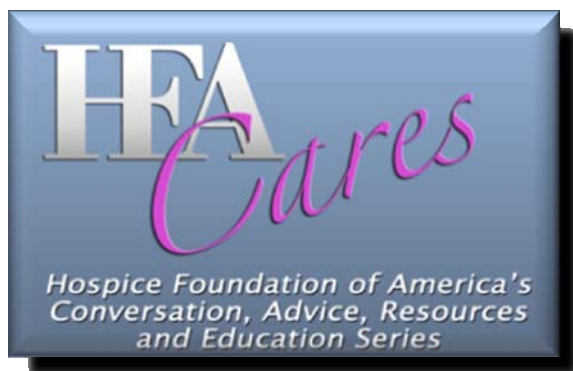


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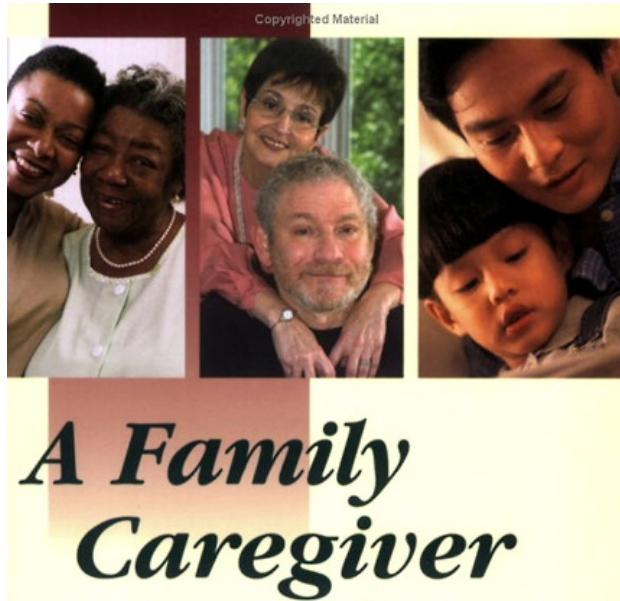
Family Caregiving: Coping with the Challenges

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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 Tough to Be a Family Caregiver

- 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**?

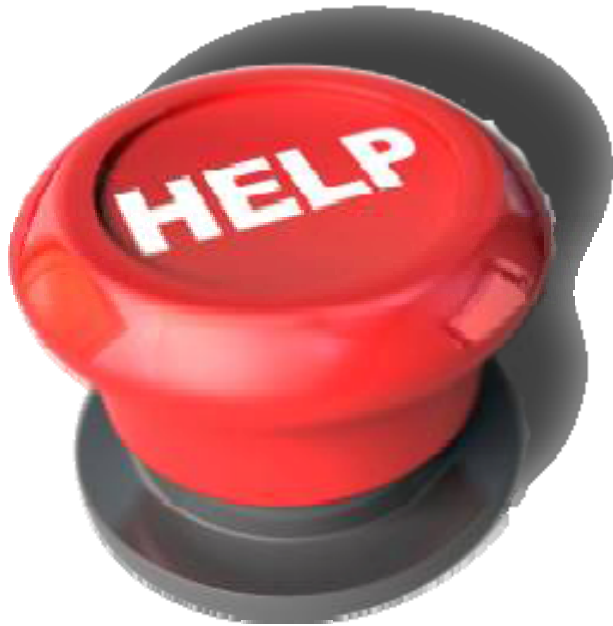


The Importance of Respite

- 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

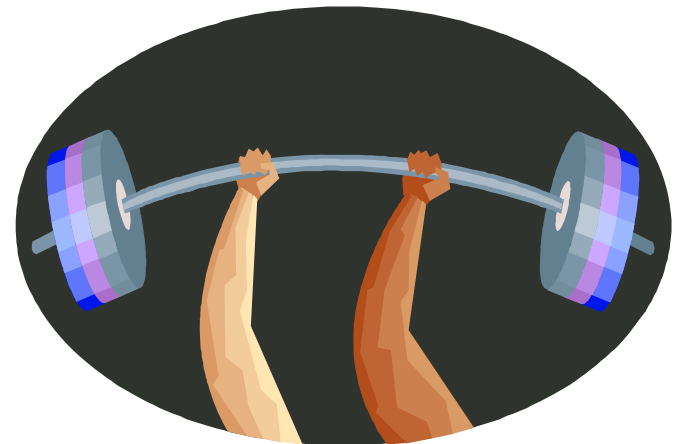
There Are Professionals Who Can Help

- 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 to 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.



It Is Important to Plan for the Future

- 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?



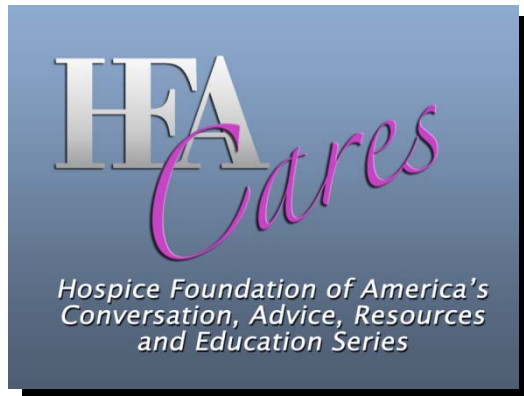
The Gift of Illumination



- 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.

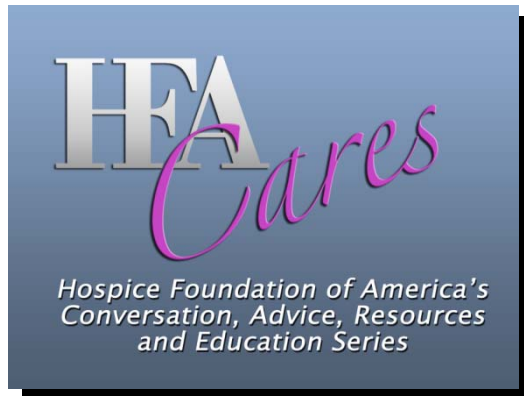
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For more information on hospice care, grief and bereavement, caregiving and end-of-life issues, please visit our website at www.hospicefoundation.org.

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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