

# Managing Alzheimer's – straight talk and planning

BY BERNARD A. KROOKS

In Westchester County, 22,000 people are currently diagnosed with Alzheimer's. It's a disease that realigns the entire family constellation. From the bewildering uncertainties of diagnosis through the painful acceptance that someone's world is contracting, no one is untouched. Submerged family dynamics can surface, creating long-remembered conflict. But candor, communication and preparation can lower the stress level and improve quality of life.

Certain decisions are best handled dispassionately, long before Alzheimer's intervenes.



It's hard to talk about the things you fear, but the sooner families begin speaking about health care and finances the better.

Individuals should prepare for the possibility that someone else will be making decisions in their stead and the more their wishes are understood, the less argument there'll be later on. Designating a health-care proxy and power of attorney, then explaining choices, can avoid future clashes.

Putting the rest of the estate plan in order – creating trusts, implementing a will – can contribute order and security during times of emotional tumult. In New York, nursing home care can cost more than \$200,000 annually and it's not covered by Medicare. Long-term care insurance should, therefore, also be considered in any estate plan.

Today, though, 70 percent of the nation's nursing home residents depend on Medicaid,

which has strict income and asset requirements. So many individuals create Medicaid asset protection trusts to guard their life savings in the event of serious illness. In order to be exempt from Medicaid means testing, funds must be transferred to such a trust more than five years before applying.

The rate of depression among family caregivers is reportedly 33 percent. "Often it's caused by denial," explained Burton Greenberg, executive director of the Caregiver Insights Foundation, a nonprofit that provides information to individuals whose loved ones have Alzheimer's. "Suddenly your spouse or parent has this burden and there are new constraints on your own life. Support groups can make a big difference. Just talking about how you feel helps, but there's also a sharing of how to handle everyday problems. It breaks down the sense of isolation."

The strain of caregiving can create ongoing conflict with the ailing person which can lead, in turn, to the wandering that so often worries families.

In-home professional care can help alleviate the stress. "Give your in-home helper tips about what snacks your loved one likes, which music, if he or she likes to take walks," said Greenberg. "Help them to maintain a familiar environment."

But he cautions that bringing professional caregivers into the home can also create tension. Aside from the cost, a healthy spouse may feel that the family home has been "invaded." Routines have been disrupted; they may worry about theft. This sometimes masks an unconscious desire for the "outsider" to fail, a belief that only the spouse can do an adequate job.

One possibility to consider is the creation of a caregiver agreement, under which an adult child or other relative receives remuneration for providing full-time care to the individual. This may be especially appropriate if someone must give up employment in order to assume that responsibility. Such agreements, though,

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are fraught with legal and tax implications and should not be implemented without the assistance of an experienced elder-law attorney.

State and federal budget-cutting discussions further complicate family planning. Who knows what Medicaid and Medicare will look like in the future? New York's 2011 budget capped Medicaid spending and empowered officials, if necessary, to modify benefits and provider payment rates. At the national level, there's discussion about changing Medicaid to a block grant program, giving states increased control over the use of funds.

Medicare, too, is under scrutiny. Although the national dialogue is controversial, for the first time in history both parties agree something must be done about the deficit. This terrible uncertainty should spur families to have early discussions about the health care needs of seniors.

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