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Planning for Chronic Illness

A Conversation with Martin M. Shenkman

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Chronic illness may be the forest that gets overlooked amidst the trees. It is all around us, affecting about one out of every two American adults. Yet, incredibly, it is often invisible to practitioners and ignored during the estate and financial planning process.

How should financial planning be modified to address chronic illness? Here we examine basic strategies and talk to Martin M. Shenkman, CPA, MBA, JD, PFS, AEP, who has developed resources to assist professionals in facing these challenges.

"With the waning importance of the estate tax, planning for chronic illness is an area where estate planners can do a lot of good for many people."

—Martin M. Shenkman, CPA, AEP, PFS, MBA, JD

Estate Tax is Passé

Ivan Pavlov demonstrated classical conditioning by ringing a bell when feeding dogs and then documenting that the dogs would

salivate at the mere ringing of a bell. Modern estate planners now exhibit such a Pavlovian response at the mere mention of the Federal estate tax, focusing undue attention on what has become a political scrimmage.

Headline: "Will Congress tweak the $5 million estate tax exemption?" Can you force yourself to not read this article? An estate planner can become fixated on such news, even if his or her professional practice doesn't have a single client with a taxable estate and never will. Less than 1% of estates have any exposure to Federal estate tax.

While approximately 20 states have decoupled from the Federal estate tax, the tax rates pale in comparison to what the combined Federal and State tax used to be. In many estates, obtaining a stepped-up basis outweighs the State estate tax savings. So estate tax planning is no longer the elephant in the estate planning room.

By contrast, nearly a third of the clientele for every estate planning professional has some form of chronic illness, and those clients have financial plans that could benefit from specialized adjustments.

Astonishing Statistics

According to the Center for Disease Control (CDC), chronic diseases are the leading cause
of death and disability in the United States. The statistics that back up this conclusion are staggering:

- In 2005, 133 million Americans – almost 1 out of every 2 adults – had at least one chronic illness. By 2020, about 157 million Americans will be afflicted by chronic illnesses.

- Each year, 7 out of 10 deaths among Americans are from chronic diseases. Heart disease, cancer, and stroke account for more than 50% of all deaths each year.

- About one-fourth of people with chronic conditions have one or more daily activity limitations.

- Arthritis is the most common cause of disability, with nearly 19 million Americans reporting activity limitations.

- Diabetes continues to be the leading cause of kidney failure, nontraumatic lower-extremity amputations, and blindness among adults ages 20 to 74.

- More than 88% of Americans over 65 years of age have at least one chronic health condition (as of 1998).

- There are an estimated 400,000 Americans with multiple sclerosis, a disease that can become progressively worse.

- An estimated 5 million Americans may have Alzheimer's disease in various stages, from preclinical diagnosis, a middle stage with mild cognitive impairment, to a final stage of Alzheimer's dementia. With current population trends, that number could double.

- An estimated 25 million Americans are living with chronic obstructive pulmonary disease (COPD).

Hidden in Plain Sight

Notwithstanding the vast number of people suffering from chronic illnesses, society has taken very little notice. As a result, a National Invisible Chronic Illness Awareness Week is held every year in September. This is actually a worldwide effort to raise awareness of how many people are living with an invisible chronic illness in our midst.

A number of diseases are in the "invisible illness" category because those who are ill don't necessarily exhibit external signs. These illnesses include multiple sclerosis (MS), fibromyalgia, chronic fatigue syndrome, interstitial cystitis, diabetes, heart disease, chronic pain, cancer, eating disorders, mental illness, and depression.

As discussed below, there are also misconceptions about how the chronically ill should appear. We may associate chronic illness with an elderly person in a wheelchair, when many people who are ill are not only young or middle aged but show no outward sign of any illness.

A Life-Changing Diagnosis

After experiencing chronic illness in his own family in 2006, estate planning attorney Martin M. Shenkman was surprised to find that information and resources about financial and estate planning for the chronically ill was very limited.

Since his wife's diagnosis, Shenkman has created a website filled with resources. He's written books and articles, generated PowerPoint presentations, and traveled all over the United States to educate professionals and inspire them to help others with chronic illnesses.

Many accolades have resulted. In 2012 alone, Shenkman was named the Pro Bono Financial Planner of the year by Financial Planning Magazine, received the 2012 Sidney Kess Award for Excellence in Continuing Education from the AICPA, and was inducted into the NAEPC Estate Planning Hall of Fame.

However, Shenkman has remained consistently on purpose, turning out dozens of helpful resources, giving more than 50 speeches over the past five years, and spending months on the road, traveling to meetings and events.

Despite this incredible whirlwind of activity, Shenkman was extremely gracious about making himself available to discuss planning for chronic illness with us for this issue.

A Conversation with Martin M. Shenkman,

CPA, MBA, JD, PFS, AEP

Q: Your pro bono efforts regarding chronic illness have resulted in a number of road tours. Where did your travels take you this year?

A: My wife's condition makes it difficult to fly, so we always travel by RV and spend about two months per year on the road. This year, we lectured in North Carolina, Michigan, Ohio, Illinois, and South Dakota.

Q: What types of groups do you speak to?

A: It varies from professionals to the chronically ill. I gave three presentations in North Carolina for the Bar Association, two on post-ATRA planning and one on chronic illness planning, as well as a presentation for a disabilities rights counsel in the town of Cary. The AICPA taped a series of videos for their website in Durham, and I gave a consumer presentation on planning for chronic illness in Marion. This year, I also spoke to the Michigan Association of CPAs on both planning for chronic illness and current topics. Then, in Chicago, I filmed a series of videos for insurance consultants on Post-ATRA planning, as well as for the MS Society about planning steps that apply when someone is diagnosed with a chronic illness. In South Dakota, there was a presentation on chronic illness and another session on ATRA planning for the local NAEPC chapter in Sioux Falls. And finally, in Huron, there were four consumer sessions with people who are affected by chronic illness.

Q: Why has planning for the chronically ill been largely overlooked?

A: There is significant focus in our country on acute, in contrast to chronic, illness. As one simple indication, the international symbol of disability is a stick figure in a wheelchair. This image is terribly misleading because, in reality, only 7% of those with a disability use any kind of walking aid. So a lot of practitioners are under the misconception that if the client doesn't exhibit significant signs of disability, then they must be "okay." Most symptoms are invisible. Chronic fatigue is not visible. Chronic pain is not visible. Mild cognitive issues are not visible. Overall, 96% of chronic illnesses have invisible symptoms.

Q: You mentioned that your talks try to combat various myths and misconceptions. What are some of the other major ones that you address in your talks to professionals?

A: First of all, chronic disease affects more than just the elderly and is not just about Medicaid planning. It affects a whole range of ages, and 60% of the chronically ill are between the ages of 18 and 64. We have to combat the myths. In general, Alzheimer's is a disease of the elderly, but there are those who are diagnosed with the disease in their 50s. And MS is typically diagnosed in the mid-30s, but not always. COPD is typically diagnosed in someone's 40s. So if you are planning investments and the estate of someone with a chronic disease, the planning must be different for a client in their 70s than for someone in their 40s, who may have a longer life expectancy.

Q: Should investment planning for the chronically ill be conservative, based on a short life expectancy?

A: Not necessarily. For example, someone young who has MS or young onset Parkinson's disease may need to have a more aggressive approach to investing and also cut spending dramatically so that savings can be built up. This client may well have a long life expectancy but a shortened work expectancy (although Michael J. Fox is doing a laudable job breaking down some of those work expectancy barriers).

Q: How can professionals incorporate planning for chronic illness in working with clients?

A: Every estate planning interview should have an inquiry into health issues. Professionals should not assume that everyone is healthy or that people with illnesses will volunteer that information. Many clients will not readily disclose their health challenges. It is okay for professionals to ask questions. We can't really protect clients or help them optimally without understanding their real circumstances. Most clients will be grateful that someone is trying to help them.

Q: Do you recommend planning with the affected party and a spouse, or should other family members be included in a meeting with the financial planning team?

A: It depends on the circumstances and whether cognition is affected, or if there are difficulties communicating. Bringing a family member or friend to help out or even take notes might be helpful. We try to provide an agenda and a follow-up list of steps.

Q: What misconceptions do the chronically ill have?

A: Clients don't understand how much planners can help. For example, someone diagnosed with a significant disease may get scared and cancel his or her life insurance in order to conserve cash. This can be an obvious mistake. In some cases, clients should instead convert their policies from term to whole life while they still can. Someone facing a shorter working career as a result of chronic illness might need to invest more aggressively, not less. This is counterintuitive, but assets need to be built up quickly while the client is still working.

Q: Are there more resources for the chronically ill than when you first got involved seven years ago?

A: There are always a lot of materials on special needs and Medicaid, but resources are woefully inadequate beyond that. There are now at least 50 articles and books that I've written

over that time period, and that's why I've developed *chronicillnessplanning.org.* The website was originally for professionals, but then I added material for consumers. Also, laweasy.com has resources. I am about to undertake a major new book, tentatively to be co-published by the American Academy of Neurology and the American Bar Association, on planning for neurologic conditions, which should add a wealth of new resources. Any royalties will be donated to the American Brain Foundation to fund a consumer version of the book.

Q: Does your website require registration or a fee?

A: No. People were initially suspicious of this and asked, "Why are you giving all this away, and why are you speaking for free?" I wanted to make information available. My current goal is to add more information on other diseases every year to cover the most common chronic illnesses that affect people.

Q: How should one approach planning for chronic illness?

A: For health challenges, you need to understand how they affect each client. There are widely different examples. Someone with bipolar disorder may have no physical disability, but, because of potential mental health issues, the person should not be trustee of his or her own trust. Yet planning and drafting can be undertaken in a manner to empower the client, not further disempower him or her. For example, using a fully funded revocable living trust with an institutional trustee might make sense for the client. Nonetheless, the trust could mandate that the institution maintain a smaller dollar account outside the name and tax ID number of the trust so that the client can have a credit card, debit card, and check-writing ability like anyone else. As the balance is reduced, the institutional trustee can replenish it. If a problem develops, the size of the account can limit the harm done. Empowerment and protection are key goals. Conversely, someone with MS may have no cognitive limitations and can be a trustee.

Q: Are there particular techniques that are useful for chronic illnesses?

A: Every technique—powers of attorney, living trusts—all can be tweaked for the specific disease issues. For example, many documents include disability clauses that are impractical, especially if the client is already disabled. Review and modify them to fit the client's circumstances. Many chronic diseases, such as Crohn's, colitis, COPD, MS, and epilepsy, for example, can be marked by sudden unpredictable attacks. The disability clause in most living trusts would remove the grantor/trustee for disability. This can be impractical because, when the attack resolves, the client has to be reappointed as a fiduciary. Consider instead providing for the grantor alone that disability will not be triggered for purposes of removing him or her as a trustee or co-trustee for 30 days. That might avoid the on/off appointment/removal of short-term attacks. There are a myriad of ways to "tweak" documents like this to better tailor them to a client's particular disease challenges.

Strategies for the Chronically Ill

A Budget: Establishing a budget with good records can keep a client's savings program on track and provide a clear system that will be understood when a family member or other agent assists in the future.

POA and Proxy Forms: It is common sense to sign forms while the client is still able to make good decisions. Both short-term as well as prolonged disability should be planned for. For example, most powers are silent as to the compensation of the agent. If a chronic disease may result in the agent handling the client's finances for a decade or longer, providing for compensation really warrants consideration.

Corroborate Mental and Physical Capacity: Having a letter from a physician, neurologist, and/or psychiatrist that describes the client's current and likely future status, both as to mental capacity and physical challenges, if applicable, can be crucial to making optimal planning decisions.

Limited POAs: Assistance isn't always an "all or nothing" proposition. A power of attorney can provide for someone to assist with a limited role, such as just paying bills from one particular account.

Long-Term Agents: Someone who is facing a long-term disability may need agents for health care and financial matters for a long period of time. With this in mind, documents should provide for multiple backup agents, possible compensation for agents, and perhaps some method for the replacement of agents over time.

Simplify Finances: For someone whose cognitive functions will diminish in the foreseeable future and who may require assistance, it makes sense to have fewer bank accounts, brokerage accounts, and credit cards. Keeping things simple can make it possible for the client to remain involved longer and with less stress.

Customize the Living Will: The generalized sentiment that extraordinary methods not be utilized should be modified based on the client's specific medical conditions. A particular client with chronic breathing difficulties, for example, should modify "standard" clauses that may prohibit the client from using the very breathing apparatus he or she is using when signing the documents! What some documents treat as "heroic" are ordinary and essential for someone living with chronic disease. Many clients want experimental medical treatments and to donate organs or tissues to help find a future cure for their diseases. This should be specifically addressed.

Will Provisions: People with chronic diseases may want to make charitable bequests to the organizations that helped them.

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