

One hundred twenty million Americans live with chronic illnesses; thus, a significant portion of clients are affected by the issues chronic illness creates. Part 1 of this series, which appeared in the January/February issue, reviewed general drafting issues and illustrative provisions for living wills, health proxies, and other documents. This conclusion to the article evaluates distribution, investment, and ancillary considerations.

### **Modifications to Distribution, Investment, and Related Provisions to Address Chronic Illness Generally**

A number of unique issues can arise in formulating distribution standards for a beneficiary living with chronic illness. The primary goals sometimes conflict. On the one hand, the beneficiary should be given as much latitude as feasible; on the other, the beneficiary has to be protected. These goals can be especially complex when the beneficiary has enigmatic cognitive issues or disabilities that vary.

#### **Distribution Standards**

Distribution standards provided for in a trust might warrant modification in a number of respects. 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 effect on trust operations, not the more typical "disability" provisions.

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 of 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 the medical literature.

Martin M. Shenkman is a member of the Paramus, New Jersey, firm of Martin M. Shenkman, P.C., and the co-chair of the Emotional and Psychological Issues in Estate Planning Committee. Joshua Rubenstein is co-managing partner in the New York, New York, office of Katten Muchin Rosenman LLP and national chair of its trust and estates practice.

## **Chronic Illness** Practical Planning and Drafting, Part 2

**By Martin M. Shenkman and  
Joshua Rubenstein**

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.

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 as Grantor's illness progresses. This may include the installation of elevators, guard rails, and any other protective or safety device.

When a chronic condition presents an on/off circumstance, it is more difficult to use more common disability provisions found in many documents. To determine whether or not the client is "disabled" skirts the real drafting challenges. If, for example, a client has 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 would not provide either the protection or the control desired.

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 the 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 too 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 from time to time and in the discretion of the Trustee a small dollar value checking account that 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 to limit the available cash resources that could be abused or that especially could cause harm of any nature to the Special Beneficiary.

**When a chronic condition presents an on/off circumstance, it is more difficult to use more common disability provisions found in many documents.**

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.

requirements of qualifying for a state or federal estate tax marital deduction using a Qualified Terminable Interest Property ("QTIP") trust (recognizing further that following the execution of this Trust the federal estate tax may be repealed and that there may be no federal estate tax marital deduction)). In applying such provisions, it is Grantor's express intent that the provisions contained in these distribution provisions provide 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 that 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, if applicable].

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 and on 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 an 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 an investment policy that reconciles these goals. Grantor acknowledges the difficulties and inherent conflicts in these directives and accordingly provides the Trustee with the broadest indemnification permissible in the Trustee's efforts to implement this provision.

#### **Safeguards**

For clients with significant health issues, integrating additional safeguards into their documents is advisable. Mandate that an independent social worker periodically interview the client in his or her home setting to provide valuable insight to fiduciaries responsible for the client. This can also be a safeguard to prevent "elder abuse," which is more appropriately characterized as abuse of anyone who is 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 than 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 and any other relevant observations and recommendations, to the fiduciary, within fifteen (15) days of the interview.

The power of attorney can provide for the appointment of a monitor, a concept embodied in the recent revisions to the New York power of attorney statute. A modified version of the monitor appointment can provide a further safeguard to

## **For clients with significant health issues, integrating additional safeguards into their documents is advisable.**

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

assure that agents act appropriately. This role can be tailored to achieve goals important for each client's particular circumstances. For example, an independent CPA can provide monthly statements from all 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 homes and permit some portion of their portfolios to 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. A trustee may be precluded, however, 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 to 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 a 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 so at a later point. If significant transactions are to be engaged in, for example, a complex note sale to a defective trust, counsel should endeavor to corroborate that, at that time, the client was in fact capable of understanding the transaction.

For chronically ill clients, the most difficult issue for counsel may not be 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. 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 Parkinson disease (PD) symptom called Parkinsonian masked facies; the un-emotive facial expressions may be misinterpreted as a lack of understanding.

There also are significant differences between different illnesses, and even for each illness based on the client's experience. PD can be similar to multiple sclerosis (MS) or amyotrophic lateral sclerosis (Lou Gehrig's disease 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 disease (AD) lose memory, the ability to reason, and the understanding of the consequences of their decision making. American Bar Association & 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. It does not necessarily mean, however, a lack of intelligence or loss of intellectual capacity. After a sleepless night most people have cognitive dysfunction and attention

**For chronically ill clients, the most difficult issue for counsel may not be 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.**

problems, yet they are not demented or intellectually incapacitated. 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.

The effect of cognitive impairment can be subtle and may 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 of the thought process. It is the mental correlate of bradykinesia (slowing of movement), but the physical symptoms of bradykinesia should not be presumed to imply the cognitive effect of bradyphrenia. It can take longer for a 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, multitask, 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 can lack judgment and be unable to make decisions effectively. For some PD clients, however, their ability to make key decisions will never be undermined. Assumptions should not be made.

Other issues to consider:

- The use of codicils to amend a will and revocable trust is sometimes frowned on because 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, on the one hand, 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. Often additional health issues can 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 effect given the assumptions, or even ignorance, of so many people about the effect 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. Counsel should evaluate what the medical letter really means. What should it say? For example, it may be helpful to have a letter from an internist stating that no medical issues might impair the 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



## SOUTH DAKOTA TRUST COMPANY LLC

*Serving Families in Perpetuity.*

- ✓ **Trust accounts** representing more than \$9 billion in assets under administration;
- ✓ **250 combined years of experience;**
- ✓ Worked with more than **15% of the Forbes 400;**
- ✓ Work with all **outside investment managers and custodians** of the **Clients' Choice** globally;
- ✓ Work with most types of **Non-Financial Assets;**
- ✓ **Excellent, timely and inexpensive reformation/ Modification and decanting** statutes and processes;
- ✓ **Established and Administer Private Family Trust Company relationships** worth in excess of **\$60 billion;**
- ✓ **Popular trust structures and statutes** for **international families;**
- ✓ Rated the **#1 Trust Jurisdiction** in the U.S. by *Trusts & Estates Magazine*, (Jan. '04, '07) / Highest ranked state: #1 in all categories (Jan '10).

Pierce McDowell

201 So. Phillips Avenue- Suite 200

Sioux Falls, SD 57104

(605) 338-9170

sdtrustco.com

Al King

51 E. 42<sup>nd</sup> Street- Suite 701

New York, NY 10017

(212)642-8377

directedtrustco.com

privatefamilytrustcompany.com

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

A host of ancillary planning issues need to be addressed for clients living with chronic illnesses. The following is a partial checklist of some 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. For a client living with a chronic illness the duration and magnitude of responsibility could be substantial.

#### 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 three-quarters of AD clients are cared for by their families. AD also has a dramatic effect on the AD client's caregivers and immediate family.

#### 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.

#### Life Insurance

Evaluate existing life insurance policies. Identify and evaluate all planning opportunities, which can 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, can 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:

- shortened work expectancy,
- costly improvements to make the client's home accessible,
- costs of having an independent social worker periodically meet with the client in his or her home, interview the client, and issue a report (this can be invaluable in assuring proper care),
- using an institutional trustee and paying the fees involved,
- paying for experimental medical treatments that insurance will not cover, and
- 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. Clients can have varying experiences over time. The client's risk profile and time horizon is not the same as for "other" clients. Risk may be affected by fear, medical costs,

or the 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 from a chronic illness executes an estate plan that is unpopular with one or more beneficiaries, the very existence of a chronic illness gives would-be contestants a "leg up" to contest decisions that the client is in fact perfectly competent to make. The estate planner can consider many steps to help avoid contests of plans executed by those living with chronic illnesses 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 a self-proving affidavit;
- review the applicable statute 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; and
- consider sharing unpopular plans with beneficiaries to avoid surprises.

### Conclusion

Planning and drafting for clients living with chronic illnesses present unique challenges, and often issues that 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 that might warrant consideration in serving these types of clients. ■