

Helping People with Dementia Deal with Loss and Grief

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Most important for us to remember when telling a person with dementia any “emotional” news is that the person with dementia still has his/her emotional memory intact. While their emotional memory is intact, however, their ability to deal with emotions rationally, logically, and/or reasonably is greatly impacted by their dementia. So that person’s response to emotional news may be worse or less than we expect. In addition, where their disease process is challenges their responses even more so. Thus, we need to approach loss and grief with a greater awareness based on these facts. Most importantly, we need to keep it simple and reassuring and follow their lead.



Listen to the Emotion Behind the Questions/Words

Appreciate the fact that the person with dementia has emotional memory. Thus, don't dismiss it or underestimate its power. If the person who has died was active in the life of the person with dementia, we need to be honest about why that person is no longer here. Making up stories like “he’s at work”, “she’s out right now”, can leave the person with dementia expecting they are coming back and when they don't, this is more upsetting for them. So respect their right to know the truth.

Be honest but keep it simple. Use direct words and not a long explanation. If it is to initially announce that someone has died, have only one person do this task. Too many people explaining at the same time can confuse and overwhelm the person with dementia. Have one person explain that a loved one “has died” and offer the same comfort (i.e. hug or rubbing back or taking one’s hand) that you would offer if the person didn't have dementia. Gauge how the person with dementia responds to see how much they are recognizing “the death”. Depending on where they are in the disease, they may grieve as expected or may appear more confused and continue to ask questions. Some may not react at all, again, depending on where they are in the disease process.

If they keep asking, continue to keep it simple and use the same words. Respond to their grief by reassuring them of their impact on the person who has died. For example: “You took wonderful care of Dad.” “You were a wonderful husband to Mom.” This validates their love/feelings for the person who has died.



Read the emotion behind the words they say. Often after someone has died, the person with dementia will ask for them again and again – hours, days, weeks after the death. They are unable to remember this “new memory”. But, they may be asking because they are worried about the person.

Where is your Father? I can't find your Mother.

Rather than repeat over and over that their loved one has died, reassure their emotions with a simple statement like “he’s okay, he’s fine now”. Perhaps saying, “she’s in a good place and doing great” comforts them even on a spiritual level. But, follow their lead with how much to say and what words to use. Keeping it vague and generic often works because the emotion behind their question is not “what happened” but rather, “should I be worried”. By saying “he’s fine” lets them know everything is okay and they don’t have to worry. They really don’t need all the details, which they can’t process. They just want to know if the person is okay.

Did he die? Is your mother dead?

At some point, the person with dementia may come right out and ask, “Did he die?” or “Is she dead?” Once again, listen to their words and follow their lead. If they use the word dead/die, be honest by answering “yes” and reassure the person with dementia how much he/she helped and loved the person who died. For example: “You took such good care of Dad, Mom.” “Dad you never let Mom go without.” This may help ease and/or prevent hopeless or powerless feelings. They did all they could do for their loved one. This is reassuring.

Validate the Feelings and Emotions of the Person with Dementia

Again, by gaging their response, read if they need more comforting, solace, more to be said. Rather than focus on the details of the death, validate how difficult it must be to hear this and feel it. If the person with dementia likes to be hugged or hand held, do these things. Comfort them through physical touch. Acknowledge their sadness. Reminisce about the person’s relationship with the person with dementia, careful however, to avoid words like “remember”. For example: “That time that you brought Mom roses when it wasn’t her birthday or anniversary – you really hit it out of the park, Dad.” “The cake you made for Dad every year was one of his favorite things.” Reminisce by stating facts, telling a story rather than using words like “remember when you...”



And when you feel it can be respectfully done, re-direct their attention to something more positive. Giving them time to grieve is very important. Leading them to a more positive moment after they’ve expressed their grief is equally important. They have more difficulty refocusing (or may be unable) so helping them to re-direct their attention on something positive is key to their emotional health. Knowing what brings them joy, what makes them smile, what makes them feel safe and loved comes in very handy at moments like this.

Have that knowledge in your tool box to pull out as necessary and use to comfort and console the person with dementia.

Their Expression of Grief Also Reflects Where They are in the Disease

Some families are surprised if the person with dementia doesn't appear to be as upset as expected. Adult children can be shocked, for example, that Mom isn't mourning or devastated over Dad's death. They may try to "remind" the person that someone has died. Don't project your own grief on the person with dementia. Everyone handles grief in their own way and this is no different for the person with dementia. Add to that personal "grief style", the fact that the person with dementia may be beyond processing what death means, due to where their disease is. Trying to get them to acknowledge a death if they cannot is not helpful to anyone. Let them grieve how they best can and remember, it's about their feelings, not ours.

