charge for this multigenerational planning session. It may be awkward to suggest that the family should come together for three or four hours for the purpose of discussing this. Families may have a difficult time understanding the value in this type of meeting. The general approach of people who are not in a crisis situation is that they do not have to deal with these issues now. When a problem arises, then they will get together.

## Don't Count on It!

It is difficult for clients to see any immediate or tangible benefit in spending money on planning for something they don't want to consider will eventually happen if they live long enough. If you are charging for an estate plan, clients see the value in the trust you have set up. They understand the flowcharts and calculations that explain how much they will save in federal estate taxes and how much more by avoiding probate.

In addressing the end of life issues, all you can do is relate the experiences of others who failed to plan, and try to make your clients understand how much easier it will be, and how much better they will feel when the time inevitably arrives. I would share my insights on the most efficient billing strategy for these planning sessions, but frankly, I don't think I have found one yet. Many clients are not motivated to spend money for this planning.

### Postscript: The Saga Continues

I stumbled across yet another pothole during the recent tax season. While preparing returns for my mother and aunts, I discovered that neither aunt had filed federal or state tax forms for several years. In addition, I don't know where my aunts buried all the necessary 1099s, statements and paperwork. There were pension payments, 401k and IRA distributions, various other investments and, of course, Social Security. The question was where is the documentation? Securing this information from the various companies has proven difficult. Because of privacy considerations, they first require proof that I am my aunt's legal guardian. This means providing the proper court-appointment documentation, which must be timely because these legal documents have a shelf life of only a few months. I must go back to court and ask for a copy of the paperwork with a current date. More time and money!

Since I was unable immediately to complete the prior year returns, I tackled the current year returns. I was able to collect the current tax data because I was the caretaker for most of the year, but there were other problems here as well. My older aunt passed away last November, so two returns must be filed on her behalf for 2004: one for the 10 months she

was alive, and an estate tax return for the remaining two months following her death. I began reading the IRS publications on these matters. I interpreted the information to say that I could not file my aunt's final return until I first filed all the outstanding returns from previous years. I needed help. I tried to get advice from the IRS but they were busy because April 15 was approaching and could offer only basic information. At that point, I decided I would wait and have an experienced accountant help me. More time and money. The IRS probably owes money to both aunts, but does the amount owed justify the time required to produce the documentation?

As I worked on income taxes, I began thinking about their past real estate tax payments. The state of Illinois offers senior citizen and homestead exemptions for homeowners, but they must be refiled every year to remain in effect. If I can find the necessary age and residency data for the homestead exemption, I can collect for any errors during the past three years. Again, I'm not sure if the result would justify the effort. As guardian, I feel a responsibility to do everything correctly, but the scope of my duties continues to grow. Every time I think I might have my arms around this, another firestorm of time-consuming details and obstacles arises. With proper planning and a little organization, many of these difficult issues that I am encountering can be avoided. Any cost spent for planning will be many times repaid in time and expense savings later on not to mention peace of mind in knowing that the end of life is proceeding peacefully and in accordance with the intention of the person needing care. No one wants to become a burden to another, especially to someone they care about. End of life planning eases the burden on the person requiring care and the person who is standing by them to help.

