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To Tell or Not To Tell: Discussing a death with your loved one.

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“My sister just passed away, I don’t know how I am going to tell Mom,” says Mary, referring to her mother who is in the **early stages** of Alzheimer’s disease. “I feel that it is only right to tell her since it is her oldest daughter, but I also think this news might really upset her; what should I do?”

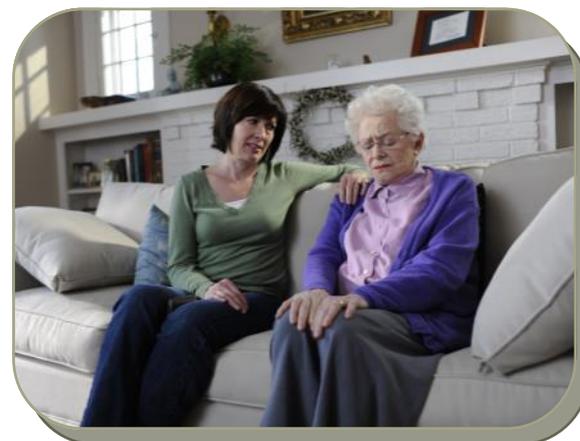
What Mary is going through is not unique. Many family members feel obligated to tell a person with dementia that a loved one has died, yet do not want to cause them additional depression or anxiety. It is difficult for family members to know when and how to discuss this topic, let alone if they should discuss it at all.

Dealing with grief and loss is something many of us have to do at some point in life. Grief is a necessary and natural response to the loss of someone very dear. A healthy brain can process grief and loss, but with dementia the brain cannot process the experience the way it used to.

People with dementia experience many types of personal loss: memories, sense of self, skills and abilities, judgment, reasoning, independence, and other areas of cognition. When confronted, people with dementia will not be able to adjust to the death, even if the loss was someone important to them. People living with dementia cannot manage the various stages of grief. They lack the ability to make reason out of reality and pain which mitigates their ability to adjust to life without their loved one. So the question: To tell or not to tell?

If Mary tells her mom...

Since her mom is in the **early stages** of the disease, it is likely that she is still capable to retain memory in some capacity. She may have difficulty remembering names or familiar



words, but when her mom does remember she is able to demonstrate appropriate emotion. When Mary offers a prompt in way of a name or a picture, it is very likely that her mom will still remember her oldest daughter. Mary may notice that loss of cognition does not equate to loss of emotion.

Her mom will be upset about the death of her daughter; there are tips and tools that Mary, as the caregiver, can use to support her mom so that the grieving process will be as natural as possible.

Mary should be compassionate, understanding, and kind when communicating the news. It is difficult to affirm such news to another, especially since Mary is grieving the loss as well. It is important for Mary to be as calm as possible, because her mom will mirror Mary’s emotions.

Mary’s participation in a support group provides her with knowledge from caregivers like herself. This support highlights the importance of finding a time of day when her mom is rested and at her best. Mary is encouraged to add non-verbal communication such as holding her mom’s hand while speaking to her. The best thing for Mary to do is to talk one-on-one with her mom because a



DO's

- Give short, one sentence explanations
- Allow plenty of time for comprehension, and then triple it
- Repeat instructions or sentences exactly the same way
- Eliminate "but" from your vocabulary substitute nevertheless"
- Avoid insistence, try again later
- Agree with them or distract them to a different subject
- Accept the blame when something is wrong (even if it's fantasy)
- Leave the room, if necessary, to avoid confrontations
- Respond to the feelings rather than the words
- Be patient and cheerful and reassuring
- Go with the flow
- Practice 100% forgiveness

DON'Ts

- Don't reason
- Don't argue
- Don't confront
- Don't take it personally
- Don't question recent memory
- Don't remind them they forget

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group may become overwhelming and increase her mom's anxiety.

Mary might choose to use euphemisms such as "passed away" or "at peace now." Since her mom is in the early stages of the disease she may be able to understand what Mary is saying. However, Mary may notice that her mom might not be able to think through the news because she is no longer able to concretely understand the situation. Her mom may become more confused. While her mom is in the early stages Mary should be prepared to frequently repeat the information if mom is unable to understand. Mary may even choose to repeat the information in a different way. When talking to someone with dementia it is best to break the news as directly as possible.

If her mom were in the **middle to late stages** of the disease she might show physical and verbal aggression upon hearing such news. It is highly likely that her mom would not be able to appropriately process or express her emotions. This is because in the middle to late stages cognitive abilities decline, causing behavioral changes. Although there are common behavioral symptoms associated with each stage of dementia, it is important to note that each individual goes through the disease differently. All in all, the key to helping a person with dementia cope is to be patient and compassionately responsive.

If Mary does not tell her mom...

Mary did not share the news of her sister's death in an effort to protect her mother from emotional pain. In the **early stage** her mom might notice the absence of her daughter and may ask Mary questions as to where she is. Mary must find tools to redirect the

conversation. Mary might say something like, "She is on a business trip; she will return soon." Mary can avert the attention from the loss and ask her mom: "Do you like traveling?" This might work temporarily, but it is also very possible that the same question will be repeated over and over. Mary can either use distractions, or repeat the same information in the same way.

When deciding if it is best to share difficult information it is best to consider the relationship of the deceased to the person with dementia. In this case, Mary's mother and older sister were not very close. They occasionally saw one

another on holidays and other family gatherings, but they did not have regular contact, so it is possible that the mom may not notice her daughter's absence. If the case was different it is likely that the Mom would be asking about her daughter's whereabouts.

Mary may notice that her mom may not be able assimilate the news because she is no longer able to concretely understand the situation. Her mom may become more confused.

It is difficult to predict the outcome when making the choice to tell or not to tell; individuals react to the news of loss differently. Some family members choose to tell their loved one with dementia about a death in the family and some family members choose not to. Regardless of the decision, education about dementia is helpful. Caregivers who are knowledgeable about the disease have realistic expectations for their loved ones with dementia. Education provides an awareness of the particular stage of dementia and this knowledge better informs caregiving techniques. Remember, you do not have to go through this alone. Ask friends and family members for help and guidance. No one should have to face difficult times alone.

"Have patience. All things are difficult before they come easy." —Saadi



IMPORTANT TOOLS

Remember you do not have to go through this alone. Ask friends and family members for help and guidance. No one should have to face difficult times alone. The Alzheimer's Association is here to help you through this difficult time by providing education, care consultations, respite services, emotional support, guidance and support groups. Call us at 800 272-3900.