

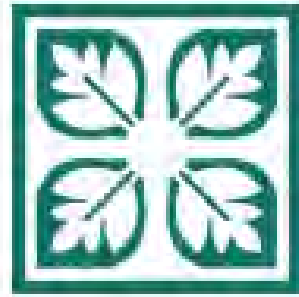


MENTAL WELLNESS FOR DEMENTIA CAREGIVERS: SELF-CARE AND HEALING FROM GRIEF AND STRESS

Facilitated by Dr. Mestisa C. Gass

Program Director at Mental Health America of Hawai'i
for Catholic Charities Hawaii, January 19, 2024

Sponsored by



CATHOLIC CHARITIES
HAWAII
CIRCLE OF CARE FOR DEMENTIA




These caregiver workshops are made possible by the Elderly
Affairs Division of the City & County of Honolulu
through Federal Older Americans Act funding.

Objectives

- Brief review of statistics and the impact of dementia caregiving
- Discuss the spectrum of mental wellness and the importance of self-care as a dementia caregiver
- Identify the role grief has on identity, healing, and support during and after dementia caregiving
- Review the mental health strategies to address stress, anxiety, trauma, and grief
- Identify helpful apps, community resources, and skills to help in healing

“BEING DEEPLY LOVED BY
SOMEONE GIVES YOU
STRENGTH, WHILE LOVING
SOMEONE DEEPLY GIVES YOU
COURAGE.”

— LAO TZU



Hawai'i State Facts

A Public Health Crisis

- 29,000 people aged 65 and older living with Alzheimer's
- 6.7% aged 45 and older have subjective cognitive decline

Caregivers

- 60,000 family caregivers in Hawai'i
- 91 million hours of unpaid care= \$1.9 billion in unpaid care

Cost

- \$240 million cost to state Medicaid programs

A public health approach is important in improving quality of life and care for individuals and families.

Hawai'i State Facts

Caregiver Health

- 49.6% of caregivers with chronic health conditions
- 16.5% of caregivers with depression
- 8.1% of caregivers in poor physical health

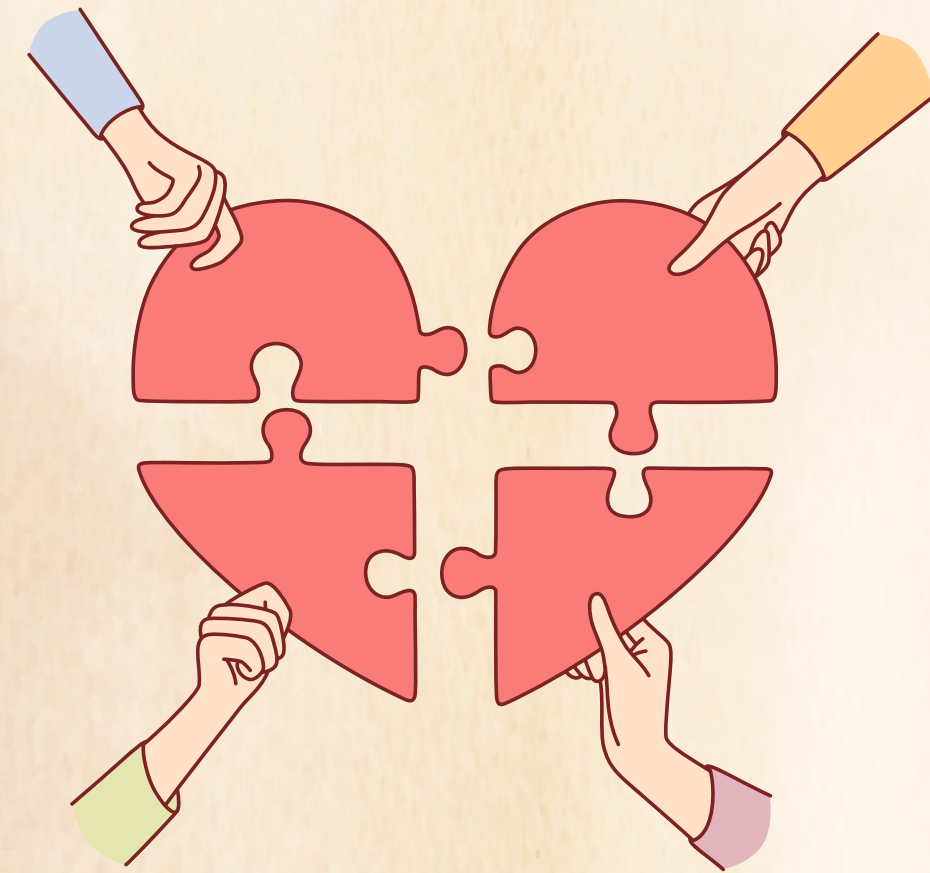
Prevalence

- In 2020, 29,000 people aged 65 and older were diagnosed with Alzheimer's
- Projected- In 2025, 35,000 people aged 65 and older were diagnosed with Alzheimer's
- Estimated % Increases 20.7%

TABLE 3-1 What Family Caregivers Do for Older Adults

Domain	Caregivers' Activities and Tasks
Household tasks	<ul style="list-style-type: none"> • Help with bills, deal with insurance claims, and manage money • Home maintenance (install grab bars, ramps, and other safety modifications; repairs, yardwork) • Laundry and other housework • Prepare meals • Shopping • Transportation
Self-care, supervision, and mobility	<ul style="list-style-type: none"> • Bathing and grooming • Dressing • Feeding • Supervision • Management of behavioral symptoms • Toileting (getting to and from the toilet, maintaining continence, dealing with incontinence) • Transferring (e.g., getting in and out of bed and chairs, moving from bed to wheelchair) • Help getting around inside or outside
Emotional and social support	<ul style="list-style-type: none"> • Provide companionship • Discuss ongoing life challenges with care recipient • Facilitate and participate in leisure activities • Help care recipient manage emotional responses • Manage family conflict • Troubleshoot problems
Health and medical care	<ul style="list-style-type: none"> • Encourage healthy lifestyle • Encourage self-care • Encourage treatment adherence • Manage and give medications, pills, or injections • Operate medical equipment • Prepare food for special diets • Respond to acute needs and emergencies • Provide wound care
Advocacy and care coordination	<ul style="list-style-type: none"> • Seek information • Facilitate person and family understanding • Communicate with doctors, nurses, social workers, pharmacists, and other health care and long-term services and supports (LTSS) providers • Facilitate provider understanding • Locate, arrange, and supervise nurses, social workers, home care aides, home-delivered meals, and other LTSS (e.g., adult day services) • Make appointments • Negotiate with other family member(s) regarding respective roles • Order prescription medicines • Deal with insurance issues
Surrogacy	<ul style="list-style-type: none"> • Handle financial and legal matters • Manage personal property • Participate in advanced planning • Participate in treatment decisions

SOURCES: Spillman et al., 2014; Wolff, 2007.



Emotional and social support

- Provide companionship
- Discuss ongoing life challenges with care recipient
- Facilitate and participate in leisure activities
- Help care recipient manage emotional responses
- Manage family conflict
- Troubleshoot problems

Brodaty H, Donkin M. Family caregivers of people with dementia. *Dialogues Clin Neurosci* 2009;11:217–28.

Chiao, C. Y., Wu, H. S., and Hsiao, C. Y. (2015). Caregiver burden for informal caregivers of patients with dementia: a systematic review. *Int. Nurs. Rev.* 62, 340–350. doi: 10.1111/inr.12194

Cohen, G., Russo, M. J., Campos, J. A., and Allegri, R. F. (2020). Living with dementia: increased level of caregiver stress in times of COVID-19. *Int. Psychogeriatr.* 32, 1377–1381. doi: 10.1017/S1041610220001593

"THE INVISIBLE SECOND PATIENT"



- Physical: pain, fatigue, sleep issues
- Emotional: Irritability, mood swings
- Behavioral: withdrawal from support, unhealthy coping skills
- Cognitive: racing thoughts, difficulty focusing



Mental health spectrum



Common Signs of Stress

- Denial
- Anger
- Withdrawing socially
- Anxiety
- Depression
- Exhaustion
- Sleeplessness
- Emotional reactions
- Lack of concentration
- Health problems



Common Signs of Burnout

- **Lower Energy/Exhaustion**
- **Easily and Frequently Sick**
- **Increased Irritability and Decreased Patience**
- **Avoiding Connecting with Social Support System**
- **Not Enjoying Activities Previously Enjoyed**
- **Personal Needs Unfulfilled**
- **Thoughts of Hurting Self or Others**





*Does it feel like holding back
a dam of water with your
finger in the hole?*

Let The Air Out of the Balloon

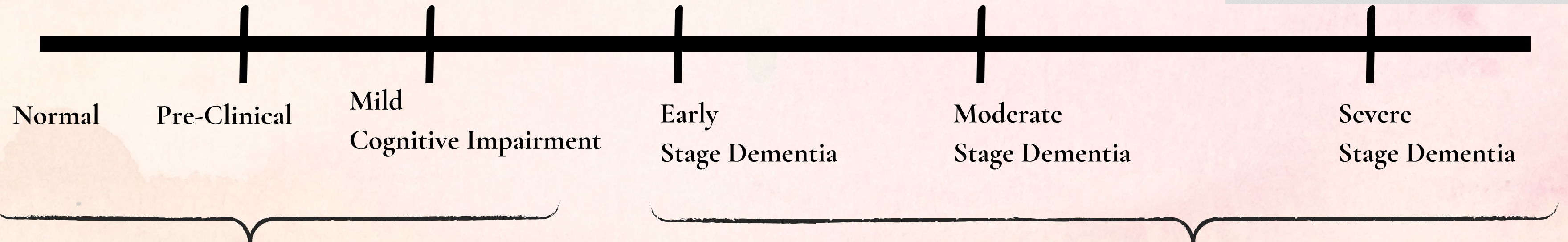


Consequences of Caregiving

- Emotional Distress (anxiety, stress, burden, depression)
- Missed Days at Work

- Emotional Distress (anxiety, stress, burden, depression)
- Financial Strain, Physical Stress, Social Isolation
- Decline in Protective Health Behaviors

- Emotional Distress (anxiety, stress, burden, depression)
- Financial & Physical Strain
- Social Isolation



Potential Needs of Caregivers

Engagement in health-promoting lifestyle including exercise, diet, social engagement, cognitive, stimulation

Education, support, understanding capacity, problem solving skills, compensatory strategy use, advance care planning, care coordination skills

Education and support, Home modifications, Understanding capacity, Counseling, Skills training, Taking Care of Self, Financial Support

Grief Counseling, Social Support, Knowledge of palliative strategies

Caregiver stress assessment checklist

Answer the following questions by selecting "never," "sometimes" or "often."

Questions	Never	Sometimes	Often
Do you have difficulty falling asleep?			
Do you wake up in the middle of the night?			
Do you have stressful dreams?			
Are you anxious or do you have panic attacks?			
Have you gained or lost weight recently without meaning to?			
Do you get sick more often than you used to (e.g. frequent colds or the flu)?			
Have you developed chronic health problems (e.g. backaches, headaches, high blood pressure)?			
Do minor upsets make you cry, become angry or get unusually agitated?			
Do you find it difficult to control your temper?			
Do you feel pressure to hold things together?			
Are you feeling hopeless about your situation?			
Have you given up hobbies or interests that you enjoy?			
Are you spending less time with others?			
Is caregiving affecting your career?			



If you answered "sometimes" or "often" to many of these questions, you may need help balancing care for the person living with dementia and care for your own well-being. No matter how close you are to the person, you may want to consider including others in the caregiving role. Caregiving involves a range of responsibilities. Sharing these responsibilities will help you and the person living with dementia have a better quality of life. Staff at your local Alzheimer Society can help evaluate options for sharing care in various settings.

*Who can I talk to about my
experiences and feelings?*



SELF-CARE TIPS

Sleep*

Sun/Nature

Time to unplug

Mastered skills

Aromatherapy

Cozy blankets

Relaxing sounds

Warm beverages

Activity Buddy

Learn coping skills

Take care of something

Nourishing meals

Gentle exercise

Journal

Mindfulness & Gratitude*

Share your feelings

Avoid isolating

Find spiritual support

Practice radical acceptance

Increase grief literacy



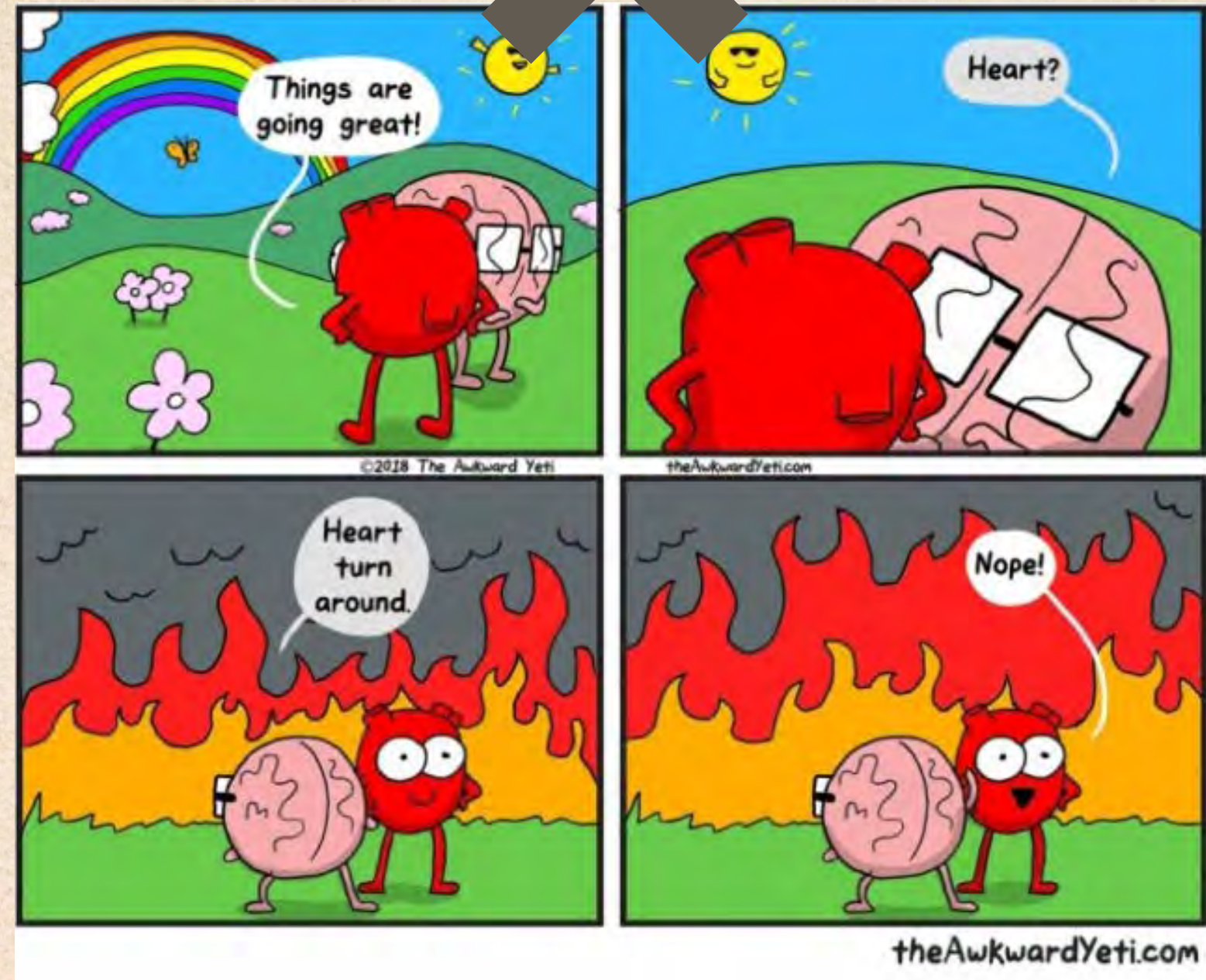
STAY PRESENT

- Past, Present, Future: Choose the present focus
- Radical acceptance*
- Meditation/Prayer
- Single task vs Multi task
- Accessible, responsive, engaged
- Be a good listener



RADICAL ACCEPTANCE

- Accept reality
- Move away from "it isn't fair" and "it shouldn't be this way"
- Acceptance is not agreement
- Daily choice. Requires practice
- Pain avoidance through denial
- Fighting reality takes the energy you may need to make change
- Alternative to forgiveness



What is your favorite form of self-care?



GRATITUDE IS THE ATTITUDE

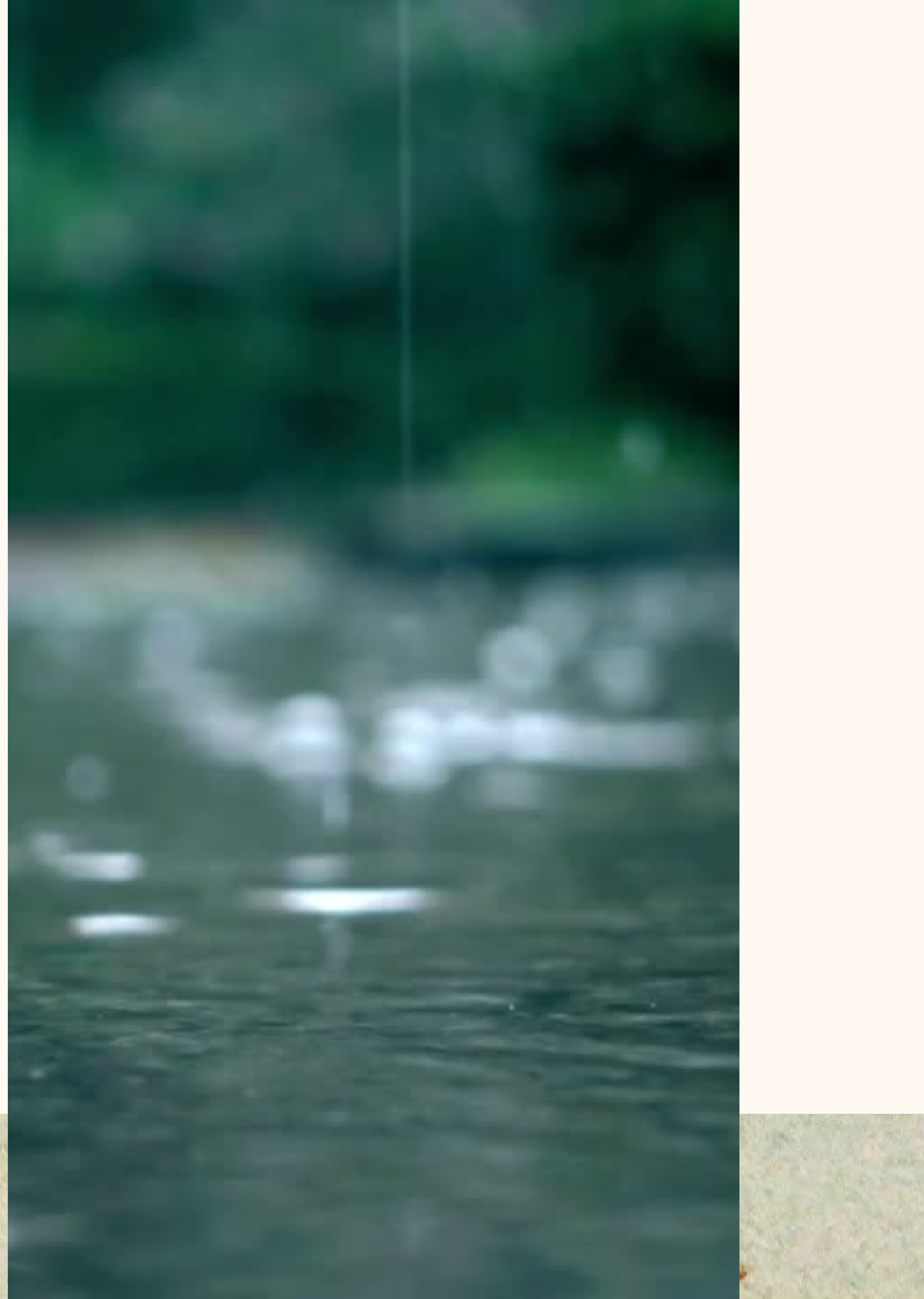
1. What am I grateful for today?
2. What relationship am I most grateful for in my life?
3. What challenging part of my life am I grateful for because it taught me about myself?

"I am grateful for my grief because it reminds me I have been loved and have loved."



GRIEF

- Loss of something or someone
- Pre-existing history of trauma
- Existing self-care & coping skills
- We all cope differently
- We all grieve differently
- Honor the process
- May place grief “on a shelf” to focus on caregiving or delay grief post-care



GRIEF: KUBLER-ROSS MODEL

- Denial: "Not here. Not me." Shock.
- Anger (Anxiety): Feelings of loss of control or helplessness
- Bargaining: If I do ____, then ____
- Depression: Increased in sadness and/or grief
- Acceptance: Radical acceptance, settling into the new "new"

COURSE OF GRIEF

- Numbness
- Pining
- Disorganization/Despair
- Re-organization

Parkes C. M. (1998). Bereavement in adult life. BMJ (Clinical research ed.), 316(7134), 856–859. <https://doi.org/10.1136/bmj.316.7134.856>



TYPE OF SUPPORT

- Instrumental: Help with loved one or housework
- Emotional: Friends, family, mental health professional*
- Informational: knowledge from health professionals or support peer groups
- Unwelcome: Adds additional stress



POST-CARE SUPPORT

- Social Health- Spending time with family/friends, formal support groups, professional support
- Emotional/Spiritual Fitness- Improving grief literacy, focus on personal growth, practice gratitude, use self-care, engage in faith/beliefs, honor loved one, make time to reflect on caregiving experience
- Reclaiming Activities- Charity work, staying active in home and community



WHAT WE GAIN

- Enjoying togetherness
- Sharing activities
- Feeling a reciprocal bond
- Spiritual and personal growth
- Increased faith*
- Feelings of accomplishments and mastery

**55-90% of
dementia
caregivers report
positive
experiences**

Family Caregivers of People with Dementia; Henry Brodaty, MD, Dialogues in Clinical Neuroscience, 2009

Sanders S. Is the glass half empty or half full? Reflections on strain and gain in caregivers of individuals with Alzheimer's disease. Soc Work Health Care. 2005;40:57-73.






TOP 3 INTERVENTIONS:

- Evidence-based Interventions- Resources for Enhancing Alzheimer's Caregiver Health (REACH)*
 - Individual therapy
 - Peer support groups
- + Leisure and physical activities

Cheng, ST., Au, A., Losada, A. et al. Psychological Interventions for Dementia Caregivers: What We Have Achieved, What We Have Learned. Curr Psychiatry Rep 21, 59 (2019). <https://doi.org/10.1007/s11920-019-1045-9>

Wiegelmann, H., Speller, S., Verhaert, LM. et al. Psychosocial interventions to support the mental health of informal caregivers of persons living with dementia – a systematic literature review. BMC Geriatr 21, 94 (2021). <https://doi.org/10.1186/s12877-021-02020-4>

REACH Community is a highly successful evidence-based caregiver training & support program that has been proven to:

-  **Improve overall caregiver self-care, confidence, health, and emotional well-being**
-  **Reduce feelings of stress and burden from caregiving**
-  **Improve caregiver management of problem behaviors related to dementia**
-  **Empower the caregiver with self-care and self-efficacy techniques and strategies**
-  **Ensure the highest quality of care & safety possible for the person with memory loss**

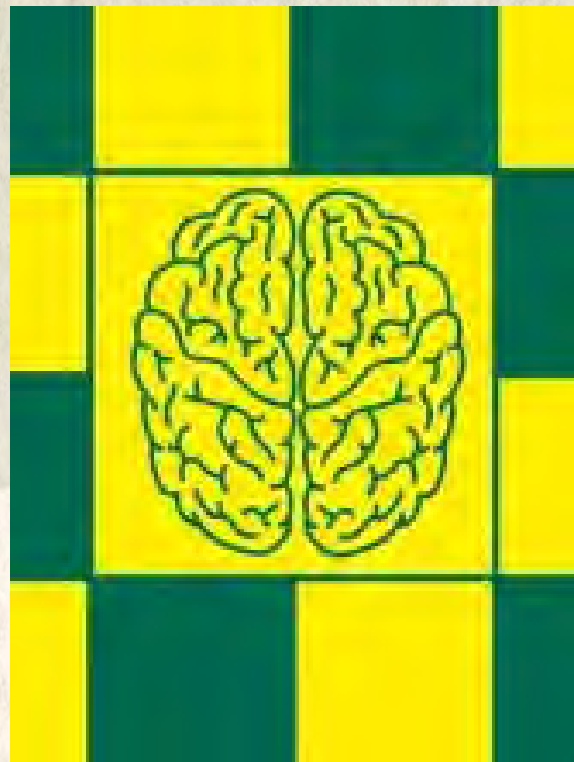
The 4- session training is FREE and personalized to your needs.

Sessions are offered on a one-to-one basis by a Certified Hawaii REACH Community Coach in your home, by telephone, or using a telehealth virtual connection – whatever is agreed upon by you and your assigned Coach. You will receive a Caregiver Manual as part of the program. REACH increases caregivers' knowledge of dementia and the caregiving role and teaches them skills to help themselves and their loved one.

For more information, call Catholic Charities Hawaii Senior Intake Line at 527-4777
Or email info@catholiccharitieshawaii.org



APPS



Dementia Emergency designed for caregivers, family members, emergency personnel guides how to communicate with dementia patients in a crisis



Dementia Talk App (free on Apple and Google Play Store)

- behavior tracker and care plan
- medication list
- scheduler
- My team and caregiver corner
- caregiver corner

The COVID Coach app was created to support self-care and mental health during the COVID-19 pandemic.

It is available on iTunes and Google Play.

The CBT-i Coach app is designed to help people experiencing symptoms of insomnia, who would like to improve their sleep.

It is available on iTunes and Google Play.

Date	Time in Bed (Avg. = 7.0h)	Time Asleep (Avg. = 6.2h)
Sep 24, 2017	7h 55m	7h 30m

APPS



MindMate

- founded by former caregivers
- available on phone and PC
- mental exercises, workouts, recipes, etc
- app is based on data from clinical trials



AURA



headspace

InsightTimer



GreyMatters: Reaching Beyond Dementia

- portable scrapbook app that can contain pictures, videos, and music to help preserve memories and share joyful moments
- creator of the app made this based on their experience taking care of their grandmother with dementia
- based on Reminiscence therapy tactics



RxSaver is a free app to help caregivers and older individuals save money on prescription medication by giving discounts and coupons. Also compares prices across various pharmacies to help you find the best deal

WHERE TO FIND PROFESSIONAL HELP



CATHOLIC CHARITIES
HAWAI'I
CIRCLE OF CARE FOR DEMENTIA

The Counseling Center Hawaii
<https://www.counselingcenterhawaii.com>
Openings for tele-therapy (video or phone)
Call for appointment: (808) 527-4470



HAWAI'I PSYCHOLOGICAL
ASSOCIATION *FOR A HEALTHY HAWAI'I*

Find a Psychologist
<https://hawaiipsychology.org/page-1828511>

Psychology Today

Find a Therapist
<https://www.psychologytoday.com/us>

RESOURCES

*Catholic Charities Hawaii Website: https://www.catholiccharitieshawaii.org/caring-for-persons-living-with-dementia-webinars-and-presentations/***

Alzheimer's Association: www.alz.org

Alzheimers.gov: <https://www.alzheimers.gov/life-with-dementia/tips-caregivers#tips-for-caregivers-taking-care-of-yourself-->

National Alzheimer's and Dementia Resource Center: <http://nadrc.acl.gov>

*National Institute on Aging, Dept. of Health & Human Services:
<https://www.nia.nih.gov/health/alzheimers-caregiving-caring-yourself>*

RESOURCES

Support Groups, Education Sessions

Alzheimer's Association – Hawaii

24/7 Helpline:

Hawai'i (808) 591-2771

National (800) 272-3900

Virtual support groups for Hawai'i available

<https://www.alz.org/hawaii>

No Shame Get Help

IT ALL STARTS WITH A CONVERSATION

WHERE CAN I GET HELP DURING AN EMERGENCY?

The following resources can help you or a loved one in time of a mental health crisis.

All are open 24 hours a day, 7 days a week.

IF YOU OR SOMEONE YOU KNOW IS IN IMMEDIATE DANGER

Call 911 immediately. Tell the operator there is a mental health crisis, explain the current situation, and share the person's mental health history.

[CALL 911](#)

The National Suicide Prevention Hotline

The National Suicide Prevention Lifeline provides free and confidential support for people in distress, as well as prevention and crisis resources for you or your loved ones, available 24 hours a day, 7 days a week.

[Call 1-800-273-8255](#)

[Visit Website](#)

Hawaii Cares (Local Crisis Line)

Hawaii Cares is a free local mental health and substance use call center that is open 24 hours a day. They provide support for adults and adolescents through crisis, treatment, and recovery.

[Oahu: \(808\) 832-3100](#)

[Neighbor Islands: 1-800-753-6879](#)

The National Crisis Text Line

The Crisis Text Line provides support 24 hours a day, 7 days a week through text messaging for those in crisis. Text "**ALOHA**" to **741741** from anywhere in the United States to text with a trained Crisis Counselor.

(Message and data rates may apply)

[Visit Website](#)

CRISIS RESOURCES

For Mental Health Emergencies:

You are not alone. If you or someone you know is suicidal, don't wait!



National Suicide & Crisis Line

National 24/7 crisis line
988

Hawai'i CARES

Hawai'i's 24/7 crisis line
O`ahu: 832-3100
Neighbor Islands Toll Free:
1-800-753-6879



CRISIS TEXT LINE |

Crisis
Text Line

Free, 24/7
Text ALOHA to 741-741
www.crisistextline.org

Trevor Helpline

National 24/7 hotline for
LGBTQ Youth
1-866-4U-TREVOR (488-7386)
www.thetrevorproject.org



The Trevor Helpline
866.4.U.TREVOR
THE LGBTQ+ AND GENDER-IDENTITY YOUTH
HELPS AND COUNSELING, 24/7

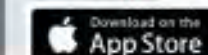


Online Screening

Free mental health
screenings
<https://bit.ly/3yGjJdN>

COVID Coach

Created to support self-care
and mental health during the
COVID-19 pandemic.





Mental Health America
of Hawai`i

1136 Union Mall #208
Honolulu, HI 96813

mentalhealthhawaii.org

808-521-1846 (Oahu)

808-242-6461 (Maui)



Screenings:

<https://bit.ly/3yGjJdN>



FACEBOOK

@MHAHawaii



INSTAGRAM

@livenaau

@mhahawaii



TIKTOK

@mhahawaii



TWITTER

@MHAofHawaii



YOUTUBE

@mhaofhawaii