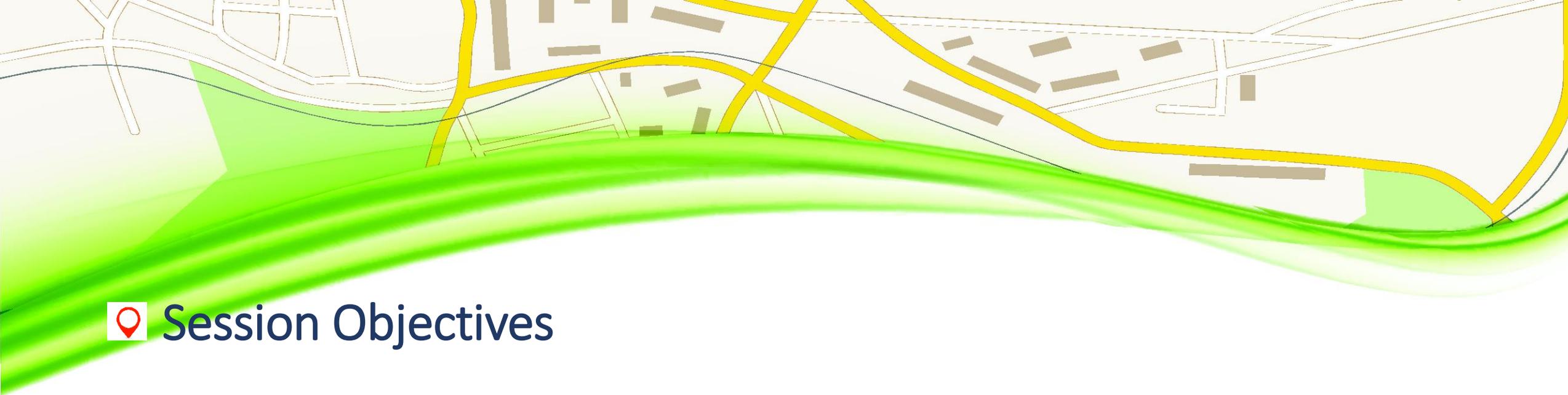




Ambiguous Loss: Living with Uncertainty

Alzheimer's – Patient & Caregiver Perspectives



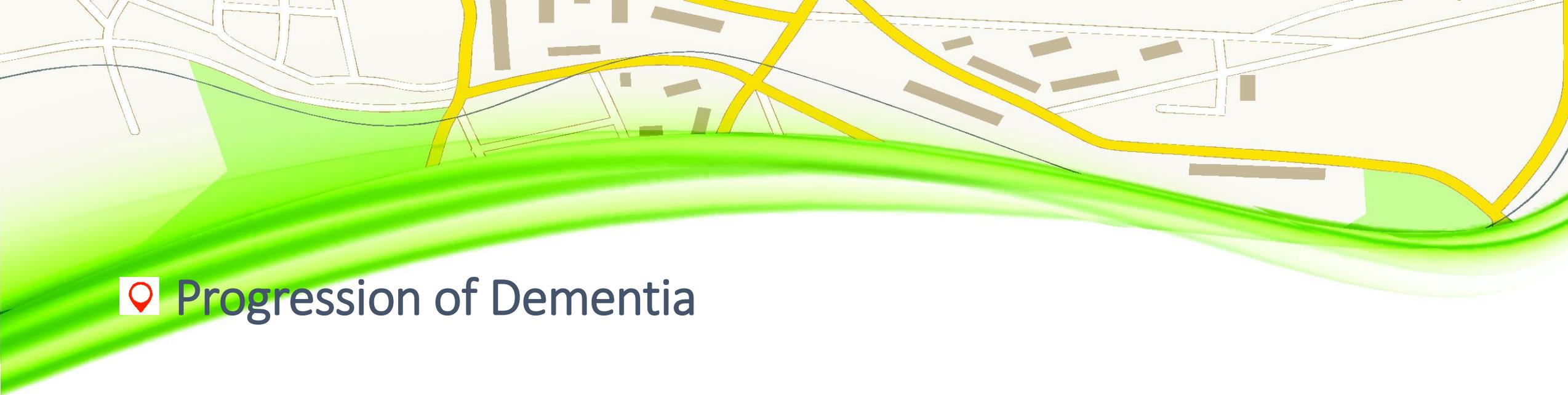
Session Objectives

- What is dementia / Alzheimer's Disease?
- What ambiguous loss is and why it is important
- How it differs from other loss and grief
- New approaches toward increasing tolerance for ambiguity and change



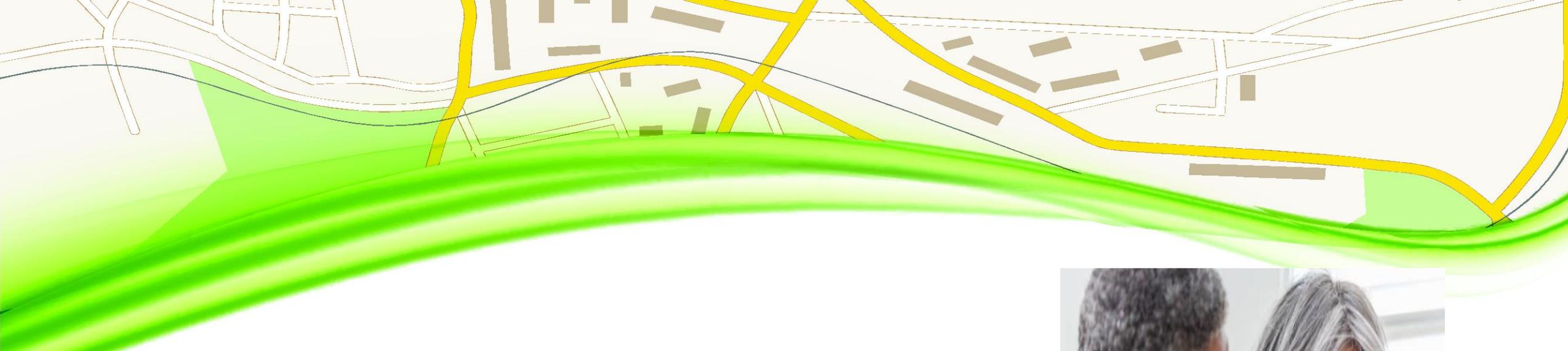
Dementia

- General term that describes a category of diseases that result in impairment of:
 - Memory
 - Language
 - Personality
 - Behavior
 - Judgment



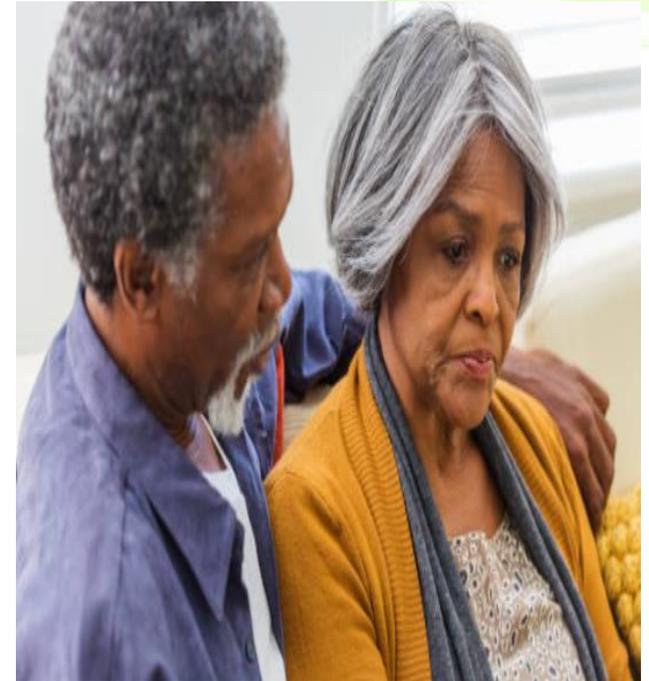
Progression of Dementia

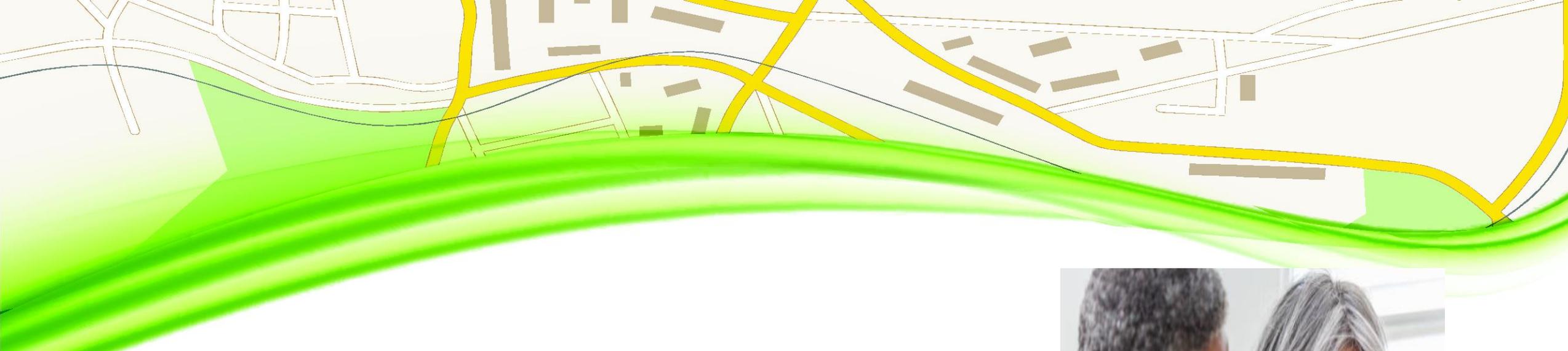
- Typically: 7-10 years
- Stages:
 - Early (Mild)
 - Middle (Moderate)
 - Late (Advanced)
- Requires different services & strategies along the way



📍 Ambiguous Loss

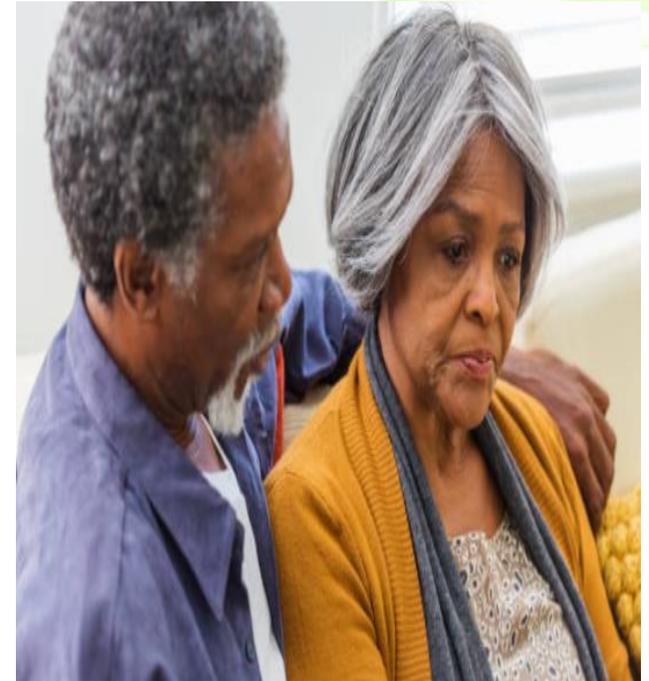
- Loss that is unclear, has no resolution and no closure
- Developed by Pauline Boss Ph.D.
- Dementia creates ambiguous loss
- The person is physically present, but psychologically absent as they once were

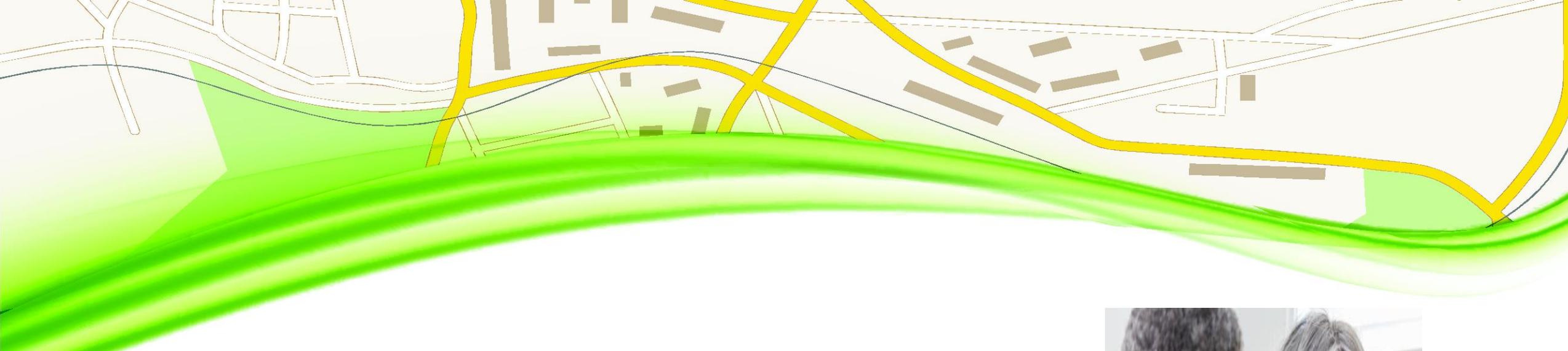




📍 Ambiguous Loss- The Missing Link

- Caregivers often reports stress and burden
- Concept helps us understand this may be related to chronic loss and grief resulting from the disease.
- Model was developed to name or describe a unique loss
 - Unlike traditional loss
 - Loss that is unclear
 - No resolution no closure





📍 Ambiguous Loss

- The physical body is absent but psychologically the person is still present to family and loved ones
 - Lost soldier
- The body is present but psychologically the person is changed or absent from how they had been previously
 - Dementia
- Challenging because others do not recognize the loss
- Loss is unclear, confusing and unpredictable
 - Moments of lucidity in dementia that become confusing
 - Cannot be cured or fixed
 - No closure

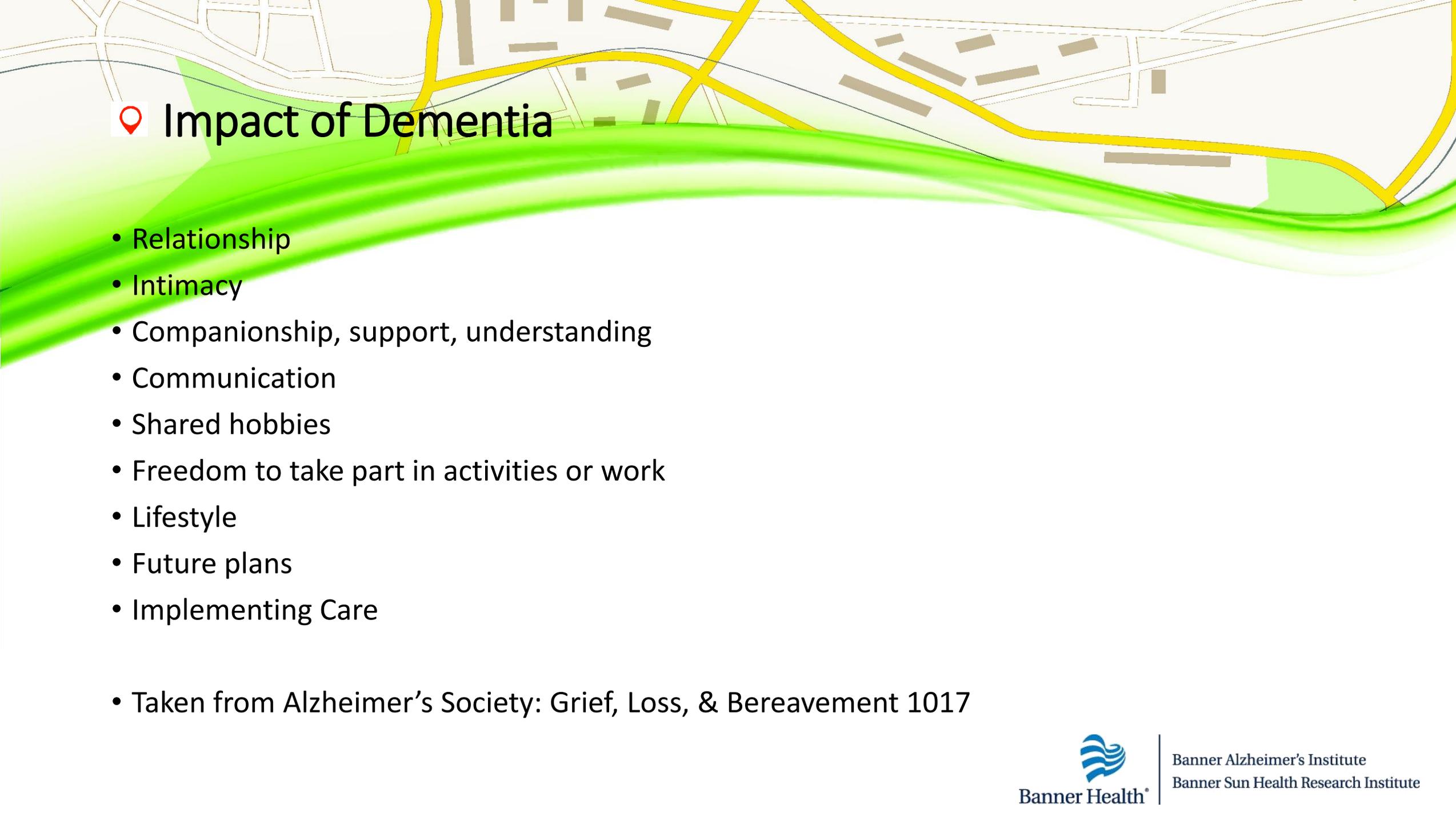




📍 Differs From Other Losses

- Complicates loss/grief
- Continued losses throughout the course
- Confuses relationships
- Important to grieve as you go





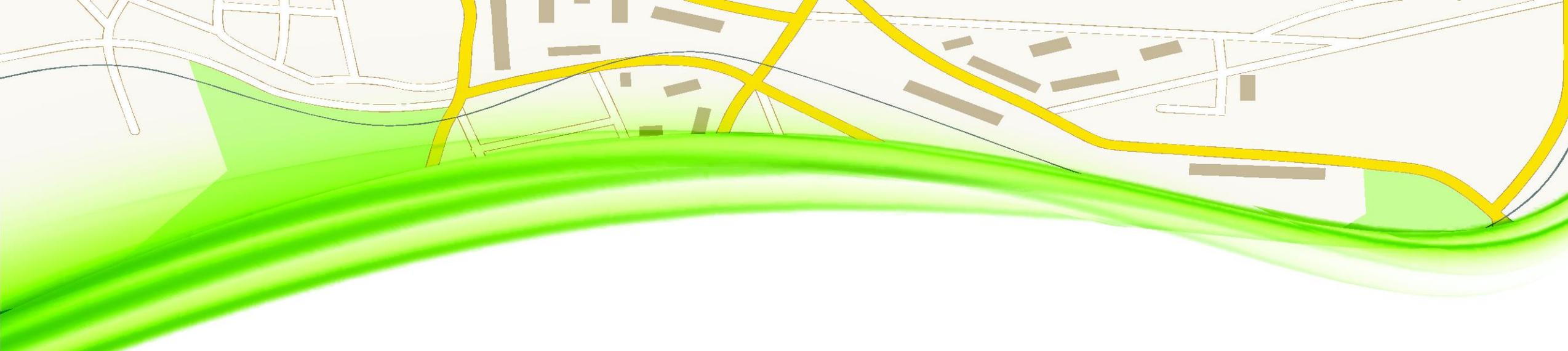
Impact of Dementia

- Relationship
 - Intimacy
 - Companionship, support, understanding
 - Communication
 - Shared hobbies
 - Freedom to take part in activities or work
 - Lifestyle
 - Future plans
 - Implementing Care
-
- Taken from Alzheimer's Society: Grief, Loss, & Bereavement 1017



📍 Why It Is Important

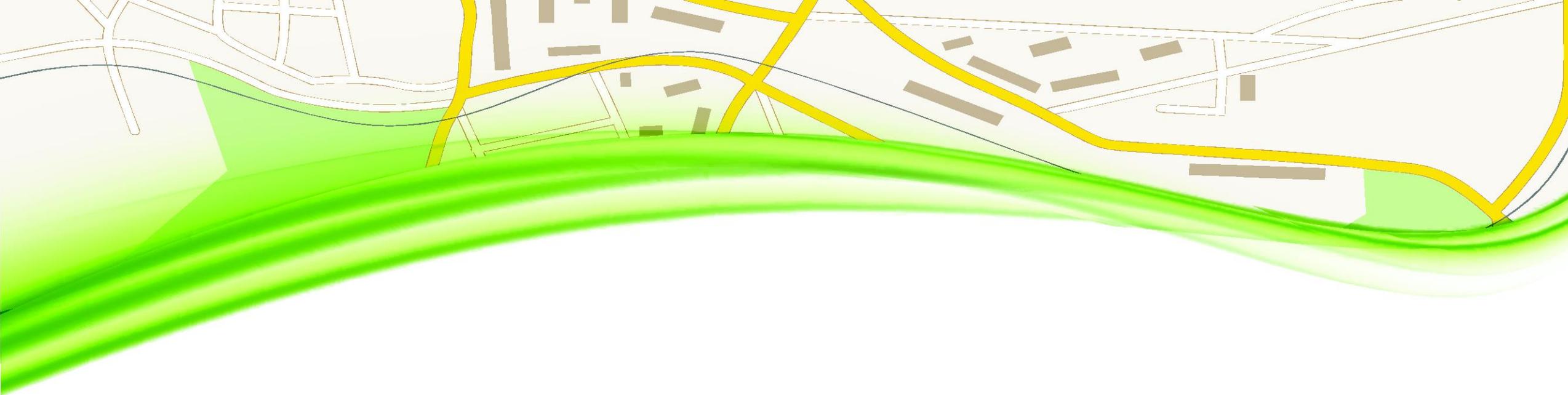
- Provides a pathway for caregiver to accept and live with a new reality
- Allow us to appreciate our person for who they are now instead of longing for the person they once were
 - More effective use of energy
 - Redefining our relationship



📍 Why It Is Important

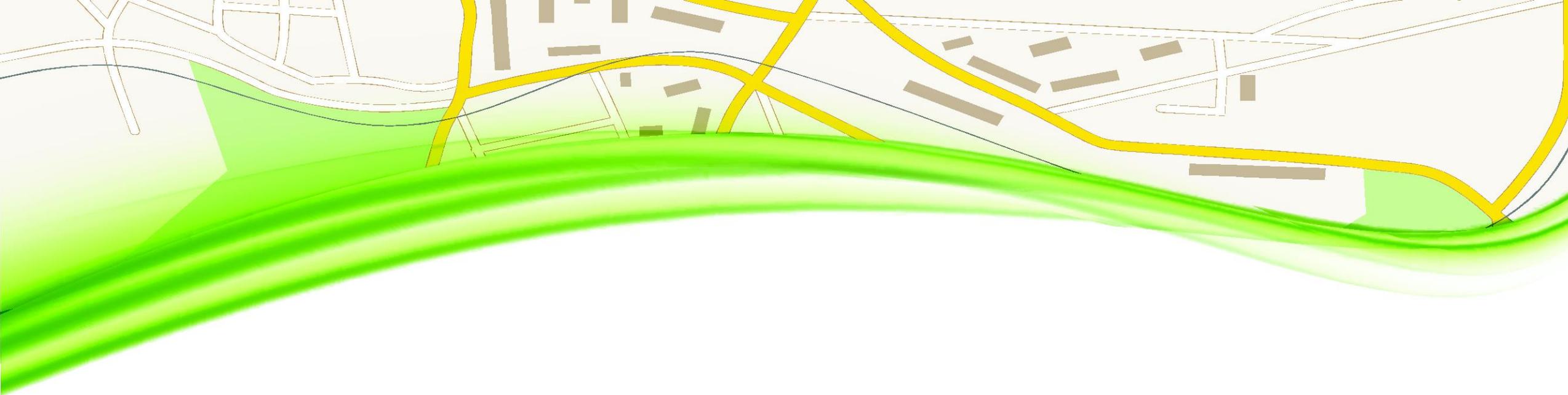
- Changing our perception

- Cannot control the disease, we can control or change our perceptions
- Helps us find hope
- Pathway to accept and live with it.
- Helps us connect to the person as they are now with the disease
- Conscious choice to change how we see things
- Enables us to appreciate the positive moments



📍 Why It Is Important

- Provides guidelines to help develop our own plan to care for the person we love while caring for ourselves simultaneously
- Provides a model to increase resiliency



📍 Why It Is Important

- Offers fluid considerations toward development of our own plan
- Allows us to provide care AND take care of ourselves as care partner
- Increases our comfort with ambiguity of this situation and future situations
- Feel more relaxed not knowing the ending



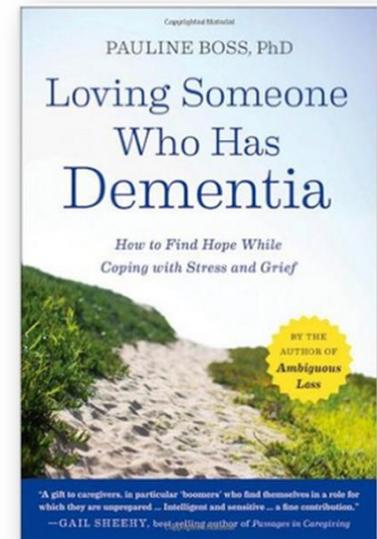
📍 Why It Is Important

- Resiliency
 - Caregiving can make you stronger
 - Flexibility can increase strength
 - Adaption requires of seeing the upside of situation- not just the losses/changes
 - Learning to tolerate and feel comfortable with the uncertainty of life
 - Increase our maturity
 - Cease resisting the challenges and begin to go with the flow



📍 How To Begin

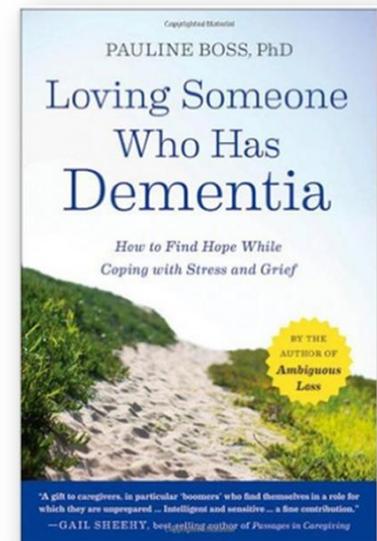
- Name the problem: Ambiguous Loss
 - Can help us cope
 - Partial loss creates ambiguity
 - Barrier to coping and grieving
- Paradoxical thinking: Both/And
 - Hold two opposing/contradictory ideas at the same
 - No right answer
 - Trust things will work out. As a caregiver I have lost _____ and I have gained _____

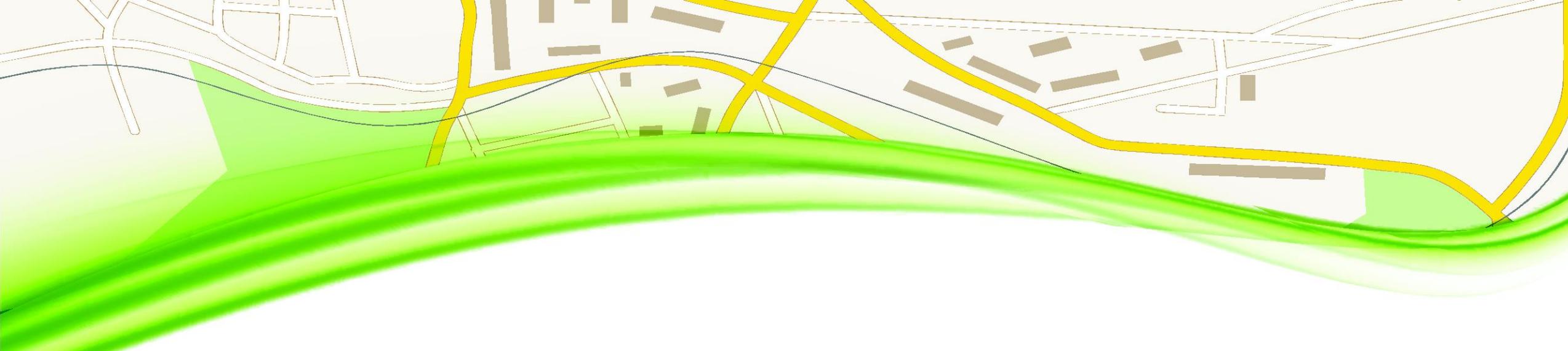




📍 How To Begin

- Less than perfect solutions/ finding the middle ground
 - Avoid fixing things
 - Accept less than perfect solutions

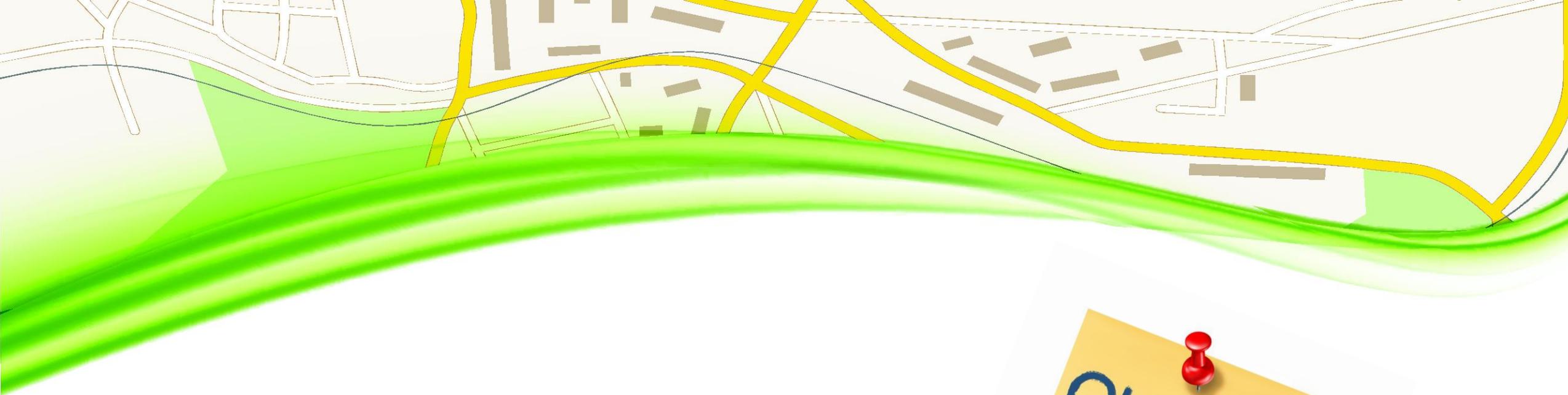




📍 Guidelines to Cope



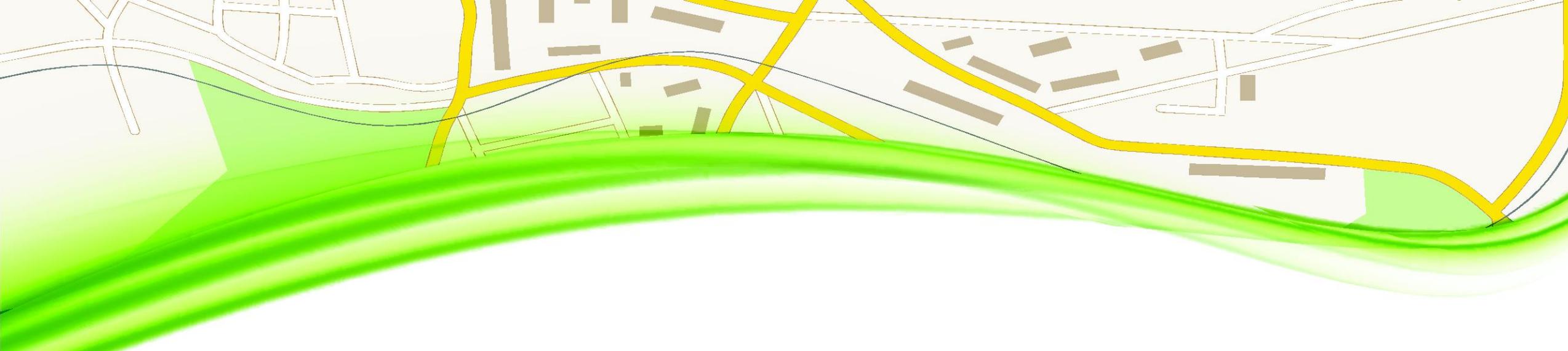
- Find Meaning
- Balance Control with Acceptance
- Broaden Your Identity
- Manage Your Mixed Emotions



Guidelines to Cope

- Hold On And Let Go
 - Revising attachment: letting go while remembering/ loved one is both here and gone
 - Grieve what you lost, celebrate what you still have
 - Find new human connections
 - Alleviate expectation of closure
- Imagine New Hopes and Dreams
- Take the Time to Mind Yourself





📍 Increase Your Comfort Living with Ambiguity

- Let go of your need for certainty and embrace ambiguity
- Change your perceptions of a situation/diagnosis that cannot be changed
- Find hope in ambiguity
- Find meaning in the relationship that has changed





📍 A Good Enough Relationship

“When you love someone with dementia the goal is not perfection. The new standard for your relationship is simply for it to be good enough. Life with dementia can be less than ideal and still be pretty good. That perceptual shift is under your control.”

Pauline Boss, PhD



Questions?

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