

**Chronic Illness:  
Estate, Financial and Related  
Planning**

# Chronic Illness: Estate, Financial and Related Planning

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120 Million Americans live with Chronic Illness  
Planning Needs to be Tailored

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## Caveats

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## Planning for Chronic Illness

### Introduction and Overview

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## Many Clients are Affected by Chronic Illness

- † 120 million Americans are living with chronic illness or disability
- † By 2020, about 157 million Americans will be afflicted by chronic illnesses
- † 26% of those ages 65-74 have had their lives significantly impacted by chronic illness
- † 50% of those age 85 and older have had some cognitive impairment
- † 9 million people are cancer survivors with various side effects from treatment
- † Issues affecting those living with chronic illness are important to your practice

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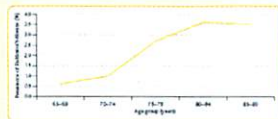
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## Incidence of Parkinson's Disease



At age 50: < 10 per 100,000

At age 80: >200 per 100,000

Average age of diagnosis: 60

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## Planning for Chronic Illness is Not Only About The Elderly

- † 60% of those living with chronic illness are between the ages of 18 and 64
- † Studies suggest 2 to 5% of all people with MS have a history of symptom onset before age 18; 8,000-10,000 children have multiple sclerosis in the United States, and another 10,000-15,000 experience disorders that may be related to multiple sclerosis
- † 5-10% of people with Parkinson's disease are under the age of 45 (Young Onset Parkinson's disease, or "YOPD")
- † 70% of suicide may be in part motivated by physical illness or uncontrollable physical pain and more than 50% of these suicidal patients were under 35 years of age

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## Incidence of Multiple Sclerosis



▶ Average age of diagnosis is 30, although range is from childhood to over 50  
 ▶ Female predominant disease: 4:1

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## Why Do I only Know of a few Clients Affected by Chronic Illness?

- 96% of your clients who are living with a chronic illness live with one that is largely **invisible**. These clients do not use any assistive device and may "look" perfectly healthy to the untrained eye
  - To inform people having this misconception, the National Multiple Sclerosis Society has published an on-line booklet aptly entitled "But You Look So Good"
  - Many neurologic symptoms are hard to see: fatigue, pain, cognitive problems like memory loss or trouble solving problems, weakness, blurred vision, numbness, prickly or tingling sensations, heat sensitivity, dizziness, and bladder problems
- Those living with chronic illness get tired of explaining their symptoms, or of justifying why they cannot do certain things. Some feel that they have to defend that they may "look good" even though they have a significant chronic illness. Empathy will create an environment conducive to communication
- Most clients living with chronic illness assume that there is nothing you can do to help. Communicate your skills and ability to help
- Many fear "coming out of the closet" for fear of negative reactions, loss of job or worse

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## Multiple Sclerosis Associated Features:

### Fatigue



- Can be mental and/or physical
- Number one reason people with Multiple Sclerosis disease leave the work force
- Fluctuates during the day

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## Do Good and Do Well Planning for Chronic Illness

- † Many of your clients are touched by chronic illness (they are living with chronic illness, have a love one affected, or they are a caregiver)
- † It is the compassionate thing to help
- † Its good for your business! With \$5M exemption and portability only 5,600 estates per year will file federal estate tax returns. The "tax driver" can no longer be relied upon as the sole, or even primary, generator of business
- † Helping clients affected by chronic illness, and growing your practice by better serving the many potential clients affected by chronic illness, is good business
  - This program will help you identify clients affected by chronic illness
  - [www.RV4TheCause.org](http://www.RV4TheCause.org) has practical resources to draft documents, undertake tax planning engagements, create a financial plan or analyze a disability policy, turn-key materials for you to lecture to prospective clients and build your practice: power points for consumer lectures, sample invitations, and more

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## Planning for Chronic Illness Requires a Broad Approach

- † Special Needs Trusts (SNTs) may be vital for those of more limited means. But many people living with chronic illness or disability have high net worth and need specialized investment, estate and other planning
- † People living with chronic illness and disabilities have a wide range of planning issues – no aspect of planning is untouched
- † Living wills, health proxies, HIPAA releases and more need to be tailored to each person's situation, but this is just the beginning

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## Parkinson's Disease

### Cardinal Features:

- ▶ Rigidity
- ▶ "Pill rolling" Tremor
- ▶ Bradykinesia – slowness of movement
- ▶ Postural instability – poor balance



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## Multiple Sclerosis

### Illustration of another Chronic Illness

- † MS is an autoimmune disease that affects the central nervous system ("CNS"), i.e., the brain and spinal cord
- † Characterized by an inflammatory process that results in the destruction of the myelin sheath that surrounds and insulates the axon (nerve fiber), and ultimately causes damage, or in worse cases, destroys the axon
- † The MS lesions, referred to as demyelinating plaques, are typically detected through magnetic resonance imaging (MRI). In progressive forms of MS scientists believe that the cells that create new myelin, called oligodendrocytes, are also destroyed. This would preclude repair of destroyed myelin (re-myelination) making improvement in the client's condition unlikely

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## Multiple Sclerosis

### Possible Planning Impacts

- † Someone diagnosed in their early 30s might have a 15 year estimated remaining work career. A more aggressive savings and investment plan may be warranted to create a retirement nest egg in time for an early retirement
- † Significant cognitive impact is unlikely for many years if ever
- † Sporadic exacerbations (attacks) may warrant special powers of attorney and other planning
- † The client living with MS, because they are likely to have graduated college and begun a career may have disability insurance, but is often too young to have addressed long term care coverage
- † 4/5ths of those diagnosed with MS are women, 70% are single

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## Planning for Chronic Illness

### Client Interactions: Meetings, Phone Calls, Memoranda

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## Considerations for Meetings with a Client Living with Chronic Illness 1 of 2

- † It is OK to ask the client "what are your challenges so I can tailor my work to meet your individual needs?"
- † Plan short, separate meetings rather than one long meeting. Be aware of fatigue issues
- † Have an agenda and bullet list for the meeting
- † Use a smart board or flip chart with outlines of the meeting agenda and topics
- † Ensure that a bathroom is available and allow extra time for breaks
- † When you are explaining concepts, be certain to inquire at frequent points along the way whether the client understands, or has any questions. Client intelligence may be intact, but they may process slower

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## Considerations for meetings with a client living with Chronic Illness 2 of 2

- † It may be beneficial for some clients to tape record the conversation so they can replay it many times to assure they understand all the key points
- † Have someone such as a friend, family member, or other adviser, accompany the person with chronic illness to the meeting to provide a second pair of ears
- † At the end of the meeting, provide a bullet list of important conclusions
- † Because of tremors, hand weakness or other symptoms, some people with chronic illness might not be able to take notes. Many may have difficulty multi-tasking so taking notes while listening might be difficult. It might be more productive for someone else to take notes and let the client simply listen
- † If the client has "to - do" items, a succinct list should be written down

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## Planning for Chronic Illness

### Income Tax Planning

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## Income Tax: Insurance Payments

- † **Disability insurance** payments are income tax free if paid personally
- † **Long term care insurance** payments are generally treated as payments from accident and health insurance and are tax free (except for dividends)
- † **Life Insurance** accelerated death benefits under a life insurance contract, or viatical settlement before the insured's death, are generally tax free if client is terminally or chronically ill. Definition of "chronically ill" is so extreme as to exclude most people: (1) Unable to perform (without substantial help) at least 2 activities of daily living (eating, toileting, transferring, bathing, dressing, and continence) for a period of 90 days or more due to loss of functional capacity; or requires substantial supervision to protect from threats to health and safety due to severe cognitive impairment

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## Income Tax: Settlements

- † Chronically ill clients may require legal action to enforce employment, disability income, and other rights
- † Proper characterization of an award may depend on the types of remedies that are available, and the causes of action asserted in the claim
- † If the settlement agreement contains specific allocations to the amounts claimed as taxable and non-taxable and the parties are adverse, the IRS will more likely respect the allocation. *Robinson*, (1994) 102 TC 116, aff'd (1995, CA5) 70 F3d 34, 95-2 USTC ¶150644
- † If agreement is silent as to allocation, recovery from a suit against an employer or partners for discrimination, damages, back wages, etc. must be allocated to each tax category. This is sometimes done using relative values of the claims asserted in the initial complaint
- † Recovery allocated to punitive damages is not attributable to personal injuries and is taxable. *Pauline Barnes*, (1997) TC Memo 1997-25
- † Characterization of the payments by employer and employee not binding on IRS. PLR 200303003

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## Income Tax: Deductibility of Legal Fees

- † Legal fees may not provide a deduction because of the 2% floor on itemized deductions or the AMT trap
- † IRC Sec. 62(a)(20) may provide a mechanism to obtain a full deduction as an offset to AGI instead of as a miscellaneous itemized deduction
- † Costs involving discrimination suits, etc. may be deducted from gross income to arrive at AGI. Caution: no line exists on Form 1040
- † *"Any deduction allowable...for attorney fees...paid by, or on behalf of, the taxpayer in connection with any action involving a claim of unlawful discrimination...The preceding sentence shall not apply to any deduction in excess of the amount includible in the taxpayer's gross income for the taxable year on account of a judgment or settlement (whether by suit or agreement and whether as lump sum or periodic payments) resulting from such claim"*

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## Income Tax: Home Modifications

- † Medical expense deduction may be allowed for special equipment and home improvements if the main purpose is medical care: adding an accessible entrance ramp, installing a lift, widening doorways, building handrails, modifying cabinets, etc
- † Cannot deduct your expenditures to the extent of any increase in the value of your home
- † Have house appraised before and after the improvements

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## Income Tax: Deduction for Special Work Related Expenses

- † Extra business expenses ("impairment related expenses") to do work satisfactorily are deducted as business expenses instead of as medical expenses under IRC Sec. 67(b)(6)
- † This can avoid the 7.5% (increasing to 10%) limitation on medical expenses that might prevent a deduction
- † Self employed deducts these on Schedule C; Employee completes Form 2106 "Unreimbursed Employee Business Expenses"
- † While most employee business expenses are reduced by 2% of adjusted gross income impairment related expenses are not

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## Income Tax: Maximizing Medical Expenses

- † Take affirmative steps to enhance the likelihood that certain expenditures will qualify as deductible medical expenses
- † How can the client corroborate that an otherwise personal expense is for medical care?
- † What is motive and purpose for incurring the expense?
- † Has a physician recommended the item or expense to treat a diagnosed medical condition? Has this been confirmed in writing?
- † Can the taxpayer establish that the item would not have been bought but for the disease or illness? IRC Sec. 213(d); INFO 2009-0209

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## Income Tax: Medical Expense Examples

- † **Car:** A car specifically designed to compensate for disabilities, the portion of the price attributable to its special design is a medical expense. Rev Rul 76-80, 1976-1 CB 71
- † **School:** Cost of a special school for a handicapped dependent may be deductible as a medical expense if principal reason for attendance is special resources for alleviating the handicap. Room and board are included. Reg. § 1.213-1(e)(1)(v)(a)
- † **Home Sale Exclusion:** Taxpayer becomes physically or mentally incapable of self-care the taxpayer is treated as using such property as his principal residence during any time during such 5-year period in which the taxpayer owns the property and resides in any licensed facility (including a nursing home) to care for an individual in the taxpayer's condition. IRC Sec. 121(d)(7)

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## Planning for Chronic Illness

### Investment and Financial Planning

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### Investment and Financial Considerations: Take A Broad Perspective

- **Title to Accounts**
  - Revocable trust
  - Joint
  - Other
- **Beneficiary designations**
  - For client assets
  - Of others that benefit client living with chronic illness
- **Account Management**
  - Duplicate statements
  - Consolidation and simplification
  - Geographic proximity
  - Access to safe deposit box
- **Automation**
  - Organizing records
  - On line payments
  - Set up on computer so can enlarge visual
  - Automatic deposits

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## Cash Flow and Budgeting

- † Budget and projections are the foundation of every plan
- † Standard assumptions may not suffice (e.g. inflation of medical costs, expense patterns may differ; etc.)
- † May need to target cash flow for specific milestones that differ from others: ceasing work, modifying home, etc.
- † Cash sources:
  - Distributions from retirement accounts
  - Borrowing from retirement or other accounts
  - Insurance
  - Home equity
- † Expenditures:
  - Home accessibility
  - Aides
  - Medication/therapies
  - Other

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## Investment Plan for Client with Chronic Illness

- † Tailor an investment plan in light of the client's specific circumstances, not generalizations or assumptions
- † Understand disease trajectory and its impact on expenditures, life expectancy and other factors
- † Each chronic illness differs from other chronic illnesses
- † Each client's experience is unique to that client
- † Client's can have varying experiences over time

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## Time Horizon and Risk Tolerance

- † Time Horizon
  - Short vs. long term vs. anticipated disease milestones
  - Depending on illness long term planning may be essential
  - Don't focus only on short term unless anticipated disease course requires it
  - Time horizon can vary – new drug therapies can lengthen
- † Risk Tolerance
  - May not be the same as for other clients
  - Risk tolerance may be affected by fear, medical costs, or need to retire early
  - Might be higher or lower than other similar age/wealth investors – depends on circumstances and objectives, e.g. YOPD at age 40 and estimated retirement at age 55

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## Investment Planning: Other Considerations

- † **Liquidity:** Investors with chronic illness might generally prefer more liquidity. Expenses might be higher, so might the "rainy day fund". Others, may not. Barbell asset allocation concept?
- † **Retirement:** Target retirement age and impact on risk and asset allocation. Example: May need more aggressive allocation to equities and alternatives to create sufficient wealth by an early retirement age.
- † **Needs Analysis:** Consider an independent evaluation that addresses medical and care costs, disease projection, etc.
- † **Meetings:** Annual meetings are vital to document a pattern of investment planning and keep abreast of health and other developments.
- † **IPS:** Power of attorney and/or revocable trust – who will be signing the IPS?

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## Planning for Chronic Illness

### Insurance Planning

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## Life Insurance Considerations

- † Exercise conversion options in term policy to convert to permanent policy
- † Accelerated death benefit option
- † Borrowing against cash value to meet urgent need
- † Viatical Settlements
- † Sale of policy versus surrender for cash surrender value

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## Life Expectancy

### PARKINSON'S DISEASE

- Among people who have lived with PD for 15-20 years, the survival rate was only slightly lower than the population
- Heart disease is the leading cause of death

### MULTIPLE SCLEROSIS

- Average life expectancy for people with MS is only slightly shortened- average of 7 years
- In people with advanced MS, Medical complications of the disease process may be etiology for death: aspiration pneumonia, urosepsis

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## Property and Casualty Insurance

### † Property and casualty

- Does coverage have to be updated to protect home health aides and others
- Scheduled property adjustments for life changes
- Which property is covered? (changes, e.g. sell vacation home, buy weekend home)
- Automatic payment (e.g. debit to checking account to avoid lapses) and value increase provisions

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## Long Term Care Insurance Considerations

- † Is it still feasible to obtain coverage
- † What does existing coverage provide
- † How does coverage affect budgeting and other planning
- † Help client evaluate product options
- † Post diagnosis – review of policy reporting and other requirements; ascertaining benefits that will be obtained and revising the financial plan to reflect them

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# Planning for Chronic Illness

## Disability Planning

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## Disability Insurance to Replace Income

### † Disability policy

- Reviewing disability policy calculations. They are complex and CPA involvement is often essential: CPI inflators, allocations of income and expenses, etc.
- Proving disability with "invisible" chronic illness raises issues
- Residual disability – may depend on % reductions that CPA should confirm
- Issues of undefined terms – many track tax terminology
- Income and other calculations
- Dealing with disability insurance company abuse
  - Outrageous policy interpretations
  - Communications and actions to intimidate and stress claimant

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## Business Disability Considerations

### † Buy sell and other Business Agreements

- Shareholder/Partnership/Operating Agreements
  - Buyout and other business arrangements
  - Temporary versus permanent disability definitions and consequences
  - Health status and timing of sale of equity interests – will disabled equity holder have ability to negotiate terms
  - Definitions may differ under: ▶ business continuation insurance ▶ employment agreement ▶ shareholders' agreement ▶ disability income replacement ▶ disability buyout
- Disability buy out insurance (contrast with disability income replacement insurance)

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## Business Disability Considerations (continued)

### † Buy sell and other Business Agreements

- Employment agreements
  - Disability provisions
  - Bands
  - Definitions
  - Coordination or lack of coordination with disability insurance
- Business Continuation Insurance Coverage
  - Disability definitions
  - Expense definitions

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## Planning for Chronic Illness

### Competency And Cognitive Issues

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## Cognitive Issues

### PARKINSON'S DISEASE

- Memory Loss
- Hallucinations
- Disorientation
- Confusion

### MULTIPLE SCLEROSIS

- Fund of knowledge  
normal

Distractibility  
Slowed thinking  
Irritability  
Lack of motivation

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- Counsel's determination is key
- **Competency is a Legal not medical decision**
- See below concerning documentation for tax and other purposes
- Are letters really adequate
- Neurologist letter
- Physician letter
- Medical letters/conference calls to inform and advise planner
- Getting the professionals comfortable / knowledgeable enough to ask pertinent questions
- Getting someone to open up is often a large part of the challenge
- What is current status of client

Competency Issues

(continued)

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Parkinson's Disease Associated Features:

Masked Face

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- Don't make assumptions about cognitive impairment
- There may be no impact on cognition
- Parkinsonian masked faces does not mean incompetence
- Many neurological diseases have widely different impact on different people
- Alzheimer's disease will assuredly result in dementia, but Multiple Sclerosis does not result in a competency issue for most living with MS
- May impact differently at different times during the day or medication cycle: cognitive fatigue may just flip on
- May affect different "spheres" but not others

Competency Issues

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## Competency Issues (continued)

### What is the likely future trajectory of client's illness?

- How to plan now to address future changes
- What is disease course likely to be
- Can changes be monitored periodically so adjustments can be made
- New drug therapies may change

### Documenting Competency

- Physician/neurologist letter
- Legal determination by attorney
- Client statements
- Complexity of matter involved influences degree of competency required to handle it
- Potential for overall harm to client from matter – the more the potential harm, the greater the level of competency that should be necessary
- Video tape or not to video tape – not a simple issue

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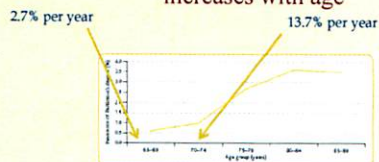
## Thinking, Memory and Cognitive Issues

- Prevalence: varies significantly by disease, and even within the population of a particular disease
- Even if many people with a particular disease experience cognitive impact – the degree may vary
- Memory: Long term memory may not be affected
- Slowed information processing
- Executive functions (planning, prioritizing, etc.) may be impacted
- Word finding difficulties
- Cognitive fatigue

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## Dementia and Parkinson's Disease

Incidence of cognitive impairment  
increases with age



For the 20% of people with Parkinson's Disease who go on to develop dementia, there is an average of a 10-15 year delay from time of diagnosis of Parkinson's disease

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# Planning for Chronic Illness

## HIPAA Releases

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## HIPAA Releases Essential To Planning

- T HIPAA = acronym for the Health Insurance Portability and Accountability Act of 1996 (Pub. L. No. 104-191, 110 Stat. 1936 (1996)); 45 C.F.R. Sec. 164 (2002). HIPAA, as amended (GINA too)
- T Maintaining the confidentiality of PHI means protecting info from being made available or being disclosed to unauthorized persons
- T If you're ill, can your daughter-in-law the doctor get to see your patient chart to monitor your care
- T If you're a successor trustee, and the current trustee is forgetting to pay insurance premiums and respond to correspondence, can you replace her
- T Your partner is disabled and you need to take over your professional practice, how can you obtain the requisite physician letter mandated in your shareholders' agreement to demonstrate his incompetence to be able to trigger the replacement provision
- T Be cautious of the "standard" form

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## HIPAA Releases

### Writing

Authorization should be in writing and should acknowledge that its being made voluntarily.

### What

Describe the health information to be disclosed. This could be the entire medical record, or only specified components. Could specify that only medical records between certain dates be released. The HIPAA paradigm is that only as much info should be disclosed as necessary

### Who

Which medical provider should make the disclosure? This could be a specific physician or hospital or a list of providers. A broader approach could be used to indicate a category of providers. For example, "any physicians, hospitals or other medical providers who have provided treatment, other medical services or payment for same, from June 1, 2004 through and including the date of this Authorization."

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## HIPAA Releases (continued)

### Term

When does the authorization to disclose PHI expire? This could be: "upon a child attaining age 21." It could be "2 years from the signing of this authorization." "Upon the conclusion of my court case" may suffice for a litigation matter, although issues of appeals, etc. might warrant consideration in setting the parameters. "One year from death"

### Revocation

A statement that you retain the right to revoke any authorization to disclose your PHI. Any revocation, however, is not binding on a medical provider until they receive it. This minimizes the issue of their liability for disclosing information based on an authorization they held prior to the revocation

### Re-Disclosure

The release may state that certain information, such as HIV testing results, cannot be disclosed by the person receiving it. However, the release should also acknowledge that once other information is disclosed, it may thereafter be re-disclosed by the person receiving it without the HIPAA safeguards

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## HIPAA Releases (concluded)

### Purpose

The purpose for the disclosure should be explained. This might be limited to the minimum information to determine whether you have the ability to function as a trustee or should be replaced, or only that information necessary to underwrite you for life insurance

### Signer

If you are signing the authorization, the signature line should merely state that you are the patient. If, however, another person is signing for you, the authorization should state that that person qualifies as your personal representative under and that they have authority to make health care decisions for you

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## Planning for Chronic Illness

### Estate Planning

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## Overview of Estate Planning for the Client with Chronic Illness

### • Powers of Attorney

- Springing vs. not
- General vs. Special
- Why standard forms aren't suffice
- Special provisions to include

### • Health Proxies

- Special considerations in selecting agent
- What is different for the chronically ill client

### • Living Wills

- What they are and why they are important
- Address specific health issues
- Experimental procedures
- Organ and tissue donations

### • Revocable Living Trusts

- Unique importance
- Boilerplate forms rarely address nuances needed
- What can and should your client have

Each of these will be addressed below in detail

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## Chronic Illness: General Estate Planning Impact

† **Disease Disempowers/Planning Should Empower:** Given the uncertainty many chronic illnesses create, planning should provide the client maximum control over her financial and legal affairs, while creating an appropriate safety net in the event cognitive or other impairment becomes significant.

† **Client as Co-Trustee:** Even when assistance with daily activities is required, the impact of chronic illness on some clients living with disease is such that the client may be able to, and want to, serve as a co-fiduciary. Administrative burdens can be shared while keeping the client involved and in control. This is preferable when feasible, rather than eliminating the client's involvement as may be the case with, for example, a more advanced stage of Alzheimer's disease.

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## Powers of Attorney for a Client with Chronic Illness

- † Why standard drafting may not suffice – how much control should be given up now
- † Springing vs. not; General vs. Special – when to use each
- † The problems of triggering a springing power are common to all clients. If a client is insistent on a springing power, even a client with a chronic illness, the power may only have to be triggered once, when the level of incapacity reaches a point where an agent has to permanently take over – what about a client with relapses
- † Compensation of agent – most powers ignore but agent may act for years or decades; consider quick action for short duration during an attack

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## Powers of Attorney for a Client with Chronic Illness - Continued

- † MS client have long periods when they are capable of handling all financial matters
- † These may be interrupted by brief periods of exacerbations lasting days or weeks when it is difficult or impossible to cope without an agent's assistance. These exacerbations are unpredictable, and even the causes that trigger them are uncertain
- † If the appointment of the agent is effective immediately upon execution, unencumbered by the springing mechanism, the agent will be able to help during a short term exacerbation or relapse, and then can cede control back to the client as soon as feasible
- † With a springing power, by the time the agent can legally demonstrate the principal's disability, the attack may have resolved
- † Consider a limited power that is effective immediately and a springing power that is effective in the case of more permanent disability

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## Living Wills for Client with Chronic Illness

- † **Disease Modifications:** Modifying documents to address specific health issues -- what disease does the client have, at what stage and with what anticipated disease course -- how if at all should these matters be reflected
- † **Experimental Treatment:** Specification to provide non-proven experimental treatment is a common modification -- must agent under power of attorney fund this
- † **Tissue Donations:** Since AD can only be confirmed 100% through a brain autopsy, many suffering with AD will wish to include a specific consent in their living will directing that a brain autopsy be permitted and their brain be donated to promote scientific research into AD. Religious issues should be addressed.

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## Health Proxies for Client with Chronic Illness

- † **Health Proxies**
  - What is different for the chronically ill client
  - **Residence:** Powers to grant to move to new state for different laws. Will this suffice
  - **Guardianship:** Alzheimer's disease: Given the progressive nature of AD and the certainty of cognitive issues, a guardianship designation should be included in the health care proxy (or a separate guardian designation prepared). Some state laws expressly permit this.

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## Revocable Trusts for Client with Chronic Illness

### † Revocable Living Trusts

- What provisions should the trust contain to address the client's health status
- Who should be the trustee? With advanced Alzheimer's the client may not be a trustee at all
- With earlier stages of Parkinson's the client may be the sole trustee
- Some clients may best be served by a hybrid approach. Naming a client living with MS as a sole trustee may prove problematic during an exacerbation, the severity of which can't be predicted. Not naming the MS client as trustee cedes control from a client who generally has the capacity to make decisions.
- Consider having the MS client and another person as co-trustees from inception, with either being granted authority to act independently to take the actions that might be required during periods of an MS exacerbation, or a 30 day disability period for removal.

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## Planning for Chronic Illness

### Charitable Planning

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## Charitable Planning for the Chronically Ill Client

- † Tailor charitable planning to coordinate with the needs and personal objectives of the chronically ill client or the client's chronically ill loved one.
- † CGAs – Charitable Gift Annuities
  - Watch % of assets committed
  - CRTs for wealthier clients
- † Creative uses of CRTs
  - Charitable bail out of closely held business which will have to be sold as disease progresses
  - Management, certainty, cash flow
- † CLTs – time not just to zero out but to end when the chronically ill child will be in financial need

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# Planning for Chronic Illness

## Conclusion

# Conclusion 1 of 2

- This affects many of your clients, so addressing the implications of chronic illness is not only the compassionate thing to do, it's good business
- Don't make assumptions, you don't have to be an expert – Ask questions
- Standard documents and planning will often not protect the chronically ill client
- [www.RV4TheCause.org](http://www.RV4TheCause.org) has resources to help you adapt planning cost effectively
- Understand the specific impact on the specific person and what it means to their planning and to the planning of their loved ones

# Conclusion 2 of 2

- Don't be uncomfortable to ask – not addressing these issues is far more difficult for the client than addressing them
- Be creative, often a little "tweak" to a standard planning technique can work wonderfully to help
- Empathy [understanding, being aware of, being sensitive to, and vicariously experiencing the feelings, thoughts, and experience of another], not sympathy is the attitude that will facilitate planning

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## For Additional Information

- † Estate Planning for People with a Chronic Condition or Disability available from Demos Health. See Demos Medical Publishing (Demos Health)  
[http://www.demosmedpub.com/prod.aspx?prod\\_id=9781932603668](http://www.demosmedpub.com/prod.aspx?prod_id=9781932603668). All proceeds to charity
- † [www.RV4TheCause.com](http://www.RV4TheCause.com), see the "chronic illness resources tab". If the resources you need aren't available, email us
- † [www.laweasy.com](http://www.laweasy.com) section on chronic illness has podcasts, articles, and sample forms

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## 3 Ways to Make a Difference

- † Better serve current clients living with chronic illness
- † Host a professional seminar for referral sources
  - [www.RV4TheCause.org](http://www.RV4TheCause.org) provides sample PR, press releases, a web presence and more at no cost to you
  - Local charities, local professionals and other potential referral sources can attend a program in your location
- † Conduct a seminar for prospective clients
  - Build business by speaking to prospective clients who may be living with a chronic illness
  - [www.RV4TheCause.org](http://www.RV4TheCause.org) provides PowerPoints, handouts, materials, sample invitations, press releases, and more to help you

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## Simple Steps Will Help

- † [www.facebook.com/rv4thecause](http://www.facebook.com/rv4thecause)  
Join/"Like" our Facebook page and tell us how to help you and your clients
- † Encourage clients to join our Facebook page to tell their stories and share planning ideas
- † Recommend your professional organization get involved as a sponsor of programs
- † Donate to the charities listed on [www.RV4TheCause.org](http://www.RV4TheCause.org) or other deserving charities serving those living with chronic illness and their caregivers

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**Thanks for Joining Us**

**Thanks for helping making a  
positive difference**



**National  
Multiple Sclerosis  
Society**

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Rethinking Modern Portfolio Theory • Becoming a Media Source

# NAPFA ADVISOR

The Journal of the National Association  
of Personal Financial Advisors

www.napfa.org

## Roadtrip: Educating advisors about chronic illness



*How NAPFA  
member Martin  
Shenkman is  
delivering unique  
advice about the  
financial impact  
of chronic illness.*

October 2010



By Chris Hale

## Financial Planning



### On the Road With Martin Shenkman

RV4TheCause Breaks New Ground In Financial Planning for Long-Term Illness

**M**artin Shenkman appreciates the value of a good list. A NAPFA member with training as a lawyer and CPA, he uses lists to help his clients manage the many details of estate and tax planning. But he also knows that lists can't account for everything—like when a loved one is diagnosed with a chronic illness. When that happens, even the best-laid plans need adjustment.

So when Shenkman's wife Patti was diagnosed with multiple sclerosis in 2006, he set out to adjust his own estate plan, and he began creating new lists for eventualities he'd never imagined dealing with. Along the way, he realized that all he was learning about MS and about living with chronic illness in general could be useful to other professional advisors—not to mention those whom they advise.

"After Patti's diagnosis," he said, "I combed the professional literature and found little to nothing on the subject of estate and financial planning for people living with MS or other chronic illnesses."

Shenkman combined what he was learning about chronic illness with his knowledge of estate planning to publish several articles that eventually led to a book, *Estate Planning for People with a Chronic Condition or Disability*. Later, he wrote *Funding the Cure* for

the National Multiple Sclerosis Society. (The proceeds from both were donated to charity.)

#### On the Road

But Shenkman knew how many people are affected by chronic illness and how many still weren't getting the message about planning their finances to deal with the impact of these illnesses. So he decided to take that message to them personally—in an Airstream trailer. He launched a national initiative, RV4TheCause, to educate professional advisors in several disciplines (CPAs, attorneys, financial planners, insurance consultants) on how they can better advise clients whose families have been affected by MS, ALS, Alzheimer's Disease, Parkinson's Disease, and other chronic illnesses.

By targeting professional advisors, he knew he'd extend his reach to their clients as well as their clients' loved ones. Since, as his website states, 120 million Americans live with chronic illness, he knew

there was a good chance his message would resonate with many people.

Before he left, though, he made a list.  
*Tire pressure gauge. Check.*  
*Torque wrench and sockets. Check.*  
*Air compressor. Check.*

In August, he hitched up his Airstream and hit the road.

"After our last effort at a two-day vacation and the attendant difficulties with food, organized tours infringing on fatigue time, and more, 'RV' popped into my head," Shenkman says on the website RV4TheCause.org. "If Patti is fatigued, we can pull over at the next rest stop, and she can take a nap. If we can't find appropriate food, no problem, we can jump into our trailer and make whatever she needs. No worry keeping



Martin and Patti Shenkman with their dog Elvis.



medications refrigerated if we're towing our fridge.... An RV just seems to solve it all."

But the Airstream isn't simply a more convenient means of travel. It's also a means of generating buzz around the campaign.

"Hopefully, this journey will build media interest, which will build awareness with the general public about the silent and invisible health issues facing so many," Shenkman said. "Awareness facilitates greater compassion and consideration."

## Networking Through NAPFA

NAPFA's network of financial advisors is an important part of Shenkman's plan. Using NAPFA members as key contacts, Shenkman and his wife lined up seminars in Pennsylvania, Ohio, Indiana, and Michigan on their first road trip, which took place on Aug. 30 through Sept. 8.

One of their stops was at Capelli Financial Services, in Bloomfield Hills, MI, where NAPFA member Marilyn Capelli Dimitroff, CFP®, and her staff pulled together an audience of about 25 professionals and several clients who have relatives dealing with chronic illness. "Marty provided all the tools we needed," said Dimitroff.

The presentation already is paying dividends beyond the hour or so Shenkman spent with the group. "We are now talking with an estate planning attorney who attended the session about similar presentations for families dealing

with these chronic illnesses. The head of Michigan's Multiple Sclerosis Society was an attendee, and we will seek cooperation from him and others. Yet another all-around win," said Dimitroff.

In Bethlehem, PA, Shenkman invited the head of the local library to come to the presentation. Then he donated books on planning for chronic illness to the local library, along with a check to cover the cost of shelving the books. "I asked them to put together a resource list on long-term care," he said.

In Carmel, IN, the mayor paid a visit to Shenkman's seminar and declared the visit to be Chronic Illness Education Day.

NAPFA has made a financial contribution to RV4TheCause, and NAPFA's staff members are reaching out to the media to draw attention to this important project. NAPFA and Shenkman are emphasizing the importance of having advisors with high ethical and fiduciary standards working with people who have chronic illnesses.

Through the early presentations, Shenkman is refining his program that will make it even more productive as he reaches out to other NAPFA members, health activists, other professionals, and civic leaders. Besides valuable knowledge for themselves and their clients, professionals attending these sessions with Shenkman could be eligible to receive free accounting, law, and financial planning education credits, thanks to Lorman Education Services, based in Eau Claire, WI. NAPFA

members interested in hosting their own event can download marketing materials, as well as checklists, from RV4TheCause.org.

"This way," Shenkman said, "they can focus their efforts on the marketing aspects, which is what will make the program a success. I want to make this so easy that it's almost silly not to do it."

Other than marketing, Shenkman says all that's required is a room to meet in and a spot to park the RV.

## Hospitality of the RV Community

Following the seminars, Shenkman and his wife (and their dog Elvis) pulled the Airstream into local campgrounds or RV parks to spend the night. There, they discovered the extravagant hospitality of other RVers. And they found that RVing and charitable causes go hand-in-hand. In fact, RV4TheCause has been nominated for the Good Sam Club RVer of the Year Award. The award recognizes "admirable individuals and couples who've helped make the world a better place through volunteering, fundraising, or building awareness for worthwhile causes."

They've also gotten the attention of Bob Wheeler, president and CEO of Airstream. "While we've always considered Airstreams to be good investments," Wheeler said, "to see the Shenkmans using theirs for such a worthy cause is inspiring. We hope that their Airstream helps to attract attention to RV4TheCause, while allowing Mrs. Shenkman to travel in greater comfort. We wish them much success!"

With one trip successfully under their belts, Martin and Patti currently are making plans for two more: one from New York to Florida in the spring, and another to Texas. They're encouraging anyone along the way to get in touch (via their website or at facebook.com/RV4TheCause) so that they can conduct as many seminars—and reach as many people—as possible.

For now, they'll do what they've always done—prepare for the future.

*Swap trailer EZ pass (blue) for regular EZ Pass (white). Check.*

*Remove all perishables. Check.*

*List "to do" or supply items for next trip. Check.*

NA



Visit [RV4TheCause.org](http://RV4TheCause.org) for more information about Martin Shenkman's work.

Chris Hale is the associate editor of the NAPFA *Advisor* magazine. He can be contacted at [cghale@gmail.com](mailto:cghale@gmail.com).



**RV4TheCause**



[Www.RV4TheCause.org](http://www.RV4TheCause.org)

# Upcoming Lectures and Webinars

**The mission** of [www.Rv4thecause.com](http://www.Rv4thecause.com) is to educate professional advisers (attorneys, accountants, CPA, insurance consultants and others) as to how they can tailor planning to better serve their clients living with chronic illness. This will be accomplished by presentations throughout the country under the auspices of various chronic illness organizations (National Multiple Sclerosis Society, The Michael J. Fox Foundation for Parkinson's Research, Association of Hole in the Wall Camps and COPD Foundation), and hosted by professional advisers, including members of The National Association of Personal Financial Advisors (NAPFA) and the Financial Planning Association (FPA). Professional education credits will be given when feasible, under the auspices of Lorman Education Services, who has graciously and generously agreed to provide credits at no cost to help the RV4TheCause in its mission. Details for each seminar appear on [www.rv4thecause.org](http://www.rv4thecause.org) in the Seminar Administration/ Seminars-Meetings tab.



## March/April 2011 RV4TheCause Professional Seminars/Webinar

The following seminars, and one webinar, will be held as part of the upcoming RV4TheCause tour. These seminars are primarily directed towards professional advisers but others are welcome. Contact the seminar host for more information.

1. Date/Time: Thursday, March 24; Noon lunch; Seminar 12:30-1:30. Host: Traust Sollus Wealth Management. Phone: (609) 779-6700 ext. 103 <http://www.tswealth.com/about-us/>, and David Neufeld, Esq. (609) 919-0919. Location: Jasna Polana, 4519 Province Line Rd., Princeton, NJ 08540. Phone (609) 688-0500. Topic: "Estate and Financial Planning for Chronic Illness and Disability."
2. Date/Time: March 25 Friday morning. Topic: "Estate and Financial Planning for Chronic Illness." Location: Fox Hill's Performing Arts Center, 8300 Burdette Road, Bethesda, MD 20817, (301) 996-7044. Hosts: Barry Korb, Lighthouse Financial Planning, LLC <https://lighthousefp.com/Home.html> and Sunrise at Fox Hill. Supplemental discussion for social workers will follow the main presentation.
3. Date/Time: Monday March 28; Noon lunch; seminar 12:30-1:30. Location: The Siena Hotel, 1505 E. Franklin St., Chapel Hill, NC 27514. Topic: "Estate and Financial Planning for Chronic Illness and Disability." Host: James R. Miller, CFP® President Woodward Financial Advisors, (919) 929-2495 [www.WoodwardAdvisors.com](http://www.WoodwardAdvisors.com).
4. Date/Time: Thursday March 31 Webinar, 1:30-2:30 pm EST. Host: Stephan Leimberg of Leimberg Information Services, Inc. ("LISI"). Topic: "Estate and Financial Planning for Clients Living with Chronic Illness." <https://www3.gotomeeting.com/register/511935478>. Anyone can join. Also see [www.leimbergservices.com](http://www.leimbergservices.com) for more information.
5. Date/Time: Thursday March 31, 2011, 6:00 – 8:00 pm: Host: Carolyn McClanahan, M.D., CFP, Life Planning Partners, Inc. [cmccclanahan@lifeplanningpartners.com](mailto:cmccclanahan@lifeplanningpartners.com), (904) 448-5158. <http://www.lifeplanningpartners.com/> Location: Hyatt Regency Jacksonville Riverfront, 225 E. Coastline Drive, Jacksonville, FL 32202. (904) 360-8682. Topic: "Estate and Financial Planning for Chronic Illness -- Keeping Your Practice Thriving After the 2010 Tax Act".
6. Date/Time: Friday April 1, 2011, 10:00 – 11:00 am: Host: Carolyn McClanahan, M.D., CFP, Life Planning Partners, Inc. [cmccclanahan@lifeplanningpartners.com](mailto:cmccclanahan@lifeplanningpartners.com), (904) 448-5158. Location: University of North Florida, 1 UNF Drive, Jacksonville, FL 32224. (904) 620-1000. Topic: "Estate Planning for Chronic Illness: Patients and Loved Ones."
7. Date/Time: April 5, 2011, 9:00 – 11:00 a.m. breakfast meeting. Host: Tampa chapter of the FPA - Financial Planning Association. Christine Brown, local FPA (813) 855-1017 [www.planningtampabay.org](http://www.planningtampabay.org). and Holly P. Thomas, LLC <http://www.hollypthomas.com/>. Topics: "Estate and Financial Planning for Chronic Illness" and "Estate and Financial Planning After the 2010 Tax Act." Location: Renaissance Tampa International Plaza Hotel - Jim Walter Blvd, Tampa, Tampa, FL.



## **Free Consumer Webinars**

### **Good Sam RV Club Special RV4TheCause Programs**

These seminars will be presented using gotowebinar by Citrix. Each Webinar will be 30-60 minutes in length and will be a non-technical but practical presentation designed for consumers. PowerPoint presentations will make it easier for attendees to follow along. Recordings of these webinars will be posted on [www.RV4TheCause.org](http://www.RV4TheCause.org). Just follow the links below and register.

1. 3:00 pm Friday March 25, 2011 EST "Estate Planning Introduction and Overview" broadcast from the Good Sam RV Park: Cherry Hill Park, 9800 Cherry Hill Road, College Park, MD <https://www3.gotomeeting.com/register/953573070>
2. 7:00 pm EST March 28, 2011 "Estate Planning when you or a Loved One is Living With Chronic Illness," broadcast from the Good Sam RV park: Rvacation Campground, 428 Campground Rd., Selma, NC. <https://www3.gotomeeting.com/register/404676406>
3. 10:30 am EST March 30, 2011 "Powers of Attorney – What they Are and What you Need to Know," broadcast from the Good Sam RV park: The Campground At James Island County Park 871 Riverland Dr Charleston, SC. <https://www3.gotomeeting.com/register/599441782>
4. 7:30 pm EST April 4 "Living Wills, Health Proxies: Vital Documents for Everyone," broadcast from the Good Sam RV park: Camp Nebraska, 10314 North Nebraska Avenue, Tampa, FL. <https://www3.gotomeeting.com/register/720834694>
5. 9:30 am EST April 7, 2011 "Revocable Living Trusts and Chronic Illness," broadcast from the Good Sam RV park: Alltoona Landing Campground, 24 Alatoona Landing Rd SE, Cartersville, GA. <https://www3.gotomeeting.com/register/883458286>



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