Planning for Clients With Multiple Sclerosis

MS—like Crohn's and ulcerative colitis—creates unusual challenges for practitioners seeking to safeguard sufferers' legal rights and autonomy

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About eight months ago, my wife was diagnosed with multiple sclerosis (MS). We immediately started to learn everything we could about the disease, so that we could make informed decisions concerning treatment, lifestyle and other critical issues. Once those major issues were addressed, we had to consider revising our personal estate planning documents.

The expected planning steps—durable power of attorney, revocable trust, health care proxy, living will and so on—immediately came to mind. However, these common planning techniques, with which practitioners are so familiar, need to be applied in a manner that reflects the unique characteristics of MS. The course of the disease, and hence planning for those who have it, is quite different from other neurological diseases such as Amyotrophic Lateral Sclerosis (ALS) (commonly known as Lou Gehrig's disease), Parkinson's and Alzheimer's.

In fact, every disease has nuances that need to be considered in estate planning. A look at the issues we considered vis-à-vis my wife's illness, can provide ideas not only for clients with MS, but also other chronic illnesses, particularly Crohn's disease and ulcerative colitis.

The key point is that too many practitioners mistakenly assume that all chronic illnesses are the same from a planning perspective. Not

only are there dramatic differences between different chronic illnesses, but also the disease course even for clients with the same illness can vary substantially—and so too must planning for them.

NATURE OF A DISEASE

First, whenever dealing with clients with a chronic and/or progressive illness, it's essential to truly understand the nature of their disease and how it will affect them over time.

It's said that there are more than 400,000 people in the United States living with MS; about 2.5 million people worldwide. But these estimates are likely to be understatements. Every week, another 200 receive a diagnosis.

Among the most important aspects of this disease that planners need to know is that it is unpredictable and its effects range from mild to devastating.

There are four categories of MS. Practitioners must know which category of MS a particular client has, as this will directly affect planning and drafting:[1]

- **Relapsing-Remitting**—Eighty five percent of MS patients begin with this subtype, which is characterized by unpredictable flare-ups called attacks, exacerbations or relapses. The fact that there are flare-ups and then the patient returns more or less to normal makes planning for MS clients different from planning for clients with other chronic illnesses, such as Alzheimer's and Parkinson's. An MS attack might be characterized by symptoms similar to a stroke, involving severe visual, motor and sensory problems. Attacks can last for a short time, or as long as weeks. Months or years can pass between attacks. After an attack, the client may recover completely or partially. About 10 percent of those with MS regain all function after an attack subsides.

- **Secondary-Progressive**—Unfortunately, about 50 percent of those who begin with relapsing-remitting MS advance to the secondary-progressive category within 10 years of their initial diagnosis. With secondary-progressive MS, full recovery does not occur after an attack. The disease progression seems "step-like." An attack is followed by partial or even no recovery. The next attack is again followed by only partial or no recovery. Each attack brings a higher degree of neurological impairment.

With any illness, it's essential to consider the disease's impact on cognitive versus physical impairment.

- **Progressive-Relapsing MS**—In about 5 percent of MS patients, the disease is characterized by continued progression, even between attacks. This contrasts unfavorably to relapsing-remitting MS, in which people tend to remain stable between attacks.

- **Primary-Progressive MS**—For about 10 percent of MS patients, the disease worsens progressively, without distinct exacerbations. Planning for this type of MS is thus more akin to planning for clients with Parkinson's or Alzheimer's.

COGNITIVE IMPACT

Of course, as with any illness, it's essential to consider the disease's impact on cognitive versus physical impairment.

Cognitive impairment affects an estimated 30 percent to 50 percent of those with MS. Of those with cognitive impairment, 34 percent experience mild impairment; for 22 percent, it's moderate impairment.

Cognitive impairment, which affects the small proportion of patients with MS, may impact certain activities (for example, the ability to balance a complex bank and brokerage statement), but not others, such as the ability to make many of the macro decisions often addressed in planning for disabled clients (for example, choosing to downsize to a smaller house.) While such cognitive impairments may make it more difficult for some clients to retrieve information, their IQs are not diminished and they generally suffer no long-term memory deterioration. Information processing and the ability to reason remain intact. Clearly, this makes planning for a client with MS very different than planning for those with Alzheimer's dementia. Most MS clients can remain in control of key decision making. Only about 5 percent—and a similar percentage of those with ALS—experience significant difficulties with decision making to the point of being characterized as having dementia. While practitioners need to be careful to identify the clients who are in this minority, it's equally important not to assume mental incapacity in cases of chronic illness where incapacity is unlikely.

In contrast to MS and ALS, Alzheimer's is, of course, an illness that is accompanied by significant cognitive impairment. Those with Alzheimer's do lose memory and the ability to reason. Also, they often lose the ability to understand the consequences of their decision making.

Crohn's disease and ulcerative colitis have similar planning implications as all except the most severe form of MS. While Crohn's and ulcerative colitis are chronic digestive disorders of the intestines for which there are no cures, their symptoms like most forms of MS vary in an unpredictable manner and some people recover after a single attack. Some are in

remission for years before another unexpected attack. Others may face frequent hospitalizations and surgeries. The existence of unpredictable attacks may make it impractical to manage financial and other affairs for weeks at a time. All such clients have their full mental faculties, but may need the assistance of an agent for a short-term and unanticipated basis to handle routine, not major, matters.

INTERVIEWING CLIENTS

So how do you as a practitioner start to plan for clients with MS? Step one, you must question your clients about their experience with the disease and be direct about it.

But, be warned, Obtaining the relevant factual information is often not easy as many MS patients, even long after their initial diagnosis, deny the impact MS is having on them. It's human nature, I suppose. It's difficult emotionally for many struggling with a chronic illness to address the reality of their circumstances. Of those willing to discuss these circumstances, many lack the medical understanding to adequately convey their likely disease course so that practitioners can modify planning and documents appropriately. For example, it was only after we told a close friend—who also happens to be my client—about my wife's diagnosis that he first revealed to me that he's had MS for years. Clearly, as his lawyer, I should have been told long ago. I suggest all practitioners ask potential clients if they suffer from any health issue, including chronic diseases such as MS, Crohn's, etc., explaining that the reason you ask is to help them protect themselves legally by tailoring their planning, and your drafting, to address their circumstances. In some instances, it may prove helpful; you also may want to emphasize that all information you receive will be kept confidential.

Even when a client reveals his diagnosis, he may not fully understand or be able to communicate accurately his experience of the disease. Yet a practitioner needs that clarity to be truly helpful. So I strongly recommend you consider requesting a clarifying letter or, better yet, a telephone conference with the client's attending neurologist. This will likely require the client to give his physician a release under the Health Insurance Portability and Accountability Act (HIPAA).

NAMING FIDUCIARIES

Guiding an MS client in selecting fiduciaries is generally similar to the exercise for any client, except for these special considerations:

• For clients who have unpredictable, relapsing attacks, lasting for days or weeks (as with remitting, secondary-progressive or progressive-relapsing MS)—the on/off use of an agent requires fast reaction for short durations with no notice. The agent selected under a power of attorney or health care proxy must be suitable to deal with this unique circumstance. It's important to prepare the agent in advance.

• For clients with a steadily deteriorating chronic illness (Alzheimer's, Parkinson's and primary progressive MS)—an agent under a durable power, or a successor trustee under a living trust, might have notice of the pending need to serve as the client's condition worsens, and in advance of taking control of the client's affairs.

• Often, agents are selected based on their understanding a client's major objectives and wishes. However, for most MS clients the focus is different. The agent for a durable power, or a successor trustee under a living trust, should be ready, willing and able to handle routine details rather than macro decisions. The MS client will in most cases have the mental presence to make major decisions, even if those decisions have to wait for a recurrence to subside.

• Because only a small minority of clients with MS will develop significant cognitive impairment, in the vast majority of cases, the client can be given a power to replace trustees, rather than abrogating that right to a third party, such as a trust protector.

POWER OF ATTORNEY

Durable powers of attorney for MS clients also should take into account the characteristics of MS. The decision whether to use a springing power of attorney warrants special consideration. If the appointment of an agent is effective immediately upon execution, unencumbered by a springing mechanism, the agent will be able to help during a short-term relapse, then be able to cede control back to the client as soon as feasible. But, with a springing power, by the time the agent can demonstrate legally the principal's disability, the attack may have subsided.

For clients with primary-progressive MS, though, it may be feasible to use a springing power, as the power may have to be triggered only once when disability has reached a level requiring the permanent use of an agent.

Compensation provisions also should be tailored to these unique circumstances. For any client with a chronic illness, an agent under a durable power may serve for a long time. Some drafters use state law compensation for a trustee as a gauge in calculating the agent's compensation. For a client experiencing MS attacks, but thereafter regaining the ability to manage, the agent's involvement may be for a short duration. Yet attacks may recur several times a year. In contrast to an agent for a typical client, who may not be concerned

about compensating an agent who steps in once for a couple of weeks duration, the on-again, off-again, responsibilities of an agent for an MS client may warrant compensation. Compensation based on statutory trustee fees as a paradigm would be impractical (prorating a statutory percentage of assets for a week-long period) and may not suffice for the emergent and recurring nature of the agent's involvement. Thus, some stated minimum compensation each time the agent acts may be preferable. This type of compensation could change to a more traditional approach if the agent begins to operate on a permanent basis. For the majority of MS clients, a two-tier compensation structure might be advisable.

I've actually opted for two separate powers of attorney for my wife. I felt that this best protects her, while preserving her independence:

• **First Tier**—This is a typical general durable power of attorney with springing provisions for agents other than me. Should the degree of disability increase to the degree that an agent will have to operate on an ongoing basis, this broad power of attorney, similar to that used for clients generally, will be available.

The springing mechanism was modified to address MS with this language: "The Grantor shall be deemed disabled when Grantor is unable to manage Grantor's affairs and property effectively for a period anticipated being more than thirty (30) days [This duration was included to avoid triggering the power of any successor agent to act, as a result of a short-term MS exacerbation.] Disability may be determined to exist for reasons such as mental illness, mental deficiency, physical illness or disability, advanced age, chronic use of drugs, chronic intoxication or for any other reason allowable by law. In addition to any other method allowed by law to determine disability, it shall be deemed conclusive proof that the Grant to the Alternate Agent is effective upon a sworn statement being executed by Grantor's attending neurologist with regards to an MS triggering disability, or physician for any other triggering disability."

• **Second Tier**—This tier is a limited power of attorney, effective immediately with no springing provision. This power limits the agent's rights to those matters that might need addressing during a short-term MS exacerbation. No power is provided to make gifts, change beneficiary designations on insurance and retirement plans, sell real estate, etc. This provides a secure option in the event the agent under a broad general power is unable to help her. This approach does not cede powers that she should retain for the foreseeable future and that MS will likely never impact, yet it should facilitate quick assistance, if needed. This power of attorney does not require the purported protection that some clients believe a springing power provides because of the limitations on the rights granted to the agents. The same people could be named agents so there can be no conflict between the two powers.

Compensation under this limited power could be provided as follows: "In the event an agent acts hereunder, the agent shall be compensated at the rate of $[monetary amount] per week for any week in which the agent provides any services or acts hereunder, up to a maximum of six (6) weeks in any given year. Compensation has been provided at a level to encourage the agent's involvement, and in recognition of the potential for having to act with little notice and at inconvenient times." I want to reward and motivate the agents to act, even though they are close friends or family who would act without compensation. Even the occurrence of several exacerbations during a year should readily be covered by the six-week period. But this cap will prevent the intended reward from becoming an unreasonable expense if a permanent issue arises.

LIVING WILLS

Living wills and health care proxies for an MS client will generally be similar for most clients, with these added considerations:

The potential for exacerbations that are unexpected but short-term might suggest preparing a stand-alone HIPAA medical release authorizing an agent to receive medical information, but not triggering an agent's decision making as under a health care proxy. There may be no need for the MS client to abrogate decision making, but it might be desirable to permit a spouse, partner or other family member to monitor medical matters during an exacerbation.

The MS client might wish to include an express provision concerning donating brain or central nervous system (CNS) tissue samples for MS research efforts. The language should be specific enough to assure that the donations will be used for MS research. Even some clients with religious preferences against organ donations may wish to provide for this. In such instances, care should be taken to explicitly acknowledge that although organ and tissue donations are against the client's religious beliefs, they are intentionally permitting the donation of CNS tissue if it can productively be used to advance MS research. Through thousands of discussions with clients over many years concerning organ and tissue donations, most were hesitant to

address the issue, especially those with a significant health problems. I was surprised by my wife's courage in raising this question so early. For her, as with many living with chronic illnesses (think of the actor Michael J. Fox's very public battle against Parkinson's), there is a tremendous desire to combat the illness and find a cure, if only for others in the future.

Given the potential for significant long-term disability, especially if your client has been diagnosed with a progressive form of MS, a guardianship designation should be included in the health care proxy (or a separate guardian designation should be prepared.) At the very least, such a designation provides clear evidence of whom the client would want to serve as guardian if a later court proceeding were necessary to confirm that guardian's appointment.

WILLS

The need for the MS client's family members to include special needs trusts (SNTs) to protect the MS client's will, as for all clients, depends on the circumstances. Many with MS will face devastating financial burdens—making SNTs essential in, for example, a parent's will for a child with MS. However, many with MS, especially those with relapsing-remitting MS (if the disabilities occurring during attacks remit), will continue their careers long after diagnosis, although they might require some accommodations, often to address the fatigue that is a common symptom. One-third of those with MS may continue working as long as 15 to 20 years after diagnosis. For many, with reasonable accommodations and monitoring by the client's neurologist, even jobs requiring sophisticated professional competence and manual dexterity can be continued.[2]

Most people with MS are diagnosed between ages 20 to 50. This is actually earlier then the age at which a typical diagnosis of Parkinson's is received: in the 50s (except for young-onset Parkinson's, which tends to affect those under 40), or Alzheimer's (which is typically diagnosed at older ages.)

MS clients at these ages may have savings, long-term disability and long-term care insurance. For many of them, an SNT in a parent's or spouse's will, would not be warranted. In fact, special needs planning may not be necessary, even if the diagnosis was at a young age for the MS client, if the category of MS he has is likely to permit him to work for decades, thus enabling him to continue saving and to maintain his health insurance coverage.

As would be expected, many MS clients with the financial wherewithal may be interested in providing charitable support to the MS center in their area that has provided them with assistance, services and support.

REVOCABLE TRUSTS

An obvious technique to help any client with a chronic illness manages assets is the revocable living trust. However, as with a specially designed durable power of attorney, there are a few nuances for the MS client. The typical revocable trust is drafted with the grantor as sole trustee. For a client with advanced Parkinson's or Alzheimer's, the client may not be a trustee. However, the MS client may best be served by a hybrid approach. Naming the MS client as a sole trustee might prove problematic during an exacerbation. Not naming the MS client as trustee cedes control from a client who generally has the capacity to make decisions. Relying on a transition to a successor trustee not only creates the expected issues with triggering the transition (as with a springing power of attorney), but also, the complete removal of the MS client as trustee may be unwarranted.

A better approach might be to have the MS client and another person as co-trustees from inception, with either being granted authority to act independently to take the actions that might be required during periods of an exacerbation. This might include signature authority over banking matters, but might expressly exclude the right to sign an income tax return (but permit filing an extension or paying tax), or sell an asset over some specified value. Significant decisions could be deferred until the exacerbation ceases, or expressly reserved to the MS client's discretion unless there is a permanent disability. The language would read: "Any Trustee, acting alone and without any requirement for joint action, is authorized and permitted to make ministerial and administrative decisions, including but not limited to routine banking, investment, and brokerage transactions."

BE AWARE, CREATIVE

MS, like any other chronic illness, affects every document and aspect of planning. Generalizations are inappropriate and will not serve the interests of the client with a chronic illness or his family. Every chronic illness has its own nuances, and hence impact on planning. ■

—The author acknowledges the assistance and input of Jeffrey N. Gingold, a former practicing attorney who is now a freelance author in Milwaukee and who is the author of Facing the Cognitive Challenges of Multiple Sclerosis. *Demos Medical Publishing, LLC, 2006.*

Endnotes

1. George H. Kraft, M.D. and Marci Catanzaro, *Living with Multiple Sclerosis A Wellness Approach,* Demos Medical Publishing LLC, 2006, at p. 13.
2. Jonathan D. Katz, M.D., "Disabled Anesthesiologist", *American Society of Anesthesiologist Newsletter,* May 2007, at p. 17.