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Estate Planning for People Living with Chronic Illness

Anticipating Estate Contests

Joshua S. Rubenstein, Esq.
Katten Muchin Rosenman
575 Madison Avenue
New York, New York 10022
Tel. (212) 940.7152
joshua.rubenstein@kattenlaw.com

Avoiding or Planning for Contests of Estate Planning Documents

A. ***Wills*** – Those suffering from chronic illnesses should take extra precautions to ensure the proper execution of their wills:

1. ***Improper Execution –*** Take pains to observe formalities of execution: have an attorney supervise execution.

2. ***Lack of Capacity*** – Specific statements regarding omissions of certain family members may also help prevent contests. Stating negatively why a certain family member has not been provided for can be problematic because such statements may incite the family member to challenge the will or be grounds for a testamentary libel claim. On the other hand, making positive statements about why the client has chosen to benefit one person over another can protect the will from contest. Consider discussing the will with witnesses.

3. ***Undue Influence*** – Retaining separate legal representation for the primary beneficiary can help protect the will from later challenges. Even if second spouses or partners are represented by the same attorney, they may also consider executing their wills separately or even interviewing separately with their attorney. In the case of clients suffering from chronic illnesses, the possibility of will contests on grounds of undue influence, collusion, etc., cautions towards taking extra measures that will shield their wills from challenge. Consider discussing the will with the witnesses.

4. ***Dependent Relevant Revocation*** – Those suffering from chronic illnesses should consider executing more than one will with substantially similar terms six months

to a year apart. This approach will create a further disincentive for others to challenge the will in the first place, in addition to providing another level of protection in case of suit.

5. **Self-Proving Affidavit** – Consider modifying the self-proving affidavit as necessary as not to "gloss" over the chronic illness.

6. ***Execution*** – Consider dispensing with initialing if that is likely to tire the client.

7. ***Codicil v. New Will*** – Attempt to avoid codicils, which leave a blueprint of a clients' changes over time.

B. ***Wills vs. Revocable Trusts***

1. ***Statute of Limitations*** – Consider the applicable statute of limitations for wills, whether admitted to common or solemn form probate, and for trusts.

2. ***Standard of Capacity*** – Consider the applicable standard for capacity to make wills, as opposed to trusts.

C. ***Testamentary Substitutes*** – Consider employing testamentary substitutes such as life insurance, jointly held property and property that passes by beneficiary designation or operation of law.

D. ***Agreements*** – Consider entering into applicable agreements that create contract rights that override wills, such as:

1. Prenuptial Agreements

2. Separation Agreements

3. Domestic Partnership Agreements

4. Contracts to make wills

5. Shareholder and Partnership Agreements

6. Buy/Sell Agreements

E. ***In Terrorem Clauses*** – Consider using *in terrorem* clauses if valid in the state of domicile.

F. ***Avoid Surprises*** – Consider discussing plans with family members likely to be disappointed.

Chronic Illness: Practical Planning and Drafting

By: Joshua Rubenstein, Esq., and Martin M. Shenkman, Esq.

Many Clients Affected at All Ages

Chronic illness is far more common than most practitioners realize. More than 5 million Americans have Alzheimer's disease ("AD"), more than 400,000 are living with Multiple Sclerosis ("MS"), and estimates are that in total 120 million Americans are living with some type of chronic illness. 22% of the population is estimated to be living with two or more different chronic illnesses. AD accounts for approximately 70% of dementias in Americans age 71 and older. Recent headlines evaluated the issues surrounding the famous New York Socialite Brook Astor, who at age 101 with Alzheimer's disease, executed a will and a series of codicils, all of which are now subject to challenge. AD is the fifth leading cause of death for those age 65 and older. Parkinson's disease ("PD") is also 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 prevalence of these issues necessitates that practitioners have techniques available to them in order to assist clients facing the problems wrought by chronic illness.

This is not an elder law issue. Chronic illness does not discriminate in favor of older clients. About 1/4th of PD cases are diagnosed before age 60 (young onset PD, "YOPD"). YOPD has been diagnosed at ages as early as 30 years. So a significant portion of PD clients may have a negative impact on their career and savings due to the early onset of their illness. A small percentage of those with AD are diagnosed in their 50s, or perhaps earlier (young onset AD). MS is typically diagnosed between ages 20 and 50, but has also been diagnosed in young children.

Many clients who are living with chronic illness are fortunate enough not to experience symptoms significant enough to modify planning for health related issues. For clients experiencing, or likely to experience significant symptoms as their chronic illness progresses, planning and drafting are obviously affected. What planning and drafting modifications might be useful in these situations? While the concepts are not technically complicated, the issues receive inadequate attention relative to their importance in terms of the number of clients affected, as well as the importance to those affected. Hopefully, the following discussion will serve as a checklist of ideas for planning and drafting for clients living with chronic illness.

Uniqueness of Each Disease and Each Client's Experience

The modifications necessary will depend on the particular chronic illness that the client has, and the nature and anticipated disease course of that illness. If a client has PD for

example, the planning may differ from that for a client with MS. This could be due to the timing onset and diagnosis of the disease (MS is generally diagnosed at a younger age than PD, but YOPD may be diagnosed at an earlier age than some with MS.) MS is characterized by attacks (called "exacerbations") that can be sudden and the disabilities that accompany an exacerbation may or may not reverse later. Debilitating fatigue is one of the most common symptoms of MS. Clients with PD don't experience the fatigue or attacks, but rather a different complex of symptoms. Each chronic illness differs in significant ways from other chronic illnesses. Each client's experience of his or her illness is likely to be unique when compared to others with the identical disease. This article cannot address many of the nuances of how planning and drafting might differ for various illnesses, or for each client's experience of a particular illness. Practitioners should inquire as to these nuances with each client, and further refine the general suggestions below, as appropriate.

Modifications to Address for Chronic Illness

There are a number of general modifications to the drafting of common estate planning documents that warrant consideration, which are discussed below. These might include disease specific provisions, modifications of trustee designation provisions in a revocable trust to empower, while still protecting, the client with consideration to the particular disease course the client is facing, housing decisions, experimental medical procedures, and so forth. In addition, each of the ancillary issues discussed at the end of this article might require additional modifications.

- **Authorization for Attorney to Communicate and Act**. If any client becomes incapable of communication or continued decision making, practitioners will face the dilemma of determining how to act and with whom they can communicate. A range of ethical rules could affect the possible actions that might be taken. Reaching out to family members, if not authorized to do so by the client, may constitute a violation of attorney ethics. When working with a client whose disease course is likely or assuredly going to lead to cognitive or other decline, consider including an authorization to communicate in the retainer agreement with the client.
    - "I expressly authorize ATTORNEY NAME to communicate with the agent named under my durable power of attorney, health care proxy, as well as my wealth manager ADVISORY FIRM NAME, and my Certified Public Accountant CPA FIRM NAME. Collectively my agents and named professional advisers, and the successors to those advisory firms, are collectively referred to as "Recipients". I understand that ATTORNEY NAME will have to exercise judgment as to what communication is appropriate in the circumstances. Therefore, I authorize ATTORNEY NAME in their sole discretion to communicate, or not communicate, with any person named as a Recipient, or any successor or alternate to them. I understand and agree that this authorization constitutes an express waiver of the attorney-client privilege which I have with ATTORNEY NAME. I,

on behalf of myself and my estate, guardian, committee or successors and assigns, hold ATTORNEY NAME harmless from the exercise or non-exercise of this power."

- **Preserving Client Independence**. Chronic illness robs the client of control over his or her life, and in the case of many chronic illnesses, life itself. Helping affected clients maximize control over aspects of their life that they can in fact control is especially important. But this must be done with a certain finesse in order simultaneously to provide protection. Utilizing a revocable trust funded with most assets that are appropriate to re-title is a commonly used, and very powerful, technique. Additional steps, however, can be taken. For example, consider recommending that the client also establish a small balance checking account, with an attached credit/debit card, in the client's own name and outside the revocable trust. If checks are inappropriately written, or the card is lost or stolen, trust assets cannot be reached. This can preserve independence by providing the client unencumbered funds and credit, within reasonable limits, while protecting the majority of the client's assets in a trust structure, perhaps with an institutional or other co-trustee. As the small account is depleted, or low limit credit card used, it can be replenished if there are no signs of abuse or mishandling. For example, a client with bipolar disorder may be well served by this approach. Independence is provided, yet if a manic episode occurs the fiscal damage is limited and controlled.

- **Residence**. It is common for those living with chronic illness to have to expend considerable sums to make their home or apartment accessible. In many instances, not only does the home become altered to remain accessible, but it also takes on an even more significant emotional role as a safe haven as illness progresses. Thus, it is not uncommon for the chronically ill client to have a stronger emotional tie to remaining in their home than other clients. Powers of attorney with standard provisions authorizing sale of real estate, as well as trusts with similar provisions concerning residential property, may all need to be tailored. Consider the following:

    - "The Grantor directs that if it is medically feasible, the Grantor wishes to remain in Grantor's residence located at 123 Main Street, Any town, Some State, and that the assets of the trust be used to hire supplemental medical and non-medical personnel to assist Grantor in Grantor's daily living needs to the extent necessary or advisable to permit same. Grantor also directs the Trustee to use the assets of the trust to modify the physical make-up of Grantor's residence to accommodate Grantor's then physical needs. Grantor further directs that if it is no longer medically feasible as determined by Grantor's then attending physician for Grantor to remain at home that the Trustee uses the trust assets to place Grantor in a first class assisted living or other appropriate facility. Any provision herein authorizing the sale of real property shall be limited in the manner necessary to conform to this directive."

- **Experimental Medical Procedures**. Clients living with a particular illness might be willing to accept a level of medical risk in pursuing a cure, or even just relief,

that others who have not experienced their pain and struggles may not understand. Provisions in living wills and health proxies may need to be revised to permit or even insist on experimental treatments, depending on the client's wishes.

- "Regardless of whether there is any hope for recovery, any medical treatments, whether experimental, alternative or other, which my agent [attending physician] believes hold any reasonable promise of improving my condition, restoring any of the damage created by Alzheimer's or other health conditions which I may be living with, are permissible and encouraged."

Provisions in a durable power of attorney, revocable trust or other documents may also have to be revised to assure that payment for those treatments are authorized.

- "Grantor is aware that this trust agreement authorizes the Trustee to pay for Grantor's medical and other health care expenses. Grantor further authorizes and directs the Trustee to pay for any experimental, unproven, alternative or other medical procedures, drug therapies or other medical therapies which [are authorized by Grantor's health care proxy] or [may assist Grantor in consultation with the medical specialists attending Grantor from time to time]."

- **Other Medical Considerations**. Clients living with chronic illness may wish to modify their documents to reflect medical care as related to their disease, or future prognosis. For example, many of those living with a particular chronic illness nonetheless desire to donate body tissues or organs to facilitate research to help cure that particular disease. For example, a client living with a neurological disorder might wish to include an express provision concerning donating brain or central nervous system ("CNS") tissue samples for research efforts. The language should be specific enough to assure that the donations will be used for the particular research the client desires. Even some clients with religious preferences against organ donations may wish to provide for these donations. Care should be taken explicitly to acknowledge that although organ and tissue donations are against the client's perceived religious beliefs, they are intentionally permitting the donation of organs or tissue if it can productively be used to advance research. To accomplish this objective organ donor cards can be signed and living wills and health proxies provisions can be modified. It is also recommended that forms be obtained from the appropriate research institutions to assure that this is properly addressed. Illustrative provisions follow:

  - "I direct my Health Care Agent to permit and facilitate a donation of selected brain tissue to further Alzheimer's research."

  - "Because I have lived for many decades with Multiple Sclerosis I expressly include this provision directing the donation of brain or central nervous system ("CNS") tissue samples for MS research efforts, but for no other purpose. I expressly note and acknowledge that my core religious preferences may mandate against organ donations, nevertheless, I expressly wish to provide for these tissue donations in spite of any such strictures."

- **No Heroic Measures**. What is "heroic" to someone who is young and well might be routine to another who has been battling a particular chronic illness for decades. Too often the generic language contained in many living wills or health care proxies is inadequate to express the feelings of a client with a particular disease. The standard language or provisions can often be tailored with modest effort to express the client's true desires, if the client will discuss the issue. Exciting research, capable of creating significant advancements in disease modifying therapies, is in process for many chronic illnesses. The hope that the client might have for the success of these endeavors might warrant inclusion in their document's provisions as well. Consider the following illustrative provisions.
    - "I have Alzheimer's disease which is incurable and irreversible and which will result in dementia. Therefore, when I reach a stage of profound Alzheimer's disease such that I have nearly a complete or a complete lack of awareness of my surroundings, I wish that no heroic measures be taken to preserve my life. If I reach a stage of severe Alzheimer's marked by disorientation psychosis, delusions, paranoia, and/or hallucinations, and also am severely injured, or have a terminal illness, then I wish that no heroic measures be taken to preserve my life.
    - For purposes of the above, "terminal illness" shall be defined as an irreversible, incurable and untreatable condition caused by disease, illness or injury when an attending physician can certify in writing that, to a reasonable degree of medical certainty, there is no hope of my recovery or death is likely to occur in a brief period of time. Notwithstanding the forgoing, if a new treatment is available that could potentially reverse my AD and potentially restore some reasonable quality of life and cognitive ability such that I could conceivably communicate with my loved ones, then all heroic measures shall be taken, including but not limited to, the provision of the new or experimental therapy. In no event shall any Agent or medical provider making this decision be held liable for their interpretation of this provision…"
- **Guardian Designation**. For most healthy clients, the prospect of having a court appointed guardian is so remote that little thought or attention is given to it during the planning process. However, for a client living with a chronic progressive illness where dementia is likely, such as Alzheimer's disease, or physical incapacity such as with Amyotrophic lateral sclerosis ("ALS"), the prospect of a court appointed guardian may be a certainty and planning documents perhaps should address this frightful eventuality. A health care proxy, or separate guardian designation document, could include an express statement of whom the client would want to serve as a guardian, should a court appointed guardian ever have to be designated.
    - "To the extent that I am permitted by law to do so, I hereby nominate my Agent, FINANCIAL AGENT NAME, to serve as the guardian of my property, and my Health Proxy, HEALTH AGENT NAME, to serve as the guardian of my person, or in any similar representative capacity, and if I

am not permitted by law to so nominate, then I request that any court that may be involved in the appointment of a guardian, special medical guardian, conservator or similar representative for me give the greatest weight to this request."

- **HIPAA Release**. The main goal of the Health Insurance Portability and Accountability Act of 1996 ("HIPAA") is to protect individuals' rights to their confidential medical information, called "Protected Health Information," or "PHI." Pub. L. No. 104-191, 110 Stat. 1936 (1966); 45 C.F.R. Sec. 164 (2002). HIPAA provides standards for the privacy of individually identifiable health information, known as the "Privacy Rule." These standards have been established as national guidelines for the protection of certain health information. The U.S. Department of Health and Human Services ("HHS") issued the Privacy Rule to implement the requirements that HIPAA has set forth. The "Genetic Information Antidiscrimination Act of 2008" ("GINA") modifies and expands HIPAA to prevent discrimination based on genetic testing and to provide that genetic information will be treated as PHI. P.L. 110-233. This could be an important restriction, as trustees seek to identify relevant information to provide for appropriate care for beneficiaries and other decisions. The penalties for violating the Privacy Rule are severe. 42 U.S.C. § 1320d-6(a)(3) and (b)(3). While all clients need to address the access to their PHI in appropriate circumstances, for clients with known medical conditions who anticipate ongoing medical care, facilitating access to medical records by the appropriate people in the necessary situations becomes essential. The following are sample provisions to consider for a revocable trust or power of attorney addressing the financial, as opposed to the medical/personal, aspects of HIPAA disclosure.

- "The Grantor expressly authorizes any Agent or successor to request, obtain, receive, and inspect any and all information including private health information ("PHI") that encompasses solely Grantor's medical bills and related information ("Bills"), and to sign whatever authorizations for release of any Bills which may be required by Grantor's Agent or any third party providers or others, and to waive any rights Grantor may have for breach of confidentiality for the release of such information to the Agent or successor Agent.
- In no event shall the provisions herein give the Agent or successor Agent hereunder any powers to make medical or health care decisions for me. These rights and powers are granted solely with respect to the implementation and conducting of the rights and powers granted herein, including by way of example and not limitation, reviewing and paying bills.
- The Agent and Successor Agent shall be treated as Grantor would with regard to the use and dissemination of Grantor's Bills. This authority applies to any information governed by the Health Insurance Portability and Accountability Act of 1996 ("HIPAA"), 42 USC 130d and 45 CFR

160-164. Grantor specifically authorizes any physician, dentist, health care professional, medical provider, health plan, hospital, clinic, laboratory, pharmacy or other covered health care provider, any insurance company and the Medical Information Bureau Inc., or any other health care organization that has provided treatment or services to Grantor, or that has paid for or is seeking payment from Grantor for such services to give, disclose and release to the Grantor's Agent and successor Agent all of Grantor's Bills. The authority given to Grantor's Agent and successor Agents has no expiration date and shall expire only in the event that Grantor revokes the authority in writing and delivers it to Grantor's health care provider."

- **Disability and Related Triggers**. A common issue affecting clients with health issues is how to determine when a fiduciary should take over the management of certain or all matters for the client. Often, the trigger for this transition will have to be tailored to the particular illness, to best protect the client, while assuring the client the maximum control over his or her affairs for as long as possible. More significantly, the mere transition to a successor fiduciary is not necessarily the appropriate paradigm for many chronic illnesses, and may in fact not achieve the client's goals. (See the related discussion below concerning short duration disability for related provisions).

    - "The authority of any individual to act as a trustee shall be suspended as of the date of a written opinion from the trustee's attending physician concluding that the trustee is incapacitated from so acting."

    Consider several alternatives to the mere transition to a successor fiduciary. A major inadequacy of the mere succession to another trustee approach is that many chronically ill clients will cycle through phases during which they need more care, and then back to periods when they can manage their own affairs. On again/off again transitions are not always advisable. Another approach is to address this dilemma from the perspective as to how a co-trustee can address the issue of the client being temporarily disabled while serving as the other co-trustee. Consider the following:

    - "If, at any time when there is more than one Trustee serving, and any particular Trustee shall become mentally or physically incapable of performing his duties, it shall not be necessary for such Co-Trustee to resign or to be removed, in order for the trust may continue to be administered. The other Trustee may continue administer the trust during such incapacity without the concurrence of the incapacitated Trustee."

    Another approach to addressing on/off disability, or periods of hospitalization not uncommon with a chronic illness, might be to permit a co-trustee independently to take action without the consent of the other trustee. This approach can avoid the on/off authority to a trustee which can be cumbersome administratively and disconcerting to third parties endeavoring to rely on the trustee's authority to act.

- "Any one of the Co-Trustees acting alone and without any requirement for joint action is authorized and permitted to complete alone any ministerial and administrative act, including but not limited to routine banking, investment, and brokerage transactions, except that when an institutional trustee is serving as a Co-Trustee hereunder only such Institutional Co-Trustee shall make investment decisions. It is the express intent of this provision to permit the Grantor when not disabled to continue to manage routine matters within the Grantor's purview, and to permit the Co-Trustee other than the Grantor to manage routine matters when the Grantor is subject to an Ignored Disability."
- "Determination of Grantor's Disability. The Grantor shall be deemed to be disabled when Grantor is unable to manage Grantor's affairs and property effectively for reasons such as mental illness, mental deficiency, physical illness or disability, advanced age, chronic use of drugs, chronic intoxication, confinement, kidnapping, detention by a foreign power or disappearance, or for any other reason allowable by statute or law. Grantor expressly states that Grantor presently has *CHRONIC-ILLNES and has the following conditions and symptoms *DESCRIBE-SYMPTOMS. Further, Grantor anticipates that *FUTURE-SYMPTOMS are likely to occur. So long as Grantor, with the assistance and guidance of the Institutional Co-Trustee is able to reasonably participate in the management and decision making under this trust, regardless of *DESCRIBE ACCEPTABLE LIMITATIONS, shall remain a co-Trustee hereunder and shall not be deemed disabled. [The objective is to tailor the definition of "disability" so that the client is only replaced as a trustee when the situation requiring removal is permanent]."

If the client has a chronic illness typified but unannounced and generally has temporary flair ups, the client should not be removed permanently as a trustee as a result of a such an episode. Perhaps an alternative is to have the client removed only if the episode lasts for a duration that indicates that it is not temporary. A similar concept might be adapted to trigger a springing power of attorney.

- "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 trigging the power of any successor agent to act, as a result of a short term 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."

- **Short Duration Disability**. Many disability provisions presume that once a client is disabled they will remain disabled. With many chronic progressive illnesses

this is in fact likely to be the case, absent a major research development into a cure that also provides for a reversal of symptoms. However, it is common for several chronic illnesses that the client will experience on/off periods of greater and lesser disability. This scenario must be incorporated into the drafting in order to assure the client of both protection and independence to the extent feasible.

- "Because Grantor is presently living with chronic illness it is possible that periodically Grantor may suffer a short term attack, exacerbation, or a period during which Grantor cannot manage Grantor's financial and other affairs ("Event"), although following Grantor may resume such responsibilities. Grantor directs that, barring an emergency situation which cannot await Grantor's recuperation or recovery from such Event, that the disability provisions in this Trust shall not be applied so long as the period for which it is anticipated that Grantor will not be able to reasonably participate in the management of this Trust shall be less than Thirty (30) days. This condition shall be referred to as an "Ignored Disability"…Grantor shall be deemed to have recovered from an Event when the other then serving Trustee receives written certification from Two (2) physicians regularly attending the Grantor, at least One (1) of which physicians is board certified in the specialty most closely associated with the alleged disability, that the Grantor is no longer physically or mentally incapable of reasonably serving as co-trustee hereunder, and that Grantor is again able to manage his or her own financial affairs within the structure of this Trust and the participation of the Co-Trustee."

Another mechanism to address on/off disability is to draft, with respect to powers of attorney, two separate powers of attorney to protect the client yet preserve independence. The first power could be a typical general durable power of attorney with springing provisions for agents. Should the degree of disability increase to the degree 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 could be modified to address chronic illness:

- "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 trigging the power of any successor agent to act, as a result of a short term attack or 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."

A second power could be a tailored limited power of attorney, effective immediately with no springing provision. This power could limit the agent's rights to those matters that might need addressing during a short term

disability or exacerbation. For example, this special power may exclude the right 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 the client. This approach does not cede powers that the client might wish to retain for the foreseeable future and that chronic illness will likely never impact, yet it should facilitate quick assistance if needed. The purported protection some clients believe a springing power provides are unnecessary in this power of attorney because of the limitations on the rights granted. The same people could be named agents so that there is no conflict between the two powers.

- **Charitable Giving**. Clients living with chronic illness are often inclined to consider making gifts to a charity that is devoted to serving those with the illness they have and funding research to cure that disease. Thus, the authority and power to make charitable gifts and buy charitable gift annuities should be considered for durable powers of attorney and revocable trusts.
- **Compensation of the agents and Fiduciaries**. The compensation for agents and fiduciaries may need to be tailored to address the unique demands the client's illness will likely create for the agents. In many instances the agent under a durable power may act for a short duration, during an emergency, or last illness. However, when a client has a known progressive, debilitating chronic illness it may be certain that an agent will have to serve for years, perhaps decades, with significant and growing responsibility. Generally, compensation under a durable power in such instances deserves greater attention. Compensation could also provide an important motivator for the agents to act, even though they are close friends or family who would, presumably, act without compensation. For other chronic illnesses, the agent may need to act quickly, and perhaps frequently during periods of unpredictable flare ups of the illness. In such instances, the agent may serve perhaps four times in a year, for a week or less each time. Compensation based on what a trustee would be paid, for example, would be insignificant. Alternatives should be considered. Perhaps a minimum or other type of compensation can be provided for these short but important periods. A cap may be advisable to prevent the intended financial encouragement to act from becoming an unreasonable expense if a permanent incapacity results.
    - "In the event an agent acts hereunder, the agent shall be compensated at the rate of $X/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."
    - "Any Agent or Alternate Agent hereunder shall be entitled to reasonable compensation for the services rendered. A bill estimating the hours spent, services performed and charges paid, shall be provided to any Alternate Agent acting hereunder with such Agent. It shall be deemed reasonable compensation for the Agent to be paid in a manner similar to that provided

for a trustee to be compensated under applicable state law for the investment and liquid assets (e.g., excluding residential real estate, but including investment real estate if any) that the Agent has authority over. In the event of a short term flare-up, exacerbation or other emergency in which the Agent shall act in an emergent basis for a short period of time, Grantor recognizes that compensation reflective of the time and effort over that short duration may be more reasonable."

- **Professional Practice Succession**. If a client who is a licensed professional is temporarily hospitalized, or incapacitated, provisions should be made to address who will sign checks and address business or professional practice matters, without violating applicable professional regulations and ethical rules. This type of short duration transition planning (not succession planning as it is temporary) can be incorporated into a special, limited, professional practice durable power of attorney. A "special" power granted to a business adviser or colleague (or in the case of a professional practice, a similarly licensed professional) can be an essential aspect of protection. For example, the client may grant a limited power of attorney to a close colleague to authorize him or her to perform certain functions relating to his or her practice during a period when the client's disease flares up, he or she has surgery, etc.
    - "The Agent is hereby authorized and directed to perform all acts reasonable and necessary to maintain Grantor's Practice, ABC Consulting Services, including payment of interest, and principal amortization payments on loans relating to same, repairs to equipment, furniture, fixtures, payment of employee compensation, [not] including reasonable bonuses, payment of taxes, to finance or otherwise arrange for the purchase of other supplies necessary to the continuation of the Practice. Grantor recognizes that Agent may largely be dependent on financing from the separate agent appointed under Grantor's personal, non-Practice, power of attorney. [This power shall only apply to an Agent who is an appropriate licensed professional. No other person who is not appropriately licensed in the profession of PROFESSION TYPE shall exercise the powers hereunder]. Any other agent appointed hereunder may act with respect to matters external to the practice (hiring an appropriately licensed professional, practice real estate matters, loaning funds to the practice, etc.), but not as to internal matters (any matter that may be subject to the purview of rules and regulations of the profession)."
- **Distribution Standards**. Distribution standards provided for in a trust might warrant modification in a number of respects. For example, a client establishing a revocable trust might wish to make clear that his or her medical care is the priority. For certain illnesses, the distribution structure may be the focal point of planning to address the client's symptoms and their impact on the trust operations, rather than relying on a more typical "disability" provision which may not be appropriate.
    - "It is the express desire of the Grantor that the Trustee apply income [and principal] liberally and primarily for the care of Grantor and in a manner

to maintain Grantor's historic lifestyle and activities to the extent feasible and practical in light of Grantor's current and future health status. These decisions shall be made without concern for the retention of any monies for future or remainder beneficiaries."

- "Grantor directs that Grantor shall receive the approximate quality medical and health care provided to the Grantor prior to the Trustee's involvement, and that the Trustee shall distribute Trust income and principal accordingly. This shall be defined, to the extent feasible and applicable, by reference to the caliber of medical care that Grantor sought prior to being deemed disabled under the provisions of this Trust, adjusted to reflect the current status of Grantor's health. Notwithstanding the foregoing, the Trustee is directed to pay for, and to the extent feasible, and not being pursued by grantor's health care agent, seek out experimental and new medical therapies to help Grantor's condition, including but not limited to alternative treatments that have received positive reviews in medical literature."

Standards and desires concerning that care can be included in the client's durable power of attorney as well as comparable provisions in a revocable trust, if used. These might indicate any personal wishes, which might include:

- "The agent shall be authorized and directed to expend funds to provide for any type of care reasonably beneficial to Grantor, including but not limited to the provision of 24/7 private care nursing and other staff; companion care in addition to private care nursing staff; medical procedures regardless of cost; and other personal wishes."
- "The Agent is hereby authorized and directed to perform all acts reasonable and necessary to maintain Grantor's customary standard of living which shall include providing and maintaining living quarters by purchase, lease, or other arrangement, or by payment of the operating costs of Grantor's existing living quarters. This shall include by way of example and not limitation any capital improvements, repairs and redecorating to facilitate Grantor's residing in any or all of such residences as Grantor ages, and Grantor's illness progresses. This may include the installation of elevators, guard rails, and any other protective or safety device."

When a chronic condition may present an on/off circumstance, it is more difficult to utilize more common disability provisions found in many documents. To determine whether or not the client is "disabled" skirts the real issues and drafting challenges. If a client has, for example, bipolar disorder, he or she may be extremely bright, currently considered "disabled" by many benchmarks, but perhaps capable and desirous of remaining involved in decision making. So a mere trigger of a "disability" clause may not provide the protection or control desirable.

- "Distributions To Special Beneficiary. Distributions may be made to or for the Benefit of BENEFICIARY NAME, the "Special Beneficiary," at

any time appropriate and advisable hereunder. This provision is referred to as 'Special Beneficiary Distribution Provision'.

- Because of the uncertainty of Special Beneficiary's current and future condition, the typical application of the term "disability" to the Special Beneficiary's situation may prove inadequate, overly restrictive, or even to lenient in providing a demarcation point for Trust distribution and other provisions. Therefore, these more fluid and flexible provisions shall apply to govern distributions to or for the benefit of Special Beneficiary and shall be reasonably interpreted based on the conditions and circumstances existing from time to time.
- It is recognized that the Special Beneficiary presently has been diagnosed and is living with Bipolar disorder [describe more precisely], and although the Special Beneficiary presently has, according to the treating Psychiatrist the capacity to understand information and make financial and legal decisions, protection and safeguarding the Special Beneficiary as a person requires that considerable diligence be exercised in making distributions to or for the Special Beneficiary's benefit, that the provision of excessive available cash funds could result in not only misuse of those funds but use in a manner that could be harmful to the Special Beneficiary, and that the situation can vary over time in unpredictable ways. Therefore, distributions for the Special Beneficiary shall be monitored by the Trustee so as to, as reasonably as feasible, assure the protection and well being of the Special Beneficiary.
- The Trustee may establish form time to time and in the discretion of the Trustee a small dollar value checking account which may, when deemed advisable or appropriate in the Trustee's discretion be linked with a cash card, debit card, credit card or other arrangement. The objective of this provision is to provide the Special Beneficiary with a reasonable degree of independence, but limiting the available cash resources that could be abused or especially which could cause harm of any nature to the Special Beneficiary.
- The Trustee may reasonably request that the Special Beneficiary be evaluated by an independent physician, psychiatrist and/or social worker, or other licensed professional, and that a report on the Special Beneficiary's condition be provided to the Trustee. The Trustee shall be indemnified and held harmless for reliance on a report from any such persons. The Trustee may reasonably restrict distributions to or for non-essential purchases and services for the Special Beneficiary in the event the Special Beneficiary unreasonably refuses to cooperate with such an independent evaluation. The evaluations referred to herein are in addition to any regularly mandated evaluations or reports provided elsewhere in this Trust.
- The Trustee is required to have an independent social worker or comparable licensed health professional interview the Special Beneficiary

in a home (or other primary place of residence) setting, at least Four (4) times per year, approximately quarterly. The person or company providing the interview or evaluation shall render a written report or letter to the Trustee as to the Special Beneficiary's condition and circumstances, and may in such professional's discretion identify or suggest improvements or steps that could be taken to help safeguard and protect the Special Beneficiary or otherwise improve the Special Beneficiary's lifestyle, living conditions and care.

- The only financial restriction on distributions to or for the benefit of the Special Beneficiary shall be to endeavor to assure the Special Beneficiary to the extent feasible a comparable lifestyle which was enjoyed at the execution date of this trust for the duration of the Special Beneficiary's lifetime with consideration to any sources of cash flow and assets available to fund distributions and without regard to preserving assets for remainder beneficiaries hereunder.
- Because of the particular circumstances affecting the Special Beneficiary distribution decisions should be cognizant to the extent feasible that larger distributions to or for the Special Beneficiary's benefit may prove detrimental rather than helpful.
- These provisions shall override any other distribution provisions contained in this Trust [with the exception of the requirements for certain distributions to meet the requirements of qualifying for a state or federal estate tax marital deduction using a Qualified Terminable Interest Property ("QTIP") trust (recognizing further that at the time of the execution of this Trust the federal estate tax has been repealed and that there is no federal estate tax marital deduction)]. In applying such provisions, it is Grantor's express intent that the provisions contained in these distribution provides and the Prime Objectives set forth above [to be added] be adhered to, to the maximum extent reasonably feasible [without undermining a significant tax benefit if one is then available (by way of example, without tainting a trust for a spouse intended to qualify for the estate tax marital deduction from so qualifying)]. In endeavoring to implement these goals for the protection of the Special Beneficiary, the Trustee may from time to time re-designate the situs and governing law of this Trust or a trust formed hereunder, to a jurisdiction whose laws and tax system better favor achieving these goals. This may include, by way of example and not limitation, changing the situs and governing law to a jurisdiction which has a Prudent Investor Act and Principal and Income Act and/or other law, permitting greater latitude in investing and distributions to minimize the required distributions for the Special Beneficiary [without violating the estate tax marital deduction requirements].
- Grantor expressly recognizes that the above standards are vague and subject to interpretation based on the state of medical knowledge now and in the future, interpretations of subtle nuances of the Special Beneficiary's condition, and that it presents a particular challenge to any Trustee serving

hereunder to fulfill these distribution objectives. In light of these difficulties, and in express effort to encourage institutional and other trustees to serve hereunder, Grantor expressly indemnifies and holds harmless any Trustee serving from any reasonable actions and decisions made in the Trustee's efforts to implement these distribution directives.

  - The Trustee shall have the greatest latitude, as provided above, to interpret this Trust and to change the governing law and situs of this trust, and to develop and investment policy that reconciles these goals. Grantor acknowledges the difficulties and inherent conflicts in these directives and accordingly provides the Trustees with the broadest indemnification permissible in the Trustees efforts to implement this provision."

- **Safeguards**. For clients with significant health issues, integrating additional safeguards, checks and balances, into their planning and documents might be advisable. In some instances, having an independent social worker or health care consultant periodically interview the client in his or her home setting can provide valuable insight to fiduciaries responsible for the client (also see the sample provision above). It can also be a significant safeguard to prevent what is too narrowly referred to as "elder abuse," but which is more appropriately characterized as abuse of anyone who is infirm and incapable of self protection:

  - "The fiduciary is authorized and directed to make payment for a mandatory independent interview by a licensed social worker, geriatric or similar consultant ("Evaluator") in Grantor's home or other place of temporary or permanent residence, not less frequently then quarterly. [The Evaluator shall be selected in the reasonable discretion of the agent under the Grantor's health care proxy.] The Evaluator shall be required to provide a written summary of the Grantor's general status addressing Evaluator's observations as to Grantor's physical and psycho-social circumstances, any other relevant observations and recommendations, to the fiduciary, within Fifteen (15) days of the interview."

  The power of attorney could provide for the appointment of a monitor. This is a concept embodied in the recent revisions to the New York power of attorney statute. A modified version of this can provide an excellent safeguard to assure that agents act appropriately. This role could be limited and tailored to achieve whatever goals were deemed important for each client's particular circumstances. For example, an independent CPA could be provided monthly statements from all bank and brokerage accounts and be engaged to review them.

- **Investment Provisions**. As noted above, many clients living with a chronic illness might wish to retain ownership and use of their home, and permit some portion of their portfolios be invested in charitable gift annuities issued by a charity serving those with the same illness or funding research for a cure into their illness. However, a trustee may be precluded from retaining a residence or purchasing such annuities by the Prudent Investor Act. If the client wished to permit this type of investment, a specific exception to protect and direct the trustees may be necessary.

- "Grantor expressly directs the Trustee endeavor to retain Grantor's personal residence located at HOME-ADDRESS if feasible for Grantor to remain there. Grantor does not make this an absolute prohibition against sale in light of the possibility that Grantor may benefit from residing in an assisted living or other facility. Grantor recommends that the Trustee consider Grantor's strong desire, but not mandate, that Grantor remain in said home, the modifications previously made to the home to accommodate Grantor and an future aide or companion, and other factors."
- "Grantor expressly authorizes, as an exception to the Prudent Investor Act, the Trustees to invest a portion of the trust estate in gift annuities provided through the auspices of CHARITY-NAME even if these gift annuities are not an optimal or advisable investment allocation. Grantor authorizes the Trustees to consider Grantor's personal goals to benefit such charity in its research efforts to find a cure for CHRONIC-DISEASE and other efforts through the use of gift annuities."

Competency

Competency is an obvious and vital issue to address for clients with a chronic illness. The analysis is often more complex and subtle than many practitioners realize. A client who 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 trust, counsel should endeavor to corroborate that, at that time, the client was in fact capable of understanding the transaction.

For some chronically ill 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. Practitioners should not judge by looking at a client whether or not he or she has impaired cognition or how severe the impairment might be. There is often little correlation between physical symptoms and cognitive symptoms. A common example is the PD symptom called Parkinsonian masked facies, the un-emotive facial expressions that may be misinterpreted as a lack of understanding when, in fact, all is understood.

There are also significant differences between different illnesses, and even for each illness based on the client's experience. PD can be similar to MS or 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. American Bar Association and the American Psychological Association, *Assessment of Older Adults with Diminished Capacity: A Handbook for Lawyers* (2005).

Cognitive dysfunction can be limited to certain "domains," such as attention and concentration. However, it does not necessarily mean a lack of intelligence, or loss of intellectual power. For instance, after a sleepless night most people have cognitive dysfunction and attention problems, yet they are not demented or intellectually incapacitated. Thus, a global determination of a client's being competent or not may miss the point. The client may have specific incapacities, but retain other faculties and abilities.

The impact of cognitive impairment can be subtle and may, or may not, change over time as the client's disease progresses. Mental symptoms of PD can include emotional difficulties such as depression, anxiety and apathy as well as problems with cognition (thinking). These other symptoms may have to be differentiated from cognitive impairment when a practitioner endeavors to make a competency determination. Some clients living with PD may also experience psychiatric side effects from medications used to treat PD, namely psychosis (delusions or hallucinations) or confusion. A client with PD may experience none, some, or all of these problems. PD may affect cognition as a result of bradyphrenia, a slowing down of the thought process. It is the mental correlate of bradykinesia (slowing of movement), but the presence of the physical symptoms of bradykinesia should not be presumed to imply the cognitive impact of bradyphrenia. It can take longer for client with PD to respond to a question even when he or she understands it perfectly well. Even early on, many people with PD have subtle cognitive difficulties that may affect their ability to concentrate, multi-task and plan effectively. These are sometimes referred to as "executive" functions. Older PD clients, and those with advancing disease, appear to be at particular risk for cognitive problems. As the disease progresses, some people develop dementia and may be disoriented as to place, date or time. These PD clients may lack judgment and be unable effectively to make decisions. However, for some PD clients, their ability to make key decisions will never be completely undermined. Assumptions should not be made.

Other issues to consider with respect to competency might include:

- The use of codicils to amend a will and revocable trust is sometimes frowned upon as codicils can raise risks of inconsistencies between the initial and subsequent documents, and sometimes are viewed as suggesting a competency issue when there is in fact none. If there were no concern about competency perhaps a revised document, rather than merely a codicil, would have been used. On the other hand, a client whose cognitive impairment has progressed may have a much easier time understanding, and demonstrating that understanding of, a short codicil, than a complex and long restated trust or will.
- Even if there is no current issue concerning competency, the likelihood of a future issue might be substantially greater so that the need to incorporate flexibility to address future uncertainty is more important to consider.
- The assumption, which frequently is incorrect, is that many living with chronic illness have a cognitive impairment.

- Age, as well as chronic illness, can be a factor affecting competency, or the perception of an issue of competency. There are often additional health issues that may affect competency beyond the most noticeable or significant illness. These should be expressly addressed in the planning and corroboration of the client's capacity.
- There is tremendous variability among clients living with chronic illness. There is even significant variability between clients with the same illness. Even more confusing, there can be significant variability in the symptoms experienced at different times by the same client, even during the same meeting.
- When implementing estate and tax planning, consideration should be given to corroborating the client's competency to avoid challenges at a later date. This should be done even if the client has no significant cognitive impact given the assumptions, or even ignorance, of so many people about the impact of chronic illness.
- Follow meetings and substantive phone conversations with an action list of prioritized bullet points the 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 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 more manageable.
- Assess the degree of physical, financial or other harm to the client from the transaction involved, and plan accordingly.
- Obtain an appropriate physician letter. There is a wide variation in the quality of communications from various medical and mental health professionals. Your lawyer should evaluate what the medical letter really means. What should they say? For example, it may be helpful to have a letter from an internist stating that there are no medical issues that might impair your client's cognitive capacity. Although the presence of hypertension, or even a history of strokes, does not imply cognitive impairment, precautionary steps should be taken to demonstrate this.
- The absence of any known physical conditions that might imply cognitive impairment does not necessarily support a conclusion of competency. The physician letter should provide details of the examination given, the client's current medical condition, the results of a current physical examination, whether there are medical issues that require further inquiry, a psychological and social history of the client, a description of the client's current living circumstances, and any other relevant facts.

Ancillary Planning Considerations

There are a host of ancillary planning issues that need to be addressed for clients living with chronic illness. The following is a partial checklist of some of the items to consider.

- **Fiduciary Selection**. Guide clients to select agents that have the wherewithal realistically to carry out the duties and responsibilities under the documents being drafted. Too often agents are selected based on the client's perceptions of the proposed fiduciary's understanding of the client's wishes. However, for a client living with a chronic illness, the duration and magnitude of responsibility could be substantial. The client needs to assure that reasonable selections are made.
- **Plan for Caregivers**. Planning for caregivers can be as important to the client's welfare and protection as planning for the client directly. For example, nearly 3/4ths of AD clients are cared for by their family. AD also has a dramatic impact on the AD client's caregivers and immediate family. Both planning and document drafting, for your client as well as for the client's caregivers, should be addressed.
- **Disability and Related Insurance Coverage.** Too often estate planning focuses primarily on planning for death, with disability planning considered, if at all, as a secondary topic. Disability insurance coverage can be a critical safety net for most working clients. Professionals and business owners are often admonished to purchase disability income insurance to replace the income lost if they become sick or disabled, business overhead insurance to keep their practice afloat, and perhaps disability buyout insurance to fund the buyout of a disabled partner. The common occurrence of chronic illness should encourage practitioners to make disability planning more of a front-burner item with clients.
- **Life Insurance.** Evaluate existing life insurance policies. Identify and evaluate all planning opportunities, which may include: accelerated death benefit options; borrowing against cash value to fund needed expenditures; viatical settlements; and possible sale into the secondary market versus cash surrender value.
- **Budgeting.** Clients with chronic illnesses, or with loved ones with chronic illnesses may face unique budgeting issues that other clients do not. Standard rules of thumb, which some advisers might use to make estimates or projections, might not be reasonable. Assist the client in reviewing any projections forming the foundation for planning to assure that they reasonably address the client's unique situation. These might include:
    - Shortened work expectancy.
    - Costly improvements to make their home accessible.
    - Costs of having an independent Social Worker periodically meet with the client in his or her home and interview them and issuing a report. This can be invaluable in assuring proper care.
    - Using an institutional trustee and paying the fees involved.
    - Paying for experimental medical treatments which insurance will not cover.

    - Paying for desired accommodations and living arrangements.

- **Investment Planning**. Tailor an investment plan in light of the client's specific circumstances, not generalizations or assumptions. Each chronic illness differs from other chronic illnesses. Each client's experience is unique to that client. Client's can have varying experiences over time. Risk profile and time horizon is not the same as for "other" clients. Risk may be affected by fear, medical costs, or need to retire early. The time horizon can vary – new drug therapies can change the course of the disease.

Planning to Avoid or Mitigate Contests

When someone suffering form a chronic illness executes an estate plan that can be anticipated to be unpopular with one or more beneficiaries, the very existence of a chronic illness gives would be contestants a "leg up" in contesting decisions that the client is in fact perfectly competent to make. There are many steps that the estate planner can consider to help avoid contests of plans executed by those living with chronic illness, or at least to make the success of such contests less likely:

- Plan to establish proper execution, testamentary capacity and lack of undue influence.
- Consider making changes by executing new wills rather than codicils.
- Consider noting the chronic illness in the self-proving affidavit.
- Review the applicable statue of limitations for contesting different types of estate planning documents.
- Evaluate the use of testamentary substitutes.
- Consider executing contracts to make wills or contracts concerning the disposition of assets that supersede wills.
- Draft, where applicable law permits, the use of *in terrorem* clauses.
- Consider sharing unpopular plans with beneficiaries in order to avoid surprises.

Conclusion

Planning and drafting for clients living with chronic illness presents unique challenges and often issues which seem simple to address will not be adequately met with standard clauses and approaches. This article has provided a survey of some of the many types of changes which might warrant consideration in serving these types of clients.