

Understanding the Needs of Family Caregivers

Prepared by DATA of Rhode Island
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Overview

- More than **50 million people** provide care for a chronically ill, disabled or aged family member or friend during any given year.

*Source: U.S. Department of Health and Human Services, *Informal Caregiving: Compassion in Action*. Washington, DC: 1998, and National Family Caregivers Association, *Random Sample Survey of Family Caregivers, Summer 2000, Unpublished**

- The typical family caregiver is a 46-year-old woman caring for a widowed or single parent who does not live with her. She is married and employed. Over **60%** of family caregivers are women.

Goal

- to learn how to help family caregivers to provide safe and quality care to their disabled or aging family member.
- Identify what to teach and how to support family caregivers, so the family caregiver can provide a safe and comfortable place for the person.
- To learn how to support the caregiver in their own self care

The importance of the family

- Beyond the human side, the value of the services family caregivers provide for “free” is estimated to be **\$306 billion** a year. That is almost **twice as much** as is actually spent on homecare and nursing home services combined (\$158 billion).

Source: Arno, Peter S., “Economic Value of Informal Caregiving,” presented at the Care Coordination and the Caregiving Forum, Dept. of Veterans Affairs, NIH, Bethesda, MD, January 25-27, 2006.

Why support the caregiver

- **Caregiving is physically stressful**
- Caregivers often have a history of chronic illness themselves and experience caregiving related stress. These persons have a **63% higher early mortality rate** than their non-caregiving peers.
- *Source: Schulz, R. and Beach, S. R., Caregiving as a Risk Factor for Mortality: The Caregiver Health Effects Study. Journal of the American Medical Association, Vol. 282, No. 23, December 15, 1999.*

Why support the caregiver

- Family caregivers are more likely than non-caregivers to experience symptoms of depression or anxiety. For spouses the rate of depression is **six times other adult averages** ; for those caring for a parent the rate is twice as high.
- *Source: Cannuscio, C.C., C. Jones, I. Kawachi, G.A. Colditz, L. Berkman and E. Rimm, Reverberation of family illness: A longitudinal assessment of informal caregiver and mental health status in the nurses' health study. American Journal of Public Health 92:305-1311, 2002.*
- Caregivers feelings toward the person they care for can be highly conflicted. Side by side with love and concern they can sometimes feel trapped, overwhelmed, angry and guilty.

Reasons for caregiver support

Active caregiver support helps

- Prevents caregiver depression and anxiety
- Reduces severity of caregiver reaction to patient behavior and supports more helpful responses
- Helps caregivers solve problems
- Helps caregiver maintain realistic expectations for self and the person they serve.
- Helps caregivers keep patients in the home and in the community

Understanding and Responding to Caregiver Needs

- Caregivers need support due to the demands of home and demands from outside. Remember that every family is different due to their specific culture, history and current situation,
- Don't underestimate the value of your sincere interest and listening toward the caregiver.
- Listen and talk with families to get an appreciation of the multi-dimensional needs.
- Help educate family members about the illness and problems of their family member
- Educate family members about community resources
- Coach family members on how to navigate the system
- Help family members problem solve logistics
- Help family members become involved with other families or community supports

Caregiver needs continued

- Families come with baggage, we are not here to change that. We are here to support them to deal with current issues at hand.
- Always be mindful about Alcohol/Drug abuse as a problem for the person or for the caregiver.
- Support caregiver self care. Ask what they usually do to relax and encourage them to do the things to support their self care, especially self care that increases socialization
- Most disabled persons are on medications. Help the family caregiver become educated about medications.

Help for Family Caregivers

- Don't underestimate the power of your support
- Offer education, training and consultation
- Promote respite services, e.g., adult day care, companion
- Help problem solve logistics
- Offer referrals for individual and family counseling to help deal with the stress and pressure
- Encourage participation in support groups

Ways to Support the Caregiver

- Care giving is a job and they need breaks when they can.
- Help educate the care giver about the illness of the person, so they are more knowledgeable supports and advocates
- Support their advocacy efforts
- Watch out for signs of depression, anxiety, increasing anger and frustration and heavy drinking with the caregiver
- Help them develop reasonable expectations
- When the caregiver is having problems supportively intervene

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Support their advocacy efforts

Watch out for signs of depression, anxiety, increasing anger and frustration and heavy drinking with the caregiver

Help them develop reasonable expectations. ***This includes reminding them that the time may come when the needs of the person are beyond what they can reasonably and safely provide..***

When the caregiver is having problems supportively intervene

Caregiver needs and mental Health

- Education is particularly important regarding issues of mental illness, addiction and co-occurring disorders
- Family members often feel heightened shame, guilt, responsibility and even anger about the other persons problems
- Help family understand that they did not cause these problems, they can't control the persons illness, nor can they cure it.
- They can provide reasonable supports better enable the person to manage their illness.
- Encourage the family member to support the person entering and remaining in treatment services.
- Encourage family to be part of the treatment and recovery process including their own support.

Addressing caregiver problems

- Sometimes caregivers have attitudes, beliefs and behaviors that are self defeating and ultimately not as helpful to the person they care for.
- Through awareness, support and problem solving many of these roadblocks can be resolved.

Helping resolve roadblocks to caregiver success

1. "I can do it all. "I don't need any help"
 - Respectfully validate their commitment and sacrifice. Support their self care and realistic expectations.
2. "Its you and me against the world."
 - Work with the person to understand that "in your face" hostile demands, might work sometimes, but as often it can make matters worse.
3. "I'm overwhelmed"
 - Support the person with self care and setting reasonable goals

Helping resolve roadblocks to caregiver success cont.

1. "Look what I have to put up with...I deserve to have a drink (or 2,3,4,).
 - Screen for alcohol problems. Motivational interviewing techniques
2. "I am trying the best that I can."
 - In matters of poor follow through, assess, problem solve logistics, set plans and follow up. Monitoring and follow up improves follow through.
3. "He or she is doing ___ on purpose to make my life harder".
 - Listen and talk through with the caregiver to help them better understand what is the illness and what is the person. Support their not personalizing the behaviors of the disabled person.

Developing plans for care coordination

- Work with the family member and the disabled person to identify needs, set reasonable priorities, identify helping resources and implement plans to address these needs.

In conclusion

- Family care giving is integral to care for nearly 65% of persons with disabilities and our elder population.
- Supporting the family caregiver enhances the care and quality of life for the person served and aids the caregiver in responding to the stress and demands of the work.
- Our support can play a vital role in supporting both the disabled person and his or her caregiver.

Wrap up and Questions

