



**National  
Multiple Sclerosis  
Society**

## **Tips for People with MS and Their Partners – Planning for the Future**

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# Financial Planning- Common Goals

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- Maintain lifestyle
- Save for emergencies
- Pay off house
- Adequate income when not working

# Income Sources

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- Employment
- Investments
  - Retirement plans including 401k, 403b, IRA
  - Stocks, rental properties
  - Disability Insurance
- Government benefits
  - SSDI
  - SSI

# Challenges with MS

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- **Person with MS**
  - Fewer earning years
  - Higher/unexpected medical expenses
  
- **Partner**
  - Loss of a 2nd income
  - Work production
  - Unplanned time off
  - Part time vs. full time
  - Flexible schedule

# General Strategies

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- Spend less than you earn
- Reduce/eliminate debt
- Accumulate retirement funds/investments
- Understand and maximize benefits

# Understanding Your Assets

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- Earning power
- Savings and investments
- Employee benefits
  - Including legal protections/rights like Family Medical Leave Act (FMLA)
- Government benefits

# Personal Financial Statement

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- What you own/What you owe
- Savings
- Retirement
- Investments
- House
- Credit cards
- Other debts

# Excess Income

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- Emergency fund
- Pay off credit card, consumer or medical debt
- Fund retirement plans at maximum
- Fund annual payments monthly in advance
- Overpay on mortgage
- Invest

# Employee Benefits

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- Health insurance
- Disability insurance
- Retirement plans
- Long-term care insurance
- Caregiver benefits/rights

# Getting Money From Your House

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- Downsize
- Forces you to declutter ... sell stuff
- Rent out a room
- Sell house to children and rent back
- Reverse mortgage

# Takeaways

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- Prepare/maintain financial statement
- Review last three months of spending
- Do something different
- Always keep score

# Legal Planning for People with MS and Their Partners

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## What Needs to be Put in Order?

- Personal Affairs
  - Healthcare Directive
  - Financial Durable Power of Attorney
  - Designating and educating decision makers
- Your Financial Affairs
  - Legal documents
  - Paying for long-term care
  - Investments/money

# Key Components to Putting Your Affairs in Order

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- Advanced Healthcare directives
- Financial Durable Power of Attorney
- Will or Revocable Living Trust
- Declaration of Disposition of Last Remains
- Ownership of property/beneficiary designations
- Keeping everything up-to-date

# Decision Makers- Fiduciary

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- Agent named in a power of attorney, trustee of a trust, executor named in a will
- The best legal document also needs a good decision maker
- A good decision maker cannot do their job with an out of date, or a bad legal document
- To work correctly you must coordinate the ownership of your property with your estate plan

# Who Should Be a Decision Maker?

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- Understand duties?
- How do you decide when the decision makers take over?
- Liability of decision makers
- Who should be named as a decision maker?
- Family Members:
  - Develop a plan if family members do not get along or will not act in your best interest
- Professional fiduciaries

# What Does a Healthcare Durable Power of Attorney Do?

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- With a Healthcare Durable Power of Attorney, your agent is authorized to make medical decisions on your behalf
- Does your agent know what you want?
- HIPAA Provision
- End of Life Decisions: Living Will or Healthcare Durable Power of Attorney- A Living Will takes end of life decisions away from your healthcare agent

# Financial Durable Power of Attorney (FDPOA)

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- Agent is authorized to perform the duties specifically listed in the document
- What does Durable mean?
  - POA will continue after individual loses capacity or in some cases is terminated upon loss of capacity
- If the document does not list specific powers and authority for the agent, it will be rejected by banks and financial companies
- Avoids court proceedings if you do not have capacity
- Know your agent

# What Should be in a FDPOA?

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- Banking
- Real Property
- Investments, life insurance, annuities, brokerage accounts, retirement accounts
- Gifts
- Authority for agent to do Medicaid planning
- Personal Property – pets, home furnishings, automobiles
- IRS, SSA, mail, credit cards
- Successor Agent – Co Agents
- Conflict between different Healthcare Agent and Financial Agent

# Government Programs That Pay A Monthly Assistance

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## Entitlement Programs

- **Social Security Disability Insurance (SSDI)-**  
Amount of payment is based upon work history; Must meet the definition of “disabled”; Unable to engage in substantial gainful employment; SSDI eligibility is not is not determined by assets or income.
- **Social Security**

## Needs Based Programs

- **Supplemental Security Income (SSI)-** Monthly benefit \$721 for single individual, \$1,082 for couple; Some states add on a State Supplement; To be eligible for SSI must meet definition of “disabled”, under age of 65; SSI is needs based meaning, there are strict income and asset requirements.
- **VA Aide and Attendance**

# Health Insurance

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- Individual policies purchased through Health Exchange
- Employer group health plans
- Affordable Care Act (ACA)- Medicaid Expansion
- Health insurance plans pay for doctor, hospital, prescriptions, rehabilitation etc.; With limited exceptions your health insurance plan does NOT pay for long-term care or assistance in home

# Paying for Long-Term Care

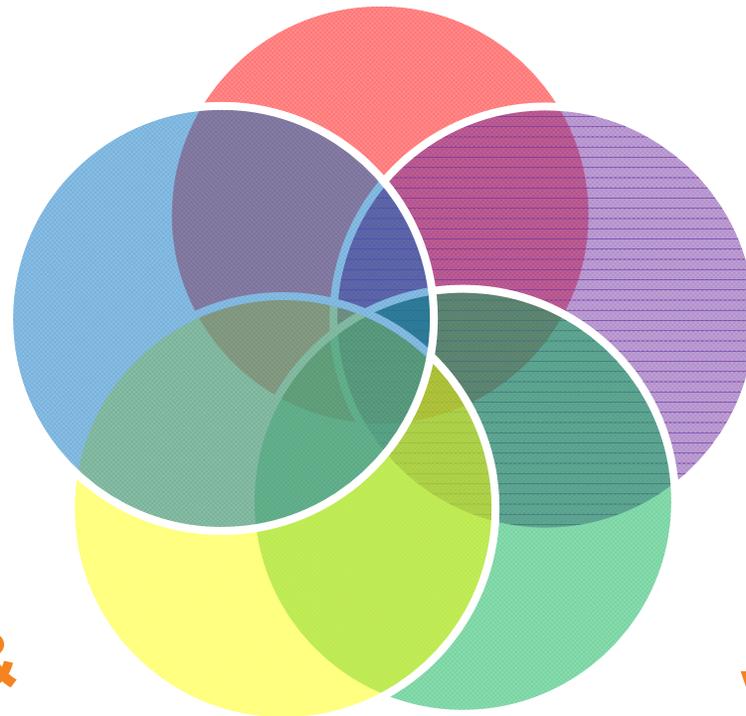
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**Private Pay**

**Long-Term  
Care  
Insurance**

**Medicaid &  
Medicare**

**VA Benefits**



# Medicare

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- Eligible when you receive Social Security benefits at age 65
- 24 months after award of Social Security Disability (SSDI)
- Medicare pays for doctor, hospital, rehab, prescription drug benefits
- Does NOT pay for nursing home costs or in-home support services; Limited to 20 days in nursing home. May receive additional 80 days with co-pay
- Medicare eligibility is not determined by assets or income

# Medicaid

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- Medicaid will pay for some in-home services, assisted living or nursing home (depending on state)
- Eligibility for Medicaid is income and asset based (needs based); You must require care and meet the financial eligibility rules
- Medicaid eligibility for long-term care or in-home services dependent on SSI qualification or qualification under your state's Medicaid waiver program

# Long-Term Care Medicaid

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- Long-Term Care Medicaid based upon a State Waiver Program. Eligibility is based upon meeting medical, income and asset tests.
  - Medical test – ADLs
  - Income
  - Assets – Exempt (home, car, personal property; Irrevocable funeral plan)
  - Community Spouse Resource Allowance. Single individuals, \$2,000 plus exempt assets
  - Five year look-back period
  - Estate recovery

# Resource Test

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## Exempt Property

- Home
- Vehicle
- Personal property
- Irrevocable burial plan
- Max of \$2,000
- Certain trusts

## Countable Property

- Any asset that is not listed as exempt
- Countable assets cannot exceed \$2,000

# Introduction to Veterans Benefits

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- While there are several different commonly known types of VA benefits available to veterans or widow(er)s of veterans, most people are unaware of the benefits available to those who need healthcare assistance
- A VA program called “Aid and Attendance” provides a monthly pension to veterans or their surviving spouses who qualify

# Special Needs Trusts Can Be Divided Into Two Categories

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- If the source of the fund are from someone other than the benefits recipient, the trust is categorized as a Third Party Special Needs Trust
- If the source of the funds of the Special Needs Trust are from the benefit's recipient, then the trust is categorized as a self-settled or Medicaid Payback Trust

**Special Needs Trust**  
**3<sup>rd</sup> party**  
**No recovery upon death of beneficiary**

**Special Needs Trust**  
**Self-Settled Medicaid Payback**  
**Medicaid Recovery upon Death of Beneficiary**

# Third-Party Special Needs Trust

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- A third-party trust is a trust established by someone other than the beneficiary as the grantor. For example, a third-party trust may be established by a spouse for his or her spouse or a parent for a child.
- If drafted correctly, the assets of the third party special needs trust will not be counted as assets of the beneficiary for Medicaid eligibility purposes.
- Trust money is used to supplement needs of beneficiary not otherwise provided by government benefits.

# Self Settled Special Needs Trusts or Medicaid Payback Trusts

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- Federal law allows a disabled individual to protect his or her own assets and maintain eligibility for SSI AND Medicaid if the following requirements are met:
  - Which contains the assets of an individual under age 65 and who is disabled; and
  - Which is established for the benefit of such individual by a parent, grandparent, legal guardian or a court; and
  - Which provides that the State will receive all amounts remaining in the trust upon the death of the individual up to an amount equal to the total Medicaid assistance paid on behalf of the individual under a State Medicaid plan.

# Donald's Story

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- Donald is 50 years old, has MS and about \$200,000 in savings. He has been rapidly spending his money on his care and he is concerned that he will soon run out of funds.
- Donald's elderly mother Sara wants to provide for his care after she passes away but is concerned on making the money last for his benefit.

## Donald's Solution

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- Sara creates a third party trust in her will for Donald's benefit. The trust created by Sara in her will provides that the money is to be used to supplement what government benefits do not provide for Donald. Upon Donald's passing, any remaining funds pass to Donald's children. Sara names her daughter Rebecca as the trustee of Donald's trust.
- A first party special needs trust is created for Donald's benefit. Donald transfers his \$200,000 into the trust account and names his sister Rebecca as trustee. Donald's first party special needs trust requires that upon Donald's passing, the state that provided Medicaid services to Donald be reimbursed to the extent of medical services provided to Donald.

## Donald's Solution

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- After Sara's passing, Rebecca is trustee of both the third party trust created by Sara and the first party trust created for Donald's benefit.
- Donald is eligible for Medicaid benefits because he is "disabled" and is otherwise financially eligible.
- Because no payback is required from the trust created by Sara, Rebecca uses the money from Donald's first party trust prior to using the money in Sara's trust.
- Because Sara did advance planning, Donald still qualified for Medicaid and she protected her grandchildren's inheritance.

# The Strategy

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- Focus on who will be in charge in the case of incapacity
- Create “Marital Special Needs Trust” in case the well spouse dies first
- Create a self-settled special needs trust for the individual’s own assets

# I Know– It's Complicated

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- Contact an elder law attorney – National Academy of Elder Law Attorneys – [www.NAELA.org](http://www.NAELA.org)
- Contact Financial Planner via Financial Education Partners [www.financialpro.org/foundation/FEP/FEPdescription.htm](http://www.financialpro.org/foundation/FEP/FEPdescription.htm)
- Additional Resources:
  - Contact an MS Navigator at 1-800-344-4867 or [www.nationalmssociety.org](http://www.nationalmssociety.org)
  - Publications- [www.nationalmssociety.org/all-brochures](http://www.nationalmssociety.org/all-brochures)
    - Adapting: Financial Planning for a Life with MS
    - Know Your Rights: A Legal Guide for People Living with MS
    - A Guide for Caregivers
    - Maximizing Independence: A Guide to Planning for Changing MS Care Needs
  - Videos- [www.nationalmssociety.org/educationalvideos](http://www.nationalmssociety.org/educationalvideos)
    - Financial Planning featuring Silvia Stazzio
    - Planning for a Life with MS featuring Dorothy Northrop
  - Online Class- Adapting: Financial Planning for a Life with MS...Together [https://nmss.sabanow.net/Saba/Web\\_wdk/Main/index/preloginclassic.rdf](https://nmss.sabanow.net/Saba/Web_wdk/Main/index/preloginclassic.rdf)
  - An 8 Step Real Life Downsizing Plan- Forbes Magazine
  - Can Do MS- Social Security & Disability Archived Webinar- [ww.mscando.org](http://ww.mscando.org)

## Q&A

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Text your questions in the chat box at the bottom left hand side of your screen

OR

the operator will assist you with asking your questions