

Best Kept Secrets

One of the saddest comments to hear in a support group is: "Oh, if only I had known that sooner." Often this revelation follows a reference to geriatric care managers, now known as Aging Life Care Professionals. They are usually nurses and/or social workers who assist families caring for aging or disabled relatives. These professionals are trained and experienced in helping families locate help, facilities and other appropriate resources. Many times parents are unwilling to accept the suggestions of their adult children because parents still think of them as "their kids." When a professional tries to help, this person may get more respect, with the elders more willing to cooperate.

It is like "the doctor says" only the expertise of the care manager extends to assessment skills, long-term planning, advocacy, long-distance caregiving, transportation, attending doctor's appointments and other duties as assigned. They also help families with problems of communication and understanding, health questions and the doctor's instructions as the client's needs change.

If the client needing care and supervision is separated from his or her family by distance, the care manager can monitor his or her care as the family's eyes and ears and be accountable to them as their agent. The care manager can consult with the elder law attorney when necessary, oversee financial situations and bring in financial planners as needed.

Sometimes the family may not have the time or the patience to do what the care manager is trained to do. Or maybe they can't try one more time. Disagreements among family members desperately call for professional intervention.

Aging Life Care Professionals are private pay but are usually worth their weight in gold. The Aging Life Care Association recognizes advanced professionals who have: 1) formal higher education in a relevant field; 2) established and supervised work experience in the field; and 3) a professional certification such as Care Manager Certified (CMC), Certified Case



Manager (CCM), Certified Advanced Social Work Case Manager (C-ASWCM) or Certified Social Work Case Manager (C-SWCM).

Role of the Ombudsman

Another little known commodity is an "ombudsman," an advocate for residents living in nursing home and assisted living facilities. Montgomery County's Long-term Care Ombudsman Program serves in 34 nursing homes and 183 assisted living facilities, and is run by the Montgomery County Department of Health and Human Services, Aging and Disability Services. In 1978, the Older Americans Act made the program mandatory in every state. In 1997, Montgomery County's program began including licensed group homes.

Volunteer ombudsman are trained by staff in Aging and Disabilities Services to improve the quality of life and care of long-term care residents. Funding from federal, state and local sources maintains the program and its services to residents of nursing homes and licensed assisted living residences. Their mission and goal is to resolve problems, initiate best practices and convey whatever is necessary and possible for the highest "degree of quality of life and care." These volunteers strive to resolve problems within the long-term care facilities for the residents, families of residents and facility staff and administration. Their assistance is needed by those vulnerable adults who need help improving their quality of life.

Those whose family members are or may become residents of facilities should be aware of this service provided by the county and share the knowledge with others.

To search for Aging Life Care Professionals, visit the Aging Life Care Association Mid-Atlantic Chapter at midatlanticgcm.org.

CAREGIVER NEWS

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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.

FREE Caregiver Support Groups

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.

Telephone Support Group

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

Caregivers of Seniors

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

FREE Caregiver Events

Held at the Holy Cross Resource Center, 9805 Dameron Dr., Silver Spring, Md., from 10:30 a.m. to noon.

February 13: "Know the Signs"

Early detection of Alzheimer's disease can give family time to plan for the future. The caregiver will learn 10 warning signs of Alzheimer's disease, including how to differentiate between Alzheimer's disease and normal aging, what to do if you see signs in yourself or a family member, diagnosis and the importance of early detection.

March 13: "The Basics of Alzheimer's: Memory Loss/Dementia and Alzheimer's Disease"

Topics include symptoms, effects and other types of dementia; how Alzheimer's disease affects the brain; causes and risk factors; how to get and address a diagnosis; the benefits of early detection; treatment; and assistance.

April 10: "Dementia Conversations"

Topics include family conversations about challenging and uncomfortable behaviors, tips for having such conversations, trips to the doctor for a diagnosis or treatment, deciding when to give up driving, and making legal and financial plans.

May 8: "Legal and Financial Planning"

For those who have received a diagnosis of Alzheimer's disease, the time for legal and financial planning has arrived. Topics include legal plans to fit your needs; legal documents and what they mean; sources of legal and financial assistance; creating a practical long-term plan of care; using available tax deductions and credits; and government assistance that may help pay for it.

Strokes: Your Guide to Before, During and After

A stroke, also known as a cerebrovascular accident (CVA), can happen to any person at any age, but we usually think of it happening to the elderly. The potential is always present, but rarely does a family have a "stroke plan" in place to help them respond to such a devastating occurrence.

Know the Signs

Caregivers should be very aware of the signs and symptoms of a stroke, because reacting quickly is critical to a person's ability to recover. In fact, intergenerational stroke programs are gaining popularity to educate younger family members how to take action. See page 4 to learn how to identify the signs of a stroke and how to react to seek immediate treatment.

Understand the Family Impact of a Stroke

According to Ellwyn Collins, author of "Unprepared! A Husband's Story of Coping with His Wife's Stroke," "A stroke has great impact on both the stroke survivor and the significant people in the patient's life. The amount of success a person achieves in taking the steps toward recovery depends to great extent on the support he or she receives from family and friends, and how closely they work with the attending team of health care professionals in conquering challenges caused by the stroke."

After a loved one suffers a stroke, emphasis must be placed on the patient's remaining strengths and abilities rather than on his or her losses and limitations.

There are two types of stroke:

1. When blood vessels are blocked and not enough blood is able to reach the brain (ischemic stroke)
2. When a blood vessel ruptures and bleeds inside or near the brain (hemorrhagic stroke)



Receive a Rapid Diagnosis and Treatment

When receiving care at a nationally designated Primary Stroke Center like Holy Cross Hospital, medical professionals focus on a rapid emergency room response, speedy diagnosis and immediate treatment intervention to restore blood flow to the brain. A CAT scan is typically used to determine the type of stroke and the treatment approach. Sometimes an MRI is needed to view smaller sections of the brain. Support from family and friends is very important at this stage.

As soon as the patient is stabilized, therapy begins and increases in intensity as the patient's condition allows.

Setting Your Loved One Up for Success After a Stroke

Those who have had a mild stroke very often go directly home and continue physical therapy as an outpatient. If Medicare is paying for home care, the patient must be homebound for the duration. Otherwise, depending on the severity of the stroke, medical staff may decide on acute or subacute (less intense) rehabilitation. Patients in a subacute facility generally receive one or two hours of therapy daily, which may be a combination of physical, occupational

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“Caregiving: The Spiritual Journey of Love, Loss, and Renewal.” By Beth Witrogen McLeod. John Wiley and Sons, Inc.: New York, 1999.

McLeod quotes Daniel Paris, a social worker at Massachusetts General: “Caregivers are ordinary people caught up in extraordinary events.” If this description describes your situation, you may want to share the author’s companionship and wisdom on your caregiving journey. McLeod describes caregiving, “the act of providing assistance to someone ill or frail,” as “one of the most catalytic challenges” in life. Often family caregivers have trouble sorting out the problems, much less being able to ask for help. She suggests asking the following questions:

- Am I listening to what the care receiver is expressing through words or body language?
- Will I appear greedy or controlling by asking about finances and estate planning?
- Should I move in with a parent? Move the parent in with my family? Or will home modifications keep my loved one independent?
- Which sibling should be in charge? How can we share duties? What other family members or friends can pitch in occasionally?
- Does it matter what others think if I institutionalize my loved one?

Many recommend a family meeting that includes all affected members with an objective third party professional. However, nothing is cast in stone and all decisions can be changed as the situation changes. McLeod notes, “The challenge for families is balancing the decision-making authority that elders need with the assistance required to make sure they’re ok.” The kinds of assistance range from running errands and yard work to continual monitoring at home or in a facility. Local Area Agencies on Aging and Villages that are popping up in our area are good sources for help and/or advice, as are support groups. The fall 2017 issue of Caregiver News (available at HolyCrossHealth.org) explains in detail the necessary legal and financial planning needed.

As life goes on, family dynamics change; adult children have to determine how to help their parents without taking away their parents’ power to also make decisions. “What matters is to give dignity and attention to a parent’s final years, even if that means unsettling our lives, giving up for a time some of our adult dreams.” Many times the experience on the journey can help repair less pleasant past relationships. “It is a caring heart that sees us through.”

Action steps include:

- Involve your parent in as many aspects of planning as possible. Listen to, respect, and have compassion for his

or her desire for autonomy and control. Work together to set up a flexible care plan and remember that it can be changed when needs dictate.

- Monitor or curtail a parent’s activities that pose safety risks, such as cooking, driving or operating machinery.
- Monitor whether your parent is eating and exercising properly, getting enough liquids, maintaining social contacts, negotiating stairs safely, and dealing with other housing elements competently. Assess housing features that may need modification.
- Work out unfinished business and old wounds – with parents and siblings alike – so that there will be no regrets or guilt about what has happened.
- Find out where legal and financial documents are kept and who the professionals and advisers are (legal, financial, medical). Assess finances, both yours and your parents’, so that if a crisis hits, you have some idea of what options are possible.
- Educate yourself about resources in your parent’s community; talk to professionals early on to learn what options, such as housing and in-home support, are

available. Sometimes there are waiting lists, especially for sought after nursing facilities or retirement communities; you may want to put your parent on those lists as a precaution.

This list of questions continues and there are more in the book providing useful and practical suggestions for caregivers who are new to the role and want to do their very best for their parents and families. A guided journey is much easier than a blind one.

Spousal caregiving differs from caring for a parent:

- The workload increases
- The loss of intimacy is accompanied by the pain of abstinence and guilt
- Financial stress
- Children are frightened
- Emotions – anger, frustration and fear

The spousal caregiver can suffer the loss of identity as he or she is swallowed up by caregiving. Even after the death of the partner, the caregiver can experience a loss of self, along with guilt and uncertainty. “It is both human nature and the nature of caregiving to feel that we alone must tend to all our spouse’s needs, always “resulting in extreme stress.” “It is not who we are when caregiving begins that defines our character and sets us free, but who we end up becoming.”

“Family caregiving is one of the most stressful endeavors we

may ever engage in.” Caused by demands on time and energy, and by fear of loss, caregiving can result in emotional loss and physical problems. Instead of denial and wishing things were the way they used to be, families need to work on coping and problem-solving skills. Instead of moving from crisis to crisis, they need a plan for long-term care. Setting limits, boundaries and priorities is essential. Pessimism can be deadly.

“A person’s outlook may be more beneficial or harmful than the event itself.” Caregivers need companionship, social support and understanding from others. When they believe no one can care as well as they can, death can follow! “Studying our aloneness, we discover the meaning of relationship is the solitude of caring, we gain compassion for ourselves and fill a world of silences.” Beware of guilt, loneliness, anger and resentment. Again coping skills can be cultivated as a defense.

Science and technology have forced us to look at death in new ways. “The dialogue on dying is not limited to terminal care but extends to the sacredness of life itself...decisions about prolonging life are having to be made among family members who always rejected such matters to be the sole domain of medicine or religion.” Life and death decisions involve the whole family as they confront quality versus length of life with medical professionals.

“Dying Well,” the philosophy of Ira Byock, MD, proposes making hospice care — a form of palliative care meant to alleviate pain and address the psychological and spiritual needs of the dying — available to all. Rather than prolonging death, hospice care provides a less painful existence with emphasis on well-being rather than curing. It treats the person rather than the disease, trains the family in comfort care, and provides spiritual and emotional support to the family.

“Where love is, there is transformation...because love is transformation from moment to moment. Family caregiving is like this: love arises from service, service has come from love. Out of this subtle exchange comes new purpose in a timeless convergence of all that we have learned and become. Caregiving magnifies and focuses the best we have to offer, and gives us permission to live an authentic life – who we are at heart rather than who we think we should be. Our urge to care has become who we truly are.”

“Deep love is unconditional, it conquers all things. Maybe caregiving should be called ‘heart-giving care.’”

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

and speech therapy. The purpose of therapy is to restore as many lost skills as possible, and to regain normal use of the body.

Eventually the patient is discharged from the rehabilitation center to go home or to long-term care. Depending on the remaining disabilities, sometimes almost overwhelming decisions must be made. How can the patient be transported? How can he or she get into the house? Can the patient climb steps or is a ramp needed? What about stairs leading to the bedroom and bathroom? Will the layout of the first floor allow for a hospital bed to be set up? Is there a first-floor bathroom? Will a stair glide or lift help the person move from one floor to another? Are the bathrooms handicapped accessible?

There are professionals who specialize in helping families make important decisions, depending on the home structure, patient’s needs and finances. Not only is professional help available for home remodeling needs, but the caregiver may need assistance, too. Certified nursing assistants and geriatric nursing assistants may be helpful in providing personal care for the patient and for the caregiver. This support can be for several hours in the morning, when the caregiver needs time away, or all day or night depending on situational needs. No one can handle all of this alone. Take advantage of professionals for advice and assistance, from building ramps, to preparing lunch, to going for a walk. It takes a village!

Holy Cross Health Resources for Stroke Caregivers and Survivors

New Stroke Support Group

This group for stroke caregivers and survivors meets on the third Wednesday of the month from 6:15 to 7:30 p.m., at Holy Cross Germantown Hospital, 19801 Observation Drive in Germantown. To register, call 301-754-8800 or visit HolyCrossHealth.org/support.

Intergenerational Stroke Education

Grandparents, bring your children, grandchildren and great-grandchildren to share this fun, educational and potentially life-saving learning experience. Participants of all ages will learn how to avoid stroke, how to identify signs of stroke, and what steps to take when they observe these signs. To register, call 301-754-8800 or visit HolyCrossHealth.org.

Saturday, February 3, 10:30 a.m. to noon
Holy Cross Senior Source
8580 Second Avenue, Silver Spring, MD

Sunday, May 6, 11 a.m. to 1 p.m.
Holy Cross Germantown Hospital
19801 Observation Drive, Germantown, MD

Holy Cross Medical Adult Day Center

301-754-7150

Holy Cross Home Care & Hospice

301-557-HOME (4663)

Holy Cross Private Home Services

Certified nursing assistants, 301-754-7780

Stroke Patient Education Guide

Visit HolyCrossHealth.org/stroke to download this free guide and to learn more about Holy Cross Health’s award-winning stroke care.

KNOW THE SIGNS OF STROKE

B E F A S T

BALANCE Does the person have a sudden loss of balance?
EYES Has the person lost vision?
FACE Does the person's face droop?
ARM Is one arm weak or numb?
SPEECH Is their speech slurred or strange?
TIME What time did symptoms start?

TIME IS CRITICAL... CALL 911!