



FINANCIAL AND ESTATE PLANNING FOR THE PARKINSON'S COMMUNITY



**For Those Living with Parkinson's Disease
and Their Loved Ones**

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FINANCIAL AND ESTATE PLANNING FOR THE PARKINSON'S COMMUNITY

Introduction

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 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.**



ESTATE AND FINANCIAL PLANNING WHEN LIVING WITH PARKINSON'S DISEASE

- » Same process as for everyone, just tailored to fit your special circumstances — your experience with Parkinson's disease (PD)
- » Even more so, it must be about planning for life to cover caregiving costs, in addition to end-of-life wishes.
 - For many, Medicaid planning and health insurance are vital. Those rules vary by state and you should consult a Medicaid attorney in your state. This presentation will not address these issues.
- » Define what “estate planning” means in light of how you or your loved ones, live with PD.





FINANCIAL AND ESTATE PLANNING FOR THE PARKINSON'S COMMUNITY

12 STEPS

BEFORE YOU BEGIN: INFORM YOUR ADVISERS

- » Includes attorney, CPA, investment adviser or financial planner, insurance consultant
- » Many attorneys, financial planners and CPAs, have limited experience dealing with Parkinson's — or even chronic illness, so you must explain PD, disease course and variability, and its impact upon your life.
- » PD affects every aspect of estate, financial and related planning. Don't use “standard” documents or planning steps without careful consideration — often small “tweaks” can make otherwise generic plans work much better for you.

You have to be proactive: Informed advisers mean a better plan and greater peace of mind for you.



WHAT TO EXPLAIN IF YOU ARE LIVING WITH PD

- » PD symptoms can be varied, some invisible, some visible but misleading -- explain yours to your advisers.
- » Parkinsonian masked faces may make communicating challenging.
- » Bradykinesia can make writing so slow as to impede signing documents
- » Micrographia may result in the letters you write getting smaller – the appearance of signatures may vary.
- » Bradykinesia, akinesia, or other symptoms, may make it difficult for you to handle some routine matters. Nevertheless you may want to remain in charge of all decisions – your planning and documents should reflect this.
- » Possible future impact on executive functioning should be planned for.





FINANCIAL AND ESTATE PLANNING FOR THE PARKINSON'S COMMUNITY

STEP 1: ORGANIZE

STEP 1: ORGANIZE EMERGENCY, FINANCIAL, AND ADVISERS INFORMATION

- » Medical information
 - Neurologist / movement disorder specialist and other physician contact information; current health status, medications and dosages
- » Emergency contacts
 - Names, relationships, phone numbers, email
- » Specific financial information
 - Account numbers, adviser(s) names, address, phone number, email
- » Passwords and security codes
- » Existing estate planning documents.
- » Legal documents (contracts), income and expense information, budget or financial plan

Planning ahead can make it easier for you to manage legal issues and finances as PD progresses.



INVESTMENT AND FINANCIAL INFORMATION IS CRITICAL TO ORGANIZE

- » Title (ownership) of accounts
 - Revocable trust — tool to manage assets, address challenges with executive functioning
 - Joint accounts — exercise caution
- » Account management
 - Duplicate statements — no cost protective tool
 - Consolidation and simplification — retain control longer
 - Access to safe deposit box
- » Automation
 - Organizing records
 - Online payments — this can relieve a lot of paperwork
 - Set up on computer
 - Automatic deposits — reduce paperwork and chance for error



FINANCIAL PLANNING IS ESSENTIAL

» Budget

- Core of your financial plan
- Foundation of insurance decisions
- Prerequisite to gift and other planning

» Investment allocation

- Time horizon (disease course)
- Risk level
- Coordination of all accounts

» Analogies to help you plan

- Rocket ship — if you're off one mile now you could miss by 100s of miles
- Sailboat — can't sail into the wind, tack back and forth — adjust every year
- 60 Second financial plan — can you live on 4 percent X your savings, plus other cash flow sources?



ACTION STEPS: EMERGENCY INFORMATION

- » Type up a list on your computer so you can update it, email it, and back it up.
- » Disseminate the list to key people, ask for their help and tell them what they might need to do (and when).
- » Each professional adviser should have the list in his / her file.
- » Organize the list by category (e.g., banking, religious adviser, professional advisers, family, neighbors).
- » List information needed for emergency action (e.g., account number, policy number, etc.)



ACTION STEPS: FINANCIAL PLAN

- » If your resources are limited, consult with a Medicaid planning attorney in the state in which you reside.
- » Prepare a budget.
- » Consider significant expenditures that might be required (e.g. making your home more accessible).
- » Review your investments.
- » Create a financial plan.
- » Implement changes suggested by the plan.
- » Update, review and revise.





FINANCIAL AND ESTATE PLANNING FOR THE PARKINSON'S COMMUNITY

STEP 2: SET A POWER OF ATTORNEY

STEP 2: DESIGNATE A PERSON TO HANDLE FINANCIAL AND LEGAL ISSUES

- » General vs. Limited
 - Consider limited durable power of attorney to address specific items you might need help with now, and a broad, general power of attorney if you become disabled at a future date.
- » Agent (successors)
 - Consider naming co-agents to build in safeguards and to share work.
- » Durable (disability).
 - Organize finances to facilitate management during a short term disability.
 - Compensation — agents are generally entitled to "reasonable" compensation, but laws differ by state
- » Begin date (trigger)
 - Symptoms, especially possible impact on executive functioning, may change when effective and scope of powers are granted to your agent.
- » Powers (authority)
 - Consider special provisions (e.g. modify my home to make it accessible even if the cost won't be recoverable when the home is sold).



ACTION STEPS: POWER OF ATTORNEY

- » Choose a trusted agent and several successors.
- » Hire a lawyer to draft powers tailored to your health and financial situation. If you cannot afford an attorney, consider online legal resources, but take precautions (get educated, find friends / family to go through the process together).
- » Discuss modifications to standard forms:
 - Limited power for some situations and broad power for permanent disability
 - Compensation to agent – in light of your current age and health
 - Definition of disability – how define in light of your PD
- » Sign several originals, distribute them to the appropriate people and instruct them what to do in an emergency.
- » Organize and simplify assets so an agent can act easily.
- » Create a monitor relationship.





FINANCIAL AND ESTATE PLANNING FOR THE PARKINSON'S COMMUNITY

STEP 3: CHOOSE A HEALTH PROXY

STEP 3: DESIGNATE A PERSON TO MAKE HEALTH CARE DECISIONS

- » Agent (successors)
- » Powers (medical decisions)
- » Signature (state law)
- » Move (state, facility)
- » Religious concerns



STEP 3: TAILORING YOUR HEALTH PROXY TO ADDRESS PARKINSON'S

- » Does your agent have sufficient knowledge of Parkinson's disease and the decisions that might be required?
- » Given the progressive nature of PD, a guardianship designation should be included in the health care proxy (or a separate guardian designation prepared).
- » Is your agent geographically close enough to respond to a sudden emergency?
- » Do your medical wishes contradict religious beliefs of your agent or family that you need to address?
- » Are there specific powers or rights which you do / don't want your agent to have?

Medical power of attorney



ACTION STEPS: SET A HEALTH CARE PROXY

- » Choose an agent and several successors who understand your health situation and wishes.
- » Hire a lawyer to draft a health proxy that accomplishes your personal goals.
- » Determine specific powers to give / not give agent.
- » Sign several originals and distribute them. Be sure a copy is included in your medical chart.
- » Discuss your decisions with family, friends and most importantly, your agents.





FINANCIAL AND ESTATE PLANNING FOR THE PARKINSON'S COMMUNITY

STEP 4: CREATE A LIVING WILL

STEP 4: COMMUNICATE HEALTH CARE WISHES AND PERSONAL CHALLENGES

- » A living will is a statement of health care wishes to guide / direct your health care agent.
- » Address broad array of decisions:
 - Lifestyle (nursing facility or home).
 - Can also direct home modifications
 - Health (experimental treatments).
 - These may differ at various points in disease course.
 - End of life (heroic measures)
 - One person's "heroic" is another's essential actions.
 - Other (funeral, burial, etc.).
- » Consider HIPAA releases — you may need help but not need to give up full control to an agent under a health care proxy.
- » You may wish to mandate donation of brain tissues to further PD research.



ACTION STEPS: MAKE A LIVING WILL

- » Review and consider personal wishes that should be reflected (e.g. religious observances, care instructions).
- » Hire a lawyer to draft a living will that communicates your personal decisions. If you cannot afford an attorney consider online resources, but take precautions.
- » Discuss modifications to forms: Religious restrictions, organ donations (e.g., brain tissue to foster PD research), experimental or non-traditional treatments
- » Sign several originals, distribute them and be sure one is included in your medical chart.
- » Discuss your decisions with family and agents.





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STEP 5: PROTECT YOUR CHILD(REN)

STEP 5: PROTECT YOUR CHILD MINORS WITH AN EMERGENCY CHILD MEDICAL FORM

- » More likely a concern for people with young-onset PD
- » If a parent is disabled, a guardian appointment under a will won't cover full care arrangements.
- » Power of attorney should address expenditures for children, not just a patient.
- » Your financial resources may be limited and disability and life insurance may not be available or limited to what you had pre-diagnosis — financial planning is vital.
- » An emergency child medical form should include the child(ren)'s medical data and insurance coverage.



ACTION STEPS: PROTECT CHILDREN

- » Review all aspects of protecting your children with your advisers.
- » Name agents under a power of attorney (and/or a successor trustee under a revocable trust) who, if you are disabled, can direct payments for care of children. The financial fiduciaries often should be different than the guardian discussed below.
- » Name guardians under your will, to provide care, and make decisions for a minor or special needs child.
- » Financial planning — set up 529 plans, review resources
- » Prepare and sign child emergency medical form.
- » Write a personal letter of instruction.
- » Include directions in your power of attorney addressing children.





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STEP 6: MAKE A WILL

STEP 6: SIGN A WILL

- » A legal document to designate where your assets should be distributed in the event of death
- » Name executors and guardians.
- » Distribute assets.
- » Tax planning (bypass and marital trusts)
- » Trusts for heirs
- » Plan flexibly — laws and life change.
- » Consider caps on amounts bequeathed to different trusts.



STEP 6: REQUEST THAT OTHERS TAILOR THEIR WILLS TO ADDRESS YOUR ILLNESS

- » Does it make sense for loved ones to name you executor, trustee or guardian? If not suggest they revise their documents.
- » If you are named a beneficiary, suggest that your possible benefactor name a trust designed to protect you, rather than name you outright.



ACTION STEPS: SIGN A WILL

- » Wills are important, but if you're facing a progressive, chronic illness like PD, it is only one step of many and perhaps not the most important one.
- » Include personal letters of instruction.
- » Consider trusts for minor children.
- » Donate to charities that have helped you — even modest donations send an important “thank you.”
- » Opt for flexibility in case you cannot update the document to reflect future changes.
- » Suggest others establish trusts for you in their wills.





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STEP 7: SET A REVOCABLE LIVING TRUST

STEP 7: TAILOR YOUR REVOCABLE LIVING TRUST TO ADDRESS PD

- » A revocable living trust allows you to manage assets while disabled or ill — unlike a will, it addresses planning while you are alive and transfers funds into a trust.
- » Depending on your current status you can serve as sole initial trustee, but initial co-trustee may be safer. You can remain in control as long as possible and ease the passing the baton to successors.
- » Trustee removal clauses should consider your symptoms now and likely disease course (e.g. you can't be removed unless disabled for 30 days to avoid your removal after a short term health event).
- » Include details on lifestyle you wish to maintain.
- » With young-onset PD, address care for children and authorize trustee to distribute for them.



ACTION STEPS: REVOCABLE LIVING TRUST

- » Coordinate with what is instructed in your will.
- » Boilerplate trusts designed to avoid probate won't accomplish your goals — be wary of the trust mills.
- » Focus of document should be protecting you (and your loved ones) and communicating your wishes as your disease progresses.
- » Tailor trustee replacement, disability and other provisions to the nuances of your anticipated disease course.
- » Fund the trust (transfer assets into the trust name) other than retirement assets or professional practices.





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STEP 8: TAILOR INSURANCE

STEP 8: BE SURE YOUR INSURANCE COVERAGE IS IN ORDER

- » Property and casualty insurance
- » Business coverage
- » Long term care coverage
- » Disability income
- » Life insurance
- » Liability coverage



STEP 8: TAILOR / PLAN INSURANCE TO ADDRESS YOUR ILLNESS

- » Does homeowner's insurance cover home health aids?
- » If you have disability coverage are you collecting; are your payments correct?
- » If you have life insurance can you borrow against it, convert it to permanent coverage, or could you benefit from a viatical settlement of your policy?
- » Does your partner / spouse have long-term care coverage? Consider the impact of your PD on him / her.



ACTION STEPS: INSURANCE COVERAGE

- » Don't make assumptions — PD doesn't mean you don't have insurance planning options.
- » Have all your insurance coverage reviewed at least every two years.
- » Evaluate all options — Can you convert term life insurance to a permanent policy? Can you sell life insurance in the secondary market to free up cash?
- » Standard homeowners coverage may not suffice — do you need a rider for home health workers / home improvements?





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STEP 9: SET BENEFICIARY DESIGNATIONS

STEP 9: FILE BENEFICIARY DESIGNATIONS AND CONFIRM TITLE TO ACCOUNTS

- » Standard provisions are not always adequate.
- » Coordinate with revocable trust.
- » What powers should agent have?
- » Give copies to your advisers.
- » Update when banks merge.
- » Revise when tax laws change.



STEP 9: REQUEST LOVED ONES TAILOR THEIR BENEFICIARY DESIGNATIONS TO ADDRESS YOUR PD

- » Should a trust for your benefit be named instead of you as beneficiary?
- » Should someone else be named beneficiary instead?



ACTION STEPS: SET BENEFICIARY DESIGNATIONS

- » Consider all beneficiary designations: life insurance, pensions, IRAs, brokerage accounts and more.
- » Be cautious about signing beneficiary designations for non-retirement accounts.
- » Obtain copies of the forms you filed and blank forms to facilitate revision.
- » Have family members who name you as beneficiary instead consider a trust for you.





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STEP 10: GIVE BACK

ACTION STEPS: GIVING BACK

- » Including a charitable gift in your plans (of any size) can communicate values to your heirs and further causes important to you
- » Make a donation — cash, insurance, stock, even real estate or other assets.
- » Include a bequest in your will. Even small bequests can make a big statement.
- » Write a heartfelt letter of instruction to heirs and thanks to those who have helped.
- » Inspire others to give who have the wherewithal to do so.





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STEP 11: COMMUNICATE

ACTION STEPS: COMMUNICATE

- » Having honest conversations with advisers and loved ones is critical:
 - » Explain your finances, family, care, disease, and so forth to your advisers — tell all so they can help properly.
 - » Discuss with family, friends or others involved in your life what help you might need and what roles they might serve (e.g. health care agent, trustee of an insurance trust, etc.).
- » Are your expectations for help from family or friends realistic? Do you have alternatives?
- » Express your wishes in face to face meetings and then confirm key points in writing.
- » Consider a consultation / evaluation by a licensed independent care manager.





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STEP 12: REVIEW — IT'S A PROCESS

STEP #12: REVIEW, REVISIT, REVISE

- » Nothing remains static.
- » Tax and property laws
- » Family situations
- » Assets and net worth
- » Health changes
- » New medications





FINANCIAL AND ESTATE PLANNING FOR THE PARKINSON'S COMMUNITY

CONCLUSION: START TODAY

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