Estate Planning for Clients with Parkinson's

*By Martin M. Shenkman**

Introduction to Series on Planning for Chronic Illness

This is the first of a series of articles addressing planning for a range of different chronic illnesses. The objective is to provide practical advice on how practitioners can plan fo deal with clients with each of many different chronic illnesses. While there are similarities between each of the illnesses that will be discussed in future articles, each has its own nuances which can differ significantly. Practitioners don't need to become experts in the medical details of any illness a client lives with, but understanding the planning implications, drafting techniques and nuances, and even simple accommodations that staff can make will enable practitioners to better serve these clients, their families and caretakers.

There is much talk of diversity in the law and other professions. The more diverse we are as a profession, the more diverse our firms are, the more open we are to everyone's differences the better. As practitioners, the more ideas, creativity and humanity we bring to our practices and our lives the better. But true diversity encompasses more than gender and racial diversity, it must include diversity in all its aspects and beauty. Religious diversity must be a component. Importantly, and the focus of this series, diversity should include those with whatever health or physical limitations they might now or in the future have. As we encourage and help those with chronic illnesses to remain active and vibrant professionals, our professions, firms and clients will all benefit. That perhaps is the ultimate goal of this series.

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Introduction to Planning for PD

Parkinson's Disease (PD) affects every aspect of a client's life, and has a dramatic impact on his or her caregivers and immediate family. No aspect of daily life remains unaffected, including estate planning. The client with PD brings a number of special nuances that estate planning practitioners need to understand to properly advise such clients and their families. PD is not rare—about one percent of all those over age 65 are diagnosed with PD. This makes PD second only to Alzheimer's in terms of the number of people affected. The average age at onset for PD is about 60 years, but it can also affect people under the age of 40 (referred to as Young Onset PD, or YOPD). This article will provide background on

PD and explore some of the ways both planning and document drafting can be modified.

Background on PD and YOPD

Parkinson's Disease is a chronic, progressive neurological disorder that can impact both physical and mental functioning. Having said this, the symptoms of PD 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). In general, one 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.

At the outset, PD can be managed with medications and lifestyle changes such that clients can live a relatively unaffected life for years, even decades, with PD. PD, however, is in all cases a *progressive* illness; symptoms will worsen over time. Thus, while planning probably does not need to be addressed on an urgent basis when a client is initially diagnosed, the likelihood of progression means it should not be put off for too long. PD is also a *chronic* illness, in contrast to an acute illness. The symptoms are permanent and will continue. Since PD generally 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. Annual reviews, after documents and initial planning is completed, to assure that this occurs, are advisable. It is likely that the client's views and feelings about a range of issues from 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 when he or she is not capable of making decisions. Be alert for indications of 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.

Since PD, other than YOPD, tends to occur primarily after age 60, and progresses over time, many PD clients will have had a relatively unimpeded career and hence estate tax and other planning concerns similar to clients without a chronic illness. This is important, because some of the other neurological disorders are likely to truncate work and career paths. However, about a quarter of PD cases are diagnosed before age 60, and YOPD has been diagnosed as early as in the 30s. So a significant portion of PD clients may have an impact on their career. The costs of care can be significant, and this too has to be factored into the planning. The bottom line is that many practitioners assume that any client with a chronic illness should be given similar planning often based around special needs trusts, *etc.* For many PD clients, this is simply not true.

The most common symptoms associated with PD and examples of how they may affect the estate planning process are reviewed below:

- The main physical symptoms of PD that affect most people, even early in the disease, include *bradykinesia*, rigidity and tremor. Bradykinesia, or slowed movement, and *akinesia*, the inability to move spontaneously. This can make it difficult for the PD client to begin, or continue, an action. A common impact of this is on 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 a significant cognitive impairment. Neither may be correct. 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. Ways to address this are discussed later in this article. As the disease progresses, balance and walking may also be affected. In particular, some people will "freeze" while trying to walk through a doorway or when approaching a chair to sit down. Their legs will simply not do what they want them to do.
- 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 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.

- In addition, clients can experience drooling, which can be embarrassing. Extra tissues should be on hand though many clients carry their own for this reason.
- 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. 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.
- Many clients with PD exhibit *bradyphrenia*, or a slowing down of thought processes. It can take longer for them to respond to a question even when they understand it perfectly well. One should try to be patient in waiting for a response. This does not necessarily imply that the particular client does not fully understand the issues being addressed. Patience is essential. Practically, you should schedule a lot more time for a meeting with a PD client so that this and other issues can be addressed in a manner that permits you to properly serve the client. 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.
- Older clients and those with advancing disease 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, multitask 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.
- As the disease progresses, some people develop dementia and may be disoriented to place, date or time. These 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. A more detailed discussion about the impact of cognitive impairment on estate planning and suggestions for dealing with it is included later, but this article does not address in great detail the evaluation and documentation of a client's competency. That too may need to be addressed in some specificity by the attorney involved in the planning. A key point to bear in mind is that, as a chronic illness, PD will progress. 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 that 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.
- 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, 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.
- Clients can experience periods of extremely poor mobility ("off" periods) and good mobility ("on" periods). "On" periods can be associated with excessive, involuntary movements (*dyskinesias*). 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 talks 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.

Practice Modifications for PD Clients

Practitioners can make a few modifications, including those noted above, in their manner of handling meetings to address these. Tripping hazards, such as throw rugs, electrical cords, *etc.*, should be removed or addressed.

When planning a meeting with a client with PD, especially a signing meeting, consideration should be given to blocking out more time for the meeting. Further, PD symptoms warrant reconsideration of 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 will make signing meetings easier for all. As a result of PD medication, the PD client instead of experiencing *akinesia* (lack of movement) may exhibit involuntary movements (*dyskinesia*). Practitioners should be aware of this and explain the possibilities to staff prior to meetings to assure that the utmost sensitivity can be shown.

Cognitive Impact of PD on Planning

Many PD clients may at some point lose the ability to make complex financial decisions, executive decision making. As much 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.

PD cognitive issues should be addressed by the estate planner:

- Assets should be consolidated and simplified. It will be easier for a PD client to interact with a single integrated wealth manager than a half-dozen or more banks, brokerage firms and other investment professionals.
- Follow meetings and substantive phone conversations with an action list of prioritized bullet points the PD client must address. This is not a multiple page memo, but a concise and clear bullet list of items.
- Break the planning process into distinct phases, each to be accomplished sequentially to facilitate completing the process in a manner that is easier for the PD client. For example, Phase I might be to complete powers of attorney, living wills, HIPAA releases, and health proxies. Phase II might be to complete a revocable living trust and will. Phase III might address beneficiary designations, insurance and an insurance trust. More sophisticated planning might be handled as Phase IV. Discrete logically organized and sequential steps will be much easier.

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 toward 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 advisors. This can address the ethical issues so that communication at a later date can be coordinated to help the PD client overcome problems that arise.

It is vital to take planning steps to protect the client prior to cognitive deterioration occurring to a level where options begin to be foreclosed. This should be done in a manner that preserves the client's independence until it does occur, and especially in the event it never occurs. This type of variability in planning makes it inappropriate for practitioners to make any general assumptions about PD. Most important for the client, every human being wants to hold on to control over their lives and their dignity. A key goal of all planning should be to give the PD client the maximum control and preserve the maximum independence for as long as possible with consideration to the unique course their PD takes.

While cognitive impairment affects a percentage of those with PD, 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 Amyotropohic 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 lose memory, the ability to reason and the understanding of the consequences of their decision making.

The key points for estate planners:

- Don't make assumptions.
- There is tremendous variability from one PD client to another.
- Whatever the cognitive impact the PD client has, if any, it is likely to worsen, so planning should not be deferred too long.
- When implementing estate and tax planning steps, consideration should be given to corroborating the PD client's competency to avoid challenges at a late date.
- A PD client may have testamentary capacity to sign a will, but may, or may not, have the capacity to engage in a more complex contractual transactions, such as a sale of a family business interest to a defective grantor dynasty trust.

Interview Questions for a Client with PD

With the above background, practitioners can formulate questions for a PD client intake or interview to understand the impact the disease will have on the specific plan:

- What are the current symptoms of your PD?
- What is your age? Dementia tends to affect PD clients over age 70 more.
- What other health issues do you have? Understanding the potential course of the client's PD and general health is important. Many PD clients have cardiovascular issues, high blood pressure and other ailments that may independently cause dementia (called "secondary dementia"), or exacerbate the client's PD dementia. Are you having any cognitive impairment, and if so, to what extent? The caregiver needs to supply the answer to this question, or possibly the neurologist. Counsel should determine whether an independent report from the client's neurologist, and perhaps internist (as to other health issues) should be obtained, and what those reports should address.
- Are there certain times of day (correlated with the impact of PD medication) that it would be preferable to schedule appointments and conference calls?
- To address the enigmatic and variable nature of PD, and often the client's lack of understanding of his or her own condition and prognosis, consider requesting a clarifying letter or phone conference with the client's attending neurologist to address the above issues. Since each PD client's disease progresses in its own unique manner, some detailed understanding is important to determine the urgency of planning. This information will be different than the focus of the competency report noted above.

Endnotes

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