

Long-Term Care Planning

Summarized by Thomas T. Thomas

We families share an overwhelming concern about the future: for when we are gone and our ill family members are on their own. At the September 28 meeting, we gave this conversation a jump start by having two experienced professionals address our group. **Linda Durston, PhD, JD**, is a local attorney whose practice involves special needs trusts, incapacity planning, and elder law, among other topics. **Sharon Toth, LCSW, CLPF** is Executive Director of IMT Associates, a professional fiduciary agency, which offers trustee, conservatorship, and case management services with a multidisciplinary staff.

Long-term planning, Durston explained, is for if and when you become severely disabled and need skilled nursing and custodial care for your basic needs. The only agency that pays for long-term care is MediCal, while Medicare will pay only for care immediately after you get out of the hospital but not for custodial care. So everyone should plan for long-term care. “The key question is,” she said, “if you needed regular custodial care, would you prefer to spend down your estate to two to three thousand dollars before accepting state assistance? Or would you want to protect your assets for your spouse and your kids?”

Although your actual plan will depend on your situation, Durston recommended the California Advocates for Nursing Home Reform (<http://www.canhr.org>) as an excellent resource for the financial considerations of qualifying for MediCal long-term care and for evaluating long-term care facilities.

In planning for care for a parent or child, either married or single, she said, you need to know what assets will be available, who owns them, whether they are sufficient for your planning goals, and how they would be accounted. For example, cash is counted but a house or first car is not, and a retirement account is not—provided you are taking minimal distributions. So, if you had both an investment account and a home mortgage, the plan might be to use the money in the account to pay off the house. You also have to plan for MediCal’s attempts to recover your assets after you die, and this might include transferring property to your spouse or kids.

The four basic parts of an estate plan, Durston said, are a revocable living trust; a pour-over will, to put assets into the trust after you die; a durable power of attorney, for financial management; and an advance health-care directive. The trustee should have the power to move property between the husband and the wife, make gifts to children and others, and create and amend special needs trusts as necessary.

A special needs trust (SNT) is a trust arrangement that holds and provides for the management and distribution of property for the benefit of a person with special



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needs. The trust is an agreement between the grantor and the trustee, including successor trustees. The trust contains any kind of assets that you are willing to put into it and the trustee is willing to manage. Typically, the beneficiary is someone who has special needs, is usually but not always disabled, and qualifies for means-tested public benefits like Supplemental Security Income (SSI) and MediCal.¹ The trust is designed to have little or no effect on the beneficiary's eligibility for these benefits.

Generally, in 2016, SSI pays \$889 a month to adults living on their own.² This benefit is supposed to cover food and shelter, which includes electricity, gas, property taxes, and other home expenses. So any money distributed from the trust to pay for these expenses will reduce the benefit. The trust can only distribute up to \$20 a month in cash without reducing benefits. But the trust can provide for any other living expenses such as transportation, entertainment, and education. However, the SNT must prohibit the beneficiary from directing distributions from the trust or revoking it.

Such a trust when created as part of your estate plan is called a "third-party special needs trust." Because situations can change, it can be made revocable by the grantor. The third-party trust lets the special needs person benefit from inherited or gifted funds and still retain eligibility for public benefits. When the beneficiary dies, the assets can then pass on to other beneficiaries the grantor has designated with no payback to the state. The trust can also be drafted to allow distributions to, or for the benefit of, others besides the beneficiary, such as the grantor's or the beneficiary's children.

Sharon Toth is a licensed fiduciary with IMT Associates in San Leandro (www.imtassociates.com), the longest running, full-service private professional fiduciary agency in Northern California. She started as a licensed social worker, but fiduciaries can come from all backgrounds, including real estate, accounting, and financial management. The process of becoming a fiduciary includes education, testing, licensing, and continuing education. IMT Associates specializes in working with the mentally ill and will do a home visit before taking on a client.

In writing an estate plan, Toth said, it's important to choose the right trustee. An adult child or sibling who is currently well might get sick and die before becoming the trustee. It's also important to find someone who will respect what's important to you. Toth recommends finding a neutral third party—one resource is the Professional Fiduciary Association of California (www.pfac-pro.org), representing more than 600 fiduciaries—and interviewing two or three people to find "the person who feels right to be taking over your life." Also, your estate planning should designate someone who has the power to remove and appoint the trustee, fiduciary, or financial manager.

¹ The Social Security Administration operates both Social Security Disability Insurance (SSDI, including Medicare) and SSI. Medicare and SSDI are earnings-based and have no limits on allowed resources or unearned income, although they do limit earned income. SSI and MediCal are needs based, have limits on owned resources (\$2,000 for a single person, \$3,000 for married), and limit both unearned and earned income.

² The amount differs if the adult is living in a board and care, is homeless, or is blind. If the person lives in someone else's home, or someone else contributes substantially to rent, the benefit is reduced by \$260 a month.

The fiduciary not only manages the beneficiary's money as trustee but also helps with his or her living situation as a case manager. This may include services like taking the client to medical appointments and arranging for his or her long-term care. If the fiduciary will be working with a disabled adult or child, she said, it's important to have him or her meet the beneficiary before the trust goes into effect. "The fiduciary will be replacing Mom or Dad in the beneficiary's life. You don't want this person to be a total stranger at what's already a stressful time."

The fiduciary becomes the advocate for a beneficiary with mental illness, dual diagnosis, or a developmental disability. They work to get the client every bit of service he or she deserves—which in this political and economic environment usually requires someone who must be willing to "chew nails" through the application and approval process—and through the inevitable refusal and appeals.

In working with difficult clients, who can be unreasonable and demanding, especially where money is involved, Toth said, "Our job is to love the unlovable."

The fiduciary is like a safety net, not micromanaging the client's life but making sure he or she gets what is needed. "A good fiduciary knows when a person is well enough to have some independence. That gives the person dignity and self-esteem." IMT Associate's services vary, depending on what the client is capable of doing, and the fiduciary renders a full accounting, including fees, at least once a year.

Q. What do these services cost?

A. IMT Associates charges \$150 an hour, and bills in tenths of an hour, like an attorney. Non-professional services, such as home health aides, charge \$35 an hour. The firm also considers the size of the estate and won't take on a client whose assets are less than \$750,000. "For a young person on a special needs trust," Toth said, "that amount has to last them for a lifetime." For those with less assets on hand, there are ways to pool with other trusts (see www.proxyparentfoundation.org).

Q. What happens if the money runs out?

A. The fiduciary's job is to manage the money so that it doesn't run out. Sometimes this can mean reducing services to the beneficiary.

Q. Can a special needs trust be activated while the grantor is still living?

A. Sometimes. If the parents are divorced, for example, they may want to start the trust to take care of a disabled child. Or they may want to start the trust to see how it works while they are still alive and able to make changes. A trust can also be set up if the beneficiary has assets, such as an accident settlement, that will need protecting.

The final recommendation of both Durston and Toth is to find a good lawyer and set up an estate plan and advance directive—and do this sooner rather than later. "You may not think you need it at age 30 or 40, but life is full of surprises and your situation can change quickly."