

Navigating Grief & Bereavement through all of CJD & beyond...

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The Memory Center at UChicago Medicine
Society for Social Work Leadership in Healthcare
Lorenzo's House
Dementia Friendly Hyde Park



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Tessa

Tessa brings 20 years working with diverse populations in the nonprofit and medical sectors. **Tessa now works at the The Memory Center at UChicago Medicine providing support for all of the outpatient neurology and neurosurgery clinics.** As a graduate student recipient of the Albert T. Schweitzer Fellowship, **she focused on bringing grief and loss support to local communities, and cultural competence 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 called upon to assist with the Healthy Aging and Alzheimer's Research Care Center and **is the medical sector lead/co-founder for Dementia Friendly Hyde Park.** Tessa is co-founding Board Member and global facilitator/designer for Youth Programs at Lorenzo's House, which **specializes in serving those impacted with younger onset dementia around the world.**





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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...

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? Cruetzfeldt 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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Objectives



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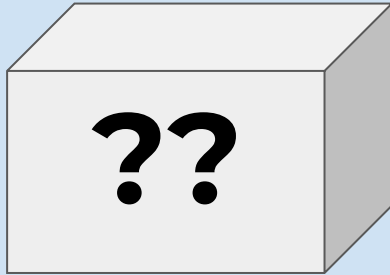
Together we will:

- Explore what grief looks and feels across all stages of the journey – recognizing and defining the different types of grief, and will share stories and specific examples along the way
- Empower ourselves with tools for navigating the different types of grief on this journey
- Share resources and coping tips for living with our grief to express emotions in healthy, constructive ways no matter where we are on the journey



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What is grief?



How does it show up in any moment?

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

Storytime! Listen ~ Relate ~ Reflect

As we are discussing the different types of grief, feel free to journal and write any notes or feelings that come up.

Questions to think about:

- Which types of grief do you relate to the most (now or in the past)?
- Are you experiencing any similar feelings during your journey with grief?
- How is grief showing up for you?



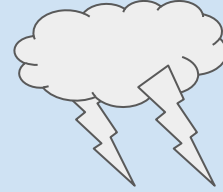
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Types of Grief & Loss (to name a few)



disenfranchised grief
(cannot openly acknowledge the loss)



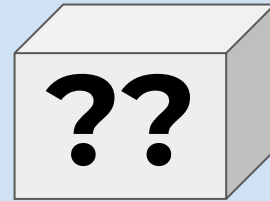
complicated grief
(chronic / delayed / exaggerated / masked / absent)



bereavement
(grief/mourning after the time of loss)



anticipatory grief
(grief before the loss occurs)



ambiguous loss
(may be physically present but gone)



Anticipatory Grief

Experiencing grief reactions and feelings before the actual loss occurs, in ‘anticipation’ of loss. It can include significant losses, such as job changes, divorce, progression of a disease, and death, aka ‘pre-loss grieving’

- Can be intense feelings (sadness, anger, anxiety, etc.)
- Natural to imagine life without the person/how to cope
- Can be a coping mechanism (may help adjust after loss)
- Includes physical impact on sleep, eating, feel fatigue



Ambiguous Loss

A type of loss with no clear resolution or definitive answer about the person's whereabouts, status, or nature of loss

A physical absence (like a missing person) with the person still psychologically present in the individual's thoughts and memories, or **a psychological absence (like a loved one with dementia) where the physical presence remains but the person is no longer the same**



Complicated Grief

(also known as Prolonged Grief)

Grief reactions persist beyond what is culturally expected, significantly interfering with daily life and functioning (at work, social life, & personal relationships)

It's characterized by intense and persistent longing and preoccupation with thoughts of them, and difficulty accepting the loss, (or as in dementia, the many losses that occur every day and beyond).

Severe, debilitating, significantly disruptive, not less w/time

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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Disenfranchised Grief

A type of loss that doesn't fit into our society. For example, **the type of loss that is not openly acknowledged, socially supported, or not visible in the public eye because others don't see it as a loss.** It is a loss that may be stigmatized in our communities and seen as insignificant, so it doesn't provide us with the space or permission to grieve openly, which can lead to feeling more isolated and be potentially more challenging to process and heal through the loss



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Bereavement

The **whole experience of losing someone important to us**. It is the period of mourning or state of intense grief, especially following the death of a loved one. The length of time varies between all individuals.

Aka while 'bereavement' is the time period, 'loss' is the actual death, 'grief' includes internal feelings, and 'mourning' includes physical outward expression of grief



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Can you relate? Let's Share

As we discussed the different types of grief, feel free to share any notes or feelings that resonated with you.

Questions to think about:

- Which types of grief do you relate to the most (now or in the past)?
- Are you experiencing any similar feelings during your journey with grief?
- How is grief showing up for you?



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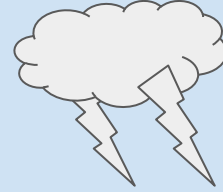
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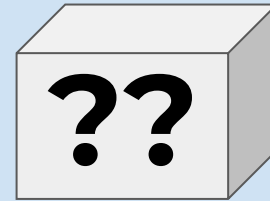
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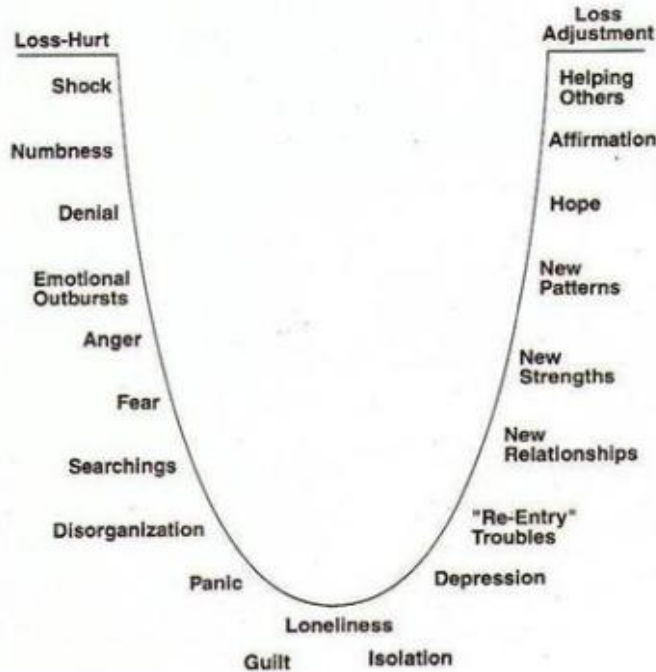
HOW WE
WANT
GRIEF TO
WORK



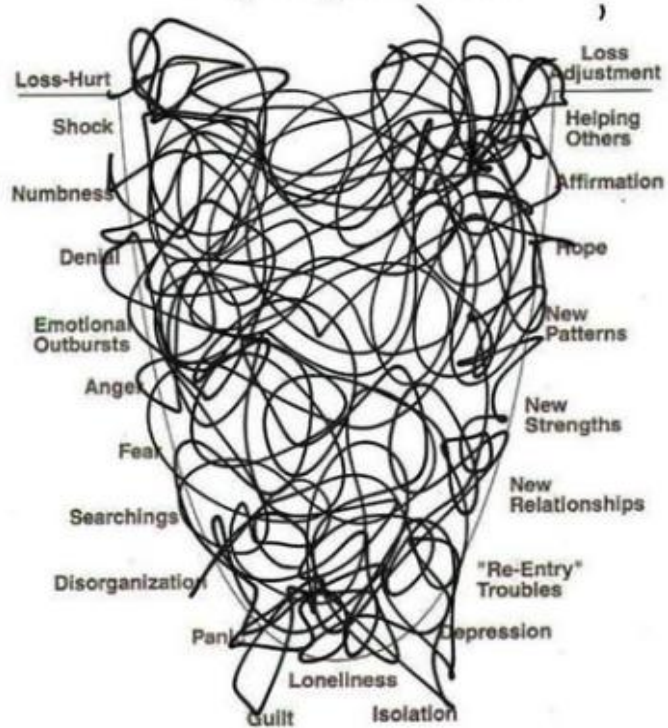
HOW GRIEF
ACTUALLY
WORKS



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.

So how do we know
when grief is happening?

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:

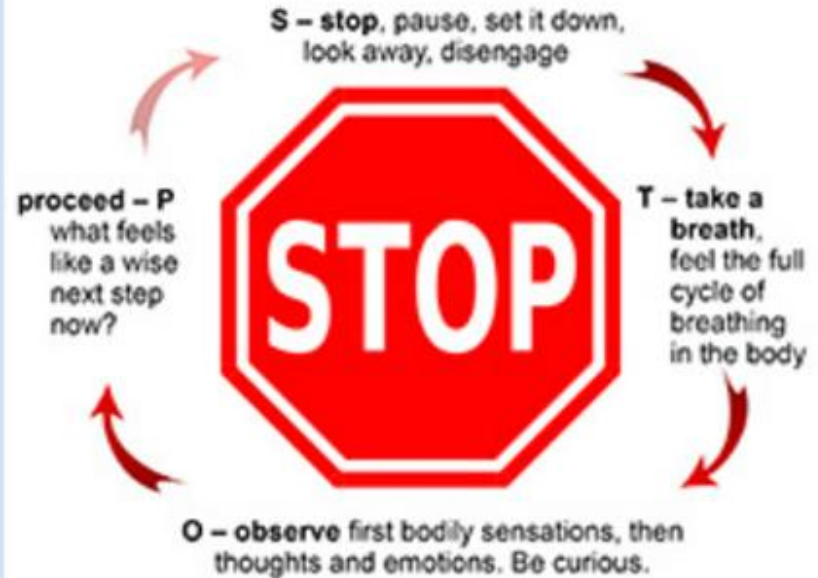


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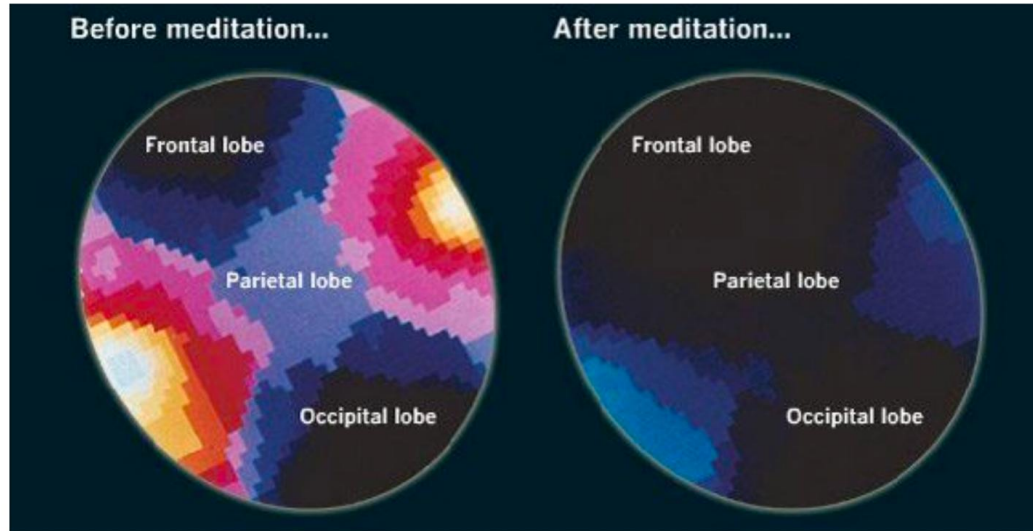
The STOP practice

*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

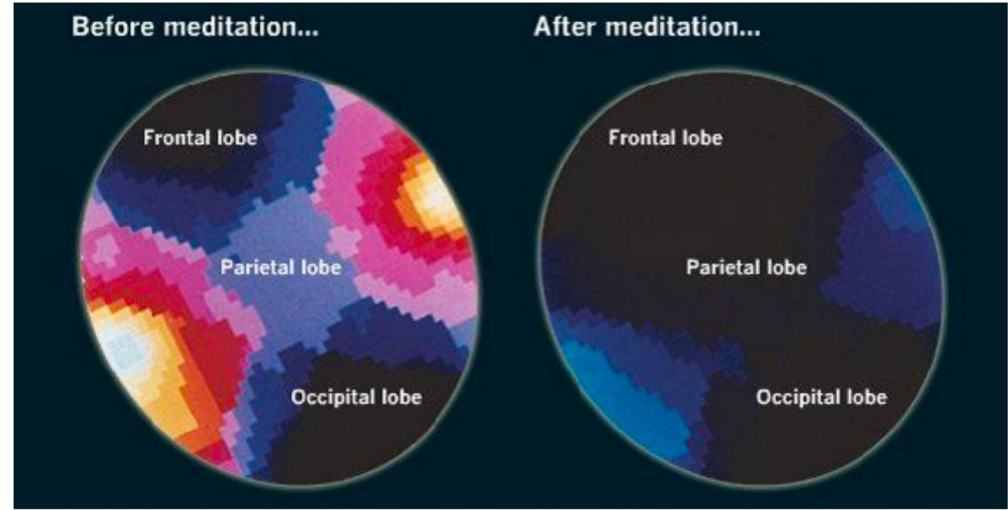


Why does this matter?

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>

How?

Pick 1 to Try

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.

6 Tips for Quick Stress Relief

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 to get help

when your stress interferes with your ability
to manage your daily activities

sleep | eat | work | socialize



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Effects of Prolonged Stress

Emotional	Physical
<ul style="list-style-type: none">■ Moodiness■ Irritability or short temper■ Agitation or inability to relax■ Feeling overwhelmed■ Sense of loneliness and isolation■ Depression or general unhappiness	<ul style="list-style-type: none">■ Aches and pains■ Diarrhea or constipation■ Chest pain, rapid heartbeat■ Loss of sex drive
Cognitive	Behavioral
<ul style="list-style-type: none">■ Memory problems■ Inability to concentrate■ Poor judgment■ Seeing only the negative■ Anxious or racing thoughts■ Constant worrying	<ul style="list-style-type: none">■ Eating more or less■ Sleeping too much or too little■ Isolating yourself from others■ Procrastinating or neglecting responsibilities■ Using alcohol, cigarettes, or drugs to relax■ Nervous habits (nail biting, pacing, etc.)

Resources



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Center for Grief, Recovery, & Therapeutic Services

www.griefcounselor.org

PsychologyToday.com

dougy.org | grief.com | nacg.org
lorenzoshouse.org

faith-based community | family doctor

What caregivers want others to know

“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.”

Additional Ideas & Tips 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'

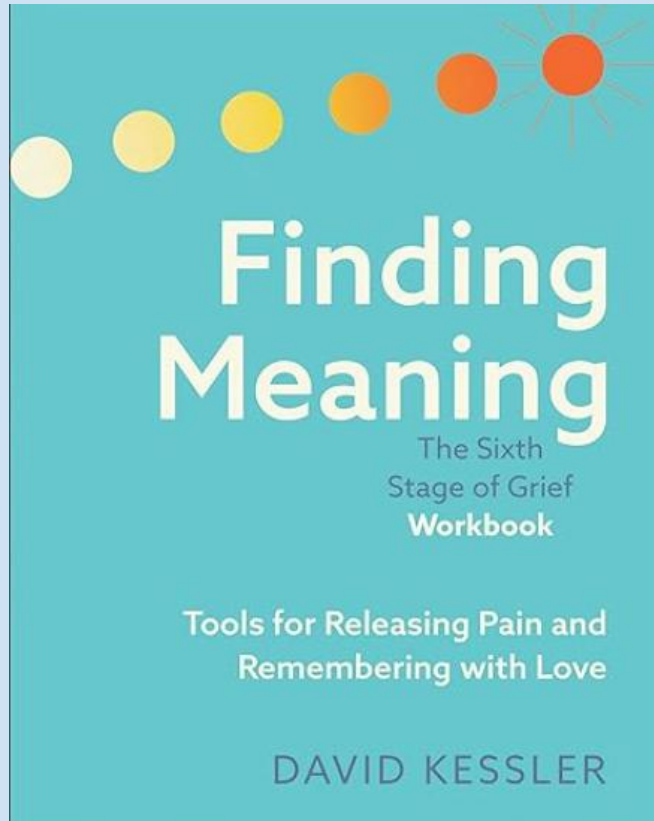
2. LEARN & GROW!

- **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!

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

Additional Ideas & Tips for Healthy Coping



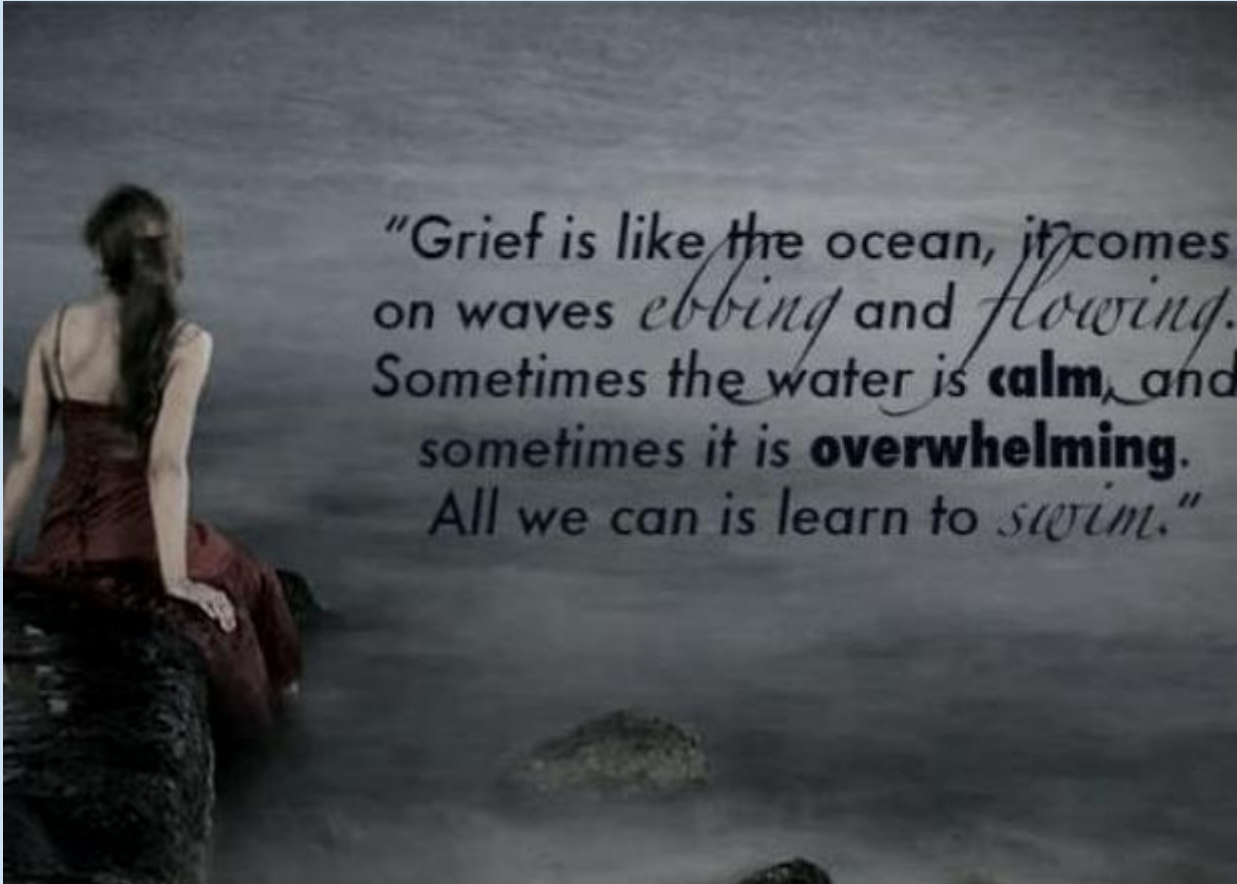
WORKBOOK:

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 woman with long dark hair, wearing a red dress, is seen from behind, sitting on a dark, wet rock. She is looking out at a vast, calm ocean under a grey, overcast sky. The water is dark and still, with a few small rocks visible in the foreground. The overall mood is contemplative and somber.

"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*."

Reflection



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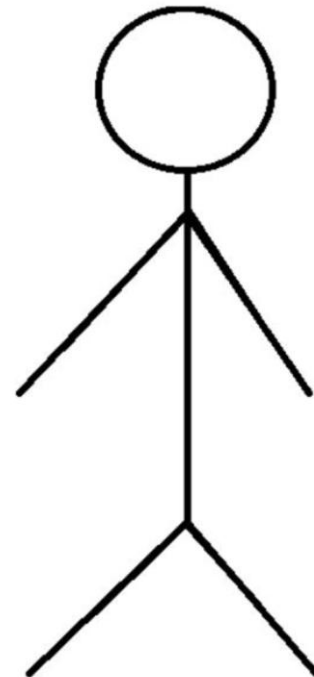
One thing you learned today



One word to describe how you feel



One thing you are going to try



Thank you!

Q/A

www.thememorycenter.uchicago.edu



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