

*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 Two

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There seems to be a lot of grief in dementia:

As a care partner, I feel like I am always in a grief state:

- Grief over the loss of my loved one, who is very different than she used to be
- Grief over the loss of my life as I hoped it would be
- Grief over the loss of other relationships I am having difficulty maintaining because I am so immersed in my loved one's care
- Grief over the death of another loved one that I cannot fully process because I am too busy in my caregiving role and I don't have the bandwidth available
- Anticipatory grief of what is to come ...

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Question: “Is What I Am Feeling Normal?”



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The real question is not if it is *normal* but rather is it healthy or helpful to feel this much grief all the time?

My answer is:

This much grieving is rarely healthy or helpful for:

- Your own health and well-being
- Your effectiveness in your care role
- Your relationship with the person over time
- Your ability to process the loss of someone you loved while filling your awake time with care

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With dementia, what are the losses? The changes? The additions?

- 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 for you
- It progresses and then reverses, and then progresses
- It adds things to your time and task plate, not removing any, unless you find a way to share the load by seeking something or someone new to help
- It is easy to be overwhelmed by what you see as *losses* and are not able to recognize as *changes*

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What are the core risks in seeing something as a loss versus a change?

- You will focus on what is no longer possible and simply add something to your plate, whether you want it, can do it, or like it.
- You will miss out on what the person is still capable of doing, causing potential conflict or frustration on their part.
- You will get surprised and then emotionally distressed any time the ability re-appears, even for a short window of time, because it feels wrong. You will not be able to see it as a gift and a moment to celebrate, if you embrace it.

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What are the core risks in seeing something as a loss versus a change?

- Losses have a sense of permanence whereas changes have a feel of temporary or just different: you have something else, you are not just losing out on something
- Over time as the person changes more and more, you view them as less, not just different and there is huge risk of de-valuing that person's perspective, ideas, emotions, reactions, and abilities. You will miss what the person still has to offer and still can do.

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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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Consider: What state are you in for each?

As a care partner, I feel like I am always in a grief state:

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