

“The Caregiver’s Compass: How to Navigate with Balance and Effectiveness Using Mindful Caregiving”

By Holly Whittelsey Whiteside. CreateSpace Publishing, 2009.

A Book Review by Sister Kathleen Weber, CSC



The highlight of this book is that the author, Holly Whiteside, guides family caregivers in journaling. Each section is followed by four questions to aid individuals in daily or frequent journaling.

“Putting thoughts out on a page, seeing them verbalized in front of you, carries much more weight than simply running them through your mind. Later you will be able to refer back to what you have written to see how far you have come and how much your situation has evolved.”

Your role as a caregiver is shaped by your personality, your ways of being and your family history.

“Your success will be determined by your flexibility in the way you navigate caregiving ... with emotional intelligence and often new thought tools ... You will be able to chart your own course through this emotional time ...”

Caregiving will change you, but you can help decide how and by how much. You can either fall into caregiving or step into it mindfully with self-awareness, meeting its challenges.

“‘The Caregiver’s Compass’ is an emotional survival handbook for family caregivers. It contains thought tools and techniques for easing your way through the periodic turbulence of caregiving. Yes, caregiving can enrich the rest of your life using the principles of: being present, shifting communications and welcoming change.”

Mindful caregiving exists only in the present moment when you are free to shift your speaking, shift your experience and embrace change. Mindfulness is what keeps you from just reacting to circumstances and having no protection for yourself. You can capitalize on any caregiving moment “by being present to possible choices, by being present to and managing your thoughts, and by being present to self-awareness.”

Where you focus your awareness determines the choices you will make. If you focus on opportunities, you will find opportunities and be better able to get your bearings. “Notice how you feel when you think, caregiving will be hard. Notice the shift in your feelings when you think caregiving will be a challenge.” Your thoughts generate your life experience.

Listening is a key in caregiving. The way you listen determines how someone else feels heard. We are always listening for something, which can alter the quality of our listening. Your experience with someone determines what you add to the meaning of what someone says. You need to train yourself to enter into a “constructive ground by cultivating a non-judgmental compassionate, learning, listening style.”

Life is change and it will change us. “In caregiving, as in life, resisting change doesn’t work well ... If you proceed mindfully and creatively while aligning with life, the changes can be for the better. Challenging moments can become learning opportunities as you grow with the changes.”

Ms. Whiteside tells caregivers that allowing others to be who they are helps them improve. It is easy for caregivers to resist life’s changes, such as your family member’s aging, but you can’t get beyond this resistance until you clearly see it. “In caregiving, the only way out is through ... I had to accept circumstances the way they were.”

The next step in caregiving is realizing your fear and learning how to deal with it. Your roles are now reversed – you are now the responsible one. You have always looked to your parents for support. Now you need to claim your authority over your emotions by “managing your thoughts.” By asking many questions, you emerge stronger and eventually become confident in your ability to do the right thing.

You need to find a middle ground between too much empathy, as you struggle with

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“Exploring Hell and Other Warm Places: Redemption Through Caregiving”

By Holly Wittelsey Whiteside. CreateSpace Publishing, 2010.

A Book Review by Sister Kathleen Weber, CSC



Sister Kathleen Weber, CSC

By popular demand, the author of the book reviewed on page 1, decided to publish her memoir as a caregiver for her mother. Reading it, after reading “The Caregiver’s Compass,” was a delight – very human balance of love versus frustration. Most of us can readily identify. Ms. Whiteside said she took the role as her mother’s caregiver because, among the three sisters, she had the best chance of survival and she wanted to find the mother she never had. Ms. Whiteside described her mother as follows:

“At arm’s length she was lovely – gracious, with a winning smile – but get too close and it can be hard to breathe. Inevitably, her fears would move in to pick apart the lives of those around her. Her life was either too much or too little – music too sweet, vacations too short, her daughters too much this, too little that ... She had dreamed of a New York life. She was stuck with Philadelphia and the ‘Reader’s Digest’ ... Trying to cram herself into a life that didn’t fit guaranteed her dissatisfaction.”

Ms. Whiteside’s mother moved to Maine to be near one of Ms. Whiteside’s sisters, after the death of her husband. However, this did not go well and her mother ended up moving to a retirement home near Ms. Whiteside’s home.

Her mother eventually became tired of living with older women and wanted an apartment of her own. Before she could move to her long-awaited apartment, Ms. Whiteside’s 80-year-old mother broke her ankle and spent three months in rehab. By then, her mother’s mind had begun to fail.

Ms. Whiteside provided for her mother’s physical needs and more importantly, “wrapped her life up nicely. She needed to know that she had done a good job, that her life mattered.”

“I worked hard to accept the unknowns and practice inner balance, but I

frequently was confronted by my own fragility. I’d find myself winding up and then, upon closer inspection, I’d see that I was resisting some aspect of Mom or our time together. Acceptance was one key to balance and resilience ... Perspective brings balance. Acceptance brings resilience.”

Ms. Whiteside found dealing with her mother’s outbursts, criticisms and blaming devastating. She mentions feeling that her mother’s actions sucked the life out of her. She realized that change had to come from her. “I was beginning to see that I could choose to be with my mother and also choose to protect myself by speaking out and/or leaving.”

Ms. Whiteside felt she needed to find the line between self-care and nurturing others. “How could I give without giving myself away?” Ms. Whiteside and her husband needed clarity about responsibility for self while collaborating in the care of others. “It was a symbiotic sandwich of a relationship that worked.” Her husband was her primary support making sure she took care of herself and pulling her back when she didn’t.

In 2002, Ms. Whiteside’s mother wanted to and eventually moved to another assisted living facility. Eight months later, Ms. Whiteside was diagnosed with an intestinal malignant tumor. Surgery and chemotherapy followed. She studied all she could about recovery and nutritional supplements. For emotional support, she joined an art therapy program and looked for people to cheer her on. She was amazed to find out how many people cared about her. “Life all of a sudden gets very much more precious.”

During this time, she was unable to care for her mother. While trying to distinguish among service, helping and fixing, Ms. Whiteside quoted Rachel Naomi Remen:

“Service is a way of connecting to each other and to life itself. Fixing and

helping may create distance between people, a sense of difference. When we know ourselves connected, service is simply the natural and joyful thing to do. Our service strengthens us as well as others. Over the long run, fixing and helping are draining, only service is renewing. When you serve, your work itself will sustain you, renew you and bless you over many years.”

When she was able to resume helping her mother, she found many issues had occurred while she was on chemotherapy. She began reciting mantras like “There is no emergency” and “Pick your battles.” She worked hardest on her mother’s emotional problems, like the sense of losing control and clinginess.

By 2004, her mother suffered a fall, which brought new problems: resistance to rehab exercise, a blood clot in her groin, confusion, urinary tract infections (UTIs), etc. These plus problems with the assisted living staff, confusion of orders, etc., resemble those that family caregivers face every day.

One day, Ms. Whiteside received a call from her mother’s college roommate who told her to stop helping her mother so much. Ms. Whiteside took the advice to heart and explained the problem, as it was, to her mother. Almost immediately, her mother began taking more initiative. She began to act like her old self.

By January 2005, her mother was confused and depressed. Antidepressants helped the latter and Ms. Whiteside worked on the former. Ms. Whiteside and her mother agreed that her mother could borrow Ms. Whiteside’s mind and ask as many questions as she liked, but her mother has to agree to believe her. Creativity goes a long way.

“Some people, when they think of their mother, can conjure up an experience

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of comfort, safety, complete trust. Recently I've begun to give myself comfort in the moment, not sourced by any other person. I give myself the gift, and then take the time to notice it and revel in it."

Her mother's dementia eventually worsened and she suffered from chronic UTIs. The nursing home doctor was not concerned, so Ms. Whiteside got a second opinion. Her mother was hospitalized immediately for kidney dysfunction, anemia and constipation. Her mother's return to the nursing facility was followed by another fall. Another fall triggered additional blood tests, which were delayed for several

days. Months passed as these medical blunders piled up.

In mid-May, Ms. Whiteside wrote:

"I feel a heavy ache mounting just below my heart. Sometimes it's up as the back of my throat. I hurt when I hope. I have expectations but they always end up having me ... for dinner. I am being eaten from the inside out by expectations."

By June, her mother perked up again and became a new, loving and appreciative person, the mother Ms. Whiteside had always wanted. However, on January 18, 2006, illness struck again as rectal bleeding that only a colectomy

could help save her life. The chances of survival were 50/50. The surgery was on Thursday and her mother lived until Sunday.

After the three daughters gave their mother permission, she died within a few minutes. Ms. Whiteside's diary includes reflection into her mother's life and death. "Now why don't I miss her? I'm just glad to know that she's free, so glad that she's finally free."

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

Innovative Virtual Care Program Empowers Patients and Cuts Hospitalizations in Half

A new virtual care service offered by Holy Cross Home Care and Hospice is helping patients avoid preventable emergency room visits and hospitalizations, while empowering them to achieve their best possible quality of life – all in the comfort of home.

Home Care Connect blends in-home, one-to-one care provided by visiting nurses and therapists, with easy-to-use remote monitoring technology and a virtual care center with specially trained nurses who provide around-the-clock support.

Home care patients who qualify for Home Care Connect, receive a kit — free of charge — that includes a tablet and wireless tools to report how they are feeling and their vital information,

including weight, blood pressure and pulse. The tablet runs with a major wireless internet provider's 4G network.

The information streams around the clock, seven days a week, to Holy Cross Home Care's Virtual Care Center and is reviewed by the patient's nurses, who take action as needed to address health changes that could lead to emergency room visits or hospitalizations.

The tablet's two-way video feature allows for virtual visits, day or night, between patients, nurses, physicians and family members.



Holy Cross Home Care and Hospice helps patients with chronic disease or who are recovering from illness or surgery to achieve health goals and return to daily activities. The team includes visiting nurses, physical and occupational therapists, speech language pathologists, social workers and other home health professionals.

Discover more about this program by calling **301-557-HOME (4663)** or visiting **HolyCrossHealth.org/HomeCareConnect**.

Review of "The Caregiver's Compass"

Continued from cover



the losses in your parent, and too little feeling. You are caught between feeling ineffective and just providing maintenance. "Your boundaries define that middle ground by determining your emotional accessibility." In the words of Ms. Whiteside, "Caring gave me the resilience to persist. Compassion made things tolerable, even forgivable."

"Since caregiving is concentrated living, it brings a denser experience of emotion and challenge. The highs and lows feel more extreme than in ordinary life. At times, you could find yourself spending undue energy in anticipation of your grief, as I did. Often, we experience life's major events to be very different than we had imagined. Those that are billed as happy can turn out to be harder than we had imagined. Those that we expected to be tragic can carry with them great joy. Even the death of your loved one will be different from your imaginings."

For the good of your physical, emotional and spiritual well-being, try your best to live in the present moment as fully as possible. As the sign in the support group reminds us, "Let whatever you do today, be enough."

When crises occur, use your support team and expand it as your needs change. Use your options. You have control over your attitude. When times are calm, focus more on being than doing. "When I found myself grieving, I thought of our good times, so as to fully honor the paths we had taken together ... You are not the cause, and you are not the solution, you are only one small part of this great rhythm of life."

Throughout the book, the author emphasizes the use of three tools: be present, shift communications and embrace change. "Step-by-step we will identify what you need to introduce into your life in order to have a consistent sense of well-being." This includes learning how to ask for help, building self-connection and recharging your spirit. This way, you will learn self-care and achieve emotional health as a caregiver. As difficult as it is, asking for help is essential in caregiving.

Ms. Whiteside explains the hows and whys and explains how empowering they can be in caregiving. "Step-by-step, you will optimize your community of support, rethink the meaning of support, and find workable ways to communicate your requests." The book even includes a chart on the tactics you need to obtain the help you need.

As a caregiver, "some of your biggest resources and major stumbling blocks will come from within you." To do your best caregiving, you need to be in touch, self-connected to your own feelings, needs and "your personal truth."

The caregiving journey is yours, "staying connected to yourself will allow you to be present so as to do your best caregiving." When you are taking care of others, there must be a balance between taking care of them and taking care of yourself. Find what self-connecting activities work best for you and practice them. "When life isn't presenting you with tasks, allow the silence to nurture, heal and guide you."

Every caregiver needs to be in touch with his/her spirit or life force, which needs to be recharged and healed frequently. "Whatever it takes, whatever it means to you, for the sake of everyone involved, make spiritual recharging time a priority." Without self-care, you cannot be a good caregiver. The author suggests packing your own parachute as an act of survival. Along with physical and spiritual health, you might want to tuck in a massage, acupuncture and/or yoga. Humor is also highly endorsed.

The author also includes principles such as picking battles as a caregiver; following commitments, which are courses of action, belief or value; and defining your role as a partner in giving care. "Intuition, backed by information, can be your mainstay as you advocate for your loved one. Educate yourself so that you can keep track of what is happening."

Our elders react differently to medications and medical treatments. They are more sensitive to environmental changes. Caregivers need to be aware of this and feel comfortable asking the physicians

for education on these matters when appropriate. Physicians know health care; you know the patient. Good health care and meaningful relations must meet in the middle. Both sides need each other and depend upon shared information.

Similar adjustments are necessary in the way we speak to seniors. It is easy to fall into treating and speaking to them like children. Ms. Whiteside reminds readers to speak to elders with respect. She says after trying to make her mother happy in her daughter role, "I gradually took my place as an adult. As I gained strength, I saw her begin to relax. It seemed that as I became stronger, she no longer felt she had to be in control and became less anxious ... As partners we moved forward."

As the end approaches, things begin to change. When death is close, try to tell your loved one it is okay to go. Giving that permission may be your final act of caregiving, by helping in this final act of life. Ms. Whiteside gives five suggestions from hospice that may be helpful at this time.

"You may feel unburdened, released, even as your loved one has been released. You have graduated, have completed your good work the best that you know how. There are few more acts of completion, then you will grieve in peace and finally be free to move forward into your new life."

Ms. Whiteside's prayer of acceptance:
"Listen here! I've done my best!
(Now I lay me down to rest.)
I won't stop here but could this be ...
(Where is thy staff to comfort me?)
Don't need to know what waits me there.
(Be there my comfort and support.)
But keep me well. And keep me whole.
(And after all, be still my soul.)"

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

Understanding Palliative Care

By Jaya Vijayan, MD, Medical Director, Palliative Medicine, Holy Cross Health

Jaya Vijayan, MD, Palliative Medicine, is the medical director of Palliative Care Services for Holy Cross Health. Dr. Vijayan works in consultation with other specialists to provide palliative services while patients are hospitalized. In this column, Dr. Vijayan separates myth from reality about palliative care.



Jaya Vijayan, MD

What is palliative care?

Palliative care is a fairly new specialized field of medicine dedicated to improving the quality of life for seriously ill patients. As a palliative care physician, I focus on managing symptoms and reducing stress during an illness. These symptoms may be the result of the illness or side effects from treatment and may include pain, nausea, fatigue, loss of appetite and difficulty sleeping.



I also work with patients and families to assist with advance care planning develop a care plan, which reflects the patient's values, treatment priorities and long-term goals.

How is it different from hospice care?

People do sometimes confuse the two. Simply put, all hospice care is palliative, but all palliative care isn't hospice care. Hospice care is provided at the end of life, when patients are no longer receiving disease-modifying treatment. Palliative care is provided at diagnosis and throughout the course of treatment of a serious or chronic illness. In either situation, we work to improve the quality of the patient's life.

Who might benefit from palliative care?

Many people can benefit from what palliative care has to offer. Most often, our patients are those with serious illnesses such as dementia, advanced heart disease, cancer, heart failure, kidney failure and chronic lung disease. In some cases, people may even live longer with care focused on providing comfort and managing symptoms.

How can patients access palliative care?

The easiest way to begin is to talk with your primary and/or attending physician. Your doctor can then contact a palliative care specialist for a consultation and assessment. During the evaluation, a care plan will be developed that reflects the patient's and family's values and goals and is coordinated with the primary physician.

To learn more about palliative care services, visit [HolyCrossHealth.org/Palliative-Care](https://www.holycrosshealth.org/palliative-care).

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

Alzheimer's Association-Sponsored Resources

ALZConnected®

A free online community for anyone affected by Alzheimer's disease and dementia.

www.alzconnected.org

Community Resource Finder

Find local resources, community programs and services.

www.communityresourcefinder.org

Helpline

Available 24 hours a day, seven days a week, by phone and by online chat.

Phone: 800-272-3900

TTY: 866-403-3073

www.alz.org/help-support/resources/helpline