



Caregiving and Compassion Fatigue Webinar

Presented by the Ohio Council on Family Relations (OHCFR), a State Affiliate of the National Council on Family Relations (NCFR)

- oh.ncfr.org
- Facebook @OHCFR

1 contact hour CEU approved by NCFR ncfr.org



Caregiving & Compassion Fatigue

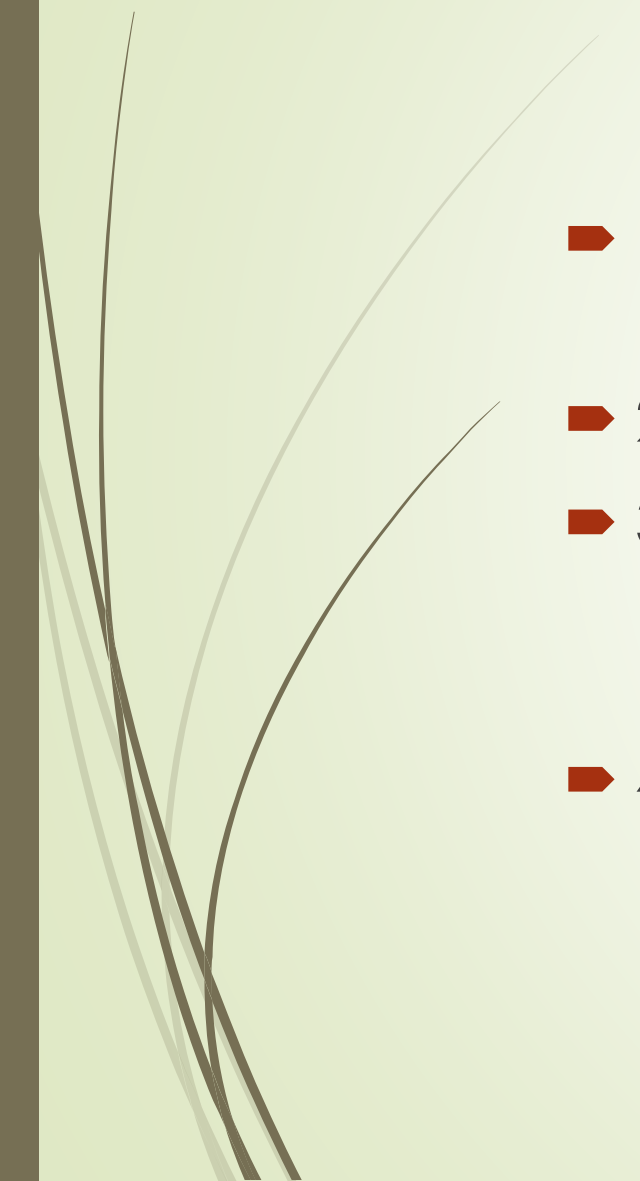
A webinar sponsored by the Ohio Council on Family Relations

Presenters

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Goals

- 1. To define the prevalence of caregiving among age, gender and racial groups
 - 2. To define compassion fatigue.
 - 3. To identify characteristics of compassion fatigue to help professionals as well as formal & informal caregivers recognize & deal with it.
 - 4. To provide personal & community resources that may alleviate the stress of caregiving.
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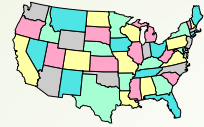
Who is a caregiver?

- Formal caregivers = paid professional and paraprofessionals
 - Doctors, nurses, health aides, psychologists, therapists
- Informal caregivers may be paid/unpaid individuals without training who provide care to family members, neighbors or friends.
 - Caregivers most commonly assist care recipients who have impairments related to aging, disability, disease, or a mental disorder (Wikipedia).

Who is Caregiving in the United States



- 21.3 % or 53 million U.S. adults provided care to an adult or child with special needs at some time in 2019 (AARP 2020)
 - 10% of grandmothers were primary caregivers for a grandchild (Doka & Davidson, 2001)
 - 61% of caregivers are female compared to 39% of males (AARP 2020)
- 11% of respondents reported a child younger than 18 years was a caregiver (AARP 2020)
 - Approximately 3.4 million children may be unreported caregivers to an adult (Young Caregivers, 2005)



**Age Range of Care Recipients
by
Number & Percent of Adult Caregivers**

	2020 Estimates		2015 Estimates	
Age Range of Recipient	% of Adult Caregivers	No. Adult Caregivers in Millions	% of Adult Caregivers	No. Adult Caregivers in Millions
0-17 years	5.7 %	14.1	4.3%	10.2
18-49 years	2.5%	6.1	2.3%	5.6
50+ years	16.8%	48.1	14.3%	34.2

Caregiving in the United States 2020 – AARP. Retrieved from <https://www.aarp.org/ppi/info-2020/caregiving-in-the-united-states.html>

Doka, K.J. & Davidson, J. D. (2001). Caregiving and Loss. Washington, D. C. Hospice Foundation of America.

Hunt, G., Levine, C. & Noreditch, L. (2005). Young Caregivers in the U.S.: Findings from a National Survey. Retrieved from <https://www.caregiving.org/wp-content/uploads/2020/youngcaregivers.pdf>.

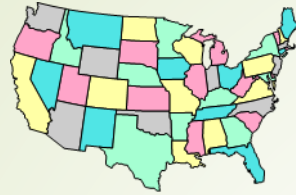


Caregiver Info - continued



- Since 2015, the number of caregivers has increased by approximately 9.5 million or 3.1% (AARP, 2020)
- Racially 38.3 % are White, 21% Latinx/Hispanic 21% African American/Black, & 19.7% are Asian-American (Pfender, 2018).
- 61% of caregivers are female
 - Mean age = 49.4 years
- 24% report caring for more than one person (AARP, 2020)

Pfender, E. (6/15/2018). Caregiving Statistics Broken Down By Age, Gender & Race. Retrieved from <https://www.caregiverconnection.org/caregiver-statistics>



Types of Caregiving

- Approximately 19% are providing unpaid care to an adult with health or functional needs.
 - spend approximately 24 hours/week caregiving
 - Rate the level of care as very intense

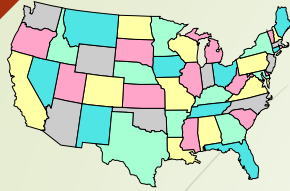


- 99% help with Instrumental Activities of Daily Living (IADLs)



- 60% with Activities of Daily Living (ADLs)
- 60% with medical/nursing tasks





Types of Caregiving Info - continued

- 26% care for someone with Alzheimer's disease or dementia (4% increase)
 - 5 million people are living with cognitive health issues such as Alzheimer's disease or another form of dementia
- 27% care for someone with emotional or mental health needs (6% increase)
 - Approximately 9.6 million adults age 18 or older had a serious mental illness in the past year

AARP and National Alliance for Caregiving. (May 2020). *Caregiving in the United States 2020*. Washington, DC: AARP. Retrieved from <https://doi.org/10.26419/ppi.00103.001>

The National Alliance for Caregiving (2015). *Caregiving in America*. Retrieved from www.caregiving.org/research/caregivingusa/

Reinhard, S. C., Samis, S. & Levine, C. (2014). *Family Caregivers Providing Complex Chronic Care to People with Cognitive and Behavioral Health Conditions*. Retrieved from <http://www.aarp.org/home-family/caregiving/info-2014/family-caregivers-providing-complex-chronic-care-cognitive-behavioral-AARP-ppi-health.html>

Caregiving in Ohio

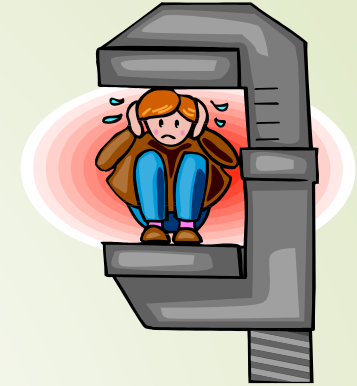


The typical Ohio family caregiver is 57 years old and cares for a loved one age 80

- 1,510,000 family caregivers in Ohio
 - Contribute 1.27 billion hours of care
 - Estimated monetary value = \$16.8 billion

AARP. *State Caregiver Profiles 2018-2019* –. Retrieved from <https://www.aarp.org/.../state-caregivers-profiles.html> & [https://states.aarp.org/ohio/ohio-family-caregivers-provide-16-8-billion-in-unpaid-care-to-family-friends-at home](https://states.aarp.org/ohio/ohio-family-caregivers-provide-16-8-billion-in-unpaid-care-to-family-friends-at-home)

Caregiving can be Stressful



- Caregiving requires the caregiver to juggle work, family & caregiving tasks
 - 57% of caregivers feel they have no choice
 - Has financial repercussions
 - 40-70% of caregivers have significant anxiety or depressive symptoms
 - 50% of caregivers with depressive symptoms meet the criteria for severe depression (Pfender, 2018).

Compassion Fatigue

- The emotional, physical and spiritual distress experienced by caregivers who care for people or animals experiencing significant emotional or physical pain and suffering (Compassion Awareness Fatigue Project).
 - Both formal and informal caregivers may experience compassion fatigue.
 - Safety workers (EMTs, police, fire)
 - Health care workers
 - Staff working in nursing homes, rehab facilities or long-term care facilities
 - Counselors, psychologists, social workers, and therapists
 - Educational personnel especially teachers
 - 3-4% exhibit chronic burnout and leave the profession (Compassion Fatigue & Teachers; 6 Ways for Educ)

Compassion Awareness Fatigue Project. Retrieved from <https://www.compassionfatigue.org/>

Compassion Fatigue and Teachers. Retrieved from <https://www.enrichingstunents.com/compassion-fatigue-and-teachers>

Six Ways for Educators to Avoid Compassion Fatigue. Retrieved from <https://Lesley.edu/article/six=ways=for-educators-to-avoid-compassion-fatigue>

Stages of Compassion Fatigue



Stage 1: Negative attitudinal symptoms affect work place interactions & family relationships (Warnecka, 2009)

- Is cynical, sarcastic, critical
- Has morbid sense of humor regarding patients/family members

Stage 2: Lack of energy & motivation to accomplish responsibilities as well as job dissatisfaction

- Physical, mental & emotional exhaustion
- Sense of isolation due to perceived loss of support of coworkers, supervisors, other staff or family members
- Physical health problems as well as changes in sleeping & eating patterns may occur

Stage 3: Burnout



- Perceived lack of support
- Perceived barriers to providing care
- Decline in well-being due to stress of caregiving or changes in personal life
- Rather than “people work” work is transactional
 - time is traded for money without benefits
 - Seen as waste of time
 - Become indifferent
 - Loss of boundaries occurs

Stage 4: Hope & Recovery enables to have sense of purpose regarding caregiving

- Balance between job & reasons for choosing to be a caregiver
- Begin to enjoy activities that are rejuvenating



Suggestions for Preventing Compassion Fatigue



Suggestions

- Focus on What You Can Control
 - Practice Self-Care
 - Set Boundaries
 - Practice Mindfulness
 - Seek Information
 - Build a Support System
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Suggestions for Preventing Compassion Fatigue

Boundaries

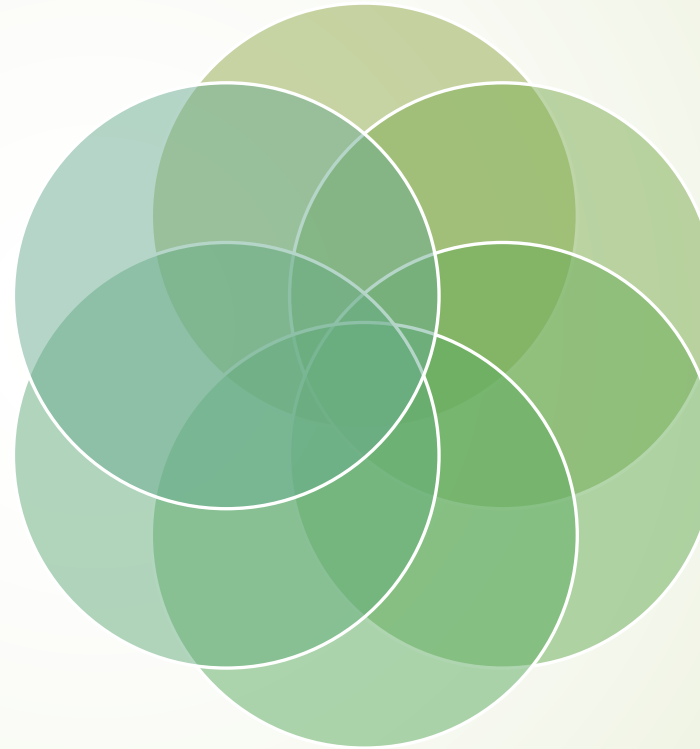
Mindfulness

Control

Self-care

Information

Support



Focus on What You Can Control

- Make purposeful choices (Lyon, 2002)
- This image available for free from Brandy, The Counseling Teacher for educational purposes <https://www.teacherspayteachers.com/>



Practice Self-Care

Definition by World Health Organization:

“the ability of **individuals, families and communities** to **promote health**, **prevent disease**, **maintain health**, and to **cope with illness and disability** with or without the support of a healthcare provider.”

www.who.int





Self-Care Requires

- Clarifying and committing to an overarching **value of self-care**
- Committing to act congruently with **personal and professional values across many domains** of living
- Practicing **self-compassion** in the process

(Fiebig et al, 2020)



Self-Care Tips

- ▶ Do not worry about advertising and marketing
- ▶ Ask for help – and be specific
- ▶ You are valued – as an individual, part of a family and a community (definition from World Health Organization)
 - ▶ Promote and maintain health, Prevent disease, Cope with illness or disability
- ▶ Self-Care can be as basic as enough sleep, exercise and healthy foods





Refrigerator

Magnet provided by Western Reserve Hospital, Cuyahoga Falls, Ohio. Original source unknown.

Caregivers Bill of Rights

- **To take care of myself.** This is not an act of selfishness. It will give me the capacity to take better care of my relative.
- To **seek help from others** even though my relative may object. I recognize the limits of my own endurance and strength.
- To **maintain facets of my own life** that do not include the person I care for, just as I would if he or she were healthy. I know that I do everything that I reasonably can for this person, and I have the right to do some things for myself.
- To get angry, be depressed, and **express other difficult feelings** occasionally.
- To **reject any attempt** by my relative (either conscious or unconscious) **to manipulate me** through guilt, anger, or depression.
- **To receive consideration, affection, forgiveness, and acceptance** for what I do for my loved one for as long as I offer these qualities in return.
- **To take pride in what I am accomplishing and to applaud the courage** it has sometimes taken to meet the needs of my relative.
- To **protect my individuality** and my right to make a life for myself that will sustain me in the time when my relative no longer needs my full-time help.
- To **expect and demand that as new strides are made in finding resources** to aid physically and mentally impaired older persons in our country, similar strides will be made toward aiding and supporting caregivers.
- To _____ (Add you own statement of rights to this list. Read the list to yourself every day.)

By Jo Horne, author of Caregiving: Helping an Aging Loved One

Family Caregiver Alliance <https://www.caregiver.org/resource/caregivers-bill-rights/>

Boundaries

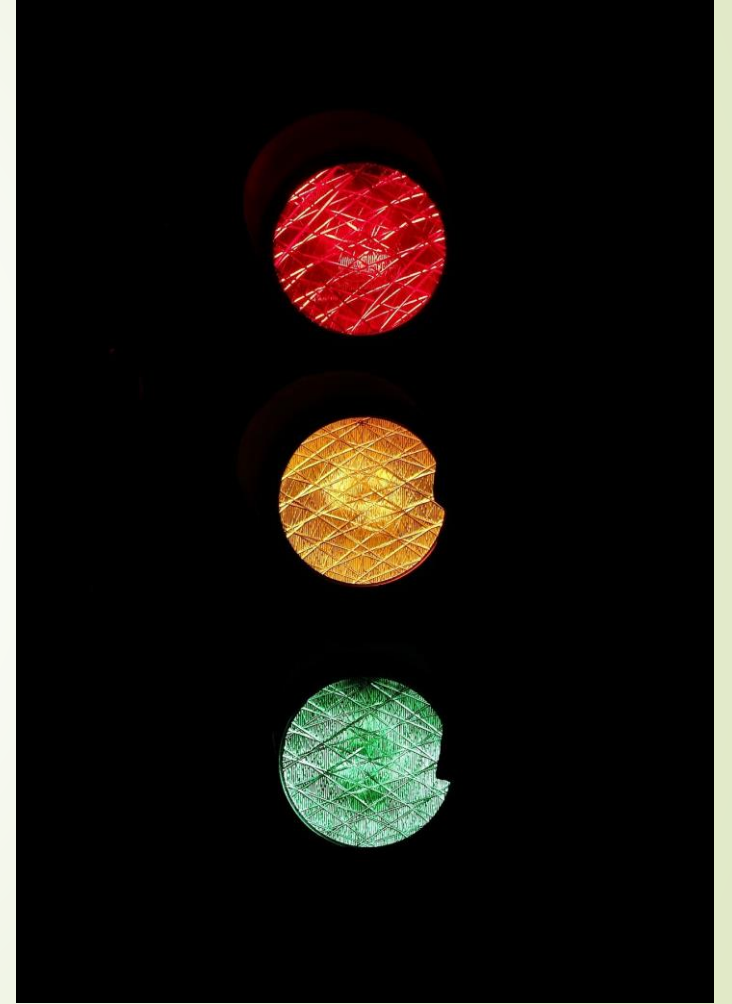


Nellie & Nish: The Maumee Bay Piping Plovers Facebook page. Left Photo: Joshua Vardous.

Set Boundaries

- Physical
- Mental
- Emotional
- Work and personal
- “There is always an interplay between the personal and the professional. Work is part of life, and life contains multitudes”.

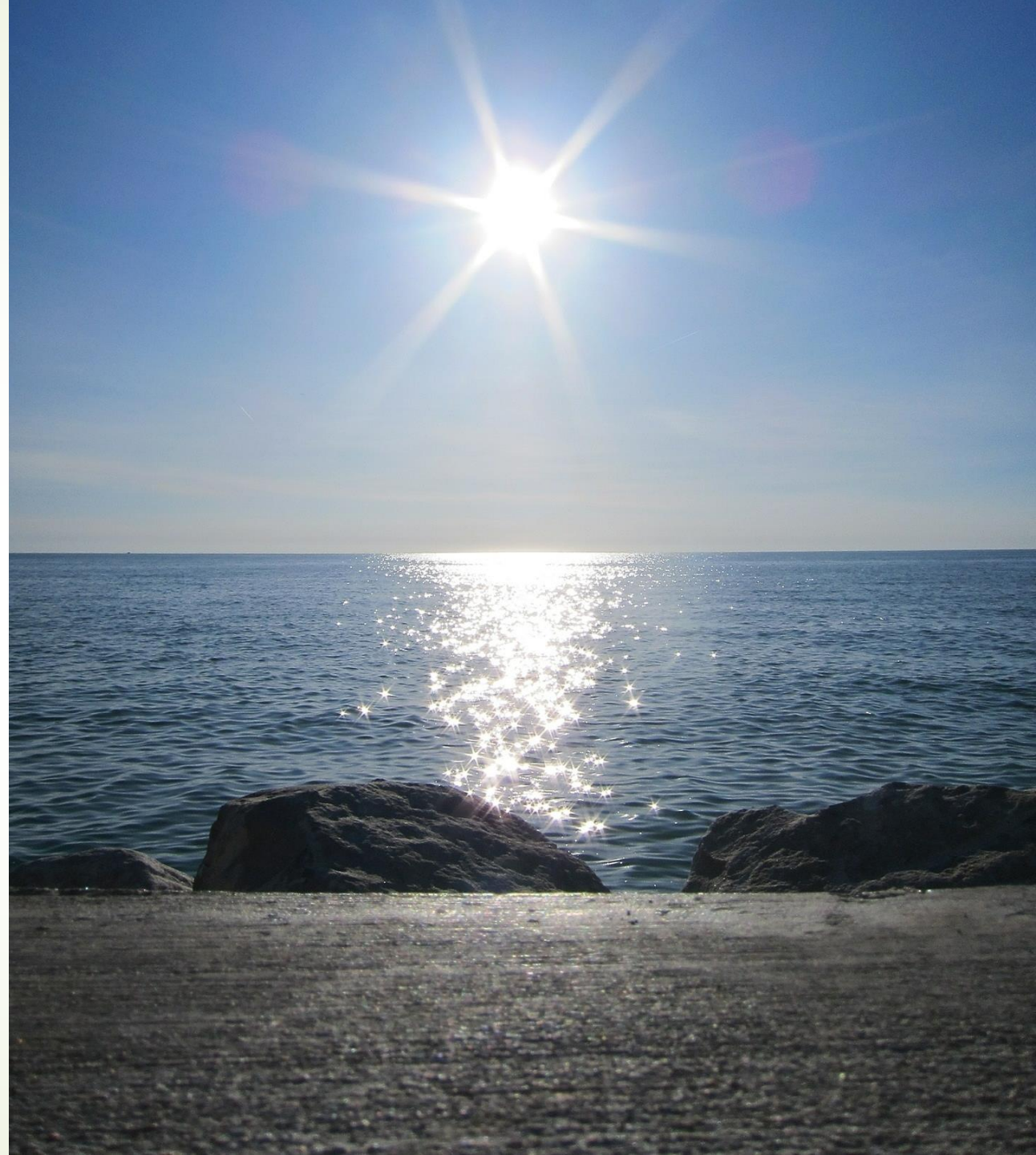
(Fiebig et al, 2020, p562)



Practice Mindfulness

- “Mindfulness means paying attention in a particular way: on purpose, in the present moment, and nonjudgmentally.”

Jon Kabat-Zinn



Suggestions for Practicing Mindfulness

- No one “right way”
- Commit to a time to practice
- Be persistent – over time



Invitation for a Mindful Moment





Seek Information

- Professional Development
 - Personal growth for self - as well as family and friends
 - Learn about disease/disability of care recipient
 - 211
 - Learn the local community (organizations, places of worship, branch chapters, etc.)
 - Online resources
- 



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Checking Out Online Sources of Health Information: Five Quick Questions

Who runs or created the site or app?
Can you trust them?

What is the site or app promising or offering? Do its claims seem too good to be true?

When was its information written or reviewed? Is it up-to-date?

Where does the information come from? Is it based on scientific research?

Why does the site or app exist? Is it selling something?

From: www.nccih.nih.gov/health/finding-and-evaluating-online-resources

For more info: go.osu.edu/mindfulapps



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AND ENVIRONMENTAL SCIENCES

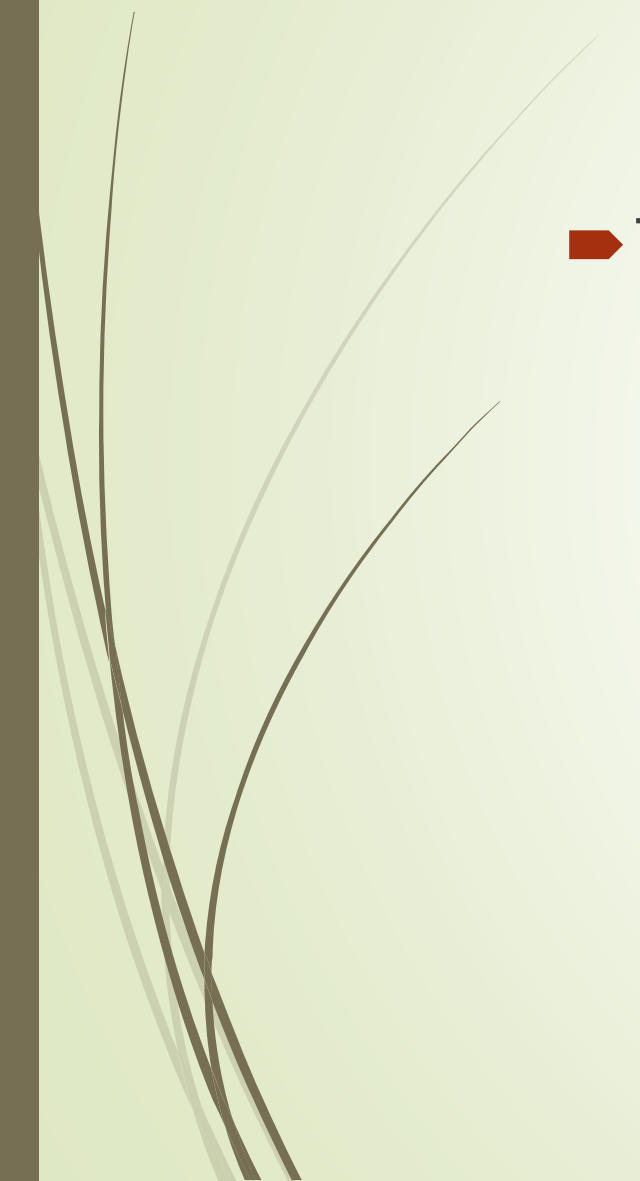
Build a Support System

Taking care is one way to
show your love. Another
way is letting people take
good care of you when
you need it.

MISTER ROGERS



Suggestions for Finding a Support System

- Tips from the American Psychological Association
 - Reach out to family and friends
 - Use technology
 - Connect with people who share your interests
 - Look for peer support groups
 - Ask for help
- 



Please Don't Forget (forget-me-nots)

- Everyone's support system will look different. It takes time to build.
- Suggestions, not "should do" or "have to do" ... not another item on a long list
- Small, doable doses! "there is no act of self-care that does not contribute to well being" (Coyne, Gould, Grimaldi, Wilson, Baffuto, and Biglan, 2020, p6)

Suggestions for Preventing Compassion Fatigue

Boundaries

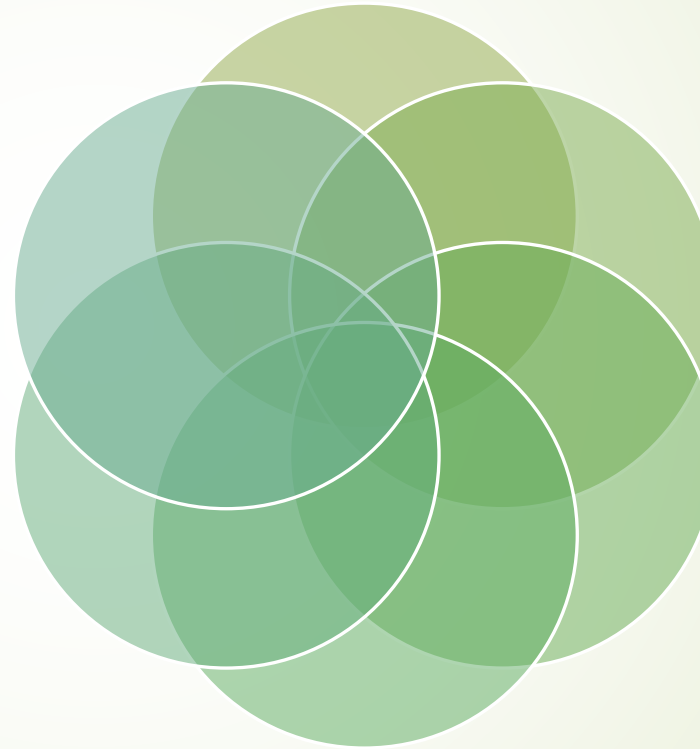
Mindfulness

Control

Self-care

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Support





Where to find details

- PowerPoint and References
- List of Resources
 - including resources mentioned in this presentation

Ohio Council on Family Relations, affiliate of
National Council on Family Relations

<https://oh.ncfr.org/>