

Lesson 7 – Beyond the Scope

In this lesson, we want to look beyond the scope of what is usually considered caregiving, at the things we tend not to address when discussing the caregiver experience, even though they affect it and can directly impact it.

A Crisis Within a Crisis - Caregiver illness

Scenario 1 - When a Caregiver has a Medical Crisis

Caregivers tend to be so focused on the care recipient's needs that they do not recognize their own health needs. Adding the constant stress into this equation, you get a person with a suppressed immune system and vulnerability to illness.

Symptoms such as fatigue, irritability or sadness could be signs of a real health problem.

Every caregiver should have a backup plan in case s/he gets sick and cannot care for his/her loved one. The backup plan needs to include the following (based on Rob Harris's work):

- Backup caregiver team of people who are ready, willing, and able to step in should the primary caregiver be away for any length of time. Among the team members there should be people that can make critical decisions (legal, financial, regarding health insurance, consult with doctors) if needed, in place of the primary caregiver. All team members should know of each other and everyone's role and responsibilities.
- Emergency contact list of relatives, friends, neighbors, and times they might be available should their assistance be needed.
- List of pre-screened, competent home health care agencies the caregiver feels comfortable calling for help.
- Health Binder
- Copies of illness summary and emergency information forms.
- List of the doctors, their locations and contact numbers plus a schedule of doctor's visits. Ensure the "substitute" is cleared to speak with these medical professionals.
- The "substitute" must be able to easily catch up with the care recipient's regiment.



Scenario 2 - When the Caregiver has a chronic illness

Some caregivers are care recipients before becoming caregivers, and some become care recipients after being caregivers.

In both cases, it's important to be able to ask for help. If the original care recipient can provide even a little bit of help, it's important to be able to be clear about one's needs and boundaries while accepting the reciprocity of care.

These are a few things to be mindful of when the caregiver is living with a chronic illness:

- Backup plan for the care recipient
- Backup plan for the caregiver (in case of a medical crisis)
- Support system for the caregiver
- Daily self-care practice

A Crisis Within a Crisis – Natural Disaster

Day-to-day caregiving is challenging enough – dealing with a disaster can be devastating. A disaster can be:

- Earthquake
- Floods
- Tornadoes
- Hurricanes
- Winter storms
- Evacuation due to natural fires
- Heat waves
- House fires
- Power outages
- Chemical spills
- Terrorist attacks
- War
- Pandemic

It's the caregiver's responsibility to identify potential challenges and take the steps necessary to prepare ahead of time. One of the most important ways a caregiver can minimize the care recipient's stress and anxiety in an emergency is by improving their coping skills and resilience.

The High Five Model of Psychosocial Preparedness (Emerging Minds. Australia)



Many caregivers think that if they talk to their care recipients about the potential threat of a disaster, they will scare or traumatize them. However, talking openly and honestly, and letting them know you are prepared and have a plan, helps them feel safer and more secure. It will also help them deal with the disaster's impact if it does happen.

A Crisis Within a Crisis – Pandemic – COVID-19 and post-COVID

2020 brought a shared international plight to the world situation. Communities struggled in new and unprecedented ways—*on top of* dealing with what was happening.

- People suddenly could not access routine care. Routine medical care is the foundation for caregiving maintenance. For many of the chronically ill, disabled, and injured, the hospital and the doctors' office are a safe refuge. The threat of catching the disease made these places unsafe.
- People became more isolated than ever before. Quarantines and lockdowns throughout the world left people alone. According to the National Institute on Aging, research has linked social isolation and loneliness to higher risks for a variety of physical and mental conditions: high blood pressure, heart disease, obesity, a weakened immune system, anxiety, depression, cognitive decline, Alzheimer's disease, and even death.
- Caregivers, care recipients and other family members faced job losses and financial hardship. In Asia-Pacific more than 81 million jobs were lost as COVID-19, in the U.S. more than 20 million, in Europe more than 6 million. Financial and job security is a basic foundation to peace of mind. Lack of peace of mind makes it very difficult to care for someone else (or for oneself).
- Organizations, NPOs, and support groups had to cancel or postpone the usual in-person programs and events. These are sources for preventing loneliness, for creating meaning in one's life, sources of strength and hope. They are vital for promoting a sense of community and worthiness.
- Dr. Lucy McBride of John Hopkins Medicine has coined the word FONO (fear of normal) for one of the outcomes of Post-COVID. It relates to the shift in the sense of security and knowledge to a longer term of knowing less and uncertainty.

Caregivers who had successfully managed the care for their loved ones were presented with additional challenges and uncertainty. Since both emotional and practical support is needed for caregivers to thrive, caregivers must constantly find creative ways to replenish themselves.

COVID-19 and the other disasters of 2020 emphasized the need to add additional tools to the Caregivers Toolbox.

Caregiving in a Mental Health Context

Being a caregiver for a care recipient with a mental illness has a lot of challenges.

Caregivers must educate themselves about the condition, symptoms, crisis conditions, triggers, and treatment of both their care recipient and themselves. Caregivers caring for someone who is mentally ill must be able to deal with the mood swings that can at times be violent and unexpected.

These caregivers find themselves coping with the stigma, bias, and ignorance around mental illnesses.

PTSD (Post Traumatic Stress Disorder)

For caregivers of people with PTSD, understanding PTSD is curial to being able to care for that person struggling with it.

Six principles that can help PTSD caregivers:

1. Listen with empathy and without judgment. Be prepared to be available to listen on the person's terms.
2. Be physically and emotionally present. People with PTSD often withdraw from other people leading to social isolation. The presence of loved ones can be an invaluable form of support, providing it follows the person's lead and respects his/her requests and boundaries.
3. Create a safe space that is dependable, sustainable, and structured to support the person's sense of security.
4. Recognize triggers to help the person avoid them or prepare for them as much as possible.
5. Have a plan for relapses and outbursts to help diffuse the situation.
6. Make sure the person is receiving professional help.

It's important to remember that Caregivers for people with PTSD are at increased risk for secondary trauma, especially if they are experiencing stress or isolation.

Dementia Illnesses (Alzheimer's, vascular dementia, mixed dementia, dementia with Lewy bodies, and frontotemporal dementia.)

Dementia and Alzheimer's are progressive illnesses.

While they can affect every area of a person's life, they are also unique to the person facing it, which means the need for specialized and personalized care becomes very important.

Since most people with Dementia or Alzheimer's are seniors, the specialized and personalized care needed is added to the existing care for the senior family member, which on it's own requires a lot.

Caring for someone with dementia or Alzheimer's requires the following:

- **Physical care/basic needs:** help with bathing and grooming, lifting and moving, walking, eating, and daily living activities.
- **Housekeeping and cooking:** help with housekeeping chores, laundering, and cooking meals.
- **Medical and nutritional care:** help with taking medication, getting to the doctors, assessing medical needs addressing dietary needs, allergies, fluid intake, and more.
- **Social interaction:** help with staying socially connected, providing companionship, and identifying emotional needs.
- **Finances:** help managing finances, paying bills, and more.

In addition, there are unique responsibilities these caregivers face:

- **Education:** caregivers must be educated about the condition, symptoms and safety protocols. This allows them to make decisions about seeking specialized care in another way/location, plan ahead, and be prepared for every situation.
- **Emotional Support:** caregivers must be able to deal with the care recipient's anxiety, disorientation, agitation and anger while remembering and accepting they have dementia.
- **Adaptability:** caregivers must be able to assess situations, notice subtle changes in the behavior, symptoms, or environment, evaluate a senior's surroundings for safety

According to the American CDC (Center for Disease Control and Prevention), caregivers of people with Dementia illnesses provide care for a longer duration than caregivers of people with other types of conditions (79% versus 66%). Over half (57%) of the caregivers provide care for four years or more.



Caregivers in the Workplace

Workplaces face a growing challenge as more and more employees are called to care for aging or ill family members.

70% of full-time employees are impacted by caregiving.

80% of working employees say it affects their productivity.

25% of caregivers are Millennials

- Employee caregivers experience clinically significant depression, serious sleep loss and disturbance, weight gain, injuries, neglect self care, and have increased risk for stroke or heart attack. In fact, as of May 2019, burnout was designated as an “occupational phenomenon” by the World Health Organization.
- Employees who have left jobs to caregive is not limited to employees in their 40’s and 50’s. Large numbers of people 18-25 have already quit to caregive. (HBR)
- 30% of workers say their careers have been adversely affected by caregiving obligations.

(Difference Collaborative - <https://differencecollaborative.com/>)

Caregivers in the workplace tend to seek coaching to address performance, well-being and work related stress. However, it is our responsibility to address the invisible elephant in the room – the fact that they are caregivers.

CAREGIVING. WHY?

FOR THE SAKE OF WHAT?

Some people give care out of a sense of obligation, many come from a place of love and devotion (and for some that obligation is the same as the sense of love and devotion). Love is what gets them out of bed for the third time in the middle of the night as they hear their loved one calling. Love is what drives them to spend hours each week organizing medications. Love is what encourages them to sit down and listen to the same story over and over again.

The overwhelm of caregiving often creates a space where the caregivers disconnect to the greatest resource they have – that of love. Yet, the act of caregiving – giving care – is one of giving and one of care.

According to the Oxford Languages Dictionary:

To give means to freely transfer

To care means to provide of what is necessary for the health, welfare, maintenance, and protection of someone or something.

When coaching caregivers, we want to help the client connect to that inner source of connectedness of why they are caregiving and to help them be able to continually connect to themselves there so that they can make the best choices for themselves and be at their best.

1. The Dipper and the Bucket Theory (Don Clifton, 1907)

Each one of us has an invisible bucket. It is constantly emptied or filled, depending on what others say or do to us. When our bucket is full, we feel great. When it is empty, we feel awful. Each of us has an invisible dipper. When we use that dipper to fill other people's buckets ~ *by saying or doing things to increase their positive emotions* ~ we also fill our own bucket. Conversely, when we have negative thoughts or criticize, become angry or show disdain, we make automatic withdrawals from our bucket and those who are the recipients.

When this is a way of life for caregivers, they are constantly replenishing their buckets, hence themselves, and like the sea, the ripples grow and more people are affected – the care recipient, the medical team, other family members, work....

Tips for filling the bucket:

1. Prevent Bucket Dipping.
2. Shine a light on what is right
3. Find creative ways to fill our buckets
4. Use our dipper freely to fill our bucket
5. Give unexpectedly
6. Reverse the Golden Rule (Do unto others as they would have you do to them)

This is especially difficult during times of crisis, and it is also especially important.

That is why the skills must be honed at all times.

Hope, it is the only thing stronger than fear.

President Snow, the Hunger Games. Suzanne Collines

2. Language of Love (based on the work of Gary Chapman)

Based on Gary Chapman's Five Love Languages of Caregiving, and how love is given and received in relationships, caregivers can express their love in many ways.

Words of Affirmation –

Speak words of appreciation, encouragement, and love to each other.

- Love does not keep a record of wrong. Use kindness in your words to each other and let the past be that; the past.
- Love is not demanding. When you need something, make a request and not a demand.
- Express gratefulness for what has been done and don't focus on what has not.

Quality Time –

Spend time together

- Really listen. Look them in the eye and do not attempt to complete another task while they are talking to you.
- Acknowledge their feelings without trying to "fix" anything, watch their body language and do not interrupt. Be fully present!
- Arrange for help with household chores to free up more quality time together.
- Make the time for quality activities — no more excuses.

Receiving Gifts –

Allow yourself to accept and receive

- Accept gifts with gratitude and love no matter how small, even if you don't like it.
- Honor the wisdom that one of the greatest gifts you can give is the gift of "self". Be present for each other and slow down! Try not to rush around completing tasks, but give of yourself and your spirit.
- Bring a gift — a small token of your appreciation that you are caring together.

Acts of Service –

come from a place of giving

- Create a list of things you would like to do to help (bring a meal, clean their bathrooms, do laundry, go to the grocery store) and ask them which day would be good for them.
- When you are visiting, look around. If there is a broom handy, start sweeping while talking. If you notice that they are low on household staples when you leave, run by the store; drop those things off to them during your next visit.
- Get a group of friends together and have meals delivered a couple times a week.

Physical Touch –

when you cannot touch physically (due to distance, an illness or virus)

- Find ways to offer your physical presence to them through a hug, holding a hand, stroking stroking their back or gently rubbing their shoulders.
- Do not shy away from their touch even if you feel uncomfortable with it at first.
- Having something soft to hold can help someone who wants physical touch. When you have to leave, bring them a pillow to hold or a blanket to lay across their lap. This can be a great comfort.
- Plan time for long calls that are intimate and close enough to almost replace physical contact.

*Listen with the ears of tolerance!
See through the eyes of compassion!
Speak with the language of love!*

Rumi

3. **Connecting to the positive aspects of caregiving**

According to the American Psychological Association, many family caregivers report positive experiences from caregiving, including a sense of giving back to someone who has cared for them, the satisfaction of knowing that their loved one is getting excellent care, personal growth and increased meaning and purpose in one's life. Some caregivers feel that they are passing on a tradition of care and that by modeling caregiving, their children will be more likely care for them if necessary.

Tips for connecting to the positive aspects of the caregiving include:

- Gratefulness
- Random acts of kindness
- Connecting to the place of love for the care recipient
- Remembering better times
- Mindfulness and meditation

Kindness is just love with its work boots on

Unknown



A Caregiver's Serenity Prayer
Karen Osborne

May I be granted with the tender, open-hearted love needed on the caregiving journey, the strength of body, serenity of mind, clarity of purpose and willingness of spirit to meet the extraordinary, everyday, constant changes and challenges of caregiving with a smile and good cheer.

And, please grant me the compassion and courage to choose the right path through the myriad decisions, making the very best choices for the highest good of my loved one, my family, and my self.

Allow me to know that I am enough, I do enough, and by giving of myself at the deepest soul level, caring with diligence for my own health and well-being, also as priority, I will experience the beautiful rewards intrinsic to caring for another.

Let me seek, find, and accept help from family, friends, community, and professionals for the journey of caring.

Let my loved one receive the gift of love from my heart and hands with gratitude and healing.

Bless the hands, hearts and spirits of both giver and receiver in the circle of light and life and keep us filled with gratitude and grace each day.