

CAREGIVER NEWS

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“Who Moved My Teeth?: Preparing for Self, Loved Ones and Caregiving”

By Cathy Sikorski, Esq. Corner Office Books: United States of America, 2016.

A book review by Sister Kathleen Weber, CSC

This book is written through two lenses: elder law and humor. They are like the cream and sugar in a good cup of coffee. The author, Cathy Sikorski, Esq., has been an elder law attorney for 25 years and her work is filled with essential legal advice that every caregiver needs along the journey, for themselves and those for whom they care. More information about Medicare and Medicaid from “Cruising through Caregiving” is featured separately in this publication and is merely the icing on the cake.

What Ms. Sikorski teaches us changes rapidly between time and place, and definitely requires the knowledge and services of an elder law attorney. Expensive as attorneys are, they can save you money and time, and help you avoid disastrous mistakes. If there is only one thing you learn from this book, I hope it is that we all need the advice from an expert who can guide us through, under and over the obstacles of law.

A durable power of attorney is a document that allows a designated person to make all health care decisions for the person who signs it. In Maryland, it is more commonly referred to as a living will that usually includes advance directives. The living will allows you to designate someone to make health care decisions for you when you are no longer able to. It gives the agent “the power to act as if you are that person” in all health care situations. The power of attorney also gives the agent power or authority to talk to whomever about

the signer’s health care. The advance directive portion sets forth what health care you would like provided or withheld or withdrawn if you are in a terminal condition and cannot speak for yourself.

The Durable Health Care Power of Attorney (POA) or living will “is the best and most powerful document you can have.” It lasts forever, unless the signer cancels it in writing.

A Durable Financial Power of Attorney gives someone the power to act as that person in all financial situations. “Never underestimate the need for this document. Everyone needs the Durable POA at every stage of adult life.” The author even includes college students who are not living at home. Different states have different laws and you need a lawyer’s advice about “how much power you need to bestow.”

Ms. Sikorski includes a list of questions to help you decide who your POAs should be. Different situations require different decisions with guidance from an elder law attorney. Ms. Sikorski advises making all these preparations before they are actually needed. It is much more expensive to handle the situations after an emergency has occurred. “No one can sign a power of attorney giving authority to an agent if the signer is mentally incompetent or has no understanding of what they are signing.”

If this has not already been taken care of, it can lead to the need for guardianship,



a much more complicated and expensive process.

Don’t be offended when the lawyer says, “I would like to speak to your mom or dad without you in the office.” This is for your protection, your parent’s protection, and it is a sign that the lawyer is doing a good job.

Information on wills, trusts, living wills and long-term care insurance follows, all of which are important for the family caregiver. The book is small but packed with vital caregiving information. Then there is “Medicare, Medigap and Medicaid ... Oh, My!” These topics are explained on page 5, with references to www.Medicare.gov or www.Medicaid.gov.

Ms. Sikorski also goes into significant detail about Medicaid obligations and benefits. Social Security benefits can be clarified by visiting <https://maximizemysocialsecurity.com>.

The book is filled with other significant information for family caregivers. The advice and guidance is well worth the book’s price.

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“The Alzheimer’s Action Plan: The Experts’ Guide to the Best Diagnosis and Treatment for Memory Problems”

By P. Murali Doraiswamy, MD, and Lisa P. Gwyther, MSW, with Tina Adler. St. Martin’s Press: New York, 2008.

A book review by Sister Kathleen Weber, CSC

In this long, comprehensive work, the authors aim to create a plan of action to enable you “to get the best diagnosis and treatment for the person in your life who has or may have Alzheimer’s. This action plan will also help you find the best support for the person with the Alzheimer’s and the person taking care of him or her.” At the time of their writing, the authors believed that most Alzheimer’s patients were brought for medical help only after brain damage was already advanced. They hope the information they are providing will help caregivers seek appropriate medical care in a timely manner enabling caregivers to develop the best action plan to meet their needs. “We are advocates who believe that people with Alzheimer’s have the right to access the best, most personalized care possible.”

Older people without a mental disorder, often with some help, can carry out their errands, handle money, plan their activities, and behave appropriately. People whose brains have been damaged by Alzheimer’s disease maintain old memories, but cannot recall recent happenings or conversations; plan and carry out tasks; find the right words or names; follow simple directions; or keep track of time and place. “The severity and the speed of the memory

loss distinguishes aging from Alzheimer’s.”

“To be diagnosed with the disease, there have to be signs that the person’s memory has declined along with one other cognitive or ‘thinking’ function, such as language, sense of time, judgment, reasoning, or executive function ...”

Those affected often lack a self-awareness that accompanies their apathy and indifference, which hit at different times. The authors cite one study in which those suffering with the disease view their problems as difficulty handling money, getting lost and forgetting what they just did. Family members saw them as unusually quiet, withdrawn and apathetic.

Getting a diagnosis of Alzheimer’s disease is no simple task, especially for those with

early-onset disease, between ages 55 and 64. In some cases, diagnosis can take one to five years. Although the symptoms of Alzheimer’s resemble those striking older people, it progresses more rapidly. “Early-onset memory loss can also result from a severe head injury, Down syndrome, stroke or vascular disease.” Other diseases such as alcohol abuse, malnutrition, HIV, syphilis, herpes and thyroid deficiencies can cloud the horizon. The authors include lists of warning signs of Alzheimer’s – of which we

should all be aware – and a self-examination tool. Lists of other possibilities and descriptions of other types of dementia follow. Another section on inappropriate medications is also included.

An early diagnosis is important because it eliminates other diseases for which treatments are available and opens the way for early treatment.

“Alzheimer’s begins damaging the brain decoder before symptoms appear, especially in people who are genetically vulnerable to the disease. By the time you notice problems, Alzheimer’s has already affected your brain. But you can do a lot to ease the stress and take control of your life if you get diagnosed early. Once diagnosed, make medication and lifestyle changes; get help from your family and participate in clinical studies. ... You can make sure your family knows your preferences, values and priorities. You can plan for where you want to live and find the right level of supportive housing or network of family and friends to see you through the upcoming years.”

To get this important diagnosis, our authors suggest seeing a geriatrician, geriatric psychiatrist, general neurologist, behavioral neurologist or a memory center. However, they suggest you start with your primary care doctor, who knows you well and whom you trust. The primary care physician should be able to refer you to one of the above.

“The severity and the speed of the memory loss distinguishes aging from Alzheimer’s.”

- P. M. Doraiswamy, MD;
L. P. Gwyther, and T. Adler

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The book gives good advice on preparing for the patient visits, preparing the patient, and what to take with you and what the doctor needs to know in advance. There is even a form for the family member to complete. It can be used to give necessary information to the doctor or to acquaint the doctor with the person's memory problems.

Physical and mental tests should follow, which will alert the physician to neurological problems that cause or contribute to memory loss. Lists of essential assessments and optional tests are also included in the book.

The book presents sections on clinical trials and medications for Alzheimer's patients. However, since the book was published ten years ago, and some progress has been made in that time span, that information is excluded from this review.

The remaining two-thirds of this book are devoted to life after the diagnosis and several appendices with resources and references. The book ends with 40 most frequently asked questions by caregivers and the answers.

All this information is invaluable to caregivers and other family members. I highly recommend it to those in search of ways to be helpful and for those responsible for loved ones with Alzheimer's disease.

The Holy Cross Caregiver Resource Center's library provides access to this book and other resources. Call 301-754-7152.

New and Noteworthy

Catholic Business Network Honors Sister Kathleen Weber, CSC, with Community Leader of the Year Award

The Catholic Business Network (CBN) of Montgomery County, Md., named Sister Kathleen "Kathy" Weber, coordinator of the Holy Cross Caregiver Resource Center, Community Leader of the Year. Sister Kathy received the award at the CBN's 25th Anniversary Gala on Nov. 30.

Each year, CBN selects one community member for this great honor, which recognizes individuals who dedicate their lives to serving others.

"I am honored to receive this award for my work at the Holy Cross Caregiver Resource Center," said Sister Kathy. "Families caring for aging or seriously ill loved ones face many challenges, and through the Caregiver Resource Center, we give them the support and resources they need, and the opportunity to bond with other caregivers."

Holy Cross Health has a long-standing commitment to meeting the specific needs of patients 65 and older, their families and caregivers. This commitment drove Holy Cross Health, with Sister Kathy's leadership, to establish the Holy Cross Caregiver Resource Center in 1992, one of the first of its kind in the state of Maryland.

Today, Sister Kathy hosts seven support group sessions each week for adults caring for aging or ill loved ones, a telephone helpline, and caregiver education classes. All services are provided free of charge.



Caregivers Need Support, Too

By Sister Kathleen Weber, CSC

The number of caregivers is rising dramatically as the number of older Americans and people with chronic conditions increases.

Caregivers take on the crucial role of caring for family members who can no longer care for themselves. Caring for a loved one can be very rewarding, but many caregivers also face challenges taking on such a demanding responsibility.

A strong support system is necessary.

Early Signs That a Caregiver is Needed

A caregiver is needed if bills are not getting paid, food is not available or fresh, the kitchen is not safe, medications are not being taken or managed properly, or safety hazards exist in the home. Other signs are issues of personal cleanliness like not showering or putting on clean clothes, or hoarding things like stacks of newspapers.

The Caregiver's Role

Family caregivers monitor the needs of the person in their care. They provide in-home care or hire professionals to provide this care. In cases of long-distance caregiving, they may need to look into care managers. They investigate residential facilities in case the need should arise, check on medical care, pay or supervise paying of bills, and assure the safety of the residence. They should be aware of financial assets and know where they are, and they should try to get advance directives clear and in writing.

Caring Challenges

The challenges are endless. Elders want to be independent and will try to conceal problems if they can or they may be resistant to receiving help from a caregiver. There are financial needs. And personal issues within the family can cause friction.

Caregivers can face burnout unless they really take care of themselves and learn how to establish boundaries. They need time for themselves. You can't give to somebody what you don't have yourself, so you've got to keep that nourishment and enrichment coming in to be able to handle difficult situations. They become so bogged down with caregiving they forget that.

Guilt is also a big thing in caregiving. Even though caregivers do everything humanly possible for their family member, they still feel they're not doing enough or that this is happening because they're not doing enough.

Ways to Cope

At the Holy Cross Caregiver Resource Center, we have a motto in our support groups and a sign on the wall that says "Let whatever you do today be enough." And I try to drum that into their heads. No, they're not perfect. They cannot do everything. But whatever they do is all they can do, and as long as they do it well nothing more is expected.

A Support System

Caregiving is not a one-person job. Your support system is very, very important, and many caregivers consider it life-saving. You need lots



of help and support from your family, your religious leaders, understanding friends, and professional help like therapists and care managers.

Support Groups

At the Holy Cross Caregiver Resource Center, we have seven support groups a week. There are usually six to 10 people in the support groups. Sometimes it's larger, sometimes it's smaller. We can accommodate 11 people comfortably without bringing in extra chairs.

Some people have been in these groups for years. Other people are new. Some people, particularly spouses, like to stay with the group for a while after the death of their loved one because that has become their support system and they've bonded so strongly that they continue to come for a while.

Other Resources for Caregivers

In addition to our support groups, there are many books and DVDs, which you can find in our Caregiver Resource Center. There are also materials you can find on the internet, such as webinars. Professional organizations like AARP, American Cancer Society and the Parkinson's Foundation offer programs, classes and other resources to help caregivers grow in knowledge and confidence.

For more information or to register, call 301-754-8800 or visit HolyCrossHealth.org.

Medicare and Medicaid

"Cruising Through Caregiving"

By Jennifer Fitzpatrick. Greenleaf Book Group Press: Texas, 2016.



A book review by Sister Kathleen Weber, CSC

In the last issue of Caregiver News, I reviewed *Cruising through Caregiving*, by Jennifer Fitzpatrick, MSW, CSP. I skipped the chapter about Medicare and Medicaid because I thought those topics needed special attention. Many caregivers are unclear about which pays for what and what expenses are self-pay.

If you see the caregiving of elders in your future, you need to meet and pick the brain of an elder law attorney for help and guidance before critical decisions need to be made and the bills start rolling in. When you find the appropriate attorney for your needs, be open with them. The lawyer must become aware of the assets, or lack thereof, of the elder reaching retirement age.

These specialized attorneys can be expensive but they often save the family more money and mistakes than they charge. Their expertise and prior knowledge of the family's assets can enable them to draw up a financial plan so the financial decisions can be made more easily and safely. With their aid, the family may be able to find additional money and determine how to make the best use of what is available.

First let's look at **Medicare** which is an "entitlement program in

a federally funded health insurance benefit that nearly all adults 65 and older qualify for." Most adults 65 and older have paid into this benefit through their work history or that of their spouse. This happens through an automatic workplace deduction. **Part A** covers an overnight stay in the hospital. It may also cover a short-stay in a nursing facility or a rehabilitation center. **Part B** covers medical services like a visit to a doctor's office. **Part D** offers prescription coverage.

There are additional programs like the Medicare Advantage Plan and Medigap Plus. The best sources of information on Medicare can be found at www.Medicare.gov, through the State Health Insurance Program (SHIP), and through your Area Agency on Aging (AAA).

“Even the wisest, most savvy and financially responsible adult children are almost never totally prepared for the financial reality of elder care.”

- Jennifer Fitzpatrick

Medicaid “is a benefit program funded by both the federal government and individual state governments.” Medicaid is not received automatically. It is needs-based, for which the needy person must apply. The federal government contributes to Medicaid, but the program is administered by the state in which the applicant lives.

Often, adults use it for long-term nursing home care. If the need persists, an annual application needs to be renewed. In some

states, like Maryland, Medicaid can be used for adult day care.

An elder law attorney can assist in completing these applications. Maryland has several Medicaid waiver programs with which an elder law attorney can assist. They can help the person and a couple with asset management. They also may be able to assist with the five-year look back period. Complete information about Medicaid is available at www.Medicaid.gov.

Care that is not time-limited and other types of aging services are usually out of pocket. Many families are totally unaware of these expenses of caring for the elderly family members. Medicare, and even Medigap, do not pay for home care aides.

“Even the wisest, most savvy and financially responsible adult children are almost never totally prepared for the financial reality of elder care. If you have been caught off guard by the responsibility of elder care, it is not too late to better inform yourself about all the additional financial challenges you will continue to face.”

Jennifer Fitzpatrick lists seven suggestions that may help you find help in this financial crisis. She continues with guidance in making a budget for this need and how, with the help of your elder law attorney and financial planner, you may find ways to help with this financial challenge.

NOTE TO FAMILY CAREGIVERS: As time passes and caregiving situations change, you may find you no longer need this newsletter or the services of the Holy Cross Caregiver Resource Center. If you find yourself in this situation, please call Sister Kathleen Weber at 301-754-7152 to have your name removed from the mailing list. These resources are provided to assist you and not to endorse any particular entity, service or event.

FREE Caregiver Support Groups

For more information or to register, call 301-754-7152.

Support groups are held at the Holy Cross Resource Center, 9805 Dameron Dr., Silver Spring, Md., unless otherwise noted.

Adult Children Caring for Aging Parents

Mondays from 6 to 8 p.m.; Tuesdays from 3 to 4:30 p.m.; or Thursdays from 10 to 11:30 a.m.

Caregivers of Ill or Aging Spouses

Wednesdays from 10 to 11:30 a.m.; Thursdays from 3 to 4:30 p.m.; or Fridays from 10 to 11:30 a.m.

Caregivers of Seniors

First and third Thursdays from 2 to 3:30 p.m. at the Benjamin Gaither Center, 80-A Bureau Dr., Gaithersburg, MD 20878.

Telephone Support Group

For spouses and adult children. Tuesdays from 6 to 7:30 p.m. Call 301-754-7152 in advance for the code.



Caregiver Resources

Clinical trials test interventions such as drugs or devices, as well as diet or lifestyle changes. Drug testing is the focus of many clinical trials. Now, more than 70 drugs are in clinical trials for Alzheimer's disease, and more are awaiting U.S. Food and Drug Administration (FDA) approval, to begin testing in people. To learn more about these trials and find out if you or your loved one qualifies to participate, contact one of the following:

- **Clinical Trials:** www.clinicaltrials.gov
- **National Institutes of Health (NIH) Clinical Research Trials and You:** www.nih.gov/health/clinicaltrials
- **U.S. Food and Drug Administration (FDA):** <https://www.fda.gov/ForPatients/ClinicalTrials/default.htm>