Preparing for the Dementia Tsunami: Helping People Prepare, Care, and Cope

St. Mary's College

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Beverly E. Thorn, Ph.D., ABPP
Professor Emerita, Psychology
University of Alabama
Bthorn@ua.edu
https://drbeverlythorn.com/

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Who Am I?

- 72-year-old, retired from UA Dept Psychology
- Former caregiver for my husband with dementia caused by Alzheimer's disease
- Licensed Psychologist, certified End-of-Life Doula
- Mother, stepmother, grandmother, painter, author
- My Website https://drbeverlythorn.com

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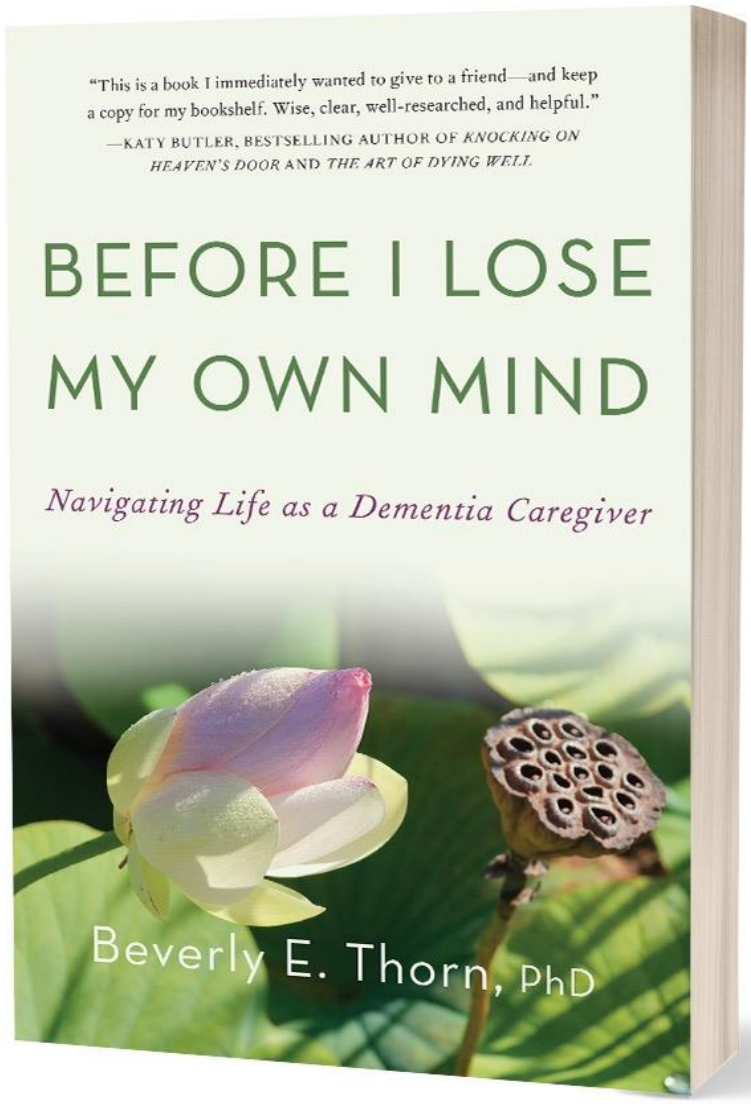
Why My New Book?
- to care for the caregiver -

- >7 million people with dementia in US
- > 12 million unpaid caregivers in US
- > 55 million people with dementia in world
- > 40 million unpaid caregivers in world
- ↓ in dementia caregiver workforce
- ↑ in dementia
- 80% caregiving by family & friends
- Long term, escalating caregiving demands pose risks for caregivers



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Knowledge, Planning, & Communication Ease Caregiver Burden

.... Oh, yes .....
and self-care....

Navigating a Life-Limiting Illness

Knowledge Is Power

Clarify What's Important

Plan While You Can

Communicate Wishes to Loved Ones

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Knowledge Is Power

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What is Dementia?

Gradual, progressive & life-limiting collection of symptoms

- Thinking/Reasoning/Problem-solving
- Memory
- Mood & Behavior Changes

Reduces ability to live independently

Later stages - total dependence & eventual death

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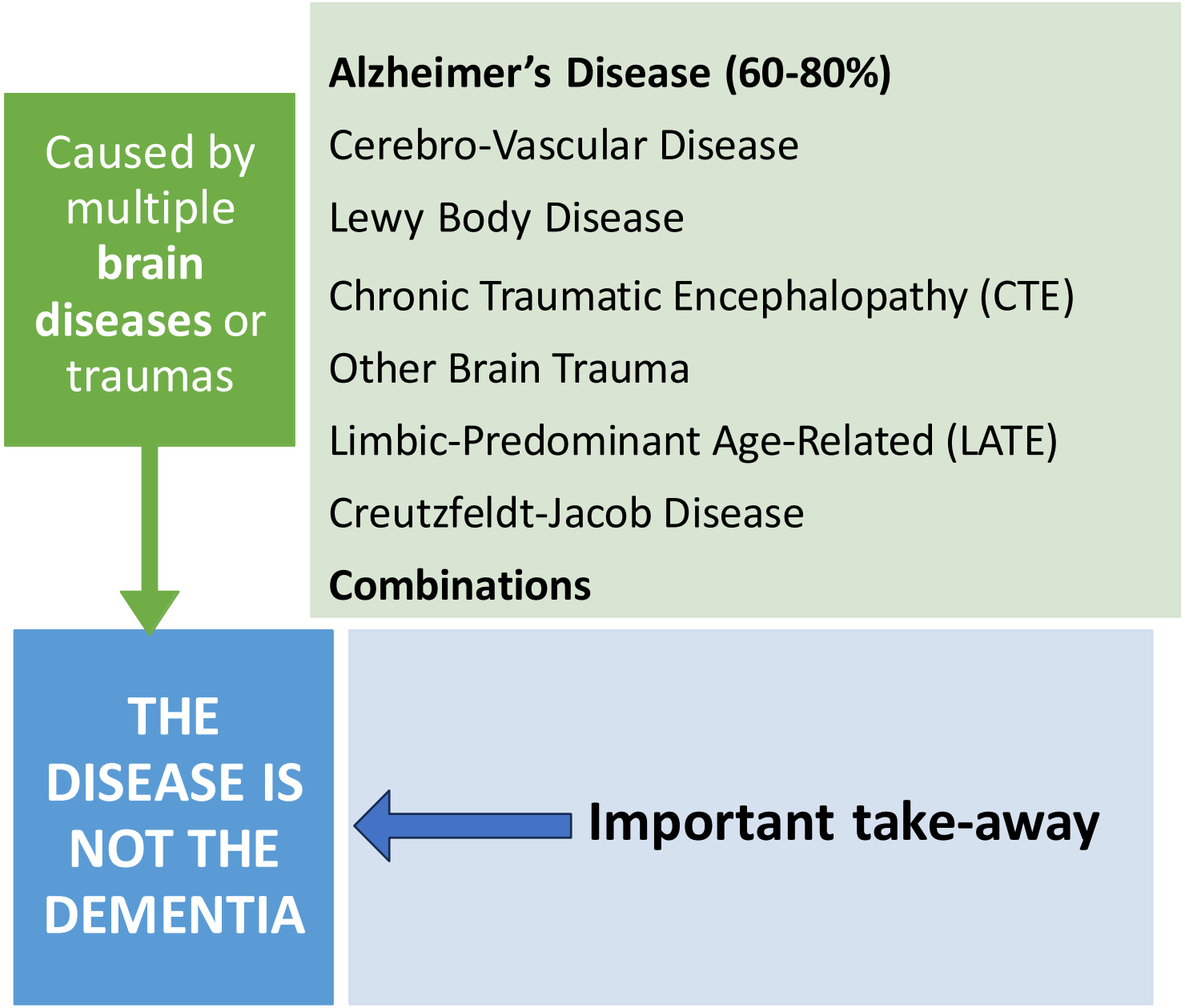
What Causes Dementia?



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Risk Factors for Dementia

Age (Older)

Sex (Female)

Race (African American, Hispanic)

Genetics (APOe4 gene –Alzheimer's)

Lifestyle (Obesity, hypertension, diabetes, sedentary lifestyle)

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Diagnosing Dementia

- Self-report of symptoms
- Significant others' report of symptoms
- Mental Status Exam (screener)
- Full Neuropsychological test battery
- Supplemented with MRI/other tests (to help determine cause & trajectory)

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Understanding the Disease Trajectory: Stages of Dementia

- Stage 1: Normal functioning, no memory loss
- Stage 2: Normal forgetfulness
- Stage 3: Mild cognitive impairment: some forgetfulness, difficulties concentrating, word-finding problems. Noticeable to others -→Not dementia
- Stage 4: Early-stage dementia: problems w/ complex tasks, remembering recent events, traveling alone, managing finances. ~ 2 yrs
- Stage 5: Mid-stage dementia. Major problems w/ memory (address, location) tasks of daily living (meal prep, bathing, dressing). Help needed ~ 1 1/2 yrs
- Stage 6: Severe cognitive decline (forget names of family, forget recent events, trouble finishing tasks, possible incontinence). ~ 2 1/2 yrs
- Stage 7: Very severe cognitive decline. Loss of communication, total dependence, often bed bound ~ 2 1/2 yrs

Clarify What's Important

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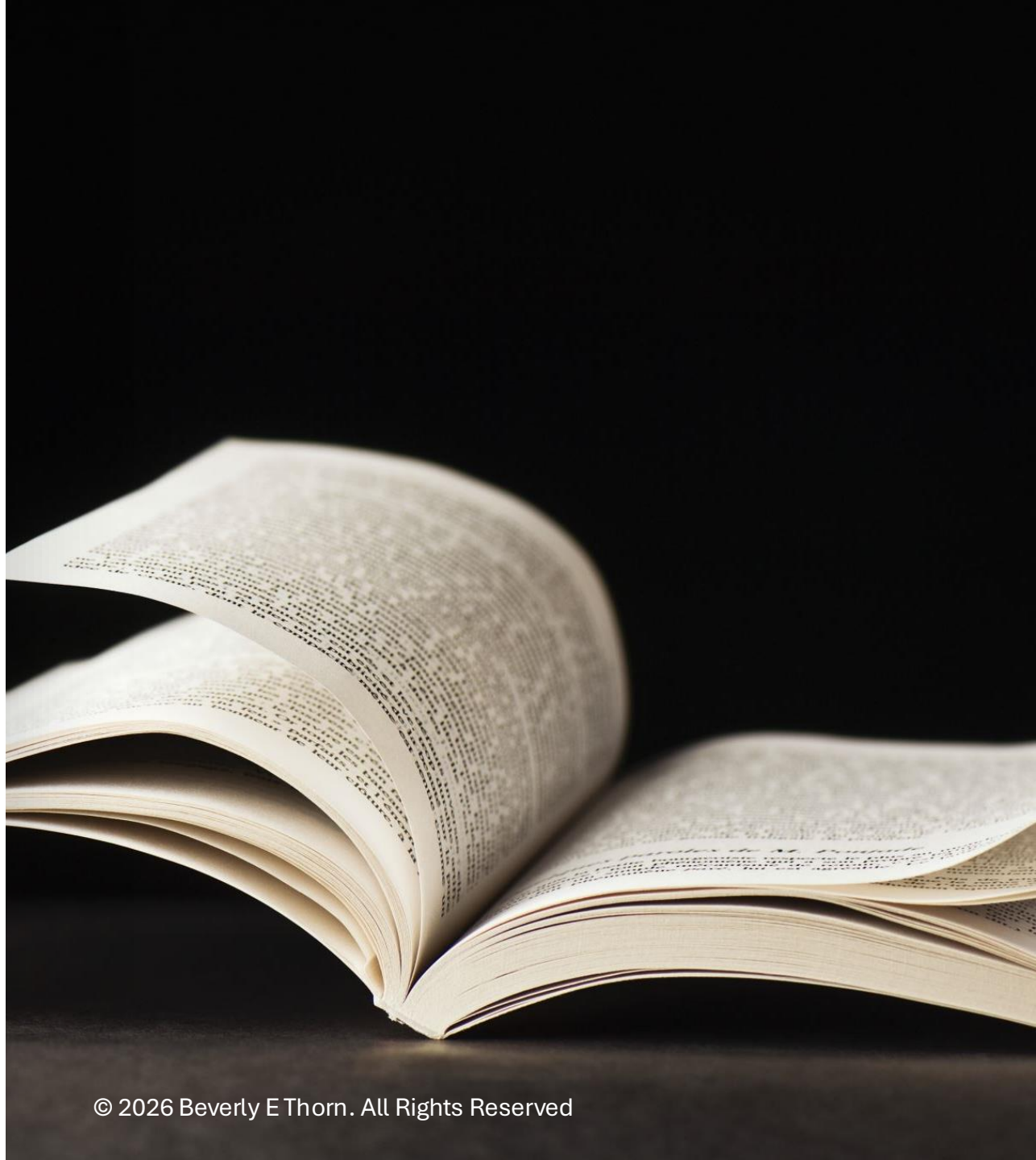
Clarify values – *When time may be short, what's important?*

Gawande, A. (2014). *Being Mortal: Medicine and What Matters in the End*. Metropolitan Books.



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Consider Your Values:

- What makes life worth living?
- What is not acceptable to lose or endure?
- What people or belief systems support you?
- What are your greatest fears or concerns about aging or dying?

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Navigating a Life-Changing Diagnosis

Winemaker, S, & Seow, H. (2023). *Hope for the Best, Plan for the Rest*, Page Two Press.

- Seek honest, accurate information
- Ask questions to make informed decisions
- Understand the pattern of the illness
- Who will be the manager of this illness?
- Reflect on your coping strategies when stressed

https://www.waitingroomrevolution.com

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Planning and Communication

Serious Illness Conversation Guide

- What is most important to you?
- What are your hopes for your health?
- What are your biggest worries?
- How much would you be willing to go through for the possibility of more time?
- Do the people closest to you know about your priorities and wishes for your care?

- https://www.ariadnelabs.org/wp-content/uploads/2023/05/Serious-Illness-Conversation-Guide.2023-05-18.pdf

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Plan While You Can

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Barriers to Making Critical **Planning** Decisions

- Denial of cognitive decline (patient, loved ones)
- Supportive/proactive/vs “giving up” on patient
- Societal taboo about death
- Clinician discomfort
- Financial
- Geographical

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Critical Planning Decisions

Advance Care Directives

- Living Will
- Dementia Addendum
- Also consider patient letter, video to supplement

Healthcare Power of Attorney

- AKA
  - healthcare proxy
  - healthcare representative

Healthcare Advocates

- Not a legal authority, but advisory
- e.g., EOL Doula

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Decision-Making Capacity

Situation-specific:

"Not knowing where I am doesn't mean I don't know what I like"
–Mozley et al. 1999

- Varies by timeline, person, and situation with dementia
- Medical decision-making and Healthcare Representative (Power of Attorney)

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How do we Assess Decision-Making Capacity? Example of Medical Decision-Making

- Do they understand relevant information?
- Do they appreciate the situation and consequences?
- Can they reason through risks/benefits?
- Can they communicate a choice?

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Communicate With Loved Ones

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Plan, Communicate, and Adjust

Include trusted others in conversations

Normalize talking about serious illness and death

Talking about later-life complications/emergencies

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Community Resources: Medical and Non-Medical

- Finding/nurturing medical relationships
- Building your circle of support
- Asking for/accepting help
- Respite communities
- Hiring help
- Residential care
- End-of-life Care

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Care for the Caregiver/ Self-Care

Care for the Caregiver: Barriers

- Culture of individualism
- Difficulty asking for/accepting help
- Loved one wants only YOU
- Guilt
- Feelings of self-worth

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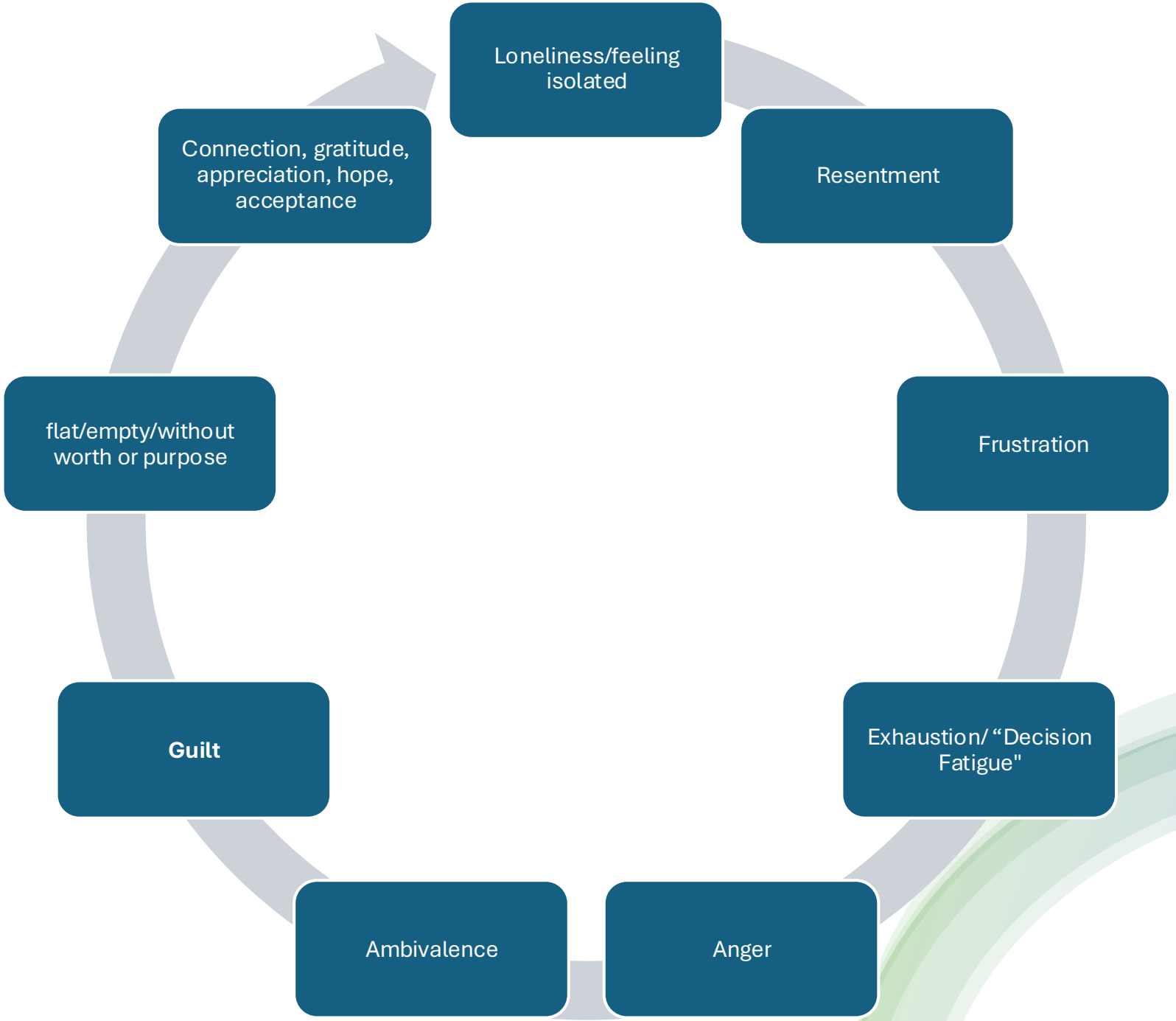
Caregiver Emotions



More Caregiver Emotions

Grief

- Sequential grief
- Anticipatory grief
- Grief after loss

Survivor guilt

Hindsight bias

Self-forgiveness

Getting Support as a Caregiver

Self Care – Importance of recharging

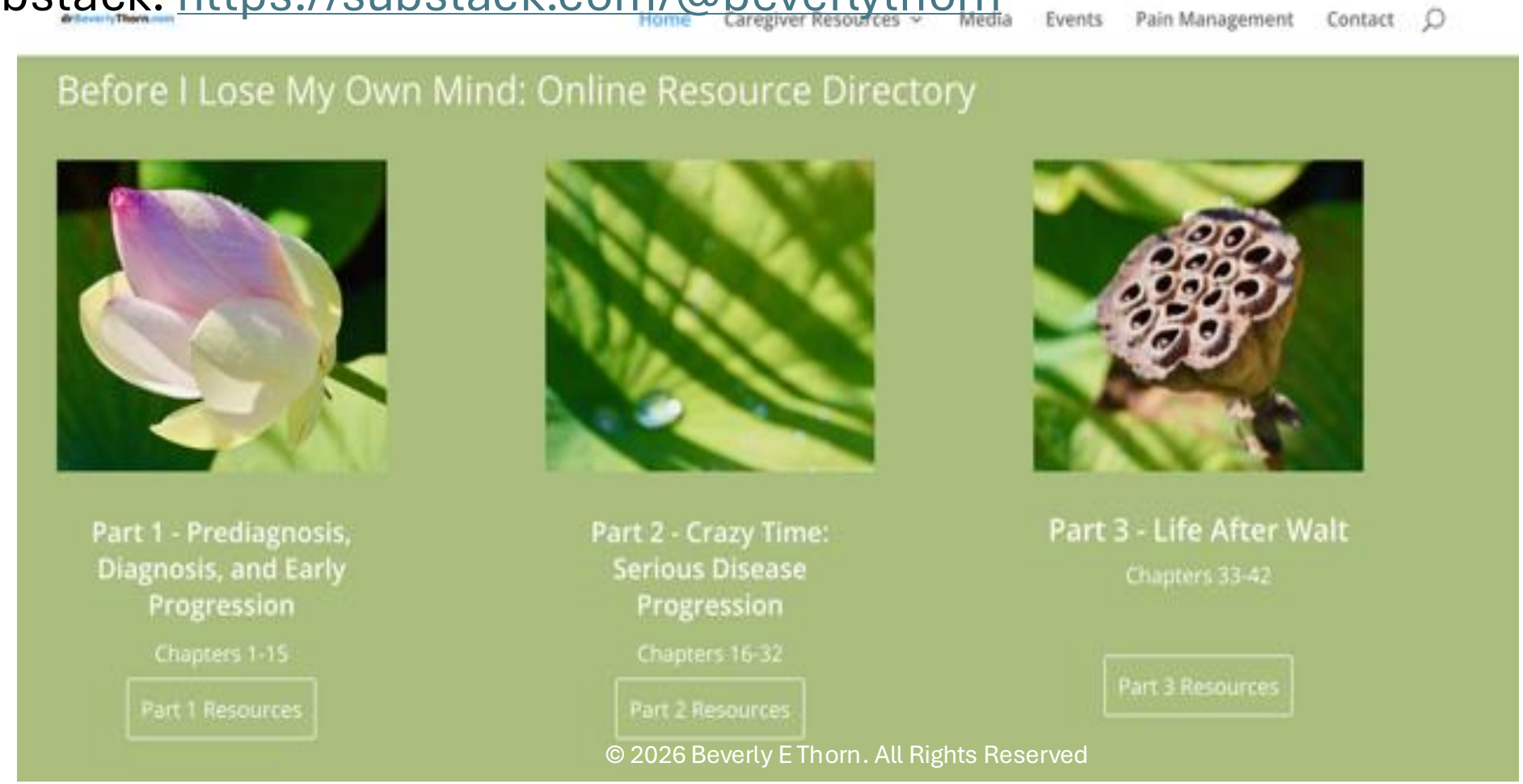
Asking for help

Hiring help

Relaxation/meditation

THANK YOU!

Beverly Thorn: Bthorn@ua.edu
Website: drbeverlythorn.com
Substack: https://substack.com/@beverlythorn



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