

# Guiding Complex Conversations at End of Life and Beyond

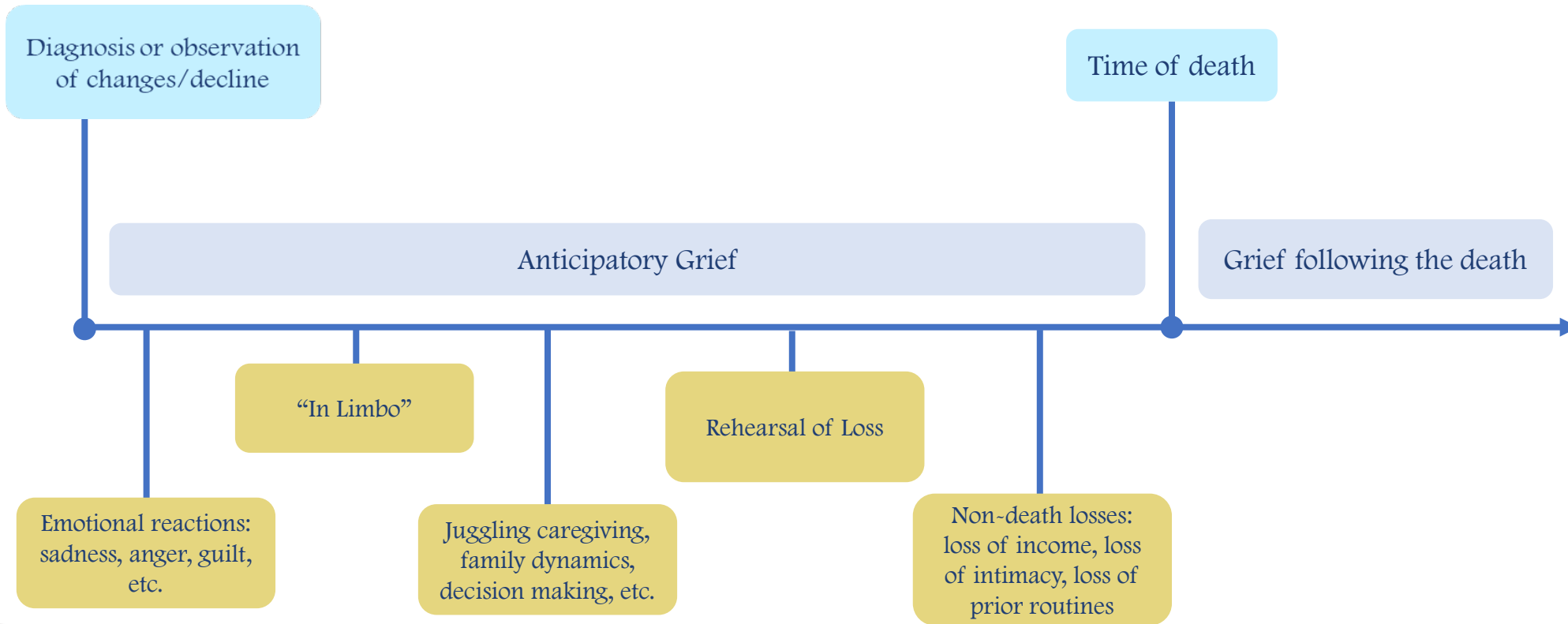
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# Grief

- The natural reaction to loss
- Involve numerous emotional, cognitive, physical, and spiritual effects and experiences
- What kind of loss triggers grief?
  - Anytime there is loss of an attachment (person, place, thing, situation)
  - Many losses along the way to end-of-life

# What is Anticipatory Grief?



# How does grief show up?

The paradox of emotions:  
Gratitude and grief can coexist

Much more than just “sadness”

Many physical and cognitive impacts as well as the more-known emotional and spiritual effects

May involve relief at time of death

Much more chaotic and wave-like than stage-like

Unique to each person

# Other helpful considerations

- The intensity or heaviness may be different than you were expecting
- We each have a unique relationship with the person who is dying which results in a unique course of grief
- We come with our own ideas of death and grief

# Complex Conversations

- End-of-life planning
- Wishes/choices
- Expectations
- Changing dynamics

# Factors that Influence Conversations

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What makes these conversations challenging?

# Societal Norms

- Discomfort with talking about the tough stuff
  - Family/relationship dynamics
  - Death
  - Grief
- Avoidance of these subjects further pushes these norms, continuing the cycle

# Expectations vs. Reality



VS.



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# Expectations vs. Reality

- The ideal plan for a “good death” may not be the reality
  - Keeping the dying person at home, honoring wishes, avoiding certain medications or scenarios
  - Guilt/regret
    - Not being able to honor wishes
    - Breaking promises
  - Shame
    - Judgment about choices (place, medications, type of care)
    - Judgments about abilities/limits (comfort in giving meds/providing care, acknowledging the toll of caregiving)
    - Towards self (“I should be able to do this”) or from others (“Why are you giving up?”)

- 🌱 Can guilt, regret, and shame always be prevented?
- 🌱 What can help?
  - 🌱 Keep expectations in check
  - 🌱 Be mindful when making promises
  - 🌱 Give yourself and others grace for abilities and choices
  - 🌱 Communicate with family members\*
  - 🌱 Remember that you are a human being with human limits!

# Relationship History

- ❑ Complicated relationship with the person who is dying
  - ❑ A negative relationship or estrangement may lead to more intense, complex grief
  - ❑ May also impact caregiving abilities/choices
  - ❑ Normal to grieve for what could have or should have been
  - ❑ Expectations for apologies and forgiveness may not be met
  - ❑ Boundaries are important

- ❑ Complicated relationships between others in the family
  - ❑ Can impact decision making, communication, direct care
  - ❑ Common to hope that the dying person will bring a family together
- ❑ What can help?
  - ❑ Communication
  - ❑ Boundaries
  - ❑ Expectations
  - ❑ Compromises

# Assumptions

- Our own emotions drive our thinking and cause us to assume others are feeling the same way
  - Often about our own emotions rather than those of the person who is dying
- Autonomy
  - Who should decide what someone can and cannot handle?
  - Taking away the dying person's opportunity to have these conversations

# Navigating Challenging Conversations

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Family Members and Professionals Alike

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# Using Direct Language

- Don't be afraid to use practical terms (dying, death, hospice)
  - Using proper terminology can prevent misconceptions and misinterpretations
- Avoid euphemisms and platitudes
  - These can be invalidating and confusing

# Defining a Good Death

- What does a good death look like to everyone?
- Defining a good death
  - Subjective!
- Are there things you're afraid of?
- Questions to open up for loved one

# Logistics & Planning Conversations

- Funeral planning
- Logistics
- Moving someone into care
- Family conversations once coming into hospice
- What room do you want to die in?
- Who do you want there?

# Unspoken Fears and Denial

- Many are not having the conversations with their partner about what their coping might look like when the partner dies
- Are they fearful?
- How to approach that conversation
- What happens when the dying person was in denial and did not share with their family?
  - Grieving family may blame themselves
- Not always a denial- it's a biological process at times

# Advocacy and Differences

- ▣ Advocating for the kind of death you want to have, especially if it's different from the family norm
  - ▣ What's assumed vs. what you want
- ▣ Wishes for the person vs. wishes for yourself
- ▣ Faith differences
- ▣ Holding what would be good for you and your children with a death going on
  - ▣ Wanting to tell your kids there is a heaven to have an answer of where someone is, even if you don't believe it

# Before and After Goodbye: The Words We Hold Back

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- ❖ Thoughts and feelings that might not feel “acceptable” either to feel or to say out loud
  - ❖ Relief “I’m glad they aren’t suffering/I’m glad I don’t have to worry about them every time I’m away”
  - ❖ Impatience “I’m tired of living in this limbo/I didn’t realize it would take this long”
  - ❖ Resentment “I’m stuck here caring for them while my siblings live their lives/I’m unable to care for my own needs”
  - ❖ Anger “I’m frustrated they left me with this mess/They didn’t take care of themselves like they should have”

# What We Hold Back

- ❑ Unsaid words as your loved one is dying—kept in to try to protect who's dying and the memory of their final days
  - ❑ “I don't know if I'll be ok without you”
  - ❑ “Is there something else we can try to keep you here longer?”
  - ❑ “I'm so exhausted/I don't know how much longer I can do this”
  - ❑ “Are you afraid of death/what comes after?”
  - ❑ “I wish things had been different in our relationship/I wish you had taken better care of yourself”
  - ❑ “What do you envision for my future without you?”
  - ❑ “I wish I showed you more love/I wish you showed me more love”

# Grief, Unspoken

- “Taboo” topics that may be left unexplored in grief
  - Missing intimacy, both physical and emotional
  - Feeling joy
  - Not feeling as sad/not missing them as much as you imagined
  - Feeling happy about aspects of “new” life without them
  - Keeping photos of them from final days/days of suffering
  - Guilt for complicated dynamics
  - Trauma for how the death occurred

# What We Carry Forward

- ❑ Changes in identity “I no longer feel like a wife/a father after the death”
- ❑ Changes in friendships “I feel like a third wheel/my friends didn’t show up for me how I wished they would”
- ❑ Relationship with grief itself “I’m afraid to stop grieving because I don’t want to forget them/I’m afraid to let myself grieve for fear that I may never stop crying”
- ❑ Fear of Moving Forward “If I’m no longer grieving, I must not have loved them as much”

# Making Space for the Unspoken

- Silence often reflects love and protection, not avoidance
- These thoughts and feelings are often common and expected
- Though not shared, they may still need to be acknowledged in some way
- There is no “right” way to think, feel or behave in grief
- Self-compassion is needed

# Bringing It Together

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- You can plan everything and it can still go differently
- Grief and disappointment can coexist
- No one is going to get 100% of what they want
- Everyone copes differently
- Give permission for conflicting emotions
- Reinforce practical tools, language to use, and questions to ask
- How to support yourself through this

# Practical Reminders

- There is no one perfect way to say something or have a conversation
- Use proper terminology rather than euphemisms to ensure clarity
- Give everyone space to share and to process
- It's okay to ask the tough and scary questions!
- If possible, ensure the basics are covered before diving into these conversations (hunger, fatigue, pain, discomfort)

# Take Care of YOU

- 🌱 Acknowledge that this is hard work
- 🌱 Allow yourself the grace to not always get everything “right”
- 🌱 Be aware of your own coping needs
- 🌱 Typical coping mechanisms may not be as accessible
  - 🌱 What is realistic right now?
- 🌱 It’s okay to ask for help!

Thank you!

Questions?



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