

## ESTATE PLANNING

# Plan for the Care of a Chronically Ill Spouse

**W**hen Howard Eisner was diagnosed with Alzheimer's disease several years ago, he was only in his mid fifties. He retired from his teaching job, and he and his wife, Susanne, started living off his pension and her salary as a county administrator. Howard lives at home and is still aware. But he can no longer speak clearly or drive. "When he started getting worse, I realized if something happened to me, what would he do? He couldn't manage," says Susanne, now 58.

Last year, the couple, who do not have children, met with a representative from MassMutual Financial Group who specializes in planning for special-needs dependents. The planner advised them on actions to take, such as drawing up a will and medical directives. Howard participated in the discussions. "I wanted him to understand the decisions he's making," Susanne says.

There's always the chance that you could die before your spouse, especially if you have an acute condition, such as heart disease. If your spouse has a chronic illness or disability, you need to arrange for the management of your spouse's finances and caregiving in the event you die first.

The first step is to draw up an advance health-care directive and a durable power of attorney. If your spouse becomes incapacitated and has not appointed an agent to make legal, financial and health-care decisions, you'll have to go to court to become a guardian. "If it's an early diagnosis, you should put documents in place so you'll have control," says Dennis Sandoval, an elder-care lawyer in Riverside, Cal.

Typically, spouses will name each other as health-care and financial agents. But if your spouse is chronically ill, you should appoint someone else to be your agent. And your spouse should have a backup agent.

Susanne Eisner named her sister as her health-care and financial agent, while Howard named Susanne as his agent and Susanne's sister as a successor agent. "If I'm not around, then my sister would make decisions for him," Susanne says.

You may also want to work with a financial planner. Cynthia Haddad, a certified financial planner who specializes in families with a special-needs member, starts out by taking inventory of all the couple's assets, income, insurance and legal documents. "We want to make sure the money is not going to run out for the healthy spouse," says Haddad, who works for Bay Financial Associates in Waltham, Mass. She also checks beneficiary designations on IRAs and other accounts.

### Creating a Support Group

Haddad has worked with one couple—an ill husband and a caregiving wife, both in their eighties—who assembled a team of advisers, including Haddad, a geriatric-care manager, an accountant, a lawyer and a home health agency. Haddad organized a team meeting, and members stay in touch by phone and e-mail. For several months, the wife and a health aide cared for the husband at home until he moved into a nursing home. The wife eventually moved into an assisted-living facility. Haddad works with the accountant on tax returns and with the lawyer, who holds the power of attorney and is the health-care proxy for both spouses. The couple have no children.

Haddad set up a bill-paying system. The geriatric-care manager oversees medical care. “In the event that either spouse dies first, the surviving spouse has a support team in place,” she says.

Alternatively, you could allow relatives to make all arrangements. But if you and your spouse don’t spell out your wishes, conflicts could erupt, says Sandoval. One child may want to move Mom into an assisted-living facility, and another may push for home care.

If your spouse has a serious disability that impairs his decision-making capabilities, don’t leave your money outright to him because he could be unable to manage it. Instead, consider setting up a special-needs trust, which would take effect upon your death and provide for your ailing spouse. “The amount you put into the trust will depend on the anticipated costs of care and the life expectancy of the ill spouse,” says Peter Strauss, a senior counsel at Epstein Becker Green, in New York City. You would select a trustee to make disbursements to pay for your surviving spouse’s care.

A special-needs trust also protects the disabled spouse’s eligibility for certain government benefits, such as Medicaid and Supplemental Security Income. Such trusts are drafted so that the assets are not considered to belong to the disabled spouse in determining eligibility for public benefits. For instance, without the trust, the disabled spouse could be required to spend nearly all of his or her assets before becoming eligible for Medicaid, which pays for nursing-home care. Assets in a special-needs trust are not counted when Medicaid eligibility is determined.

Even if Medicaid is not an issue, the trust could be useful. It could pay for a home health aide, a private

nursing-home room, extra therapies, entertainment, a wheelchair or a geriatric-care manager. “It really adds quality to a person’s life,” says Rebecca Berg, an elder and disability-planning lawyer in Jacksonville, Fla.

Special-needs trusts are tricky and the laws are state-specific, so make sure your lawyer has expertise in setting them up. To find a lawyer, visit the Web sites of the National Academy of Elder Law Attorneys ([www.naela.org](http://www.naela.org)) and the Academy of Special Needs Planners ([www.specialneedsplanners.com](http://www.specialneedsplanners.com)).

A trustee must become familiar with community resources for seniors and follow strict rules. Therefore, naming a reliable trustee is a critical decision. “Trustworthiness is perhaps more important than financial knowledge,” says Strauss. “You could always hire someone to give investment advice.”

Your child may not be the best person to carry out trustee duties. Bradley Frigon, an elder-law attorney in Englewood, Colo., says an adult child could have a conflict of interest. “The child that’s administering the trust might be ultimately inheriting it,” he says. To build in accountability, you could appoint a bank or another child to serve as co-trustee.

Both spouses should consider creating a letter of intent. This is not a legal document, but it would advise relatives and caregivers, upon your death, of your or your surviving spouse’s needs and preferences. It could include information about your financial advisers, lawyers, clergy, medical history and preferred living arrangements. It can also answer questions such as: Who should receive a special heirloom? What charities should be supported? “It’s a chance for people to express freely what their wishes are,” Haddad says. “It’s a chance for goodbye.” **K** — KATHRYN A. WALSON

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