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Caregiving Is Different For Everyone

As America ages, more of us will find ourselves caring for a spouse, partner, parent, other family member or close friend. In fact, family members and friends provide about eighty percent of long-term care in our country today. The high cost and shortage of trained caregivers, the desire to provide personalized care within the family, and the varied and changing demands of caregiving, all mean that more people are learning new skills and making adjustments in personal, family, and work life as a result of caregiving responsibilities.

Uniqueness of Caregiving Experiences



Caregiving experiences are just as unique as the people involved. Each caregiver has different needs, feelings, challenges and rewards. And each family member's relationship with the care

receiver is unique, influencing expectations and the overall caregiver experience. Much has been learned about the differences in these experiences as the result of a growing body of research. For example:

- Men tend to think about and approach caregiving differently than women.
- Husbands and wives differ from adult children or other relatives in what they do, how they do it, how long they do it, and when they consider letting others help.
- Each of us forms personal expectations of ourselves as caregivers. These expectations are shaped by past experiences and observations, societal rules, our cultural heritage and our own family rules.
- Caregiving can affect us in multiple ways. It

can cause changes in physical and emotional health, finances, and time available to participate in other family, social, work, leisure or community activities.

- Caregiving can be stressful at times. Yet, people who perform the same task may have very different experiences. One person might feel very uncomfortable emptying a commode, while someone else may not give it a second thought. Caregivers also experience different types and levels of stress over time.

Rhonda Montgomery, PhD, has been studying family caregiving experiences for more than 20 years with her colleague Karl Kosloski, PhD. Out of their work has emerged a theory called Caregiver Identity Change. In essence, it says the caregiving experience over time involves a systematic process of change--in activities, responsibilities, and in the partner-like relationship between the caregiver and person receiving care. It also involves a change in the way the person giving care views him- or herself in relation to the person being cared for. This new role grows out of the earlier relationship between the two care partners.

The Caregiving Journey Changes You

The caregiving role unfolds over time as the caregiver takes on greater responsibility--helping with everyday household affairs, personal care and decisions. Caregiving involves an identity change process. At some point, the person providing care begins to identify himself or herself as a caregiver in addition to being a wife, a son or other kind of relationship. The journey is different for each person in terms of when and how we begin to identify ourselves as caregivers. Caregivers who are providing assistance for a short period of time may never see themselves as a caregiver, while those providing care for years may

EXTENSION COMMUNITY

see themselves and act more like a caregiver than spouse or adult child. This is reflected in a statement repeated by many adult children: "I feel as if I'm the parent now and not the child." They have assumed a caregiving identity and lost their identity as an adult child to their parent.

Personal rules and expectations play an important part in how we each feel about what we are doing in the caregiving role. Montgomery and Kosloski find caregivers experience increased levels of stress when a mismatch occurs between what they are doing and what they think they *should* be doing on behalf of the individual receiving care. Often, the source of distress is not the activity itself, but how the caregiver feels about it.

The first step to lowering caregiver distress is to identify its source. Once this happens, caregivers can work toward reaching a new comfort level. A number of strategies have been shown to help reduce caregiver distress:

1. Adjusting or modifying the expectations we have of ourselves.
2. Changing what we are currently doing--perhaps by making room to let others help or by letting go of some current responsibilities.
3. Changing the way we view or judge our own actions.

Caregiving Journey Stories – Do Any Describe You?

What is your caregiving experience like so far? Take a look at the following stories to find the caregiver experience that most closely matches your own at this point in time.

Information Iris: Caregivers Who Want Information



Story: A woman just found out her mother has breast cancer. She searched the Internet to learn more about the disease and what to expect from different types of treatment. She got some fact sheets from the American Cancer Society and she asked her mother's doctor to direct them to other resources to learn more about what the future might hold.

Description: Information-seekers are often just beginning to start their caregiver journey. They usually do not have a high stress level. They do not question who they are or what they are doing on behalf of their relative or friend at this point in time. Caregivers in this situation generally do not contact agencies for help except to ask for specific information. Agencies can best serve these caregivers by letting them know about community services they may want to consider in the future. Typically this caregiver's experience will change as they move through the caregiver journey and assume more caregiving tasks and responsibilities.

No Way Nasturtium: Caregivers Who Are Highly Committed



Story: Mrs. Nasturtium has been caring for her husband with multiple medical problems for five years. Their three children help when she requests it but she does not like to impose on them. They have been spending more time at home since Mrs. Nasturtium's husband became ill. They play cards, watch TV and talk about the news. Her husband needs more help now with getting dressed and bathing. He is



EXTENSION COMMUNITY

very particular about how tasks should be done and is starting to show signs of dementia.

Mrs. Nasturtium has concerns about her husband's judgment but has resisted taking over tasks like paying the bills. This sometimes creates tension between them. He insists on paying their bills and will not ask for help. Creditors have called twice about missing payments. Mrs. Nasturtium loves her husband and will do whatever she needs to take care of him. However, she gets frustrated. She is not sleeping well at night and is losing weight. She will not listen to their children's suggestions to move him into a care facility.

Description: Caregivers in this situation experience high levels of stress because of changes in their partners' abilities and greater needs for care and support. Caregivers may feel anxious, angry or frustrated about assuming new roles their partners performed in the past. They may also find that caregiving interrupts other aspects of their lives, such as having a job or raising a family. Despite this, these caregivers are highly committed to their relationships and their partners.

In general, these are people who enjoy providing care, but struggle with the demands of caregiving. They have no intention of giving up their caregiving role in the near future, nor do they plan to move their partners into another setting. They are caregivers with high stress levels who do not intend to relinquish the caregiving role. This group is at great risk for developing physical and mental health problems.

Placement Posey: Caregivers Ready to Let Go of Responsibility



Story: This single mother of two teenagers works full time and has cared for her father since her mother died a year ago. He has Alzheimer's disease and lives

alone in his own home. Posey has become more aware of her father's limitations since her mother died and realizes he should not live or spend time alone during the day. Posey is an only child and feels responsible for her father. She promised her mother she would take care of him after her mother was gone.

Posey and her father have always had a rocky relationship. Her mother was the peacemaker. She believes her father does not approve of the way she is raising her children, nor of her career. Her sons are very involved in school activities. Posey was just promoted to a manager position that requires travel. She has a short fuse sometimes when it comes to her children and colleagues. She feels exhausted and does not know where to turn. Posey finds herself thinking that life would be easier if her father had died, too. A neighbor has called to report that her father goes outdoors late at night and early in the morning. He sometimes forgets where he is. Neighbors say he yells or swears at people who try to help him go back inside. Posey is thinking about moving her father into a nursing home. She realizes that things cannot continue as they are. She does not see any other option.

Description: Caregivers in this situation often feel greatly overwhelmed by their caregiving role and activities. They may also be experiencing stress in other areas of their lives, such as raising their own children or job obligations. Another source of stress may be long-standing strain in the relationship they have with the person needing care. Caregivers often think they ought to be up to the job of providing the care their relatives need. Or they may feel trapped by long-held beliefs or promises such as, "I said I'd always look after Dad and I will." These individuals may need to step back to look at how their beliefs are affecting their actions. When caregivers do this and can make changes in the way they view the situation, they may understand that outside support can help.



EXTENSION COMMUNITY

A number of community service agencies offer caregiver education and support. One form of community assistance can come in the form of a case manager or care consultant, usually found at the local or area aging office. These individuals are aware of local resources and can help identify options for an individual or family as they think about how to provide assistance for a family member. They also help people recognize how the experience of caregiving changes a person's sense of self or identity. Some of the services they suggest might include those that help caregivers accept themselves in their new role, affirm what they are doing well, or ease their current load. People under great stress who are ready to leave the caregiving role are much more likely to move family members needing care into another care setting. This is often the case when they think placement into such a setting is the only available option.

Relationship Rose: Caregivers With High Levels of Strain and Stress



Story: Rose has been caring for her husband with Alzheimer's disease for four years. He often shows signs of acute distress and embarrasses her when they are out together. She has

stopped taking him with her. He is afraid to be alone and can become highly distressed before Rose returns. She feels saddened and frustrated by the loss of their earlier relationship. She resents having to take on more responsibilities. Rose sometimes thinks she cannot manage much more. She was doing fairly well until her husband's temper flare-ups began to get worse. Rose has a lot of stress and feelings of anger and guilt. It surprises and worries Rose that she has these strong feelings. She does not know what to do.

Rose recently saw a news item about the Alzheimer's Association. She looked it up on the computer and discovered a local support group for caregivers. Rose called the agency and spoke with a care consultant. She has joined a support group and is taking a class on understanding the behavior of people with Alzheimer's disease. She also called the Helpline late one night. The class has helped Rose understand some of her husband's actions. She has learned new ideas about how to talk with her husband and ways to respond when he is upset. Rose has made two friends from attending the support group. She calls them when she feels low or wants advice.

Description: Some caregivers find that their relationship with the care receiver is strained. Their relationship strain can be from past experiences such as conflict, abuse, neglect or something else. Sometimes the caregiver/care receiver relationship can become strained when the caregiver does not have a good understanding of their partner's condition. Some caregivers also find that their relationship with the person needing care has changed during the caregiving journey and they may resent the demands of caregiving causing strain in the relationship. For example, a caregiver may not understand why someone with Alzheimer's disease asks the same question over and over. This can cause strain even in a good relationship. Feelings of shame or embarrassment about the care receiver's speech or actions can also strain the relationship.

Caregivers may need to learn more about their partners' true abilities and the caregiving journey in general. This will help them better understand the care receiver's needs and what is required in the caregiving situation. Learning about a partner's illness, strengths and limitations can help a caregiver develop new skills. In some cases, caregivers may need to address long-term relationship issues so they can learn coping strategies that enable them to continue being a caregiver.

EXTENSION COMMUNITY

Juggling Juniper: Caregivers Who Juggle Activities and Other Responsibilities



Story: Mr. Juniper believes no one else can provide the same kind of care for his wife. He remembers the excellent care she gave him after a painful back injury. He vowed he would do the same for her. His wife has had a number of complications from hip replacement surgery. She

needs daily help with personal care. She receives physical therapy three days a week. Mr. Juniper is doing all the cooking, laundry and housework. He works full time but gave up his weekly golf game. He does not accept invitations when friends call. The Junipers' children have stopped offering to help because he does not want it. Mr. Juniper is a proud man. He believes husbands and wives take care of each other and should not ask for help.

Description: Caregivers in this situation try to juggle multiple roles and duties. They have a comfortable relationship with their partner. They are not troubled by what they are doing but just don't have enough time to do everything that needs to be done. They are not considering placing the individual receiving care in any type of care facility or giving up caregiving themselves. However, they find caregiving activities are impinging on other aspects of their lives. This can include a job or career, involvement in civic or faith activities, and time for other family members. Community agencies can inform caregivers of resources that will ease their overall workload and encourage them to use services. Some caregivers may need help adjusting their personal expectations or code of ethics before accepting help from others

Stressful Snap Dragon: Caregivers Under Stress Due to Life Circumstances



Story: Mrs. Snap Dragon's husband, Sam, has become depressed after his second heart attack. The couple has always had a close relationship. She does not find Sam's care or need for emotional support very stressful. She is good at handling tough situations and gathering information. She also usually knows when to ask for help. However,

her job has recently become more stressful since her supervisor took another position and was replaced by someone with little experience. This worries Mrs. Snap Dragon a lot. Co-workers look to her for help with meeting deadlines. In addition, a good friend was injured and is now on a leave of absence. Mrs. Snap Dragon is often too busy to take a lunch break. She feels too tired to fix dinner by the time she gets home, and is not sleeping well.

Description: Caregivers like Mrs. Snap Dragon generally have good relationships with the people they are caring for. They understand the overall situation and the kinds of care their loved ones need. Their stress and overall anxiety stem from things outside the caregiving role. They may be having problems at work. Or, they may have a conflict with a friend, neighbor or relative. Caregivers in this situation can benefit from understanding the effects stress can have on their health and well-being. They may be helped by learning and practicing new techniques for managing stress.

Share Your Caregiving Journey With Others Through Research



Montgomery and Kosloski's research on the differences in caregiving experiences continues to move forward with the help of a national caregiver registry called



EXTENSION COMMUNITY

the League of Experienced Family Caregivers (see <http://www.familycaregivers.uwm.edu>). The purpose of the League is to help create better services and resources to support family caregivers. Caregivers share their knowledge and insights by completing brief questionnaires in one of three ways--telephone interviews, mail-in surveys or online.

More than 1,000 caregivers are currently enrolled. The research has identified 22 different categories or pathways of caregiving experiences. These have been further distilled into six broad groups of caregivers. Each is derived from a different set of circumstances. Caregiving experiences are likely to change over time as one moves through the caregiving journey. Thus, a person can move from one category to another.

References

Based on the work of Dr. Rhonda Montgomery and is a work in progress. A paper spelling out her work is being published. Dr. Mary Brintnall-Peterson is working with her to translate the caregiver identity change theory into practice.

Brought to you by members of the eXtension Family Caregiving Community of Practice

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