

The Caregiver's Toolbox: Preventing and Managing Chronic Disease

Holy Cross Health's community health programs are dedicated to building healthy communities through engagement and action. If you or your loved one is at risk, or is already managing a chronic disease, there are programs that can help you move forward and improve your quality of life.

"Our Community Health department offers a wealth of resources that empower people with the information, practical skills and support they need to take control of their health, including managing chronic conditions," said Kimberley McBride, vice president, Community Health, Holy Cross Health.

Programs to Help You on Your Path

Chronic Disease Self-Management Program: This class helps anyone living with a long-term health condition such as arthritis, diabetes, asthma, migraine headaches or high blood pressure develop strategies to improve overall health and quality of life. FREE.


Diabetes Prevention Program (offered in English and Spanish): This 12-month lifestyle modification program offers nutritional guidance, exercise sessions and support to help prevent or delay type 2 diabetes onset. For those diagnosed with pre-diabetes or who have risk factors of pre-diabetes. FREE.

Diabetes Self-Management Education: For individuals diagnosed with type 1 or type 2 diabetes, this four-session program provides education on a full range of lifestyle and health issues related to diabetes including nutrition, exercise, medication, blood glucose monitoring and problem-solving. Cost: covered by most

Caregiver Resources

These two programs are offered through the Family Caregiver Alliance® National Center on Caregiving:

1. **FCA CareJourney** at Caregiver.org/carejourney
2. **Family Care Navigator** at Caregiver.org/family-care-navigator.



"My class, Living Well: A Chronic Disease Self-Management Program, helped me to realize that supporting my chronic illness wasn't just about seeing doctors," explains Sheila. "It was about my lifestyle—eating well, exercising and maintaining my strong mental health."

insurance plans, including Medicare; \$400 without insurance. To register or learn more, call 301-754-8200.

Diabetes Self-Management Program (offered in English and Spanish): An evidence-based, six-week program developed by Stanford University, it is designed to help people with diabetes improve self-management of their symptoms. FREE.

Falls Prevention: Participants learn about fall risks, how to prevent falls, and fall risk reduction measures. FREE.

Memory Academy: This four-week class covers how memory works, quick strategies to improve memory and basic memory tools. Not intended for people with Alzheimer's disease or dementia. Cost: \$5

Holy Cross Medical Adult Day Center: This program offers nursing services and daily stimulating activities for adults with chronic medical conditions. The goal is to decrease isolation for medically compromised adults, and increase respite for caregivers at an affordable rate. For more information or to schedule a free trial, call 301-754-7150. Subsidies are available for those who qualify.

For more information about these programs, visit HolyCrossHealth.org or call 301-754-8800.

Through its senior services offerings, Montgomery County, Maryland, provides a monthly e-newsletter of resources for caregivers. You can subscribe at MontgomeryCountyMD.gov/senior/social.html.

CAREGIVER NEWS

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"The Dementia Handbook: How to Provide Dementia Care at Home"

A book review by Sister Kathleen Weber, CSC

This tiny book, written by Judy Cornish and published by CreateSpace Independent Publishing Platform, is a very valuable tool composed of practical ways to help every caregiver along the long, difficult journey of caring for a dementia patient at home. However, I found nothing in this resource that could not and should not be applied to patient care in a facility. Ms. Cornish has created a program called the "Dementia and Alzheimer's Wellbeing Network" or DAWN, which is habilitative in philosophy and person-centered in approach.

Her premise is that dementia care at home is superior to that in an institution in terms of individualized and directive care and cost. All of her information is extremely valuable for any caregiver, but I cannot agree that all dementia care should be provided at home. There are simply too many variables in many families to assume that "one size fits all." But, her knowledge and practicality can help us all.

The author describes dementia as a "condition of cognitive impairment" that has reached epidemic proportions and currently is incurable. Therefore, she feels it is imperative that "we need to be equipped to provide dementia care safely and economically." She encourages families to avoid the stigma of dementia by embracing its presence "as bringing a specific set of disabilities (which) we could focus on helping our loved ones and clients develop the skills and abilities they have left... So, when someone loses memory and rational thought, why don't we take care of those functions for them and help them



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become better at using the intuitive skills that remain?"

Ms. Cornish feels this can best be accomplished by "habilitative care," which she explains as evaluating the person's limitations and then changing their environment to better

support their emotional needs and remaining cognitive abilities. In family homes and in many facilities a similar attempt is called "person-centered care." As rational thought fades away, intuitive thoughts remain and grow stronger. "Our intuitive thought processes include some of the most enjoyable ones we have: the ability to recognize our own feelings and those of others, the ability to enjoy music and creativity, and the ability to perceive and enjoy beauty." Habilitative care and caregiver education along these lines "can maximize functions, preserve dignity and keep our loved ones at home longer."

(review continued on page 4)

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 for the code.

Caregivers of Seniors

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

Caregiver College: Save the Dates

Motivated by last year's successful Caregiver College, the Holy Cross Medical Adult Day Center and Arden Courts of Kensington are planning three summer sessions to cover topics that impact the lives of family and professional caregivers. Mark your calendars:

- Saturday, July 21
- Saturday, August 4
- Saturday, August 18

For more information, call 301-754-7150.



Attention Medicare Recipients: New Cards are Coming

To help protect your identity and keep your personal information more secure, the Centers for Medicare & Medicaid Services will be mailing new Medicare cards to recipients on a rolling basis between April 2018 and April 2019. Instead of listing a person's social security number, the new card will include a new Medicare number unique to the recipient. For more information, visit Medicare.gov.

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“When Reasoning No Longer Works: A Practical Guide for Caregivers Dealing with Dementia & Alzheimer’s Care.”

By Angel Smits. Parker Hayden Media: Colorado Springs, 2017.

The author has creatively woven her valuable information and helpful techniques into the lives of Rose and Lou, a happily married couple whose lives are turned upside down by Alzheimer’s disease. Rose’s strange and unexplained behavior and the help of her daughter finally get her to a doctor who, after running every known test, tells Lou and daughter Melody that their loved one has a disease for which there is no cure. The doctor explains: “There are several drugs to help slow the progress and make it easier on all of you, but there’s no cure yet.”

Many caregivers, having heard that same verdict, can remember the loss, fear and frustration that comes with it. Now what? Where do we go from here? What can I do? The doctor advises helping Rose understand as much as possible and planning for the future in legal, financial and medical arenas. Lou resolves to do everything he can to keep Rose with him as long as possible.

Dementia is an umbrella covering many, many types of mental deterioration—some reversible and some not. Some conditions like urinary tract infections, thyroid malfunctions, improper

nutrition and drug interactions can mimic, exacerbate or cause dementia symptoms and are among those that can be treated medically. Other conditions like vascular dementia or multi-infarct dementia, caused by strokes, mild cognitive impairment, and Lewy body dementia are progressive diseases that cannot be cured currently. Among those, Alzheimer’s disease is the most common and the fourth leading cause of death in adults. It is not a normal part of aging but aging makes seniors more vulnerable.

Our whole medical system is impacted by the disease and its ever-increasing number of victims. “The total average cost of care for an Alzheimer’s patient from diagnosis to death is \$174,000.”

This rampant disease “means fewer professional care providers, fewer trained personnel, and more dependence on families to fill the gaps. In 2005, unpaid caregivers, usually friends and family, provided 18.1 billion hours of care—care that would have cost \$226.3 billion.”

The goals of this book are: 1) to help family caregivers, who face their own health problems accompanied by the added tension of caregiving, learn to care for their own health, and 2) to teach family caregivers the skills of professional caregivers. Families and the community at large need to learn the skills explained in this book. Ms. Smits explains how the brain works and how it is affected by the varying



dementias. Different dementias attack different parts of the brain and are exhibited in differing ways. Much testing is done by a neurologist or a neuropsychologist to assess cognitive competence. This testing is accurate about 99 percent of the time.

A realistic fear of family and professional caregivers alike is Catastrophic Reactions. These may or may not occur but the author explains them well, helps caregivers avoid them, and teaches techniques for handling them should they occur.

She defines Catastrophic Reaction “as an intense reaction to what seems to be a trivial event.” These can produce verbal abuse and even physical violence.

Reactions like this have “triggers.” We, too, are triggered but we can figure out what our triggers are and handle them logically and safely. Because dementia patients cannot analyze and rationalize, they are not aware of their triggers. They can be internal or external, present or past. Once we can identify a trigger in them, we must determine how to prevent that event from happening again.

But when triggers do occur, backing off is the best reaction for the caregiver. Arguing or trying to use reason will not help.

“Any behavior, if handled inappropriately, can result in a Catastrophic Reaction. Caregivers who understand they can stay in control of a situation and deal with all behaviors are safer and better off.”

Ms. Smits includes eight pages about analyzing triggers and guidelines for caregivers to handle them. In a chapter on fear and paranoia the author explains how dementia can change a personality.

“One of the first noticeable signs of dementia is a change in personality. Part of this is due to the chemical changes in the brain. Another part is due to the loss of ability to analyze the environment around them. We act the way we do by taking cues from the people and events around us.”

With dementia our learned behaviors are being eradicated.



Our human development is being erased in reverse. Eventually even the events of our past will disappear and only our emotions are left. And that is what the caregiver needs to concentrate on. How can we do that? Six pages are devoted to guidelines for the caregiver. They all will not apply for every person, but many will.

The bulk of the book follows the same format dealing with confusion, wandering, repetitive speech and questioning, searching for lost objects, delusions and hallucinations. To imagine a situation for which Ms. Smits has not included suggestions is almost impossible. Her work is a virtual handbook to read and then keep handy for an emergency review.

There are also sections dealing with topics that often come up in support groups. Referring to “therapeutic fibbing” she says: “If the information is something we know will upset them, or that they won’t be able to do anything about anyway, then there’s no reason to tell them or give specific details.” Ms. Smits also highlights Naomi Feil and Validation Therapy. Quoting Ms. Feil she writes:

“To validate is to acknowledge the feelings of a person. To validate is to say that feelings are true. Denying feelings invalidates the individual. Validation uses empathy to tune into the inner reality of the disoriented. Empathy, or

walking in the shoes of the other, builds trust. Trust brings safety. Safety brings strength. Strength renews feelings of worth. Worth reduces stress. With empathy, the Validation Worker picks up their clues and helps put their feelings into words. This validates them and restores dignity.”

Amazingly, I know from experience that it actually works.

Another favorite topic is sundowning describing the “phenomenon of increased behaviors and emotional upheavals that occur as the day fades into evening.” Wandering and combativeness increase at this time.

Even the last sections of this book are a treasure. Included is a glossary of legal terms, services to bring into the home, types of caregiving facilities and examples of available government aid. The book includes four appendices involving Reisburg’s Global Determination Scale, the Folstein Mini Mental Exam, a collection of terms we should know, and websites of programs that can be vital to family caregivers from Safe Return Programs to Social Security.

This is a small, compact book that could be a good crutch. Use it to help you along your caregiving journey.

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

Review of “The Dementia Handbook”

continued from cover



The author then proceeds to tell us that dementia sufferers usually lose memory first. Memory is divided into: memories that disappear, memories that are altered and those that are false. “It is lost memory and altered memories that wreak havoc in relationships and daily routines, because they dramatically change the person’s belief of what is true in the present” or their perception of reality. Complicating the problem can be anosognosia, the inability of people to recognize their impairments.

Rational thought disappears, but intuitive thought remains. Lost are cause and effect, sequencing, prioritizing, language and motor skills. Remaining are our intuitive thought processes including: feelings, appreciation of beauty, sensory feedback and the fight or flight response. “Fortunately our intuitive thought processes enable us to access and appreciate feelings, beauty and sensory information.”

Our experiential selves can gather information but its interpretation, without rational thought and memory, is unable to change the mood that results. If caregivers are sick or frustrated, the person with dementia becomes caught in the same mood. They lack the skills of memory and rational thought to alter these feelings and moods. Caregivers need to provide a strong feeling of security and well-being. The patient’s dignity and autonomy can best be maintained by working with rather than directing them.

“Further as their sense of reality becomes increasingly divergent from ours, we accept it as the inevitable result of progressive cognitive impairment and accommodate it rather than demand that they use skills that no longer exist. While we are doing this, our clients begin to relax and feel secure in the knowledge (through experiential learning while with us) that we will take care of their growing needs and escalating confusion.”

Enhanced well-being provides more comfort and peace of mind for all of us. In dementia, patients can be fostered through social success strengthened by the caregiver; sense of control provided by the opportunity to make choices; and a sense of value by assigning responsibilities with opportunities for success.

“When we pay attention to both the abilities and the disabilities that come with dementia, we are choosing to provide person-directed care rather than treatment...Providing care means maximizing someone’s quality of life through recognizing and supporting their changing abilities and disabilities.”

“Beauty is everywhere – in sounds, flowers, colors, textures and scents. The smallest dose can soothe, satisfy, ever revitalize. As caregivers, it’s our duty to identify and bring what works to the people we work with.” Sensory stimulation should be used whenever and wherever we find it.

The goal of Ms. Cornish’s program is “to provide all interactions with people who have dementia to preserve their dignity and autonomy to the greatest extent possible and for as long as possible” by:

- scheduling one activity a day
- focusing on the present
- relating to their favorite stories
- introducing forgotten memories

And many, many other practical suggestions for various situations.

The book is small but packed with hints for care and logical explanations for successes and improvements. Some we need to learn; others of which we need to be reminded. Keep your copy handy. It helps to validate what you are doing and suggests ways of improvement and adding to our skill set.

“Dementia is bad, but not all bad. There is still much to be shared if we understand that our loved ones are not losing their intuitive thought skills or their experiential selves. We can continue to live with them and care for them when we focus on the skills they retain rather than on those they are losing. There is hope in dementia. It lies in the way we provide care.”