

Diane Finnestead MAT, Ed. S.

Who will hold my hand? Caregiving in America

Dedicated to Jayne Finnestead and Eddie Ellis

According to AARP in 2020, 53 million Americans were taking care of family members as unpaid caregivers which is an increase of Five million over what was reported in 2016. One in three Americans today will need long term care after the age of 65 and with 10,000 Americans turning 65 everyday as the Baby boomers age into Medicare at age 65, that means the number of those unpaid family caregivers will only increase. Let's start the conversation of how we can be prepared for this need as a society and as individuals and what we can do to not just meet the needs of those we love but grow into the best caregivers we can be for ourselves and our loved ones.

When I started in the long- term care insurance business way back in 1997, I had personal motivation; my former mother-in-law and my father in-law were on the precipice of needing care and lots of it. It was expensive then and is more expensive now! At the time I had one year of teaching under my belt before entering the car business at Saturn; a GM division that would not haggle off the sticker price on the car and competed with imported 90's foreign brands like Honda, Toyota and Mazda by producing small, niche, trendy American competitor in the economy car market.

After smiling my way through five years as a Saturn sales representative, the easiest job I've ever had, and becoming one of their national sales leaders rapidly approaching selling my 1,000th car to my 100th customer, I met my future boss with Genworth formerly GE(General Electric) Financial Assurance. As he and I struck up our initial conversation about the difference in car sales and insurance sales, he thought he'd hook me as his newest recruit when he asked if I was paid on the anniversary date every time a customer kept their car another year. After telling him that the car business doesn't work like that, He winked and stated, "Well, the insurance business does". That's when I assured him that I was more motivated to do the right thing than just earn money because thankfully, in my 20s I had become a firm believer that when you do the right thing, no matter what business you're in, money will come. Sensing my passion and motivation to help others, he quickly switched gears, went in a different direction and pulled on my heart strings when he asked, "Have you known anyone needing or who has ever needed long term care?" My answer to that question and the opportunity that developed from my answer changed the direction of my life. I explained that my Grandfather and later my Grandmother needed long term care before they passed and at the time, my in laws were quickly approaching needing homecare. He asked thoughtfully "how would their lives and the lives of those who love them be different today if they would have had long term care paid for and coordinated by professionals instead of family members? He elaborated about how having insurance could/would cover a medical social worker, a home health aide day care. in home

care, assisted living and nursing home care too the impact which I had to admit would have relieved a lot of the headaches, heartaches, sacrifices and the impact on generational wealth that affords quality education leading to quality jobs and an abundance of opportunities.

Over my 20+ years in insurance, the biggest advantage for me personally as a caregiver and for my clients is, without a doubt, the fact that long term care insurance reduces the emotional burden, guilt and sometimes debilitating stress one can acquire when caring for a spouse and/or family member(s). It's quite a juggling act that no unpaid caregiver can prepare for. It's a big ask to become the unpaid caregiver in a family because you don't know what the sacrifice will be nor the expectations. That's why when one becomes the unpaid caregiver, it's usually an assumed role. Those needing care assume someone in the family will do the job typically having no idea the burden the job can be. The unpaid caregiver does the job out of love. After reading this you may be thinking if the unpaid caregiver is their spouse, they made a vow to love, honor and cherish them in sickness and in health til death they do but nowhere in there did that any of us have to suffer in silence or suffer at all.

Long term care insurance and short term care insurance can alleviate emotional, physical and financial burden. The average cost per day in a nursing home for a shared room according to Genworth is just over \$72,000 nationwide and the average stay is 2 and half years unless there is Alzheimer's disease, dementia or a cognitive disorder. One in three adults over the age of 65 will need long term care. Knowing these shocking statistics, it's strange how we insure everything like our cars, homes, property, life yet the cost of long term care is not just the greatest risk you face going unprotected but the only thing that would force you to spend your money beyond your control. But, long term care insurance is only for those who have assets to protect and are healthy enough to pass the health qualifying questions. The introduction of short-term in-home care and/or facility care application concentrate less on one's health history and is a mere fraction of the monthly costs of today's long term care premiums. Because this option is available to so many more Americans with health challenges, it's one to seriously consider to prevent one from being a burden to their family while protecting assets.

Let's say you or loved one do not have long term care insurance or short-term care insurance, how do you pay for care? Medicaid (state aid for those who qualify under the guidelines for low income) is the largest provider of long-term healthcare nationwide. Veterans have benefits if they served during war time and financially qualify as low income for Aid and Attendance home care benefits. Veterans also may have earned their place in a VA Home for skilled nursing. However, the only other option is to self-pay where you pay out of your pocket. One of my clients in St, Louis is currently paying \$12,000 a month for she and her husband in Assisted Living. She gasped when she got her first bill. I believe the high cost of care is why the unpaid caregiver always has a job in our society.

In 2017 AARP Policy Institute announced that about 41 million family caregivers provided 34 billion hours of unpaid care in 2017 where the collective estimated value of this unpaid occupation totaled \$470 billion. I began educating everyone I know about their choices and resources after returning to the health insurance industry full time eight years ago after being an elementary Principal and Associate Professor in Education. The collaboration with senior industry professionals as well as professional and non-professional/family caregivers began with offering "Giving the care back to the Caregiver" classes/seminars in the community for free. By conducting those classes, I was began to notice patterns of behavior and similar emotions I had experienced when I had been a caregiver myself.

I observed and identified with two distinct behaviors solidified the understanding of the psychology behind caregiving; the theory of elasticity and the imposter syndrome. The theory of elasticity, which applies to many different fields, arose first in mathematics and has spread far beyond that subject. This theory assumes that humans are like rubber bands and as we stretch ourselves, we grow yet we desire to be what we once were. We know there is a new normal but the old normal is what we seek because that was and still may be our comfort zone. Like a rubber band, we reshape to what we were originally yet we might have few stretch marks.

Our elasticity is what's being tested when we are thrown into situations that we're not prepared for like when many of us, 50 million in fact, are thrust into unpaid caregiving. We begin this journey by flying by the seat of our pants spearheading the challenge and synthesizing information and resources to become the unofficial "official" chief communicator in all family matters relating to the member needing care. These family members we are communicating to somehow skipped the appointment or designation to be "named" the "official" caregiver. This uncertain expectation comes from siblings and spouses as to how to fulfill this role as caregiver. Often times, a family member's evaluation of one's performance skills are subjective where unsolicited opinions are unhelpful and create stress. Not every unpaid caregiver is resilient enough to withstand the judgement of their loved ones. When a caregiver is doing the best they can with their skillset and is scrutinized for their best efforts this can lead to imposter syndrome. Someone they love or another family member might think they're not doing a good job which leads to the caregiver doubting themselves or worse yet, feeling defeated and wondering, "If they only knew how much I don't know."

This is the point in the caregiver journey where we pretend to know and fully grasp the physical, mental, financial and medical situation of whom we are caring for and hope no one will notice we're just improvising the best we can. Most of us, including myself, just put on a mask of confidence and competence to pretend to be something that we might not have been trained for or went to school for but do it anyway. Needles, baths, Hoyer lifts, rollators, wound vacs, wheelchairs, medication management, infusions, meal prep, wigs, shaving and sometimes all in the same day, we do it! Why? Because today, caregiving

encompasses being a nurse, a health advocate, a legal representative, a physical therapist, a bath aide, an occupational therapist, a home remodeler, a housekeeper, a chauffeur, an appointment setter, a secretary, a laundress, a gardener, a librarian, a book keeper, a chef, a nutritionist, a therapist and much more!

As we assume the all-encompassing role as caregiver, others around us assume we can do it competently even without the expertise, experience and credentials often needed to meet societal, parental or spousal expectations. Being the caregiver to our parents or our spouse or even an ill or disabled child can create imposter syndrome that manifests in stress, depression and anxiety leading to chronic caregiver fatigue. The only way to combat this is allow room to grow by learning about yourself, the person you are caring for and seeking out solutions or resources in order to mitigate the initial crisis and life balance needed for the future.

To combat the theory of elasticity and imposter syndrome as it relates to caregiving. I strongly suggest we familiarize ourselves with the psychology of Carol Dweck in her book Mindset. In this work, Dr. Dweck explores two opposite mindsets. One mindset is abundance and growth and the other is a fixed, scarcity mindset suggesting we have limited aptitude and possibilities.

The growth mindset suggests one has the ability to learn and grow into infinite possibilities. This mindset is much more forgiving and loving towards oneself allowing positive brain connections to occur to create new pathways, ideas and understanding. What can caregivers do to stay in this positive frame of mind to allow growth and learning?

Five steps to maintain a positive frame of mind when caregiving:

Make time for you to feel like yourself

Try your best to keep up your hobbies-you just might have to modify it. For me, I like to sing so I found an outlet to do so. It wasn't a two hour choir rehearsal and singing at church every Sunday for 2 more hours but I could meet friends for an hour and sing some Karoke. For my sister, a big Sunday dinner is what she likes to prepare but when Mom got really sick, instead of preparing it all in the same day, she took a portion to prepare and store each day so we could still enjoy the tradition. So if you like reading, facials, bubble baths, walks in the park, working on cars, collecting antiques, shopping, sports or making cards, whatever your fancy, just reimagine it and incorporate happiness in your life and routine. Your brain and everyone around you will thank you.

Embrace the life-long learner inside you

Realize that no one on this Earth can possibly know everything or know it on command, To walk and speak, we had to learn it. Don't be so hard on yourself. Trust in your higher power and reel in the amazing and multi talented person you are becoming, Everyday, you may want to journal or have a conversation about what you learned today. Reflecting on that today, next week and a year from now will give that shot of dopamine you'll need and proof you are growing as a person. Some call this a gratitude journal but I call it magic!

Reach out to your community- seek support

Why is it so hard to do this? Again. Our ego and fear of judgement get in the way. No of us want to look stupid but I will challenge this...if the answer to your question is one you seek because the information could help you or someone else then as a former educator, you need to ask that question. For example, when I would speak to the healthcare professionals about my Mom I had a list of questions, her recent records and a full list of her medications. I was ready to say, explain that again to a Fifth grader and I have two Master's degrees which didn't matter when it came to getting the information and options that would help my Mom. The questions you ask are out of love and support, don't ever leave a conversation kicking yourself for not getting clarity. This rule goes when dealing with healthcare professionals as well as the supporting medical community at large. There many organizations that exist for the sole purpose to help people like you and those you love.

Connect with whom you are caring for

You may think you know a person especially if it is your own Mom like in my caregiving days but the time spent together can unveil a gift to rediscover your loved ones favorite memories and life experiences. Storytelling is a wonderful way for both the caregiver and person receiving care to connect and you may just hear something added to the story that changes the version you had always been told like when I found out that my Mom had first seen my Dad on a street corner and while pointing to him from a bus window she proclaimed to her sorority sister, "That's the kind I want, right there." So their love story was a love at first sight story not at all the version I had grown up with. These revelations can deepen your relationship, build trust, breed understanding and allow our synopsis to positively charge. Get curious and ask some questions- your family history might just get rewritten.

Share what works for you

If you have a tip or a tried and true resource that makes your life or the life of the person you are caring for better, time to share. Share it with your family, your community, the groups you are involved in, your community, and please share with me. Opening the conversation about how to be the best caregiver is empowering and could positively affect 50 million lives plus the lives they serve.

Review the finances and all insurance

These are two easy tasks to do accomplish. Work with someone you know, like and trust. Ask questions like what should I be asking you and if this was your loved one, what would you suggest? Work with someone whom is unbiased and licensed in your state. And choose a professional who knows you are important and is motivated to make all lives involved better because of their knowledge, interaction, communication and character.

What's the driving force for these actions to create better caregivers? It is the willingness to be vulnerable because it leads us to the universal language of love. If 50 million Americans caregiving for a family member got that dose of love consistently, what a difference the mental health of our country would experience. Be the change, grow beyond measure, love more than

love more deeply, honor yourself, and honor your family. Hold your head up and hold thr hand of your loved one someday you will want the same from whom holds your hand.

The End

Continuing the caregiving conversation-Start of the Resource page (coming)