

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 constant stress to this equation results in 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:

- A 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 who can make critical decisions (legal, financial, health insurance, consult with doctors) if needed in place of the primary caregiver. All team members should know each other and everyone's roles and responsibilities.
- An emergency contact list of relatives, friends, and 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 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.

- Routine medical care is the foundation of caregiving maintenance. People suddenly could not access routine care. For many of the chronically ill, disabled, and injured, the hospital and the doctors' office are a safe refuge. Unfortunately, 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, and in Europe, more than 6 million. Financial and job security is a basic foundation for 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, creating meaning in one's life, and sources of strength and hope. They are vital for promoting a sense of community and worthiness.
- Dr. Lucy McBride of Johns 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 for 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 their care recipient and themselves. Caregivers caring for someone who is mentally ill must be able to deal with mood swings that can sometimes be violent and unexpected.

These caregivers find themselves coping with society's stigma, bias, and ignorance around mental illnesses as well as their own.

PTSD (Post Traumatic Stress Disorder)

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

Six principles that can help PTSD caregivers:

1. Listen with empathy and without judgment. Be prepared 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 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 themselves 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 unique to the person facing it, so 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 stay socially connected, provide companionship, and identify emotional needs.
- **Finances:** help with 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, 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 employees are called to care for aging or ill family members. As a result, some organizations have started working with Corporate Wellness Specialists to address the issue from the organization's perspective.

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

80% of working employees say it affects their productivity.

25% of caregivers are Millennials.

According to The Harvard Business School (HBS) article "COVID Killed the Traditional Workplace. What Should Companies Do Now?" the pandemic has compelled organizations to place a spotlight on employee health and wellness—and keep it there. While in the past, health and wellness may have often felt like HR references and not areas of primary focus areas, the pandemic has shifted that dynamic in a very real way. As a result, today, we see more and more organizations focusing on employees' mental health, implementing policies enabling and encouraging physical health, and prioritizing the safety of the workers' environment.

According to the Rosalynn Carter Institute for Caregivers, an estimated 18 to 22% of US workers provide care for an elderly, sick, or disabled family member, while almost three-quarters of employees said they had some type of current caregiving responsibility in a 2019 report from Harvard Business School.

Caregiving affects the workplace!

- Employee caregivers experience clinically significant depression, serious sleep loss and disturbance, weight gain, injuries, neglect self-care, and have an 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 caregiving obligations adversely affect their careers.

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

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

Loss & Grief

For some caregivers, the caregiving ends when the care recipient dies.

To coach a client through grief, we must truly meet that client where s/he is. Be present. Be accepting. Let them be real with us.

Grief has three timeline anchors:

1. Past – what was experienced and shared and can never be regained
2. Present - losses that are experienced as time passes and death approaches
3. Future - losses anticipated to be experienced after the death

As caregiver coaches, we want to encourage our clients to identify their authentic way of grieving and help create grieving spaces that allow their grief to be heard and processed.

Important reframes:

- There is no right or wrong way to do grief. People are doing grief perfectly, always.
- Grief doesn't have an agenda or a timeline.
- If clients say they are lost – we meet them at the “lost.”
- Mourning and grief are not the same. Grief is the emotional reaction to loss, and Mourning is the social “doing” of grief.

The Six Needs of The Grieving/ David Kessler

1. To Have Your Pain Witnessed
2. To Express Your Feelings
3. To Release the Burden of Guilt
4. To Be Free of Old Wounds
5. To Integrate the Pain and the Love
6. To Find Meaning in Life After Loss

1. To Have Your Pain Witnessed

Loss is an event – Grief is the process of coming to terms with the loss.

We begin by acknowledging the loss and letting them know they are seen, and their grief is witnessed.

This is about making loss real and validating the grieving person's experience and emotions. When we see our sorrow in the eyes of another, we know our grief has meaning and that the pain we are experiencing is both real and normal.

We can do this by:

- * Meeting the clients where they are without an agenda.
- * Asking them about their loved ones and truly listening.
- * Helping them develop comfort with the pain and the emotions by being fully present with them and whatever they bring to the space.

2. **To Express Your Feelings**

Once clients become more comfortable with their pain and discomfort, it is important to invite them to express it and attach language to how they feel.

Our job is to invite them to go beyond the grief story, which is often overwhelming, be present, and connect with how they are feeling at this moment.

We are living in a death-phobic society, and we are not taught the sound, narrative, colors, and experience of grief. As coaches, we empower our clients to discover the language and voice of their grief and emotions and express it.

3. **To Release the Burden of Guilt**

Guilt and grief often go hand and hand.

It is natural to wish things could be different or that we could do things differently.

When it becomes clear that this is beyond our control, our minds create guilt so we don't feel helpless.

A reframe you can use is switching the "what-ifs" to "even-ifs."

As we invite the client to explore feelings of guilt in grief, we want to extend an invitation to release guilt and open a space for forgiveness for self and others.

4. **To Be Free of Old Wounds**

Grief will often bring old wounds to the surface.

Most of us have old wounds, trauma, and childhood experiences that shaped who we are and how we process our grief today.

As coaches, we help our clients develop the ability to observe these old wounds with self-compassion and make a conscious decision on how to address them.

5. **To Integrate the Pain and the Love**

Acceptance doesn't mean that everything is okay or will be okay.

Acceptance means that we can be okay and that being okay doesn't happen all at once.

People tend to look for a lightning-bolt moment of acceptance, and when it doesn't happen (because grief doesn't work that way), they feel they are failing in their grief.

Our job is to help them remember with more love than pain.
The care recipient will forever live in the caregiver and his or her memories.
Grief doesn't get smaller over time. It is us that get bigger

6. To Find Meaning in Life After Loss

Finding meaning means finding a way to sustain the love for the care recipient after their death while moving forward and reintegrating back into life.

It doesn't mean we stop missing our loved ones; it means we can experience a heightened awareness of how precious life is.

Finding meaning after loss can be challenging. We are constantly having to make choices between moving forward toward healing or remaining stuck in pain because we can't move into the future without leaving the past.

our job is to help our clients expand their emotional scope so they can savor the love, find meaning in their memories, and take that good into their future.

Moving through the pain and releasing it can feel like betraying our loved ones, minimizing the loss, and taking the risk of being left with nothing, but the truth is, when the pain is gone, we connect in love, and we grow.

A few additional words about finding meaning:

- * Meaning is relative, subjective, and personal.
- * Meaning takes time. Sometimes, it takes months or even years after a loss
- * Meaning does not equal understanding.
- * Finding meaning, it still isn't worth the cost of losing someone.
- * Meaning does not negate loss.
- * Loss is not a test, a lesson, or something to handle, and meaning is not a gift or a blessing. Loss happens in life, and finding meaning is a choice.
- * No one can find meaning for us. Only we can find our own meaning.
- * Meaningful connections will replace painful memories.
- * Creating meaning remembers the loss and honors life and the living.

Clients can subtly feel what we think and feel about their loss, loss in general, and losses we have experienced. That is why coaching a client through loss requires us to examine our beliefs, values, thought patterns, and emotions around loss.

Anticipatory Grief

Anticipatory grief relates to grief that occurs in expectation of one's death or that of a loved one. It has three additional unique characteristics:

1. There is time to "look forward" to the death
2. There is chronic stress
3. There are characteristics of a Liminal Phase

Therese Rando (Clinical Psychologist - Thanatologist – Traumatologist) detailed the many aspects of anticipatory grief and the factors that influence the anticipatory grief of individuals. Out of the many factors she mentions, these are the ones that are relevant to our work as Caregiver Coaches.

Caregiver's anticipatory grief is affected by the following factors:

1. The duration and nature of the illness
2. Characteristics of the person and/or relationship that are lost
3. The secondary losses that will result from the death
4. The personal characteristics of the griever
5. The griever's previous experience with/or personal expectations regarding illness, dying, and death
6. The griever's knowledge and response to the illness and ultimate death
7. The type, frequency, and intensity of the griever's involvement in the dying person's care and treatment
8. The griever's perception of the preventability of the illness
9. The location of the dying individual (home, hospital, nursing home, relative's house)
10. The griever's evaluation of the quality of care, treatment, and resources provided
11. The griever's physiological condition
12. The dying individual's subjective experience/ attitude and response to the illness and its ramifications
13. The quality of the dying person's life after the diagnosis or before death
14. The family constellation and specific characteristics of the family system
15. Quality and quantity of the griever's social support system
16. The griever's sociocultural, ethnic, and religious-philosophical background
17. The griever's financial resources and expected stability
18. Family and community rituals for illness, dying, and death

CAREGIVING. WHY?

FOR THE SAKE OF WHAT?

Some people give care out of a sense of obligation. Some 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. Others have different reasons, sometimes very clear to them and at other times not.

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 criticism, 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

- Listen. Make eye contact, and don't multitask 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 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". So 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, shop) 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 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 weekly.

Physical Touch –

- Find ways to offer your physical presence to them through a hug, holding a hand, stroking their back, or gently rubbing their shoulders.
- Do not shy away from their touch, even if you initially feel uncomfortable.
- 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.
- When you cannot touch physically (due to distance, an illness, or a virus), plan time for long calls that are intimate and close enough almost to 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. In addition, some caregivers feel that they are passing on a tradition of care and that, by modeling caregiving, their children will be more likely to care for them if necessary.

Tips for connecting to the positive aspects of 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 myself.

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.