

## Family Caregiver Education Series



Living with Dementia:  
Self-Care for the Caregiver  
June 8, 2023 • 10:00 a.m.

**Debbie Emerson, M.S., Community Health Educator**  
CARES® Dementia Specialist

**Gia Barsell, Manager of Dementia Services & Education**  
PAC™ Advanced Dementia Trainer and Consultant



## Upcoming Webinar

### Handling Grief and Loss

Thursday, July 14, 2022

10:00 – 11:30 a.m.

**Guest Presenter:**

Michele Shimamura, MFT  
Certified Thanatologist

**Register at:** [www.HopeHospice.com](http://www.HopeHospice.com)





## Archived Dementia Webinars

- **Next Steps After a New Diagnosis**  
May 2023
- **Managing Daily Care**  
February 2023
- **Understanding Behavior as Communication**  
December 2022
- **Dementia Basics**  
September 2022
- **Dementia or "Normal" Aging?  
How to Tell the Difference**  
August 2022

Access at: [www.HopeHospice.com/family-past](http://www.HopeHospice.com/family-past)



## Session Agenda

- Change
- Causes of Caregiver Burnout
- Coping Strategies
- Understanding Emotions
- Rewards of Caregiving
- Questions





“Life is not the way it’s supposed to be. It’s the way it is. The way you cope with it is what makes the difference . . .

The way in which we respond will direct and influence the event more than the event itself.”

-Virginia Satir, noted family therapist and author



## Dementia Care in General . . .

- Each journey and timeline is unique.  
*If you’ve met one person with dementia, you’ve met **one person** with dementia.*
- However, there are similarities:
  - Progression of independence to total dependence.
  - Role of caregiver evolves with each change; increasing responsibility for care.
  - Stress level increases.
  - Getting help is essential. One person can’t provide all of the care all of the time.
  - Those who receive loving support can maintain a good quality of life and well-being.





Caring for a person with dementia  
is the most stressful of all  
caregiving experiences.

*Why do you think this is the case?*



Some possible reasons . . .

- Dementia is unpredictable
- Uncertainty about what is to come
- Moments of lucidity = false sense of hope
- Personality changes
- Change in relationship = role confusion
- Mourning the loss of the relationship
- Dealing with family members with different perceptions
- Dementia-related behaviors
- Providing care can be all-consuming





## A Word About Change

- Change involves not just a beginning of something, but also an ending of what was.
- Remember that whatever the change or how out of control things might seem, you always can choose:
  - Whether or not you deal with the change.
  - **How** you deal with a change.
  - **Your attitude** about the situation.
  - Whether you look ahead and plan for potential changes . . . or ignore them and wait for a crisis.

**Resource:** *The Caregiver Helpbook*



## Denying Change

Caregivers who deny change or try to maintain the status quo:

- Waste time and energy trying to keep things the same.
- Lose opportunities for the care recipient to take part in planning for his/her future.
- Develop unrealistic expectations – more likely to believe that the care recipient can function if s/he just tries harder.
- Burn out because they can't accept that the care needs are more than they can handle.

**Resource:** *The Caregiver Helpbook*





The only constant is change . . .



*Can you use it as a chance to learn and grow?*



*Burnout: A state of physical, emotional, and mental exhaustion*

**Physical symptoms:**


- Headaches
- Muscle aches and pains
- Sleep disturbances/irregularities
- Chronic fatigue
- Changes in appetite
- "Knot" in stomach
- Increased susceptibility to illnesses
- Excessive alcohol consumption

**Feelings:**

- Overwhelmed
- Frustrated
- Depressed
- Hopeless
- Loss of interest
- Withdrawn
- Irritable
- Unable to concentrate
- Impatient




**DO YOU HAVE CAREGIVER BURNOUT?**




1. YOU NO LONGER FIND PLEASURE IN THINGS YOU ONCE FOUND ENJOYABLE.
2. FRIENDS AND FAMILY HAVE EXPRESSED CONCERNS ABOUT YOUR WELL-BEING.
3. YOU'RE GETTING NEGATIVE FEEDBACK AT WORK.
4. YOU'RE HAVING PROBLEMS WITH YOUR SPOUSE.
5. YOU EXPERIENCE INTENSE AND RECURRENT FEELINGS OF ANGER, SADNESS, WORRY OR FEAR.
6. YOU HAVE DIFFICULTY CONCENTRATING.
7. YOU HAVE TROUBLE SLEEPING, DRASTIC WEIGHT CHANGES OR OTHER UNEXPLAINED HEALTH PROBLEMS.
8. YOU USE A SUBSTANCE TO COPE WITH, MANAGE OR SUPPRESS PAINFUL FEELINGS.

**Resource:** *A Caregiver's Guide to Coping with Stress and Burnout*



## Typical Causes of Caregiver Burnout

- Role confusion
- Unrealistic expectations and demands
- Lack of control
- "Priority paralysis"
- Family conflicts
- Too much stress and too few rewards





## Role Confusion

- Am I a wife (husband, son, daughter), or a care provider?
- What can be done?
  - Practice “both/and” thinking.  
*Example:* I am BOTH a care partner AND a person with my own needs.
  - Make time in the day to focus on your relationship.
  - Bring in help to handle some of the care responsibilities.



## Unrealistic Expectations and Demands

- Self
- Family members
- Care recipient







## Lack of Control

Regarding . . .

- the caregiving situation.
- the care recipient's behavior.
- the lack of resources.
- the lack of skills to deal with the situation.



## Priority Paralysis

- Defined: *When you have so much to do and are feeling so overwhelmed that you are not motivated to do anything.*
- What can be done?
  - Accept that there will NEVER be enough time.
  - Accept that you are not perfect (not even close!).
  - Just do something!





## Family Conflicts



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## Make a commitment . . .

- Try to accept family members as they really are – not who you wish they were.
- Accept and respect differing perspectives.
- Recognize that with ideas come responsibilities.
- Ask yourself what help you really want from your family . . . or, do you just want emotional support?
- Steer clear of the cycle of guilt and anger when asking for help.
- Avoid power struggles.
- Don't let inheritance disputes tear apart your family.

**Resources:** *Easing Aged-based Sibling Rivalry; Holding a Family Meeting*

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## Make a commitment . . .

- Communicate with everyone:
  - Hold a family meeting
  - Discuss roles and responsibilities
  - Avoid exclusive alliances; don't exclude "difficult" family members
  - Don't withhold information
  - Document, document, document
- Share what you learn and what works.
- Cope with changes and loss **together**.
- Make your loved one's care a priority.
- Seek outside help from a trusted 3<sup>rd</sup> party, if needed.

Resources: *Easing Aged-based Sibling Rivalry; Holding a Family Meeting*



## How to Minimize Burnout

- Seek understanding and knowledge.
- Form a team: Ask for and accept help. Now.
- Reframe the situation/modify your thoughts.
- Take care of yourself. *The care you give to yourself is the care you give to your loved one.*
- Focus on the rewards of caregiving.





## Forming a Care Team

- Determine what you need
- Identify who can help
  - Family
  - Friends
  - Co-workers
  - Paid caregivers
- Establish a system of task management and communication  
(Ex. Care Village, CareZone, Lotsa Helping Hands)



## What do I need?



- What would I like others to know about what I'm feeling?
  - Who can I talk with for emotional and/or spiritual support?
  - Who can help with caregiving or provide brief respite?
  - Who do I feel comfortable calling at the last minute?
  - How can others help me?
- |  |   |
|--|---|
| <input type="checkbox"/> Companionship for me                              | <input type="checkbox"/> Home safety and maintenance    |
| <input type="checkbox"/> Companionship/socialization for my care recipient | <input type="checkbox"/> Housekeeping                   |
| <input type="checkbox"/> Brief respite                                     | <input type="checkbox"/> Help with personal care needs  |
| <input type="checkbox"/> Activities & recreation                           | <input type="checkbox"/> Medication management          |
| <input type="checkbox"/> Meal preparation                                  | <input type="checkbox"/> Transportation                 |
| <input type="checkbox"/> Grocery shopping/errands                          | <input type="checkbox"/> Legal and financial assistance |
| <input type="checkbox"/> Accompany to medical appointments                 | <input type="checkbox"/> Other                          |



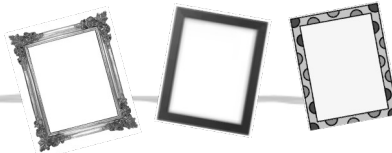


## Reframing

- When dealing with an uncontrollable situation, you do control one thing . . . your response to that situation.
- It's not the task that overwhelms, but how the caregiver PERCEIVES the task.
- Redefine and reframe role/situation/event.
- Can you make stress your friend?  
TED Talk: Dr. Kelly McGonigal, Health Psychologist  
[www.youtube.com/watch?v=RcGyVTAoXEU](http://www.youtube.com/watch?v=RcGyVTAoXEU)



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## Cognitive Distortions

- Overgeneralization
- Discounting the Positive
- Jumping to Conclusions
  - Mind-reading
  - Fortune-telling
- “Should” Statements
- Labeling (negative self-talk)
- Personalizing (self-blame)

**Resource:** *Dementia, Caregiving, and Controlling Frustration*  
Family Caregiver Alliance [www.caregiver.org](http://www.caregiver.org)



## Caring for Yourself



“Self-care is not an option, it’s a necessity. To care for another, you must care for yourself.”

- Marty Richards, CareSharing





## Understanding and Accepting Emotions

If only we were perfect, we would not feel . . .

- |             |               |                 |
|-------------|---------------|-----------------|
| ▪ Anxious   | ▪ Embarrassed | ▪ Unappreciated |
| ▪ Angry     | ▪ Afraid      | ▪ Lonely        |
| ▪ Bored     | ▪ Frustrated  | ▪ Grief         |
| ▪ Irritable | ▪ Guilty      | ▪ Resentful     |
| ▪ Sad       | ▪ Impatient   | ▪ Exhausted     |
| ▪ Disgusted | ▪ Jealous     |                 |

**Resource:** *The Emotional Side of Caregiving*

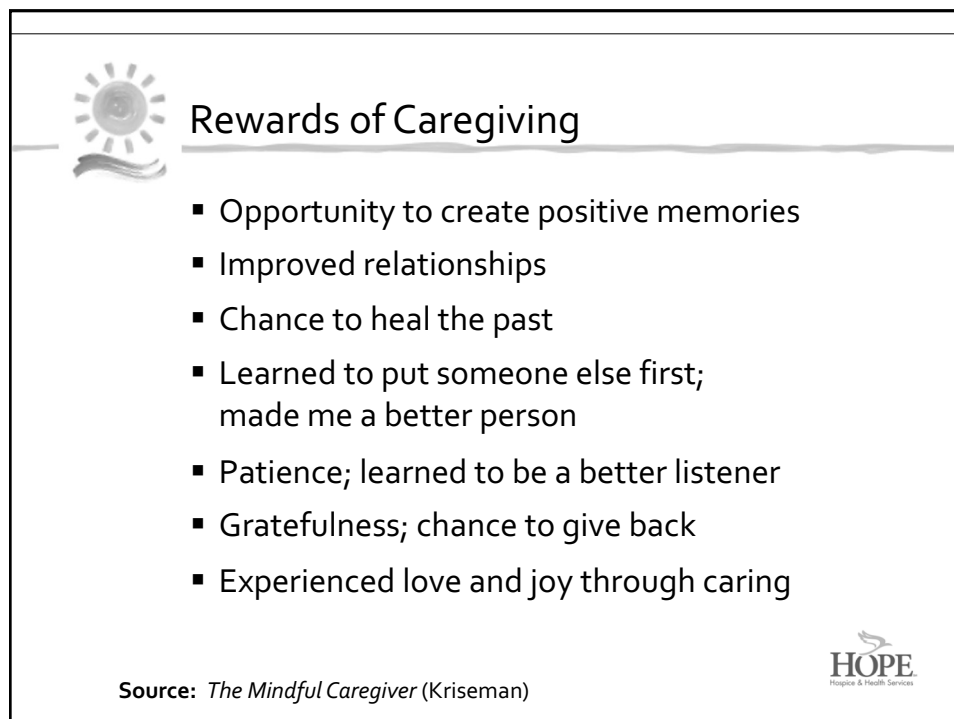
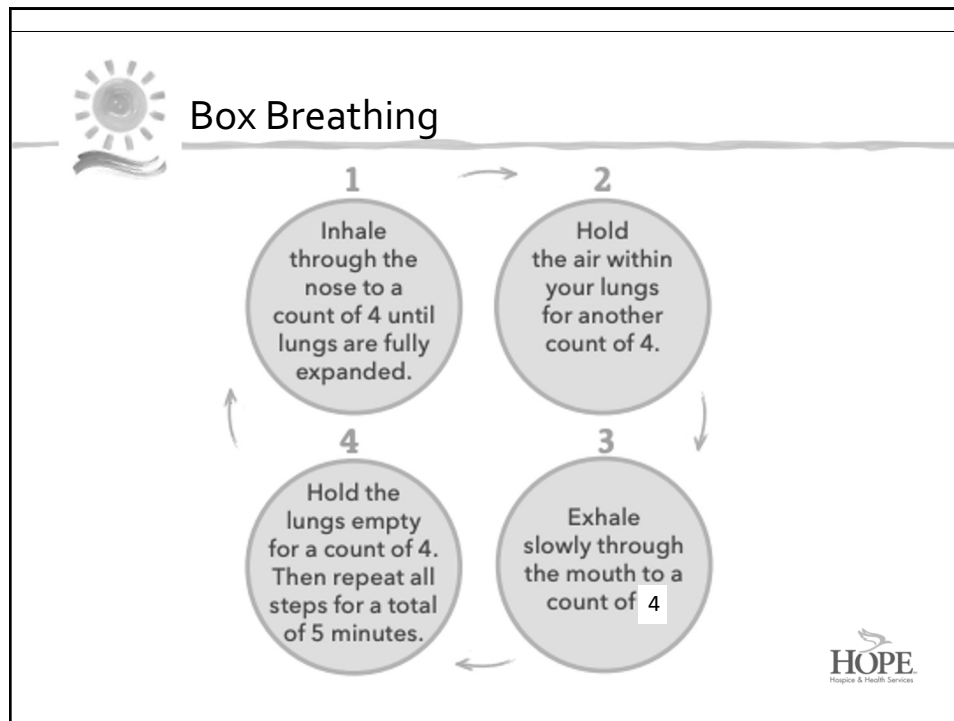


## Self-Care Strategies

What works for you?

- |  |  |  |
|--|--|--|
| <input type="checkbox"/> Physical activity     | <input type="checkbox"/> Dancing                     | <input type="checkbox"/> Counseling/therapy            |
| <input type="checkbox"/> Reading               | <input type="checkbox"/> Being with family & friends | <input type="checkbox"/> Taking classes                |
| <input type="checkbox"/> TV/Movies             | <input type="checkbox"/> Laughing                    | <input type="checkbox"/> Going to the theater          |
| <input type="checkbox"/> Spa treatments        | <input type="checkbox"/> Napping                     | <input type="checkbox"/> Learning something new        |
| <input type="checkbox"/> Meditating            | <input type="checkbox"/> Writing                     | <input type="checkbox"/> Anything involving creativity |
| <input type="checkbox"/> Music: listen/play    | <input type="checkbox"/> Enjoying nature             | <input type="checkbox"/> Other _____                   |
| <input type="checkbox"/> Socializing           | <input type="checkbox"/> Praying/spiritual           |  |
| <input type="checkbox"/> Traveling             | <input type="checkbox"/> Arts and crafts             |  |
| <input type="checkbox"/> Recreational shopping | <input type="checkbox"/> Sports: watch/play          |  |









## More Rewards of Caregiving

- Role model for next generation of caregivers
- A way to honor my loved one
- No regrets; peace of mind
- Had time to say goodbye
- Changed my priorities; learned what's important
- Developed new skills and competencies
- Personal fulfillment; satisfaction of a job well done

Source: *The Mindful Caregiver* (Kriseman)



## I have the right . . .

- To take care of myself, including resting when I'm tired, eating well, and taking breaks from caregiving when I need to. This is not an act of selfishness. This will enable me to take better care of my loved one.
- To seek help from others even though my loved one may object. I recognize my own endurance and strength and acknowledge that I don't have to do it all by myself.
- To socialize, maintain my own interests, and do the things I enjoy.
- To acknowledge my feelings of frustration, anger, and depression and express these feelings in constructive ways.
- To disallow any attempt by my loved one (either intentional or not) to manipulate me through guilt, anger, or depression.





## I have the right . . .

- To receive consideration, affection, forgiveness, and acceptance for what I do for my loved one as long as I offer these qualities in return.
- To take pride in what I am accomplishing and to applaud the courage and creativity it has sometimes taken me to meet the needs of my loved one.
- To protect my individuality and my right to make a life for myself that will sustain me at the time when my loved one no longer needs my full-time help.

-Author Unknown

*Various versions have appeared in Caregiver's Handbook (DK Publishing); Family Caregiver Alliance Fact Sheets; The Mindful Caregiver (Kriseman); etc.*



## Thank you!

Webinar recording and resources posted on:  
[www.HopeHospice.com/family-past](http://www.HopeHospice.com/family-past)

Don't forget to complete the online evaluation upon leaving the webinar – or when you get the link in the follow-up email tomorrow.

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