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Recognizing the needs of older folks

By Don Kuehn

There is a link between planning for retirement and eldercare issues, whether for oneself or for aging parents—from investing to maintain a good standard of life in older age, to the need to grow and preserve assets so you can leave some inheritance to children or grandchildren, to the quality and scope of care as health and financial needs increase. And don't forget the importance of learning about state and federal programs that can help when times get tough. It's all a complex puzzle that has to be pieced together.

Some of us will spend as many years in retirement as we did in our careers—so it makes no sense to live for today and hope for tomorrow.

In some cultures and families, there is a strong tradition of bringing parents and grandparents into the family home for their late-life care. Far be it from me to say what's right or wrong in each situation, but as a general rule, better care can be found outside the home, at a lower price—both financial and emotional.

I have been down this road myself with parents who were children of the Great Depression and World War II. It is never easy to watch the gradual deterioration of their health and, just as bad, the depletion of the financial resources that would let them live the life you want for them. So, if you'll pardon the personal references, here in a nutshell is my parents' story:

After serving in the war, my father came home and he and my mother—high school sweethearts—raised four kids together. Dad spent his life self-employed in the advertising business, and while we kids never really knew much about the family's finances, we assumed, with the naiveté of the Ozzie and Harriet generation of the 1950s, that we were okay.

I learned much later in life that money and my father had an arm's-length relationship. Mother told me before her death that we were close to losing our home several times as dad's business traced the ups and downs of the economy. Rent and employee salaries always came before his own paycheck. When my parents sold the family home in the Chicago area and retired to Florida they had, for the first time in their lives, some money to invest. They asked me for guidance and I obliged.

Florida was great for both of them. They made friends easily and for more than 20 years felt lucky to have made the move. More than once, my dad told me that, after more than 65 years shoveling snow in the winter, he couldn't believe he could be sitting in a boat catching fish on New Year's Day.

But age and health conspired to dim the sunny life they lead. Dad had a couple of bouts with cancer, each treated as successfully as could be expected, and had various other maladies associated with getting close to 90. Mom gradually lost her vision to macular degeneration.

I took on the responsibility of handling their finances and caring for their needs—not an easy task from 1,500 miles away. But it is from this perspective, and the research I did to be sure my decisions were in their best interests, that I have come to the conclusions about the advanced planning and care decisions I write about.

Whether you live in the same house, the same town or far from your parents, there are some warning signs that you should be sensitive to when you visit, according to www.AgingCare.com.

Maybe the mail's piling up, or you notice unexplained weight loss; maybe a parent's personal grooming isn't being maintained at the level you've come to expect. When you ask, they assure you there is nothing to worry about, but you still feel something may be wrong. Here are some warning signs that you should be on the lookout for:

- spoiled food;
- missing important appointments;
- unexplained bruising;
- trouble getting up from a seated position;
- difficulty with walking, balance and mobility;
- uncertainty and confusion when performing once-familiar tasks;
- forgetfulness;
- unpleasant body odor;
- infrequent showering and bathing;
- dirty house, extreme clutter and dirty laundry piling up;
- stacks of unopened mail or an overflowing mailbox;
- late-payment notices, bounced checks and calls from bill collectors;
- poor diet or weight loss;
- loss of interest in hobbies and activities;
- changes in mood or extreme mood swings;
- forgetting to take medications—or taking more (less) than the prescribed dosage; and
- unexplained dents and scratches on a car.

No one wants to lose their independence. Admitting that help is needed and being willing to accept are not easy for people as they age. There are dark myths about “nursing homes” and the kind of care one can expect to receive, but a missed appointment or a bruise that can't be explained doesn't mean they're headed to a nursing home.

There are many levels of care and assistance that could be called upon to help your aging parent. They run the gamut from adult day care or periodic in-home services to independent living, assisted living, skilled nursing and long-term care. I am a believer in finding facilities and services in the area where your parents live and introducing them to what's available so that when the time comes, they can be part of the decision-making process.

At a point where my mother was unable to use kitchen appliances because of her vision, and my dad couldn't handle stairs, I was able to persuade them to look at a couple of nearby facilities that I had previously checked out. We ended up agreeing on a “village” that included independent living (with housekeeping and full meal

service in a common dining room); the facility also had assisted living and skilled nursing on the same campus. Eventually my parents did “graduate” to each successive level of care before my father died in 2007.

My mother decided to stay in Florida for a while, but eventually we convinced her that she should be closer to family. Her move to Iowa (where my younger brother lives) was hard. We found an assisted living facility where she was very comfortable. She had a private room, regular meal service and medical care as needed; prescriptions were distributed on schedule, and there were social and religious activities that kept her active. This kind of care doesn’t come cheap—even in Iowa. Her monthly costs were more than \$5,500 per month.

But her healthcare needs increased after a brief hospital stay, and I had to look for another place for her. Knowing that her financial resources were being depleted at a rapid clip, it was critical that she move to a place that was both Medicare and Medicaid certified. That way, if her money ran out she would not have to move yet again.

Medicaid will cover the costs of a semi-private room after one’s financial resources have been spent down to a state-determined level (in Iowa it’s \$2,000). The place we found for her last move was certified and had a good patient/staff ratio, but as important, it didn’t have any semi-private rooms. That meant Mom could stay in her own private room after her financial resources were spent and not have to share a room or re-learn new surroundings.

If you’ve never had the experience of caring for the needs of an elderly person, you’d be shocked to learn just how expensive it can be. My mother received Social Security and, toward the end when she “means-tested,” she was able to get a small Aid and Attendance benefit from Veterans Affairs because my father was a wartime vet. She still had a little of that nest egg left from the sale of the family home some 30 years before. Her income was less than \$2,500 a month.

On the other side of the ledger, her monthly expenses for room and board were about \$5,200; Medigap insurance, telephone, Medicare Part D (prescription drugs) premiums and incidentals ran about \$100 to \$200. Her total costs ranged from \$5,500 to more than \$7,000 per month depending on the amount of prescription drugs she needed and whether she had fallen into the dreaded Medicare Part D “doughnut hole.”

At this rate, it didn’t take long to burn through what was left of her savings and investments and qualify for Medicaid (Title XIX as they like to say). At that point, the state Department of Human Services worked with me to set the exact amount her care would be reimbursed. To oversimplify, it meant we paid the long-term care facility an amount about equal to her income, and the state paid the rest.

The notion of long-term care insurance was unheard of when my parents were at a point that they could consider it. For me, it’s a no-brainer. I encourage almost everyone to at least investigate LTC insurance for themselves (see: “No Generation Gap ... they’re all at home” www.aft.org/newspubs/periodicals/yourmoney/index.cfm). Today’s LTC policies can cover a variety of services, including in-home services, adult day care, respite services for stressed caregivers, and a range of assisted living to long-term residential care.

I have to say that I was among the very fortunate. I got to see both of my parents advance to a ripe old age in very good mental health. Not so lucky are those whose parents begin to show signs of dementia or Alzheimer’s disease. Watching your parents’ decline, witnessing unprovoked and uncontrolled outbursts toward children or strangers, worrying that a parent will wander off while you are coping with the strains on your own marriage, family and job can be devastating.

“Hindsight can make us pretty smart,” says Carol Bradley Bursack writing on agingcare.com. “We should not tell our parents we’ll never put them in a nursing home, since we have no idea what the future will bring. Also, [making] that promise just underscores their view of the old style nursing homes, which were truly depressing places.”

But today, long-term care facilities are way better than the stereotype of years ago. Even if you have committed to “never” putting your parent in a nursing home, you might one day have to renege on that promise for their own well-being. Their health, your ability to help or other financial considerations all could lead to a re-evaluation of circumstances. That’s OK.

If you are trying to juggle your own family, your job and home while caring for a parent with dementia or Alzheimer’s, it’s easy to get burned out yourself. Before you get to that stage, look for help. Search the Web for your state’s services on aging. A few clicks can bring you the help you need to get the parent you love the kind of care he or she deserves. For your sake and for the rest of your family, find the resources that can make your loved one’s life as comfortable as possible.

Here are a few tips from www.eldercarelink.com to help families trying to care for a loved one:

- **Take a break.** Allow yourself and your partner to get away. Go on a date, take a walk together. As mentioned, some LTC policies offer respite care which gives in-home caregivers a chance to get away while a professional sits in for a day or two.
- **Talk about it.** Ask your significant other what is, and is not, working in the arrangement. Be an active listener, take notes and find help if there are issues that need to be addressed. Do a daily “download” by sharing your feelings at the end of each day. Sit in a quiet place, share a glass of wine, cry if you need to, but don’t bottle up your feelings and don’t hide them from your partner.
- **Skip the guilt.** Unless others in the family want to take over the caregiving chores, ignore their criticism. You are in charge, you are doing your best to provide the kind and degree of care that your loved ones deserve. Unless someone else has “walked in your shoes,” he or she can’t understand the stress and dedication associated with your job.
- **Prepare for the change of place.** There may well come a time when in-home care is no longer appropriate and a move to a higher level of care is required. Scout out facilities in your area ahead of time. Often, there will be waiting lists for the best places, so be prepared to take action when the time is right.
- **Nurture your love.** Let your spouse or partner know how much you need them and how much you appreciate their support.
- **Most important, remember to live, laugh and love—each other and your elders.**

I would add that your area’s Agency on Aging (or local hospital, hospice, senior center or adult day care center) will be able to direct you to support groups for people who, like you, are putting the needs of a family member at the top of their priority list. Check them out.

Nearly every person who has ever lived has had to go through the heartache of watching those who came before them get sick and eventually pass on. “It is a universal law, but even with all that has been written, when it happens to you—there are no words that describe the depth of the sorrow. No one should ever have to face that alone, so be sure to get into a support group right away—you’ll be glad you did!” So says Jacqueline Marcell, author of *Elder Rage* and host of her own radio program “Coping with Caregiving.”

Living far from your loved ones can complicate caregiving, but it's still possible to take a healthy and active role wherever you live. Whether or not you are the primary caregiver, you can ask tough questions, you can call a family meeting to discuss long-term care and contingency plans as well as to clarify the roles and responsibilities of all family members.

If you have a meeting, be sure all medical records, including durable powers of attorney, physicians' names and contact numbers, current prescriptions, living wills and advanced directives are together in one place and that all family members know and understand their contents. If your parents are alert, be sure they are involved at each step. Don't treat them like children. Don't be condescending or patronizing. Don't strip away their independence.

Remember that you and your family are not in this alone. You don't have to be a pioneer and blaze this trail for the first time. There are resources out there to help you, and you should take advantage of them.

More than 50 million Americans are taking care of a family member or friend—and 20 million of them are baby boomers caring for an aging parent. One day they (*you*) will be on the other side of this equation. The better you prepare your finances, your important documents and your outlook for that day, the better off you and your caregivers will be. It's *your money*. The more you save and invest, and the more steps you take (like buying long-term care insurance), the easier it will be for everyone concerned.

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