

A Look at Grief

When a loved one has dementia
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Dementia creates losses for the person living with dementia and those around them, and these losses can cause someone to grieve. Grief is a normal response to the loss or anticipated loss of someone or something that is significant to us and can include many different reactions. It can leave us feeling empty and numb, we may be angry and have feelings of guilt, we can feel a lack of energy, have confusion, and changes in sleep patterns, we can have trouble making decisions, focusing, and sometimes we will even withdraw from people and activities that were once important to us. These feelings and responses can have a big impact on our life and can feel overwhelming when we combine it with a significant loss.

Grief is a natural and normal process and is individual to each person who experiences it. There is not a formula or timeframe that each person will experience. Therefore it is important for us to recognize that the process and timeframe may look different for each person. When someone is grieving, supporting them in the process and allowing each person the time and space to grieve their loss will be critical to grieving a loss in a healthy way.

There are many things that we grieve when it comes to dementia. We grieve the loss of relationship, a change in family roles and dynamics, and an unexpected change in our way of life. Sometimes we grieve the fact that other family members are not supportive and respond to dementia in ways that we feel are not helpful. Sometimes we grieve choices we have to make such as having our loved one live in a facility rather than their home. We grieve the anticipated loss of our loved one and then we grieve when they die.

Grief, like life, is a cycle and when we are able to go through this cycle with support and understanding, grief can lead to the person being able to move forward in their life. The stages of grief include: denial, anger, bargaining, sadness, and acceptance. Each stage helps us work through and deal with loss. When we are in denial, anger, and bargaining, we are trying to protect ourselves from the shock, fear, and/or anticipation of the loss of someone or something important to us. While these reactions are natural and normal, it is important not to get stuck in them because they do not complete the cycle. What does it look like to get stuck? It looks different for different people. Therefore, it is also important to not judge ourselves or one another when we or someone else is grieving. When we hold on to our denial, anger, or bargaining in a way that becomes unhealthy, we may be getting stuck. Since these steps in the cycle can buffer us from the shock and pain of a significant loss, they do have an important place. But when we stay in these steps and don't move forward, it can make things more difficult for us and for those around us. For example, someone who is diagnosed with a terminal disease may opt for an aggressive treatment. At some point, if the treatments do not have the intended outcome, what is helpful is to step back, reassess the situation and the

possibilities, and begin to have new conversations. The new conversations will become more about quality of life and end of life rather than a curative treatment.

Being supportive for someone who is grieving the loss of someone with a diagnosis of dementia includes having an understanding of the disease process; what is possible and how to help celebrate the life being lived in the present moment as well as understanding that grief can happen in each stage of the disease.

The step in the cycle after bargaining is sadness. Sadness is difficult to both experience and to watch people go through, but it is an important step because sadness leads to acceptance. Acceptance is a place where we can begin to envision life again. In acceptance we can still be sad, we can still miss our loved one, our relationship, and we can still miss what could have been, but we also can move forward. Because grief, like life, is a process, we can move back and forth, in and out of the different stages during our life. For example, when there is an anniversary, birthday, or significant time, we can experience sadness, anger, a sense of disbelief, or we may feel guilty about things we may have or may not have done.

We will experience grief when someone lives with dementia and the person living with dementia may experience grief as well. However, as with all things in life, understanding and supportive environments and people will help someone who is grieving. If you are the one who is grieving, be compassionate with yourself and find people and places who will support you in your own individual process. If you know someone who is grieving, try to see their process as unique and individual and give them the space and support they need to be able to work through their loss.