

*Changing the Culture of  
Dementia Care  
One Mind at a Time*

Positive®  
Approach

**GEMS**®  
Dementia **Aware**  
Dementia **Knowledgeable**  
Dementia **Skilled**  
Dementia **Competent**

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# **Coping with Grief, Loss and Death in the World of Dementia**

**Providing Positive Approach  
to Care® Support**

## **Question One**

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# First Question → Set of Questions

- “My husband, 82 years old, was recently diagnosed with Alzheimers disease after a year of not going on what was going on. From what I’ve witnessed and read, I think he is in the early moderate stage. Since his diagnosis I find myself going through a range of reactions. Relief that I know finally what is happening, a lot of anger, etc.
- **My question is, are there steps or phases like there are in grieving for the caregivers after a diagnosis of dementia?**
- **What can I expect?**
- He also has stage 4 cancer that I’ve been handling pretty well up until now. There is also guilt because I think about me and my future with what is coming a lot, instead of feeling bad about what he is going through.
- **Is that ‘normal’?”**

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# Are there *normal* stages of grief and loss?

- Is what you are feeling normal for someone who has recently discovered the person they love has a new condition, not the one they thought they were dealing with, and that the new condition is bad news on so many fronts?
- Why do you have the feelings you have?
- What previous experience with dementia have you had? Sounds like you have a handle on cancer... how do those experiences relate to this one? How are they different?
- What is one possible change you can make to help you work through these very real feelings and thoughts?

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# 1960-70s: Psychiatrist Kubler-Ross came up with Five Stages of Grieving

**Five stages were identified as:**

- Denial**
- Anger**
- Bargaining**
- Depression/sadness**
- Acceptance**

**They are not always sequenced and not everyone experiences all of them**

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# Your Question: “What can I expect?”

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# With dementia, what is the loss? What is the change?

- It's complicated
- Unstable change in a partner
- Unstable change in at least one relationship
- Unstable changes in routines and patterns
- Inconsistent changes in many areas = instability
- Unstable availability of support

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# The changes that happen with dementia are unique in so many ways

- The changes are not always predictable, so you keep going back and forth: are the abilities gone or not?
- The changes are not always present, so when they show up again, it can start the whole series of reactions over.
- The changes are sometimes sudden and sometimes very slow, which can make it harder to feel that you know what to do or how to cope.
- The changes are invisible to many people much of the time, which can make you feel as though you are grieving alone.
- The changes keep on coming and you can't seem to get to a new normal, which is exhausting and can trigger a return to previous processing.

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# A loss happens or is Identified and we try to take it in....

- What??
- Why??
- How??
- What Can I Try??
- Pause and Reflect: Is it Helping???

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# States of Grief and Loss:

- **Disbelief – Shock – Denial**
- **Confusion: trying to make it make sense, trying to negotiate or bargain to establish some sense of taking control**
- **A sense of relief that the uncertainty is over and the transition is done, but guilt due to that *sense of relief* or a feeling that “I should have done more or better” or “What if...?”**
- **Anger due to a sense of unfairness**
- **Sadness due to missing something, someone, or somewhere**
- **Fear: anticipatory distress due to feeling “What else?” or “What’s next?”**
- **Remembrance due to moments of shared satisfaction or pleasure**
- **Acceptance: new normal, with sneaky peaks of pain**

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# Time Frames for Grieving:

- No set time frames for going through grieving and reaching a new normal for going forward and being more comfortable with the change
- Anniversary dates are usually powerful
- First times without or with the change are usually powerful
- Another loss that is similar or related in some fashion are powerful
- Unmet personal human needs are powerful
  - Hunger or thirst
  - Fatigue
  - Pain or discomfort
- Environmental cues can be powerful: sensory, spatial, social, or surface contacts

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## Possibilities to Try:

- What are you feeling?
- How deeply, frequently, and extremely are you feeling it?
- When have you felt this way before?
- What helped last time?
- How would you apply that or modify it based on the last time?

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# General Resources on Grief and Loss:

- <https://www.helpguide.org/articles/grief/coping-with-grief-and-loss.htm>
- <https://www.psycom.net/depression.central.grief.html>

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