

## Caregiving Through a Doctor's Eyes

By K.L. Anderson

Caregiving can be anticipated yet untimely, long distance or right next door, two hours a week to 24 hours a day. Caregiving is universal. It knows no boundaries of age, race, religion, profession, or economic status. Caregiving will touch all our lives at some point along the way.

Dr. Dan, a family physician practicing in the Midwest, was living during a thriving medical practice while also juggling the responsibilities of a husband and father of three in a bustling family household. Life couldn't be fuller. Then, all at once, he found himself being called away from his normal routine into the world of caregiving. He was now facing the urgent needs of his elderly parents who lived over 1,000 miles away, and his perspectives of caregiving were about to make a dramatic shift.

Dr. Dan and his family made yearly trips to Florida to visit his parents and they eagerly anticipated this time together. Upon their recent arrival, it became painfully clear at the front door that everything had changed since their last visit. Although Dr. Dan and his family had kept in touch regularly, the current situation seemed to have gotten out of hand and the health and stamina of his father and mental capacity of his mother had significantly declined. How could this have happened? Where were the red flags?

For years, Dr. Dan's father, a former minister, had been faithfully providing care for his wife who suffers from progressive dementia. He was always in control of the situation, never complained or seemed ready to ask the family for help. All along, his father compensated for his wife's loss of abilities, minimized their needs, and downplayed the changes that were happening over the years. His father seemed to insulate the rest of the family from the real problems he faced and kept his own depression and isolation hidden. Unbeknownst to his family, the profound weight of caregiving for his wife had finally taken its toll and his health was now in jeopardy. Although the family realized there were obvious needs, they



feared they would have to wait until a crisis occurred before help would be accepted. That crisis was now upon them.

After arriving in Florida, Dr. Dan rushed his father to emergency care for tests and an assessment of his symptoms and health condition. It was difficult not to ask questions or suggest tests. Dr. Dan found himself torn between his role as a caring son and his profession as a physician. At one point, he was even faced with the temptation to jump in and take over his father's care. He felt pulled in many directions. Then a greater sense of urgency and alarm emerged when the test results revealed a blood clot followed by indications of cancer. The reality of the situation hit hard, and Dr. Dan knew that some major decisions would have to be made quickly. His mother could no longer care for herself and needed constant supervision and help with her daily needs. His father would require further testing, possible surgery, and treatments. Dr. Dan had to get his family back home, return to his medical practice and plan for his parents to move north as soon as possible. Caregiving was about to take center stage.

Upon returning home, all family members were contacted to discuss a plan of care. It was decided that the best alternative

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## Mission

To provide a comprehensive and coordinated system of services designed to promote the independence and dignity of older persons and their families in Muskegon, Oceana, and Ottawa – a mission compelling us to target older persons in greatest need but to advocate for all.



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was to have the parents move in with Dr. Dan and his family to allow medical treatments to begin for his father. Fortunately, Dr. Dan's wife, a former nurse, was willing and able to provide the daily care and supervision of her mother-in-law during this time of uncertainty and transition. Once the parents were resettled, a geriatric care manager was consulted for the purpose of support, planning, and connecting to resources. Dr. Dan was also able to partner with his fellow physicians to take over the medical care needs of his father at the local hospital.

The roles of a son and the patriarch of the family were once again challenged, as Dr. Dan took control of the situation, became the decision-maker, and assumed a leadership position. He became an advocate for both of his parents as they were now displaced from their home, had lost their independence (at least temporarily) and had to live within the hectic pace and lifestyle of their son's family. Relationships had to be reestablished while still maintaining the parents' dignity. His father, once a strong and capable leader who had served as a missionary in Africa and even fought off lions (literally), was now very ill, fragile from surgery and cancer treatments and had to be fully cared for along with his wife. This was one of the lowest moments his father had ever experienced and the weeks that followed proved to be difficult for the entire family. Everyone's routine was disrupted, and the impact of caregiving permeated all of their lives.

Over the next couple of months, his father completed his treatments and gained back enough strength and perseverance to again provide care for his wife. They have since moved in with their daughter, who took over the next stage of caregiving, and are awaiting admission to an assisted living "campus of care" where they will reside in an apartment with supportive services. When Dr. Dan's mother is unable to remain at this level of care, she will be moved to an adjoining nursing home where her husband can readily visit her. Everyone involved met this plan with strong approval. Through it all, Dr. Dan recalls that his ability to become a caregiver was fueled by the love and support of his family and help from his colleagues. This truly allowed him to remain steadfast and focus on the needs of his parents until the health crisis finally stabilized.

Dr. Dan shares these final thoughts on how this journey has reshaped him as a person, a son and as a physician:

"First of all, my empathy and sensitivity index for caregivers has increased a hundred-fold and I am now better qualified and prepared to support and assist the caregivers and patients I see in my practice. I have an enhanced appreciation for the trials, decisions, and the urgency for help that caregivers face, along with the strength it takes to endure these circumstances over time. My experience has added to my worth and credibility as a physician and I find I am able to personally share my story with many of my patients.

"Secondly, I have an increased awareness of Alzheimer's disease and how it truly affects families. I have now seen the full spectrum of my mother's dementia from the early stages of confusion and unexplainable behaviors to her need for 24-hour supervision and daily assistance with her personal care. I marvel at how my father was able to remain fully committed to caregiving through these very difficult years and I have an even greater empathy for the caregivers I serve.

"This experience has drawn me closer to my parents, especially my father, and has strengthened our family bonds as we have tried to pull together to provide

the best of care. It hasn't been easy, and we have had to resolve some past family conflicts that surfaced during this time. Fortunately, we have been able to focus on honesty and the importance of making decisions that will benefit the whole family.

"Lastly, I appreciate the delicate nature of life and have realized that I cannot take life for granted. I have a greater understanding of the larger picture of caregiving, the impact on family relationships and the patience and diligence it requires. I am also struck with the importance and value of asking for help and realize that our situation could have been dealt with more directly if my father had only asked sooner.

"I feel a sense of relief that the pieces are falling into place and that we now have a plan, yet I am saddened at the fact that my parents will no longer live independently. I have had to get beyond my own denial and face reality as I ponder my parents' increased needs as well as the end of their lives. I am once again a long-distance caregiver for my parents and will continue offering support and monitoring their ever-changing needs along with those of my patients and their caregivers." ❖



## VOICE OF A CAREGIVER

- C Connecting with you is difficult and painful because you no longer recognize me.
- A Able to match pieces of the past to the present to help us understand.
- R Realizing that none of this is your fault or in your control.
- E Embracing those seconds when I look into your eyes and we connect.
- G Guilt, yours, and mine, over choices made or opportunities missed.
- I Involuntarily, without choice, being dragged along in this rough ride yet.
- V Victories, small and large, are celebrated and keep me moving forward.
- E Ever marching on, whether I will it, life keeps going on.
- R Remembering who you always have been to me. ❖



## August's Website

[www.caregiver.com](http://www.caregiver.com)

## Quotes

*"Caregiving will never be one-size fits all."*

– Nancy Kriseman

*"You would not be where you are today if your heart wasn't growing."*

– Carole S.

*"Never give up!! You are stronger than you think."*

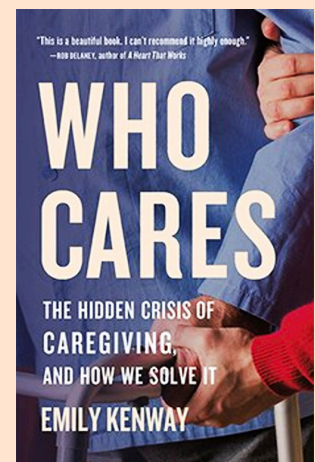
– Unknown

## This Month's Book

### Who Cares

By Emily Kenway

When Emily Kenway became the primary caregiver for her terminally ill mother, her life was changed forever. Millions of caregivers all around the world are silently suffering from poverty, isolation, and burnout.



## Look for the Signs!

*Source: National Institute on Aging*

When caring for an aging parent or relative from afar, it can be hard to know when your help is needed. Sometimes, your parents will ask for help. Or the sudden start of a severe illness will make it clear that assistance is needed. But, when you live far away, some detective work might be necessary to uncover possible signs that support or help is needed.

A phone call is not always the best way to tell whether an older person needs help handling daily activities. The person may not want to worry you or may be embarrassed to admit that he or she cannot handle certain daily activities.

### Recognizing Differences in an Aging Parent's Behavior

It may be difficult to notice differences in behavior when you don't live close to a family member. A family member may withdraw from activities, forget to take medication, or stop taking care of themselves or their home. These signs may seem small, but they are crucial for an aging parent or relative's safety and well-being.

With the person's permission, you could contact people who see the person regularly—neighbors, friends, doctors, or local relatives, for example—and ask them to call you with any concerns. You might also ask if you can check in with them periodically. Look for safety issues and at the overall condition of the home and try to determine the older person's mood and general health status. Sometimes people confuse depression in older people with normal aging. A depressed older person might brighten up for a phone call or short visit, but it is harder to hide serious mood problems during an extended visit.

### What to Do When an Aging Parent Needs Help

*Continued on page 5*

## Promoting Independence for the People We Love

*by Carol Nelson, RN, BSN, MBA*

**A**s a family caregiver, it's natural to worry about your loved ones when you're not around. They need you. But in the desire to always protect them, it's easy to deprive them of the degrees of independence they are capable of and want.

Before caregiving became necessary, Mom and Dad had lived all their adult lives on their own. And they still want to be adults who can care for themselves, to whatever degree, even needing help now and then. Your parents' role was to take care of you. They were the problem-solvers. Now that you are taking care of them, the role reversal is challenging for both of you.

### Compromise

Maybe while growing up, you thought your parents were a little overprotective. There were things you wanted to do without supervision and without somebody saying no all the time. It was frustrating. Well, what comes around...

Now, you're the one hovering. So many things can go wrong, and maybe they can't be depended upon to make the "right" choice. At least in your eyes. Maybe Mom doesn't want to stick to the prepared meals meant to keep her healthy. Maybe Dad wants to go for walks around the neighborhood, and that's not safe. He could fall. Maybe they both insist on living at home by themselves. And all that's not going to happen on your watch.

Time to back up and breathe. Family caregivers can't put loved ones in a bubble, no matter how hard they try. It's impossible to completely protect them and dictate every moment of their lives. Within reasonable boundaries, aging loved ones still deserve the ability to live life as they wish. They can't be protected every moment.

Perhaps finding a regular walking partner for your father would help. He might be willing to limit his excursions to when he has a companion and can enjoy the chance to have conversations with them. Or your parents might accept letting a



paid caregiver come in and help them out with chores and meal preparation in the evenings or several times a week. That would help assure you that they're in good hands and someone would be checking on them.

Sometimes it can help to put the need on you: "I need someone to assist you so that I don't worry. I cannot work when I worry about you at home. I worry because I love you—you taught me that. I want to be your daughter/son. You cared for others all your life, now it's time for you to be on the receiving end."



### Degrees of Care

As adults, we enjoy our autonomy and our ability to make simple choices for ourselves each day, and it's easy to assume that it will last forever. But it doesn't. People age, their capabilities change, and they might not be able to function completely independently anymore.

That doesn't mean they don't want to be as independent as possible. Nobody wants to lose control of their lives. The thought of a complete loss of independence can be just as scary for aging loved ones as the family caregivers who are scared for their safety. Understanding this, it's important to have an open dialogue and listen to what the loved ones have to say about the degree of help they want.

As a caregiver, you can help provide them with the tools to give them as much independence as possible. This could mean changes like accident-proofing their bathroom, having a sit-down, walk-in shower installed or adding assistance bars near the toilets. It could also mean hiring a home care professional to visit two or three nights a week just to help.

Have the discussion around making these changes to help maintain their independence. "Mom, I'd like to remove these throw rugs. I don't want you to fall and get hurt. That would prevent you from staying home and independent. I know that's what you want, and I want that for you. Can we agree to make your home safe?"

### Keep an Eye Out

Allowing older adults the independence they deserve is good for them emotionally. It can help stave off depression and keep them mentally sharper. That said, keep an eye out for what they're not telling you. Perhaps they need more support than they thought. Keep in communication, listen to them, and be ready to step up the support as needed.

Older adults are still adults. Valuing and encouraging independence in their lives will benefit everyone. They'll be happier and your relationship will grow stronger knowing there is mutual trust. It will also give you more space in your own life. Caregiver burnout is real, and by trying to do everything and be everything, you can risk your own health. So, value the independence of your loved ones and your own independence from having to take charge of every moment of their love. ❖

*Look for the Signs, continued from page 4*

When you notice signs that your aging parent or relative needs help, it is important to know what steps to take next. Some signs may require a simple fix, like needing new glasses or a new prescription. But other times, you may need to provide more help. When you visit, look around the home for possible trouble areas. If you can't fix everything during your visit, see if you can arrange it with someone else to help finish.

Having to make important healthcare decisions for an aging parent can be hard on both family members and caregivers. Be sure to voice your concerns to your family members and explain to them why you are feeling this way. Your first consideration should be to try to fulfill the wishes of your parents wherever possible. If not, try to make similar decisions to ones they may have made in the past. This way, you can ensure you are trying to do what is in the best interest for your parent. It is also handy to have a list of local resources in their area to contact if you need to.

In some cases, you may be in the position of having to help your parents make difficult healthcare decisions. If a parent is sick, it is important that they assign a power of attorney for health care to allow someone to act on their behalf in medical situations.

### What are the signs of self-neglect?

- Hoarding
- Failure to take essential medications or refusal to seek medical treatment for serious illness.
- Leaving a burning stove unattended
- Poor hygiene
- Not wearing suitable clothing for the weather
- Confusion
- Inability to attend to housekeeping
- Dehydration ❖

## Home Safety Tips

Improving support and safety throughout the home:

- Have smoke detectors been installed near the kitchen and bedrooms?
- Are there safety rails in showers and tubs?
- Install handrails upstairs and in bathrooms!
- Use non-slip flooring in kitchens and bathrooms.
- Remove any loose rugs.
- Move furniture around to create less confusion.
- Remove any dangling phone cords.
- Mirrors can distort the loved one's view when walking, and should not be placed where they can easily be bumped into.

Ways to correct visibility and lighting problems:

- Use bright, vivid colors to light up rooms.
- Make sure hallways and stairways are well lit.
- Lighted switch plates make finding switches at night easier.
- Have night lights in between bedrooms and bathrooms.



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## When Hoarding Is a Disorder

*Source: National Institute of Mental Health*

**Y**ou may have seen reality TV shows about people who hoard mail, gadgets, cats, and even trash. Or, maybe for you, the reality is a little closer. It could be a neighbor or a family member.

When people can't throw things away, piles can grow to the ceiling. These piles can make it impossible to use bathrooms, bedrooms, and kitchens.

The piles may fall over, trap, and injure people. They can catch fire. Cluttered homes and yards may attract pests. Neighbors may call the police. Parents may lose custody of their children.

People don't choose to be hoarders. And they aren't being sloppy or lazy. "This is a very real mental disorder," says hoarding disorder expert Dr. David F. Tolin of Hartford Hospital's Institute of Living. "It is important to recognize that people with hoarding disorder have lost control of their decision-making abilities."



Tolin's NIH-funded research suggests why it's hard for people with this disorder to part with items, even things with no real-world value. He found that brain activity was different between people with hoarding disorder and healthy people.

"We're always puzzled by the fact that many people with hoarding disorder often don't seem terribly bothered by their circumstance," he says. "If they don't have to make a decision, the parts of their brain that are largely in charge of becoming bothered are underactive."

But if they are forced to decide about whether to discard something, that part of the brain becomes overactive. "And so, the brain is essentially screaming that everything is important."

Doctors don't know what causes hoarding disorder. There's no X-ray or blood test for a diagnosis. Instead, doctors assess how well people are functioning in their lives.

Hoarding disorder can start during a person's teens or later. It may grow more severe over the decades.

Try not to start an argument. "If a person is not really motivated to do something about the problem, they can dig in their heels. Arguing can even make the problem worse," Tolin warns.

There's no effective medication for hoarding disorder, although studies are in progress. Tolin says, "Right now, cognitive behavioral therapy is the only evidence-based treatment we have for hoarding." This is a type of talk therapy that teaches people how to change their thinking patterns and react differently to situations.

Tolin's team hopes to improve cognitive behavioral therapy so that it's even better at helping people to discard items. They're analyzing the brain activities of people before and after they're successfully treated for hoarding disorder. If the research team can identify the biological mechanisms of successful treatments, they may be able to develop treatments that are even better.

Some people with hoarding disorder are helped by joining a support group with others who have the disorder. There are also organizing professionals who specialize in helping people get rid of clutter.

### How to Help a Person Who Hoards

Explain why you're concerned:

- "I'm worried that you could fall or become trapped."
- "I'm concerned that you may lose custody of your children."
- "I'm afraid your home will catch on fire."

Then say how to get help:

- "I can help you find a therapist who specializes in hoarding."
- "We can look for a self-help program on how to let things go."
- "We can find support groups for people who hoard."
- "We can ask the county for resources." ❖

## Vision Impairment is Associated with Dementia

Source: *National Institute on Aging*

NIH-funded research suggests that existing treatments for vision problems—including eye exams, glasses prescriptions, and cataract surgery—could have potentially prevented about 100,000 cases of dementia in the United States. The study investigators used data from the University of Michigan Health and Retirement Study (HRS), a longitudinal study tracking changes in health and economic circumstances for more than 20,000 older adult volunteers.

Researchers noted that about 1.8% of U.S. dementia cases were associated with visual impairment, and projected that, by 2050, that total would rise to around 250,000 cases. The study also showed that incidence of vision impairment in older adults was higher for Hispanics, at 11%, compared to 8.3% on average overall for Blacks and non-Hispanic Whites.

The researchers found that existing vision correction technologies and treatments, including eyeglasses and cataract surgery, are underutilized in the United States and globally, especially among disadvantaged communities. Additional research is needed to determine if addressing correctable vision problems may be an effective intervention to protect cognitive health. ❖



*Home Safety Tips continued from page 6*

- Use easily reached cords that can turn a light on and off in closets.
- Basements should be very well lit considering the steepness of the stairs going up and down.

Methods to improve movement and sight throughout the house:

- Use bed rails to support movement getting in and out of bed.
- Use lever handle doorknobs instead of circular knobs.



- Use a flexible shower head and a chair for your loved one to sit on when bathing.
- If they're in a wheelchair, have a ramp installed that can be used to get them up the front steps or stairways.
- Use large button telephones.
- Clocks should be large enough with both numbers and dials easily seen.
- A commode near their bed can be used in emergencies.
- Shelving in closets should sit low enough for easy access.
- Place a raised toilet seat in their bathroom.
- Chairs need to sit high enough and be supported by arm rests so there's some security when they sit. ❖



Hello

August

To all those who are reading this, I really hope something good happens for you this month.

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