

Maintaining Relationships

Understanding how dementia affects relationships and what will help

Maintaining relationships throughout our life helps us develop our identity and a sense of connectedness with others. A diagnosis of dementia will affect relationships both within and outside the family. It is not unusual for family conflicts to arise as dementia progresses and roles and responsibilities change while key decisions need to be made. Social relationships are also impacted for the person with dementia and for the caregiver. It is important that persons with dementia continue to have opportunities to engage with friends and family and for the caregiver to maintain relationships with others.

How dementia affects family relationships

Family relationships and communication patterns are formed before dementia is diagnosed. Previous life experiences and situations can affect the family dynamic and result in fragile family relationships. For example, it is possible that, in the past, there has not been a loving relationship with the person with dementia. How a family responds to the diagnosis of dementia varies and depends partially on the strength and coping mechanisms of the family. Even when family relationships are positive, emotions may be on a continuous roller-coaster ride.

- **As a spouse:** You will become responsible for someone who has previously been a partner. This could result in feelings of resentment, loss of emotional support, social isolation, abandonment, and fatigue.
- **As a daughter or son:** You will face a role reversal in caring for your parent. If you have siblings, you will all need to work together to share responsibilities and make important health care decisions. This could result in feelings of resentment, guilt, anger at unequal sharing of caregiving, and feelings of being ignored due to “caring from a distance.”
- **As a grandchild:** Children and teens can be confused and upset by the changes they are seeing in a parent or grandparent with dementia. This can result in

feelings of not being welcome, resentment at having reduced time with parents, and feeling deprived of experiencing the grandparent relationship. On the other hand, it can also provide the grandchild with an opportunity to learn about caregiving.

- **As a friend:** Many friends withdraw and ‘disappear’, because they can no longer bear to see the changes that are taking place in their diagnosed friend and may not understand the effects of the disease.

Providing care for a family member with dementia can cause new sources of stress within the rest of the family. Some family members may not be able to accept the person’s illness; you may resent the lack of help from other family members who don’t feel able, for whatever reason, to help out. You may also disagree on decisions about finances and care. On the other hand, caring for a person with dementia may cause families to come together, grow closer and find unexpected rewards in caregiving. Whether or not the experience is positive dementia is a family experience, one that is shared by all.

Maintaining relationships with others

It is important to develop a plan of care that uses the strengths and abilities of family members and friends as caregiving needs evolve and family dynamics change. This will keep everyone involved, as they are able, and will maintain connections with each other. Some of the items to include in a plan are:

- Task lists.
- A monthly schedule of appointments, visits, etc.
- Team meetings to resolve issues. Refer to **“When Families do not Agree” Fact Sheet** www.alzheimer.ca/ottawa
- Communicating with health care providers and long distance family members.

Positive communication

Positive communication strategies are needed as you work together to provide care. Good communication is evident when you spend time talking, share feelings, face conflict honestly and openly, try to resolve problems with win-win methods, show understanding for feelings and ideas, develop speaker and listener roles, communicate verbally and non-verbally, recognize what actions say, and communicate directly with each other.

Communication in the family unit should involve all family members including the person with dementia. There are strategies that you can use to enhance your communication with the person who has dementia. You can find more information regarding these strategies at <http://www.alzheimer.ca/en/Living-with-dementia/Helping-with-communication>

Understanding and acknowledging feelings

One of the most important strategies for coping with the effects of dementia is to understand and acknowledge feelings. Naming feelings and their affects helps caregivers to understand how to help themselves and to seek support and help from others.

Caregivers often experience a continuous and profound sense of loss and subsequent grief as they experience the changes associated with the progression of the disease. There may be grief for the losses that are occurring in the caregiver's life as well as in the life of the person with dementia.

Grieving is an up and down process. In the early stages of the person's dementia, you may swing between despair and wild optimism that a cure will soon be found. You may even deny that anything is wrong with the person and try to suppress your feelings. Later, as you gradually accept the situation, you may find that there are periods when you can cope well and make the best of things. At

other times, you may feel overwhelmed by sadness or anger, or you may simply feel numb.

Feelings like these are a normal part of grieving, but it is also important to realize that you may be under a great deal of stress and may need to seek emotional support. For more information on how to cope, refer to the ***"Grief Related to Caregiving" Fact Sheet*** available through the Alzheimer Society of Simcoe County.

Funerals and deaths in the family

It can be particularly challenging to decide how to break the news of a close relative or friend's death to a person who has dementia, and, to decide if the person with dementia should be part of memorial events.

How do you break the news? When do you let them know? How much information do you provide? Should they attend the memorial service? There is no one answer to these questions as each person with dementia is unique and each family situation is different. As a family you will need to decide on a course of action. However, be prepared to amend it as your plan may change based on the reactions of the person with dementia. What is important is that you discuss this as a family and, if appropriate, discuss with others such as health care workers, who know the person and how the person with dementia is coping. A good resource to read is from the Alzheimer Society of Guelph-Wellington: ***"Funerals and deaths in the family"*** www.alzheimer.guelph.org/

In closing

Take the initiative to contact family and friends and explain that while dementia has changed your lives in some ways, you value their friendship and support. Consider inviting a few friends or family members over. Let them know in advance of any physical or emotional changes in the person with dementia. Provide them with

suggestions about how to communicate with the person and what activities they might be able to do together. Remember, maintaining relationships is important for both you and the person with dementia.

This Fact Sheet is provided courtesy of the Alzheimer Society of Ottawa and Renfrew County

Further information on this topic

Visit the following websites:

- www.alzheimerbc.org
- www.alzheimer.ca

August 2013

