Family Caregiving: 
Coping with the Challenges

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Are You a Family Caregiver?

- A family caregiver is a person who provides essential unpaid assistance to someone with a chronic illness and/or disability.
- “Family” denotes a special relationship with the care recipient, one based on birth, adoption, marriage, or declared commitment.
- “Caregiver” is the job description, which may include providing personal care, carrying out medical procedures, managing a household, and interacting with the formal healthcare and social service systems on another’s behalf.
If You Are a Family Caregiver, You Are Not Alone!

- Most persons involved in hospice care depend on family caregivers.
- More than 65.7 million family caregivers
- Caregivers are predominantly female (66%). They are 48 years of age, on average.
- One third take care of two or more people (34%).
- A large majority of caregivers provide care for a relative (86%), with over one-third taking care of a parent (36%).
- 7 in 10 caregivers take care of someone 50 years of age or older.
- 14% take care of an adult age 18 to 49.
- 14% take care of a child under the age of 18.
It is the equivalent of a full or part-time job—on top of other responsibilities.

- We can feel alone and isolated.
- It can affect our mental and physical health.
- It can be costly.
- It is emotionally difficult. We are often caring for someone who would rather not need care.
We May Experience Many Losses in Caregiving

- Loss of independence
- Loss of plans for the future
- Loss of friends
- Financial and lifestyle losses
- The misnomer of *anticipatory grief*
It May Affect Others

- Caregiving affects the family.
- Spouses may feel neglected or resentful, placing strain on the marriage.
- Children too may feel neglected, scared, and confused.
- Siblings and parents may differ on plans and responsibilities.
To Sum Up: What Factors Make Family Caregiving Difficult

- Some circumstances can make it difficult.
  - Sleep disturbances
  - Incontinence
  - Dementia
  - Non-ambulatory

- Yet, it is important to remember that our sense of burden will be greater when our relationship with the person we are caring for was difficult.
What Family Caregivers Need

- Education and training
- Physical assistance and respite
- Emotional support
- Financial assistance
What Can You Do to Make Your Caregiving Easier?

- Learn as much as possible about your loved one’s diagnosis.
- Be as organized as possible.
- Be sure you are comfortable with any medical procedures (injections, changing dressing, etc.) that you are asked to do.
- Ask for HELP.
- Share your thoughts with, and learn from, other family caregivers.
- Do your best to stay healthy.
- Learn skills that will make you more effective and efficient.
- Become an advocate and work to change the status quo.
What Can You Do to Make Your Caregiving Easier?

- Understand that your feelings, including feelings of grief, are normal.

- Deal with your feelings about your caregiving experience.

- Find a confidante with whom you can honestly discuss frustrations—and sometimes joys.

- Assess your support. Who are your doers, listeners, respite friends?
We need our own respite, or time off from caregiving.

We may need to take small steps—gradually trusting others to provide care in our absence.
Remember, Help Is Not a Dirty Word!

- Family caregiving is not a one-person job.
- If you fall apart, who will fill your shoes?
- A lot of people actually do want to help, but they don’t know how.
A Program for Getting Help

- Asking for help is a sign of strength. It’s not a weakness.
- Caregiving isn’t one thing but rather made up of many individual tasks.
- Make a list of the tasks that need to get done in any given week.
- In what ways can family and friends help you?
Family and Friends Can Help!

- Assist with chores
- Mow a lawn
- Clean house
- Assist with care
- Run errands
- Grocery shop
- Pick up prescriptions
- Prepare meals
- Maintain contact
- Call
- Come by
- Financial help
- Offer respite
- Help with care
- Join you for dinner or a weekend
- A weekend respite
There Are Professionals Who Can Help

- Care Managers
- Social Service Agencies
- Elder Care Attorneys
- Financial Planners
- Offices of Aging
- Other Agencies and Organizations
- National Family Caregivers Association
How Professionals Can Help

- Professionals can help you assess how you are doing with caregiving—what your strengths and limitations are.
- They can help you identify your support.
- They can assist you in examining the ways that caregiving is affecting your own health and well-being.
While we may feel we are better off just taking it a day at a time and we may be anxious to look ahead, it is important to plan.

Illness is never static.

Ask yourself: When will this become too difficult to do?
As Death Nears

- The importance of Advance Care Planning
- Hospice as a resource at the end of life
After a Death

- Understand your own grief.
- You may need to understand the ways that this experience affected you.
- You may need to review and restore your memories of the person—prior to the illness.
After a Death

- How has this experience changed you?
- Who are you now?
- What do you wish to take from your old life into your new life?
  - What do you want to leave behind?
  - What do you need or wish to add?
The Gift of Illumination

- Not any easier; more understandable.
- The journey is still difficult, but a light can make it less treacherous.
This webinar was developed by Kenneth Doka and Suzanne Mintz. Dr. Doka is Professor of Gerontology at the College of New Rochelle and a Senior Consultant to the Hospice Foundation of America. Suzanne Mintz is the President, Co-Founder and CEO of the National Family Caregivers Association.

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For more information on hospice care, grief and bereavement, caregiving and end-of-life issues, please visit our website at www.hospicefoundation.org.

Or call us toll-free at 1-800-854-3402.

You can also visit the National Family Caregivers Association at www.thefamilycaregiver.org
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