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Financial and estate planning for people with Multiple Sclerosis and Alzheimer's Disease

By

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Financial planning and estate planning are usually done for healthy families and individuals but there are times when a client is diagnosed with a life changing disease that requires immediate attention. Two common neurological diseases that combined, range across the adult life of a client, are Multiple Sclerosis (MS) and Alzheimer's Disease (AD). Both diseases may share a common mechanism of neurodegenerationⁱ due to pathophysiological functions of the human amyloid precursor proteinⁱⁱ. Both diseases also have increased levels of neurofilament light protein that is indicative of neurodegeneration^{iii, iv}.

While the vehicles and recommendations for early diagnosed clients may be the same as for healthy clients, there is a greater sense of urgency to implement recommendations upon diagnosis.

Multiple Sclerosis

Multiple sclerosis (MS) is a chronic autoimmune and chronic inflammatory disease that affects over 1,000,000 people in the United States and over 2.8 million are living with MS worldwide^v. Improvements in data quality have 14 new countries being able to report data for the first time in children and young people under 18. MS is typically diagnosed in young, active people between ages 20 and 40^{vi} and is two to three times more prevalent in women than men. There has been a sharp increase in MS prevalence over time throughout the world including a much larger number of children and young people under 18 living with MS than was known before^v. The reasons for the increase in the prevalence of MS are unknown. However, evidence suggests that genetic and environmental factors and their interaction contribute to the etiology of MS^{vii} as do immunological factors in genetically predisposed individuals^{viii}.

Common symptoms of MS vary case to case but can include upper and lower extremity disabilities, visual disturbances, balance and coordination problems, spasticity, altered sensation, abnormal speech, swallowing disorders, fatigue, bladder and bowel problems, sexual dysfunction, and cognitive and emotional disturbances. In mild cases, a person might experience minor symptoms such as numbness in the limbs. MS can substantially and adversely affect an individual's quality of life and is associated with high costs for MS patients, their families, and society as a whole^{ix}.

The cause of MS is not well understood but it is known that the disease begins when T cells (a type of white blood cell) cross the blood brain barrier and attack the protective substance of neurons both in the brain and spinal cord. Continued erosion of this protective substance,

myelin, damages and breaks nerves, thereby impacting the flow of electrical impulses from the brain to the muscles.

The economic burden of MS

MS affects individuals, their family, and the economy, with total costs for all people with MS in the United States estimated at about US\$28B annually^x.

The average annual costs for someone with MS in the United States, including direct and indirect costs (i.e. lost wages; caregivers time) is around \$69,000^{xi}. Approximately, \$39,000 consists of health care costs^{xi}. People with primary progressive MS are more likely to be unemployed than those with relapsing-remitting MS (82% vs. 42%)^{xii} and have higher associated costs^{xiii}. In 2010 numbers, the total lifetime cost per patient with MS was estimated to be \$4.1 million^{xiv}.

A study by Himmelstein et al. (2009)^{xv} found that 62.1% of personal bankruptcies in the United States are due to medical costs and that MS is associated with the highest out-of-pocket expenses with a mean of \$34,167; exceeding mean out-of-pocket expenses of people with diabetes (\$29,096), stroke (\$23,380), and heart disease (\$21,955).

The two largest indirect costs associated with MS are early retirement and employment^{xiv}. The health impact of MS results in lost productivity in the workplace. Deteriorating health can eventually result in early retirement and thus a financial strain on the family and on those who become caregivers. Indirect and caregiving costs are incurred even at low levels of physical disability^{xvi}. Loss of income during the years considered productive working years for patients with MS by necessity results in increased medical claims and disability claims to both insurance providers and government programs. A US analysis showed that employees with MS had a higher rate of medically-related absenteeism than those without MS and with more than 6 times the number of sick-leave days compared with employees without MS^{xiv} and increased sick-leave costs. A 2016 study found that 43% of unemployed people with MS retired within the first 3 years after diagnosis citing fatigue as the main reason^{xvii}. Loss of productivity and ultimately early retirement of workers affects the economy with decreased output and increased costs to the employer.

Not only is there financial strain on the family when a person of working age with MS misses work and/or has to retire but family and friends that are caregivers also miss work due to their responsibilities as a caregiver. In some European countries, MS informal caregivers provide 150 hours a month of care to people with MS, the equivalent of full-time employment^{xviii}. Informal caregivers also report hypertension, high cholesterol, sleep abnormalities, depression, and anxiety^{xix} creating an additional layer of loss of productivity, financial stress, and use of healthcare resources^{xix}.

Financial planning

Ideally, all clients do comprehensive planning before being diagnosed with any disease. And that planning should include assessing the need for cash reserves, disability insurance, life insurance, and long-term care insurance. It is difficult to convince a young client to buy long-term care insurance, but it is an insurance that they could use with any life event that forces them to retire at a young age and which renders them incapable of 2 out of 5 activities of daily living.

Medical Insurance - It goes without saying that employed individuals should enroll in their employer provided medical insurance. Individuals not employed but married or in a long term relationship should consider insurance through the other's employer-sponsored medical insurance. The majority (90%) of people with MS have some form of health insurance, but 70% report difficulty paying for health care^{xx}.

Disability and Life Insurances – An employee has the option to enroll in the employer short-term- and long-term disability with one's employer immediately. Keep in mind that not all short-term disability coverage is 100% of gross salary, it may have a sickness period elimination period, and the employer benefit is taxable. Long-term disability employer coverage is typically 60% of gross base salary and if paid for by the employer the benefit payment during the time of disability is taxable. Any bonus is not covered by long-term disability coverage. [There are exceptions i.e. for C-suite employees that do get additional employer disability coverage]. Just over half of people with MS report that they have long-term disability insurance^{xx}.

Financial planning takes into account how much additional disability coverage is needed based on one's expenses, income, and existing coverage. One can purchase additional disability coverage from several insurance companies. The benefit paid out during disability is tax free because the client purchased the insurance. A client can add future purchase option and inflation riders on private disability insurance policies. If the state of MS will deny one getting additional coverage, but the client is still employed, it's possible the employer provides additional coverage for an additional cost. Typically, one can buy up to additional coverage to get a total of 67-70% coverage. Keep in mind, any employer coverage ends once the client leaves the job. And although employer provided long-term disability is to age 65, the employer may find a way to 'terminate' the position and hence all coverage.

Typically, one times base salary is the default life insurance benefit through an employer. A comprehensive financial plan can determine how much additional coverage to buy either through the employer or privately through an insurance company. Employer coverage ends once the client leaves the job unless group universal life was purchased and has a portable option. Private insurance will last until death and many life insurance contracts provide a long-term care coverage rider -- coverage that can be used by a client with MS while alive.

HSAs - If available, an employee should consider taking advantage of a Health Savings Account (HSA). These are accounts offered by employers and allow people to set aside pre-tax dollars,

these dollars grow tax-deferred, and are tax-free for qualified health care expenses. Employers will sometimes match contributions, too. Employer contributions may be excluded from your gross income. Annual contribution limits are \$3,650 a year for individuals and \$7,300 for families (2022). The HSA can be used to pay for medical expenses as well as costs like disability and long-term care insurances.

Cash reserves - The general rule of thumb is that 3-6 months of cash is needed to cover core expenses. This is more meaningful when one knows there could be periods of time one is out of work due to illness and knows that employer disability coverage is not 100% of salary.

Home Equity Line of Credit (HELOC) - If one is a homeowner with equity in the house, a HELOC could be used for extended periods of illness and medical costs. The interest rate is typically lower than a personal bank loan and may be tax deductible. Unlike a cash out option or home equity loan, the interest on a HELOC is only on the money taken from the line of credit.

Retirement Savings - While employed, a client should save into the retirement plan; at a minimum, consider contributions to at least match the employer's contributions. 401k limits for those under age 50 are \$20,500 (2022). Although not required, a retirement plan may allow participants to receive hardship distributions. Distributions can be taken out with proof of hardship and the amount of a hardship distribution must be limited to the amount necessary to satisfy the need. This rule is satisfied if the distribution is limited to the amount needed to cover the immediate and heavy financial need, and, the employee couldn't reasonably obtain the funds from another source. Distributions are taxable and may be subject to a 10% premature distribution tax. For self-employed individuals, they should work with their accountant and financial advisor on what is the best retirement plan to put into place and save as much as possible into it.

Veterans benefits - Veterans who are prevented from working as a result of their MS may be able to receive a monthly VA disability called total disability based on individual unemployability.

Supplemental Security Income (SSI) - When applying for Social Security Disability (SSDI) benefits for living with MS, it is necessary to demonstrate to the state-run Disability Determination Services (DDS) that a claimant's capacity to perform gainful work activity has been severely limited by the condition. Even if a claimant can provide strong medical evidence of disability based on MS, it is important to provide detailed information about the symptoms of the condition, particularly the limitations imposed on the day-to-day functioning of the patient. Corroborating a neurologist's diagnosis of Multiple Sclerosis with a long-term record of symptoms and impairments provided by a primary care physician will greatly strengthen a case for disability benefits. Medical evidence that will strengthen a MS disability case includes:

- proof of demyelination from a magnetic resonance imaging (MRI)
- spinal tap that shows increased myelin basic proteins
- evidence of slowed, garbled or halted nerve impulses from Evoked Potential Tests including VEP, BAEP'S, and SSEP'S

Impairments that Qualify for MS Disability Benefits:

1. Visual impairment:
2. Mental impairment involving behavioral and psychological abnormalities manifested by the presence of certain mental disorders;
3. Persistent motor function disorganization in the form of paralysis or paresis, ataxia, tremor and sensory disturbances that may occur in different combinations; and
4. Significant motor function fatigue with considerable muscle weakness particularly when performing repetitive activities.

Obtaining disability benefits due to MS can be difficult, particularly for younger claimants. Working closely with medical professionals, along with a qualified Social Security attorney or disability advocate, should increase the efficiency with which benefits are obtained.

Alzheimer's Disease

Currently, 6.2 million Americans are living with Alzheimer's Disease (AD)^{xxi}. Diagnosis is typically from ages 50 onwards. Older Black Americans are twice as likely to have AD than older Whites and older Latinx are 1.5 times more likely to have AD than older Whites^{xxi}. Two-thirds of Americans with AD are women^{xxi}.

AD can be determined by cognitive tests and with biomarkers found in cerebrospinal fluid (CSF) and positron emission tomography (PET) images that the proteins beta-amyloid and tau, the valid proxies for neuropathologic changes of AD, are present in the AD brain^{xxii}. PET imaging uses radiotracers to bind to these proteins (amyloid plaques or tau aggregates) in the brain. The PET scanner detects the radiotracers and provides a brain scan that offers high diagnostic accuracy and localized information^{xxii}. While proteins are evidence of AD pathology, tau PET may be more sensitive than amyloid PET for detection in early diagnosis *and* plasma (a component of blood) because phosphorylated-tau protein levels were found increased during the early preclinical states of AD before detectable levels of tau by PET^{xxiii}. Obviously, detection in the blood is faster, less expensive, and less invasive than CSF extraction and PET scan. Most people who are amyloid positive with no other markers have not developed AD dementia during their lifetime^{xxiv}. Advancements in science promise early detection of AD brain pathology.

Reports indicate 13 potentially modifiable risk factors for dementia: lower education, hypertension, hearing impairment, smoking, obesity, depression, physical inactivity, diabetes mellitus, low social contact, excessive alcohol consumption, traumatic brain injury, air pollution^{xxiv}, and dental care^{xxv}.

Recently, it was hypothesized that chronic inflammation triggers amyloid plaque pathology^{xxvi} and increased tau tangles resulting in brain damage and cognitive impairment^{xxvii}. Sleep disturbance is hypothesized to increase inflammation leading to AD^{xxviii}.

People with dementia have increased rates of other illnesses^{xxiv}. Multimorbidities in people with dementia is associated with faster functional decline and worse quality of life for such individuals and their caregivers^{xxix}. Distress on the part of family caregivers is associated with increased odds of institutionalization of the person with dementia, exacerbated behavioural and psychological challenges in the person with dementia and increased likelihood of people with dementia being abused^{xxx}. Individuals with dementia are more likely to be hospitalized if their caregiver has less than one year of caregiving experience when compared with caregivers who have provided help for more than one year^{xxxi}.

Advance care planning might reduce caregiver's uncertainty in decision making and improve perceptions of quality of care^{xxxii}.

We will focus on planning for clients with preclinical Alzheimer's Disease or diagnosed with mild cognitive impairment (MCI) due to Alzheimer's Disease or clients taking care of such family members. Planning with abstract concepts is more difficult beyond the MCI stage. Ideally, all planning should be done before developing dementia. Early diagnosis provides the opportunity to prepare financial and end-of-life plans while cognitive impairment remains mild. In the mild stage, most people can function independently in many areas but are likely to require assistance with some activities to maximize independence and remain safe. They may still be able to drive, work, and participate in favorite activities^{xxxiii}.

Economic burden of AD

Dementia affects individuals, their family, and the economy, with global costs estimated at about US\$1 trillion annually^{xxxiv}. In the United States, over 6 million people have AD with an economic burden greater than US\$355 billion^{xxi}. Most people with Alzheimer's disease or other dementias will eventually need long-term care services and many will require nursing home care.

In 2010, nearly 15 million family and other unpaid caregivers in the U.S. provided an estimated 17 billion hours of care to people with AD and other dementias, a contribution valued at more than USD \$202 billion. Medicare payments for services to beneficiaries aged ≥65 years with AD and other dementias are almost 3 times higher than for beneficiaries without these conditions^{xxxv}. In 2017, caregivers of people with Alzheimer's or other dementias provided an estimated 18.4 billion hours of unpaid assistance, a contribution to the US valued at \$232.1 billion^{xxxvi}, in 2019 was valued at an estimated \$244 billion^{xxxiii}, and in 2020, unpaid assistance was valued at \$256.7 billion^{xxxvii}. It is estimated that 250,000 children and young adults between ages 8 and 18 provide help to someone with Alzheimer's or another dementia^{xxxviii}.

The total lifetime cost of care per person with dementia is \$341,840 and includes associated family care \$143,735 in the value of informal care and \$95,441 in out-of-pocket-expenses related to care in 2017 dollars (\$102,664 are paid by Medicare, Medicaid). Compared with an individual without dementia, the incremental lifetime cost of dementia was \$196,002 in 2017 dollars. The cumulative lifetime savings in medical and long-term care costs under the full early

diagnosis is \$7.9 trillion^{xxxix}. Out of pocket expenses include the costs of medical care, personal care, and household expenses; and personal expenses and medical care for the caregiver. Caregivers of dementia patients experience in particular, higher levels of depression and anxiety than care givers of non-dementia patients. Caregivers to patients with AD have been shown to have higher rates of stress, physical ailments, increased cardiovascular disease, and weakened immune systems, and poor sleep. One study showed that as the comorbid diseases in patients with AD progressed and dependence on the caregiver increased, healthcare utilization and costs of the caregiver increased^{xl}.

Average annual Medicaid payments per person for Medicare beneficiaries with AD or other dementia's were 23 times as great as average Medicare payments for Medicare beneficiaries without AD or other dementias^{xli}. Based on Medicare administrative data from 2013 to 2015, preventable hospitalizations represented 23.5% of total hospitalizations for individuals with Alzheimer's or other dementias^{xlii}.

Hospitalization in people with dementia has high economic costs because people with dementia experience longer and more frequent admissions and readmissions with 1.4 to 4 times more hospital admissions than others with similar illnesses^{xliii,xliv,xlv}. Health care expenses for people with moderate-severe dementia is around double that of people without dementia^{xliv}.

Financial Planning for individuals and for caregivers

In addition to financial resources described in the MS section, one can also consider the following for an individual with AD.

Reverse mortgage – A reverse mortgage is an option for those age 62 and older. The Home Equity Conversion Mortgage (HECM) is a federally insured reverse mortgage that is generally less expensive than private-sector reverse mortgages, though mortgage insurance premiums may be charged. The age has dropped to 55 (Nov. 2021).

FMLA - If the caregiver is employed, they may be covered by the Family Medical Leave Act (FMLA). With this federally mandated program, eligible employees can take up to 12 weeks of unpaid leave to care for an immediate family member while health benefits continue. Some companies allow employees to stockpile sick days and vacation days; days that can be used for caregiving and still be paid.

Long-Term Care (LTC) Insurance typically covers the cost of care provided in a nursing home, assisted living facility, and Alzheimer's special care facility, as well as community-based services such as adult day care, and services provided in the home, including nursing care and help with personal care. It may also provide respite care for the caregiver. Because the length of having AD can extend over 10 years, most people exhaust their LTC insurance lifetime benefit long before death.

Medicare and Medicaid - The most important point to remember about Medicare is that it is not for long-term care coverage because Medicare does not pay for all care costs.

Medicare covers inpatient hospital care and some of the doctors' fees and other medical items for people with AD or dementia who are age 65 or older. Medicare Part D also covers many prescription drugs. Medicare will pay for up to 100 days of skilled nursing home care under limited circumstances. Medicare covers care planning services for people recently diagnosed with cognitive impairment, including AD and other dementias. Care planning allows individuals and their caregivers to learn about medical and non-medical treatments, clinical trials and services available in the community, and additional information and support that can contribute to a higher quality of life. There are Medicare Special Needs Plans (SNPs) available for individuals with dementia, including AD. SNPs are Medicare Advantage plans that specialize in care and coverage for beneficiaries with dementia. Only Medicare beneficiaries (have Part A and Part B) with dementia can enroll in these plans.

Medicaid covers all or a portion of nursing home costs, is jointly funded by federal and state government, and is typically administered by each state's welfare agency. Eligibility varies state to state but it generally follows that if the person with dementia is eligible for Supplemental Security Income (SSI), he or she is usually automatically eligible for Medicaid. Those not on SSI must have limited income and assets. Not all nursing homes accept Medicaid. Beneficiaries with Medicare and Medicaid will have most of the costs of joining a Medicare SNAP be covered.

Social Security Disability (SSDI) - The Social Security Administration has added early onset (younger-onset) AD to the list of conditions under its Compassionate Allowance program, giving those with the disease expedited access to SSDI and SSI.

Veterans Benefits - Veterans with AD or other forms of dementia may be eligible for certain benefits and services from the U.S. Department of Veterans Affairs (VA). Elderly veterans with dementia may also qualify for home- and community-based care programs and residential long-term care. Generally, there are no separate VA eligibility criteria or application processes for veterans with dementia.

Caregiver interventions include case management, educational and psychotherapeutic approaches, respite care options, and support groups. Education on the progression of the disease, how to find and access help, and optimal usage of resources to assist in providing AD care have shown to have a positive impact on AD caregivers^{xlvi}.

A caregiver's out-of-pocket costs may be tax deductible. Certain states have additional tax deductions or tax credits to provide financial relief to caregivers.

Estate Planning for clients with MS and MCI

Individuals who receive MS or MCI-AD diagnoses should move quickly to address their estate plans before legal incapacity makes it impossible to implement or update estate planning documents. Estate planning should focus on three interrelated issues: incapacity, long-term care and death.

Planning for Incapacity - Estate planning for incapacity typically involves relatively straightforward, but essential documents such as powers of attorney, health care powers of attorney or proxies and living wills, which are also referred to as advanced directives. The full benefits of these documents can only be understood when compared to the state law “alternatives” that address decision making in the absence of these documents. Revocable trusts may also serve some incapacity planning functions. Each document, and the state law alternative is discussed below.

Financial Power of Attorney – With a financial power of attorney, an individual (the principal) designates another person or persons (the agent) to handle the principal’s affairs and property during the principal’s lifetime. A financial power of attorney should be carefully drafted and tailored to the principal’s assets, personal needs, tax planning and family dynamics. Principals with MS or MCI diagnoses should be sure to designate multiple successor agents to serve. This will protect against an original named agent unexpectedly dying or becoming incapacitated at a time when the principal is incapacitated and unable to execute a new power of attorney or appoint a successor.

Generally, the state law alternative for a power of attorney is guardianship. With guardianship, a court determines an individual’s incapacity and appoints one or more guardians to act for the incapacitated. Even “friendly” guardianship proceedings can be expensive, obtrusive and time-consuming. Guardianships can also involve ongoing reporting and significant restrictions on how assets can be used.

Trusts – In addition to disposing of assets at death, trusts may also aid with incapacity during the settlor’s lifetime. If the trust is funded, a successor trustee can manage and disburse the assets of the trust for the benefit of the settlor. The trustee’s authority, however, is limited to the trust assets. The trust should not be considered as a replacement for a financial power of attorney. There is no state law alternative to a trust in this context.

Health Care Power of Attorney or Proxy – A health care power of attorney authorizes agents or proxies to make health care decisions if an individual (the principal) is unable to make or communicate such decisions. Such documents are essential for individuals with MS or MCI diagnoses.

State law alternatives vary but may include the need for guardianship or the appointment of close family members as representatives for decision making. Some individuals may not be

satisfied with the family members designated by state law. State law may also limit the types of decisions that can be made in the absence of an executed health care power of attorney or proxy.

Living Wills – These documents, which are also known as advanced directives, provide an opportunity for individuals to state their preferences about end-of-life care and to provide guidance for health care decision makers. Some individuals with MS or MCI diagnoses may have strong feelings about life prolonging treatment as the diseases reach advanced stages. Living Wills are essential to maximize personal autonomy. Such autonomy is particularly important given the effects of the diseases.

State law alternatives to living wills may not exist. Although state law may empower health care decision makers to make end-of-life care decisions, a living will may represent the only opportunity for the individual to express their own wishes in an enforceable manner.

Other Practical Steps in Planning for Incapacity - While principals with MS or MCI diagnoses have capacity and knowledge of their assets, they should prepare and update asset schedules for future use by their agents. Such schedules will allow agents to more quickly locate and take control of assets. This will ensure smoother transitions and less disruption. Individuals may also want to provide their health care providers with copies of health care powers of attorney and living wills in advance of incapacity. Such individuals may also want to discuss with their providers and health care agents or proxies their views on end-of-life care.

Incapacity Planning to Avoid Financial Abuse - Individuals with MS or MCI diagnoses are at particular risk for financial abuse. To minimize these risks, principals should involve agents and successor trustees in their affairs to an appropriate degree before the principal becomes particularly vulnerable. Co-agents and co-trustees may provide checks and balances and reduce such risks. Powers of attorney should be thoughtfully drafted with respect to gifting powers and powers that could be used by an agent to alter the principal's estate plan.

Corporate fiduciaries may also be available to provide services and greater protection of assets. In extreme cases, individuals with MS or MCI diagnoses who anticipate future problems could consider incorporating an irrevocable trust into their planning to reduce the incentive for some types of financial abuse. An irrevocable trust might stop an individual with weakened intellect from being coerced, but it comes at the loss of flexibility and should only be implemented after careful consideration.

Planning for Long Term Care – Long term care planning often lies at the intersection of financial and estate planning. Estate planning in this context may be as simple as helping the individual qualify for long term care benefits. More complicated planning in this context involves structuring financial resources and potentially transferring assets to protect resources for spouses and future generations while maintaining eligibility for benefits.

Given the incredible costs of care discussed above, individuals with MS and MCI diagnoses should carefully consider such planning as early as possible. For Medicaid, certain transfers may only be possible well in advance of the need for benefits. The same transfers close in time to the need may disqualify an individual for benefits. Such planning can also take into account Medicaid estate recovery, which permits states to recover certain assets of deceased individuals who previously received Medicaid.

Planning for Death – Individuals with MS and MCI diagnoses should plan their estates consistent with their wishes and tax considerations. Such planning may involve wills, revocable trusts where appropriate, other types of trusts, asset titling and beneficiary designations. Such planning should prioritize achieving the individual's goals for the beneficiaries as well as the orderly and efficient administration of assets after death.

Conclusions

Both MS and AD have a 2-3 higher incidence in women than men. The costs for treatment is exorbitant. Early diagnosis could save trillions of dollars. The costs of care for the affected are exacerbated by the cost of care for the care giver.

Ideally, financial planning and estate planning are done earlier enough in life to be prepared for debilitating illnesses and death. We know that many clients do nothing until there is a crisis. We need to encourage our clients to put their wishes in writing.

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