HMCI Health and Medical Coaching Institute

Lesson 2 - The Caregiver Journey

The Caregiver Journey is a concept that encompasses the various dimensions and facets of a person's experience as a caregiver. Several models attempt to illustrate this experience by structuring its elements according to activity, roles, timeline, pain point, emotions and thoughts to create a realistic snapshot of the caregiver experience at any point during the caregiving period.

As Caregiver Coaches, we use these models to deepen our understanding of our clients' experiences, enabling us to help them expand their awareness and provide accurate coaching throughout their challenges.

When coaching caregivers, we hold a space for both the **Doing** and the **Being** aspects of the various Caregiver Journey models.

While addressing the **Being** aspects invites us to a deep coaching exploration, addressing the **Doing** aspects requires that we be both coaches and mentors.

In this lesson, we will look into four models based on the concept of a Caregiver Journey.

The Caregiver Journey

This model provides a relational perspective on the different phases of the caregiving experience, focusing on the position of the Caregiver in relation to the caregiving experience.

From our perspective, the stages of this model are not linear, not every Caregiver goes through every stage, and not every stage necessarily comes right after the stage before.

1. Preparing to become a Caregiver

The client realizes they will be taking on the role of caring for a loved one in the near future. The timeline might be clear, and it might not.
At this stage, there are practical discussions to be held, questions to be answered, and information to be learned. As any caregiver consultant will teach, the expectant Caregiver needs to learn and understand the care recipient's health, financial, and emotional needs.
At this point, the care recipient is not usually the focus of the future Caregiver's life. It is a time of inquiry as to what the care recipient wants and/or needs. From the Caregiver Coach perspective, it is time to connect to why the Caregiver is taking on this role and/or why not.

As Caregiver Coaches, we will invite our clients to look at:

Being

- The reasons they take on this role
- Values and beliefs around the role of being a caregiver in general
- Values and beliefs around this specific caregiving
- Paradigms
- Family myths and traditions
- Their lives and those of their loved ones

Doing

- Caregiving resources, current and missing
- Caregiving skills, current and missing
- Caregiving information current and missing
- Communication skills
- Relationships

Aviva is one of three children. Both of her parents are in their mid-70's. They are vibrant and ready for this retirement that they are finally enjoying. They are moving their home to be near Aviva and her family. Aviva feels that she is now a part of their "management" team. She is afraid that if they don't have the necessary insurance, income, recreational activities, friends, and so much more, that their lives will be her responsibility. Even though they are both vital and vibrant, Aviva is certain that she must know where their legal information and passwords are so that should anything befall one or both of them, she can cope. She spoke about this with her siblings and they insisted that she not worry and that everything is fine. She tried to speak about it with her parents who also insisted that everything is fine and taken care of.

Jack and Jill are in their fifties. They each have children from previous marriages and one they share. Jill fell recently and even though the leg she broke is healing nicely, Jack realized that they

are both getting older and that they need to "get things in order". Jill won't even listen to the thought that they discuss "getting things in order".

Craig and Mary have a two-month-old son. He was just diagnosed with spina bifada or something like that. Their first son is now two years old. He is healthy, beautiful, and perfect for his age. When the doctors said "spina bifada" Craig and Mary looked at each other. Mary shed some tears and Craig remained stiff. They had been expecting thisyet , the words that came out of the doctor's mouth were a surprise. What to do? Where to start? What will be? What does that mean? What about their other son? Is there a cure? Is this forever?

2. Becoming a Caregiver

The client's routine has begun to change as s/he starts taking on the role and responsibilities of a caregiver. More and more requests are being made of the Caregiver, and these additional requests need to be added to the Caregiver's other responsibilities.

At this stage, many clients feel they don't know where to turn to get help. In some cases, they don't even know what help they want or need. Clients might feel like they are losing control and everything is unorganized.

As Caregiver Coaches, we will invite our clients to look at:

Being

- Self-identity
- Existing relationships
- Connecting to personal energizing resources
- Additional support systems
- Self-care
- Emotions

Doing

- Setting boundaries
- Relationship building
- Caregiving resources, current and missing
- Caregiving skills, current and missing
- Caregiving information, current and missing
- Learning more about the care recipient's illness
- Connecting to personal energizing resources
- Executive function skills
- Additional support systems
- Self-care
- Emotional Agility

Ros' mother lives far away. For many years, they spoke regularly on the phone. Ros' mother worked full time, spent time with friends and family. Everything was "as it should be". A few of Ros' mother's friends starting showing signs of ageing and both Ros and her mother had open discussions of how Ros's mother wanted to age – in her home for as long as possible. The two continued to speak regularly and Ros discerned that her mother was losing some of her insight and needed help with cleaning and shopping. Ros felt that this was her responsibility and decided to drive the three-hour drive to her mother once a week to help out.

Avi was diagnosed with lung cancer three months ago. He and his wife of 35 years heard the doctor's words together. Avi reached for his wife's hand. She held on tight. She immediately knew that she would take care of him no matter what, that she would see him through this. She went home and read everything about the illness, joined an on-line support group, made doctor's appointments, and called her sister. She has accompanied him to his doctor's appointments and arranged a schedule for his accompaniment to treatments. She is still working full-time and her boss of 25 years knows her situation and is still lenient with her time and responsibilities.

Geraldine's daughter and her new husband were in South America when a car crashed into them, instantly killing her husband and leaving her in dire need of serious medical care. Geraldine flew to South America to her daughter and brought her daughter home. Her daughter was in a coma for two months and is now slowly recovering. It is clear to Geraldine that her daughter will not go back to her new home, but to the home she grew up in. Geraldine has taken a three month leave of absence and will have to return to work very soon. Geraldine's husband is cool and relaxed and is certain that somehow everything will work out.

3. <u>Advanced Caregiver</u>

The client is functioning as a caregiver on a regular basis, and this plays a large part in their activity and identity.

At this stage, Caregiving is beginning to take a toll, and signs of physical, mental, and emotional fatigue might be showing. This is when caregiver burnout and caregiver stress are often discussed. For many, life seems like a rollercoaster of emotional ups and downs.

As Caregiver Coaches, we will invite our clients to look at:

<u>Being</u>

- Self-care
- Emotions
- Receiving support
- Relationships that change as a result of situations that change

<u>Doing</u>

- Self-care
- Emotional agility
- Adding support systems for the care recipient
- Boundaries
- Communication skills
- Receiving support
- Finding creative solutions to new issues

Ros has now been helping her mother out for several months. In addition to the once-a-week shopping and cleaning, there have been a few doctor's appointments. Ros feels that the long drive has become a nuisance and, even though she loves her mother and would do anything for her, it is impacting her work and the time she should be spending with her husband and children.

Jane has a teenage daughter who suffers from pain throughout her body. The pain fluctuates from her back, her abdomen, her stomach, and headaches. Jane's daughter has been hospitalized back and forth, and the doctors don't seem to be able to agree on her diagnosis. The rest of Jane's family no longer believes that there is truly something wrong with the girl. Jane is certain that there is. She is worn out and also won't let herself be worn out (for the sake of her daughter).

Sam's Parkinson's has gotten worse, and Helen seems to have no life of her own left. She hasn't slept a full night for months. She's afraid to leave Sam alone at home for even half an hour, and their help quit two weeks ago (this is a good thing since, according to Helen, she was rude and obnoxious). Sam and Helen's children live in another country and have not been able to visit for months because of COVID. They have, however, been very free with advice and instructions for Helen. Helen is overwhelmed, tired, and feeling ill herself.

4. <u>Seasoned Caregiver</u>

The Caregiving has been going on for some time– sometimes years, sometimes decades. At this stage, the client has been accompanying the loved one to hospitals, doctors' appointments, trials, community services, and organizing family and friends. The client has become the loved one's advocate and an authority about the loved one's condition and needs. At this stage, the Caregiver is very practical about the "doing" of Caregiving, and to outsiders, it might seem that she has become "cold", "removed", "and distant". This shift into being practical opens, for some caregivers, the space to reexamine their identity and purpose.

Often at this stage, there are changes in the nature and volume of the caregiving responsibilities and, as a result, the client experiences challenges coming to terms and coping anew. There is a need to fill the void, to reconnect.

As Caregiver Coaches, we will invite our clients to look at:

<u>Being</u>

- Identity
- Perspectives - Metaview
- Personal development
- Spirituality
- Positivity
- Self-care
- Coping with changes

<u>Doing</u>

- Personal development
- Spirituality
- Self-care
- Maintaining relationships and creating new ones
- Exploring "My Journey as a Caregiver"
- Coping with changes

Aaron has had cancer for two years now. Naria quit her job (she was near retiring anyway) and has been accompanying her husband on this journey of his. She goes for a walk on her own three times a week and enjoys grocery shopping since this provides a respite. The doctor they have been going to is transferring to another hospital for a year and Naria is in the process of deciding whether or not to go with her. Aaron will do whatever Naria decides.

After several years, the doctors diagnosed Jane's daughter, JoAnne, with endometriosis. Both Jane and JoAnne are now experts on the illness. They participate in support groups, read up on every new treatment, JoAnn even blogs. JoAnne's symptoms flare up regularly and she doubles over in pain. To JoAnne and the outside world, Jane seems insensitive and cold to her daughter's

plight. She tells her daughter to "deal" with the pain, not to let it get the better of her. JoAnne tells her mother that she is alone in this and that even though Jane accompanies her everywhere and is with her whenever necessary, she feels that her mother is distant and uncaring. Jane, on the other hand, feels that if she shows any softness or sensitivity, she will not be able to function as required.

Tracy's body is aching. She has been taking care of her brother for the past three years. He was a big man and now, when the help is on vacation, she has to help him get in and out of his bed. Lately, he has been losing more and more functions and Tracy has been helping out more and more. Since his diagnosis, she has always accompanied him. They are twins and at the age of 34, Tracy knows exactly what needs to be done and is fed up.

5. <u>Post-Caregiving</u>

The client's role as a caregiver is ending.
Whether Caregiving has ended because the loved one has passed away, recovered or one party has chosen to end the caregiving relationship, the client is no longer a caregiver.

At this stage, the client might be exploring the possibility of becoming an advocate of Caregiving, offering advice, raising awareness, writing about their experience, facilitating support groups, or offering one-on-one support to other caregivers. Some clients might be looking into entering a new caregiving journey. On the other hand, the client might feel the need to take that long-awaited breather and re"find" themselves.
This is similar in many ways to the "empty nest" syndrome in which people who have had full homes with many children find themselves in a quiet home without the children – either alone or just with their partners.

As Caregiver Coaches, we will invite our clients to look at:

<u>Being</u>

- Identity
- Purpose
- Coping with changes
- Coping with loss and grief
- Revisiting old personal goals and interests
- Setting new goals
- Grief

<u>Doing</u>

- Grief
- Self-care
- Exploring "My Journey as a Caregiver"
- Coping with changes
- Coping with loss
- Reevaluating priorities
- Personal development
- Mourning

<u>A.</u>
Geraldine has been taking care of her daughter on her own for two years now. Her daughter is functioning very well and is ready to move out of her parent's home. This period has been very hard on Geraldine as she feels like she has been alone for these two years. Even though she saw her husband every day and slept with him at night, he was not with her. Geraldine is certain that life is a gift and that she and her daughter have been given a second chance. Her daughter is taking that chance. What will Geraldine do?

Daria was diagnosed as bipolar as a teenager. Her parents have provided the best possible care for her. She is now 47. Her mother passed away several years ago and her father, Joe, is always there if and when there is a relapse. Joe has been taking care of his daughter for 47 years. He sees the relapse as it approaches. He has a system in place and together they have been able to conquer this bipolar for almost a half a century. Joe is now looking for someone to take over for him should he not be able to help his daughter.

Linda excitedly agreed to her grandmother staying with them. Actually, she and her husband moved in with Grandma. Linda envisioned tasting her grandmother's wonderful cooking and feeling what she felt as a child when visiting grandma – love and warmth. Over the years, Linda's grandmother has aged. Seven years ago, when they moved in, Grandma was vital and could do almost everything. For the past five years, she hasn't been able to feed or clothe herself. The doctors say that the end is near. Linda's grandmother is often angry and violent and it has become unbearable at times to be at home. Linda takes everything in stride. No longer gets angry or even reacts to the situation. But, at least once a week, she feels almost incapable of getting out of bed – her loss and sadness are so great.

B.

Rona's husband died two years ago. She has mourned for him night and day. Slowly she reconnected to herself and found that it was time to fill that void of the emptiness that life without him left her with.

Tamar's daughter is managing her pain and her life. After 5 years of Caregiving, Tamar is now "free" to go back to what she did before. Is this what she wants? Is she the same?

Tim has been caring for his daughter, Carrie, who suffers from BiPolar disorder for the past fifteen years. At the age of 30, Carrie has a wonderful job, has moved out of the home and is in control of her life. Tim is now 50 and doesn't remember his life without taking care of Carrie.

"The Caregiving Years - 6 Stages to a Meaningful Journey"

One of the most commonly known Caregiver Journey models today is "The Caregiving Years - 6 Stages to a Meaningful Journey" by Denise M. Brown.

Stages of the model:

1. "The Expectant Caregiver – In the future, I may help a family member or friend."
2. "The Freshman Caregiver – I am starting to help a family member or friend"
3. "The Entrenched Caregiver - I am helping a family member or friend"
4. "The Pragmatic Caregiver - I am still caring for a family member or friend"
5. "The Transitioning Caregiver - My role is changing"
6. "The Godspeed Caregiver - My caregiving role has ended"

In this link, you can find more information about the model and stages - https://www.careyearsacademy.com/the-caregiving-years/

The Caregiver's Journey Version of the Hero's Journey

Everyone has an internal hero. Based on the Hero's Journey (Joseph Campbell), this approach invites the Caregiver to find and connect to his/her inner hero through an empowering, meaningful narrative whilst offering caregivers a different perspective on what they are going through.

As in the Hero's Journey, the Caregiver's Journey has stages. Within the journey some stages are linear and some spiral. The Journey often begins with a ***Call.***

The Call is an inner realization and understanding that the client is called to start a new phase, which in some cases means leaving what is familiar and known and venturing into something unknown and unfamiliar.
The *Call* can actually be a call (like a telephone call), it can be intentional or unexpected. On the part of the Caregiver, it may also be unwelcome and unwanted.

The second stage is the stage of **Commitment.**
The Caregiver then makes a formal commitment to become a caregiver. This means the person agrees and makes it known that s/he has agreed to take on some or all of the caregiving roles.

Once the commitment is made, the Caregiver enters the actual **Caregiving**.
This part is spiral and not linear, and it includes three stages that intertwine:

Developing Resources –

- Identifying, enhancing, and creating emotional and cognitive resources and capabilities.
- Identifying allies (medical team, community, family members, friends)
- Creating support systems
- Setting administrative systems and logistics in place

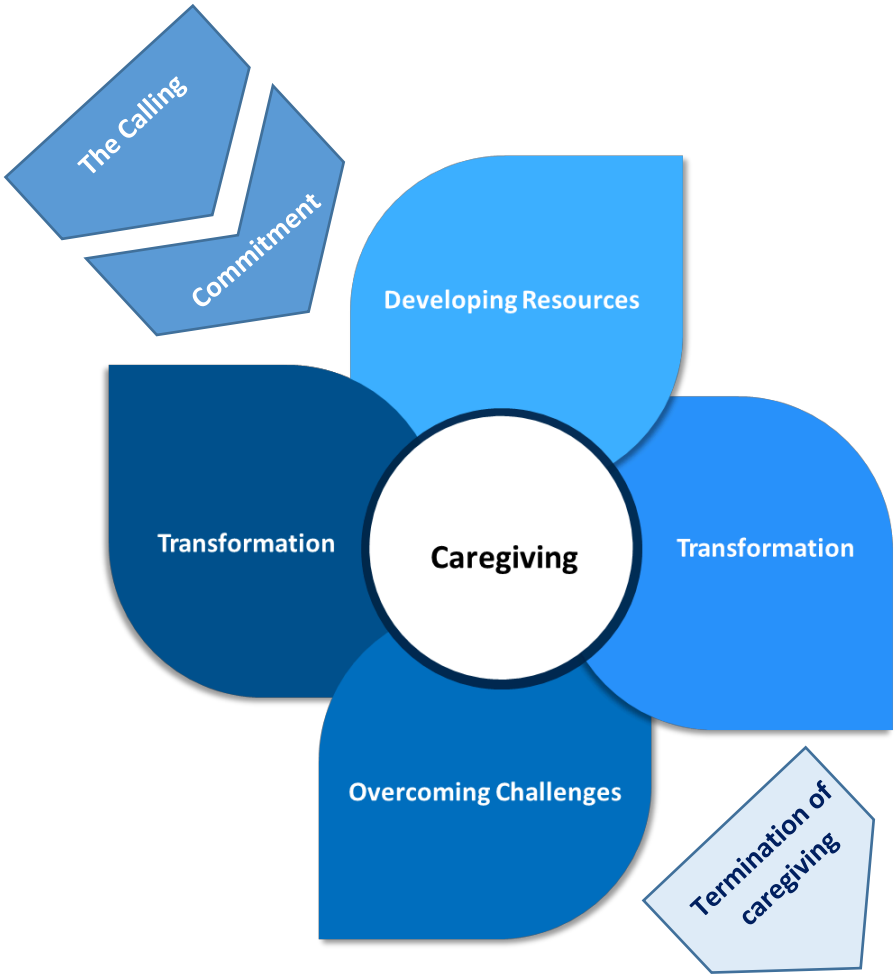
Overcoming Challenges:

- Setbacks
- Logistics
- Medical issues
- Stress and burnout
- Emotions
- Limiting beliefs and paradigm

Transformation:
Transformation occurs when caregivers internalize and own the achievement of developing resources and/or overcoming a challenge, and those become part of their caregiving toolbox. The transformation occurs across six levels of change: purpose, identity, values & beliefs, capabilities & skills, behaviors, and environment.

At the **Termination** Stage, the Caregiver returns home.

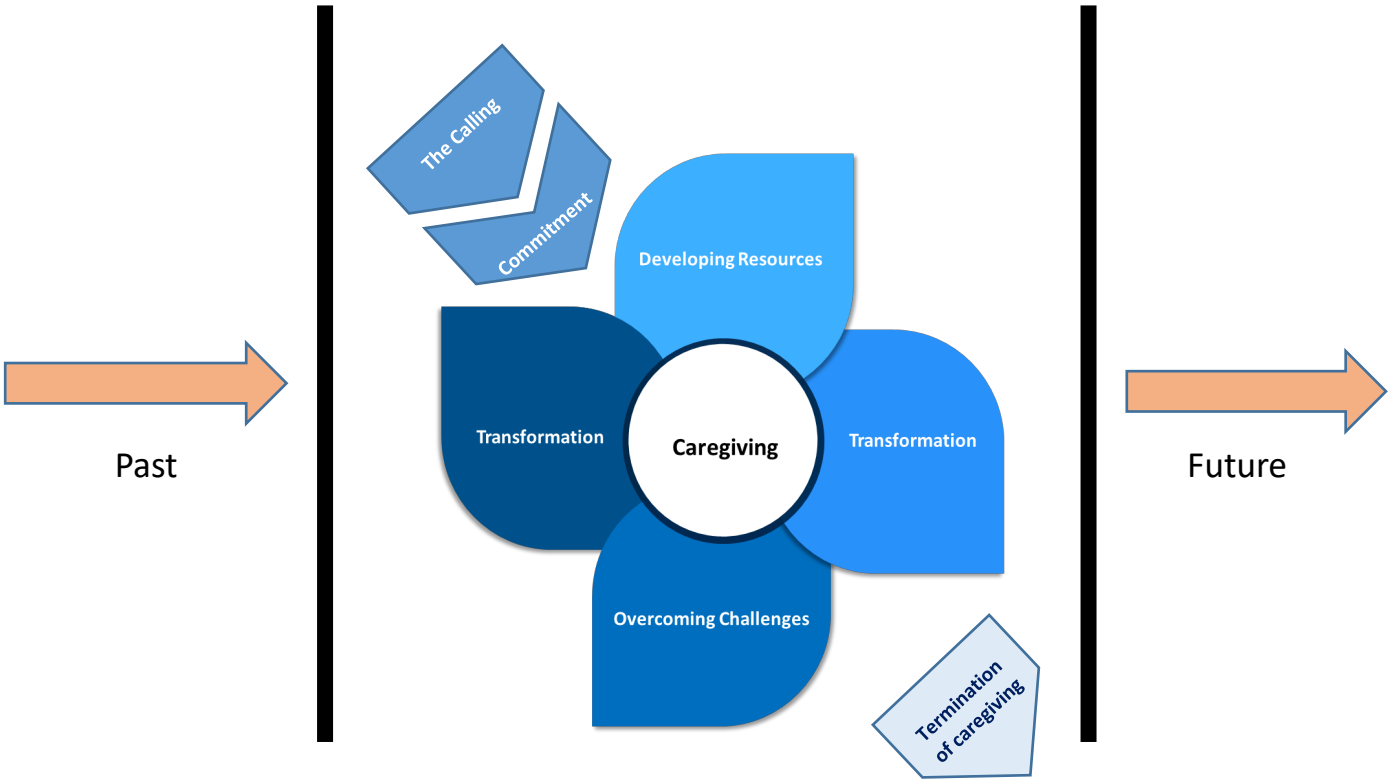
At every level, the Caregiver Coach asks the client:
"Who are you?", "What do you need?", "Who are you becoming?"



The Liminal Journey

A **Liminal Space** is a transitional phase between two well defined states or periods.
In this case the two defined periods are as the period before the caregiving started and after the caregiving ended.

The 'old' life has ended and there needs to be a rite of passage so that the person can cross the threshold into a new life of a caregiver. We are in between and in neither of the two.



"Can you promise I will come back?" asks Bilbo. "No, but if you do, you will not be the same".
Gandalf, The Hobbit