



Fred Hutch · Seattle Children's · UW Medicine




Promoting Resilience as a Foundation of Wellness

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Outline and Aims for today


- Bill of Rights
 - Stages and States of Caregiving – emotional and practical
 - Assessment tools and characteristics of burnout
 - Traits and tools of resilience
 - Impact of Family/Friends on the caregiver experience
 - Crowdsourcing wisdom
 - Building Caregiver wellness
 - Doable TO GO plan
 - Resources – handouts, videos, references
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Caregiver Bill of Rights

I have the right to:

- Care for myself.
 - Seek help from others.
 - Express difficult feelings.
 - Reject any attempt to cause guilt.
 - Take pride in what I am doing.
 - Protect my individuality.
 - Maintain parts of my own life.
 - Receive consideration, affection, forgiveness, and acceptance.
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Practical Stages of Caregiver Journey – Not time based

- New – eager to do it all perfectly
 - Entrenched – in the middle of all the overwhelming details
 - Pragmatic – get it done, less than perfectly
 - Transitioning – letting go of the role
 - Moving forward – moving to a place of comfort with the past
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Emotional States of Caregiving

- Confusion
- Realization
- Frustration
- Collapse
- Acknowledgment
- Acceptance of situation and limitations



When you get it from all sides

- Family
- Friends



A Caregiver's Guide to Handling Criticism

Unfortunately, it is common for family caregivers to face unapologetic, uninvolved critics; it's one of their top stressors. And far too often, caregivers who are victims of intolerable critics go on autopilot - apologizing automatically, or believing they really are at fault.



Why did you do that? It was a big mistake!



Why are you doing it that way? You should do it this way.



Seems like a lot of things are going wrong.


Use "I" statements to repeat the criticism back to the critic and in a way that shows how those words make you feel. Say things like: "It hurts my feelings when you say things like..." "It really upsets me when you criticize everything I do." "I have a hard time spending time with you now because I never know when your critiques are going to come, or the reason that you are making them."

Don't believe it. Say things like: "I may handle things differently, but it doesn't mean that it is the wrong way." "I am not a bad person."

Apologize only if you really are at fault. Say things like: "I goofed up! The good news is that all is well that ends well! No harm done, so please don't make more of this than is necessary," versus "I am sorry I forgot to call you! I wish I hadn't done that."



Factors that have a negative impact on the caregivers' stress level

- Repetitive negative thoughts about one's self
 - Rumination
 - Isolation
 - Low self-esteem
 - Perfectionism
 - Other responsibilities
 - Multiple roles
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Caregiving impacts all types of wellness


- Physical
- Social
- Emotional
- Financial
- Spiritual



Where are you on the resource/demand ratio?



Caregiver Simple Check-in

- I feel rested, calm and gentle with myself and others.
 - I am getting enough sleep.
 - I have someone to talk to.
 - I am eating right.
 - I am exercising regularly.
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AMA Self-Assessment

American Medical Association
Physicians dedicated to the health of America

Caregiver Self-Assessment Questionnaire

How are you?

Caregivers are often so concerned with caring for their relative's needs that they lose sight of their own wellbeing. Please take just a moment to answer the following questions. Once you have answered the questions, turn the page to do a self-evaluation.


During the past week or so, I have...

- Had trouble keeping my mind on what I was doingYes No
- Felt that I couldn't leave my relative alone.....Yes No
- Had difficulty making decisionsYes No
- Felt completely overwhelmed.....Yes No
- Felt useful and neededYes No
- Felt lonelyYes No
- Been upset that my relative has changed so much from his/her former self.....Yes No
- Felt a loss of privacy and/or personal timeYes No
- Been edgy or irritableYes No
- Had sleep disturbed because of caring for my relativeYes No
- Had a crying spell(s)Yes No
- Felt strained between work and family responsibilities.....Yes No
- Had back painYes No
- Felt ill (*headaches, stomach problems or common cold*)Yes No
- Been satisfied with the support my family has given meYes No
- Found my relative's living situation to be inconvenient or a barrier to careYes No
- On a scale of 1 to 10, with 1 being "not stressful" to 10 being "extremely stressful," please rate your current level of stress. _____
- On a scale of 1 to 10, with 1 being "very healthy" to 10 being "very ill," please rate your current health compared to what it was this time last year. _____

CAREGIVER SELF-ASSESSMENT QUESTIONNAIRE

<http://web.mit.edu/workplacecenter/hndbk/docs/questionnaire.pdf>

What are characteristics of caregiver burnout?

- Withdrawal from friends and family
 - Loss of interest in activities previously enjoyed
 - Feeling blue, irritable, hopeless, and helpless
 - Changes in appetite, [weight](#), or both
 - Changes in [sleep](#) patterns
 - Getting sick more often
 - Feelings of wanting to hurt yourself or the person for whom you are caring
 - Emotional and physical exhaustion
 - Excessive use of alcohol and/or [sleep medications](#)
 - Self-neglect
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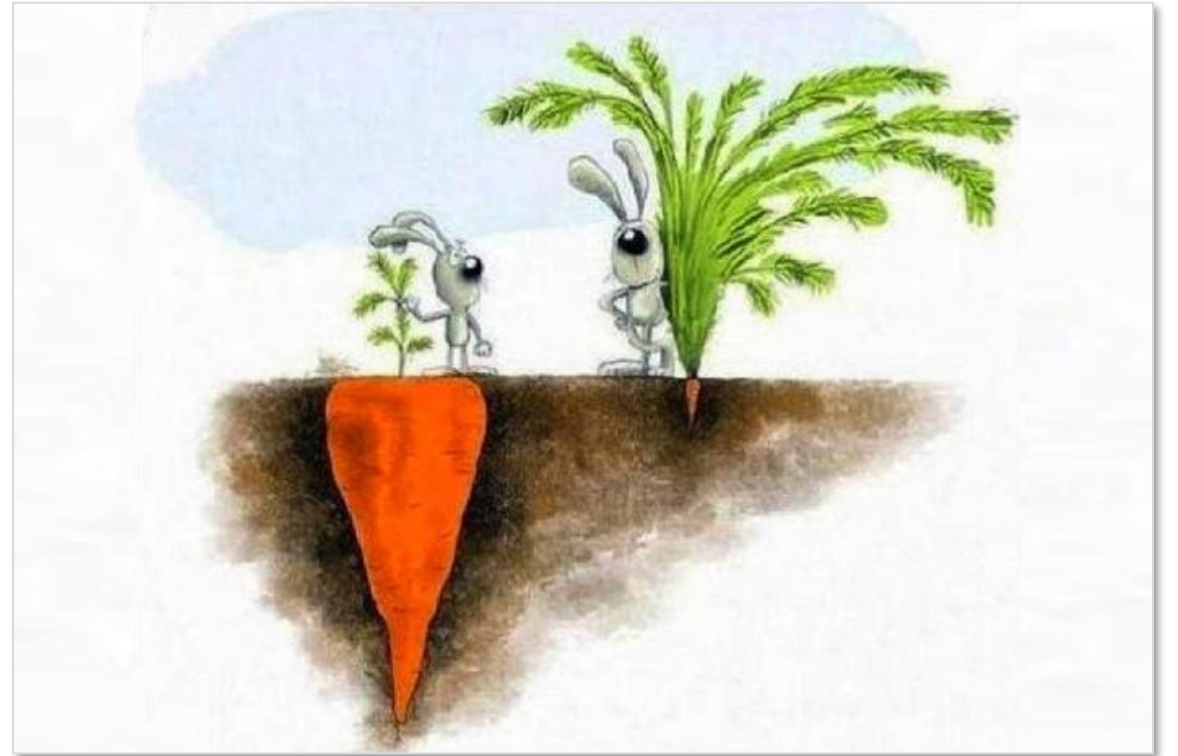
What does resilience look like?

- Calm and emotional awareness
- Support
- Flexible
- Humor
- Peaceful
- Perspective



Self check-in as move to crowdsourcing

- What stage am I at?
- Where am on the self assessment scales?



Crowdsourcing Wisdom: Sharing tips

- Talk with one another and come up with one suggestion that helped you and may help another person. What has not worked? (Sticky Notes)
- Report back to the group and share what works and what does not.



Characteristics of Healthy Coping

- Connectiveness – less isolation
- Flexibility
- Economic resources
- Decisive actions
- Meaning and sense of purpose




Traits of Resilience (see handout)


- Emotional awareness
- Perseverance
- Internal sense of control
- Support
- Humor
- Perspective



Tools for Building Resilience and Grounding

- Slow down, relaxation, mediation
 - Check in with yourself over coffee, prayer, looking at nature daily
 - Appreciation for positives in life – 3 good things
 - Find pockets of restorative time
 - Offer yourself compassion
 - Changing perspective
- 


More Foundational Work

- Identify barriers
 - Identify your boundaries (see next slides)
 - Set goals
 - Seek solutions
 - Communicate constructively
 - Ask and accept help
 - Work collaboratively with the medical team/s (Family Caregiver Alliance)
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Boundaries: what are they? (reference slide)

Boundaries are guidelines, rules or limits that a person creates to identify *for themselves* what are reasonable, safe and permissible ways for other people to behave around them and *how they will respond* when someone steps outside those limits. Boundaries are not rules for someone else to follow.

Sometimes they'll be described in terms of "your stuff<---//--->my stuff." But what does that mean? It means the ability to recognize what is our responsibility (and what is truly within our power to control) and what isn't. Boundaries are an essential ingredient to creating a healthy self. They define the relationship between you and everyone else around you.



Boundaries, cont'd (reference slide)

Healthy boundaries help us to create our own destiny. They ensure that we are taking responsibility for our own lives; that we knowingly accept the consequences and/or reap the benefits of our choices. And, just as importantly, they ensure that we let others do the same for themselves.


A key to boundaries is knowing your inner self: your beliefs, desires, needs, and intuitions.

Emotional Hygiene


- Offer yourself emotional first aid
- Stop rumination – distract yourself (e.g., audiobooks, podcasts, Ted talks)
- Protect your self-esteem
- Take action
- Reach out to others to lessen loneliness and burden




Social, Emotional Self-care

- Meditation
 - Affirmation – I am calm and doing the best I can
 - Check in with yourself
 - Talk to safe person/s
 - Journals
- 

Suggestions for Relaxation

- Deep breathing
 - Meditations on YouTube
 - 3 good things practice
 - Videos
 - Audiobooks
- 


Physical Self-care

- Exercise
 - Healthcare follow-up
 - Nutrition
 - Sleep hygiene
- 


Spiritual Connection



Financial and Legal Health

- Check with a social worker
 - Organizations
 - Request assistance if needed
 - Address medical power of attorney, wills
- 

Self-care Plan TO GO

- Know thy self
 - What are 1-3 simple changes you can make?
 - Examples: gratitude (3 good things), deep breathing, walking, healthcare appointments, call a friend
 - How will you deal with the barriers and know your boundaries?
- 

Caregiver Series Flyer



Caring for the Caregiver Series

Come to learn, share, and discuss the caregiver experience. The Caring for the Caregiver Series will touch on different topics and strategies for taking care of yourself while caring for your loved one.

Communicating Constructively
Thursday, June 13th at 1pm
Room 1008 (1st floor)



Future Topics

Impact of Family and Friends on Caregivers

If you cannot attend in person, but still want to join the meeting, please conference call in at (877) 369-0926 or (408) 638-0968. Meeting ID: 208 307 2502.

Questions? Feel free to call Ann Breen (206) 606-2125 or Tammy Weitzman (206) 606-1083.

Compassionate Meditation

“May you be well, may you live in peace – yourself, a loved one, a challenging individual”

Meditation of Loving Kindness: may you be calm, live in peace



https://www.youtube.com/watch?v=-d_AA9H4z9U

Videos on Emotional Health



<https://www.youtube.com/watch?v=F2hc2FLOdhI>

Compassion Fatigue for Caregivers



<https://www.youtube.com/watch?v=7keppA8XRas>

Articles of Interest

- <https://www.mentalhealthamerica.net/31-tips-boost-your-mental-health>
- <https://www.psychologytoday.com/us/blog/women-s-mental-health-matters/201510/9-ways-you-can-improve-your-mental-health-today>
- <https://www.nami.org/Find-Support/Family-Members-and-Caregivers/Taking>
- https://www.npr.org/sections/health-shots/2019/05/05/719780061/from-gloom-to-gratitude-8-skills-to-cultivate-joy?utm_source=instagram.com&utm_medium=social&utm_campaign=npr&utm_term=nprnews&utm_content=20190506

Resources

- **National Cancer Institute** 1-800-4-CANCER (422-6237)
<http://www.cancer.gov>
- **Facing Forward - Life After Cancer Treatment**
www.cancer.gov/cancertopics/coping/life-after-treatment
- **When Someone You Love is Being Treated for Cancer**
www.cancer.gov/cancertopics/coping/when-someone-you-love-is-treated
- **Taking Time: Support for People with Cancer**
<http://www.cancer.gov/cancertopics/takingtime>

Resources

- **National Institute on Aging**
- So Far Away - Twenty Questions and Answers about Long-Distance Caregiving
www.nia.nih.gov/health/publication/so-far-away-twenty-questions-and-answers-about-long-distance-caregiving
- **Guide for Family Caregivers in Cancer**
<http://www.cancer.gov/about-cancer/coping/family-friends/family-caregivers-pdq>
- **Caring for the Caregiver**
www.cancer.gov/cancertopics/coping/caring-for-the-caregiver
- **When Someone You Love is Being Treated for Cancer**
www.cancer.gov/cancertopics/cancerlibrary/ebooks/when-someone-you-love-is-being-treated
- **Employment Rights Cancer and the Americans with Disabilities Act**
www.eeoc.gov/laws/types/cancer.cfm
- **The Job Accommodation Network**
<http://askjan.org>
- **UW Medicine Virtual Clinic**
<https://virtualclinic.uwmedicine.org/#/home> 1-855-520-5250

References

- **Caregiver.com**
www.caregiver.com
- **Family Caregiver Alliance**
www.caregiver.org
- **Lotsa Helping Hands**
www.lotsahelpinghands.com
- **Well Spouse Foundation**
www.wellspouse.org
- **Personal Websites to Communicate with Friends and Family**
www.caringbridge.org/
www.carepages.com/
- **Organizing Help from Family and Friends**
www.mealtrain.com
<http://www.standwith.com>

Packet

- Assessment
 - Emotional Resilience
 - Prescription
 - Companion Guide
 - Bookmark
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