

# **FAMILY RELATIONS AND CAREGIVING**

---

## **The Journey Through Caregiving**



# **FAMILY RELATIONS AND CAREGIVING**

## **The Journey Through Caregiving**

Materials developed by Greg Sanders, Ph.D.

North Dakota Family Caregiver Project  
North Dakota State University  
283 EML Hall  
Fargo ND 58105

North Dakota Family Caregiver Project  
North Dakota State University

2003

Developed for:

The North Dakota Family Caregiver Project  
North Dakota State University

This project was supported, in part, by award number 190-04642, from North Dakota Department of Human Services, Aging Services Division, Bismarck, ND 58504.



❖ **FAMILY RELATIONS AND CAREGIVING** **5**

---

**WHAT CAN I DO TO KEEP THE CAREGIVING ROLE FROM STRAINING MY RELATIONSHIPS WITH THE PERSON I AM CARING FOR AS WELL AS THE REST OF MY FAMILY?** **6**

COMMUNICATION 6

APPRECIATION 9

TIME TOGETHER 10

COMMITMENT 11

**SOMETIMES THE PERSON I CARE FOR DOESN'T COOPERATE. WHAT CAN I DO TO GAIN MORE COOPERATION?** **13**

**HOW DO I WORK WITH SIBLINGS, CHILDREN, AND OTHERS TO MAKE DECISIONS?** **15**

**HOW CAN I DEAL WITH OTHER RELATIVES WHO ARE CRITICAL OF MY CARE DECISIONS?** **17**

**I OFTEN FEEL ANGRY WITH MY BROTHERS AND SISTERS BECAUSE THEY DON'T HELP WITH CAREGIVING. WHAT CAN I DO TO IMPROVE THE SITUATION?** **19**

**I'VE NEVER GOTTEN ALONG WITH MY FATHER. NOW HE NEEDS CARE AND I AM THE ONLY CHILD AVAILABLE. WHAT SHOULD I DO?** **21**

**ON WHAT OTHER ISSUES SHOULD I FOCUS?** **21**

❖ **RESOURCES** **24**

---

## ❖ FAMILY RELATIONS AND CAREGIVING

Family caregivers, the first line of support to an elder in need, begin by helping an elder who is living in his/her own home but it can expand to full-time care and can continue even if the older person moves to an institution. The stress of caregiving, the need for decision-making, and the conflicts that might arise can affect the relationships of the caregiver with both the elder receiving care and with other family members.

Strengthening the quality of family interaction both reduces the stress and increases the rewards of caregiving. While relationships between caregivers and those receiving care are usually not extremely unfriendly, having a poor relationship can lead to greater stress, poorer care, and an increased likelihood of abuse and neglect. The decision to become a caregiver or to continue in a caregiving role should be based in part on the strength of the relationships among those involved.

In this module, we will take a family strengths approach to the issue of caregiving and will focus both on the caregiver-care receiver relationship and the relationships between the caregiver and other family members and friends. A family strengths approach is an emphasis on the positive qualities that strengthen family interaction. The question and answer format below describes a variety of issues families may experience and a number of characteristics which are strengths for families.

## **What can I do to keep the caregiving role from straining my relationships with the person I am caring for as well as the rest of my family?**

---

Taking a family strengths approach to caring relationships is important for the whole family. By focusing on the quality of relationships, we build the skills to weather difficult times, to make important decisions as a family, and to support each other as individuals. All of these aspects are important in a caregiving situation. Working on the following strengths will contribute to a more positive care system and provide more rewards for the family caregiver.

### **Communication**

Families' communication patterns have developed over time and can be positive, ineffective, or negative. Communication styles that include lots of negatives like sarcasm, put downs, and criticism increase the stress in relationships. Negative communication can put an already stressed caregiver into a crisis. Ineffective communication, such as not sharing feelings or not being specific, makes it difficult for families to work together and support each other in the care tasks. Positive communication both gets the message across accurately and emphasizes positive aspects of relationships or positive solutions to problems.

Good communication requires that we listen to each other and clearly understand the message that is sent. Because most disagreements are caused by miscommunications, it is often helpful to restate or rephrase the message to be sure you understood correctly. A key to effective communication is to not make assumptions about feelings and thoughts. Often our reaction is to

want to present a solution rather than to be a good listener and really understand the issue or feeling.

Example of jumping to a solution:

Susan (the care receiver): “I don’t like that woman coming over here to clean the house.”

Beth (the caregiver): “Oh, now, she is a nice person and does a good job.”

Rephrasing allows you to clarify the message:

Susan (the care receiver): “I don’t like that woman coming over here to clean the house.”

Beth (the caregiver): “You don’t think she does a good job?”

Susan: “Oh, she does very good work. It’s just that the vacuum is so noisy.”

Beth: “Perhaps we could use the time she is here to do our errands?”

Susan: “That’s a great idea.”

In this example, even though the rephrase was not accurate, it gave Susan the chance to restate her concern. This, in turn, allowed them to make a positive change.

Communication that focuses on the positive, is specific, and is both honest AND kind creates an environment for caregiving that is less stressful, more rewarding, and one in which many of the small problems can become easily solved.

In the following example, Mary is a caregiver of her dad and is visiting with her brother Steve. Mary becomes very frustrated.

Steve: “You should stop feeding dad all that health food stuff. You know he really likes a good steak.”

Mary: “ You criticize everything I do. Yet you never help!”

Positive communication can have a different result than the fight that may have ensued between Steve and Mary.

Steve: “You should stop feeding dad all that health food stuff. You know he really likes a good steak.”

Mary: “ I understand what you mean, dad does like his meat and potatoes. But his doctor said he should cut back on that, plus it is expensive and our budget is already tight. Do you have any ideas?”

Steve: “Well, what if I took him out to dinner once a week and he could have whatever he wanted? That would also give you a break from having him here.”

Mary: “That would help so much!”

## **Appreciation**

Appreciation, an essential reward in a caregiving family, should be given and accepted gracefully even for little things. Even if people “know” you appreciate them, they will not “feel” appreciated unless you show them. Conversely, a warm “thank you” in response to someone expressing appreciation for you will encourage continued expressions.

### **There are several ways appreciation can be used in the caring relationship:**

- **Express appreciation to the care receiver for things past and present, even if it is something small.** This shows the importance you place on expressing appreciation. It can also help the person receiving care feel that although he/she needs support, he/she still has something to give in return.
- **Make a weekly appreciation calendar for each family member.** Family members can write something on the calendar each week that they appreciate about you and each other.
- **Let each family member contribute to caregiving and have a special outing each month to show your appreciation.**
- **Do an appreciation silhouette by drawing an outline of each family member and writing within each outline all of the things you appreciate about that person.**

## **Time Together**

Caregivers often have a difficulty finding time to spend with family members. But it is important for your own well-being and for the quality of your family relationships that you find that time. If the person receiving care can be included in family time, that's great. But it is also important to take time away from the caregiving role.

### **Here are some ways to take time away from the caregiving role:**

- Find a good respite care provider.
- Have a respite exchange network with other caregivers.
- Have a rotation of caregivers for a few hours each week where one family member stays with the care receiver while the others do a fun activity.

Time together reduces loneliness and isolation and creates opportunities for positive communication and for creating family memories. While it is important to find time just to relax and talk with each other, doing activities together can set the stage for interaction. Physical activities especially can help reduce stress. Activities could also focus on enriching the social, emotional, and spiritual life of the family.

**Some examples of family activities could include:**

- Write a family history together with stories about accomplishments, humorous events, and special memories.
- Record the life story of the care receiver.
- Do a scrapbook of favorite family recipes, photos, family tree, etc.
- Create a new tradition to be shared during holidays.
- Go for a bike ride together.

## **Commitment**

Commitment to a family is a strength that can be demonstrated in many ways. Providing care and support for a family member is one. Taking time for other family members and working to build healthy family relationships is another. For caregivers, commitment implies understanding the aging process, the elder's health conditions, and how best to provide support. Other family strengths--communication, respect, appreciation--need to be expressed in an atmosphere that is free from negative myths about aging and focused on the reality of the care receiver's needs.

Caregiver commitment involves advocating for care receivers with physicians and other care professionals. Commitment doesn't mean keeping elders in your home at any cost. When elders need support that they can

only get from professionals in a long-term care facility, commitment means helping them make the adjustment and advocating for them in their new living environment.

For the family as a whole, commitment gives members a sense of security in knowing that even if there is disagreement over care issues, the family will stick together and keep working at it. Commitment ensures that the family will make the effort to find time together, to keep building communication skills, and to express appreciation even when things are stressful.

## **Sometimes the person I care for doesn't cooperate. What can I do to gain more cooperation?**

---

Dependent elders often feel a loss of control over their lives. They are no longer able to do many of the things they once could and they may feel inadequate and frustrated. Being uncooperative is one way to get back a sense of control. You can help gain cooperation by doing the following:

- 1. Consider the capabilities of the care receiver.** What is your family member still capable of doing on his/her own or with a little help? Knowing the abilities of the elder can help us assess the activities and decisions in which he/she can still participate.
- 2. Include the person in the decision-making process.** A sense of control can be enhanced by asking for the elder's participation in decisions ranging from meal choices to living arrangements. He/she can help you consider the available options and the positives and negatives of each choice. You can also learn more about the elder's preferences. It is important not to offer choices that are not realistic. For example, if the older person cannot drive safely, continuing to drive is not a choice he/she should be offered. However, getting a ride from the caregiver, a friend, taxi service, or a bus might be legitimate choices the elder could make.
- 3. Be patient in allowing the elder to accomplish the tasks they are capable of doing.** Even accomplishing small tasks can be important to someone who has declining abilities. We might find ourselves rushing to

button up elders' shirts or zip their coats. Although we mean to be helpful, we can be taking away another task from them and another piece of dignity. Planning for a little extra time to allow elders to accomplish a task can make them feel less dependent.

- 4. Be knowledgeable about how you can remove barriers to maintaining independence.** Often little things can make a big difference in task accomplishment. For example, shirts with zippers rather than buttons can make it easier for people with arthritis to dress themselves. In addition to removing these small barriers, being aware of support services can help the elder stay in a less restrictive environment.

## **How do I work with siblings, children, and others to make decisions?**

---

Making decisions together as a family can help reduce criticism about choices regarding care and enhance cooperation of all family members. If others are involved in making decisions, they are less likely to complain about them. If possible, a person should not have to be alone in making those difficult decisions about caregiving. Discussing decisions together, if done in a positive manner, can strengthen the entire family and improve the quality of care for the elder.

### **Consider the following basic guides to shared decision making:**

- Share information, especially with distant family members.
- Include the person receiving care in discussions whenever possible.
- Have the care receiver share his/her wishes with whole family when possible.
- Find a role for a variety of family members in the caregiver network.
- Work to maintain family strengths.
- Be educated about the care receiver's health problems and share that information.

**Focus on the issues by asking your family group a few simple questions:**

1. What is the specific issue that needs to be addressed?
2. What are the possible solutions to that issue?
3. What else do we need to know about the issue and what resources are available to help us?
4. What are the positives and negatives of each possible solution?
5. What are the feelings and concerns that family members have about the issue?

If family members can work together to make decisions and everyone involved feels that their views have been heard, most of the time the result will be more cooperation, strengthened family relationships, more sharing in the care responsibilities, and a higher quality of care for the older person.

## **How can I deal with other relatives who are critical of my care decisions?**

---

Following the process outlined above can greatly reduce the conflicts related to caregiving. Unfortunately, some family members may still be critical and some may refuse to be involved directly but still want to criticize. It can be helpful to try to understand what their real concerns are and reflective listening can help. They may feel guilty that they are not doing more and see critiquing your efforts as a contribution. They may also be fearful and worried about the changes in the family member receiving care and this anxiety may come out critically. Understanding the source of the criticism can help you to not personalize critical comments. Keep all family members informed about changes in the elder's status, needs that the elder has, and needs that you as a caregiver have. Sometimes it can help to have a person from outside the family lead the conversation with the whole family. Lay some ground rules using qualities of good communication discussed above.

If you can share your feelings about how negative comments make you feel and also listen to the concerns others have, the communication might become more positive. Critical people may even become a support over time if fears and misunderstandings are brought out in the open. It is easy to get defensive when others are critical of your decisions and efforts. This is especially true if you are a stressed caregiver doing the best you know how to do. If you can apply positive communication rather than defensiveness, you will be modeling a better interaction style and may even strengthen those relationships. Although you cannot control how others

react, you are more likely to get a positive reaction by being positive than by being angry and defensive.

## **I often feel angry with my brothers and sisters because they don't help with caregiving. What can I do to improve the situation?**

---

It is important to make caregiving a family matter rather than an individual one. The first step to making this work is to keep everyone informed about what is happening. A planned weekly call, meeting, or email can create regular opportunities to keep family members informed. Share information about the physical and mental health status of the care receiver, medications, events in your life, and specific caregiving requirements and the skills it takes to carry them out.

Second, find ways that everyone can contribute, even if it is in small ways. Perhaps a sibling could come to provide respite for a weekend. A niece could be your researcher by looking up medications and their side effects on the Internet. A nearby family member might provide a meal each week. Asking other family members for help makes them feel that they are a part of the caregiving network. As part of this “team” they may find other ways to help as well.

Enhance this cooperation by using positive communication discussed above. A family strengths approach is most appropriate here as family members must make a commitment to being part of caregiving, positive communication must be used to be an effective caregiving team, and appreciation makes being part of the care network rewarding.

It is also important that family members work to have a relationship beyond the caregiving role. Another strength, time together, should focus on common interests and activities, as well as sharing old family memories and

creating new ones. Families should be sure that once the caregiving role ends, the family ties continue.

## **I've never gotten along with my father. Now he needs care and I am the only child available. What should I do?**

---

Taking on the caregiver role for a family member with whom you have a poor relationship can increase the stress level considerably and set the stage for abuse and neglect. Ideally you should work to improve the relationship before taking on the full responsibilities of caregiving, but that is not always possible when there is a sudden change in health status or need. Applying the family strengths discussed in this module is critical to improving the relationship. As you use positive communication, show appreciation, and spend quality time together the relationship will likely improve. However, improvement will take time and patience. In some relationships, professional help may be required to deal with some difficult issues. A family therapist can help even if there are no major problems.

## **On what other issues should I focus?**

---

Along with building quality relationships and family strengths with all family members, there are a few other tasks that are important to caregivers:

### **1. Enhancing the elder's continued interaction and roles**

Sometimes we create barriers to elders' continued involvement in the family and community because we have not clearly assessed their abilities and we want to be helpful. In trying to help we sometimes take over things the elder could do and perhaps wishes to do. When we take away these roles and involvement, we take away the elder's sense of purpose and contribution, making them feel dependent and worthless. If we encourage and facilitate

continued involvement in and contributions to family, church, and community, the elder will be happier and more cooperative. Work with the elder, doctors, family members, and other professionals, to carefully assess the elder's abilities and to learn about the help that could be provided to support continued involvement.

*Example: Mrs. Olson had volunteered in her local community for years. After she broke her hip, she was less mobile and was unable to do her volunteer work at the local hospital. She began to feel that she was just a burden on everyone. After visiting with a local volunteer organization, Mrs. Olson's daughter shared ideas for volunteering that were appropriate for someone with her mobility challenge. Mrs. Olson started doing phone reassurance for "older people" in her community. She really enjoyed giving to others as well as having the social contact.*

## **2. Allowing independence and control**

Many studies have demonstrated the importance of a sense of control. As discussed in the section above on cooperation, people are more cooperative if they have some say in what they do. Allow decision making where possible. You can facilitate this by assessing the elder's abilities as discussed above and by providing supports to help maintain independence.

*Example: Sonia's dad had always loved gardening. But now that he was confined to a wheel chair, he felt that his gardening days were over. With the help of a local scout troop, Sonia had several raised beds built along the sidewalk. It was amazing how many vegetables and flowers her dad could grow in a relatively small space.*

The way we communicate can facilitate a sense of control. Offering choices and learning preferences can make a person feel more in control of his/her situation. Be aware of services and supports that facilitate independence.

### **3. Maintaining independence in face of dependent parents**

A network of care helps primary caregivers maintain their own independence. Even a little help can reduce stress. Maintaining friendships and other involvements, and having opportunities for respite, can help prevent burnout and enhance the quality of care. Because professional respite care is limited in many areas, the caregiver may need to develop a network of respite support with family or friends or in exchange with other caregivers.

*Example: Caring for her husband was a full-time job for Meredith. His Alzheimer's had gotten worse and her involvement with church and connections to friends had slowly dwindled. She found it difficult to even have the time to buy groceries. A caseworker helped her with a plan. She enrolled her husband in adult day care two days each week. On one day she went to bible study and then to lunch with friends. The other day she used to catch up on errands and appointments. Her son started to make it a tradition to come and fix Sunday dinner and then spend the afternoon with his dad. Meredith could go out for a walk and take a much-needed afternoon nap.*

## ❖ Resources

### Activities

#### 1. Family Commitment Through Stories

Our elders have much to offer in their family experiences and in their history of family commitment. By sharing their family stories they are passing on the sense of continuity of which they have been a part. By being given the opportunity to share their experiences they receive a sense of belonging and a feeling of commitment from other family members. Having younger family members start a journal of the stories their elder's share about family commitment is an excellent beginning.

#### 2. Caring Behaviors

We show our commitment on a regular basis through our actions. Have each family member make a list of one caring behavior he/she will share with other family members. These behaviors could include giving a hug, making dinner for the family, or just saying "I love you." These behaviors should meet the following standards:

1. They must be positive
2. They must be specific
3. They must be done regularly

When lists are complete share the ideas as a family.

(adapted from Building Family Strengths, 1986)

## **Audiovisual Materials**

Churchill Media (Producer). (1990). *Just for the summer* [Motion picture]. (Available from Churchill Media, 6901 Woodley Ave, Van Nuys, CA 91406)

Medical Audio Visual Communications Inc. (Producer). (1997). *Behind the faces* [Motion picture]. (Available from Medical Audio Visual Communications Inc., Suite 240, 2315 Whirlpool Street, Niagara Falls, NY 14305)

Medical Audio Visual Communications Inc. (Producer). (1997). *Bridging the gap* [Motion picture]. (Available from Medical Audio Visual Communications Inc., Suite 240, 2315 Whirlpool Street, Niagara Falls, NY 14305)

Medical Audio Visual Communications Inc. (Producer). (1997). *Communication: The heart of the matter* [Motion picture]. (Available from Medical Audio Visual Communications Inc., Suite 240, 2315 Whirlpool Street, Niagara Falls, NY 14305)

## References

- Bronfenbrenner, U. (1989). Ecological systems theory. In R. Vasta (Ed.), *Annals of child development: Vol. 6. Six theories of child development: Revised formulations and current issues* (pp. 187-249). Greenwich, Ct: JAI Press.
- Erikson, E. (1964). *Insight and responsibility*. New York: Norton.
- Erikson, E., Erikson, J., & Kivnick, H. (1986). *Vital involvement in old age*. New York: Norton.
- Havighurst, R. (1953). *Human development and education*. New York: Longmans, Green.
- Heckhausen, J., & Schulz, R. (1995). A life-span theory of control, *Psychological Review*, 102, 284-304.
- Kotre, J. (1984). *Outliving the self: Generativity and the interpretation of lives*. Baltimore: John Hopkins University Press.
- Levinson, D. J. (1978). *The seasons of a man's life*. New York: Ballantine Books.
- Levinson, D. J. (1996). *The seasons of a woman's life*. New York: Knopf.
- Peck, R. (1968). Psychological developments in the second half of life. In B. Neugarten (Ed.), *Middle age and aging* (pp. 88-92). Chicago: University of Chicago Press.
- Perlmutter, M. (1988). Cognitive potential throughout life. In J. E. Birren & V. L. Bengtson (Eds.), *Emergent theories of aging* (pp. 247-267). New York: Springer.