



Financial Prescription

by: Shelly Banjo and Kristen McNamara, Wall Street Journal | Apr 13, 2009

As a legal advocate, Jennifer Jaff helps chronically ill people gain more control over their lives. So, when she was diagnosed with a serious stomach disease last August, she decided to take control, too -- and create a comprehensive estate plan.

She "wanted to get everything in order to make sure my wishes were carried out," says Ms. Jaff, an attorney and founder of Advocacy for Patients With Chronic Illness Inc.

Among other things, Ms. Jaff asked her brother to act as her health-care proxy. She was concerned that her father wouldn't follow her wishes to refuse a feeding tube when she is no longer able to take in nutrients on her own, she says. Her brother didn't agree with her decision but agreed to abide by it, she says.

Estate planning, with its legal jargon and focus on death, can be daunting. But those facing a chronic illness need to be particularly attuned to certain aspects of a plan. Developing an arrangement that addresses the likely progression of your disease and your future needs can help you maintain control, even as your health declines.

Here are a few key items to consider as you develop your own plan:

Get Legal, Financial Help

It's important for everybody to line up someone who can take legal and financial action for them if they become incapacitated. But there are some considerations that people with chronic illnesses should watch out for.

First, here's a quick refresher on some basic concepts. The document that lets somebody take over for you is called a durable power of attorney. It lets you designate an "agent" to perform a range of activities, from paying bills, filing tax returns and overseeing retirement accounts to selling property and making investments. You can set the scope of the agent's authority and spell out whether the power of attorney becomes effective immediately or "springs" into effect when you become incapacitated.

People with chronic illnesses may face the prospect of being incapacitated for decades. In that case, it's especially important to name backup agents who can step in if the primary agent becomes unable or unwilling to act on your behalf.

What's more, if you have a condition that may incapacitate you temporarily, be careful with "springing" durable powers of attorney. These may be cumbersome, since they require proof

that you're disabled before your agent can act for you -- then you must be able to demonstrate you've recovered if you want to reclaim control.

One alternative might be to use two separate durable powers of attorney, says Martin M. Shenkman, an attorney in Paramus, N.J., and author of a book on estate planning and chronic conditions. One durable power of attorney could become effective immediately but limit the agent to addressing matters that might arise during a temporary attack or hospitalization. The agent could, for example, be given authority to pay bills but not to make major decisions such as changing beneficiary designations on insurance and retirement plans.

The second durable power of attorney would include springing provisions that allow an agent to assume broad, ongoing responsibility for your affairs if your disability prevents you from managing them any longer. You could name the same person to serve as your agent in both instances.

Other attorneys suggest simply having one durable power of attorney, effective immediately, and naming someone you trust completely to act on your behalf.

Remember, though, that a durable power of attorney doesn't always allow someone to make health-care decisions for you, such as authorizing certain treatments. For that, you need a health-care proxy, also known as a power of attorney for medical directives.

These are particularly important for individuals with chronic illnesses who can lapse into a debilitated state very quickly. Without a health-care proxy, a friend or relative of a chronically ill patient would have to go to court to be appointed as guardian and get approval to make any medical or legal decisions.

A separate but related document is a living will, which states your end-of-life wishes. These include your feelings about the use of ventilators or artificial nutrition to keep you alive. Your agent is legally bound to follow your wishes. In fact, it's a good idea to have both a living will and health-care proxy to make your wishes clearly known when you can't communicate them.

But be sure to create your living will in coordination with your physician, since it should reflect the particular nuances of your disease. People with Lou Gehrig's disease, for example, could customize the document to address the likelihood they'll need help breathing at some point. And destroy any living wills and health-care proxies created before your diagnosis to avoid confusion later.

If you have a serious illness, consider carrying a card in your wallet that shows you've signed a living will and health-care proxy and provides emergency contact information, says Bernard A. Krooks, founding partner of the New York law firm Littman Krooks LLP. This can be helpful if you wind up at the hospital unexpectedly.

It's also important to consider what happens to your assets after you die. A revocable living trust can help you manage your assets during your lifetime -- and then bypass the sometimes expensive and time-consuming process of settling your estate, known as probate, after your death.

Here's how it works. After you set up the trust, most of your assets can be transferred to it. (Retirement accounts should remain outside the trust for tax reasons.) After your death, the

living trust will dictate how any estate tax should be paid and how your assets and property should be distributed -- without forcing your heirs to go to probate.

You can create a "pour-over will" to transfer any assets that do not end up in the trust when you die. These assets still go through probate but then end up in the trust and are distributed under the terms of the trust, simplifying administrative matters.

Naming yourself and a co-trustee to oversee a revocable living trust often makes sense for someone with a chronic illness who's still able to make decisions, Mr. Shenkman says. This allows you to maintain control and makes it easy for the co-trustee to step in quickly if necessary.

If you suffer brief periods of incapacitation, you could specify in the trust document that the co-trustee can handle routine banking and brokerage matters when you're unable to -- but not take other action, such as selling assets over a certain value.

If your disease will lead to long-term incapacitation, naming a successor trustee to replace you when you can't act on your own behalf is important. The trust should specify how to determine you're disabled and who should take over.

Note, though, that a loved one who's caring for you isn't necessarily the best successor trustee. Caring for a parent or other family member can be stressful and tiring; an institutional trustee might be a better choice to take on these additional responsibilities, Mr. Shenkman says. The fees associated with an institutional trustee probably won't make sense if you have less than \$500,000 in assets, however.

Choose Carefully

Beyond all that, there are some general things to remember when working on your estate plan. Most important: Deciding whom to entrust with decision-making power is a serious matter. Before naming a trustee or agent, "have a thorough discussion as to what the document entails," says Claudio De Vellis, chair of the trusts and estates practice group at Abrams, Fensterman, Fensterman, Eisman, Greenberg, Formato & Einiger LLP.

What's more, figure out if your agent of choice will be able to deal with the specifics of your illness. If you've been diagnosed recently, consider how friends and family members have responded to your illness. You want to name people who have demonstrated the ability and willingness to step in for what could be a long period of time.

Also consider flexibility. If you have a disease characterized by unexpected attacks that can leave you incapacitated for days or weeks, you'll need someone to step in quickly with little notice.

When it comes to health and end-of-life decisions, you'll also want to name people who will follow the wishes you've laid out and not be swayed by their own emotions or religious beliefs. Would the person you name be able to withhold or withdraw nutrition and hydration, for example?

One final consideration: Illnesses such as Huntington's disease can be hereditary, so a blood relative may also develop the disease and become disabled, Mr. Shenkman says. In that case,

you'll want to name backup agents to make sure you're protected.

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