Financial & Estate Planning for those Living with Pulmonary Hypertension (PH)
Financial & Estate Planning for those Living with Pulmonary Hypertension (PH) in 12 Steps

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Introduction
What is financial planning?

- The process of providing peace of mind for you, and your loved ones (however you define the term).
- It should address both the issues you may face while you’re alive, and those that might occur after your death, including the variables and uncertainties associated with having a pulmonary arterial hypertension.
- It is more about planning for **life** rather than death.
- It is an integrated plan that coordinates your investments, insurance, emergency and disability planning, retirement and other needs.
- Define what “estate planning” means to **you**.
What is financial planning if you are living with pulmonary hypertension?

- Same process as for everyone just tailored to fit your special circumstances – your experience with your pulmonary arterial hypertension.
- It must contemplate the course of what PH will bring barring a cure – putting off tough decisions only makes them harder for your and your family or loved ones.
- It must be about planning for life rather than death.
- An integrated plan that coordinates your investments, insurance, emergency and disability planning, retirement and other needs – but each component must be modified as required.
- Define what “estate planning” means to you in light of your, or your loved ones, living with your challenges of pulmonary arterial hypertension.
Examples: Planning if you are living with a pulmonary hypertension

- Powers of Attorney – everyone names an agent to handle financial and legal matters, but your document might need to differ:
  - Standard forms might not suffice – e.g. what about compensation if the agent might handle all your finances for several years as your situation deteriorates.
  - Perhaps a special limited power (handle banking, don’t sell my house) effective immediately is a better way to protect you from an exacerbation or sudden hospitalization – most people don’t consider this approach.
  - An immediate single agent “limited power” contrasted with a springing or co-agent “general power” (may permit the sale of your house, change of your beneficiary designations and more) may retain greater control but help address challenges.
  - A fully funded revocable trust may be a better approach.
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The 12 Steps
Introduction to the 12 Steps

- Every person is unique – it has to be your plan and address your challenges
- Reflect your personal wishes and circumstances
- Create a strong foundation of documents, steps and a plan, to build upon

Hope can grow from the soil of... illness

www.invisibleillness.com
• It’s a **process**, not signing a document.
• Begin the process.
• Break the process into manageable steps, each tailored to **your** circumstances.
• Stick with it.
• Do as many steps at a time as you can handle properly and comfortably – staying committed to the process is more important than how many steps you tackle at once.
• Make an Action Plan – We’ll show you how … Step by Step.
Before you Begin

- Gather information.
- Select advisors:
  - Attorney.
  - CPA.
  - Investment advisor or financial planner.
  - Insurance consultant.
  - If you cannot afford or don’t need a particular expert consider creative “work-arounds” such as software, websites, friends, etc.
- Start thinking about the process.
Action Step: 12 Steps Begin by Informing Your Advisors

- Pulmonary hypertension affects every aspect of estate, financial and related planning – don’t use “standard” documents or planning steps without careful consideration of what might be different for you.
- You must explain your circumstances to all of your agents (discussed below) and advisors or they will not be able to guide you.
- Those not touched by similar challenges often do not understand the symptoms, disease course, or the urgency of planning.
- You have to be proactive – Informed advisors mean a better plan and more peace of mind for you.
Example: What to Explain if you are living with PH

Symptoms of PH may include:

- Shortened life expectancy
- Possible lung transplant
- Breathlessness
- Chest pain
- Dizziness
- Fainting
- Loss of energy
- Swelling of the arms, legs, ankles or abdomen
- Dry cough
- Raynaud’s phenomenon
Example: What to Explain if you are living with PH

- PH disease progression can vary.
- Explain your current circumstances and symptoms, and what your physicians indicate your likely disease course to be to your advisers.
- Understanding the limitations on physical activities is vital as it will affect your interaction with your advisers. Example: If some meetings can be held by web conference permitting you to remain at home avoiding the strain of traveling to a lawyer or other advisers office, that might make the process easier, even safer, for you.
- Your advisors must understand the time frame so they know how urgent planning might be.
- Planning generalizations must give way to planning for your circumstances.
If Your Loved One Can No Longer Sign Legal Documents

- If PH has progressed to the point where your loved one no longer has legal ability (capacity) to sign documents review existing documents with an attorney.

- You might be able to use an existing power of attorney to change ownership (title) to assets, make gifts and take other actions to improve or correct existing planning.

- Discuss the pros/cons of a guardianship and whether it is necessary or advisable.
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Step #1: Organize
Step 1: Organize Emergency, Financial, Information and Advisors Information

- Passwords and Security Codes.
- Existing estate planning documents.
- Legal documents (contracts).
- Income and expense info.
- Any budget or financial plan.
- Advisor contact info (name, firm Phone number, email, etc.).

This is the planning you should undertake to make it easier for you to deal with legal issues and finances as you age and (if) your condition progresses.
Step 1: Organize Emergency, Financial, Information and Advisors Information

- Medical information (physician contact info; current health status, etc.). See templates provided on the www.pahassociation.com website to organize this data electronically or in a binder.
- Emergency contact info (names, relationships, phone numbers, email addresses).
- Specific financial information (account numbers, contact person, address, phone number).
Investment and Financial Information is Critical to Organize

- **Example**: IF PH makes it difficult to travel to banks, etc. organizing, consolidating and automating can minimize or even eliminate the need to.
- **Title (ownership) of Accounts**:
  - Revocable trust – tool to manage assets, address fatigue issues.
  - Joint accounts – exercise caution.
- **Account Management**
  - Duplicate statements – no cost protective tool.
  - Consolidation and simplification – retain control longer and minimize efforts required to manage accounts.
  - Access to safe deposit box.
- **Automation**
  - Organizing records.
  - On line payments – this can relieve you of a lot of paperwork.
  - Set up on computer – family and others can help, even if they live far away. Reminders can help.
  - Automatic deposits – reduce paperwork and chance for error.
Financial Planning is Essential

- **Budget**
  - Core of your financial plan.
  - Foundation of all decisions.
  - Prerequisite to gift and other planning.

- **Investment allocation**
  - Time horizon (disease course).
  - Risk level/liquidity.
  - Coordination of all accounts.

- **Analogies to help you plan**
  - Rocket ship – if you’re off 1” 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% x your savings plus other cash flow sources.
Action Steps #1: Emergency Info

- Type up a list on your computer so you can update it, email it, and back it up. Better yet, use automatic backup. Even better still might be using an app that stores key information like keeper security.
- Disseminate the list to key people, ask for their help, and tell them what they might need to do to help and when.
- Each professional advisor should have the appropriate list, or portions of it, in their file.
- Organize the list by category (e.g., banking, religious advisor, professional advisors, family, neighbors).
- List info needed for emergency action (e.g., account number, policy number, etc.).
Action Steps #1: Financial Plan

- The survival period for those diagnosed with PH can vary from 2-3 years after diagnosis to 30+ years for others. It is important to have a frank discussion with your physicians after diagnosis and as you care plan is implemented and evolves so that a reasonable time frame for legal and financial planning addresses your realities not generalizations.
- Prepare a budget that reflects your health course.
- 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.
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Step #2: Power of Attorney
Step 2: Designate a Person to Handle Financial and Legal Issues

- General vs. Limited
- Agent (Successors)
- Compensation
- Begin date (Trigger)
- Powers (Authority)
- Durable (Disability)
Step 2: Tailoring Your Power to Address PH

- Your challenges now and in the future with PH affect when effective and scope of powers granted your agent.
- Consider naming co-agents to build in safeguards and to share work.
- Plan for fatigue and physical challenges affecting mobility and activity level. Organize your finances to facilitate management during as your PH symptoms worsen. Consider an immediate general durable power of attorney (or a funded revocable trust).
- Consider special provisions – example, don’t sell my home, modify my home to make it accessible even if the cost won’t be recoverable when the home is sold, etc.
- Consider mandating a monitor relationship (a person other than your agent or successor agent to receive regular reports). Checks and balances may be vital to your security as your health declines.
Action Steps: Power of Attorney

- Choose a trusted agent and several successors.
- Hire a lawyer to draft powers tailored to your disease course and financial situation. If you cannot afford an attorney and use online services, study before preparing a document and then review it and see what modifications might be advisable for you.
- Discuss modifications to standard forms:
  - Compensation to agent.
  - Definition of disability – how/when begins/ends (e.g., exacerbation).
- Sign several originals, distribute them to the appropriate people and instruct them as to what to do in an emergency.
- Organize and simplify assets so an agent can act easily.
- Create a monitor relationship (e.g., a CPA gets duplicate copies of all monthly statements and reviews them).
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Step #3: 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 and HIPAA Release to Address your pulmonary hypertension

- Does your agent have sufficient knowledge of PH generally, and your health challenges specifically, and the decisions that might be required?
- 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 (e.g. donation of organs for PH research)? Address these points in detail.
- Are there specific powers or rights which you do/don’t want your agent to have?
Action Steps #2: 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, distribute them, be sure a copy is included in your medical chart.
- Discuss your decisions with family, friends and most importantly, your agents.
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Step #4: Living Will
Step 4: Communicating Your Health Care Wishes

- Statement of health care wishes to guide/direct your health care agent.
- Address broad array of decisions:
  - Lifestyle (nursing facility or home).
  - Health (experimental treatments).
  - End of life (heroic measures).
  - Other (funeral, burial, etc.).
Step 4: Tailor Your Living Will to address your Particular Challenges

- What some call “heroic” may be essential to you.
- Differentiate level of treatments at different stages of your disease course.
- Carefully modify quality of life decisions to reflect issues relevant to PH.
- Do you have specific feelings about transplant that should be addressed?
- Direct home modifications if advisable.
- Do you wish to mandate donation of organs to further research?
- If you experience pain you may wish to specify maximum pain relief even if it shortens life. Specific instructions are especially important if some family members may have contradictory religious views.
Action Steps #4: 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.
- Discuss modifications to forms: religious restrictions; organ donations; Intubation in light of PH, experimental or non-traditional treatments; pain relief perhaps regardless of the impact on life expectancy
- Sign several originals, distribute them, be sure one is included in your medical chart. A POLST (physician orders for life sustaining treatment) is a physician prepared document that may be ideal to have added to your patient chart.
- Discuss your decisions with family and agents and your medical providers.
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Step #5: Protect Your Child
Step 5: Protect Your Minor Child With an Emergency Child Medical Form

- Disclose child’s care information.
- Indicate medical data.
- Disclose insurance coverage.
- Consider definition of “issue.”
- If PH is hereditary – insurance.
Step 5: Tailoring Planning for your Children to Address Your Health Challenges

- Naming a guardian is all most people do, but your child may need formal care arrangements if you are alive but disabled and a guardian appointment under a will won’t accomplish this.
- Power of attorney should address expenditures for children not just you.
- A revocable trust designating a successor trustee and authorizing that trustee to provide financially for both you and your child may be advisable.
- 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.
Action Steps #5: Protecting Children

- Review all aspects of protecting your children with your advisors.
- Name trustees under a revocable trust while you are alive and disabled and direct payments for care of children, and trustees and guardians under your will, to provide care.
- 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: Will Revocable Trust
Step 6: Sign a Will/Trust

- Name executors and guardians.
- Distribute assets.
- Be certain “issue” and “heirs at law” are appropriately defined in your will and those of your benefactors (e.g., parents) to include surrogate or adopted children.
- Trusts for heirs.
- Plan flexibly – laws and life change.
- Medicaid planning in the event needed – be certain benefactors use appropriate trusts.

A legal document to designate where your assets should be distributed in the event of death.
Step 6: Wills and Those with PH Challenges.

- Whether or not there will be urgency, or no particular time pressure, on you to get your documents and planning in order will depend on your particular circumstances. However, whatever your situation, getting financial and legal matters in order earlier than later will often be preferable.
- Depending on your personal situation, if you want to change your will, discuss with your attorney whether using a codicil (amendment) which won’t revoke the prior will, might be safer. This may be important to preserve what was in the prior will in case there is a challenge based on your declining health.
- Have your lawyer draft flexibly and considering many potential changes in law and your personal situation so if you are not able to legally amend your will the flexibility will give your executor and trustees greater ability to address the new circumstances.
- Be certain benefactors (parents) properly provide for you in their will (e.g., Supplemental Needs Trust rather than outright bequest) and proper definition of “issue” or “heirs.”
Step 6: Request that Others Tailor Their Wills to Address Your Illness

- Does it make sense for loved ones to name you executor or guardian? Will the physical difficulties of carrying out these duties be too hard for you? 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. If you are receiving Social Security or may apply for Medicaid a Supplemental Needs Trust is essential.
Action Steps #6: Sign a Will and Perhaps

- Wills are important but if you’re facing a progressive chronic illness it is only one step of many and perhaps not the most important step. Consider the advantages of a funded revocable trust.
- Write personal letters of instruction.
- Consider trusts for minor children.
- Donate to charities that have helped you – even modest donations send an important “thank you.” Let the agent under your power of attorney prepay these.
- 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
Revocable Living Trust
Step 7: Create a Revocable Living Trust

- Transfer assets to a trust during your lifetime.
- Avoid probate and intestacy.
- Contains dispositive provisions of your will.
- Manage assets during disability or illness – unlike a will addresses planning while you are alive and well, or disabled.
Step 7: Tailor Your Revocable Living Trust to Address Your Challenges

- Depending on your current status (e.g., fatigue, possible cognitive impairment) you can serve as sole initial trustee, but serving as initial co-trustee may be preferable. In this way the other co-trustee can handle matters that may be too draining for you, such as a trip to a bank.
- Tailor clauses to retain control while protecting you.
- Trustee removal clauses should consider your challenges now and likely disease course – e.g. you can’t be removed unless disabled for 30 days to avoid your removal for a short term hospitalization, etc.
- Include details on lifestyle you wish maintained.
- Address care for children and authorize trustee to distribute for them.
Action Steps #7: Revocable Living Trust

- See comments for “Wills” above and coordinate.
- 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 PH disease course.
- Fund the trust (transfer assets into the trust name) other than retirement assets or professional practices.
- Use a tax identification number not your Social Security number on for the trust.
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Step #8: 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 Your Insurance to Address Your Challenges

- Does homeowner’s insurance cover home health aids?
- If you have disability coverage are you collecting; are your payments correct?
- Consider obtaining additional excess liability coverage in case you health status is raised after an accident.
- If you have life insurance can you borrow against it, convert it to permanent coverage if it is term, can you benefit from a viatical settlement.
- Does your partner/spouse have long term care coverage – consider the impact of your condition on them.
Action Steps #8: Insurance Coverage

- Don’t make assumptions – living with pulmonary hypertension doesn’t mean you don’t have insurance planning options.
- Have all your insurance coverage reviewed at least every 2 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: Beneficiary Designations
Step 9: File Beneficiary Designations and Confirm Title to Accounts

- Standard provisions are not always adequate.
- Coordinate with trusts under will or Revocable Trust.
- What powers should agent have.
- Give copies to your advisors.
- Update when banks merge.
- Revise when laws change.
Step 9: Request Loved Ones Tailor/Plan Their Beneficiary Designations to Address Your PH

- Should a trust, e.g. a supplemental needs or special needs trust, for your benefit be named instead of you as beneficiary?
- Should someone else be named beneficiary instead?
Action Steps #9: 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
Step 10: Give Back

- Thank those that have helped.
- Inspire others to give.
- Give however you can.
Action Steps #10: To Give Back

- Make a donation (time, cash, insurance, even stuff).
- Include a bequest in your will – even small bequests can make a big statement (but consider giving the agent under your power of attorney the right to prepay).
- Write a heartfelt letter of instruction to heirs and thanks to those that have helped.
- Inspire others to give that have the wherewithal to do so.
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Step #11: Communicate
Step 11: Communicate

- Educate and inform your fiduciaries/family.
- Preparation of beneficiaries.

Having a real conversation is one of the most important steps you can take.
Action Steps #11: Communicate

- Explain your finances, family, care, disease, and so forth to your advisors – tell all so they can help properly.
- Discuss with family, friends or others involved in your life what help you might need.
- Can those you expect to rely on really help – 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.
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Get Started Now
Make an Action Plan
And Get Started
Protect yourself and your loved ones
For more information

- See [www.chronicillnessplanning.org](http://www.chronicillnessplanning.org)
- The website is being rebuilt and should be re-launched by year end.
- [www.laweasy.com](http://www.laweasy.com) being rebuilt.
- [www.shenkmanlaw.com](http://www.shenkmanlaw.com)
- Visit [www.PHAClassroom.org/FinancialPlanning](http://www.PHAClassroom.org/FinancialPlanning) website for an article and copy of this power point.
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