

Adapting Validation Theory for Family Caregivers

Naomi Feil, MSW, ACSW, grew up in a nursing home of which her father was the administrator. Combining that experience with her social work training and experience, she introduced in 1963 what has become known as the Validation Method. This technique, which is still embraced today, is designed to help dementia patients over the age of 80 reach resolution of issues in their earlier lives.

Validation grows with trust and intimacy in a secure environment created by the practitioner. She explores the personal reality of the elder "to create an empathetic exchange of feelings wherein the client feels motivated to express himself/herself both verbally and nonverbally." The person helps the client express repressed emotions and helps them resolve these issues from the past. "The goal is to help the client feel a sense of renewed self-esteem and emotional relief." Ms. Feil sees the basic human needs as love, identity and being able to express emotions. The listener, non-judgmentally, explores the individual, and accepts and shares the individual's feelings and emotions. This enables them to enter into and validate that person's reality.

For those of us who are family caregivers, Naomi Feil's daughter, Vicki de Klerk-Rubin, has published "Validation Techniques for Dementia Care: The Family Guide to Improving Communication." The validation method, according to Ms. Klerk-Rubin, is a method of communicating with and helping people with dementia in their final stage of life. "The goal of validation is not to make disoriented elderly better, but rather to help caregivers to change themselves so that they can enter the personal reality of the person for whom they are caring." Family caregivers who embrace the validation method can help the elderly feel less stressed, more accepted and more valued. Caregivers can feel relief and

Caregiver Resources

Alzheimer's Foundation of America
www.alzfdn.org/caregiving-resources

Offers caregiving resources, education, support groups, etc.

Montgomery County E-newsletter

www.montgomerycountymd.gov/senior/caregiver.html

Published monthly with available offerings for caregivers.



more competent in their caregiving role by being able to communicate about stressful or misunderstood issues. This book can help you get started by forming realistic goals and examining the behavior of people over the age of 80 in a new light. Its chapters help you understand what happens to people as they age, how to best communicate with them and how validation works in a family.

FREE Validation Method Workshop

The Holy Cross Resource Center will offer a workshop for family caregivers who would like to further explore the Validation Method, its goals, techniques and results, and how to enrich the lives of people over 80 who have dementia. Registration required.

Date: Thursday, October 18, 2018
7 to 9 p.m.

Location: Holy Cross Resource Center
9805 Dameron Drive
Silver Spring, MD 20902

RSVP: Call 301-754-7152

National Institute on Aging (NIA)

www.nia.nih.gov/health/caregiving

Offers resources, caregiving tips, research and updates about Alzheimer's disease and related dementias.



Holy Cross Health Inc
1500 Forest Glen Road
Silver Spring, MD 20910

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

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.



Join Us for an Open House!

In honor of Adult Day Services Week, the Holy Cross Medical Adult Day Center and Holy Cross Caregiver Resource Center are hosting an open house for families and care providers.

Join us for a tour and light refreshments, meet our staff, and learn more about our programs and services.

Date: Wednesday, September 19, 2018

4 to 6 p.m.

Location: Holy Cross Resource Center

9805 Dameron Drive, Silver Spring, MD 20902

RSVP: Call 301-754-7150

or email willkast@holycrosshealth.org

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CAREGIVER NEWS

FALL 2018

"Cruising Through Caregiving: Reducing the Stress of Caring for Your Loved One"

A book review by Sister Kathleen Weber, CSC

Jennifer Fitzpatrick, a frequent presenter on caregiving topics in our area, has combined much of her knowledge, experience and wisdom into this book. In her conclusion she writes: "I hope you have gotten ideas and inspiration about how to save money, energy and time while caregiving to reduce stress for yourself and your caregiving crew."

In the beginning she describes the caregiving crew as the primary caregiver, secondary caregivers and tertiary caregivers. She is trying to prove that successful caregivers "don't have to always be exhausted, harried or suffering psychological and physical symptoms of caregiver burnout." She insists she knows many who take vacations and enjoy spending time with friends. My experience has been that burned out caregivers are not those who come to support groups. The purpose of a support group is learning how to be a caregiver who has time for a life. "It is possible to be a loving, responsible caregiver and not give up your entire life." Jennifer's goal is to help caregivers emerge "emotionally, physically and financially healthy."

A primary caregiver is the "person in charge, the organizer, who often does the bulk of the caregiving tasks" in close proximity or long distance. To complete "the caregiving crew" there should be secondary caregivers who assist and support the primary caregiver. The tertiary caregivers also help the primary caregiver, but often do so without direct contact with the older person. "When caregivers are truly comfortable in their respective roles, they tend to suffer less stress."

Most of us don't plan to become caregivers, and since "caregiving doesn't come with directions," many are unprepared for their new role. There are many reasons why people become caregivers, "but if you are honest with yourself about why you are a caregiver, it helps you figure out what strategies you need to apply to make caregiving less stressful for you." Struggling with the stress, lack of



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confidence, fear of the unknown, loss of time for personal and family needs, guilt, etc. can create a very difficult situation. NEVER make promises (to the care recipient or to yourself) that you will never put your care recipient in a facility or bring in professional help. Caregivers cannot

know how situations may evolve and that promise could have a negative effect on the patient or cause guilt for the caregiver. "Your goal is to provide the best care you can for the older adult. Putting your ego or emotions to the side can help reduce the stress of caregiving."

Depending on the care recipient's disease and/or advanced age, caregivers can easily begin treating the person as a child by trying to take over the life of the person. Sometimes caregivers believe they are the ones to be in charge. Making decisions may seem more efficient. Talking down to the elder, assuming more responsibilities or answering for them are examples of how easily this can happen. It often takes someone else to make the caregiver

(review continued on page 4)



Moving Life AheadSM

“Slow Dancing with a Stranger: Lost and Found in the Age of Alzheimer’s”

By Meryl Comer. Harper One: New York, 2015.

The introduction to this book is like nothing I have read before. Ms. Comer states:

“I write for all of us who are still well, but have seen the devastation of Alzheimer’s disease.

I write to clinicians, reluctant to diagnose because they can’t effectively treat.

I write to...the generations of our adult sons and daughters, who struggle to understand our lives as we care for a loved one with Alzheimer’s.

I write for my grandchildren because, no matter how hard I tried, Alzheimer’s blanketed my home with sadness.”

Dr. Harvey Gralnick, the author’s husband, was a prominent researcher at the National Institutes of Health (NIH) with an international reputation among the scientific community. He worked there since the 1960s and spent chunks of time traveling to Europe attending and giving conferences, etc. Harvey’s work took precedence over his marriage and family life. He missed dinners, holidays and special events. But on weekends, he enjoyed life to the fullest. In the book, Ms. Comer is writing about the 20 years during which everything changed. “The man I knew, loved and married has been absent and anonymous for

years, even though he lives at home and is cared for by me. How do I write about a 20-year gaping hole in our lives – an intimate part of our history – when it’s still not over?”

Harvey’s behavior began to change with his family wondering if the changes were caused by stress at work, and work colleagues began to suspect problems at home. Searches for “lost” articles began. Unread newspapers stacked up; misplaced checks were neither cashed nor deposited. “At the beginning of his illness, his moodiness just seemed like a more intense version of the way he sometimes was, moving quickly between charm and impatience.” Changes in his behavior became more noticeable as the disease progressed. Clinical details slipped away; medical explanations changed in mid discussion. Colleagues began to question his cognitive abilities.

“Now I was learning that the scaffolding of Harvey’s identity – his work as a doctor – was falling apart...His personality was also shifting from type A in overdrive to something more aggressive. Egocentric and emotionally abusive, it took all Harvey’s mental capacity to hold himself together at work, so he exploded at home.”

Harvey endured hours of neurological tests and appointments with his peers. Their medical and fraternal relationships kept the real diagnoses from being made. Despite his wife’s pleading, the fellow physicians cleared him



to take a trip to a professional conference in Europe. Harvey denied any deficits, “his skill as a diagnostician undermined by the unperceived creep of mild cognitive impairment...I was now the point person for two, with one of the two resisting my efforts every step of the way.”

To drive or not to drive became a very divisive question. No one, from his wife to his neurologist could convince him to stop driving. As a last straw his wife snuck into the garage one night and disconnected the lines to the battery and circuitry. “For the next five years, I told Harvey that his car was in the shop getting repaired...Even then Harvey didn’t have the presence of mind to check the garage himself where the car remained.”

Harvey forgot almost everything except his visit to the neurologist who told him he was fine. Nothing could convince him otherwise.

Harvey began to see his wife as an enemy whom he could not trust. It was impossible to convince him not to travel to London alone. Finding himself unable to function while in the middle of a leukemia study presentation at the conference, he asked to return to his hotel room. For Harvey, the conference focus changed from the study of leukemia to what was wrong with him. Instead of seeing a doctor, he insisted on flying to

Paris unaccompanied. While there he closed a bank account, but the money was never accounted for. Upon his return to Dulles, his wife set up a series of brain tests to determine a diagnosis. The doctor explained: “His PET scan offers us a 65 percent certainty that Dr. Gralnick’s condition presents as a form of dementia. It may even be Alzheimer’s. It is typical in a person of his age, education and level of physical fitness.” Ms. Comer heard the words she had been dreading and searching for over two and a half years.

Enter denial on the part of the author. “I had never heard of the disease, and no doctor had ever mentioned it. Could he be mistaken? What were our options? What’s in store for us? Wouldn’t it be prudent to get a second opinion?” The examining doctor had to report his diagnosis to NIH and Harvey’s medical career ended.



Ms. Comer faced the same financial concerns of all caregivers and felt she needed to continue working. Even with a hired caregiver, Harvey slipped away. After a long search, his wife found him propped against a tree with his two briefcases. He said he had spent the morning doing research at NIH and decided to walk home for lunch.

The search to learn more about the diagnosis began with more tests and an outpatient assessment. Treatments undertaken included working with psychiatrist Peter Rabins, MD, author of “The Thirty-Six Hour Day,” and cognitive and physical exercises. As time progressed, so did the disease now including spells of violence. There was hospitalization, locked units and heavy sedation but no improvement. “All I saw now was the dark side of his mind. Harvey was locked away not only in the hospital but inside this strange insidious illness. For the first time, he seemed completely out of reach.” Eventually Ms. Comer brought her husband home, against medical advice for her own safety, with 24-hour care. Nothing was familiar to Harvey! Their first floor was converted to meet his care needs and the staff took classes in self-defense. At home, Ms. Comer continued to care for her husband and got more help, striving for continuity of care to avoid Harvey’s flare-ups.

As time went on, “I felt myself become quiet and removed in conversation on rare times out. It was as if I had forgotten how to banter and relax. Color faded from

my wardrobe as did the brightness from my eyes. I wore only black from head to toe like a widow. In many ways I was one.”

When one would think nothing else could go wrong, our author’s 84-year-old mother developed dementia. After several failed tries in care options, Ms. Comer moved her mother into a room adjacent to Harvey’s. The male nursing team, with a pay raise, agreed to care for both dementia patients with Ms. Comer taking the 12-hour night shift. As the long journey continued, she began to work politically to advance Alzheimer’s research, in every possible way – from testifying publicly to raising funding and writing.

“My own experience made me adamant that there was nothing to lose in showing the general public images of the disease... Alzheimer’s patients lived behind closed doors. At this point, I already knew Alzheimer’s would win at home. Nothing I could do could change Harvey’s fate. But I did start to believe if people saw the real face of Alzheimer’s, they might be alarmed and offended enough to band together politically.”

May her work inspire us to do likewise.

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

Review of “Cruising Through Caregiving”

continued from cover

aware of his or her mistakes. If we take over their tasks, they may lose the ability to do whatever for themselves.

“Helicopter caregivers” fall into the bad habit of making decisions and forgetting that the care recipient is an adult. “If an older adult is competent and has capacity, it is important for the caregiver to respect her decisions...This means that the caregiver’s instinct to do what’s best for that person has to constantly be tempered with treating that person with dignity and making sure her opinions and choices are honored.” Jennifer provides thought-provoking questions to help caregivers evaluate if they are truly treating the adult with the respect and dignity they deserve.

Caregivers must realize and remember that caregiving is only a part of their lives, but not their entire life. They often exceed reality that caregiving can become a very long journey. Rather than waiting for life to get back to normal, they don’t realize this can be the new normal.

It is essential that caregivers set boundaries in their lives. These involve the older loved one, but also among the caregiving crew themselves. “Every relationship in order to be functional and healthy, must have boundaries...It is essential to hold firm to what you know will help restore balance to your life.” Support groups can help in reaching those goals.

Many people believe that the best way of caring for and protecting their loved one is by moving in with them which is not always the case. Some older family members just expect this to happen. In some cultures it is a given. “Consider the benefits and challenges of moving in with an older loved one before making such an important decision.” These are carefully explained in the book’s narrative. Base your decision on logic, not emotions. “Many family members and older adults balk at the idea of relocating the older loved one to an assisted living or nursing home, but they later will admit that it was a great decision. The older person was more physically active and cognitively stimulated in the new environment that is set up for older persons struggling with limitations.” But before making a decision, the caregiving crew and other family members should be involved. The big surprise is that care receivers don’t want us moving in with them or them moving in with us. And, no decision is written in stone. The author also shares excellent questions and thoughts to consider before quitting a job to be a caregiver. Family and Medical Leave Act (FMLA) and Employee Assistance Program (EAP) may also help.



Ms. Fitzpatrick’s chapter on martyrdom is one of my favorites. She warns: “Don’t be a martyr (because martyrs die)...When it becomes ‘caregiver martyr syndrome,’ it can have grave consequences that can include physical and mental health declines for the caregiver, conflicts and estrangements among the caregiving crew, and even – though unintentional – possible damaging abuse and neglect of the older loved one.” Or as the author continues, the martyr syndrome is sacrificing one’s life caring for an older loved one. Caregivers often neglect their own health. They are frequently dragged down with anger, guilt, fear, loneliness and resentment. The author describes these problems in detail and provides a symptom check list. One of her tips is: “Give yourself permission to be an imperfect caregiver.”

When working with the caregiving crew, each member must remember that he or she has control over his or her own actions. Caregivers can seek help by talking things over with an objective friend, a spiritual advisor or a psychotherapist. To obtain more aid from crew members the caregiver needs to be thorough when explaining what kind of specific help is needed. Try to match needs with resources.

Ms. Fitzpatrick examines the senior care system explaining that when caregivers discover it is not perfect, that too can be stressful. Help can be extremely expensive and a shock to caregivers. Their expectations also exceed reality. When researching residential facilities or home caregivers, Ms. Fitzpatrick suggests agreeing upon three non-negotiables. Caregivers should also consult the older loved one about his or her wishes. Try to judge each facility on its merits and avoid stereotypes about religious versus non-religious; non-profit versus for-profit; family-owned versus large chains. Resign your expectations to accept good enough. No place or no one is perfect.

Our author also discusses the role of doctors, medical care, advance directives and death and dying. Her book is well indexed and contains a section called, “Meet the Experts,” several of whom are local. Don’t hesitate to consult her references if and when you need help. She also includes a physiological benchmark used to track exercise intensity, metabolic equivalent for task (MET) exercise worksheets, and workshops for family caregivers.