



THE MYOSITIS ASSOCIATION

Advanced care planning: Home care support, medical directives, aging

- ▶ Practical planning steps you should consider taking now.
- ▶ Essential legal documents you should consider to protect yourself now.

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Practical Estate and Financial Planning for those Living with Myositis

Advanced care planning: Home care support, medical directives, aging

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Planning with Myositis: How is Financial and Estate Planning Affected?

- ▶ Myopathy and myositis are neuromuscular conditions that cause muscle problems, such as stiffness or weakness. Many people with these conditions have not been diagnosed or may have been misdiagnosed with another illness.
- ▶ Symptoms of myositis may include:
 - ▶ trouble rising from a chair.
 - ▶ difficulty climbing stairs or lifting arms.
 - ▶ tired feeling after standing or walking.
 - ▶ trouble swallowing or breathing.
 - ▶ muscle pain and soreness that does not resolve after a few weeks.
 - ▶ known elevations in muscle enzymes by blood tests (CPK or aldolase).
- ▶ Fatigue, muscle weakness, and other symptoms may make it difficult to manage finances and other matters, and should be addressed by a plan to protect you, preserve dignity, minimize effort, etc.

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Planning with Myositis: Webinar Objectives

- ▶ **Advanced care planning: Home care support, medical directives, aging.**
- ▶ During this webinar you will learn about what you need to know about what advance directives, powers of attorney and revocable trusts, you should consider discussing with a lawyer as someone who is living with a chronic condition. You will learn how to plan for home care support or aging in place and what you need to discuss with your financial planner as you plan for a future living with chronic illness.
- ▶ Practical tips on making your finances safer and easier will be presented.

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What is estate and financial planning?

- ▶ The process of providing peace of mind for you, and your loved ones (however you define the term).
- ▶ It should address **concerns? priorities?** while you are alive, during varying health issues, and after your death.
- ▶ It is more about planning for **life**. An integrated plan that coordinates your investments, insurance, emergency and disability planning, retirement and other planning.
- ▶ For the wealthy, tax planning is vital, but this presentation will not cover tax planning.
- ▶ Define what “estate planning” **means to you**.

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Tailor all Planning and Documents to Reflect Your Personal Situation, Including Myositis

- ▶ Consider the realities you or your loved one faces: your current and future health impact of Myositis.
- ▶ Be practical, conservative and plan ahead.
- ▶ Unique considerations of a Covid world
- ▶ Financial impact of Myositis might include additional medical and care costs. If Myositis reduces your ability to work, there may be a negative financial impact from that as well.

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Write An Emergency Financial Roadmap

- ▶ Document simply but clearly key information you will need to manage your financial and legal matters and that someone will need to help you.
- ▶ Examples:
 - ▶ Bill paying: practical information such as which bills are to be paid, to when, to whom, how (online, etc.).
 - ▶ Key people to contact: medical, financial, legal, family, etc.
 - ▶ Account and other data: for all key financial accounts including passwords, etc. (so make this secure).

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Review your Financial Plan

- ▶ If you don't have a budget and financial plan - create one now.
- ▶ Get professional help - there are lots of options and a wide range of costs from none (online resources) to more costly (your personal wealth manager).
- ▶ Covid has changed a lot so be certain your legal documents and planning address this new risk.
- ▶ Financial modeling for years or decades to come under many different scenarios and "what if" assumptions is desirable. You want this knowledge to minimize the risk of running out of money.

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Long Term Care Myths and Reality

- ▶ I'm never going into a nursing home.
- ▶ Medicare will pay for the cost of my care.
- ▶ Medicare does **not** pay for long-term care
 - ▶ Skilled nursing care v. custodial care
 - ▶ Acute v. chronic illness
 - ▶ No expectation of recovery
 - ▶ Alzheimer's disease v. heart attack
 - ▶ Long term care
 - ▶ Help with activities of daily living, such as bathing, dressing, toileting, transferring, continence, eating
- ▶ The United States has **no** health insurance system for long-term care.
- ▶ Most Americans are in for sticker shock if they or a loved one ever requires long-term care
- ▶ Long-term care is expensive - Average annual cost exceeds \$100,000.

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Create An Investment Policy Statement (IPS)

- ▶ This is a statement of how your assets should be invested.
- ▶ It will keep you on track and provide a great roadmap if anyone has to step in to help you.
- ▶ Consider:
 - ▶ Financial goals (see suggestion to create financial forecasts above).
 - ▶ Religious, social or philosophical considerations.
 - ▶ Cash flow needs now and in the future (e.g. if your disabilities progress).

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Automate Your Bills, Deposits and Other Finances

- ▶ Goal is to minimize paperwork and efforts so as to make it safer for your financially, limit efforts required to manage your finances, and make it easy if a friend or family member has to step in to help.
- ▶ Bills should auto-bill to your credit card.
- ▶ If the vendor won't bill a credit card have them auto bill your checking account.
- ▶ Credit cards should be paid automatically from your checking account.
- ▶ Deposits should be set up to automatically/electronically go to your checking account.
- ▶ You want as much of your finances on autopilot as you can.

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Do a Wallet Dump

- ▶ Dump your wallet on a table.
- ▶ Photograph the front and back of every item including ID (license), credit cards, and more
- ▶ Be sure your phone has password protection.
- ▶ Save to your laptop and be sure its encrypted and backed up to the cloud.
- ▶ In an emergency you will have all the information needed to cancel credit cards and replace your wallet contents.

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Estate Planning Documents Generally

- ▶ Every adult must have these documents - if you don't get them. If you do make sure they are current and work for you. Finally, make sure they work for your health challenges and during a Covid environment.
 - ▶ Pour over will.
 - ▶ Revocable trust.
 - ▶ Financial power of attorney.
 - ▶ Health care proxy for medical decisions.
 - ▶ Living will to state health care wishes.
 - ▶ HIPAA release to authorize access to personal health information (PHI).
 - ▶ POLST - physician order for life sustaining treatment if you are terminal.

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Technology Can Help

- ▶ Use web meetings to minimize driving to advisers' offices.
- ▶ Use web meetings to tie in all of your advisers, family and other important people once a year cost-effectively.
- ▶ Consider recording the web meeting (no additional cost using most web conference programs).
- ▶ Transcribe the web meeting to create a record to help you and your key people have a checklist to follow up. Also useful if hard for you to taken notes.

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Do a Legal Document Dump

- ▶ Get photocopies of all your key estate and other planning documents, and beneficiary designations, as PDFs in a secure and backed-up online portal others can access in an emergency.
- ▶ Have copies saved on an encrypted and cloud backed-up laptop.
- ▶ Getting all your important documents saved in the cloud can make it easy, with a few keystrokes for you, or an agent under a power of attorney trying to help you, to find any key document.

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Review Ownership (Title) To Each Asset

- ▶ Who owns what?
- ▶ What is the title?
- ▶ POD/TOD - pay on death or transfer on death accounts pass to the named party on your death.
- ▶ ITF - in trust for - is an account that passes on death to the named beneficiary.
- ▶ Joint accounts - the joint owner can use the funds. This is often used as an informal substitution for having a power of attorney that names an agent to act on an asset in your own name.
- ▶ Revocable trust - your co-trustee or if you are incapacitated your successor trustee can manage assets and take other actions on trust assets.

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Write a Letter of Instruction

- ▶ What have you provided for in your will/revocable trust, and why?
- ▶ What medical care do you want? Do you want experimental treatments? Do you want heroic measures?
- ▶ Explain religious preferences, if any. If none state so.
- ▶ How should children be raised?
- ▶ Provide guidance on important personal wishes and matters that do not belong in formal legal documents.

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Can You Sign Electronically?

- ▶ The law is not quite up to snuff everywhere, but emergency measure might enable you to sign legal documents without the health risks, or difficulties, of leaving home.
- ▶ Be careful, those temporary measures will end and you don't want to rely on them after they are no longer applicable. Also, be careful as the rules vary by state.
- ▶ There are lots of ways that might provide a work around such as the “through the looking glass” or “20-paces” signings.

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Durable Power of Attorney for Financial Matters

- ▶ A legal document in which you name an agent to make legal, tax and financial decisions/actions for you.
- ▶ Who should be named agent?
- ▶ Are the people listed in an existing document appropriate? Do they understand the challenges you face?
- ▶ How old is the document? Is it stale (so old banks may not accept it)?
- ▶ What powers have you given the agent?
- ▶ Watch out for springing powers during Covid-19. A springing power comes into effect only when you are disabled. During Covid it may be impractical to get two doctors to sign letters stating you are disabled (the typical mechanism).
- ▶ Also, do your symptom suffice for you to be disabled? Perhaps they make it difficult for you to handle certain matters but not enough for you to be incapacitated. That would make a springing power useless to help you.

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The Real Issue with Powers of Attorney

- ▶ If you are isolated, not having family you can name, if you do not have trusted and appropriate people you can rely on to serve as agent, what do you do?
- ▶ Vulnerable people need more than a typical or standard power of attorney which are no safeguards.
- ▶ Even if an appropriate agent is identified, educating the agent, preparing financial and legal matters to facilitate the agent operating, and more, is essential.
- ▶ Trust but verify should apply to every fiduciary appointment.
- ▶ Consider naming a “monitor” - who oversees your agent.
- ▶ Consider using a revocable trust as the primary document.

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Health Care Proxy (Medical Power of Attorney)

- ▶ A legal document in which you designated an agent to make medical decisions for you.
- ▶ Who should be named agent?
- ▶ Are the people listed in an existing document appropriate?
- ▶ How old is the document? Is it stale?
- ▶ Watch out for blanket prohibitions e.g. against intubation - are they really appropriate especially during Covid-19?
- ▶ Consider authorizing electronic and remote decision making

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Create an Emergency Envelope

- ▶ Print a copy of your HIPAA release, health care proxy and living will and put them in a clearly marked emergency envelope.
- ▶ Including a summary of your current health status.
- ▶ Explain the nature of your Myositis, symptoms and prognosis.
- ▶ Including a detailed listing of all medications and vitamins you take.

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Will and Revocable Trust

- ▶ What is a will. A will that appoints a personal representative to manage your estate, a guardian if you have a minor child, and distribute your assets.
- ▶ What is a pour over will? Instead of distributing your assets it pours them into your revocable trust which distributes them.
- ▶ What is a revocable trust and why might you want one? It is a contract between you and a person you appoint, called a trustee.
- ▶ You might be your initial trustee, but with health issues consider naming a co-trustee who can assist. If you become sufficiently incapacitated a successor trustee can take over managing your trust and affairs.
- ▶ Are the people listed in an existing document appropriate?
- ▶ How old is the document?

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Conclusion

- ▶ Take proactive and practical steps to secure your financial and legal affairs.
- ▶ Consolidate and simplify your financial and legal affairs to make it easier for you if your symptoms worsen and/or as you age. These same steps will make it easier for people you have appointed to take steps to help you.

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Additional information

- ▶ Contact Martin M. Shenkman via email at shenkman@shenkmanlaw.com

