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THE CAREGIVER JOURNEY

Caring for Yourself

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Meet Our Experts

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Caregiver Burnout is Real

Abigail Costley, MSW

Direct Programs Manager, ElderSource



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Caregiver Burnout and Caring for the Caregiver

What is caregiver burnout?

- ▶ A state of emotional, mental, and physical exhaustion.
- ▶ When you get to that point, both you and the person you are caring for suffer.



Caregiver Burnout Facts

- ▶ In the past five years, over 40 million family caregivers provided 37 billion hours of care for loved ones.
- ▶ About 85% of family caregivers in the U.S. do not receive any respite care.
- ▶ Depression affects up to 40% of all caregivers.

Common signs and symptoms of caregiver burnout

- ▶ Irritability
- ▶ Withdrawal
- ▶ Fatigue
- ▶ Insomnia
- ▶ Apathy
- ▶ Appetite Changes
- ▶ Guilt

Root Causes for Caregiver Burnout

- ▶ Expectations of self
- ▶ Expectations from others
- ▶ Identity discrepancy
- ▶ Not taking breaks or asking for help
- ▶ Feeling guilty about taking time for yourself
- ▶ Little appreciation or support

Impact of Caregiver Burnout

- ▶ Poor quality of care
- ▶ Strained relationships
- ▶ Increased risk of depression or anxiety
- ▶ Potential substance use
- ▶ Risk of caregiver becoming a patient



Tips to Prevent Burnout

1

TAKE REGULAR
BREAKS

2

NOURISH YOUR
MENTAL AND
PHYSICAL
HEALTH

3

STAY SOCIALLY
CONNECTED

4

ASK FOR AND
ACCEPT HELP!

Simple Daily Self-Care



Eat something nutritious every day



Move your body (even a short walk counts)



Take 5 minutes to breathe or stretch



Listen to music, read, or do something small that brings you joy



Self-Care Putting on Your Oxygen Mask FIRST

Caregiver Programs Available Through ElderSource

TCARE - A Burn Out Prevention Program

The Tailored Caregiver Assessment & Referral Program (TCARE) is designed to support family members at risk for burnout. Caregivers are interviewed to identify stressors and then a care plan is created to help them address the root causes of burnout.

TCARE helps prevent caregiver burnout:

- ▶ Reduces stress and provides strategies for reducing root causes of caregiver burnout
- ▶ Creates a care plan that offers support and improves effectiveness as a caregiver
- ▶ Connects caregivers to resources that best meet their needs

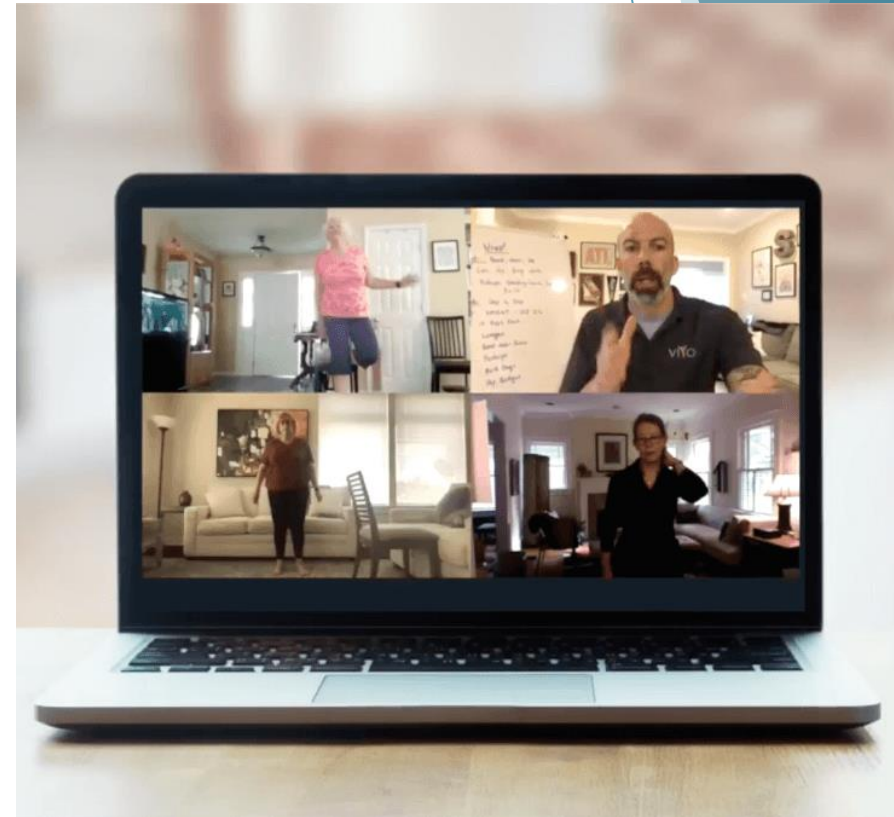
Virtual Support Group



- ▶ Share information, ask questions, voice personal feelings and stories
- ▶ Caregivers connect face-to-face in real time with other caregivers using today's technology.
- ▶ Internet access
- ▶ Smart phone, laptop, iPad, desktop computer to connect
- ▶ 60-minute sessions

Vivo - Online Exercise Classes

- ▶ Aimed at improving strength, balance, and overall well-being.
- ▶ FREE live and interactive, online, small group strength training program scientifically tailored for older adults and caregivers.
- ▶ Program Details:
 - ▶ Meets virtually twice a week for 45 minutes each session.
 - ▶ Join from the comfort of your home.
 - ▶ Provides welcome kits with exercise bands





Start with the Helpline!

1-888-242-4464

CaregiverSupport@MyElderSource.org

Remember...

Burnout is not a sign of failure —
it's a signal for support.



Anticipatory Grief: Mourning a Loss Before It Happens

Mary Beth Hunt, LCSW, ACHP-SW

*Social Work Manager for Long-term Care,
Community Hospice and Palliative Care*



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Anticipatory Grief: Mourning a loss before it happens

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Social Work Manager for Long-term Care, Community
Hospice & Palliative Care

Definitions

Grief – a natural response to any kind of loss or change. It's the emotional suffering you feel when something or someone you love is taken away.

Bereavement – the emotional and physical reactions to loss of a loved one. (*cognitive, spiritual & behavioral*)

Anticipatory Grief – is grief expressed in advance of a loss that is perceived as inevitable, as distinguished from grief that occurs at or after the loss. Anticipatory Grief may either increase or decrease in intensity as the expected loss becomes imminent.

- *From Synopsis of Psychiatry, 7th Edition*

Normal Anticipatory Grief Reactions

- Caregivers often experience the following:
 - Feeling overwhelmed
 - Changes in eating and sleeping patterns
 - A wide range of emotions (guilt, expressions of sadness, anxiety)
- Other normal reactions/symptoms can include:
 - Fears of:
 - Living life without a loved one
 - Breakdown of family structure
 - Losing a social life and companionship
 - Forgetfulness; poor concentration
 - Fatigue
 - Denial and/or acceptance



Anticipatory Grief Interventions

The Four Things

The Four Things That Matter Most

The Four Things



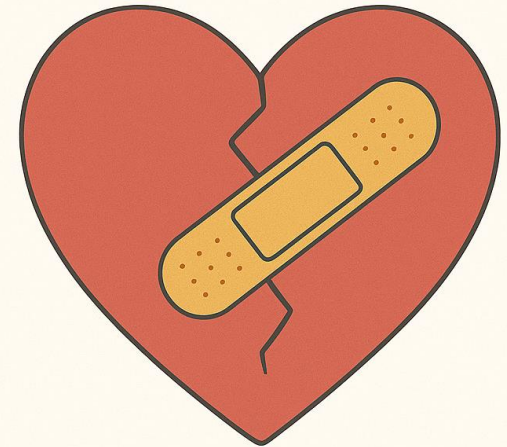
- Please forgive me.
- I forgive you.
- Thank you.
- I love you.

- Completing the relationship
 - Affirms relationships
 - Recognizes difficulties
 - Reconciles relationships

Why these Four Things

- Improves relationships with the dying person
- Encourages assumptions to be spoken
- An opportunity to enhance important relationships
- Potential for emotional wholeness & healing
 - Focus is to free the speaker; focus is not on outcome
- It helps prepare people to say good-bye
- Provides a starting point – it is a tool

Why These Four Things Matter



- Mends broken relationships
- Appreciates important people
- Offers closure

Why Forgiveness Is Important

Why Forgiveness Is Important





- Shifts the focus from anger
- Helps heal emotional pain
- Brings a peaceful mindset

“Many people confuse forgiveness with exoneration. Forgiveness does not excuse someone from doing something wrong. Forgiveness is a strategy for you to become free of emotional baggage.”

Forgiveness

- All religions stress the power of forgiveness
- Practicing forgiveness establishes a positive legacy
- What forgiveness is:
 - A strategy to become free of emotional baggage
 - A bridge that can re-establish connection and allow for healing to happen
 - An act of volition and will versus a feeling
- What forgiveness isn't:
 - It does not excuse the wrongdoing
 - It does not lessen the transgression

Forgiveness: What It Is and Isn't

What It Is	What It Isn't
	
<ul style="list-style-type: none">• An act of compassion• A choice to let go of resentment	<ul style="list-style-type: none">• Condoning or excusing• Forgetting that the harm occurred

Examples from the Field

- Nursing- Dying father unsure what to say to his son whom he has been estranged from for years. Nurse advised him to start with:
 - “I’m sorry”
 - Patient’s effort allowed his son to feel valued and safe enough to express his own feelings.
 - Another option for someone to consider – “Please forgive me for

Why Gratitude Is Important

- Humans have a need to express gratitude and to feel appreciated
- People at the end of life have a particularly strong need to hear they've made a difference
- Feeling recognized and appreciated can lead to a sense of resolution
- Tips
 - State the obvious
 - Don't assume the other person knows
 - Be as specific as possible



Gratitude



- Practicing gratitude brings joy into our lives
 - Expands us
 - Focus becomes what we have vs. what we lack
 - Usually realize we have what we need
 - Dying people seem to grasp the abundance of their life experience
 - Can be filled with grace and love while facing the ultimate loss
 - Most common when they have support that includes humane, loving, palliative care

Gratitude

- Challenges of Alzheimer's/dementia
 - Can feel robbed of opportunity if loved one has dementia
 - Lesson is to say the 4 things early and often
 - Remember that moments of clarity can happen
 - Saying thank you transcends knowing whether or not it's been received and even if it's not returned



Examples from the field

- Hospice Aide: Wife maintaining bedside vigil knowing her dying husband is concerned about her wellbeing and ability to take care of herself.
 - Wife encouraged by CNA to say “Thank you for taking such good care of me and I’m sorry I didn’t make more effort to learn how to pay the bills, pump gas, cut the lawn...”

Why Love Is Important

WHY LOVE IS IMPORTANT



“The most important thing in life is to learn how to give out love, and to let it come in”

- Morrie Schwartz
Tuesdays with Morrie

Love



**Love is the
most
powerful
human
emotion**



**Love requires
no justification,
it has inherent
value**



**“I Love You” –
one of the most
important
sentences in
any language**



**Saying and
hearing “I love
you” near death**

Is a life-affirming act

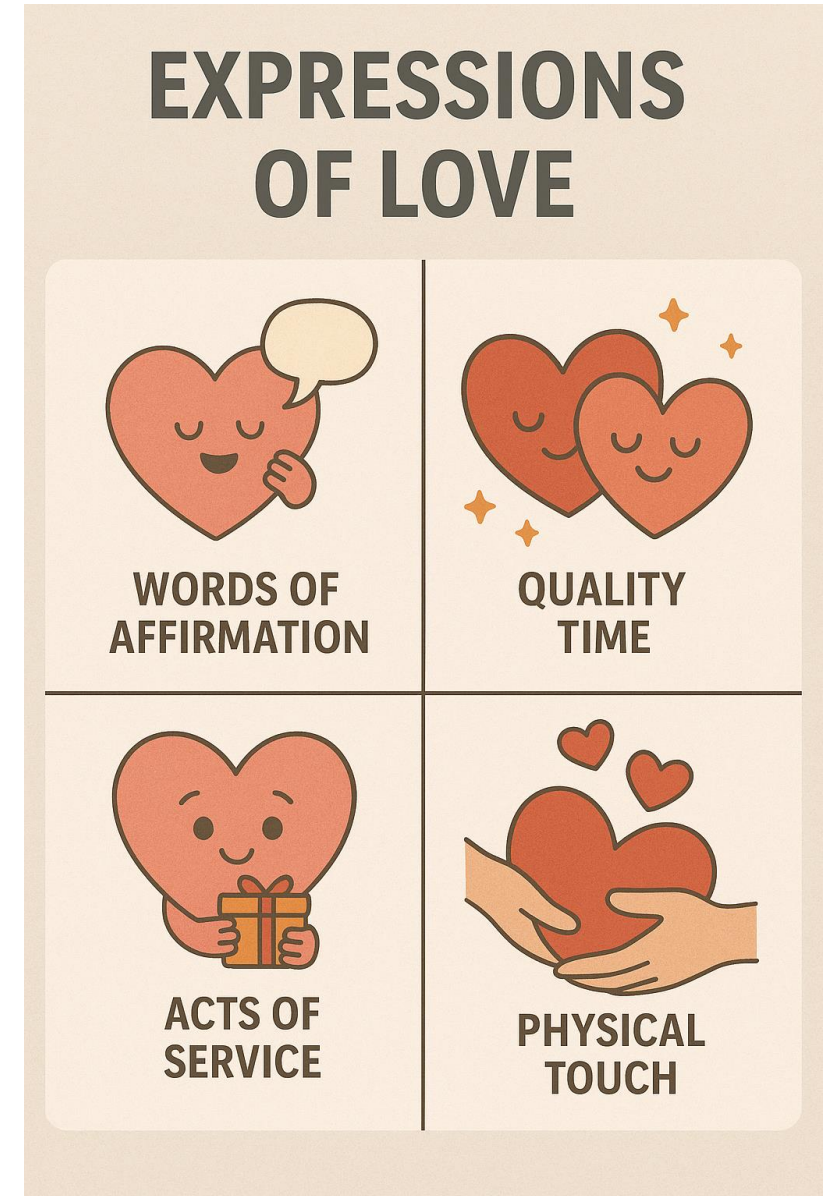
Declares that the
relationship matters

Is how many patients
choose to spend their
limited time and energy

Helps to decrease
guilt/regrets after death

Love

- There is no “right way” to say I love you.
- Love can be expressed in different ways and is influenced by our culture, upbringing, gender, religious beliefs, and communication style
- Ways of expressing love
 - Physical touch
 - Quality time
 - Words of affirmation
 - Gifts
 - Acts of service



Examples from the Field

- Social Worker – Couple married 50+ years, and patient expressed his readiness to die. Spouse expressed the opposite. Social worker asked, “what do you need to say” and witnessed:
 - Spouse saying: “I don’t think I’ve said I love you enough”
 - Patient saying: “I don’t think I’ve said thank you enough”

“We must realize that dying is a spiritual process with medical implications, not a medical process with spiritual implications.”

Gwendolyn London, D.Min., former Director, D.C. Partnership to Improve End-of-Life Care

Finding Meaning, Purpose and Hope in Caregiving

Support for the Spirit of the Caregiver

presented by

Chaplain Jeannie Chapman

System Administrator for Spiritual Care

Baptist Health

Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred. - Dr. [Christina M Puchalski](#)

The Caregiver's Spiritual Journey

Caregiving is sacred and transformative.

Involves love, grief, fatigue and deep presence.

It can reveal inner strength and growth.

Finding Meaning in Caregiving

Meaning is found in relationships, love, and compassion.

Reflection Questions:

What am I learning about myself?

What values guide my caregiving?

Even small acts hold deep significance.

Purpose as a Source of Strength

Purpose grounds us in hard times.

May evolve as caregiving unfolds.

Ask: Who am I becoming through this experience?



Hope in the Midst of Uncertainty

Hope is not denial – it's possibility.
Hope for comfort, peace, and meaning.



*“Hope is the ability to hear the music of the future.
Faith is the courage to dance to it today.”*

Practices That Nurture Spiritual Health

Reflection or journaling.

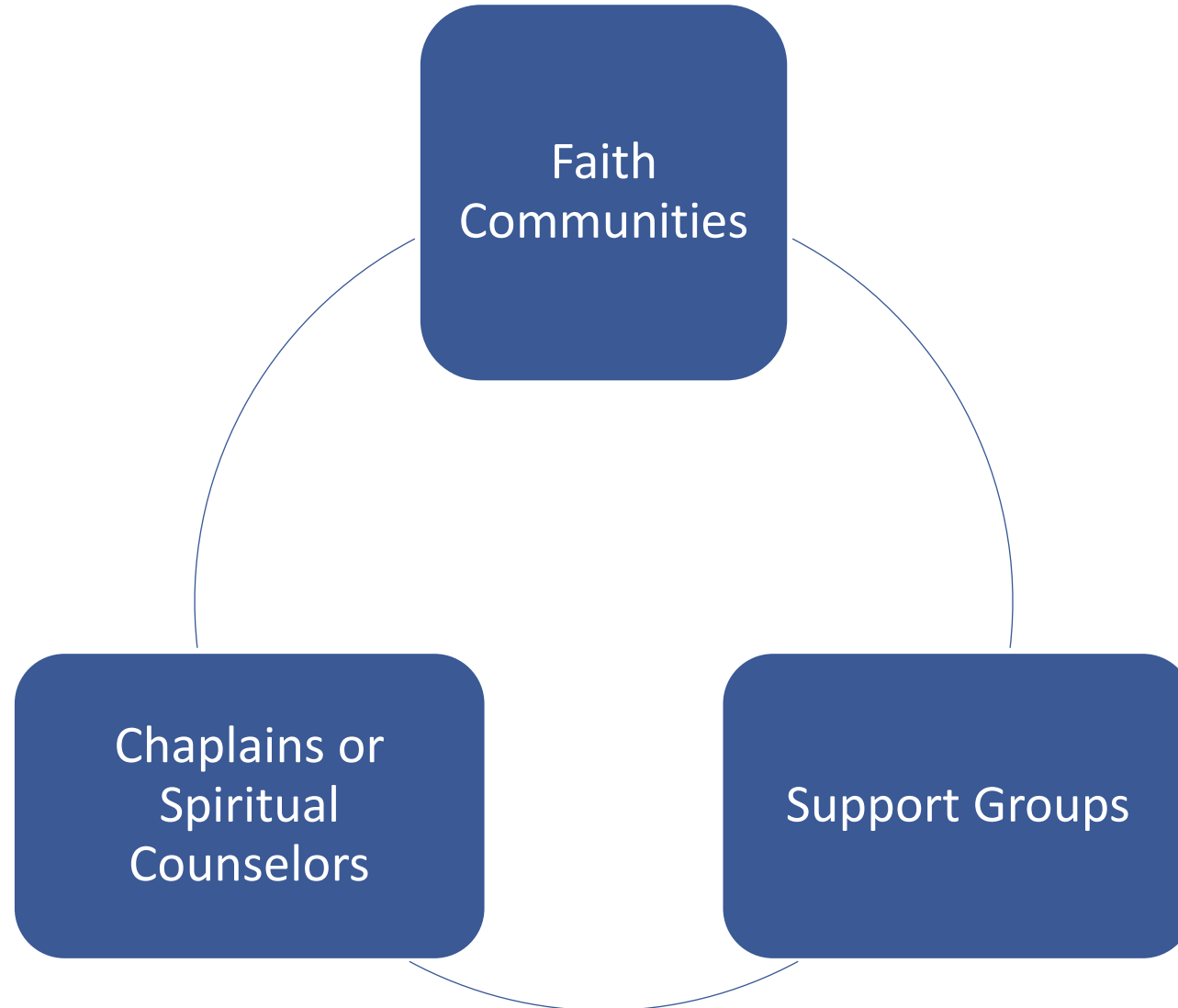
Prayer or meditation.

Daily gratitude.

Connecting with others for support.



The Role of Community & Support



Gentle Reminders for the Journey

YOU ARE ENOUGH.....

Mixed emotions are natural.

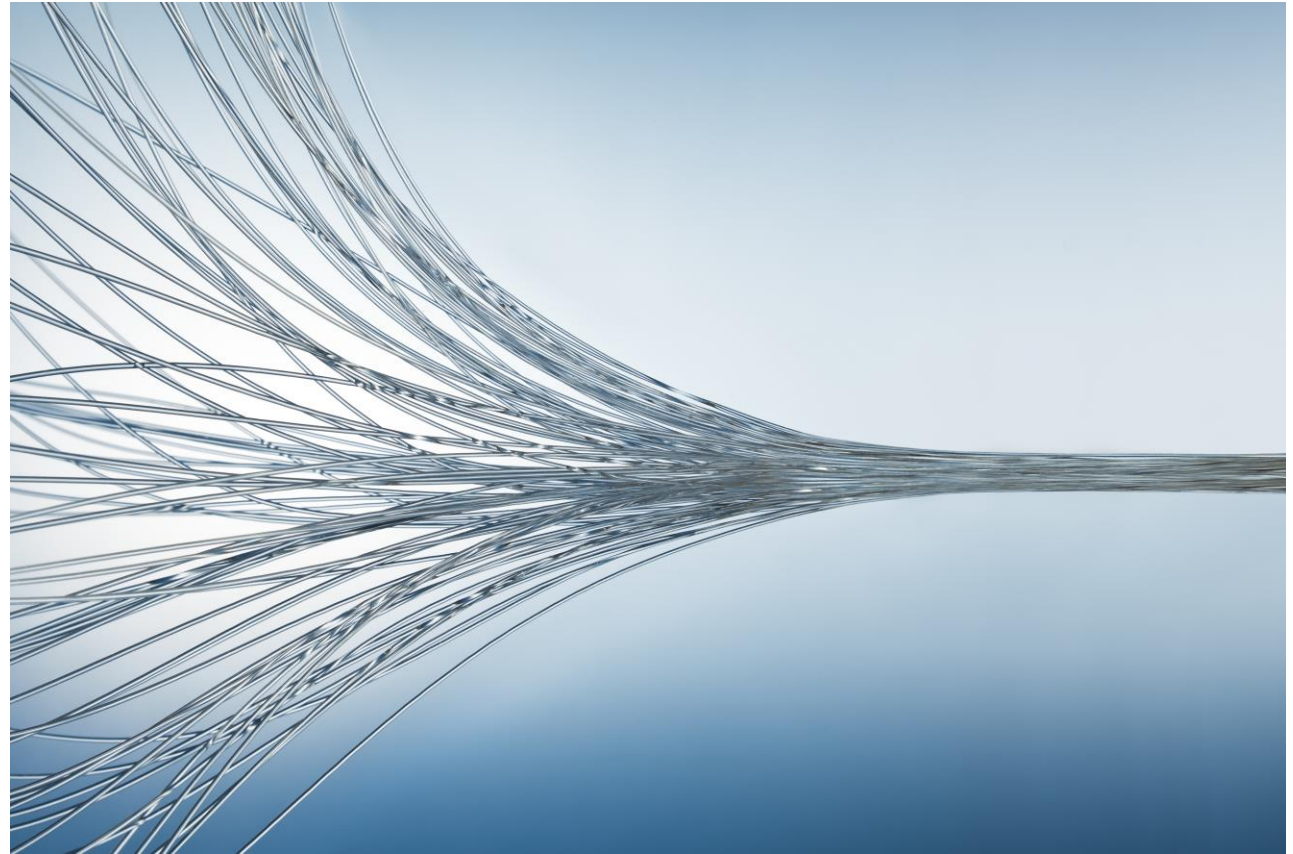
Your caregiving matters, in ways seen and unseen.



Closing Reflection

What gives me strength in this moment?

What do I want to carry with me from today?



Resource & Support

Family Caregiver Alliance – caregiver.org

Alzheimer's Association – alz.org

ARCH National Respite Network – archrespite.org

“The Caregiver’s Companion” by Debra Kelsey-Davis & Kelly Johnson

Podcasts: "The Caregiver Space Radio" & "Happy Healthy Caregiver"

Local chaplain, pastor or spiritual director.

Thank You & Encouragement

Thank you for your presence and care.

Take one small step this week to care for your spirit.

“Caring for others begins with caring for yourself.”

Questions



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Caregiver Reflection Guide

This reflection guide is designed to accompany the presentation "Finding Meaning, Purpose, and Hope in Caregiving." Use it for journaling, personal reflection, or group discussion.

Spiritual Health in Caregiving

How do you define spiritual health for yourself?

What supports your inner strength when caregiving feels overwhelming?

Finding Meaning

What moments in your caregiving journey have felt meaningful to you?

What have you learned about yourself through caregiving?

Living with Purpose

What keeps you going when caregiving is especially hard?

How has caregiving shaped your sense of purpose or identity?

Holding on to Hope

What does hope look like for you today?

What small things give you hope in your daily life?

Spiritual Practices

Which of these might support you? Circle one to try this week:

Journaling Prayer or meditation Gratitude list Talking with someone you trust

How could you make space for this practice in your routine?

Final Reflection

What is one thing you want to remember from the presentation?

What is one kind word you would offer yourself today?

Caregiver Spiritual Health - Resources

Below are spiritual and practical resources to support your caregiving journey. These include websites, books, podcasts, and ways to connect with community.

Websites & Organizations

- Family Caregiver Alliance <https://www.caregiver.org> Offers support, education, and advocacy for caregivers.
- Alzheimer's Association - <https://www.alz.org> Resources and a 24/7 helpline for caregivers of those with dementia.
- ARCH National Respite Network - <https://archrespice.org> Helps caregivers find respite care services near them.
- National Alliance for Caregiving - <https://www.caregiving.org> Research and support tools for family caregivers.

Books

- [The Caregiver's Companion](#) by Debra Kelsey-Davis & Kelly Johnson
- [No Act of Love Is Ever Wasted](#) by Jane Marie Thibault & Richard L. Morgan
- [The Conscious Caregiver](#) by Linda Abbit

Podcasts

- [The Caregiver Space Radio](#) - Real caregiver stories and support.
- [Happy Healthy Caregiver](#) - Self-care strategies and inspiration for caregivers.
- [Daughterhood The Podcast](#) - Focuses on women caring for aging parents.

Spiritual Support

- Speak with a hospital or hospice chaplain - available regardless of religious background.
- Seek out a spiritual director, faith leader, or counselor familiar with caregiving.
- Join a support group through local community centers, churches, or online networks like GriefShare or Dementia Care Central.