

Sharing Bad News

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Sharing bad news about the illness or death of a loved one is difficult under the best of circumstances. When it involves telling bad news to someone with Alzheimer's disease or dementia, the process becomes laden with doubt and confusion. Should you tell? How should you tell? Who should tell? And the list of questions goes on.

This article will address these and other complex issues. First, it provides guidelines to assist in making the decision to share bad news, for example serious illness or death of a loved one, with the person with dementia. Secondly, it offers suggestions to help with the process of telling the person with dementia bad news.

People with dementia can and do experience grief. They may grieve new, old or imagined losses. Helping them through the process of bereavement is an important on-going skill for family members and other caregivers.

The following information is applicable to most people with dementia. However, every individual and situation is different and needs to be addressed from that perspective. A team approach that may include family members, professional caregivers, clergy and other significant people will best meet the needs of the person with dementia.

When to Share Bad News

When a loss occurs, the first question to ask is: should you tell the person with dementia? This decision needs to be made thoughtfully and based on the person's current cognitive and functional status. The following questions will help in making this decision.

Will the person with dementia notice others are sad or upset? People with dementia have dementia-they're not stupid. In fact, they can be exquisitely aware of the emotional climate around them. They perceive the sadness of those close to them and respond to these emotions with distress even if they don't understand the reason for the sadness. The sense of fear associated with not understanding the reason for the sadness can be worse than the grief associated with the actual loss. The person may go through the grief process without understanding why.

Was the sick or deceased person a consistent part of everyday life? Even if a person with dementia is very impaired, he or she may recognize the absence of a caregiver or frequent visitor and notice a change in routine. While the person may not be able to verbalize concerns, behavioral changes may reflect the confusion experienced. Caregivers can help the individual with dementia process the loss at a level consistent with the remaining cognitive abilities.

However, if the person was important in the past but is not significantly integrated into current daily life, the person with dementia may not be aware of their absence and reintroducing him or her into their life as loss may only cause unnecessary pain.

Can the person with dementia process the loss?

When the person's cognitive abilities are so impaired he or she does not recognize caregivers or family members and has a limited awareness of people nearby, dwelling on the issue of the loss or illness of a loved one will not be helpful. Trying to force understanding will not help the person grieve or deal with unresolved issues. Remain aware of the person's possible response to the grief surrounding them and address that as necessary.

Why do you want to tell them? Lastly, evaluate the motivation to tell. Well-meaning caregivers may forget that the rules of dealing with people with dementia are different and assume the person with dementia "needs" or "has a right" to know about the death or illness of a loved one. This may be because this would have been important to the person before dementia or so he or she can participate in rituals. What is important in the life of the individual with dementia is the here and now and what's best under the current circumstances.

How to Share Bad News

Once you make the decision to tell the person with dementia bad news, choosing how to do this is equally important. The approach used can help the person cope with the loss in a more healing way. Individualizing the interactions to the person's strengths and remaining abilities will assist in the grief process.

How should you tell?

Choose the place and time carefully and to meet the needs of the person with dementia. Only under very rare circumstances can bad news not wait until morning. Try to arrange to tell the person at a time of day when he or she is rested and in a safe, comfortable, and private place. Avoid having large groups of mourners coming in together; choose one familiar person to give the bad news with other important people nearby to help if necessary. Arrange to have someone available to stay with the person if he or she needs support and comfort.

What do you say?

Simple is best. Use language that is appropriate to the level of disease. Avoiding the use of abstractions (i.e. "passed away," "loss of your loved one") can reduce confusion about the situation. Expressing your own feelings may help the person with dementia find the words to express theirs.

What do you do?

Again, keep things simple. If the person with dementia needs to interact with a person who is seriously ill, keep the visit short and in a supportive environment if possible. Be prepared to deal with both appropriate and inappropriate responses. Expect delayed and postponed reactions. If possible, try to have a support person available to provide additional help if necessary.

Helping the grief process - Rituals

Rituals are an important part of the grief process for many people. They can give a large measure of comfort and peace, and participation needs to be supported if this will help the person with dementia process the loss. Just because attendance at the funeral or services is expected is not a good enough reason. Sometimes it is necessary to modify or simplify rituals to make them manageable to the person with dementia. Having private visitation, arranging for participation in part of the ritual (for example, the funeral but not the burial) or having a local memorial service instead of traveling to the funeral are examples.

Reminiscence

Reminiscence is an important part of grieving for many people. The person with dementia may benefit from talking about the person or looking at pictures and sharing memories. This is healthy and will help the process of grief.

Empathetic communication

Caregivers can help the person process the information by using empathetic communication. Phrases such as "looks like," "sounds like," "seems like," followed by your observations, may put the person's feelings in words. Sharing your own loss can also help ("I miss him, too.")

Be responsive to the moment

Pay attention to the mood of the person and respond appropriately. If the person seems unaware of the change, don't try to force reality on him or her. If the person seems sad or angry, provide support for these emotions. Be prepared to revisit the experience or to never again address it depending on the response of the person with dementia.

Conclusion

The key to helping a person with dementia cope with the loss or illness of a loved one is to be patient and responsive. Remaining present in the situation will help responses be authentic and supportive. Take time to address your own feelings of loss or grief. Be honest with yourself and with the person with dementia. And don't hesitate to ask for help from others in dealing with other's grief or with your own.