

Coping With Changes in Relationships

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When a family member develops Alzheimer's, your life is inexorably changed. Over time, it is likely you will assume responsibility for tasks you never thought you would be expected to handle. Issues such as management of care, confusion and misunderstandings about what the person with dementia needs, and changes in family structure can cause tension, stress, and discord for many families. As a caregiver, you may often feel alone or disconnected from others. However, while your relationship with the person for whom you are caring will change, it can remain meaningful and rewarding. You can take steps to adjust your expectations of relationships and maintain the support you need.

Adjusting to Changes in Relationships

Caregiving has a dramatic impact on your relationship with the person with dementia and with other family members and friends. All of us have a place within our families that has developed over time. However, Alzheimer's disease can threaten these familiar roles. Some families discover that old relationship battles with the person with dementia come to the surface. Reconciliation and resolution of these past hurts may not be possible due to changes caused by



Alzheimer's Association

Alzheimer's. In addition, conflicts with other family members may reemerge under the strain of giving care. Seeking out a professional, who is a skilled counselor and thoroughly understands the challenges of Alzheimer's, is helpful for many families.

When a parent develops dementia, it is natural to want to remain in the traditional role as son or daughter. In Dan Kuhn's book, *Alzheimer's: Early Stages*, one daughter speaks to this by saying, "I do not want power over my mother. I am her child. I want to be her child." Although you may find yourself taking on more care responsibilities for a parent, your relationship with your mother or father will always reflect the history you have shared.

continued on page 2

Tips for Adjusting to Changes in Relationships:

- Set realistic expectations for the person with dementia.
- Remember that changes in relationships are normal; expect and accept changes as they occur.
- Recognize your limits.
- Allow yourself to grieve the loss of the relationship you had.
- Focus on what you are still able to do together.
- Hold on to your memories; realize you cannot change the past.

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continued from page 1

As Alzheimer's disease progresses in a life partner or spouse, that individual gradually loses the ability to fulfill part of the "nurturing bargain." It becomes more difficult to be a partner, friend, helper, advisor, and intimate companion (see related article on pg. 3). In order to continue to find emotional satisfaction within the relationship, you will need to redefine your expectations. Needless to say, this requires flexibility and patience.

In their book *The Best Friends Approach to Alzheimer's Care*, Virginia Bell and David Troxel point out that caregivers are often distressed at how their relationship with the person with dementia changes. They suggest that families "recast their relationships with the person to embrace a model of friendship." By doing this, caregivers are better able to look at present interactions and form new relationships by accepting persons with dementia as they are now.

Maintaining Your Support Network

It is easy to become isolated from people who provide you with support and enjoyment. This can happen without your realization. Here are some ways to help maintain ties with friends and family and gain needed support:

- Inform them of the diagnosis; provide education about the disease.
- Evaluate your expectations of yourself and take a look at what responsibilities can be shared.
- Use community resources, including support services available through your local Alzheimer's Association chapter office.
- Share your feelings with a friend, support group, or spiritual leader.
- Return to some of your normal activities, such as golf or gardening.

Accepting People with Dementia for Who They Are Now and What They Are Able to Offer. Alzheimer's disease robs persons with dementia of their familiar place within the family, and the world. They are often very aware of these changes. Comments such as, "I feel as though I have fallen into a deep, dark hole," "The days used to go by so fast, but now one day seems like a year," and "I feel so useless...as though I should be doing something. But I don't know what to do," demonstrate this deep sense of loss. You can enable the person with dementia to be a more successful contributor by changing your expectations and showing appreciation for his contributions.

Conclusion

All families are unique; there is not a "one size fits all" answer. Having realistic expectations of the person with dementia, adjusting your approach to the relationship, and seeking support from family, friends, and community resources may allow you to continue to provide care in a way that supports the person as they are. It can also help you find emotional support throughout your journey.

The Alzheimer's Association offers many options for assistance, including a 24/7 Helpline, care consultation services, and support groups. Help is available by calling 800.337.3827. •

Support Groups Offer Help and Hope

Take time to get the support you need. Talk with a friend or attend an Alzheimer's Association support group in your community. Caregivers indicate they attend support groups because friends and family often do not understand the challenges of caregiving. All support groups are free of charge and offer a confidential setting where caregivers can talk openly about their feelings.

A support group gives you an opportunity to:

- Share your experiences and be understood
- Increase your feelings of self-worth
- Decrease your sense of isolation
- Learn from others in your situation and about helpful resources
- Receive encouragement and moral support from other caregivers
- Receive help with problem solving
- Receive updates on treatments, research, and dementia care strategies

To locate a support group in or near your community, call the chapter office nearest you at 800.337.3827 or visit www.alzmidgreatlakes.org. If you need someone to stay with your loved one while you attend a support group meeting, please call the office for a list of respite providers in your community. Please join us at an upcoming meeting. •

Addressing Sexuality and Intimacy Issues

If your spouse/partner has Alzheimer's, you will likely experience significant changes in your intimate relationship as the disease progresses. While there is no single best approach in adapting to the changes in an intimate relationship, the following tips may help you respond to these changes:

- *React to your spouse/partner with patience and gentleness.*
- *Provide physical contact in the form of hugging, stroking, or patting.*
- *Offer reassurance through touch and gentle, loving communication.*
- *If the person fails to recognize you, you may be unsure if the person can consent to sex under such circumstances.*
 - *Look for verbal and non-verbal signs.*
 - *If the person seems willing and able to enjoy the encounter, sex can provide connection and closeness.*
 - *If the person shows fear or reluctance, respect that.*
- *The person may repeatedly initiate sexual encounters because he or she forgets just having sex.*
 - *Remember it is acceptable to say no.*
 - *Use delay tactics; the request for sex may be forgotten.*
 - *Consider sleeping in separate bedrooms.*

For more information on sexuality and intimacy issues related to Alzheimer's disease, call the chapter office nearest you at 800.337.3827. •

Resources

Books

"The 36-Hour Day"
(Third Edition)

Mace & Rabins, 1999
\$12

Combines practical advice with specific examples and covers the medical, legal, financial and emotional aspects of caring.

"Alzheimer's Early Stages"
(Second Edition)

Kuhn, 2003
\$15

Discusses practical ways to manage the disease and offers advice on how to relieve caregiver stress.

"Behaviors In Dementia"

Kaplan & Hoffman, 1998
\$32

Presents best practices on preventive measures, intervention strategies, and staff training methods.

"The Best Friends Approach to Alzheimer's Care"

Bell & Troxel, 1997
\$25

Teaches strategies on how to solve problems, encourage positive behavior, and improve communication utilizing the strengths of the person with Alzheimer's.

"The Loss of Self"

Cohen & Eisdorfer, 2001
\$32

Provides practical guidelines on the general care of people with Alzheimer's.

Videos

"A Thousand Tomorrows: Intimacy, Sexuality and Alzheimer's"

Terra Nova Films
Available through

Chapter Lending Library
Explores issues surrounding intimacy, sexuality, and Alzheimer's.

To obtain these and other resources, call the chapter office nearest you at 800.337.3827.