Working through grief with dementia

By Kate McCarthy, Director of Operations at HomeAid Health Care

We all experience grief. Unfortunately, at one time or another everyone will suffer a loss of someone dear to them. Although people grieve in different ways depending on the nature of their relationships and their past experiences with loss, the grieving process is quite normal and necessary. Grieving helps an individual adapt and accept the reality of their loss, work through the pain and adjust to all the life changes caused by the death of their loved one.

Going through the grieving process is very difficult for people in general; but for people with dementia, the process can be far more complicated. People with dementia experience grief, but their reaction to their loss is largely affected by their own cognitive understanding of what has happened to their loved one, the connection they had with the person they are grieving for and how well they can express their sorrow.

It is wrong to assume that because a person cannot remember the name of their missing loved one they do not feel that loss in their lives. Those with dementia generally live with feelings that things are not right, or a constant state of “wrong-being,” but are usually unable to put their finger on what the problem is. Most individuals suffering with dementia are somewhat aware of their confusion and live with grief over lost abilities, memories and understanding. Add in the loss of someone dear to them and their confusion can be compounded. Grief and the mourning process can be experienced by those with even advanced dementia, regardless of their cognitive ability to resolve or make sense of their feelings. So in most cases it is better to share the news of a death than to try to pretend nothing has changed.

There are several considerations to keep in mind when helping a bereaved person with dementia work through grief.

- Choose carefully when to share bad news – According to Melanie Bunn, RN and Alzheimer’s training consultant, consideration must be given to the bereaved person’s cognitive condition when choosing when to share the news of a loss. Select a time of day when the bereaved is rested and feels comfortable and safe. Many people suffering from “sundowners,” a type of dementia, find late afternoons and evenings especially challenging and would be better able to process difficult news in the morning hours.

- Choose carefully how to share bad news – Have a familiar and trusted person talk to the bereaved in a clear, calm and simple manner. It is best to have only one person relay the news of a death. People with dementia can be deeply affected by the emotional climate of grieving family members and respond with increased agitation and restlessness. Experts advise avoiding abstract phrases like “passed away.” It is much more effective to plainly state that the person “died.” Keep sentences short and do not overwhelm the bereaved person with dementia with too much information at once. Be prepared to
frequently repeat the information as they will need time and repetition to process it. Do not be surprised by a delayed reaction or lack of response.

- Help the immediate grief process – Those suffering from dementia can benefit by participating in the rituals of death. According to the article, “Sharing Bad News,” by Melanie Bunn, it may be necessary to modify rituals to make them more workable for the person with dementia. She suggests private visitations rather than participating in public gatherings, attending the funeral but not the burial or hosting a local memorial ceremony rather than traveling great distances to attend a funeral.

After the funeral, it is helpful for the individual suffering from dementia to reminisce about their loved one. Talking about memories while looking at a photo of the deceased will aid in the grieving process. Often the person with dementia needs help expressing their grief and speaking to them using empathetic phrases will help them verbalize their mourning. According to Alzheimer Scotland’s article, “Loss and bereavement in people with dementia,” phrases like, “You sound like you really miss him. Tell me what you miss about him most.” aid those who have a hard time finding words to express the emotions they feel.

- Help with long-term grief – Constant assessment of the cognitive state of the bereaved is very important. Ignoring the mood of the day and trying to force a person with dementia to understand a death can be detrimental to the grieving process. Try to have all people in contact with the person diagnosed with dementia be consistent and patient as they work through their grief over time.

By focusing on the person with dementia and validating their emotions, even though the source of the emotions are lost to them, the grieving process will be made easier for the person suffering from dementia and the entire family.

Sources:  
“Sharing Bad News” by Melanie Bunn  
“Loss & Bereavement in People with Dementia” by Alzheimer Scotland  
“Grief and Dementia” by Kenneth J. Doka

Kate McCarthy is Director of Operations for HomeAid Health Care which provides non-medical home services for the elderly who wish to remain safe and independent at home. HomeAid is a sister company to Prairie Home Assisted Living which has served the physical, spiritual, mental and health needs of their residents since 1999. Together the two companies provide comprehensive care that meets the needs of the elderly in the Fox Valley.