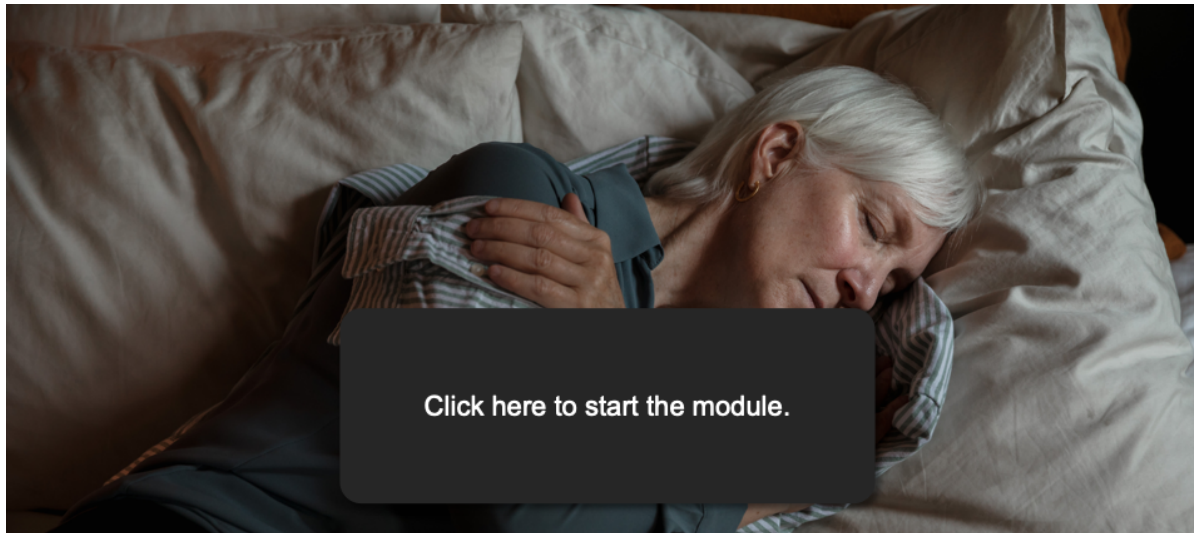


Slide 1




Click here to start the module.

End of Life and Grief

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or the **Exit** button to leave the module.*


Use the forward arrow to continue.




End of Life and Grief

*At any time, feel free to select the **CC** button to see captions text or the **Exit** button to leave the module.*

Use the forward arrow to continue.






Learning Objectives

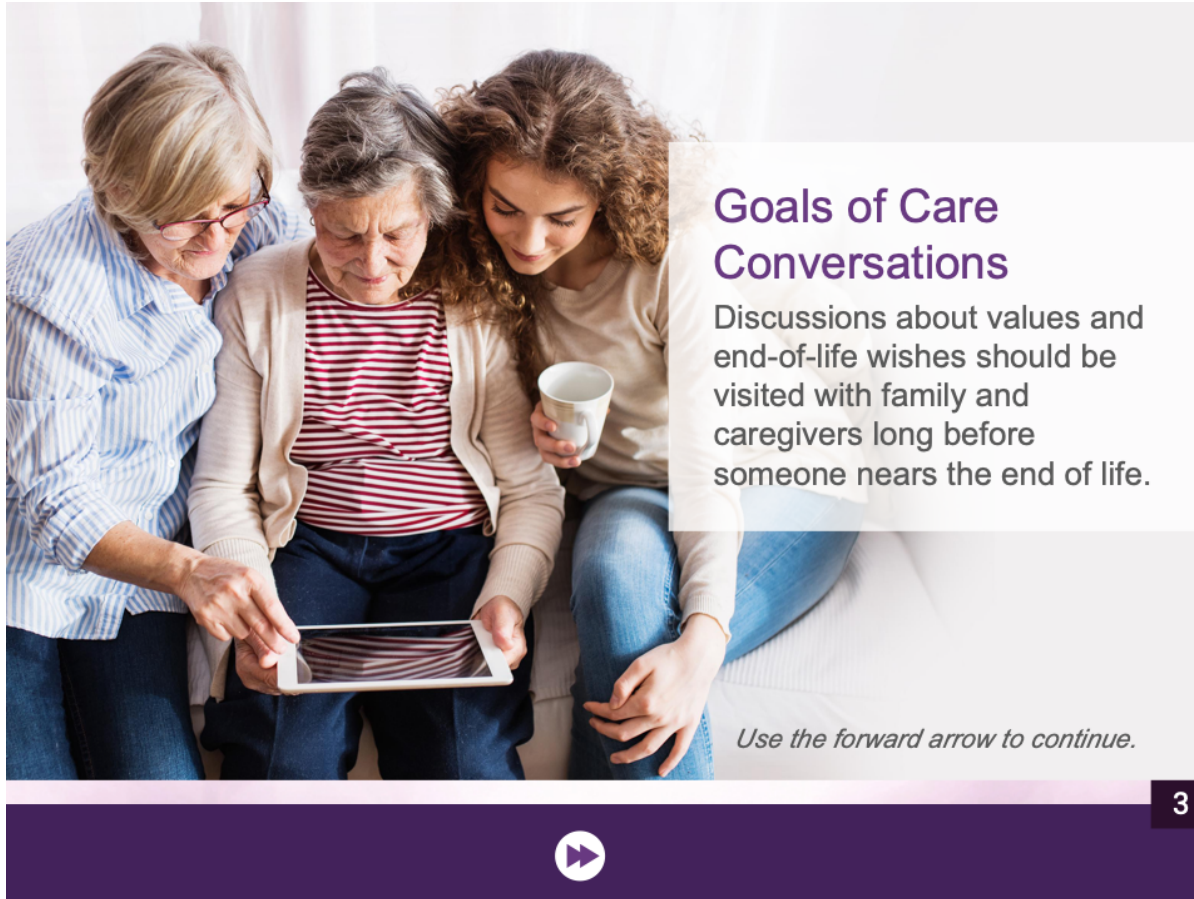
After this completing this module, learners will be able to:

- Identify strategies to communicate with older adults about end of life and goals of care
- List various supports available for people nearing the end of life
- Recognize ethical and legal considerations
- Describe various types of grief
- Describe prolonged grief disorder diagnosis, assessment, and evidence-based treatments

Use the forward arrow to continue.

2




A photograph of three women of different ages looking at a tablet together. One woman is pointing at the screen. The scene is indoors, likely a home or care facility, with soft lighting.

Goals of Care Conversations

Discussions about values and end-of-life wishes should be visited with family and caregivers long before someone nears the end of life.

Use the forward arrow to continue.

3



Advance Care Planning and Goals of Care Discussions

- Have these conversations long before the end of life
- Can increase feelings of empowerment/dignity
- Can help make informed choices based on values, goals, wishes
- Not associated with increased emotional distress
- Associated with less aggressive medical interventions near death
- Allows time for information to be shared with chosen family
- Caregivers report better quality of life, less regret, reduced risk for major depression

Use the forward arrow to continue.



Barriers to Goals of Care Conversations

- Discussing death/dying can be uncomfortable
 - Limits of available treatment options and mortality
 - Fear of causing patient and family excessive distress
 - Lack training in goals of care conversations
- Belief that accepting palliative care or hospice care is giving up



Use the forward arrow to continue.

5



Goals of Care Conversation Components

- Don't need to address all objectives in a single meeting
- Conversation components
 - Collaboratively set an agenda
 - Assess how much information patient/family are ready to learn
 - Assess illness and prognosis understanding
 - Assess coping strengths and needs
 - Deliver medical and prognostic information
 - Hold space for emotional reactions
 - Explore values and preferences
 - Discuss treatment options
 - Offer recommendations based on patient and family values
 - Finalizing a treatment plan
 - Revisit plans in follow-up conversations

Use the forward arrow to continue.

6



How to Have Goals of Care Conversations

- Create a calm setting
- Use appropriate body language
- Evoke the thoughts and goals of the patient
- Provide education and dispel myths
- Respond to the patient and family's emotions
- Collaboratively establish a plan for care
- Have multiple disciplines involved in these conversations
- Collaboratively negotiate a meeting agenda
- Gauge how much information patients/families are ready to receive
 - Taking cues from the patient and family
 - Directly ask patients and families how they would like new information to be communicated

Use the forward arrow to continue.

7



Expecting Difficult Emotions

- Goals of care conversations can be emotionally challenging
 - Normal and expected
- Emotional reactions signal that the information was heard and is being appropriately processed
- Clinicians should be mindful of own discomfort
 - Avoid providing false reassurance
 - Offer reflective listening and empathy



Use the forward arrow to continue.

8



Responding to Difficult Emotions

- Therapeutic silence
- Leaning in to convey support
- Eye contact
- Holding space for the emotion
- Statements conveying empathy (NURSE)
 - **N**aming the emotion
 - **D**emonstrating **U**nderstanding
 - **R**especting their reaction
 - **E**mphasizing **S**upport
 - **E**xploring emotional reactions



Use the forward arrow to continue.

9



Resources for Goals of Care Conversations



Choosing what matters.
Doing what works.

The Education in Palliative
and End of Life Care Program

the **conversation** project

Use the forward arrow to continue.

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Take Home Message


- Discussions related to end-of-life care can be uncomfortable
- They help empower older adults to set goals of care that reflect values
- Mental health clinicians play an important role in such conversations
- Important skills include eliciting what matters most to the older adult, holding space for strong emotions, and emphasizing ongoing support



Use the forward arrow to continue.

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Supporting Older Adults and Family at End of Life

Being informed about end of life care and support options is imperative to best meet the needs and values of older adults.

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Palliative Care

- Focuses on enhancing quality of life for people with serious/life-limiting illness
 - Physical, psychosocial, spiritual needs
- Ideally begins at the time of diagnosis
- Uses a team approach
- Delivered in multiple settings
- Has been shown to reduce unnecessary hospital admissions, use of health services, can extend life
- May be provided alongside curative care



Hospice

- Focuses on care, comfort, quality of life near end of life
- Appropriate when an illness is no longer responding to disease-directed therapies or decision to stop treatment
- Provided for those with a serious illness that will likely die within six months
- Disease directed treatments are stopped
- Treatment goals shift to comfort
- Health care may continue if improves quality of life or functional ability
- Provided in variety of medical settings



Spiritual Care

- Chaplains are spiritual support specialists in the medical setting
 - Available in hospitals, hospice care, nursing facilities
 - Work with those from all faiths, belief systems, cultural backgrounds
 - Assist with processing end of life
 - Assist with prayer or meditation
 - Assist in complex medical decision making
 - Provide appropriate support resources
- Chaplain services associated with improved quality of life and decreased expenses at the end of life
- Patients receiving spiritual care are more likely to use hospice services and less likely to die in the hospital



Emotional and Mental Health Support

- Psychiatrists, psychologists, social workers, and counselors play a key role in meeting the psychosocial needs of patients and families near the end of life
- Palliative care teams that include psychologists and psychiatrists as core members demonstrate improved patient well-being
- Psychotherapy is effective in treating depression and anxiety
 - Cognitive Behavioral Therapy and related treatments including mindfulness and acceptance-based approaches have been particularly beneficial

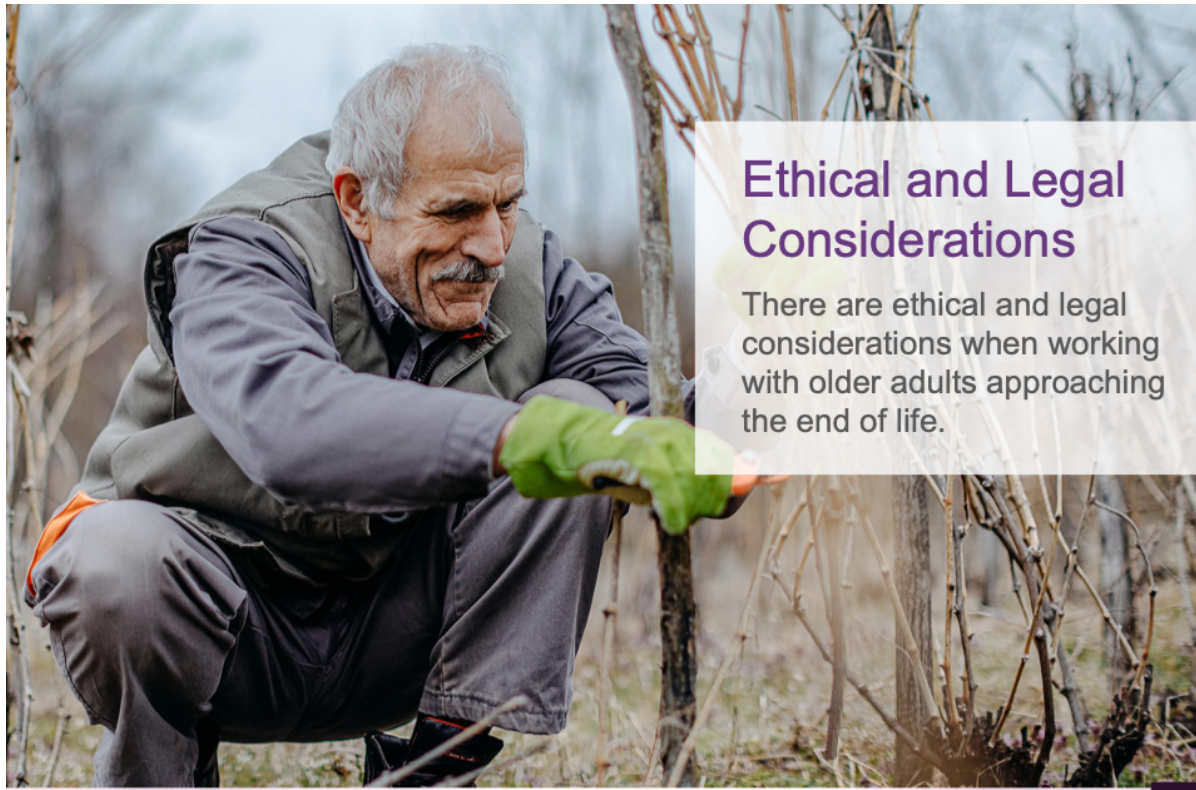




Take Home Message

- Palliative care focuses on enhancing quality of life for people with serious or life-limiting illness through prevention and relief of suffering
- Hospice focuses on comfort care for a person that is nearing the end of life
- Spiritual and emotional support services can be valuable at end-of-life
- These services are available in various settings, including in the home






Ethical and Legal Considerations

There are ethical and legal considerations when working with older adults approaching the end of life.

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Respect for Autonomy

- Right of every person to make choices on own behalf
- Autonomy may be compromised if reduced capacity for making and/or communicating decisions
 - Surrogate decision maker
- Imperative for clinicians to respect patient's wishes when decisional capacity is not compromised



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Beneficence

- Clinicians have a moral obligation to act in best interests of their patients
- May look different for older adults reaching the end of life
 - Weigh costs and benefits of care choices
- Clinicians must be mindful of own attitudes/biases
- Place patient values first when deciding what options are in their best interest



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Nonmaleficence

- Do no harm and make efforts to maximize safety
- Common dilemmas with older adults at the end of life
 - Ethical pain management
 - Forced nutrition
 - Life-prolonging and sustaining treatments
 - Withholding or withdrawing nutrition and treatment

Clinicians do no harm to their patients and make efforts to maximize safety

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Justice

- Treat patients fairly, equitably, justly
- Avoid making decisions influenced by ageism/age-discrimination



Legal Issues

- Laws around the topic of end of life vary state by state
- Legal issues regarding end of life care commonly relate to patient rights and competency



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LGBTQ+ Legal Concerns

- Older LGBTQ+ adults face specific legal concerns with end-of-life issues
- Without written advance directive documents, health care providers operate without clear guidance to support an LGBTQ+ person and their family
- Even with advance directives in place, LGBTQ+ people have seen wishes disregarded



Legal Documents


- Healthcare power of attorney
- Financial power of attorney
- Living will
- Physician Orders for Life Sustaining Treatment, or POLST
- For more detailed information about advance care planning documents, please refer to the Common Life Issues module



Take Home Message

- There are unique ethical dilemmas and legal considerations at end of life
- Ethical principles when working with older adults include autonomy, beneficence, non-maleficence, and justice
- Legal considerations include competency in decision making, surrogate decision makers, and legal documents






Life's Last Days

The dying process often begins long before death. The recognition of this process can help survivors process their grief.

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End of Life Behavioral Signs

- Withdraw from people and activities
- Revisit old memories and consider relational regrets
- Sleep more
- Lose interest in engaging in previously enjoyed activities
- Become less active physically
- Resistant to any movement
- Interest in food or drink may decrease or totally cease
- Swallowing medications may be troublesome or difficult to digest
- Hospice workers can help families cope with challenges
 - Medications, making environmental modifications, teaching comfort care measures



Mental Status Changes

- Some experience terminal delirium at end of life
 - Confusion, agitation, or restlessness
 - Delusions such as paranoia
 - Unrealistic thoughts of things they could accomplish
 - Hallucinations
- The dying person may:
 - See or speak to people who aren't there
 - Have mild sense of euphoria
 - Have an abrupt return of alertness shortly before death
 - Can bring up mixed emotions/false hope of recovery
 - Experience fading consciousness as death nears
 - Stop communicating and become unresponsive
 - Still be able to hear and feel pain or distress



Immediate Signs that Death is Near


- Decreasing body temperature
- Decreasing blood pressure
- Irregular heartbeat or pulse
- Increased perspiration, skin color changes
- Drooping lips or a mouth slightly open
- Breathing changes occur: a rattling sound, cough or irregular breathing
- A period of rapid breathing followed by no breathing periods
- Jerks or sudden arm or leg motions occur
- Spontaneous speech decreases
- Unresponsiveness
- Eyes open but unable to see
- Hearing is the last sense to leave



Take Home Message

- Cognitive, emotional, behavioral, and physical changes occur at end of life
- Knowing these changes can help clinicians, families, and caregivers prepare for this challenging transition, support the dying individual, and navigate grief






Grief

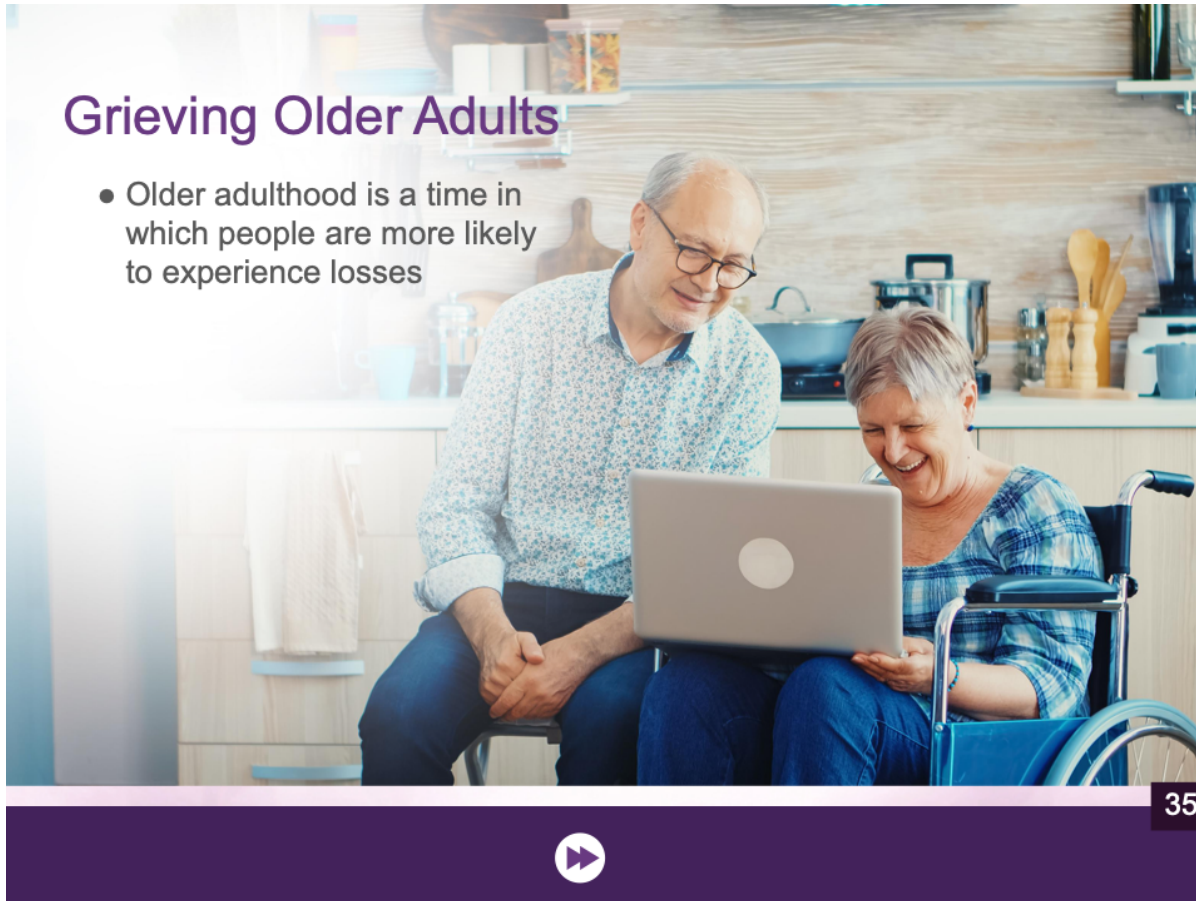
Grief is a natural process that most people experience with loss, though it can look very different across groups and individuals.

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Grieving Older Adults

- Older adulthood is a time in which people are more likely to experience losses



Theories of Grief

- Psychoanalytic models of grief
- Bowlby's attachment theory of grief
- Continuing Bonds Theory
- Elisabeth Kübler-Ross's stage theory
- Irvin Yalom's existential characterization of grief
- William Worden and Therese Rando Task models



Types of Grief

- Grief comes in many forms
 - Anticipatory grief
 - Acute grief
 - Integrated grief
 - Prolonged grief disorder



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Prolonged Grief Disorder (PGD)

- Previously referred to as complicated or traumatic grief
- Criteria for PGD
 - Significant loss more than twelve months ago
 - Grief response most of the time for at least a one-month period
 - At least three of the following: identity disruption, marked sense of disbelief about the death, avoidance of reminders the deceased is dead, intense emotional pain, difficulty moving on in life, emotional numbness, meaninglessness, intense loneliness
 - Significant distress or impairment in functioning
 - Symptoms exceed expected social, cultural or religious norms
 - Symptoms not better explained by other mental/medical condition



Prevalence and Correlates

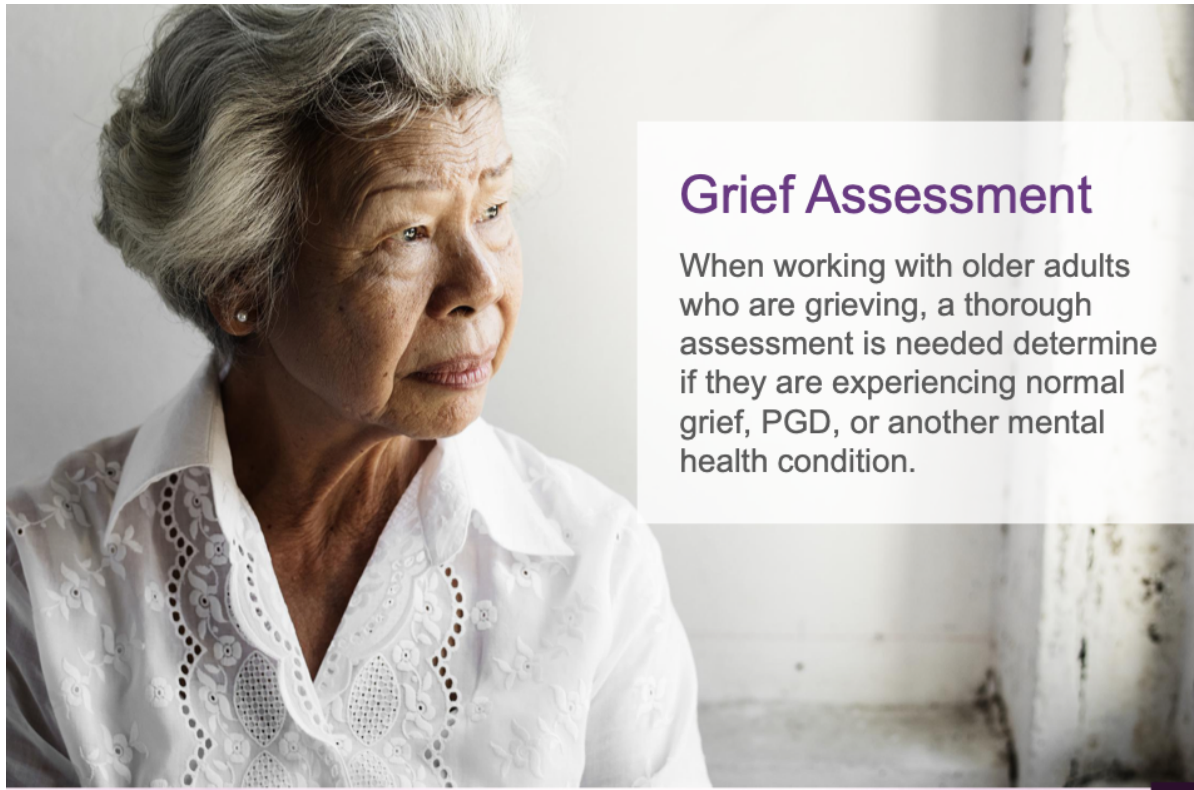
- About 10% of bereaved older adults meet criteria for PGD
- Compounded effects of loss may increase burden associated with bereavement in older age
- Higher rates of PGD among persons bereaved by disaster, violent deaths, or parents who lose children
- Associated with reduced quality of life, sleep disturbance, increased suicidal ideation, depression, anxiety, deteriorating health, cognitive impairment



Take Home Message

- The process of coping with bereavement is referred to as grief
- It is normal to experience emotional, functional, and physical changes when we lose a loved one
- When someone struggles to cope with grief beyond what is expected, they may be experiencing prolonged grief disorder






Grief Assessment

When working with older adults who are grieving, a thorough assessment is needed determine if they are experiencing normal grief, PGD, or another mental health condition.

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Normative Grief V. PGD

- Normative grief
 - May involve profound grief reactions
 - May temporarily disrupt psychological functioning
 - There is no prolonged functional impairment
 - Able to re-engage in life
 - Normative grief varies greatly from person to person
 - Some people do not experience distress or impairment after a significant loss
- PGD
 - Clinically significant difficulty readjusting to life after a loss which continues for more than one year



PDG Differential Diagnoses

- PGD is often comorbid with major depressive disorder and PTSD
- Can also occur in isolation to these other disorders



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PGD Versus Major Depression

PGD

- Focus of symptoms on the separation from loved one
- Experience of inappropriate self-blame related to the death
- Avoidance of reminders that loved-one is gone
- Difficulty accepting a loss
- Role confusion after a loss

DEPRESSION

- Focus is more generalized and/or shifting in focus
- Experience general guilt or worthlessness
- Avoidance in the form of withdrawal in depression
- Appetite change, sleep disturbance, psychomotor retardation or agitation, fatigue, and concentration problems



PGD Versus PTSD

PGD

- Intrusive or preoccupying thoughts, emotional numbing, and avoidance
- Intense yearning, loss, or emptiness
- Avoidance in PGD: reminders that the loved one is gone
- Often co-occurs with PTSD

PTSD

- Intrusive/preoccupying thoughts, emotional numbing, avoidance
- Fear, anger, guilt, shame, anxious hyperarousal
- Intrusive thoughts: focused on the event of the death, involve feelings of threat
- Avoidance in PTSD: related to fear/threat
- Nightmares, flashbacks, aggression
- Often co-occurs with PGD



Grief Assessment Tools

Please click on each scale below for more information on each tool

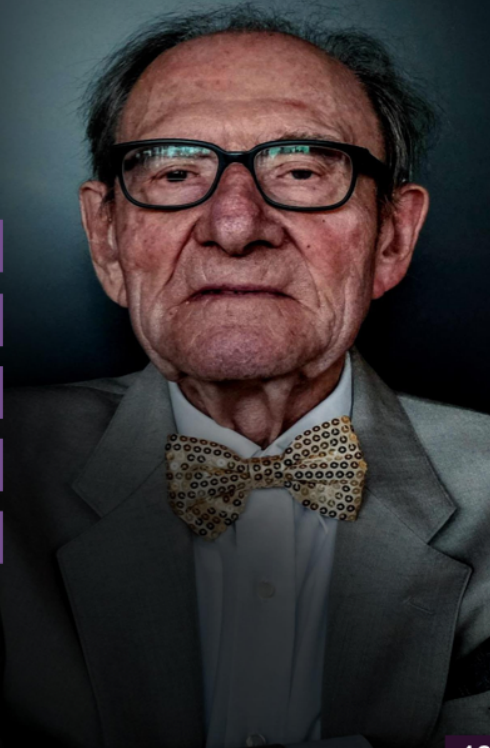
[Inventory of Complicated Grief](#)

[The Brief Grief Questionnaire \(BGQ\)](#)

[Prolonged Grief Disorder-13 \(PG-13\)](#)

[Caregiver Grief Scale](#)

[Core Bereavement Item \(CBI\) Scale](#)



Grief Assessment Tools

Inventory of Complicated Grief

- 19-item self-report scale designed to assess PGD
- Validated in an older sample of bereaved spouses
- Good to excellent psychometric properties
- Available in multiple languages
- Cut-off score of greater than or equal to 30 for detecting PGD

[Back to Grief Assessment Tools](#)



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Grief Assessment Tools

The Brief Grief Questionnaire (BGQ)

- This 5-item questionnaire developed to assess grief following the September 11 terrorist attacks
- Validated in an older sample of bereaved adults but an exclusively older adult sample
- Strong psychometric properties
- Quick to administer and score as a screening tool

[Back to Grief Assessment Tools](#)



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Grief Assessment Tools

Prolonged Grief Disorder-13 (PG-13)

- 13-item rating scale is based on DSM-V and ICD-11 PDG diagnostic criteria
- Designed as a structured diagnostic interview
- Has been used in self-report form
- Although it hasn't been validated in an exclusively older adult sample
- Validated in heterogenous validation samples
- Demonstrating strong sensitivity and specificity

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Grief Assessment Tools

Caregiver Grief Scale

- This 11-item rating scale was designed to measure pre-death grief
- Four domains: emotional pain, relational loss, absolute loss, and acceptance of loss
- Validated in sample of dementia caregivers
- Demonstrates sound psychometric properties

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Grief Assessment Tools

Core Bereavement Item (CBI) Scale

- 17-item scale measures core grief and bereavement experiences
- Scoring yields a total score and three subscales: Images and thoughts, acute separation, and grief
- Strong psychometric properties
- Validated in a sample of adults over the age of 50
- Endorsed by the Social Work Hospice and Palliative Network

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Take Home Message

- When assessing grief in older adults, it is important to know the characteristics of normative grief and how it differs from PGD
- Common differential diagnoses include major depression and PTSD
- There are multiple assessment tools available to measure grief in older adults and caregivers






Treatments for Older Adults Struggling with Grief

There are several evidence-based psychotherapeutic approaches for grief

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Cognitive Behavioral Therapy (CBT)

- Has been adapted for use in PGD
- Good efficacy in reducing grief symptom severity
 - Psychoeducation
 - Elements of prolonged exposure, cognitive restructuring
- More research is required in the context of grief with older adults

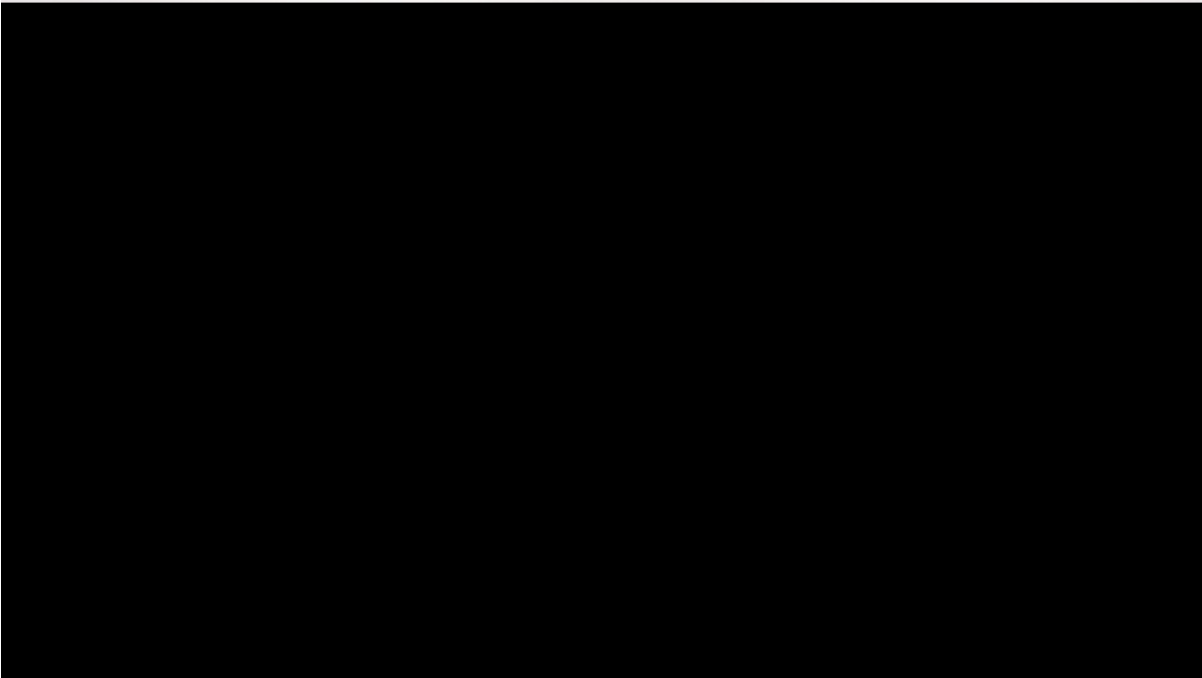


Complicated Grief Therapy (CGT)

- Manualized treatment specifically focused on symptoms of grief
- Demonstrated good efficacy in older adults
- 16 sessions
- Developed from attachment theory model
- Integrates techniques from interpersonal therapy, CBT, prolonged exposure, and motivational interviewing



Kimberly Hiroto, PhD, ABPP



Meaning-Centered Grief Therapy (MCGT)

- Manualized therapy that combines aspects of CBT and existential therapy
- 16 weeks
- Lack of research in older adults



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Accelerated Resolution Therapy (ART)

- A brief mind-body intervention
- Evidence-based treatment for trauma, stress-based disorders, depression
- Includes rescripting, memory reconsolidation, guided visualization with use of eye movements, desensitization/processing of distressing memories, exposure
- Demonstrated good efficacy in reducing complicated grief symptoms in caregivers aged 60+ years



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Pharmacological Treatments

- Very little evidence supporting pharmacotherapies for PGD in adults
 - Even less in older adults



Clinician Grief

- Important to prioritize self-care and wellness
- Support to help clinicians process emotional challenges associated with providing care
- For more resources on coping with clinician grief, please refer to our reference list for this module



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Take Home Message

- Cognitive behavioral therapy, complicated grief therapy, meaning-centered grief therapy, and accelerated resolution therapy are evidence-based therapies for grieving older adults
- There is very little evidence supporting the efficacy of pharmacological treatments for grief



In Summary

In this module, we learned:

- ✓ Important to discuss goals of care before end of life
- ✓ To have documents in place to establish values/preferences around end of life care
- ✓ There are supports available at end of life
- ✓ Grief is the natural process of coping with losing a loved one and takes many forms
- ✓ Individuals with significant functional impairment may have PGD
- ✓ Evidence-based psychotherapies are efficacious for older adults struggling with grief





Next Steps

- Please see the reference list for more information about End of Life and Grief

[Click here to end presentation](#)

Then click the close button to proceed to the post test

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