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Ambiguous and Anticipatory Grief:

How to Grieve the Loss of the Living and the Unknown Future

Hollie Glover, MA, LPC, NCC



- ▶ Hollie Glover, is a Licensed Professional Counselor, who works for the James L. West Center for Dementia Care in Fort Worth. She is the Director of Education and Family Support Services. She facilitates the center's family support groups and is involved in many of the numerous education services provided by the center.
- ▶ Hollie is a Dementia Care Specialist and Certified Grief Counseling Specialist. She has over twenty-eight years of experience in education and working with people of all ages. She has degrees from Southwestern Oklahoma State University, Sam Houston State University, and Dallas Baptist University. She also attended Southwestern Theological Seminary to obtain hours in theology.
- ▶ Hollie has been recognized as a national and statewide speaker on topics such as Dementia, Hospice, Grief, Loss, and Bereavement as well as Professional and Caregiver Stress. One of the highlights of her career includes getting to meet and speak before First Lady Rosalynn Carter and Senator Elizabeth Dole. She has also written a therapy to be used with patients at the end of life, that focuses on the individual needs of the person and their family.
- ▶ Her passion is educating the public and helping families who have a loved one diagnosed with dementia.
- ▶ Hollie is married and has one daughter who is following in her footsteps. Joanna graduated from the University of Texas at Arlington in August of 2020 with her Master's degree in Social Work, specializing in hospice care.

Course Objectives:

1

This course will discuss Ambiguous and Anticipatory Grief and the impact it has on individuals.

2

Define Ambiguous and Anticipatory Grief, specifically how it relates to families with a dementia diagnosis.

3

Review grief, loss, and bereavement.

4

Discuss ways to overcome Ambiguous and Anticipatory Grief.

5

Examine the emotional impact of Ambiguous and Anticipatory Grief.



GRIEF

- ▶ Grief is the loss of something or someone. It is a natural emotion.
- ▶ We generally associate grief with death.
- ▶ We grieve many things such as job loss, divorce, relationships, dreams, etc.
- ▶ Grief is different from sadness. Sadness is feeling sorrow or being unhappy. Grief is a dull ache that shows up when we least expect it and takes over our emotional well-being.
- ▶ Tears often take the place of words with grief. They are an act of love



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LOSS

- ▶ The fact of losing something or someone
- ▶ Physical, emotional, or economical harm or damage
- ▶ Losing possession of something
- ▶ Deprivation from separation



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BEREAVEMENT

- ▶ The action or condition of loss
- ▶ A period of mourning
- ▶ A time of intense grief
- ▶ A process where one is deprived of someone or something
- ▶ Normal process after a loss



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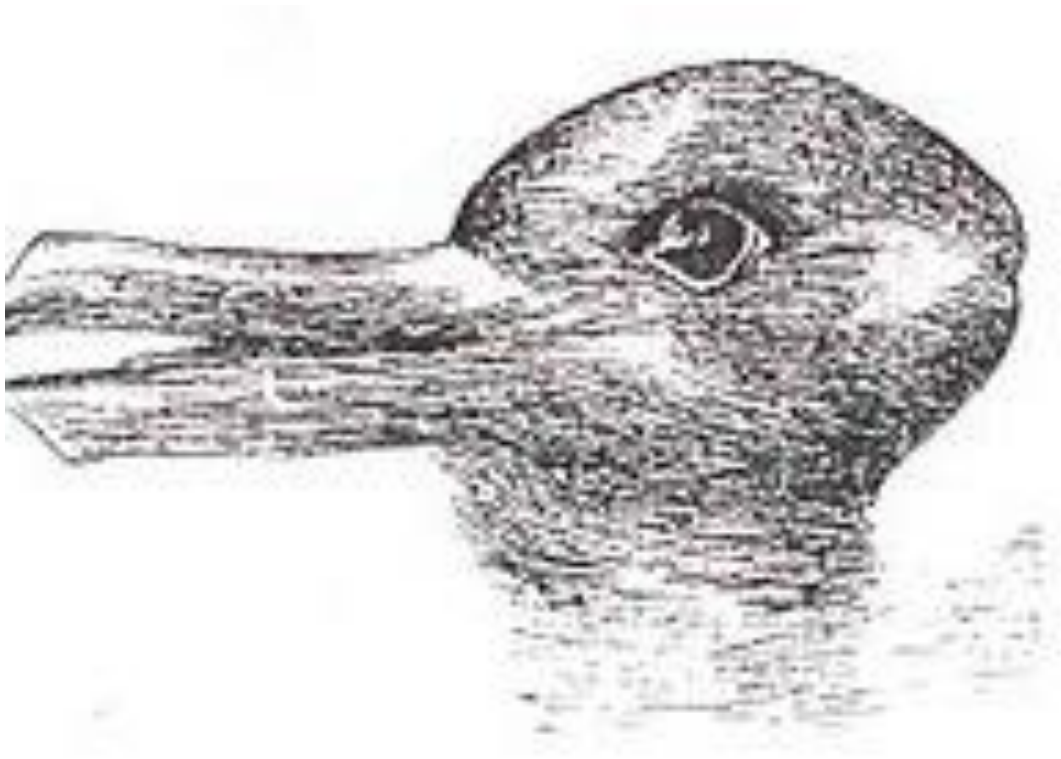
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THERE IS NOTHING MORE
DIFFICULT THAN GRIEVING
THE LOSS OF A LOVED ONE WHO
IS STILL ALIVE.



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What is Ambiguous Grief?



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- ▶ **Ambiguity:** the quality of being open to more than one interpretation/having a double meaning
- ▶ **Ambiguous Grief:** a loss without finality which leaves us disoriented and not understanding the loss or how to move forward. We are left with many unanswered questions and a changed relationship.



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You Have Experienced a Significant Relationship Loss

- ▶ The person you are losing is still alive.
- ▶ Divorce
- ▶ Infertility
- ▶ Mental Health Issues
- ▶ Addiction
- ▶ Desertion
- ▶ Missing Person (MIA)
- ▶ Dementia
- ▶ Without a physical death, we can become consumed thinking that life might return to normal. **We don't have the closure we might have in other situations.**

You Have a Sense of Shame or Embarrassment Over Your Loss

- ▶ Ambiguous grief is born from an event such as a divorce or a **diagnosis**.
- ▶ The loss can feel like a **personal failure**, or it might carry a **perceived stigma**. We may start to blame ourselves and wonder what we could have done to prevent it. **Our brain searches for logical answers to the illogical.** We can become frozen in place.
- ▶ *This is a normal reaction to an abnormal situation.*
- ▶ This can prevent us from feeling comfortable sharing the news with others.
- ▶ Examples: a parent embarrassed that their child is an addict, a wife ashamed of her husband's affair, a husband embarrassed over his wife's Alzheimer's Diagnosis and his inability to care for her.

You Haven't Acknowledged the Pain Publicly

- ▶ When a loved one is lost to death, there is an understanding, and we know what to do. (bring food, send flowers, etc.)
- ▶ **After a death we reorganize family roles, and somebody takes over what the deceased used to do. But we now must do that, and they are still alive.**
- ▶ During ambiguous grief we might not even know how to talk about what we are feeling, therefore, we receive no support.
- ▶ Some families go so far as to say, “family matters are private” and won't allow conversations about what they are experiencing.
- ▶ We are preventing others from helping, supporting, and encouraging us to help promote our healing.



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List of Roles

- Friend
- Gardener
- Parent
- Business partner
- Provider
- Listener
- Mechanic
- Companion
- Playmate
- Child
- Spouse
- Bill Payer
- Cook
- Lover
- Tax preparer
- Driver
- Handyman
- Confidant
- Stabilizer
- _____
- _____
- _____



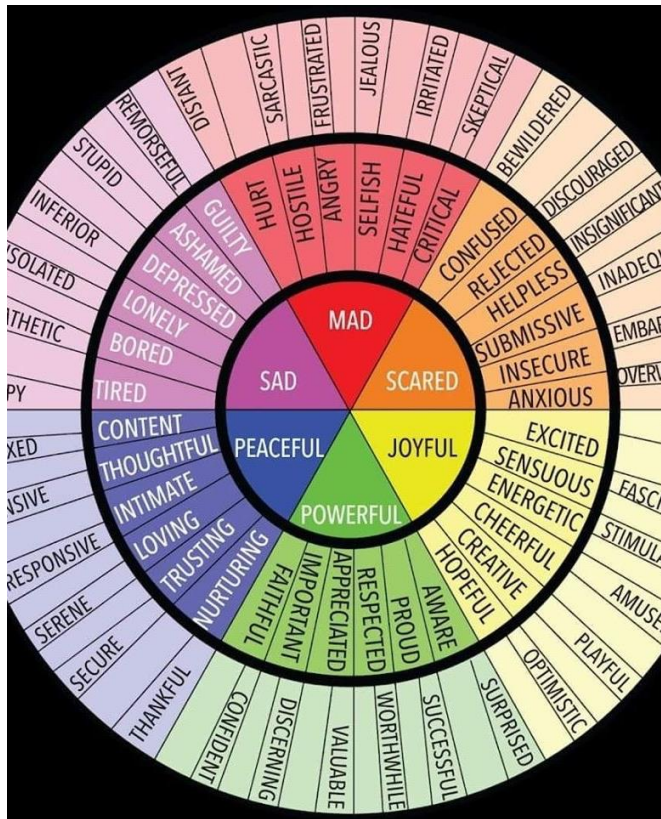
It's Okay, to not be Okay.



- ▶ Give yourself permission to grieve the loss of the person and the relationship. It is alright to grieve someone who is still living.
- ▶ Grieving is moving forward through feelings.



What You Can Do About It



- ▶ **Name it to tame it.** Being able to identify and name this grief is the first step in healing. Realizing that your emotional relationship doesn't end. Replaying events delays the healing process and prolongs grieving. *Work on saying the words: "Our relationship has changed. It is a real and permanent change. They are not going to snap out of it or come back like they were."*
- ▶ **Find support for yourself.** Connect with others who can relate. A therapist, friends, clergy, support groups, etc. are great resources. There are many online forums dedicated to grieving caregivers as well. One of the worst things we can do is isolate ourselves. (www.grieving.com)



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What You Can Do About It



- ▶ **Take care of yourself physically.** It is common to develop depression, anxiety, phobias, negative expectations, and other health issues. See your doctor and explain what you are going through.
- ▶ **Tap into a positive emotion.** Find a ritual that brings you pleasure and do it each day. It will give you **something to look forward to**. It can be a song, a smell, a feeling, **something sensory** that makes you feel good will help ground you.
- ▶ **Connect with your Higher Power.** Create a daily meditation or prayer time.



What You Can Do About It

- ▶ **Write a letter of release.** Say goodbye, to the relationship that was, through words and release it to God, the Universe, your Higher Power, etc.
- ▶ **Build your resilience.** Begin a daily gratitude list. Think of 3 things you did well during the day. This can take less than two minutes to do. It will help you measure your growth to see how far you've come in your grief.



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Moving Forward

- ▶ Ambiguous grief takes time to work through. There is NO timeline.
- ▶ You will emotionally distance yourself from the unanswered questions.
- ▶ The only way to move forward is to feel the hard feelings and replace the need to understand with a commitment to move forward.



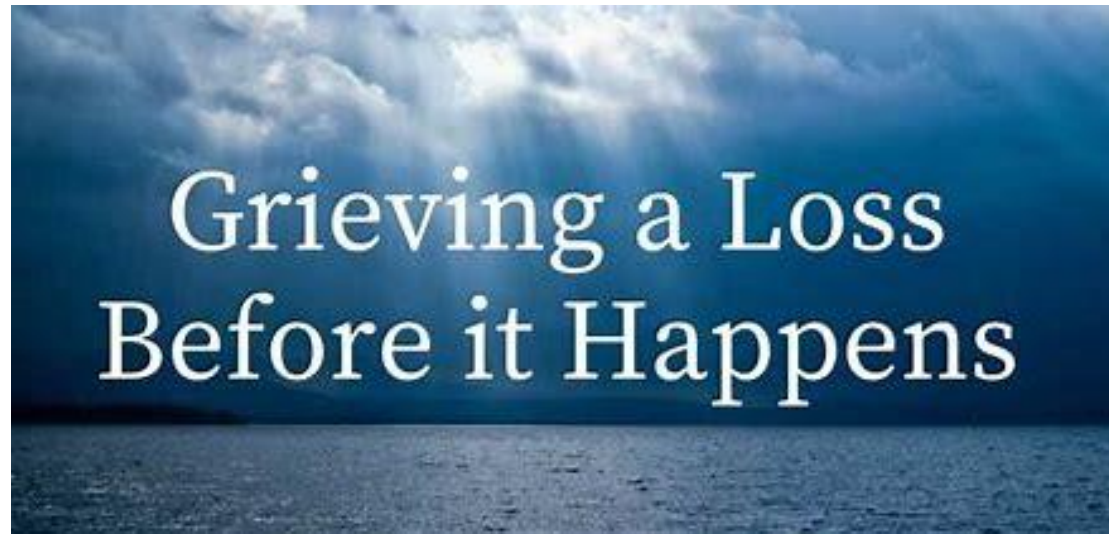
Moving Forward



- ▶ **Celebrate what remains.** **Be open to a new type of relationship.** Learn to embrace happy/sad. There are silver linings. Look for what they can still do. They may even start doing something like art that you never knew they could do. The present doesn't override the past.
- ▶ **Understand the illness isn't the person.** Understanding their illness can help you divert some of your angry feelings.
- ▶ **Find meaning in what you are experiencing.** You may meet new people, grow closer to friends and/or family, discover things about yourself. Develop a skill set you never new you had. It allows us to make sense of and use our pain in a way that helps us and others cope.



What is Anticipatory Grief?



- ▶ Grieving that occurs prior to the actual loss
- ▶ The total set of cognitive, cultural, and social reactions to expected death
- ▶ The unconscious process of “letting go” and having closure before the loss occurs
- ▶ Absorbing the loss gradually and beginning to prepare for the inevitable
- ▶ Common in those facing the eventual death of a loved one OR their own death



Why don't we talk about it?



- ▶ Most people are familiar with grief after a death (conventional grief)
- ▶ Some people are hesitant to express the deep pain experienced before the death
- ▶ Therefore, they don't receive the support they need



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How does it differ from Conventional Grief?

- ▶ It involves more anger
- ▶ More loss of emotional control
- ▶ More atypical grief responses (intense sorrow, numbness, bitterness, lack of trust, etc.)
- ▶ In-between balancing act of “holding on” and “letting go”
- ▶ 40% of women in a study said that Anticipatory Grief was worse than the post-loss grief
www.verywellhealth.com



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What are the Symptoms of Anticipatory Grief?

- ▶ Grief refers to the reactions that we experience when loss upsets the usual routine of our life
- ▶ They are physical, behavioral, psychological (cognitive and emotional), social, and spiritual.

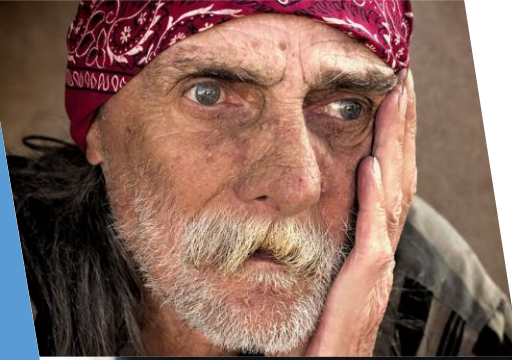


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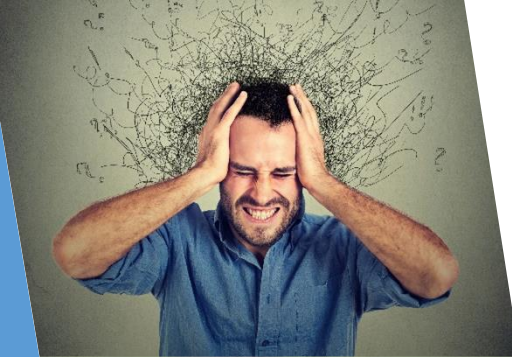
Symptoms of Anticipatory Grief

- ▶ **Sadness/Tearfulness**: can happen rapidly and often unexpectedly it is allowing grief to help prepare for the loss
- ▶ **Fear/Anger/Irritability**: Educate yourself on what is happening
- ▶ **Loneliness/Depression**: many people don't talk about loneliness, because they fear others won't understand, since their loved one is still alive. If you don't talk to someone and be proactive this can lead to social withdrawal and emotional numbness to protect your pain.
- ▶ **Resentment**: which can lead to guilt. Enlist help BUT continue to live your life.



More Symptoms

- ▶ **Anxiety:** When caring for someone who is dying you live in a heightened state of anxiety all the time. This can cause physical symptoms such as palpitations and shaking or tremors.
- ▶ **Guilt:** You may be wishing they would pass so their (and your) suffering/pain will be over
- ▶ **Survivor Guilt:** guilt that you will be able to continue with your life while they won't
- ▶ **Heightened Concern:** You may find yourself extremely concerned about their emotional, physical, or spiritual issues.



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More Symptoms

- ▶ **Rehearsal of the Death:** You may visualize what life will be like when they are gone. You may feel guilty about this, but it *is very normal and part of accepting the inevitably of death.*
- ▶ **Physical Problems:** Sleep difficulty, memory problems, muscle aches and pains, etc.
- ▶ **Fear of Loss:** Fears about what the future will hold and who will take care of you



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Benefits of Anticipatory Grief

- ▶ Chance for important conversations
- ▶ Time for forgiveness and quality time
- ▶ Ability to “let go” of guilt and anger and find closure
- ▶ Make plans for the future
- ▶ Leave a legacy and create moments that family and friends can enjoy



Unfinished Business

- ▶ Unfinished business is not only writing a will and other matters of an estate, but also being able to express appreciations and disappointments. Saying what needs to be said before they die.
- ▶ It is very beneficial to everyone concerned to “make peace” with the person passing. Otherwise, the survivors will deal with regrets once the loved one has passed.
- ▶ Families often need encouragement and permission to do this.



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Anticipatory Grief in the Patient

- ▶ People who are dying experience anticipatory grief as well.
- ▶ They are working through a type of separation anxiety. They are losing all their relationships at the same time, rather than just one, like the survivors are going through.
- ▶ It can be overwhelming, and many times patients will withdraw and face the wall in order to try and cope with the impact of their loss.
- ▶ It can also allow for meaning and closure.





Does it Help Grieving Later On?

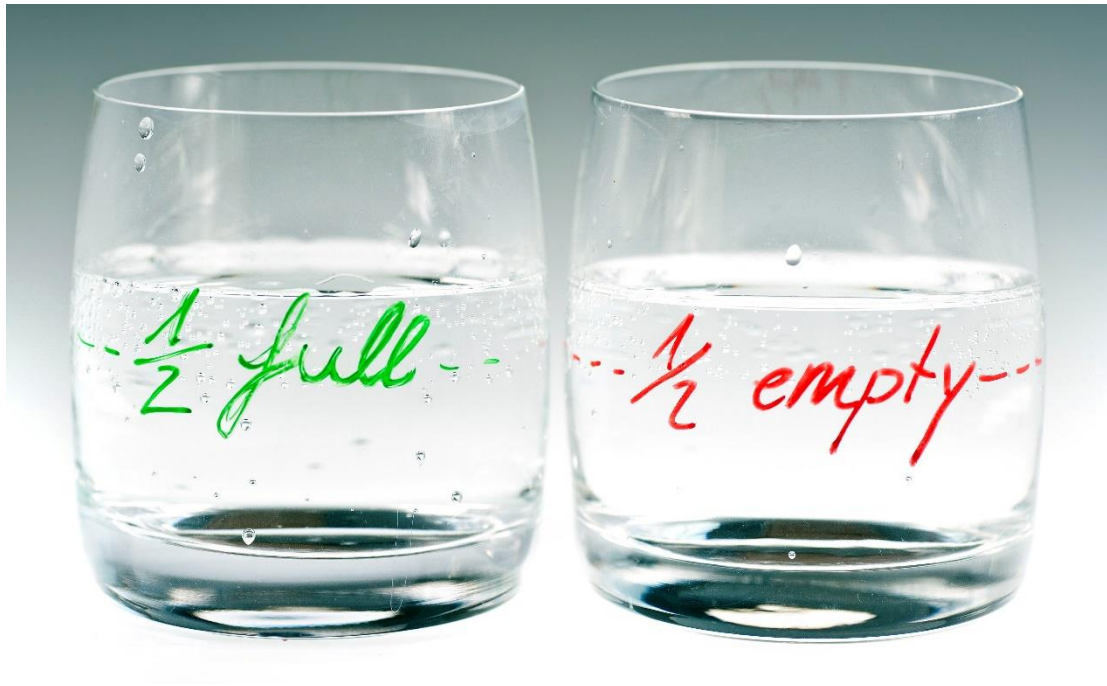
- ▶ Grief before death does not take the place of grief after death.
- ▶ It doesn't shorten the grieving process after the death occurs.
- ▶ Even when one experiences Anticipatory Grief, nothing really prepares you for the actual death.
- ▶ It isn't a substitute for other grief, BUT it does provide for closure that a sudden death does not.



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5 Ways to Cope with Anticipatory Grief



- ▶ 1. Attempting to understand and assess what is happening OR trying to reframe the situation. Viewing the glass as half full rather than half empty. The focus is on what one still has and what can be done with the time available.
 - ▶ Using techniques such as journaling, guided imagery, meditation, art therapy, massage therapy, music, etc.
 - ▶ Spend meaningful time with your loved one. Go through photos, tell stories, laugh, reminisce, cry, etc.



5 Ways to Cope with Anticipatory Grief



viewing purposes only.

- ▶ 2. Trying to do something about the loss. Trying nontraditional methods of medicine, seeking the opinion of another physician, etc. Looking for outside assistance.



5 Ways to Cope with Anticipatory Grief



- ▶ 3. Trying to control one's own reactions to the situation. Looking for meaning and turning to sources of religious or spiritual consolation. Making efforts to heal estrangements, leaving legacies, settling estates, planning the funeral, doing a life review, and saying good-bye.
 - ▶ Nurture your spirituality. This is different for everyone. It may mean organized religion and prayer, meditation, communing with nature, or listening to meaningful music.
 - ▶ Research shows that people who are dying experience a better quality of life in the last days if they have an active spiritual life.



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5 Ways to Cope with Anticipatory Grief



- ▶ 4. Counseling and/or Support Groups: Seek help from a Mental Health Professional if you find yourself having difficulty coping. You may be suffering from “complicated grief.”
 - ▶ Complicated grief happens when the usual responses to the death of a loved one do not fade over time and impair or prevent one from leading their normal life. It can include episodes of rage, an inability to focus on anything but the death, excessive avoidance of others, intense emptiness, problems accepting the reality of the death, self-destructive behavior, and/or suicidal thoughts or actions.



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5 Ways to Cope with Anticipatory Grief

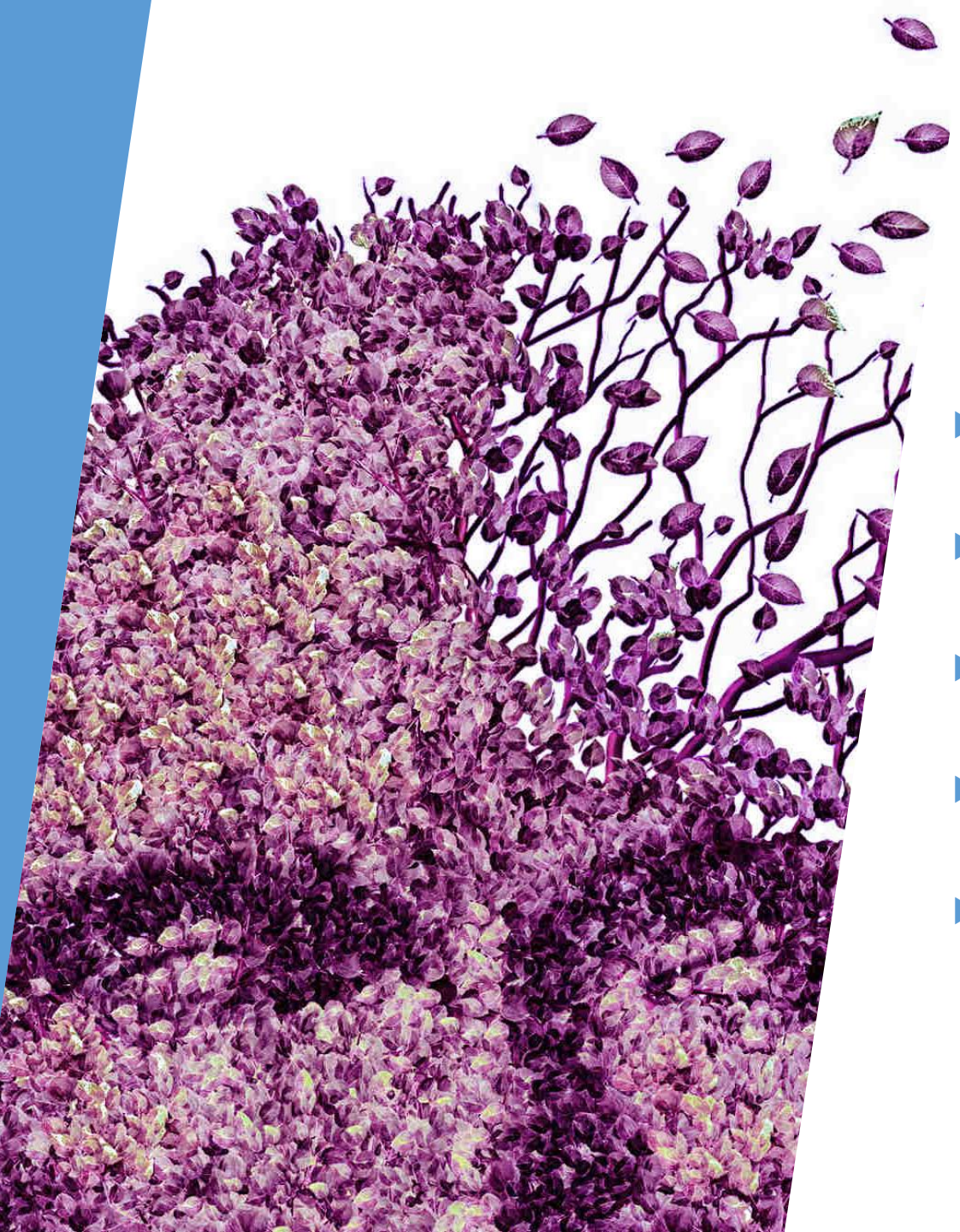


- ▶ 5. Give Your Loved One Permission to Die and Practice Forgiveness
 - ▶ Forgiveness is healing
 - ▶ Forgiving yourself is just as important as forgiving others
 - ▶ Resolve differences
 - ▶ Listen: is it important to love or to be right?
 - ▶ **Resentment is a poison you prepare for another and drink yourself.**
 - ▶ Letting go of resentment and hurt is freeing.
 - ▶ It's not uncommon for someone to hang on until they are given permission to go.



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Reality of Dementia

- ▶ She/he is both gone and still here.
- ▶ I take care of both him/her and myself.
- ▶ I am both a caregiver and a person with my own needs.
- ▶ I both wish it was over and wish that my loved one keeps on living.
- ▶ I am both sad about my lost hopes and dreams and happy about some new hopes and dreams.



Summary

- ▶ Talking about ambiguous and anticipatory grief can be very difficult and exhausting, but we can help ease the pain of both by simply acknowledging them in ourselves and others.
- ▶ These types of grief are things we will all go through in our own way and in our own time.
- ▶ Don't underestimate how you will be affected.
- ▶ Give yourself permission to grieve at your pace.
- ▶ You will never forget the sacred time you spend with someone as they transition from this life to the next.



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James L. West is a faith inspired, not-for-profit organization serving persons impacted by dementia. As a trusted expert, we provide personalized, innovative care and support for families, as well as specialized education for caregivers, healthcare professionals and the community at large.

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