Redefining Relationships, Family Dynamics & Grief in Dementia

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Land Acknowledgement



Plan

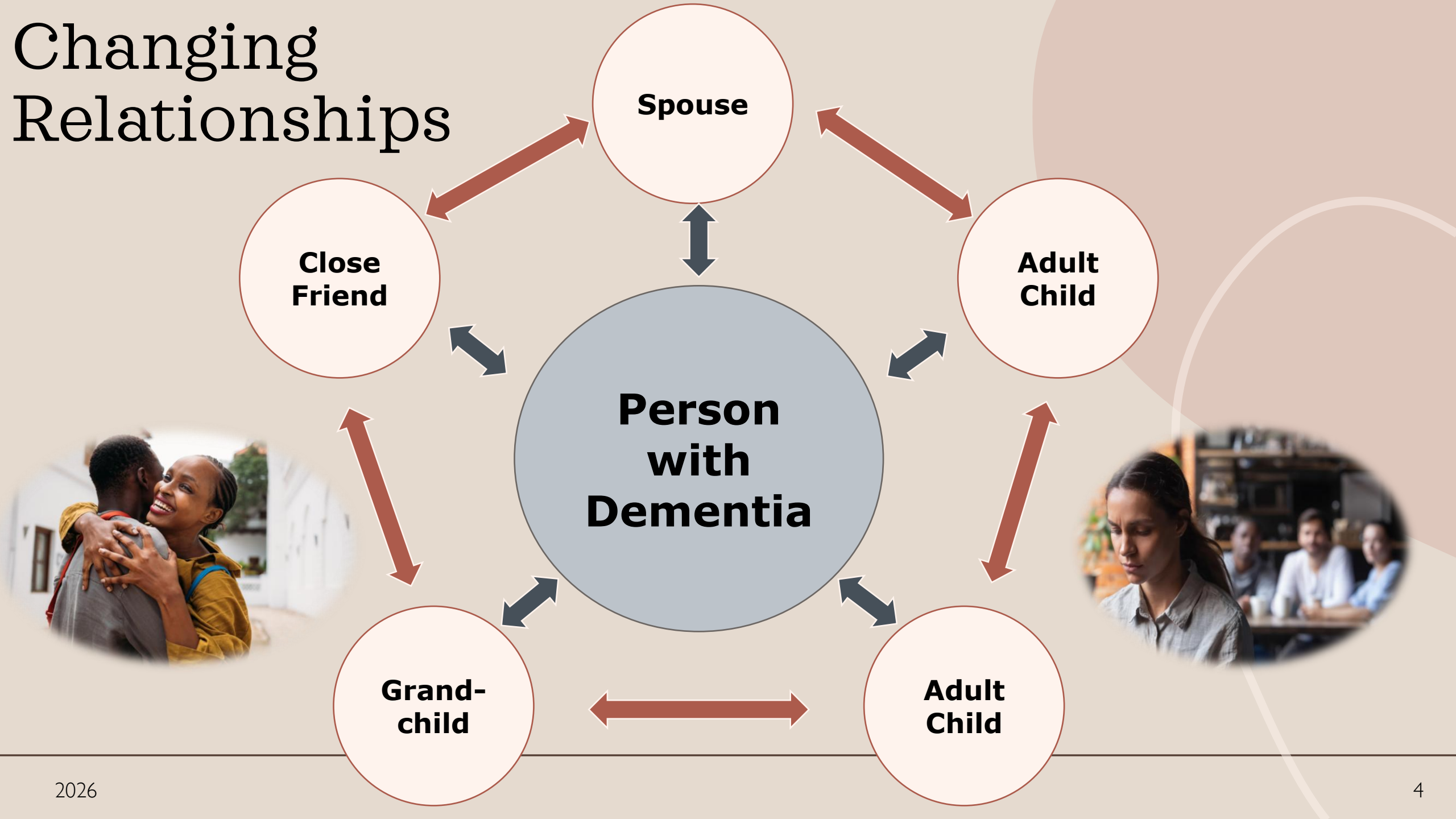
RELATIONSHIPS & DEMENTIA

- Role Changes
- Conflict
- Guilt & Grief

NAVIGATING CHANGING RELATIONSHIPS

- Making Meaning
- Social Support
- Effective Communication
- Thoughts & Beliefs
- Self-Care

Changing Relationships



New & Changing Roles

Spouse

Person with Dementia



Lover



Confidant



Partner & Collaborator



Support for daily activities



Support for medical needs



Decision-maker

New & Changing Roles

Adult Child

Person with Dementia



Confidant



Resource



Friend



Support for daily activities



Support for medical needs



Decision-maker

New & Changing Roles

Adult Child

Adult Child



Confidant



Friend

Acquaintance

Adversary



Care Coordinator



Decision-maker

Sources of Conflict



Inequality



Incompatible expectations

Communi-cation errors

Old roles & rivalries





Different values/ priorities



Heightened emotions



Insufficient resources



New Sources of Conflict

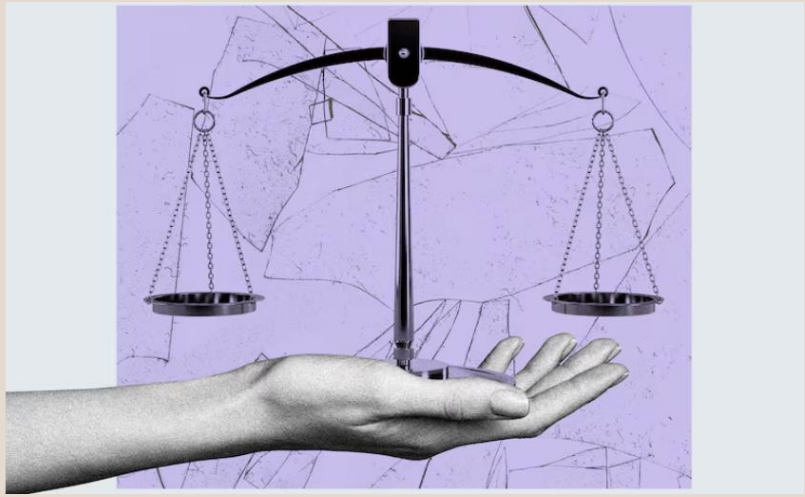
- Differing perceptions of the illness
- Unanticipated roles & responsibilities
- Longstanding tensions reignited
- Unequal/inconsistent ability to provide care
  - Location
  - Time
  - Resources
- Different ideas about what's "best"
  - Who decides?
- Lack of recognition for care provided
- Different emotional responses
  - **Guilt** vs Indifference
  - **Grief** vs Denial



The Primary vs. Peripheral Divide

On-Site Care Partner

Physical exhaustion
Direct exposure
Decision fatigue



Secondary or Remote Care Partners

Brief, pleasant visits
Delayed acceptance
Criticism without context

Guilt



Feeling that you’re not doing “enough”



Feeling like you’re neglecting other roles and relationships



Expressing anger, frustration, or resentment



Expecting to have control over things outside of your control



Taking breaks, pleasurable activities



Making reasonable decisions that go against the care-recipient’s wishes

What's Your Grief?

Ambiguous Grief

Person with dementia is physically present but mentally or emotionally different/absent

Compounded Grief

When one loss or change follows another

Anticipatory Grief

The present reaction to the losses that will occur in the future

Secondary Grief

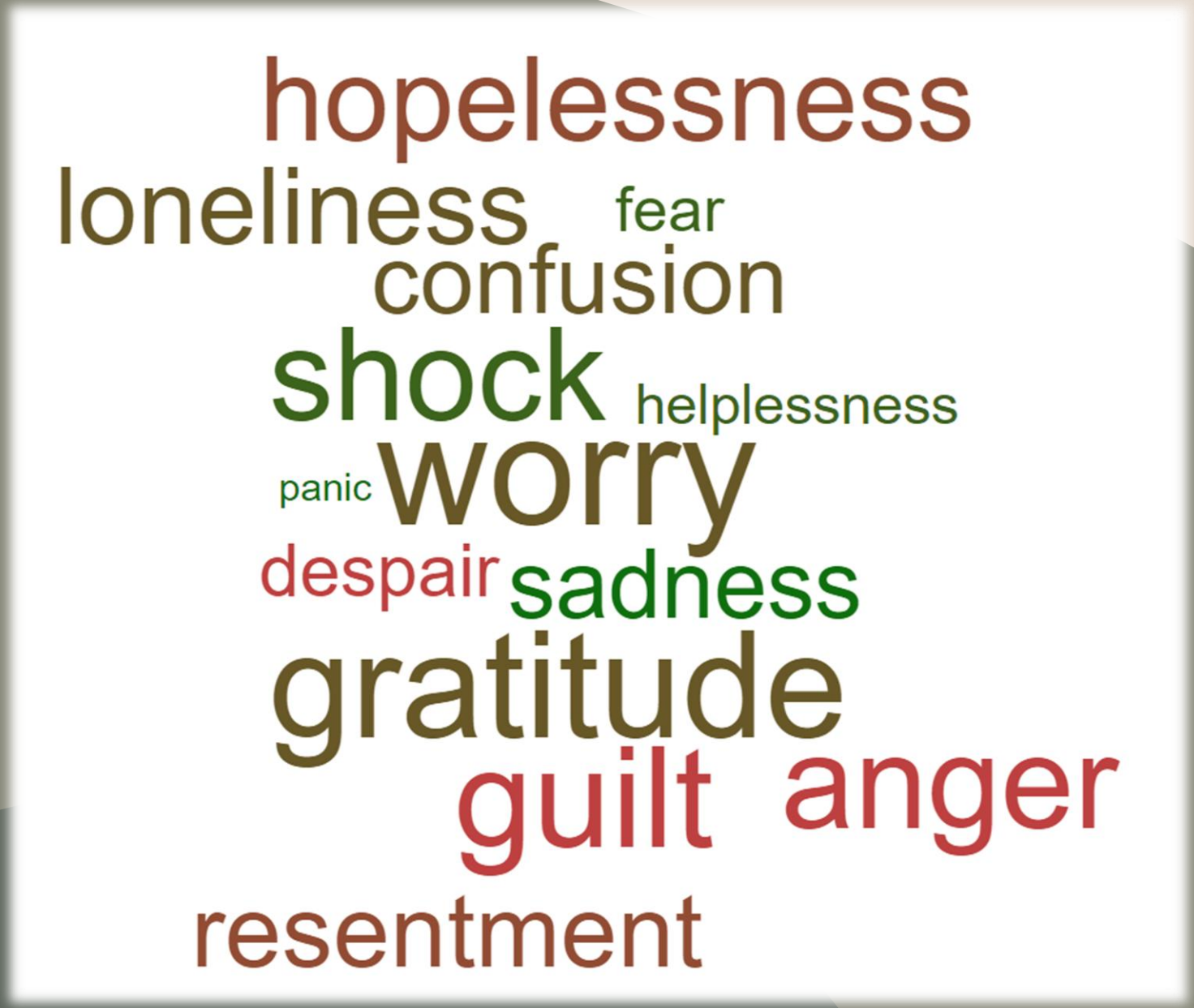
Additional losses that arise related to dementia

Disenfranchised Grief

Not acknowledged by society or by traditional social practices, thus minimizing the sadness experienced

Grief Emotions:

Not Just Sadness



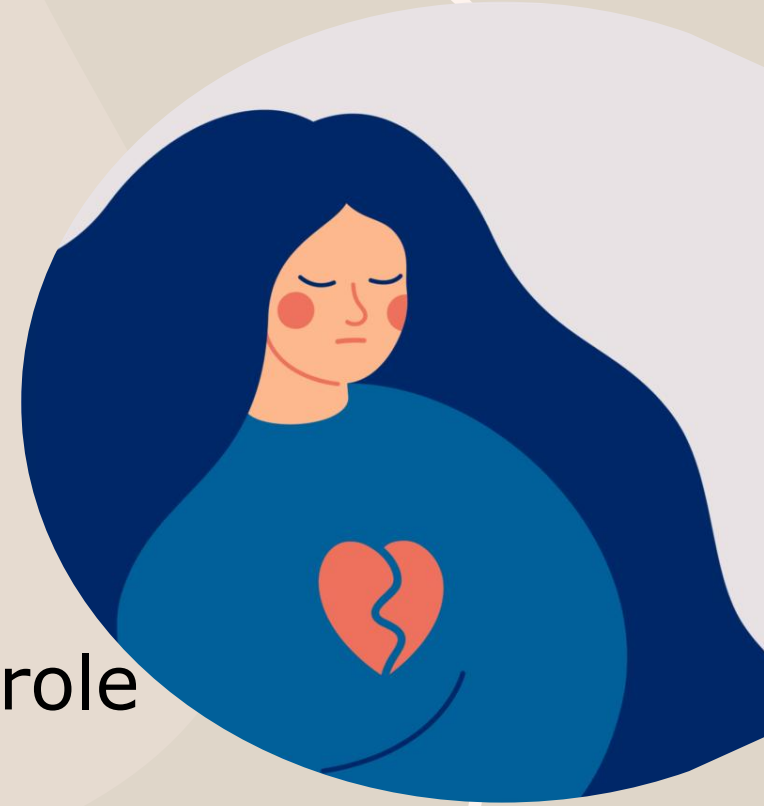
The Trajectory of Grief

- Ebb and flow in intensity
- "Stages" of grief aren't linear or predictable
- Return of previously "resolved" emotions is normal
- Progression of illness leads to new losses and renewed grief



What helps?

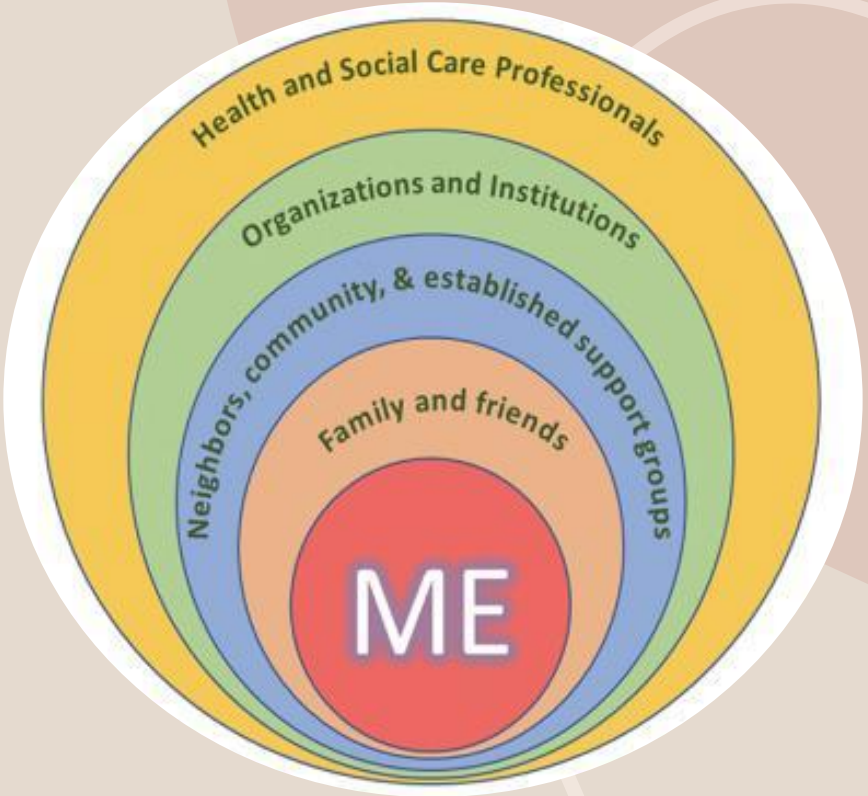
Finding Meaning



- Recognize and value growth as a person
  - New skills
  - More compassion
  - Inner strength, resilience
- Recognize and value the importance of the role
- Chance to give back, show love
- Making new memories
  - Continuing, but adapting family rituals

Increasing Social Support

- Practice direct communication with family and friends about how they can provide support
- Professional supports and support groups to fill in gaps from informal support network
- Redefining family boundaries and roles – who is in your "psychological family"?
- Use of respite time to nurture and build relationships - aim for predictable, regularly scheduled respite



Navigating Difficult Care Decisions

- Organize a structured family meeting with an **agenda**. Pick **one or two** specific issues to address.
- Identify the **shared core value** underneath the disagreement (e.g., safety, comfort, dignity).
- Rely on **objective data** (e.g., falls, incontinence, cooking accidents) to guide discussions and decisions.
- Take the burden off family members so no one is the ‘bad guy’ – rely on **objective professional assessments**.
- Seek consultation with a **neutral party** to mediate if you’re stuck.

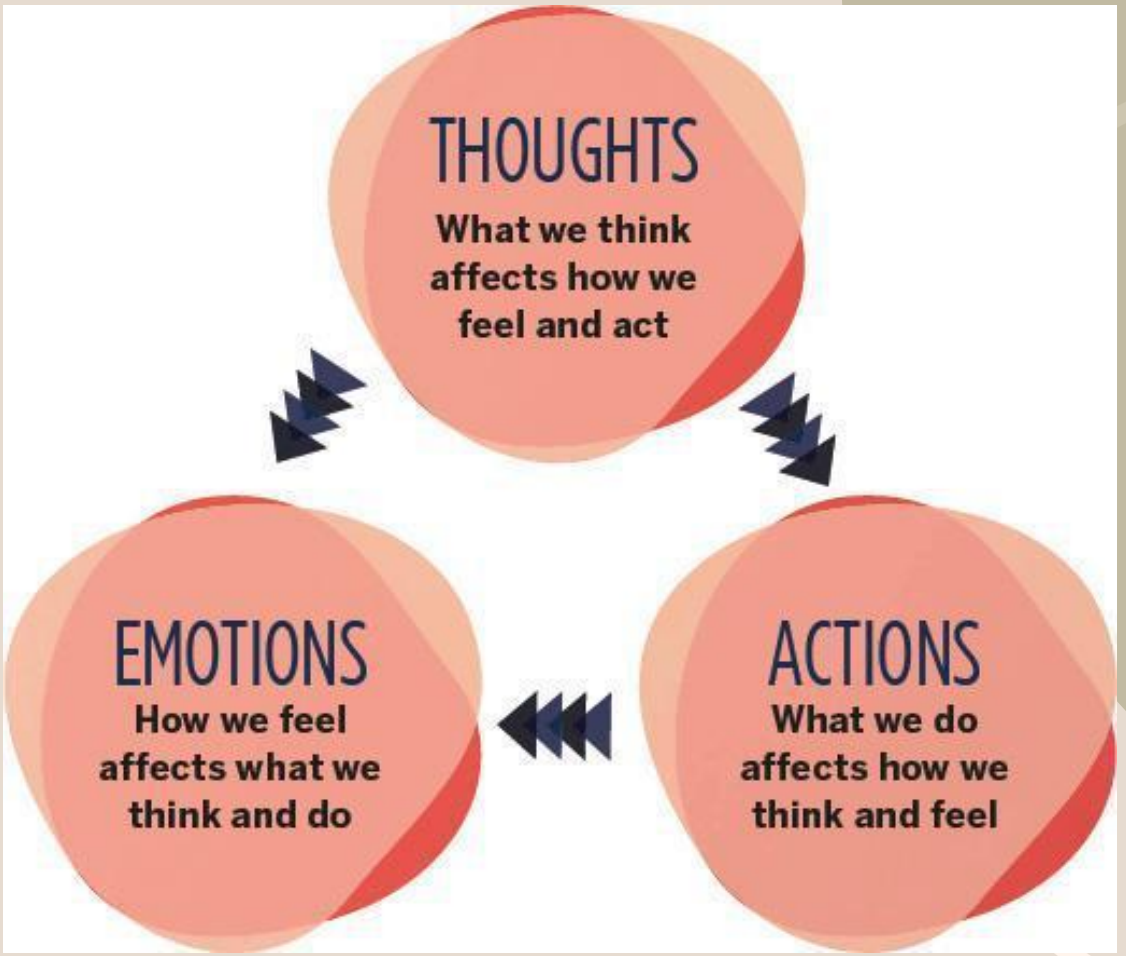
Approaches to Difficult Conversations

Active Listening	Listen for understanding rather than for formulating your response. Approach with a stance of **curiosity**.
Seek Compromise	Prioritize needs/wants (i.e., "pick your battles"). Aim for a stance of openness and **flexibility**. Focus on outcomes (e.g., safety). Identify a common goal.
Regulate Emotional Distress	Take a time out with a plan to come back. Use calming strategies to help regulate.
"I" Statements	"I feel _(emotion)_ when _(name specific behaviour)_." Avoid finger-pointing language (i.e., "you"). Focus on your experience.
Focus on Specific Behaviours	Focus on behaviours rather than intentions or traits. Use recent, concrete examples. Avoid over-generalizing and mind-reading.

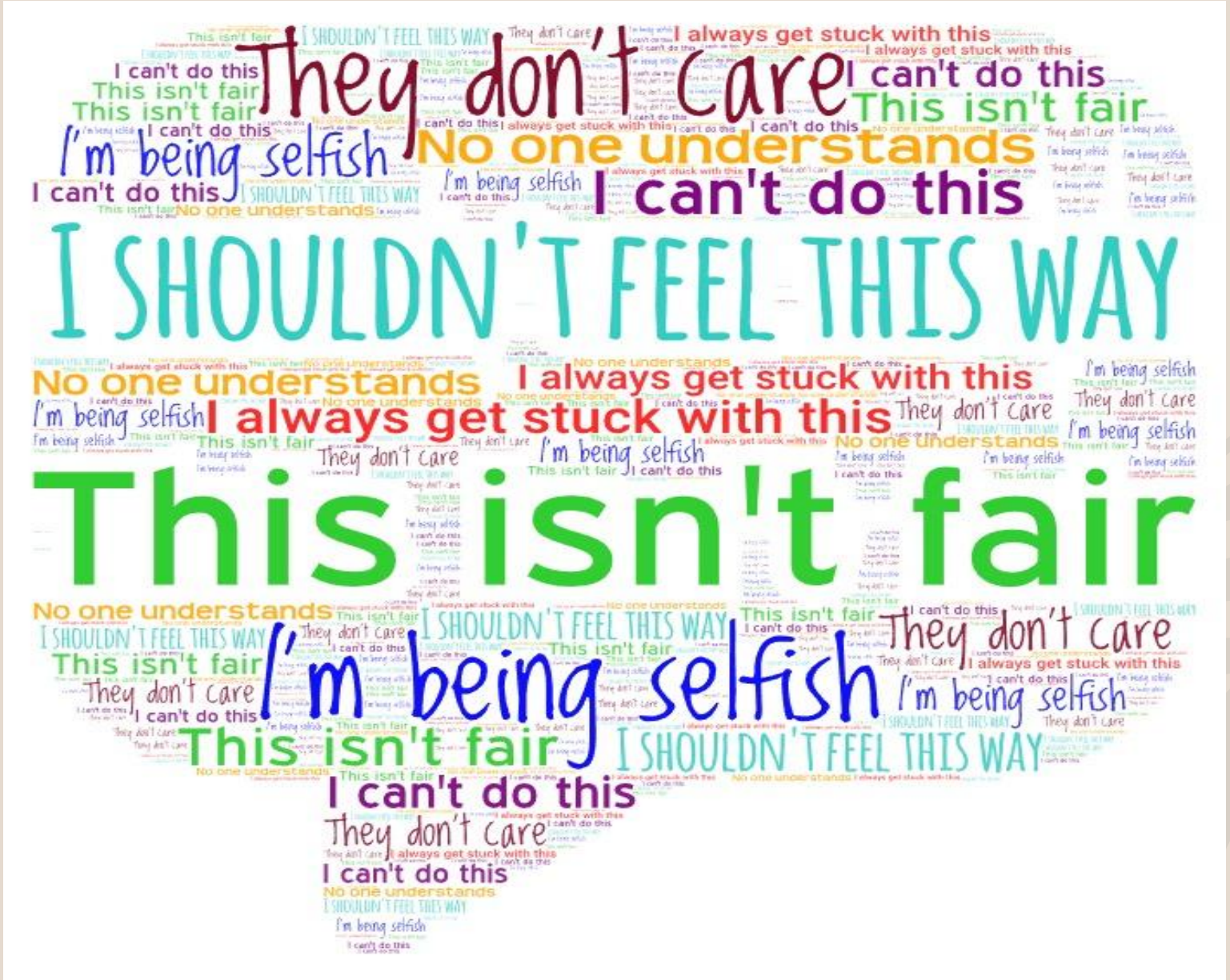
Words that Work

Instead of …. (Triggers Defensiveness)	Try… (Focuses on Collaboration & Safety)
"You have no idea how bad Mom actually is."	"She rallies for calls. Come spend a full morning with her so we can compare notes."
"If you're not going to help, stop giving advice."	"Advice adds pressure right now. What I need is someone to take her to appointments.”
"You're never here so you don't get a say in how we run things"	"We need your involvement. These are the areas you can coordinate from a distance."
"You promised we'd never put Dad in a home"	"Placement isn't abandoning him—it lets professionals handle safety so we can be his kids again."

Thoughts and Perspective Matter



Watch out for **overly negative**, **black-and white**, **self-critical**, **unrealistic**, or **unhelpful** thoughts that contribute to additional distress



Ask Yourself

- Are my expectations **realistic**?
- Is there another, more **helpful**, way to look at this situation?
- Am I **100%** sure that this thought is true **all of the time**?
- Am I **leaving out** information when I think about this situation?
- What would I say to **my best friend** if they thought the same thing?

From Either/Or to **Both/And** Thinking

I can be BOTH a wife	AND a caregiver
I don't want to move Mom out of her home	AND the care she needs can't be provided at home
I hate that I have to live this way	AND I am proud of the care I am providing
I BOTH can't wait for this to be over	AND I don't want to say good-bye

I BOTH miss the freedom I used to have	AND I appreciate time to myself even more now
I BOTH wish they could help more	AND I can find other sources of help
I am BOTH capable	AND need support
I'm afraid for the future	AND I believe I can cope with what's ahead

Self-Care



PHYSICAL

Sleep
Medical appointments
Exercise
Nutrition



EMOTIONAL

Self-compassion
Pacing of emotional work
Pursuing pleasurable activities



SOCIAL

Support groups
Time with friends/family
Recreation classes



SPIRITUAL

Meditation
Prayer
Time in nature
Inspirational literature

Allow Difficult Emotions

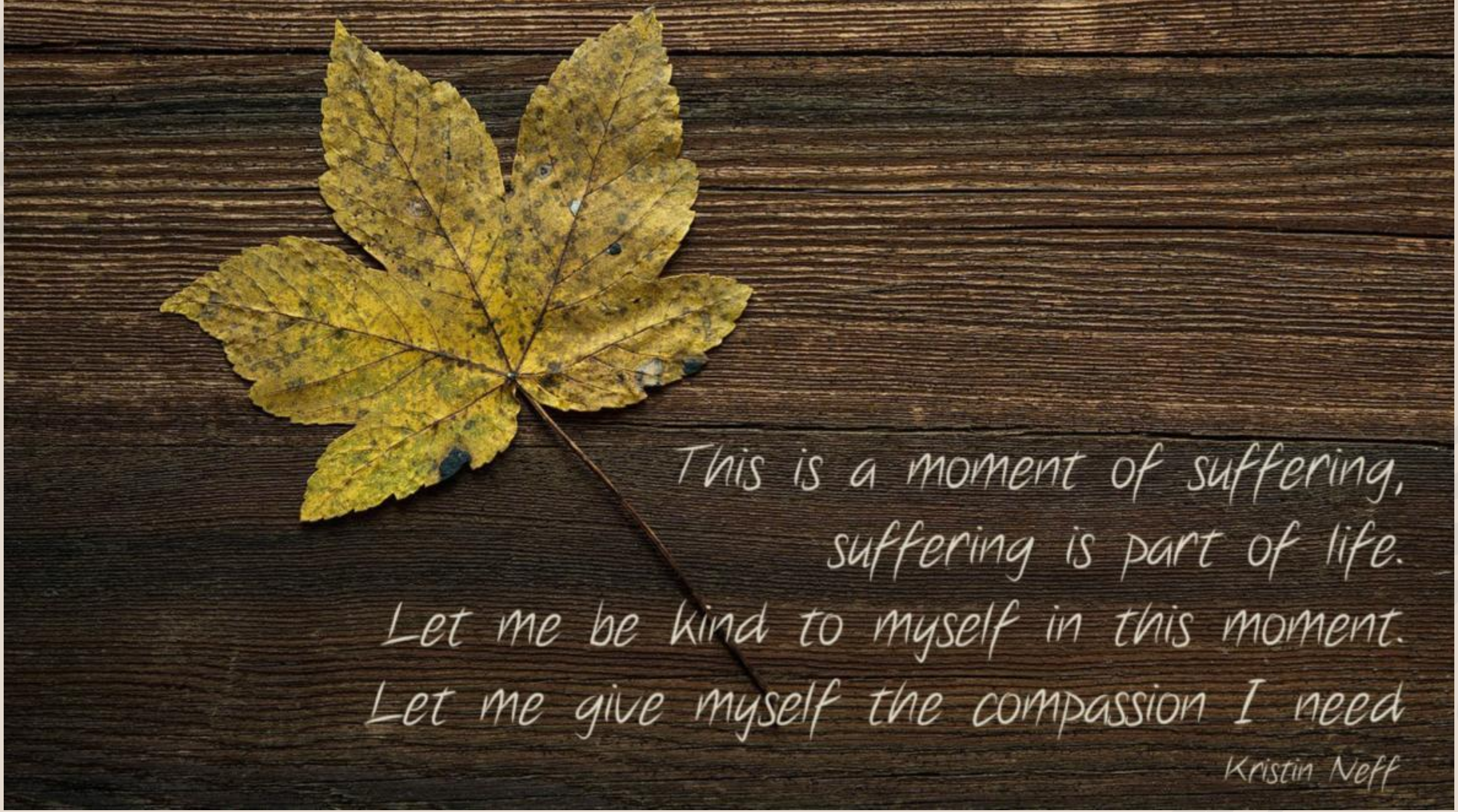
Work on **noticing** uncomfortable feelings, **labeling** them, and honouring them as valid

Make time and space to feel difficult feelings – try not to change them, talk yourself out of them, or get rid of them

Express feelings by talking about them, journaling, or through creative/artistic outlets

Do things that matter to you (e.g., self-care) ***while*** experiencing difficult emotions (e.g., guilt)




This is a moment of suffering,
suffering is part of life.
Let me be kind to myself in this moment.
Let me give myself the compassion I need
Kristin Neff

Nurture Other Roles

- Give yourself permission to identify as more than a caregiver
  - Parent, friend, sibling, teammate, colleague
  - Both/And
- Engage with activities of other roles
- Spend time with co-caregivers that is not focused on caregiving tasks/discussions



Thank you

Questions?

