

Caregiving: Relationship Challenges and Rewards

Kathy Bosch, Extension Specialist, Family Life Education
Myrna DuBois, Extension Educator, Stanton County

Introduction

Growing older is an inevitable part of life. One tends to think the time in life when you're considered "an older person" will never come, but time fleets by quickly. For example, can you remember when you were a child or teenager? To the authors of this lesson, it seems as if those childhood and teen years were yesterday! Now we have grown children of our own and have experienced the challenges of caring for aging parents and the death of loved ones.

Fear of the unknown is a large factor in whether the challenges of aging will be ignored, embraced, or cause debilitation, isolation, or even bitterness. As much as possible, each person should make decisions best for themselves and their loved ones by being aware of the issues that may be faced. Being informed is a powerful tool that can help make the transition into the next phase of life more enjoyable and even adventuresome. A positive attitude toward the changes and the challenges is a key to whether the caregiver and the elderly parent will be happy and content with their relationship and quality of life.

Facts about the elderly

Many people are facing these concerns as one in five Nebraskans is age 55 and older. By the year 2050, the number of individuals over age 65 will have doubled in Nebraska. As a percentage of the U.S. population, Nebraska currently ranks 13th for individuals age 65 and older. Today, large numbers of people can be expected to live into their 80s and 90s and beyond. Because of increased life expectancy, the demands for health care, housing accommodations, financial arrangements and caregiving have been a concern of those lobbying and working with the elderly.

In a recent study of 1000 Nebraskans (Thorson & Powell, 2004), it was found that 70 percent of

respondents age 66 and older rated their own health as good or excellent. Fewer than 5 percent rated their health as poor or very poor. Six percent said they could use help with daily living activities, but less than 1 percent needed personal assistance. Some elders are in poor health and need daily assistance. Less than 5 percent of Americans age 65 and older live in nursing homes or care facilities (U.S. Census Bureau, 2000).

The aging process

For many elderly people, later life offers opportunities for travel, hobbies, volunteering, doing enjoyable activities, and being with family and friends. Aging successfully means having good mental health, but elders also experience life events that may cause high periods of stress. Moving to a new location, dealing with health problems, or coping with the death of a loved one can be very difficult. The challenges elders face may lead to serious physical and mental health problems especially if elders have difficulty coping with stress and adapting to change, do not have supportive relationships, have difficulty relying on others, or have a negative outlook on life. Today, numerous services and agencies are available to assist the older parent and their caregiver. Elders and their families do not have to face the challenges and stressors alone.

Major changes can occur as a person ages.

As they age, elders face an increasing number of changes in their lives that effect their ability to perform various tasks of daily life, such as dressing and housework, grocery shopping, and driving. Their ability to function is closely tied to their quality of life. Social support, economic status, and their ability to access resources are key factors in overall well-being. Personal finances will influence their health, health care and insurance, nutrition, and place of residency, which affect life satisfaction.



Extension is a Division of the Institute of Agriculture and Natural Resources at the University of Nebraska-Lincoln cooperating with the Counties and the United States Department of Agriculture.

University of Nebraska-Lincoln Extension educational programs abide with the nondiscrimination policies of the University of Nebraska-Lincoln and the United States Department of Agriculture.

© 2005, The Board of Regents of the University of Nebraska on behalf of the University of Nebraska-Lincoln Extension. All rights reserved.

The elderly face many changes that may include loneliness, isolation, loss of purpose and independence, and changes in health and physical ability. In addition, those caring for others, who may be elders themselves, often face extreme stress, tiredness and loneliness.

LONELINESS and ISOLATION

- loss of a spouse, through death or divorce
- loss of family members, through death, relocation, divorce, or conflict
- loss of friends
- loss of a pet
- distance from family and friends

LOSS OF PURPOSE

- changes due to retirement
- loss of being needed
- loss of position in community

LOSS OF INDEPENDENCE

- loss of ability to drive
- lack of transportation services
- decreased financial independence
- increased health care costs
- having to move to different living situation

CHANGES IN HEALTH

- deterioration in health
- deterioration of eye sight and/or hearing
- increased dependence on others
- diagnosis of a chronic physical disease or illness
- possible mental illness

DECREASED PHYSICAL ABILITY

- changes in body that prevent from doing things
- loss of ability to live alone
- loss of energy
- loss of control over daily routine
- possible inability to do favorite things

DEMANDS OF CAREGIVING (caregiver may be an elder)

- difficulty caring for ill spouse or loved one
- loss of freedom for self and dreams (postponement of plans)

Relationship dynamics

There are many communication styles and no one is the right one. However, good communication includes openness, caring, and respect for others. Effective communication between a caregiver and an elderly parent may be difficult to achieve. Sometimes what one person felt was good communication between the two of them, was perceived as ineffective by the other.

Older parents may feel threatened when others want to discuss various issues or plans because they

sense a loss of control or privacy invasion. Caregivers must assure older parents that what the elders say is important and will be heard. When planning any change or making any decision, older parents should be involved in the discussion and decision making process as much as possible. In many cases, older parents are able to make many decisions regarding their care and should be consulted and included in discussions involving their care. They must be respected and treated with dignity even when their behavior is difficult to manage. In circumstances when the elder is unable to make decisions due to a sudden change in health status, prior planning is helpful to both the elder and the caregiver in order to carry out the elder's wishes and provide optimum care for the elder.

Communication: Problem solving skills

Basic problem solving skills may be used often in your communication with older parents, siblings, and others with whom you have contact. Although the process looks easy, effective problem solving is not always easy to accomplish.

- Determine what the problem is.
- Focus on the problem.
- Find out more about the situation.
- Describe the problem in your own words.
- Don't get stuck on what happened before the problem, deal with the present.
- Brainstorm a lot of ideas and possible solutions (don't criticize anyone's ideas).
- Think through what idea might work best; what could happen in each case?
- When appropriate let everyone involved be a part of the decision.
- Make a choice.
- Be willing to give the choice or new plan a try.
- After some time has elapsed, check to see how the plan is working.
- Revise the choice or plan if necessary and repeat the process.

Some important issues to discuss with elders:

Health needs: general health status, capability of independent living, adequate health care

Financial needs: management of finances and enough money for adequate housing, health care, food, and other necessities

Housing needs: safe and adequate housing situation, ability to live alone

Dietary needs: safe and adequate food to eat, eating at appropriate times in appropriate amounts

When you have important issues to talk about with the person in your care:

1. Define the issue. What is the issue or problem?
2. Discuss the issue. Talking and listening together will help with understanding each other's wants and needs.
3. Decide a possible approach. What should be done now? Planning for the future is also important.

Helpful communication skills to use when working with elders

Try to be gentle in your approach with elders. Your body language is a way to let older people know you care. Some elders may like to be hugged or patted on the shoulder and others may not like to be touched. However, most people, even those who are hard-nosed, need a hug occasionally. Always use your good judgement. Regardless of your situation, caring for another person takes a lot of patience. Patience and kindness are attributes that help keep channels of communication open in your relationship with elder parents, as well as with others who provide care.

When communication is a challenge:

Each person has a unique way of handling stress and difficult situations. You may tend to be a person who has a stable mood pattern and can handle stress without much difficulty or you might be a person who wants to avoid stress completely. When working with an elder who offends you, try to forgive them and not hold a grudge. Holding grudges will only hurt you and will not change the other person's position. If the conflict is over a major issue, try to discuss the issue again at a different time or use a different approach with more gentleness and patience.

Conflict may not be resolved or decisions may need to be made that are against the older person's wishes. Hopefully, this can be avoided as much as possible, but sometimes these difficult decisions must be made for the well-being of the elder. An example may be when a decision needs to be made whether to put a loved one in assisted living or a nursing home. Try to have someone else help you make these major decisions. Try to allow elders to make as many decisions as possible.

Assessing your response to stressful situations may be helpful in understanding how you might respond to an elder who is angry.

Some ways of handling difficult situations are more effective than others. Get help if needed.*

Potentially effective strategies when responding to difficult situations: redirect the problem, plan ahead, ask for help, use humor, talk with a trusted person, use mediation

Potentially destructive strategies when responding to difficult situations: avoid the problem or blame others, get sick, manipulative, get sad or become depressed, spoil the other or give in, repress anger, play the martyr

Examples of difficult situations or problems include when:

- adult children cannot get along with their siblings;
- adult children do not want to talk with elderly parent about their future, funeral plans, wills/trusts/estates/the parent's inevitable death;
- elders are hesitant or resistant to talk about finances, poor health, living arrangements, death;
- elders deny their functional limitations;
- elders are fearful of dying and death;
- elders want total control and will not accept any help or inform children about finances, health, needs, or feelings.

The Caregiver Role:

Although the average caregiver is an employed 46-year-old female with children of her own at home, caregivers may be male or female and range in age, ethnicity, and income. The role of caregiver typically begins slowly and may not be recognized as such, until gradually the older parents need more assistance, more advice, and eventually help to make major decisions. In a sense, adult children often become the "parent" to their parent. This role reversal is normal and will be experienced by most individuals.

What is the appropriate help to give?

The challenge for caregivers is to recognize where they are along the caregiving continuum from advice giver to overseeing daily care. When adult children assume more help is needed than is actually needed or wanted, older parents may be offended causing tension in the relationship. When adult children give less help than is needed or when older parents reject the help, older parents may feel hurt, lonely or be at risk. Finding the best balance is not easy and will require careful observation, wise intervention, and skillful communication.

How can a caregiver help via long distance?

Today, families are mobile and seldom grow up and settle in one location. Most families will deal with geographic separation and may not have any family members living in close proximity to their older parents. The caregiving role is difficult to accomplish long distance over the telephone, Internet, or with occasional

visits and yet can be successful when adult children are assertive and well-informed. The major responsibility of day-to-day chores or financial decisions will often fall on an adult child, trusted friend, or relative living in closer proximity to the elder. The person living away must be supportive to the primary caregiver while that person is trying to maintain a sense of balance both in their personal and work life.

Caring for the caregiver (LESSON TO BE CONTINUED IN 2006)

The caregiver must strive to maintain good physical and mental health. Caregivers experience many stressful situations. Access as many resources as possible to assist with your responsibilities. Try to trust others with the care of your loved one so you can take a break. Try to avoid feeling guilty about needing time for yourself. Spend time with people you care about and who care about you. Consider professional counseling if needed.

- Make use of resources.
- Allow others to care for your loved one so you can take a break.
- Try to balance employment, your own family and caregiving.
- Allow some time to care for yourself; do something fun.
- Consider professional counseling.

Rewards of caregiving

The rewards of caregiving are many. Think about the reasons why you wanted to be a caregiver. You may have felt as though there were no other choices. However, usually there are other options. You will provide more effective care if you want to be a caregiver and are positive about the caregiving tasks and responsibilities. It is essential to have someone you trust to relieve you of your duties for several hours (or days) each week so you can provide the best care possible. You may have additional rewards to add to this list:

- Spending time together
- Learning more about the individual
- Learning about each other
- Enjoying time together
- Giving of yourself to the other
- Sharing precious memories
- Trying to rectify past hurt or wrongs
- Sharing religious beliefs or values
- Sharing feelings with each other
- Doing something together you always wanted to do
- Learning from each other

*Elder abuse is a concern. Unfortunately, thousands of elders are abused each year in the United States. Some individuals, often women, are abused by their spouses. Many cases of elder abuse, including domestic violence, go unreported. Many of those who are abused are socially isolated. Others are socially or mentally incapable, such as elders suffering with Alzheimer's. Family members and friends must check on their loved ones often and assist with their care whenever possible. It is essential that caregivers get reprieve from their duties and access all available resources for support. The National Center on Elder Abuse (NCEA) will provide you with more information on elder abuse. You may access it on the Internet at <http://www.elderabusecenter.org/> If the elder is in imminent danger, call 911, police, or hospital emergency NOW. The toll-free hotlines available in Nebraska:

Domestic Elder Abuse
(800) 652-1999

Institutional Elder Abuse
(800) 652-1999

Nebraska Domestic Violence Sexual Assault Coalition (NDVSAC)
(800) 876-6238

National Domestic Violence Hotline
(800) 799-SAFE (VOICE)
(800) 787- 3244 (TDD)