

Navigating Grief & Bereavement through CJD: “Honoring the Journey”

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Certified Grief Recovery Specialist

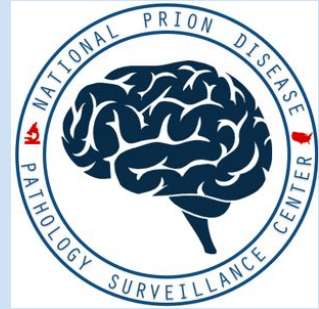
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Certified Dementia Practitioner

Certified Grief Educator

The Memory Center at UChicago Medicine
Lorenzo's House, *Co-Founding Board Member*
Global Programs Co-Facilitator/Designer



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Why I'm Here

For more than 20 years, I've had the privilege of walking alongside families affected by prion disease through my work at the Prion Center at Case Western Reserve University.

Every family's story has taught me something about love, resilience, and grief.

Today, I hope to share a few of those lessons - and most importantly, help you know that you don't have to walk this journey alone.



Tessa

Tessa brings 20 years working with diverse populations in the nonprofit and medical sectors. **Tessa works at the The Memory Center at UChicago Medicine providing dementia care navigation as well as guidance through all types of neurological conditions.**

As a recipient of the Albert T. Schweitzer Fellowship, **she focused on bringing grief and loss support to local communities, along with cultural humility and compassionate care to medical settings**, and continues to do so through speaking engagements for medical professionals, graduate students, and community members.

Tessa serves on the board for the Society for Social Work Leadership in Healthcare. She is occasionally called upon to assist with the Healthy Aging and Alzheimer's Research Care Center, known for the SuperAgers study, and **is the medical sector lead/co-founder for Dementia Friendly Hyde Park.** Tessa is **co-founding Board Member and global facilitator/co-designer for programs at Lorenzo's House, which specializes in serving those impacted with younger onset dementia around the world.**

She co-facilitates young adult and care partner support in both caregiving and grief/bereavement through younger onset dementia.

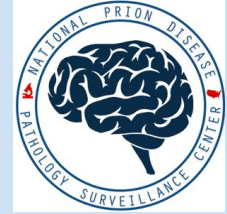




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We come from all
different places here...



...all are welcome as we
have this shared
experience.



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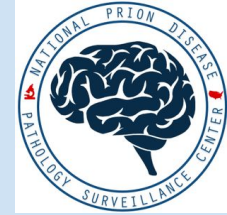
A moment of silence...

Objectives



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Together we will:

- Recognize the unique grief experienced throughout the CJD journey
- Understand practical strategies for managing stress and grief
- Leave with tools, resources, and hope for continuing forward

Our unique experience with the rarest of the dementias (CJD, GSS, FFI, any prion disease)

**Close your eyes. Let's take 3 deep breaths together.
Do any of these statements resonate with you?**

- What. Just. Happened?!
- It all happened so fast. Things changed every week.
- There's so much added trauma because it's so unknown. We don't seem to belong in the ADRD category. The club that we aren't a part of.
- What was that? Creutzfeldt what? How do you spell that? Is that like ALS?
- It's like we are grieving 3 times. For what we are losing. And again for what we have lost. And then again adjusting to being a person again after the loss.
- We JUST retired. This was SO not what we were expecting.
- If only I... I should have...
- We were forced to plan for the end so, so quickly
- They're all so afraid of us. They don't want to touch us.
- We didn't have time to learn our options for most everything
- I've never even heard of this disease and it just swept in and took my loved one.



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Understanding the CJD Experience



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- Naming “The Whirlwind”
- The Medical Maze
- The Triple Grief



1st: Each of rapid daily losses over time (both on the person & family/carers)

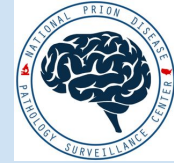
2nd: The loss itself, from the finality of the passing & adjusting to life beyond

'It's different for us:' Grieving During & After CJD



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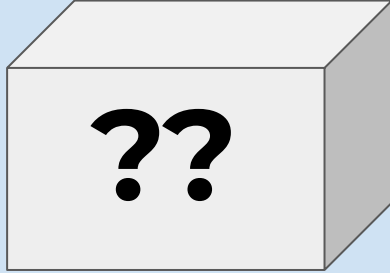
- **Anticipatory Grief:** A long goodbye at high-speed
- **The “After” Silence:** No more appointments. No more crises.
After the loss, it gets quiet. The silence is deafening.
- **The Disconnect:** “Why does support feel so distant?”
“Why do they pull away?” “They don’t ‘get it.’”

Grief after CJD doesn't follow the rules.
And neither do your feelings.

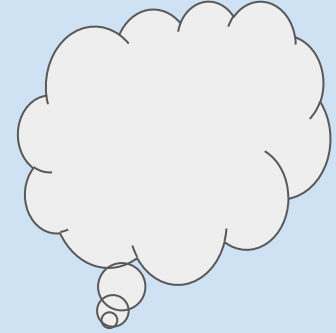


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What is grief?



How does it show up in any moment?

(hint: It happens anytime, 'from the get go')

Types of Grief & Loss (to name a few)



disenfranchised grief

(cannot openly acknowledge the loss)



complicated grief

(chronic / delayed / exaggerated / masked / absent)



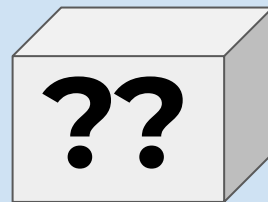
bereavement

(grief/mourning after the time of loss)



anticipatory grief

(grief before the loss occurs)



ambiguous loss

(may be physically present but gone)

HOW WE
WANT
GRIEF TO
WORK



HOW GRIEF
ACTUALLY
WORKS





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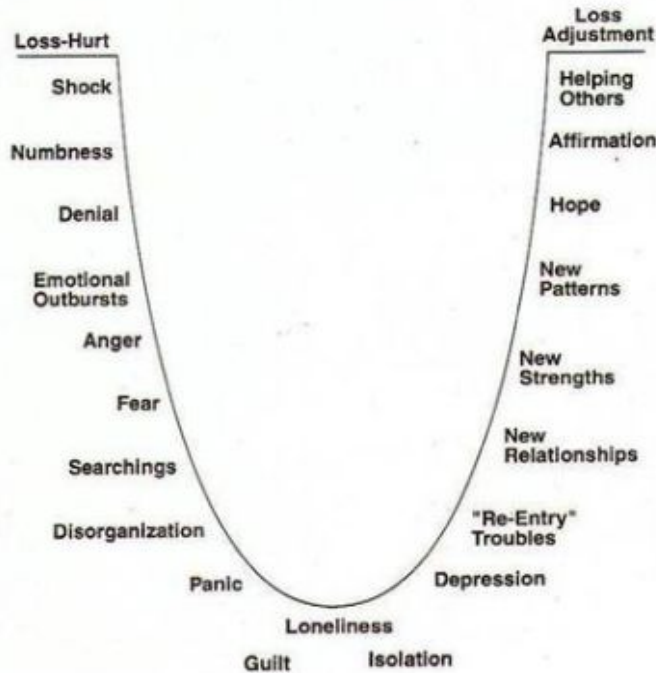
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There are no wrong feelings....

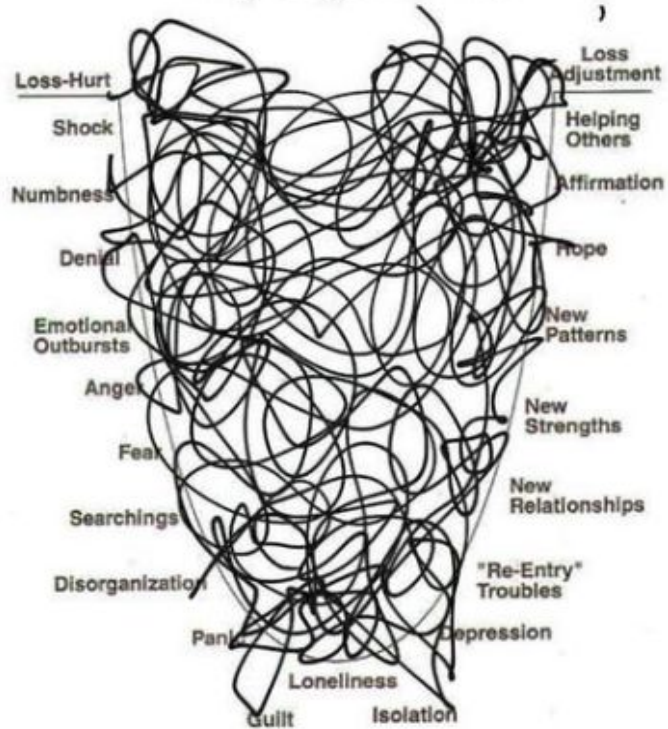
- Fear
- Anger
- Relief
- Hope
- Confusion
- Exhaustion
- Loneliness
- Love
- Guilt
- Numbness

Which one did you
feel that surprised
you the most?

STAGES OF GRIEF



My experience





People tend to believe that grief shrinks over time



What really happens is that we grow around our grief

GROWING AROUND GRIEF

HERE IS A NEW WAY OF THINKING ABOUT GRIEF AND RECOVERY:



THIS CIRCLE
REPRESENTS A LIFE
THAT IS TOTALLY
CONSUMED BY
GRIEF.



ONE SHOULD ACCEPT
THAT THE GRIEF WILL
NEVER ENTIRELY
DISAPPEAR, BUT
OVER TIME IT WILL
BECOME A SMALLER,
MORE MANAGEABLE
PART OF LIFE.



EVEN THOUGH THE
GRIEF IS STILL
THERE, A NEW LIFE
EXPANDS AROUND IT;
ONE IS ABLE TO
GROW AROUND
GRIEF.



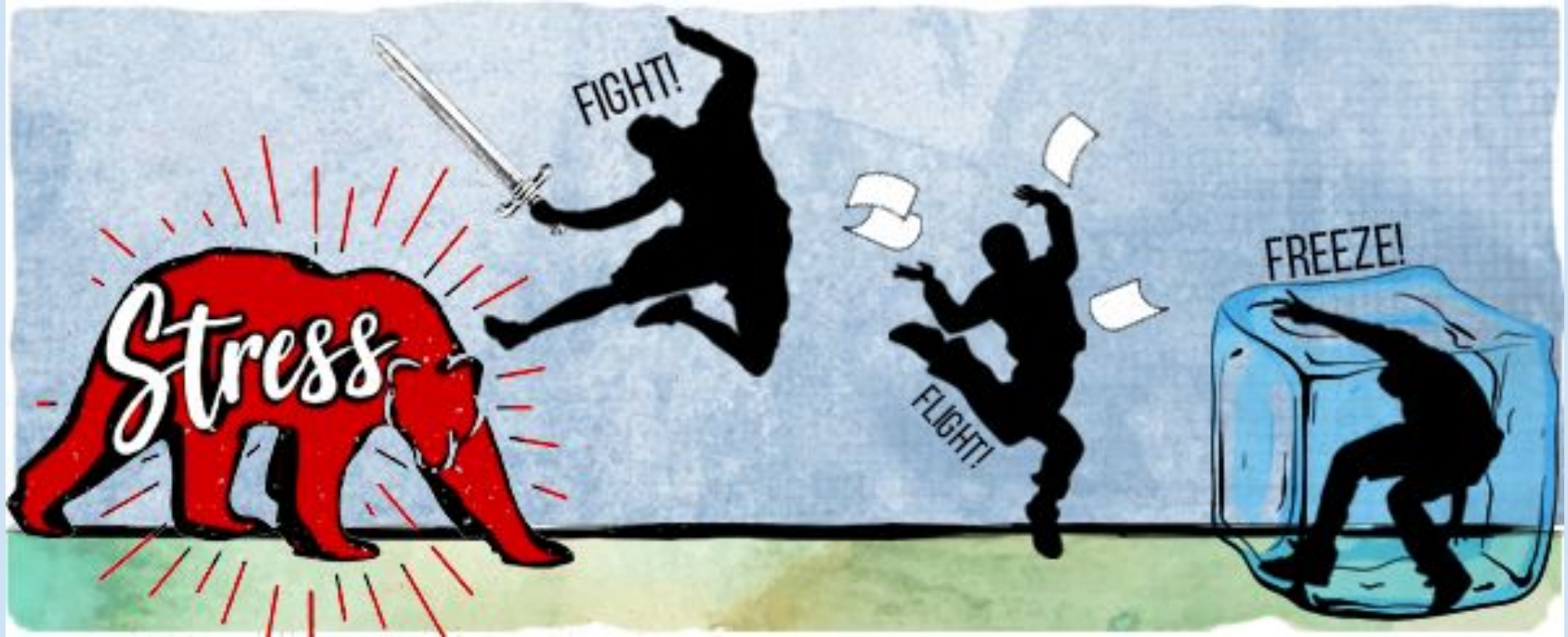
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So what happens when
grief shows up?

(What happens in our body?)

When we are hit with a wave of grief...



our body goes into STRESS mode

First: Know your stress
signal

Then: Pause before
responding

Let's try this:



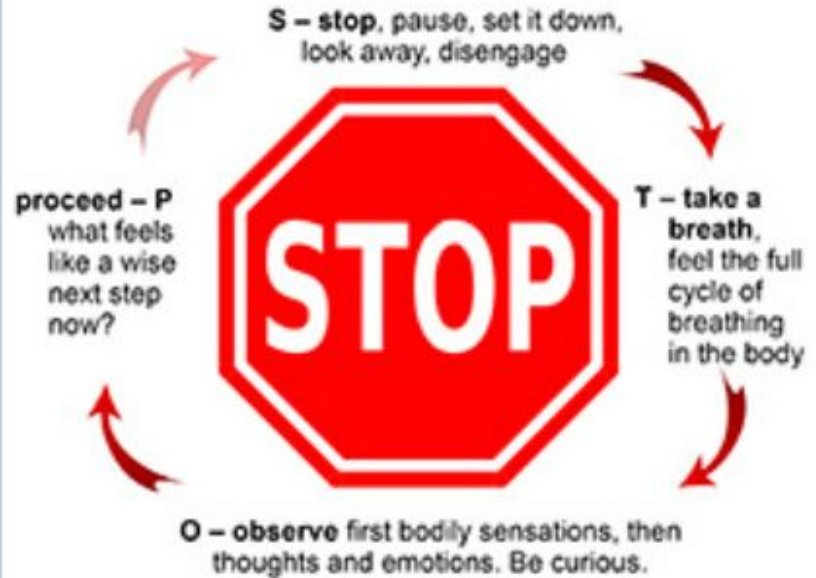
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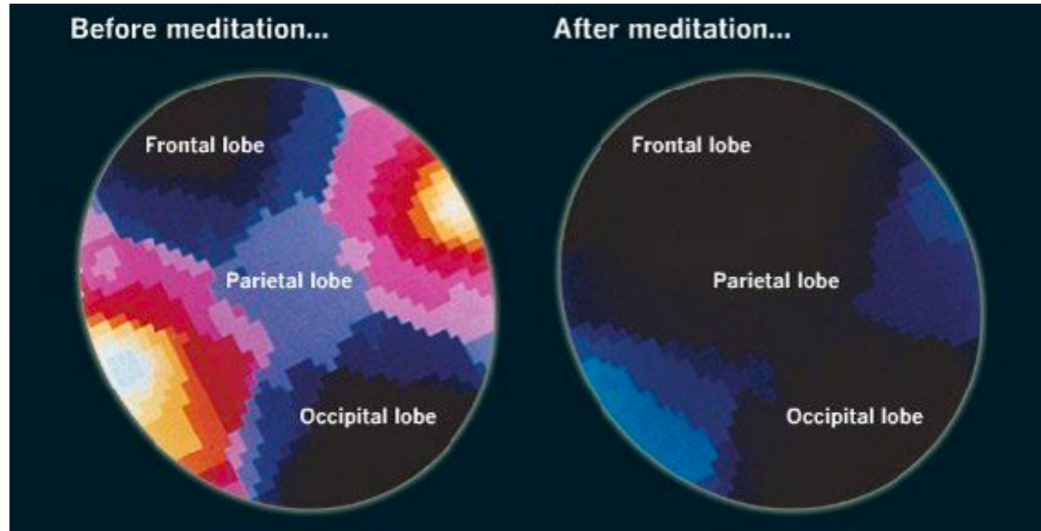
The STOP practice

*Feeling alarmed?
Stressed? Reactive?
Stop!*



How did that feel?

taking time out to slow down, pause, and breathe
literally creates room in your brain to think more clearly

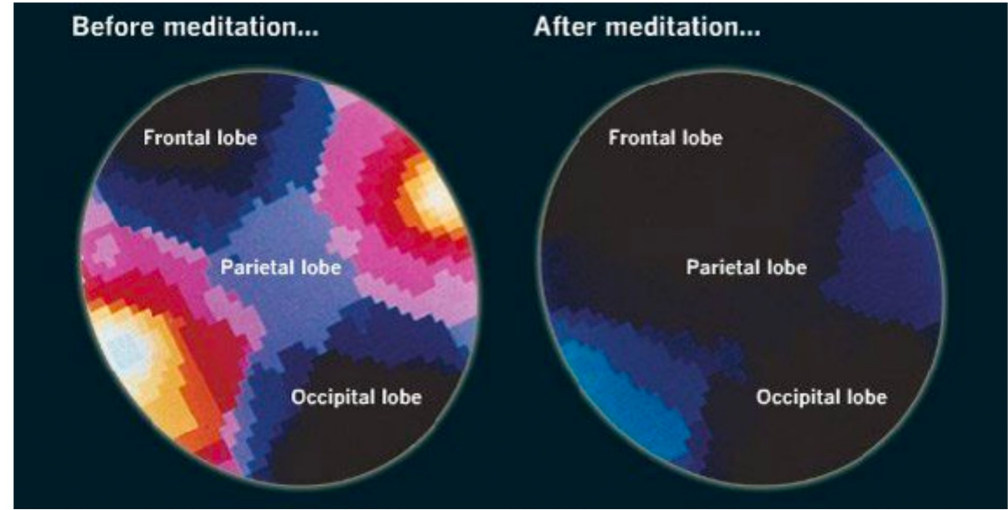


Why does this matter?

OXYGEN!



taking time out to slow down, pause, and breathe
literally creates room in your brain to think more clearly



Mindfulness based interventions on caregivers “showed greater improvement in overall mental health, stress, and depression” and they “improved anxiety, social support, and burden.”

Sources: National Institute of Health, Frontiers in Psychology Journal and Dr. Gregg Jacobs, Harvard Medical School, *The Ancestral Mind*;
<https://www.nytimes.com/2019/02/12/well/family/how-to-help-teens-weather-their-emotional-storms.html>

Which ones
feel most
doable to
you?

GROUNDING

Sit up straight, put your feet on the floor, focus on your breathing. Describe in detail 5 things you see around you. Go into as much or as little detail as you desire.

BREATHE

Get into a comfortable position and close your eyes. Breathe in through your nose and imagine breathing in a calming color, such as light blue. Exhale through your mouth, imagine your anxiety exiting your body through a color, such as red. Repeat.

CONFIRM

Say the follow things to yourself, out loud, & repeat.
*I am safe. I am not in danger.
A panic attack cannot hurt me.
I am breathing in enough air.
I am beginning to calm down.
I am going to be okay.*

OUTSIDE

Go outside. As much as you don't want to, just go. Sit or stand and breathe in the fresh air. Look at the stars or the clouds and focus on them. Feel the warmth or coolness.

OILS

Essential oils are a huge part of my anxiety coping. My personal favorites are: lavender, copaiba, cedarwood, frankincense, & peace & calming.

SHOWER

If you're able, take a shower. This sounds trivial, but it's one of my favorite ways to come down from anxiety. Just trust me.

Pick 1 to Try

Exercise



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“A Moment with your Heart”

- **The Practice:** *Anytime you're hit with a wave of grief:*
 - Try 'The Heartbeat Exercise' - Hand on your heart
 - Try 'The Deep Inhale + 1 more sip of air + Full Exhale'
- **The Story:** *Where did this moment come from? Why?*
- **The Check-In:** *“Where is my grief sitting in my body today?”*

Journal Activity: Write one word to describe your moment of grief

Quick Ways to Reduce Stress

Tip 1: Recognize when you're stressed

Tip 2: Identify your stress response

Tip 3: Bring your senses to the rescue

Tip 4: Find sensory inspiration

Tip 5: Make quick stress relief a habit

Tip 6: Practice wherever you are

Source: <https://www.helpguide.org/mental-health/stress/quick-stress-relief>

When is it okay to ask for help?

When stress begins to interfere with daily
life...

sleep | eat | work | socialize



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Effects of Prolonged Stress

Emotional	Physical	Cognitive	Behavioral
• Moodiness • Irritability • Feeling overwhelmed • Loneliness / Isolation	• Fatigue • Headaches • Muscle tension • Sleep disturbances	• Memory problems • Trouble concentrating • Racing thoughts • Indecisiveness	• Withdrawing from others • Changes in appetite • Changes in sleep habits • Avoidance

Source (and for more info): <https://wellness.uchicago.edu/healthy-living/health-information/stress/>

The following is a list of some symptoms that could be a sign of complicated grief:

- Inability to experience interest in things that used to be pleasurable or interesting
- Prolonged avoidance of reminders of loss or inability to talk about loss
- Intense anger
- Incapability to have happy memories or thoughts
- Feeling empty or meaningless
- Continued preoccupation with thoughts of suffering or death
- Extreme change in appetites or sleep patterns
- Reckless or violent behaviors
- Excessive drinking or drug use
- Suicidal thoughts

Source: <http://www.bergencounselingcenter.com/services/grief-counseling-chicago/>



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How are You Doing?

F.I.N.E

Feelings Inside Not Expressed

Sometimes “I’m fine” isn’t a feeling...it’s a response.

What Caregivers Wish Others Knew

“Most people avoid us. **Stopping by to say hi means the world.**”

“Often **we don't have the room to reach out on our own. Just show up. With your time.** With a bag of groceries. Every little bit helps.”

“Sometimes it's hard to tell people because they don't understand without going through it. **Be compassionate. Check in. Research.** Open up to help with your own feelings.”

“**Be patient to make everybody feel better,** because it's worth it.”



Ideas for Healthy Coping

1. SOCIALIZE!

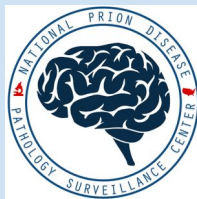
- **Make a list of favorite people & send a recurring monthly invite:**
(text, video, email, phone, letter, meet up)
Nurture meaningful connections w/friends, family, 'chosen family'

2. LEARN & GROW!

- **Knowledge is power:** Learn as much as you can about the diagnosis/condition
- **Build healthy habits:** *Nutrition, Exercise, Sleep, Hydration, Stress Management* **Use your 5 senses**

3. BE WELL!

- **Insight Timer | Calm | Headspace**
(*stress management, in-the-moment self regulation, brain training*)
- **Get it out of your body:** journal | movement | art | music | breathing



Resources



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Center for Grief, Recovery, & Therapeutic Services

www.grieffounselor.org

PsychologyToday.com

dougy.org | grief.com | nacg.org

faith-based community | family doctor | school/college

www.cjdfoundation.org

www.griefrecoverymethod.org

National Prion Disease Pathology Surveillance Center

<https://case.edu/medicine/pathology/divisions/prion-center>

Reach out to any of us here at the conference!

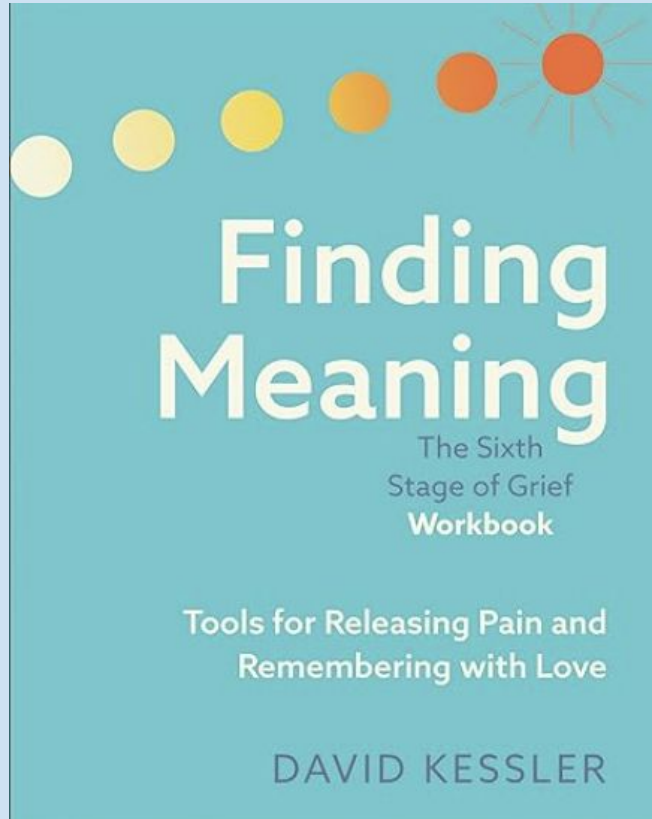


Recommended Reading



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WORKBOOK:

Finding Meaning: The Sixth Stage of Grief Workbook

Tools for Releasing Pain and
Remembering with Love

By David Kessler

And more, on

www.grief.com

A Heart In Your Hands

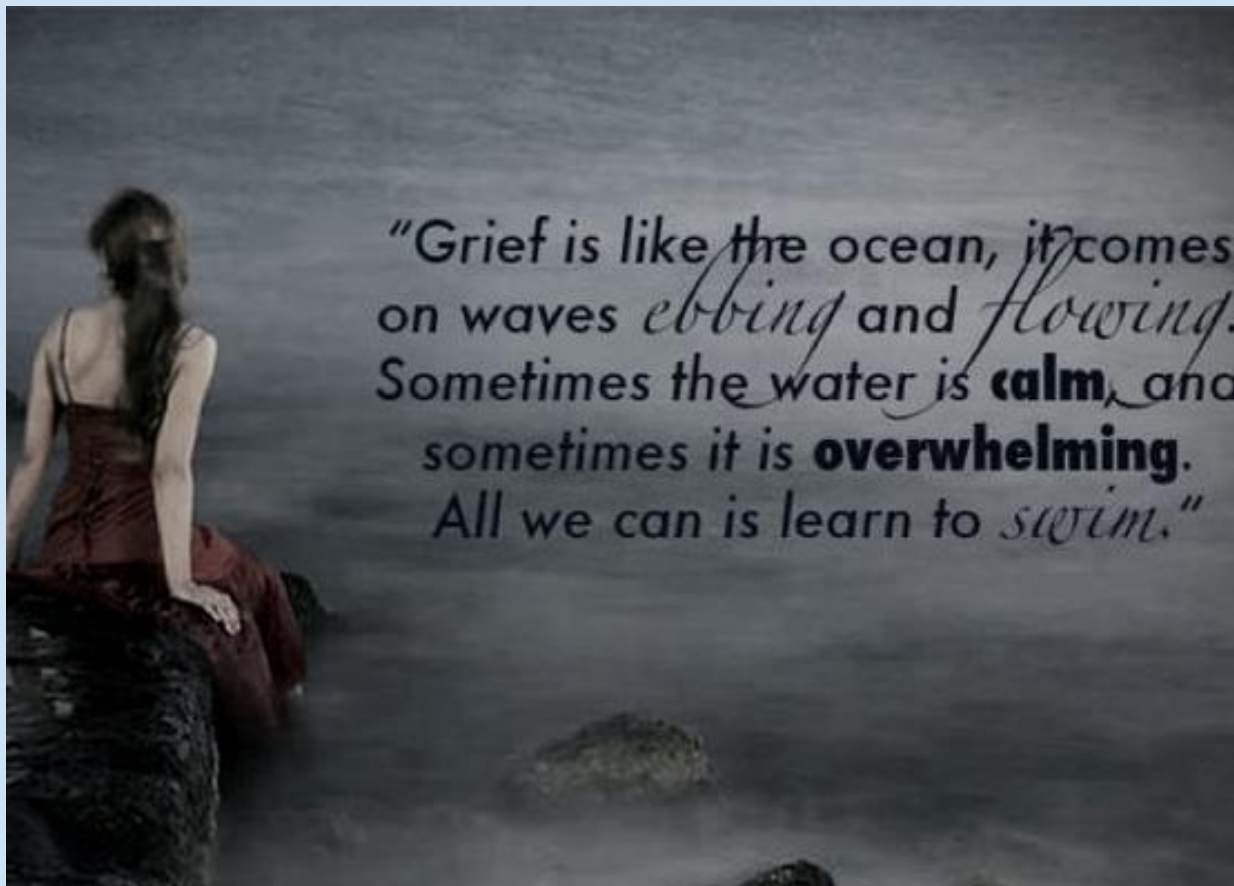
Seek Out a “Heart with Ears”



Hold your amethyst heart in your hands.

- **Feel its weight.**
- **Trace its smooth edges.**
- **Notice the unique colors and patterns within the stone.**
- **Take a slow, deep breath.**

***No two amethyst hearts are exactly alike.
Just as no two grief journeys are the same.***



"Grief is like the ocean, it comes
on waves *ebbing* and *flowing*.
Sometimes the water is **calm**, and
sometimes it is **overwhelming**.
All we can is learn to *swim*."

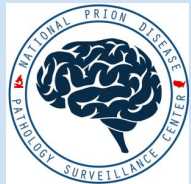
A Final Word...



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"Your love was bigger than the disease. Your grief is the proof of that love. Take this heart with you as a reminder that your story is seen."



Reflection



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One thing you're taking with you today



One word to describe how you feel

(Take your time: Slow transition is ok)



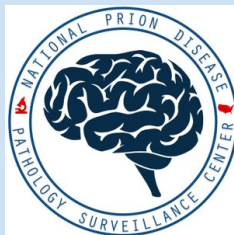
One way you'll show yourself kindness

(Think: the tips & tools you learned today)

Thank you!



Q/A



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