

Many Clients Affected at All Ages

Chronic illness is far more common than most practitioners realize. Addressing the implications of these health issues is essential to best serve clients. More than 400,000 people live with multiple sclerosis

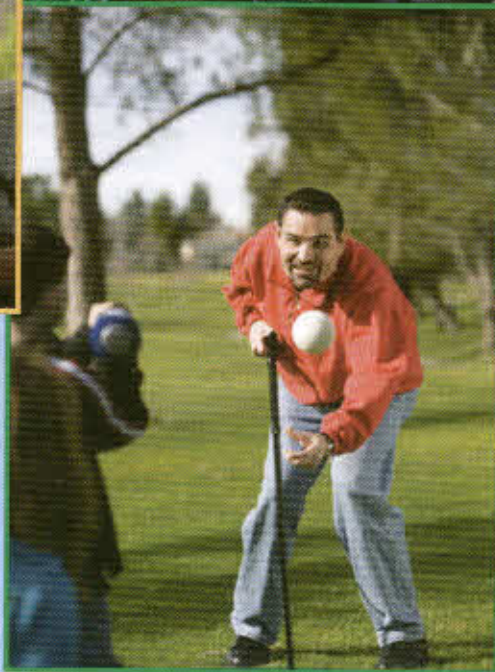
(MS), and estimates are that in total 120 million Americans live with some type of chronic illness. Of those ages 65 to 74, 26% have had their lives significantly affected by chronic illness. Twenty-two percent of the population is estimated to be living with two or more different chronic illnesses. More than 5 million Americans have Alzheimer's disease (AD). AD accounts for approximately 70% of dementias in Americans age 71 and older. Recent headlines evaluated the issues surrounding the famous New York socialite Brooke Astor, who, at age 101 with Alzheimer's disease, executed a will and a series of codicils, all of which are 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 1% of all those over age 65 are diagnosed with PD. This makes PD second only to AD in terms of the number of people affected. The prevalence of these issues necessitates that practitioners have techniques available to them to assist clients facing the problems wrought by chronic illness.

This is not an older law issue. Chronic illness does not discriminate in favor of older clients. About one-quarter 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 had their careers and savings negatively affected because of 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 live with chronic illnesses are fortunate not to experience symptoms significant enough to modify planning for health-related issues. For clients experiencing, or likely to experience, significant symptoms

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Chronic Illness

Practical Planning and Drafting, Part 1

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as their chronic illness progresses, planning and drafting are obviously affected. What planning and drafting modifications might be useful in these situations? Although 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. It is hoped that the following discussion will serve as a catalyst for new ideas for planning and drafting for clients living with chronic illnesses.

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, planning may differ from that for a client with MS. This could be because of the time of diagnosis (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 not reverse. Debilitating fatigue is one of the most common symptoms of MS. Clients with PD do not experience fatigue or attacks but 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 about these nuances with each client and further refine their drafting.

Modifications to Address Chronic Illness Generally

A number of general modifications to the drafting of estate planning documents warrant consideration. 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 on.

Authorization for Attorney to Communicate and Act

If a client becomes incapable of continued decision making, practitioners face the dilemma of determining how to act and with whom they can communicate. A range of ethical rules can 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 will lead to cognitive 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 his 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 that 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 lives that they can still influence is especially important. But this must be done with finesse to simultaneously provide protection. Using a funded revocable trust is a commonly

used technique. 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 assets in trust, 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 illnesses to have to expend considerable sums to make their homes accessible. Their homes often take on a more significant emotional role as a safe haven as the illness progresses. Thus, the chronically ill client may have a stronger emotional tie to remaining in his or her home than others. Powers of attorney with standard provisions authorizing sale of real estate, as well as trusts with similar provisions concerning residential property, need to be tailored.

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.

Modifications to Living Wills and Health Proxies

When a client has a known chronic illness, a number of modifications may need to be made to living wills, health proxies, HIPAA releases, and similar health-care-oriented provisions appearing in trusts and other documents. Following is a discussion of some of these.

Experimental Medical Procedures

Clients living with a particular illness might be willing to accept a level of medical risk to pursue 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-care proxies may need to be revised to permit or mandate 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, that my agent [ATTENDING PHYSICIAN] believes hold any reasonable promise of improving my condition or restoring any of the damage created by Alzheimer's or other health conditions that I may be living with are permissible and encouraged.

Provisions in a durable power of attorney, revocable trust, or other documents also may have to be revised to assure that payment for those treatments is 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 or drug therapies or other medical therapies that [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 illnesses may wish to modify their documents to reflect medical care as related to their disease or future prognosis. Many living with a particular chronic illness nonetheless desire to donate body tissues or organs to facilitate research to help cure that particular disease. A client living with a neurological disorder might wish to include an express provision concerning donating brain or central nervous system tissues for research. 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 affiliations that mandate against organ donations may wish to provide for this. Care should be taken to acknowledge that, although tissue donations are against the client's perceived religious beliefs, they are intentionally permitted to advance research.

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 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 young and well might be routine to another that has been battling a particular chronic illness for decades. Too often the generic language contained in many living wills is inadequate to express the feelings of a client with a particular disease. The standard language can often be modified to express client desires, if the client

will discuss the issues.

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 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 foregoing, if a new treatment is available that could potentially reverse my Alzheimer's disease 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 his interpretation of this provision. . . .

Guardian Designation

The prospect of having a court-appointed guardian is so remote that little thought or attention is given to it during the planning process. But, for a client living with a chronic progressive illness in which dementia is likely, such as AD, or physical incapacity such as with amyotrophic lateral sclerosis (ALS), the prospect of a court-appointed guardian may be a certainty and documents should address this 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 (1996); 45 C.F.R. § 164.501 (2002). HIPAA provides standards for the privacy of individually identifiable health information, known as the "Privacy Rule." This could be important when trustees seek to identify information to provide for appropriate care of beneficiaries and other decisions. The penalties for violating the Privacy Rule are severe. 42 U.S.C. § 1320d-6(a)(3) and (b)(3). Although all clients need to address the access to their PHI in appropriate circumstances, for clients with known medical conditions that anticipate ongoing medical care, facilitating access to medical records by the appropriate people in the necessary situations becomes essential.

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"), to sign whatever authorizations for release of any Bills that 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 conduct 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.

Modifications to Address Disability and Fiduciary Transition

Trusts and other documents include provisions addressing the disability of a fiduciary or beneficiary. Many common approaches are inadequate to address issues of chronic illness.

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. 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. The mere transition to a successor fiduciary is not necessarily the appropriate paradigm for many chronic illnesses and may not achieve the client's goals.

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 alternatives for the transition to a successor fiduciary. A major inadequacy of many provisions is that the chronically ill client may cycle through phases during which they need more care and then back to periods when they can manage their affairs. On again/off again transitions are not always advisable.

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 to continue to be administered. The other Trustee may continue to 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 to take action independently without the consent of the other trustee. This approach can avoid the on/off authority of a trustee that 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.

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 ILLNESS] 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 by unannounced and generally temporary flare-ups, the client should not be removed permanently as a trustee as a result. 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

to be more than Thirty (30) days. 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 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 Alternative Agent is effective upon a sworn statement being executed by Grantor's attending neurologist.

The 30-day duration is included to avoid triggering the power of any successor trustee to act as a result of a short-term exacerbation.

Short Duration Disability

Many disability provisions presume that once a client is disabled he or she will remain disabled. With many chronic progressive illnesses this is correct, absent a research development that reverses the symptoms. It is common with several chronic illnesses that the client will experience on/off periods of greater and lesser disability. This scenario must be incorporated into the drafting 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 thereafter Grantor may resume such responsibilities. Grantor directs that, barring an emergency situation that cannot await Grantor's recuperation or recovery from such Event, 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 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 to be more than Thirty (30) days. 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 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 Alternative Agent is effective upon a sworn statement being executed by Grantor's attending neurologist.

The 30-day duration is included to avoid triggering the power of any successor trustee to act as a result of a short-term exacerbation.

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. This special power can exclude the right to make gifts, change beneficiary designations on insurance and retirement plans, sell real

estate, and so on. This does not cede powers that the client might wish to retain for the foreseeable future and that chronic illness will likely never affect, yet it should facilitate quick assistance if needed. The purported protection some clients believe a springing power affords may be 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. Agents under durable powers may act for a short duration, during an emergency or last illness. When a client has a known progressive, debilitating chronic illness, it may be likely 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 also could provide an important motivator for the agents to act, even though they are close friends or family that might 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. The agent may serve several times a year, for a week 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 Alternative 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 Alternative 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, 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 because 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, or he or she has surgery.

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).

Conclusion

The discussions and illustrative provisions in Part 1 of this article have endeavored to highlight how common drafting situations can be tailored to address a range of different chronic illnesses. The second part in this series will conclude this discussion with an evaluation of distribution, investment, and other provisions and a discussion of some common issues that practitioners planning for clients living with chronic illness should consider. ■