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Living trusts for those with chronic illnesses

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Although revocable living trusts are nearly ubiquitous in estate planning, their typical use is to minimize ancillary probate or to avoid probate entirely. Whatever the merit and value of these applications, a properly crafted and planned revocable trust can be an indispensable technique to provide a protective financial and personal shield for the large and growing number of clients facing the challenges of a chronic illness, disability, or other health issue. The statistics demand that practitioners give greater attention to tailoring whatever planning and documentation that they normally would create with revocable trusts to the specific needs of clients facing these challenges.

This *Study* reviews the following aspects of revocable trust planning for clients with a chronic illness or disability:

- Significance to practitioners
- Communications
- Misconceptions about planning for a chronic illness
- Competency
- Drafting techniques to address specific client challenges

SIGNIFICANCE TO PRACTITIONERS

Estate Tax Importance Has Waned. Estate planning practitioners give considerable attention to the minimization of estate taxes for obvious reasons. However, the reality is that the impact of the federal estate tax has waned dramatically over the years. According to IRS data: "Due primarily to increases in the filing threshold, the number of estate tax returns filed decreased from more than 108,000 in 2001 to fewer than 34,000 in 2009."[1] With an exemption of $5 million and portability, estimates are that only approximately 5,600 estates per year will pay an estate tax.

Number of Clients Affected by Health Issues Is Substantial. The number of Americans facing health issues, for which planning to address their challenges is important, is incomparably greater. "Despite the fact that the majority of the US population looks rather healthy, statistics show a different story. Nearly 1 in 2 people have a chronic condition. This could be an illness like cancer or rheumatoid arthritis, or a condition such as arthritis,

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migraines or back pain from a car accident."[2]

"Nearly 1 in 2 Americans (133 million) has a chronic condition."[3]

For aging clients, the statistics are even more stark: "90% of seniors have at least one chronic disease and 77% have two or more chronic diseases." [4]

Clients Affected Not Obvious. With such dramatic statistics, why is that so few clients appear to face these challenges? Surprising to even many estate planners, the most severe symptoms of chronic illness, often the most debilitating, are not visible. You cannot easily discern chronic fatigue, chronic pain, or similar symptoms. The ubiquitous international symbol of disability, a white stick figure in a wheelchair on a blue background, is dangerously misleading. Consider the following statistics: 26 million Americans are considered to have a severe disability. However, only 7 million used a visible device for mobility, such as a wheelchair, cane, crutches, or a walker. The other 19 million severely disabled did not use any such device. In percentage terms, 73% of Americans with severe disabilities do not use any visible mobility aid.[5] The reality is that a substantial number of clients face significant challenges, and too often their estate planners are not aware.

COMMUNICATIONS

Health-Related Communications Difficult. No practitioner can plan a client's estate properly, let alone tailor the provisions of a revocable trust to safeguard the client, without understanding the specific health challenges that the client faces. This seemingly simple task is made quite difficult by the range of emotions that the client may be experiencing, the impact of the disease itself, the tremendous variation of symptoms, and the impact on planning from disease to disease — and even for clients living with the same disease. These matters can present a far greater challenge to the practitioner than the drafting or other issues on which most practitioners generally focus.

Although there are a myriad of reasons why practitioners may not be aware of a client's health challenges, there appear to be several common causes, each of which can be addressed:

- Many clients are simply in denial of their situations.
- Some clients don't sufficiently understand the medical dynamics so as to explain to counsel the impact necessary for proper planning.
- Finally, of those clients that comprehend it, many do not appreciate that disclosing what might be uncomfortable personal details to their estate planner is essential for any planner to advise them appropriately and tailor an estate plan, including a revocable trust, to their unique needs.

Clients Often Deny Health Issues and Don't Disclose. Addressing any one, or more, of these threshold issues that affect a particular client is critical to facilitate planning. From the client's perspective, many simply remain in denial of the scope of their challenges. Elisabeth Kübler-Ross has written extensively about the five stages of grief: denial, anger, bargaining, depression, and acceptance.[6] Although these stages are typically associated with coping with the loss of a loved one or a diagnosis of a terminal illness, the concepts are similar to a diagnosis of a chronic illness.

If, for example, someone is diagnosed with multiple sclerosis, and fatigue or perhaps vision impairment (optic neuritis) forces them to curtail or even terminate a career, the sense of loss is substantial. Many clients do not disclose their diagnoses to their estate planners because they remain in denial. It is important to remember that degrees of denial may exist throughout the client's life post-diagnosis. The stages that Kübler-Ross identified provide a framework to evaluate how a client deals with loss, not a neat sequence that clients traverse. This is especially so with a chronic illness.

Continuing our example of a client diagnosed with multiple sclerosis (MS) will illustrate the point. Most people living with MS have their disease course punctuated with attacks (called exacerbations, relapses, or flare-ups). An attack causes new or worse symptoms. Attacks can continue for just a few days, or as long as several weeks or months. The symptoms triggered by the attack may remit wholly or partially. For many clients, an attack is part of the emotional roller coaster that may continue or renew their denial of the scope and impact of the symptoms, disability, and disease trajectory that they face. The Kübler-Ross stages may cycle back and reappear. Thus, even years after a diagnosis, a client may be in denial and unable to communicate

his or her situation appropriately. Exacerbations are common to a number of chronic illnesses and will be discussed below in the context of drafting revocable trusts.

Chronic Illness Itself Can Be an Impediment to Communication. Another aspect of dealing with a client living with a chronic illness is that the symptoms of the disease itself may make it difficult for the client to address planning. For example, the main mental symptoms of Parkinson's disease sufferers include depression, anxiety, cognitive problems, and apathy. Apathy is one of the most common cognitive problems in Parkinson's disease sufferers and may be a significant deterrent to a client's beginning the planning process. Thus, for a client with a chronic illness, the encouragement and involvement of other family members, to the extent that ethical rules permit, may be advisable to continue the planning process. Practitioners should not misinterpret apathy toward planning as a sign that they should not continue to push the process forward. Practitioners may have to be more proactive than they are with other clients.

Care Manager May Be Catalyst to Planning Process. Finally, to address any of these threshold issues, it may be beneficial to involve a care manager in the process. Care managers are typically social workers, nurses, or other service professionals. They can evaluate the client's emotional and physical status, functional abilities, and home or other living environment. Importantly, the care manager can provide the practitioner, family, and client with recommendations as to how to address the apathy, cognitive problems, or other impediments to planning. The care manager can also act as a liaison between the client's medical team and the estate planning team to assist in interpreting and explaining the course of the disease and to help interpret medical information useful to counsel's determination of competency, etc. The National Association of Professional Geriatric Care Managers (NAPGCM) is the organization to which the different health-related professional care managers belong. It has promulgated a code of ethics and standards that may provide a greater level of assurance when hiring a care manager.[7] The care manager can make recommendations for care based on the information gathered from the assessment. This latter point will be discussed later in the context of tailoring a living trust.

MISCONCEPTIONS ABOUT PLANNING FOR A CHRONIC ILLNESS

Overview. Once the client is willing to begin the planning process, and the practitioner has been informed of the current status of the client's particular disease and anticipated disease course, the practitioner can begin to evaluate how to modify the planning and draft to address the circumstances. There are a host of misconceptions about chronic illnesses — and, hence, their impact on the planning process — that should be dispelled in order to plan. Each chronic illness has its own array of symptoms and consequences. It is not possible to plan for "chronic illnesses" as such; hence, even the title of this article is a misnomer.

Life Expectancy Impact Varies. Client life expectancy is a critical factor to consider in any planning. The success of many estate tax planning techniques depends on the client's survival. The time pressure for completing planning must be coordinated with the anticipated life expectancy of the client. The impact of different chronic illnesses on longevity varies dramatically.

For instance, patients with Alzheimer's disease have shortened life expectancies. One study showed that women lived an average of 4.6 years after diagnosis; men lived 4.1 years. People diagnosed when under age 70 lived 10.7 years, compared to 3.8 years for people who were over 90 when diagnosed.[8] So for a client with Alzheimer's, especially if some period has passed after diagnosis while the client was dealing with denial and other issues discussed above, the planning window may be relatively short. This time span will be further shortened by the cognitive decline that Alzheimer's will trigger.

Clients with chronic obstructive pulmonary function (COPD) may have no reduced life expectancy due to COPD, but they may have their life expectancy impacted by other health issues (co-morbidity).[9] However, there are differences that should be considered. Current smokers with stage 1 COPD have a life expectancy of 14 years, or 0.3 years lower. Smokers with stage 2 COPD have a life expectancy of 12.1 years, or 2.2 years lower. Those with stage 3 or 4 COPD have a life expectancy of 8.5 years, or 5.8 years lower.[10]

Life expectancy for those living with MS, according to 2002 data, is average-population life expectancy minus seven years.[11] Overall life expectancy is 95% of normal.[12] These figures continue to improve with the continued advancement in new drug therapies. So, for a client with MS, absent special circumstances, the impact on life expectancy may be modest.

Variation Within the Same Disease. Not only does each disease differ, but each client's experience of a disease can also differ substantially from someone else's experience of the same disease. It is important for practitioners to be informed of the specific current challenges that the client faces and the likely disease course for that client.

COMPETENCY

Assessing the client's competency, and the cognitive impact of his or her disease, is essential in order to ensure that a revocable trust is validly executed. The anticipated impact of the disease on the client's cognition is vital to determining what protective steps should be taken now for the client, and which might be prudent to incorporate into the trust or related planning for future contingencies.

Competency is too often viewed as a yes/no concept. The client is either competent or not. The reality, however, is far more complex. Practitioners should be careful not to make assumptions about cognitive impairment. A chronic illness may have a significant physical impact, but there may be no impact on cognition. Physical symptoms often do not correlate with cognitive impact. For example, Parkinsonian "masked faces" do not mean incompetence. The client living with Parkinson's may exhibit little facial expression, yet the unresponsiveness may be incongruous with the client's complete understanding of even the most complex estate tax discussions.

Each chronic disease has a different impact, and even the same disease may have a significantly different cognitive impact on different people. Alzheimer's disease will assuredly result in dementia, but there are different stages of the disease, and the disease progresses at different rates in different people. MS generally does not result in a competency issue for most living with the disease. But, for some, the cognitive impact can be significant. Yet fatigue, especially cognitive fatigue, may make it difficult for a client with MS to focus for a meeting of long duration. For some diseases, the client's cognitive challenges may vary at different times during the day or medication cycle. Cognitive challenges may affect different "spheres" of competencies but not others. For example, executive functioning may be impacted adversely, making it difficult or impossible for the client to balance a bank statement, but not so difficult that the client cannot make major life decisions.

A client's cognitive functioning may be evaluated by obtaining written status reports from attending physicians, who will likely administer a Folstein Mini-Mental State Exam (MMSE), which evaluates competency, or the St. Louis University Mental Status Exam (SLOMS), which evaluates cognitive decline in individuals with a higher education, as well as other tests to ascertain cognitive status. It may be useful to retain a care manager to evaluate how well clients function in their environment, how well they manage their medication, pay bills, manage other activities of daily living, etc. A care manager can conduct the evaluation in the home, which enables the care manager to identify issues in the home (e.g., piles of bills, clothes hung in the shower like a closet, etc.). These are observations that an attorney or CPA meeting in the office will not be able to make but which may be crucial to an appropriate assessment. In some instances, clients prepare for meetings with counsel, and the image that they project may not be indicative of the full picture of their situations.

DRAFTING TECHNIQUES TO ADDRESS SPECIFIC CLIENT CHALLENGES

Trustee Selection. A simple conclusion might be to avoid naming any client with a chronic illness as a trustee and, from inception, to appoint another to serve. Although this certainly could protect the client and avoid the complexity of understanding the client's personal challenges, it misses a fundamental principle of planning for clients with chronic illnesses. The illness itself disempowers the client. *Practitioners should strive to make the estate planning process empower the client, not further disempower him or her by removing decision-making and control that the client may still be able to exercise.*

Selection of a trustee is a decision process with which all practitioners are familiar, but there are nuances to consider when planning for clients with chronic illnesses, which will vary depending on the particular disease and the stage of disease that the client is currently experiencing. Many practitioners draft revocable trusts with the client as the sole initial trustee. However, for a client living with a chronic illness, the likelihood of future disability requiring a successor trustee may be so great that the mechanism for passing the baton to the successor becomes critical to the protection of the client. Often, the transition can best be handled by having a cotrustee, perhaps a corporate fiduciary, serving from inception with the client, but the analysis must consider the particular disease course.

If a client is living with Alzheimer's, incompetency is ensured. Depending on the client's current age and health status, there may be only a limited duration of time during which it may be feasible for the client to serve as his or her own trustee. Thus, prudence might, at a minimum, suggest a cotrustee from inception. Perhaps the client should not serve as a cotrustee and instead opt to appoint other trustees from inception.

If the client has bipolar disorder, the safest course of action for the client might be for him or her not to serve, even as a cotrustee. Someone living with bipolar disorder may experience severe mood swings, which could continue for weeks or months. These include feelings of intense depression, manic periods of intense elation, and possibly mixed emotions combining aspects of both. During a manic period, the client might embark on a sudden, extreme, and impulsive spending spree, also gambling, gift buying, etc. The risk of a client having financial control as a trustee or cotrustee may be too great. In fact, for many such clients, prudence might suggest not only that another serve as trustee, but also that the trustee named be able to resist demands that may be made during these periods by the client whose money the trustee is charged with protecting.

Clients facing the challenges of amyotrophic lateral sclerosis (ALS) have generally been assumed not to have any cognitive impact. ALS is viewed as a pure motor disease. However, there is indication that ALS may be accompanied by some cognitive impairment.[13] Thus, for clients with ALS, it may be reasonable for the client to serve as a cotrustee so that he or she may retain decision-making authority, but with another cotrustee to assist in the routine and physical aspects of trustee functions (e.g., bill paying and deposits).

Trust Assets. Many revocable trusts are structured as standby trusts, with little or no current assets transferred to them. For clients living with chronic illnesses, this may or may not be the appropriate approach.

In most cases, if the client is living with heart disease, diabetes, Parkinson's disease, or another chronic illness, the client may be capable of long-term management of his or her assets so that a revocable trust that is largely unfunded might be reasonable. In contrast, if the client has bipolar disorder, it might be prudent not only to fund the trust, but also to carefully limit and control the assets outside of the trust so as to minimize financial damage during a manic period.

Many chronic illnesses are marked by flare-ups or attacks. These can result in periods, perhaps days or weeks long, when it is impractical for the client to handle his or her financial affairs, due to the impact of disease symptoms or as a result of a short-term hospitalization. COPD, Crohn's disease, MS and other chronic illnesses may be marked by episodic attacks. In these instances, if the client will require assistance with financial, legal, and other matters, a cotrustee or successor trustee can assist with funding the trust with at least sufficient assets to facilitate management during these periods, which is advisable.

Distribution and Related Provisions. If a client is unable to serve as a trustee but has the competency to establish a revocable trust, he or she undoubtedly will want input as to distribution provisions. For many, there may be express wishes relating to their health challenges that should be incorporated into the revocable trust as binding directives, or as precatory language, depending on the circumstances and relationship to the trustees.

For a client facing the challenges of a chronic illness, his or her house is more than a home, it is a refuge and sanctuary from a world that is far less accommodating than most of us think it is. The home may reflect years of ongoing renovations at much expense and personal effort to make it as comfortable and safe as possible. For this client, an express

directive to retain the home and facilitate the client's continuing to reside in the home may be a priority.

For practically every disease, there is a charitable organization dedicated to serving those living with it. Many clients might wish to authorize charitable gifts to such organizations, especially to fund research to find a cure of the disease with which they struggle. The purchase of gift annuities that benefit a particular charity may be something desirable to the client but which the prudent investor act, and a lack of authorization for a trustee to make contributions, could prevent.

For a client who faces the challenges of bipolar disorder, it might be empowering for the trust to expressly direct the trustees to fund a small dollar account outside the trust that would permit the client to access funds via credit card, debit card, check, or ATM. This can enable the client to conduct his or her personal affairs similar to anyone else, generally unencumbered by the fact that most or all assets are held in a trust with another person serving as trustee. But should the client have a manic period, the damage that can be done will be limited because the account is limited, and it's not in the name or tax identification number of the trust. If the client reasonably spends down the funds, they can be replenished regularly by the trustee.

Gifts. It is common to include a provision authorizing the trustees of a revocable trust to consummate gifts to effect estate tax minimization or other goals. Although there may be no particular difference in how such a clause is drafted for the chronically ill client, consideration should be given to having a care manager create a care plan for the client that can be incorporated into the client's budget and financial plan, so that the appropriateness of gifts can be determined. Using standard budget assumptions may dangerously underestimate costs. Also, the impact of the client's health challenges on longevity should be considered.

Grantor's Disability. Disability clauses must be treated with particular care. In many instances, a client may be deemed disabled under various definitions of the term when the revocable trust is executed. Thus, the operation of the disability clause would be oxymoronic in that the grantor/client may execute a document for which he or she already is disabled. A common and simplistic approach to defining disability could be based on something like the following provision: "The Grantor shall be deemed to be disabled when Grantor is unable to manage Grantor's affairs and property effectively." Revising or, at least, tailoring the clause may be essential.

Another aspect of disability is the effect of an attack or flare-up of the client's disease. If the client has COPD and is hospitalized for several weeks, during that period of hospitalization the client may well meet the definition of disability and technically be terminated from serving as a cotrustee of his or her revocable trust. However, when the client is released from the hospital, he or she may be perfectly capable, and desirous, of resuming management of his or her own revocable trust. This could result in an on-again, off-again pattern of removal and reinstatement. Apart from the sheer awkwardness of such a provision, there could be significant issues if a third party has to determine whether a particular action was appropriately taken by the trustees. Who was the trustee on the date of the action? An alternative might be to provide a trigger mechanism that requires perhaps 30 days of consecutive disability before the grantor/client is removed as a cotrustee. The period should be selected in consultation with the client's medical advisors or care manager to coordinate with the anticipated periods of flare-ups or hospitalizations. In this way, a short-term attack will not trigger any complications to the trustee's position.

If the grantor who is living with a chronic illness is to serve as a cotrustee, consideration should be given to authorizing either cotrustee to conduct routine bill paying and banking transactions alone and without the requirement for action of the cotrustee. This will enable the cotrustee to handle the client's trust matters during a flare-up or other period of difficulty.

Additional Precautionary Provisions. A number of additional steps can be taken to provide additional safeguards to a client who is infirm now, who may be infirm in the future, or who is likely or assuredly to be totally dependent on outside help at some future date.

If a bank trustee is not employed, a monitor relationship can be created. For example, a trust protector or even an independent accountant, can be

designated to receive and review monthly brokerage and bank statements so as to provide a check and balance on individual trustees.

The trust can authorize or, if appropriate, mandate that the trustee retain an independent, licensed care manager to meet periodically with the client/grantor, conduct an interview and evaluation in the home or facility where the client resides, and issue a written report to the trustees and, perhaps, others. This can provide an objective and professional assessment of the client's status, identify any abuse or other issues that should be addressed, and revise the existing care plan to reflect any new developments. This can be invaluable to a trustee making distribution decisions.

Estate Tax Planning. Given the tremendous uncertainty as to the future of the gift and estate tax exemption amount, estate tax rates, and, perhaps, even the entire transfer tax system, additional precautions are in order with respect to revocable trust planning for clients with chronic illnesses. The issue facing all clients is: If a significant change in the law is enacted, will the client be competent and able to act before adverse changes become effective? For clients facing significant health challenges, the risk of not being able to consummate a plan is more real then theoretical. There are a number of steps that practitioners might consider in developing the revocable trust plan and drafting the document.

The gift clause often included in a revocable trust (see above) is typically focused on gratuitous transfers intended to take advantage of the annual gift tax exclusion. Perhaps the trustees should be authorized to make much larger gifts so as to utilize some portion or all of the lifetime gift exemption. This can be especially important if the exemption amount is reduced from its current $5 million level to something lower, even the historical $1 million amount. If this is to be done, the aggregate amount of transfers should be planned to be reasonable in light of the client's situation, and sufficient assets should be transferred to the living trust to be within the trustee's control so as to effectuate such transfers. Further, if large transfers are to be permitted, greater detail as to whom and how they should be permitted to be transferred should be addressed. In some cases, it might suffice to authorize the trustee to make transfers in a manner consistent with the residuary beneficiary provisions of the revocable trust.

Another approach to effectuate gifts, especially if the transfer must be consummated quickly, might be to empower a trust protector or other independent fiduciary with the limited authority to terminate the grantor's powers to revoke some portion or all of the trust, thereby transforming the heretofore revocable transfer into a completed gift transfer. Again, if this type of mechanism is to be included, discussion of the parameters of the power, who will benefit, and so forth should all be addressed.

Practitioners might wish to reconsider how the revocable trust will be funded in order to better facilitate future significant estate planning transfers. For example, if a client would otherwise be funding a revocable trust with brokerage account assets, it may be preferable to structure a family limited partnership or family limited liability company (collectively, FLP) at the inception of the trust. The brokerage assets could be transferred to the FLP, and then FLP interests could be transferred to the revocable trust. Creating the entity while the client is well may make it feasible for the trustees on short notice to consummate a completed gift or other irrevocable transfer of a discounted FLP interest that may not otherwise be practical to accomplish in a short time frame, if changed circumstances require it. Practitioners should not lose sight of the fact that tax laws aren't the only factor that may change suddenly. The hallmark of many chronic illnesses is a sudden attack or flare-up that can lead to expanded and permanent impairment. The more of the planning "infrastructure" that is prepared in advance of an event, the more feasible it may be to complete the planning that was prepared.

CONCLUSION

Planning with revocable trusts is the cornerstone of many estate plans. Yet, if this ubiquitous document is to be used most effectively for a client facing the challenges of a chronic illness, the document and related planning must be tailored. In many instances, the tailoring is no more than minor drafting differences to account for the client's specific problems. In other situations, practitioners will have to step out of what otherwise might have been their comfort zones to be more proactive, and more involved in obtaining and interpreting medical data, ensuring that the client is empowered and protected by the process.

Footnotes

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