

# Psychological and Emotional Impact of Chronic Illness on Estate Planning: Case Study Comparing and Contrasting Multiple Sclerosis and Parkinson’s Disease

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## **1. Chronic Illness and its Impact on Estate and Related Planning**

- a. 125 million Americans (45% of the population) have at least one chronic condition, such as paralysis as a result of trauma or stroke, Alzheimer's disease, mental disorders, HIV/AIDS, allergies, asthma, diabetes or high blood pressure, and so on. In the United States, approximately 60 million people (22 percent of the population) suffer from multiple chronic conditions. Source: Partnership for Solutions. Better Lives for People with Chronic Conditions "The Prevalence and Cost of Chronic Conditions." While for many fortunate people living with chronic illness will not experience significant impact on their lives or planning, for many the impact will be significant, and for a number of people, the impact will become the focus of their lives and planning. The bottom line is that there is a large number of people affected by chronic illness. Estate planners need to be informed of the issues, symptoms and planning implications to best create and implement estate plans for these people and their loved ones.
- b. The high frequency of chronic conditions in the U.S. necessitates that the entire estate planning process (from meetings with clients and advisers, to the drafting and implementation of estate plans) must all be done in a manner that is cognizant of current and potential chronic illness. Unfortunately, the guidance for practitioners to address these issues has, until now, been lacking. The common estate planning tools of durable powers of attorney, revocable living trust, special needs planning, etc. are important, but only a portion of the tools and techniques that are needed to help.
- c. The difficulty in addressing chronic illness is that each condition can vary so dramatically that generalizations can actually interfere with helping the client. To add to the complexity, the symptoms of a given illness can vary substantially from one person to the next. Further, a person living with a particular chronic illness may experience significant variations in symptoms during the course of a day, as well as over time as the disease progresses.

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- d. Another important consideration for practitioners is the fact that most chronic conditions do not improve over time. In the best case scenario, the condition may plateau while in many cases, the reality is progression in the severity of the condition and its effects on daily life. Both MS and PD are chronic illnesses, in contrast to acute illness. The symptoms tend to increase in number and severity over time and in most cases the disability burden increases as the disease continues to progress. This is quite different than dealing with acute health issues with which practitioners, and society as a whole, seem to understand and address better.
- e. While estate planning in the face of a chronic condition may seem daunting, this does not need to be the case. With a relatively modest investment in time and access to accurate information, practitioners can gain a reasonable understanding of how a particular chronic illness affects a given client (or client's loved ones) and use this knowledge to tailor planning and documents to best serve that client's needs. To illustrate how this can be done, this article focuses on the emotional and psychological issues of two chronic illnesses: Parkinson's disease ("PD") and Multiple Sclerosis ("MS"), and how each affects estate and related planning. It was felt that selecting two chronic illnesses for an in-depth comparison and case study would be more instructive than a generic discussion of chronic illnesses, or a superficial discussion of numerous illnesses.
- f. Approximately 400,000 Americans are living with MS and approximately 1.5 million Americans are living with PD.

## 2. **What is MS; What Impact Does It Have**

### a. **Definition.**

- i. MS is an autoimmune disease that affects the central nervous system ("CNS"), i.e., the brain and spinal cord. MS is characterized by an inflammatory process that results in damage to or destruction of the myelin sheath that surrounds and insulates the axon (nerve fiber). The MS lesions, referred to as demyelinating plaques, are typically detected through magnetic resonance imaging (MRI).
- ii. In progressive forms of MS scientists believe that the cells that create new myelin, called oligodendrocytes, are also destroyed. This would preclude the body repairing destroyed myelin (re-myelination) making improvement in the client's condition unlikely.

### b. **Variability.**

- i. MS affects the CNS in a random and unpredictable way so that each person's symptoms are different. Specifically, it attacks the myelin in the CNS, the fatty substance that forms insulation around nerve fibers. The analogy of the covering surrounding an electrical wire is often used to help visualize the role of myelin. MS can also

damage the nerve fibers themselves and lead to cerebral atrophy in which the brain actually shrinks in size. It is not possible to predict exactly where myelin will be damaged and so it is not possible to predict what symptoms will occur or how severe they will be.

- ii. A person living with MS cannot predict how he or she will feel from the beginning of the day to the end of the day let alone from week to week or over longer periods of time. As discussed above, there is a wide variety of possible scenarios where MS and its effects on daily life are concerned. The disease is enigmatic and can affect each person quite differently and unpredictably over time.

c. **Categories of MS.** There are a number of different categories or “courses” of MS, although there is not complete agreement on the classifications.

- i. **Benign MS.** If your client has benign MS, with little to no symptoms at the present time, there is still good reason for careful planning since MS can only be called benign in retrospect (approximately 20 years down the road). Disease progression can occur unexpectedly, and modifications in planning may be needed at any time. If the prognosis becomes more negative, substantial modifications in the plan as discussed below should be considered.

- ii. **Relapsing Remitting MS.** If the client has relapsing remitting MS the disease is characterized by periods of acute attacks (exacerbations) followed by recovery (remissions) with no disease progression between attacks. Over the years many patients transition to secondary-progressive MS (see below) during which permanent neurological problems will occur. Relapsing-remitting MS is the most common form of MS, affecting upwards of 85% of patients at onset of the disease. An attack can last for a short time, or as long as several weeks. It might be characterized by symptoms similar to a stroke involving severe visual, motor and sensory problems. The acute and short term nature of exacerbations with accompanying activity limitation must be addressed in the planning process. This is a characteristic that differentiates planning for MS from planning for many other chronic illnesses which typically involve a steady decline over time without periods of recovery.

- iii. **Secondary-Progressive MS.** Secondary Progressive MS begins as relapsing remitting MS but worsens over time. About half of patients who initially have relapsing remitting disease will become Secondary-Progressive over 15-20 years in the untreated state. Consideration of this time frame is important to planning. It is also important for advisers to understand that it is in the secondary progressive phase that the majority of disability is accumulated.

- iv. **Primary Progressive MS.** In **Primary Progressive MS** the disease worsens progressively from onset without clearly defined acute attacks. Over time, plateaus or minor improvements give way to the continued worsening of symptoms. Approximately 10% of MS patients are in this category. This course may require more significant planning in the event of disability.
- v. **Progressive-Relapsing MS.** Progressive relapsing MS affects a small proportion of MS patients, about 5%. The disease is progressive from onset, with occasional relapses or attacks along the way.

### 3. **What is PD; What Impact Does It Have**

#### a. **Definition.**

- i. PD is a chronic, progressive neurological disorder that can impact both physical and mental functioning. The symptoms of PD, however, can vary greatly from person to person, and even within an individual (e.g., over time, and from hour to hour in more advanced disease stages). Practitioners should not make assumptions about a particular client's symptoms or level of functioning without a specific understanding of the facts for the particular client, and at that particular time.
- ii. Early in the disease course PD can be managed with medications and lifestyle changes so that for the first few years following diagnosis PD clients can live a relatively unimpeded life. But PD is progressive and the symptoms will worsen over time. Thus, while planning probably does not need to be addressed on an urgent basis for a recently diagnosed client, the fact of progression means it should not be delayed long. This generally contrasts with the situation faced by a client with benign or less severe relapsing-remitting MS. Some of these MS clients may never experience the physical or cognitive impact that a PD client will have as their PD advances. Although in PD there is the possibility of a more benign course initially, after 5 to 10 years most PD patients will experience significant problems with motor function that interfere with their independent functioning.
- iii. Since PD usually progresses over many years there will generally be opportunity for the client to re-evaluate their feelings and wishes over time and modify their planning accordingly. After documents and initial planning is completed, annual reviews to assure that this occurs, are advisable. It is likely that the client's views and feelings about a range of issues including personal care, agents to name, and other personal aspects of planning will evolve as their PD progresses and they re-evaluate and consider options. Practitioners should bear in mind that the PD client is not always able to judge whether or not he or she is capable of making

decisions. Be alert for indications of impaired focus and understanding. If a PD client is unable to make decisions, a meeting scheduled at a better time in the future may be a simple option, if timing rather than progression is the issue. This is a complex issue:

1. While many people with PD experience some degree of cognitive dysfunction, only a minority develop full dementia.
2. The difference between cognitive dysfunction and dementia is very important, with implications for counsel's determination of legal capacity, and the client's issues of self-determination.
3. Cognitive dysfunction is usually limited to certain "domains", such as attention and concentration. However impairment in one or two domains does not necessarily mean a lack of intelligence, or loss of intellectual ability undermining legal competency.

#### **4. MS: Common symptoms and Their Impact on Planning**

- a. **Symptoms Puzzling and Different.** Before describing MS symptoms it is vital to keep in mind that while many of these symptoms sound familiar (e.g., fatigue), the level, scope and nature of these symptoms are qualitatively different from what healthy individuals experience. It is therefore difficult for those not familiar first hand with MS to truly understand the full ramifications of MS. It is also important to understand the distinction between "symptoms" or what the patient feels is wrong, and "disability" a term that refers to the extent to which a person's symptoms interfere with his or her ability to function in everyday life.
- b. **Attacks.** The possibility of experiencing exacerbations, (also called attacks or relapses) creates the potential for unpredictable, sudden worsening of symptoms and increased disability. This has a significant impact on the person living with MS and his or her estate planning. From an emotional perspective, the worry and fear that an attack will occur, and that it may bring new and/or more severe disabilities, and that those disabilities may or may not remit following the attack, has a significant impact on the psyche of someone living with MS. To the extent that planners cannot only create a secure safety net, but reassure the client that this safety net exists and is workable, will be helpful. The potential for unexpected attacks impacts the type of planning, the manner in which estate planning documents should be drafted, etc.
- c. **Fatigue.** MS fatigue is not the type of "tired" that a nap will necessarily improve. It is far more dramatic and disabling than most people unfamiliar with MS can appreciate. Research indicates that as many as 90% of those living with MS experience significant fatigue. Studies have indicated that

fatigue can be the most disabling symptom. This is a very difficult symptom since most people understand what it feels like to be tired, but MS fatigue is very different, often exponentially so. Fatigue can be both physical and cognitive. Cognitive fatigue is a major issue for many people living with MS. It is also a condition which is misunderstood and underappreciated. For many clients, the presence of cognitive fatigue could actually be the most substantial impediment to the estate planning process, not the impact of the physical fatigue. If MS fatigue occurs while you are meeting with a client, it may be necessary to adjourn the meeting for another day. The onset of MS fatigue can often not be anticipated by the client so it may be impossible for the client to request a meeting time that will avoid the issue.

- i. There can be a host of factors contributing to MS fatigue; the condition is complex and variable.
  1. Interrupted sleep caused by pain or stiffness, bladder problems, periodic limb movements (PLM's), sleep apnea, or some other form of sleep disorder can contribute to the presence of fatigue. Fortunately most of these conditions can be alleviated with the right treatment.
  2. Exertional fatigue is caused by working muscles to the point that their strength begins to fail. This is probably caused by the underlying damage to the central nervous system in which damaged nerves are no longer able to fire as well or as long as normal ones. It might be a feeling similar to a healthy person walking up a steep hill and experiencing the feeling of their legs turning to jelly.
  3. Primary MS fatigue, also referred to as MS lassitude, is thought to be the result of the slowing of nerve conduction caused by MS.
- ii. While MS fatigue is different for each person, common descriptions of it are:
  1. "It's a type of tired that has nothing to do with feeling sleepy."
  2. "It feels like a light switch has been flipped, it comes on quickly."
  3. "It feels like carrying chains."
  4. "It feels like swimming in quicksand."
- iii. Those living with MS will often view dealing with fatigue as "energy management". They only have a limited amount of energy, or productive hours, in a day and have to budget when and how to use it. For many, sleeping doesn't help, but resting to give the body a chance to recoup may be helpful. For others, a nap will

help. But that nap may require much more than a “cat nap,” perhaps an hour or hours depending on the individual. Without that rest functioning may be quite difficult. For others, napping will not eradicate the fatigue.

- iv. Practitioners should endeavor to advise their staff to be flexible to schedule meetings that coordinate with the MS client’s physical schedule. For most people with MS, mid to late afternoon is the peak period for fatigue and likely to be the least productive. A meeting scheduled during a time of extreme fatigue won’t be productive.
- d. **Vision**. Changes in vision (these might include loss of visual acuity, double vision, visual field defects) can be substantial. These might require printing drafts and documents in larger or bolder type, taking other precautions or making other modifications that practitioners would generally consider for a visually impaired client.
- e. **Problems with Walking**. This can come from balance problems, incoordination, spasticity, sensory problems (e.g., feet are numb), or weakness. Practitioners should consider the physical layout of their offices. Area rugs, as an example, can be a significant hazard.
- f. **Bladder and bowel Problems**. Practitioners should be empathetic if frequent or sudden interruptions of meetings are necessary.
- g. **Pain**. Primary or neurogenic pain resulting from nerve damage in the CNS is experienced as burning, stabbing, aching pains. Some experience it as overwhelming discomfort. There are also secondary types of pain—most often orthopedic—that can result from changes in gait or incorrect use of a mobility device. In the NARCOMS registry, 90% of people living with MS rated pain as a significant factor in their life. Thus, pain, along with the medications used to treat it, may also become pertinent in a person's ability to fully participate in the estate planning process.

## **5. PD: Common symptoms and Their Impact on Planning**

There should be a distinction between “symptoms” or what the patient feels is wrong, and “disability” a term that refers to the objective limitations and loss of function.

- a. **Symptoms**.
  - i. The physical symptoms of PD that affect most people, even early in the disease, include bradykinesia (slowed movement), akinesia (the inability to move spontaneously), rigidity and tremor. . These symptoms can make it difficult for the PD client to begin, or continue, an action.
  - ii. A common impact of these conditions is minimization of the facial expressions of a PD client. Practitioners should not assume that a blank facial expression indicates the PD client is not paying

attention or following a discussion, or that the PD client has cognitive impairment.

- iii. Rigidity causes stiffness, mainly of the arms or legs. Tremors can be mild or severe, intermittent or constant, and most commonly affect the hands. All of these symptoms contribute to making writing a particularly difficult task. This can have a significant impact on the PD client's ability to sign legal documents.
  - iv. Other symptoms of PD may include dysarthria (slurred speech) and hypophonia (very soft speech). This can make it difficult to understand what the client is saying and can be frustrating for the speaker and listener. Turning up the volume on a telephone, using a land phone line rather than a cellular phone, using the actual phone and not a speaker phone, can often help. In many cases, simply taking the time and having the patience to focus, will enable you to understand the client. If, however, an answer to an important question is not understood, you should and must ask the client to repeat their comment until you do understand it. Whatever discomfort you may have, or whatever frustration the client may have, pales by comparison to the damage that might be done if you don't properly understand the client's wishes.
  - v. Drooling, which can be embarrassing, is a common PD symptom. Extra tissues should be on hand though many clients carry their own for this reason.
- b. **Attacks**. Sudden attacks (exacerbations) do not occur in PD, rather PD tends to present itself as a decline over time, although the rapidity of degradation will vary by person and over the years.
  - c. **Fatigue**. Fatigue is common in PD, although probably not as severe as in MS. Often it is exacerbated by concomitant hypotension (low blood pressure), or by medications.
  - d. **Vision**. Changes in vision are a common problem in intermediate and advanced stages of PD. Many PD patient experience diplopia (double vision) and may have difficulty reading especially small print.
  - e. **Problems with Walking**.
    - i. As PD progresses, balance and walking may also be affected. After five to ten years of disease, most patients will experience some degree of difficulty with walking and balance. This may be limited to minor balance problems experienced only in more challenging circumstances (for example difficulty getting in or out of a car), or may be more pronounced, interfering with ambulation. Some PD patients experience a peculiar phenomena called "freezing of gate", that usually manifest while trying to walk through a doorway or when approaching a chair to sit down. Their legs will simply become "glued" to the floor, and do not respond to the

internal command to move. Often, as patients try to overcome the “freeze”, they fall.

- ii. Other peculiar phenomena of PD are the “long term motor complications” that develop in the vast majority of patients after years of treatment with Levodopa. While the drug is very effective in improving the symptoms of the disease, after years of treatment the duration of the benefit becomes progressively shorter, and patients fluctuate from a state of “on” (relative well-being due to the effect of the medication), to “off” (profound Parkinsonian disability as the medication fail to sustain the effect). These ON/OFF fluctuations can repeat many times during the day. “On” periods can be associated with excessive, involuntary movements (*dyskinesias*), as patients over the years become very sensitive to the effect of Levodopa, leading not just to an acceleration of movement, but to an over activation of the body. Dyskinesias can manifest as subtle wiggling movements or more severe flailing movements of the head, body, arms or legs. Subtle movements might give people the appearance of being nervous or restless when, in fact, they are not. Severe dyskinesias can make performing some tasks very difficult. Clients can transition from “off” to “on” and vice versa within minutes. Most clients are very distressed when “off” and would choose to be “on”, even though dyskinesias may occur. In fact, dyskinesias (unless severe) tend to bother others more than they bother the PD clients themselves.
- iii. Motor fluctuations are phenomena unique to PD and tend to be particularly problematic in YOPD. At first, PD medications work very well and symptoms tend to be relatively constant throughout the day. However, as the disease progresses, clients may experience a “wearing off” of their medications with a return of their PD symptoms as they are approaching the time of their next dose. It is extremely important that PD clients with motor fluctuations be permitted to take their medications on time. Water should be available and tasks should be interrupted to allow them to take their medications (which, for some PD clients, may be once an hour). A simple solution is to have a decanter of water and glasses on hand in each of your conference rooms so that such a client can help themselves comfortably whenever necessary. It is also advisable, as noted elsewhere, to cooperate with the PD client as to the timing of your meeting. If the client is inflexible about the time of day they want to schedule an appointment it might be their effort to time the meeting to best fit the above cycle.
- iv. PD ambulatory issues differ from those that affect some MS clients. While many MS clients will not have significant walking difficulties, most PD clients eventually will. While some clients living with MS may have early and even severe gait deficits, most

PD patients will develop severe gait problems, but only at the later stages of their Parkinson's disease.

- v. Practitioners should consider the physical layout of their offices. Area rugs, as an example, can be a significant hazard.

- f. **Bladder and bowel Problems**. Bladder and bowel problems are a common PD symptom. Most patients with PD experience urinary "frequency" and "urgency", or an urge to urinate frequently and the sensation of urgent need to go to the bathroom. Virtually all patients with PD have constipation, that in some cases may be severe and cause significant discomfort.
- g. **Pain**. Pain is frequent in PD, although it is rarely a major quality of life issue.

## 6. **MS Emotional and Cognitive Issues**

- a. **Emotional Impact of MS**.
  - i. The rate of depression in MS is so high that it is thought to be a symptom of MS not just a reaction to the disease. Approximately 50% of people with MS will experience a major depressive episode at some time during the course of their MS. Depression is under-diagnosed and under-treated in MS. In many cases it can hinder or prevent the client's participation in the estate planning process.
  - ii. Practitioners should be aware that mood swings could affect the progress of a meeting. If the person living with MS is experiencing depression, it might appear as irritability in contrast to the sad or blue demeanor that other depressed persons might demonstrate.
  - iii. To address the uncertainty which MS creates, and often the client's lack of understanding of his or her own condition, consider requesting a clarifying letter or phone conference with the client's attending neurologist. Many MS clients, even long after their initial diagnosis, are still denying the impact the illness has on them and their future.
- b. **Prevalence**. 50-60% of people with MS will experience some changes in cognitive functions. More than any other MS symptoms, cognitive changes may have the greatest impact on the estate planner's efforts. There are several discreet functions that may become impaired. However, only a very small percentage of people with MS have cognitive issues that are so severe that it would not be able to make the types of decisions necessary to consummate an estate plan.
- c. **Memory**. For those MS clients who are affected, the most common changes have to do with memory for recent, events. Memory for long past events is generally not affected.

- i. **Example:** A client with MS may have trouble remembering a conversation you had at the beginning of a long meeting, but no problem remembering family historical events.

d. **Attention and Concentration.**

- i. Many people with MS have difficulty with attention and focus and cannot multi-task or switch tasks easily.
- ii. **Example:** A client has difficulty focusing on the conversation with the attorney, being easily distracted by outside sounds; can't take notes and talk to the attorney at the same time; thinks of a question he or she wants to ask and then loses the thread of the conversation.

e. **Slowed Information Processing.**

- i. You might observe someone trying to think through a problem to reach a conclusion, or mentally review the steps to reach a conclusion—a process that might take the person much longer than it used to. The person living with MS can carry out all the thought processes but it might take longer. This is a very important distinction from the cognitive impact of other chronic illnesses which may prevent the client from carrying out the thought process at all, regardless of the time allotted. This is why it is unfair to the person living with MS to assume a lack of mental capacity unless the attorney knows for certain that there has been that type of impact. This is why generalizations as to the impact of “all” chronic illnesses to clients are inappropriate.
  - ii. **Example:** A client with MS is reviewing a will with her attorney. Her intelligence has not been impacted by her disease, but the speed at which she can process the attorney/reviewers discussion while reading has been. It takes longer to process the comments, and then formulate her responses and speak them. The attorney, not realizing what is happening, continues to the next Article in the will if he does not hear a reply, assuming that no reply means all is fine. The slowed information processing finally leads her to ask her attorney to pause and wait for her to indicate when he should proceed to the next section.
  - iii. If you are sitting with a client living with MS and explaining a concept, the client may be several paragraphs or thoughts back. If you continue to move on, he or she may not keep up.
  - iv. However, it is vital not to treat the client as if they are mentally disabled, or less intelligent, they may merely process more slowly.
- f. **“Executive functions”** that include planning, prioritizing, organizing, etc. may be difficult for someone with MS. It may be difficult for someone with MS to do this as quickly and efficiently as before. Again, this is not a reflection on the person's intelligence, but will require an estate planner to

present information more slowly, in chunks, and with repetitions. In addition, the estate planner may need to assume a more proactive stance in terms of laying out the steps that the client needs to complete and involving family members in the process.

- g. **Word finding difficulties.** Reading and language comprehension are not generally impaired by MS. But when the person living with MS tries to respond they might have difficulty identifying the word they want to use. While this tip-of-the-tongue phenomenon affects many people, it tends to affect someone with MS to a greater degree. The cognitive changes discussed thus far are experienced in varying form by around half of all people with MS. Some have none, some a few, but very few experience all of the symptoms. Moreover, when cognitive changes do occur in MS, they generally affect only some functions while leaving others intact.
- h. **Physical and Cognitive Symptoms Don't Correlate.** You cannot judge by looking at someone whether or not he or she has impaired cognition or how severe the impairment might be. There is little correlation between physical symptoms and cognitive symptoms.
  - i. **Example:** A very physically impaired person living with MS had no ability to move any part of his body other than his head, but he worked as a college professor.
  - ii. **Example:** At the opposite extreme was a young woman who at age 15 had little physical impairment but substantial cognitive impairment. Her judgment and ability to plan and make decisions have remained so impaired that even 15 years later when she attained age 30 she remained modestly impaired physically, but so impaired cognitively that she could still not live independently.
- i. **Cognitive Fatigue.** Cognitive changes may be accompanied by a special type of fatigue known as cognitive fatigue. Cognitive fatigue tends to occur as a result of an extended period of focus on a cognitively challenging task. When cognitive fatigue occurs, it is a good idea to break for a period of rest or focus on another activity, especially while trying to deal with a cognitively challenging situation such as a complex and long meeting.
- j. **Comparison to Other Chronic Illnesses.** How do MS cognitive changes contrast with Alzheimer's dementia? MS cognitive impairment is not global in the manner that Alzheimer's is. Further, the MS client's overall intellect is generally not affected. Instead specific functions may be affected while others are intact such as reading comprehension.
- k. **Attacks and Cognition.** How might an exacerbation affect cognition? Clients who are having an attack or exacerbation are at greater risk for cognitive changes. If they are having a relapse it is not an optimal time to meet to address estate or other planning. If cognitive changes worsen during an attack they might improve after the attack. However, once a

person has experienced cognitive changes they are unlikely to totally remit. If someone is having a pseudo exacerbation (e.g., from running a fever or being over heated) the cognitive changes will improve when the pseudo exacerbation ends.

- l. **Impact of Cognitive Issues.** Cognitive changes generally do not interfere with a person's ability to make sound decisions; nor does it mean the inability to choose an heir or sign a will. As explained earlier, the deficits in MS tend to be very focused rather than global. In contrast global dementia is commonly seen in Alzheimer's disease. This fact is often misunderstood and can lead to planners and family disabling someone with MS when this is not reasonably necessary.
- m. **MS Planning Impact.** Given the uncertainty MS creates, the focus of planning should be to provide the client with maximum control over his or her financial and legal matters, while creating an appropriate safety net in the event cognitive impairment becomes significant. Even when assistance with daily activities is required, the impact of MS on most clients living with the disease is such that the client will likely be able to, and wants to, serve as a co-fiduciary. This can help MS clients in that administrative burdens can be shared, thus easing their burden and responsibilities while keeping them involved and in control. This is preferable for the majority of MS clients, rather than eliminating the client's involvement as may be the case with, for example, a more advanced stage of Alzheimer's disease.

## 7. **PD Emotional and Cognitive Issues**

### a. **Emotional Impact of PD.**

- i. Apathy is one of the most common cognitive problems in PD. Often it is confused with depression, with which it overlaps. The other major problems are executive dysfunction, some attention problems and "Bradyphrenia", or slowing in retrieving and assembling concepts. Another important factor in cognition and PD is the pharmacological or surgical treatment of the disease, that may lead to worsening of mental functioning. Most of what was discussed above in the context of MS applies similarly to PD, with the exception of memory, that is usually unimpaired in PD. Also, PD clients do not experience, attacks (exacerbations), or the cognitive fatigue that those with MS do.
- ii. The main mental symptoms of PD include depression, anxiety, cognitive problems and apathy. Some clients may also experience psychiatric side effects from medications used to treat PD, namely psychosis (delusions or hallucinations) or confusion.
- iii. Depression and apathy may be underlying the PD client's reluctance to schedule a meeting or follow up. The encouragement and involvement of other family members to the extent ethical rules permit may be advisable to continue the planning process.

Practitioners should not misinterpret apathy towards planning as a sign that they should not continue to push the process forward. Consideration should be given to having the PD client authorize communications between the attorney and agents and family members, as well as other advisers. This can address the ethical issues so that communication at a later date can be coordinate to help the PD client overcome issues that arise.

- iv. A particular client may experience none, some or all of these problems. This is why making assumptions, or relying on generalizations about PD will undermine your ability to best serve a PD client.
- b. **Prevalence.** As many as one-half of all PD clients have difficulties with memory and thought processing. These circumstances, however, are not simple to evaluate or always obvious. For example, even if a PD client has a cognitive impact, the implications of that impact can vary from inconsequential to more substantial depending on the demands placed on the PD client. Also, many use an Alzheimer's paradigm for understanding PD cognitive impact and the cognitive impact of Alzheimer's is often not relevant to the PD client. A PD client may generally be able to function normally, but have some issues with disorganization, distractibility, prioritizing and forgetfulness.
- c. **Memory** Memory difficulties are usually not a problem for those living with PD (e.g., age related naming problems). However, another memory issue, referred to as "procedural memory" may be impaired in PD. This is the memory of "how to do things." For example, the person with PD can remember well date and facts, etc., yet may forget how to use complex motor sequences.
- d. **Cognitive Issues Generally.**
  - i. PD is often accompanied by other health issues. Also, many PD clients are of advanced age so that other factors may increase the portion of PD clients with cognitive issues. It is important that practitioners confirm the client's overall health status and which other conditions, if any, may impact the particular PD client. These other health issues may increase the likelihood of cognitive impairment and dramatically change the planning that is appropriate, or the urgency in completing planning, PD can be similar to Multiple Sclerosis ("MS") or Amyotrophic Lateral Sclerosis ("ALS"), for which only a small percentage of those affected experience significant cognitive impairment to the point of being characterized as having dementia. In contrast, those with Alzheimer's invariably lose memory, the ability to reason, and the understanding of the consequences of their decision making.
  - ii. Many clients with PD exhibit bradyphrenia, or a slowing down of thought processes. It can take longer for a PD client to respond to

a question even when they understand everything. Practitioners should try to be patient while waiting for a response. Slowness does not necessarily imply that the particular client does not fully understand the issues being addressed. Patience is essential. Practically, you should schedule more time for a meeting with a PD client so that this and other issues can be addressed reasonably. If an introductory meeting typically receives a two hour allotment on your calendar system, allow for three hours for a PD client to assure that you are not rushing through important issues.

- iii. Older PD clients, and those with advancing PD, appear to be at particular risk for cognitive problems. Cognitive impact on YOPD has not been the subject of substantial studies as yet. Even early on, many people have subtle cognitive difficulties that may affect their ability to concentrate, multi-task and plan effectively. These are sometimes referred to as “executive” functions. Try to focus meetings and discussions on a single issue at a time, and organize the issues in logical or natural sequence to facilitate discussions.
- iv. As the disease progresses, some people develop frank dementia and may be disoriented to place, date or time. These PD clients may lack judgment and be unable to effectively make decisions. However, for some PD clients, their ability to make key decisions will never be completely undermined.
- v. A client that is perfectly competent to make decisions at one point in the representation may not be at a later point. If significant transactions are to be engaged in, e.g., a large complex note sale transaction to a defective grantor dynasty trust, counsel should endeavor to corroborate that at the time the PD client was in fact capable of understanding the transaction. For some PD clients the most difficult issue for counsel is not determining whether the client’s competency has been compromised, but when competency has reached a point on the continuum that a particular level of planning might be inappropriate to consummate.

e. **Attention and Concentration.**

- i. Many people with PD have difficulty with attention and focus and cannot multi-task or switch tasks easily.
- ii. Commonly prescribed dopaminergic medications may exacerbate the problem.

f. **Slowed Information Processing.**

- i. **Example:** A client with PD is reviewing a will with her attorney. Her intelligence has not yet been impacted by her disease (but in contrast to MS it is more likely that it eventually will be). The attorney asks the client a question and receives an expressionless

reply. The attorney might interpret this as a lack of understanding, when in fact the issue was fully understood.

- ii. **Example:** A client with PD is reviewing a will with her attorney. Her intelligence has not yet been impacted by her disease (but in contrast to MS it is more likely that it eventually will be). However, the speed at which she can process the attorney/reviewers discussion while reading has been. It takes longer to process the comments, and then formulate her responses and speak them. The attorney, not realizing what is happening, continues to the next Article in the will if he does not hear a reply, assuming that no reply means all is fine. The slowed information processing finally leads her to ask her attorney to pause and wait for her to indicate when he should proceed to the next section.
  - iii. If you are meeting with a client living with PD and explaining a concept, the client may be several paragraphs or thoughts back. If you continue to move on, they may not keep up.
  - iv. However, it is vital not to treat the client as if they are mentally disabled, or less intelligent, they may merely process more slowly. However, be cautious of the opposite. Several years ago the client was expressionless, but understood the import of the questions discussed. Now, years later, the client is similarly expressionless, but in fact has experienced significant cognitive decline and is not following the discussions.
- g. **“Executive functions”** that include planning, prioritizing, organizing, etc. may be difficult for someone with PD. It may be difficult for someone with PD to do this as quickly and efficiently as before. The estate planner may need to assume a more proactive stance in terms of laying out the steps that the client needs to complete and involve family members in the process. At later stages, the impairment of executive function will often require care giving and comprehensive help.
  - h. **Word finding difficulties.** Reading and language comprehension are likely to be impaired in late stages of Parkinson’s disease. Most patients will develop “dysarthria” and “hypophonia”, but they do not lose the use of language. Also, unless there is severe dementia, PD patients have no problem with verbal or written comprehension. This result is more severe than for most MS clients. While only about half of MS clients experience cognitive changes most clients living with PD do experience cognitive decline. While cognitive changes that do occur in MS, generally affect only some functions while leaving others intact, for those living with PD the cognitive impact is more global.
  - i. **Physical and Cognitive Symptoms Don’t Correlate.** You cannot judge by looking at someone whether or not he or she has impaired cognition or how severe the impairment might be. There is little correlation between physical symptoms and cognitive symptoms.

- i. **Example:** A PD client may appear expressionless, yet have fully understood every detail of the conversation.
  - j. **Cognitive Fatigue.** Not applicable to PD.
  - k. **Comparison.** How does PD cognitive impairment contrast with MS or Alzheimer's dementia? PD cognitive impairment is likely to eventually be global in a manner similar to Alzheimer's disease. This contrasts with MS cognitive impairments which in most instances are more limited in scope. In contrast to MS, the PD client's overall intellect may be affected.
  - l. **Attacks and Cognition.** Attacks do not occur with PD.
  - m. **Impact of Cognitive Issues.** Cognitive changes should not initially limit a person with PD's ability to make sound decisions; or to choose an heir, or sign a will. But in contrast to MS, in up to half of patients with PD, the cognitive deficits are likely to become sufficiently global that appropriate steps must be taken.
  - n. **Planning Impact.** Given the uncertainty MS creates, the focus of planning should be to provide the client with maximum control over his or her financial and legal matters for as long as feasible. In contrast to most MS clients, a PD client is far more likely to experience substantial cognitive problems as the PD progresses. Creating an appropriate safety net as cognitive impairment grows should be a focus of planning. If the PD client wishes to, serve as a co-fiduciary they may be able to do so for many years, but it is likely that at some point impairment will make this impractical.
- 8. **Considerations for Meetings with Clients with MS and PD.**
  - i. It is OK to ask the MS or PD client "what are your challenges so I can tailor my work to meet your individual needs."
  - ii. Plan short, separate meetings rather than one long meeting.
  - iii. Be aware and empathetic of fatigue issues for clients with MS. For clients with PD be aware and empathetic to the "on" and then "off" times and variations as medications levels change.
  - iv. For MS clients in particular, ensure that a bathroom is available, accessible, close at hand, and allow for time and interruptions for bathroom breaks.
  - v. Have an agenda and bullet list for the meeting. Use a smart board or flip chart with outlines of the meeting agenda and topics.
  - vi. When you are explaining concepts, be certain to inquire at frequent points along the way whether the client understands it, or has any questions.
  - vii. Try to provide a written take-away, an executive summary, whenever possible.

- viii. When planning a meeting with a client with PD, or a client with MS whose handwriting is impaired, especially a signing meeting, consideration should be given to blocking out more time for the meeting. Reconsider how signing of documents should be structured. For example, some practitioners routinely have clients sign every page of a will, and perhaps even a trust. If initials will suffice in lieu of a signature, or if a signature at the end of the document will suffice in lieu of initials or signatures on each page (even if that is your preferred practice), then modifying documents for a PD client, and some MS clients, will make signing meetings easier for all.
- ix. It may be beneficial for MS clients to tape record the conversation so they can replay it many times to assure they remember all the key points. This might be more important for a PD client.
- x. Have someone such as a friend, family member, or other adviser, accompany the person with PD or MS to the meeting to provide a second pair of ears.
- xi. At the end of the meeting, provide a bulleted list of important conclusions.
- xii. Because of tremors, hand weakness or other symptoms, some people with MS and PD might not be able to take notes.
- xiii. Many with MS and PD may have difficulty with executive functions and multi-tasking, so taking notes while listening might be difficult. It might be more productive for someone else to take notes and let the client simply listen.
- xiv. Provide a bulleted list of follow up steps for what the MS client should do following the meeting.
- xv. If the client with MS or PD has a “to – do” list, it should be written down.

## **9. Undue Influence.**

- a. Attorneys need to be alert for the possibility that family members or caregivers might take advantage of an MS or PD client.
- b. Attorneys should also be vigilant for the possibility of verbal or physical abuse of MS or PD clients, since this is known to occur.
- c. Serving as a caregiver is a very challenging task. “This person is no longer the person I married.” “I am no longer a husband/wife but a caregiver,” and similar comments are not uncommon. The divorce rate is similar to that in the general population; however, some couples that did not have a solid marriage prior to the disease—and might well have split up—stay together because of the MS, financial constraints, or guilt, feeling they have no other options. This scenario can lead to abuse and neglect. The

result of all of this is that the MS client often feels abandoned, and may in fact be abandoned.

- d. Parent caregivers may be caring for a child or teen with MS, or an adult child who was already out in the world and independent and now has to come back home. From an estate planning perspective, these parents have to determine how to provide care for that child into the future.

**10. To What Extent Has the MS or PD Client Come to Terms with the Impact of their Disease?**

- a. One of the toughest challenges is to get a client living with MS to plan for the worst while hoping for the best. This is a “hard sell” for a young adult living with MS or YOPD.
- b. An MS or PD client’s comfort level in dealing with the particular issues that confront him or her will vary tremendously, not only based on the client’s personal disposition, but on the characteristics of the MS and how recently the diagnosis was made.
- c. Clients who are newly diagnosed may still be in a period of denial and/or grieving and may not even be forthcoming about their condition. Inquiring about a client’s health issues should be no different than a routine question about citizenship. It needs to be asked. Even if clients acknowledge having MS or PD, they still may deny any need to tailor their planning to address it. The mere fact that clients indicates that they have MS or PD may not mean that they have come to terms with the impact of that diagnosis to the degree that they can deal directly with the ramifications. Those living with PD often suffer with apathy and other impacts of PD, and may therefore need even more encouragement and support from family and loved ones to move forward with planning.
- d. It is vital to address the implications of MS or PD for any MS or PD client, including those reluctant to address it. This is true even for those who indicate that they have a benign form, since the clinical course of MS is unpredictable. In contrast, PD will in many cases result in significant cognitive decline in the future so that early planning is critical.
- e. But how can a practitioner address these issues if the MS client won’t acknowledge the possibility of such issues? Can or should the practitioner incorporate in a plan the possibility of future disability as he or she prepares documents-rather than forcing a conversation with an unwilling client?
- f. Is there any potential downside to addressing these issues if a client has benign MS (mild MS) and significant symptoms don’t ever materialize?
- g. What are reasonable and defensible plans for someone who has been diagnosed with an illness that may not ever adversely impact one’s functioning?

## **11. Caretakers, loved ones and family**

- a. Caretakers, spouses, and family are all substantially impacted by MS and PD. Even in early stages of MS or PD, or for less severe cases of MS, the caretaker is likely to experience considerable added stress and substantial demands on their time. Few people who have not served in the caretaker role understand the impact.
- b. When naming fiduciaries, consideration must be given to the burdens these people already experience.
- c. Caregiver and family issues impact estate planning. If there is no close and reliable caregiver, it might be advisable to require a periodic visit to the client living with MS or PD by an independent social worker to report back to trustees of a trust established for the benefit of that person (even a revocable living trust established by the person himself or herself). This can be used as a safeguard to provide independent corroboration that the person living with MS or PD is not being abused, and that appropriate care measures are being taken.

## **12. Getting the Chronically Ill Client to Address Planning**

- a. Planning is critical for everyone, especially for someone with a chronic illness like MS.
- b. Try to have MS or PD clients focus on how they can take proactive steps now to create a safety net for the issues that cause them the greatest concern. Then guide them to take steps to minimize the anxiety associated with those worries.

## **13. Anticipating Future Disabilities and Disease Course**

- a. While the disease course for any patient cannot be known with certainty, efforts are being made to develop predictive models.
- b. **MS progression.**
  - i. There are some prognostic factors that some physicians may consider. They may not always share this information with their patients unless the patients indicate they want to know. However these prognostic indicators are mainly useful for predicting average progression in large groups of patients and tend to be relatively unreliable when used in individual cases.
    1. People who begin with spinal cord lesions and balance or gait issues tend to do worse.
    2. Multiple attacks early on involving many symptoms tend not to do as well as those who have infrequent attacks with more limited impact.
    3. If someone returns to baseline after an attack they will tend to do better than someone who does not fully recover.

4. Men tend to do worse than women over time.
5. African Americans tend to do worse than Caucasians.

c. **PD Progression.**

- i. PD is invariably progressive. While the rate of progression varies considerably from individual to individual, most people will develop significant motor disability within ten years from the onset of the disease. At this time patients may lose the ability to independently perform common actions of daily living, like writing or typing, and may require help with dressing and personal hygiene. This is also the time when the on/off phenomenon, dyskinesias, and other motor complications of long-term Levodopa treatment develop. These complications may further affect personal independence, and cause additional functional disability. Older individuals are also at higher risk of developing more severe cognitive problems and dementia, that usually manifest after 15 or 20 years of disease.

**14. Religious Considerations**

- a. Religious issues can permeate much of the estate planning process including living will decisions, choice of health care agents, funeral and burial instructions, dispositive provisions, and more. Too often these considerations are ignored as outside the realm of what an estate planning practitioner should address. While this is an unfortunate and inappropriate conclusion in general, it is perhaps more problematic in the case of an MS client. A survey endeavoring to ascertain the impact of religious beliefs in coping with MS determined that 25% of those surveyed believed God gave them MS to make them a better person, 14.5% attributed their disease to sins in a prior life and 9% believed God could help them with the MS.
- b. Language could be included in such an MS client's living will to conform to that client's personal religious preferences. Similar steps to assure that other estate planning documents and steps adhere to the client's faith should be taken. See Study "Religious Beliefs of People With Multiple Sclerosis", Amoroso G, Freitas A, et.al. ABEM, Sao Paulo, Brazil, as reported in "Abstracts From the 20th Annual Meeting of the Consortium of Multiple Sclerosis Centers" 31 May – 3 June 2006, International Journal of MS Care, Volume 8, Number 2, Summer 2006, at 46.

**15. Conclusion**

- a. We all need to show empathy towards those living with chronic illness, their caregivers and loved ones. We need to do this whether or not we or our loved ones are living with a chronic illness, but because we recognize that ultimately, none of us will remain unscathed by the toll of human illness. With what will often prove a modest effort and time commitment, general estate planning can be tailored to provide considerable sensitivity,

protection and even encouragement to those struggling with the challenges of chronic illness. We should invest our hearts and minds fully in the pursuit of helping those living with disease — simply because it is the compassionate and human thing to do.