

Who Cares For The Caregiver?

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As a result of this lesson, participants will:

- Assess whether or not they have the resources to become a caregiver.
- Understand their own needs for time, health and satisfaction in their lives.
- Realize how family history and relationships affects current situations.
- Develop plans so that other family members can help carry some of the load.
- Recognize that elder abuse does occur in today's society and avoid abusive situations.

Who is a caregiver? Chances are likely that you are already or will become a caregiver. The largest group of caregivers are women, although men may also become caregivers. Many women become caregivers of someone, in some format, for some part of their life. Caregivers of aging persons are often elderly themselves.

Caregiving may take many avenues. Of course, when we are raising children, we are child caregivers. But the focus of this program is caregiving of older persons. Taking care of disabled persons of any age has many of the same issues.

The vast majority of caregiving will be either for parents or a spouse. However, some individuals care for a range of people as a source of employment. They usually become caregivers because they care about the people — the family members and others. They also become caregivers because the elders or disabled need assistance in some manner. Some people are more suited to be caregivers than others due to their personalities and temperament.

The emphasis in this curriculum is not so much how to do the work of caregiving. That was covered in the previous curriculum “Caregiving: Relationship Challenges and Rewards” by Kathy Bosch, extension

family life specialist, and Myrna DuBois, extension educator (*HE Forms 558 and 559*). The emphasis here is on taking care of yourself as the caregiver, to help you feel well both physically and psychologically.

How Much Help Can You Give?

Many people become caregivers without really assessing their ability to do so. For example, would you be able to lift the person in and out of bed if needed? Are you in good health yourself? If you have a health problem that slows you down or for which you need regular treatment, do you have enough energy to devote to caring for another person? Your time commitments must also be considered. What other responsibilities do you have? Finances may be an important factor. Does the person you are caring for have sufficient finances to cover basic needs? Would you need to assist occasionally or even frequently? If yes, do you have funds that you could devote to this?

Different Levels of Caregiving

For awhile, the caregiving you are doing for others may seem simple enough. At first, you may check on them occasionally to be sure things are going OK, that they are in good health, eating properly, and that their home is safe. This may involve rearranging their home a little to make it more safe, or grocery shopping, or other relatively simple tasks.

As time moves along, you may find yourself much more involved in caregiving. The person may become unable to tend to their yard, house or other needs. They may become unable to drive, which is very difficult for them and may leave additional errands for you or someone else to do. If there are funds, you may be able



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to hire someone to cut their grass, shovel snow or clean house. If there are no available funds, many families do these tasks themselves. This can place both physical energy and time demands on you as the caregiver. You may begin to feel depleted, as if you are pulled in different directions. There are some resources to help with these issues. Begin by talking to your Area Agency on Aging for advice about your specific situation.

Many elderly persons lose interest in cooking or do not want to cook for one person. At this time, you may order Meals on Wheels for them, which is sometimes enough food for two meals. If there is not enough, you may need to locate another source of food or even take the person an evening meal from your home. This can be a challenge even though it may be a simple procedure. If elders are in good enough health, encourage them to go to the local senior citizen center where they can get well balanced meals at lunch time. This also gives them a chance to socialize with others, get involved in activities, and feel a part of a community.

Some elders choose to live in assisted living or nursing homes, depending of the level of care they need. These are difficult decisions elders must make with their close family and friends. Many times, family members hire help if they can afford it and can find capable help. For example, they may hire a housekeeper or companion for the elder. Some caregivers eventually move in with the family member or bring the individual home to live with them. Careful planning can make this work, however the emphasis in this lesson is how to also meet your own needs. Be sure to carefully assess the impact such a move would have on your own household. Sometimes the best intentions can be extended far beyond our own ability to give. That is covered in the section below.

Take Care Of Your Health

Who cares for the caregiver? You do. You must take responsibility for your own health and wellness. Once you become a caregiver, whether by conscious decision, or as a result of something you just gradually phase in to, it is important to maintain your own health. You cannot be of any help to the other person if you fail to take care of your own physical needs as they arise. This can be related to simple every day things such as eating correctly, getting enough sleep and taking time for yourself. If you care for someone who needs considerable help at night, for example, you may need to make sure you get additional sleep in the morning or during the day in order to maintain your own health. Trying to carry out the caregiving needs in addition to your own responsibilities can easily lead to exhaustion. Sleep is important to your health. Seek resources to help you

at night that may be paid through insurance or other resources for the elderly.

Taking care of your own health also involves taking time for yourself. Some caregiving situations can become extremely time intensive. When this happens, you need to find ways to give yourself a break. Another family member may be able to take over for a few hours so you can do something for yourself, or just get away and take a walk or a nap. If there is no one else who can fill this role, again seek local resources for a respite worker who can come to tend your loved one while you take a break.

Some people have difficulty recognizing their own need for time to themselves, self-care or a break. They may be devoted to the person for whom they are caring, and/or they may simply be determined to do it all themselves. They neglect themselves and their own needs. Some people go so far as to become dependant upon their role as a caregiver, and fail to recognize that they are becoming over-involved. When this happens, the caregiver may need to talk to someone such as a trained religious leader or a counselor. Other family members may need to watch to be sure the caregiver is not over extending themselves. They can encourage caregivers to take care of themselves, and volunteer to help with both time and resources. *What three things could you do to improve your health?*

Family Issues

How did you happen to become the caregiver? Are you closest either geographically or relationship wise to the person needing care? Are there others who could help but who do not seem willing to do so? Could you ask for their help? For example, could another family member spend a few days with the loved one while you do something else? They may not have considered that they could help for a few days rather than it being a long-term commitment. Could they help financially? They may be unaware, for example, that you are paying Mom's heating bill.

What about your own family at home? If you have a spouse or children at home, it is important not to neglect them at the same time you are caring for a parent or other loved one. All of this can be overwhelming. However, it is possible that your immediate family also may be sources of help. Could your teenage son mow Grandma's lawn? Could your young adult daughter take a turn providing food or cleaning Grandma's house? Could your elementary age child spend some time singing to Grandpa or just sitting beside him? Could your spouse help with financial planning? Then it becomes something that you do together, not something that you are bogged down in or over-extended by.

The original relationship that you had with your parent also comes into play. In families where the relationship was a good one, the caregiving may feel like a natural outcome of family life. In families where the relationship was particularly difficult, it may make your role quite challenging. This is especially true if the parent was uncooperative and cranky. The ideal would be to rebuild the relationship and spend the person's latter days in peace. In cases where the caregiver was perhaps a rebellious teenager, this may be an opportunity to "give back" for previous behavior by caring for your parent now that you are an adult who is caring and capable. This can be a good feeling for both you and your parent and contribute to family peace and harmony throughout the extended family.

Remain calm if the person for whom you are caring becomes difficult. Keep in mind that the person probably does not intend to be this way and would behave differently if possible. If need be, walk away to calm yourself down, then return when you are calm. To calm yourself, take a deep breath, walk or exercise, talk to yourself about being calm, listen to music, take a break.

What are some family issues you must deal with?

Psychological Factors

Guilt is a common feeling related to caregiving. Guilt may take many forms. You may ask yourself if you're doing enough, or if things would have been better if you had done something differently. As long as you are trying hard to meet the needs of your loved one, you do not need to feel guilty. For example, if you are providing meals but can not get there due to a snow storm, it is out of your control. Make sure you have such things as crackers, peanut butter and other quick and easy items. It is important to have juice or other nutritious beverages on hand. Call and explain to elders about the situation and encourage them to have some of the pick-up items to eat and drink. They likely will be fine until you can get there again or have someone else check on them. Be sure they get regular meals, but have a back up plan in case you can't get there on a regular basis.

Resentment is another issue that may arise. On one hand you may feel resentment that your loved one is taking so much of your time, and on the other hand you may feel guilty that you feel resentment. It may become a vicious cycle. If you do find yourself feeling resentful, it is time to get some outside help, such as another family member or a respite worker, to help you. Also recognize that it is natural and normal to want time to yourself.

Fear and sadness are other feelings you may experience. Your loved one is physically and/or mentally deteriorating as the aging process or illness progresses. Your parent or spouse may now be needing the same

assistance they gave you in the past. The roles are now likely reversed. A fear of the unknown with your loved one's approaching dying and death process, coming to terms with your own mortality and spirituality, and comforting your loved one may cause an element of fear and sadness. The sadness may be coming from the times you will not have together in the future or that you wasted in the past.

Expectations are a major part of your feelings about what is happening. You may have expectations to have some time for yourself and travel or work on hobbies. Instead, you may find yourself tied down with the responsibilities of caregiving. Dealing with expectations may be difficult but you can remind yourself that caregiving gives you a chance to bond closer with your loved one. When you provide care, you will feel satisfaction by sharing your love and time with the person needing your help. In order to meet your own expectations you may need to hire someone to care for the person for several weeks while you travel or work on hobbies. In other words, you must spend some time and money on yourself to avoid feeling suffocated with too many responsibilities. Access help available in your community.

Celebration is an essential component to life and death. Include elders as often as possible in celebrations with family and friends. Caring about them as an individual is a memorable gift more priceless than material possessions. It is a gift you can also give yourself. Your attitude and generosity with your time is a characteristic that is difficult to wrap in a box. Celebrating life is something most people take for granted. Enjoy the seasons, enjoy the birds, enjoy a certain smell such as vanilla or lilacs, enjoy a taste like chocolate or fresh bread. Enjoy a memory shared together by looking at some old photographs. Talk about something funny that happened. Laugh together.

What are some of the feelings you experience?

A Word of Caution

Elder abuse is a growing concern in our country. We hear of situations in which an older person is neglected to the extent that they are not clean, are not fed properly, or are left wandering around and confused. We also hear of situations in which an older person's money is confiscated by those who should be caring for them. If you find yourself overwhelmed by the care the older person needs, ask for help of such local agencies as the Area Agency on Aging. And do keep in mind that the money the older person has is theirs, and any use of their money for anything other than their own needs is nothing short of theft. Even if you feel you deserve some payment for the tasks you carry out, be sure to go

through a lawyer and make a legal agreement. Call the National Domestic Violence Hotline Toll free at 1-800-799-SAFE (7233) if you need any help or suspect elder or partner abuse.

Summary

Caregiving can be a pleasant experience, a chance to form a closer bond with the person in your care. It also presents its challenges. Make use of available resources to meet the needs of your loved one, so you can take good care of your own needs at the same time. Your own health, satisfaction and time are also important.

References

The following provide supporting information and/or additional information for this lesson.

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