



Lesson 7 – Beyond the Scope

In this lesson we invite you to look, with us, beyond the scope of what is usually considered Caregiving. Things that we tend not to address when discussing the caregiver experience even though they affect it and can have a direct impact on 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 needs of the care recipient 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. Make sure 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 actually care recipients before they become caregivers and some become care recipients after being caregivers.

In both cases it's important to be able to ask for help and if the original care recipient is able to 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 him/herself living with a chronic illness:

- Back-up 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 situation is by coping well himself.

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 then they will scare or traumatize them. In fact, talking openly and honestly, and letting them know that you are prepared and have a plan, helps them to feel safer and more secure. It will also help them to deal with the impact of a disaster if it does happen.

A Crisis Within a Crisis – Pandemic – COVID-19

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

- People suddenly could not access routine care. Routine medical care is the foundation for caregiving maintenance. For many of the chronically ill, disabled, injured, hospitals 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 lock-downs 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.

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. 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. 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.

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.