

*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 Three

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Talking about Death with Someone Living with Dementia:

- How do I tell my loved one (living with dementia) her spouse died?
- Isn't it a necessary part of the grieving process for her to know he has died?
- What if my mom forgets every time I tell her and when I keep answering her repeated question (where's spouse?), she acts like she is hearing it for the first time every time?
- Do I answer the same way?
- Will she ever move on with her grieving?

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

- It's complicated
- Unstable change in memories: some will be lost, others changed, some variable
- Unstable change in understanding and living in relationships: flickers in time, place, situation, and people
- Unstable changes in routines and patterns: what happened, what should happen
- Inconsistent changes in many areas = instability, hence repeats and missing pieces

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

- Unstable availability of information to appreciate and understand
- It progresses and then reverses, and then progresses
- It adds things to your time and awareness memories, not removing any, unless you find a way to share the load by seek something or someone new
- It is easy to be overwhelmed by what you see as *endless repetitions* and what they experiences as a *brand-new loss* each time if you are not able to make some changes and offer support in the moment

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What are the core risks of not recognizing and adapting to the ever-changing nature of dementia and memory?

- You will focus on the concrete questions and situation – perhaps missing the more central expression of unmet need or emotional distress
- As a pair you will get locked into a dance: a conversation that is doomed to repeat itself without completion or forward movement, cycling over and over for both of you

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What are the core risks of not recognizing and adapting to the ever-changing nature of dementia and memory?

- You will get surprised and then emotionally distressed any time the question or person re-appears, even for a short window of time, because it feels wrong. You will not be able to see the person without feeling the stress or distress: person=distress
- Your loss of the other person is permanent, but the PLwD may hold on to that data as temporary and then go back to older memories, or missing the vital one

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

- The changes are not always predictable so the person keeps going back and forth: is the ability gone or not?
- The changes are not always present, so when someone is missing, it is new info that may need to be checked out
- The changes are sometimes sudden and sometimes very slow, which can make it harder to cope – they may be needing reassurance or information
- If holding on to something is not possible, what are the options?
- If repeating the same thing isn't going somewhere good, what else could be done?

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A loss happens or is identified and we try to take it in:

- What????
- If someone dies – **to share this info or test the waters**, find out what the person thinks and remembers before sharing what you know
- Before all else, **get connected** with the person and provide a time and space for comfort: what calms and connects the person to you? **Set the stage and the scene.**
- What **emotion** is the person expressing: seek it out, use empathy and reflection. Offer info that builds from where the person is and see how far you sense the person can go – be prepared to travel alongside them.

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A loss happens or is identified and we try to take it in:

- Each person deserves to know of a loss of someone they hold dear: **One Time**
- If the person is repeating a question regarding the whereabouts of their loved one, consider the possibility that their brain is simply not able to hold onto the information or their heart cannot tolerate that loss right now

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Helping Someone Move Onward:

Guide quickly through:

- **Disbelief – denial – what is true – the person is not here when you want/need them: provide support, not data.**
- **Confusion – sense of loss – negotiating the absence: offer yourself in substitution**
- **Emotional release: acknowledge and respond to the emotions as expressions of distress, loss and grief**

- **Remembrance: support memories of love, comfort, joy, connection**
- **Acceptance: support the person accepting you and now in substitution**
- **Celebrate your success and the new normal!**

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