

# Navigating the World of Caregiving

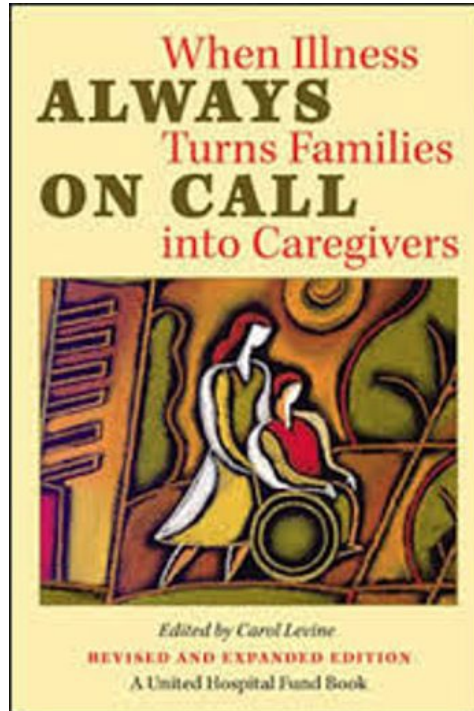
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# Illness and Dying in the U.S.



# Caregiving



“During my nine-year odyssey, I stopped being a wife, and became a family caregiver... I date my rite of passage into the role of family care giver to the first day of my husband’s stay in a rehabilitation facility... a nurse stuck my husband’s soiled sweatpants under my nose and said, “Take these away. Laundry is your job...” The underlying message was that my life from now on would consist of performing an unrelieved series of nasty chores.”

-Carol Levine, Always on Call. p.73



# Facts About Caregivers

## CAREGIVING in the U.S. 2020

The number of Americans providing unpaid care has increased over the last five years.\*



NEARLY ONE IN FIVE (19%) ARE PROVIDING UNPAID CARE TO AN ADULT WITH HEALTH OR FUNCTIONAL NEEDS.\*\*

More Americans are caring for more than one person.



More family caregivers have difficulty coordinating care.



More Americans caring for someone with Alzheimer's disease or dementia.

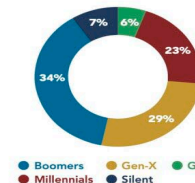


More family caregivers report their own health is fair to poor.



23% OF AMERICANS SAY CAREGIVING HAS MADE THEIR HEALTH WORSE.

Who are today's family caregivers?



45%  
HAVE HAD AT  
LEAST ONE  
FINANCIAL IMPACT



Founded as Hospice of Wake County • 1979



\*Provided care to an adult or child with special needs.  
\*\*The remainder of this data is based on the 19% or 48 million caregivers caring for an adult.  
URL: [www.aarp.org/uscaregiving](http://www.aarp.org/uscaregiving) DOI: <https://doi.org/10.26419/ppi.00103.002>



Caregiving in the U.S. 2020,  
National Alliance for Caregiving and AARP  
For media inquiries, contact [Media@aarp.org](mailto:Media@aarp.org)

# Impact on Caregivers

- **60%** of caregivers show signs of depression
- **55%** say they skip doctor appointments for themselves
- **58%** indicate worse exercise habits than before caregiving responsibilities.
- This level of stress can take as much as **10 years off a family caregiver's life.**

# Caregivers report...

- Sleep deprivation
- Poor eating habits
- Failure to exercise
- Failure to rest when ill
- Postponing or not making medical appointments for themselves



- *Again... sound familiar?*

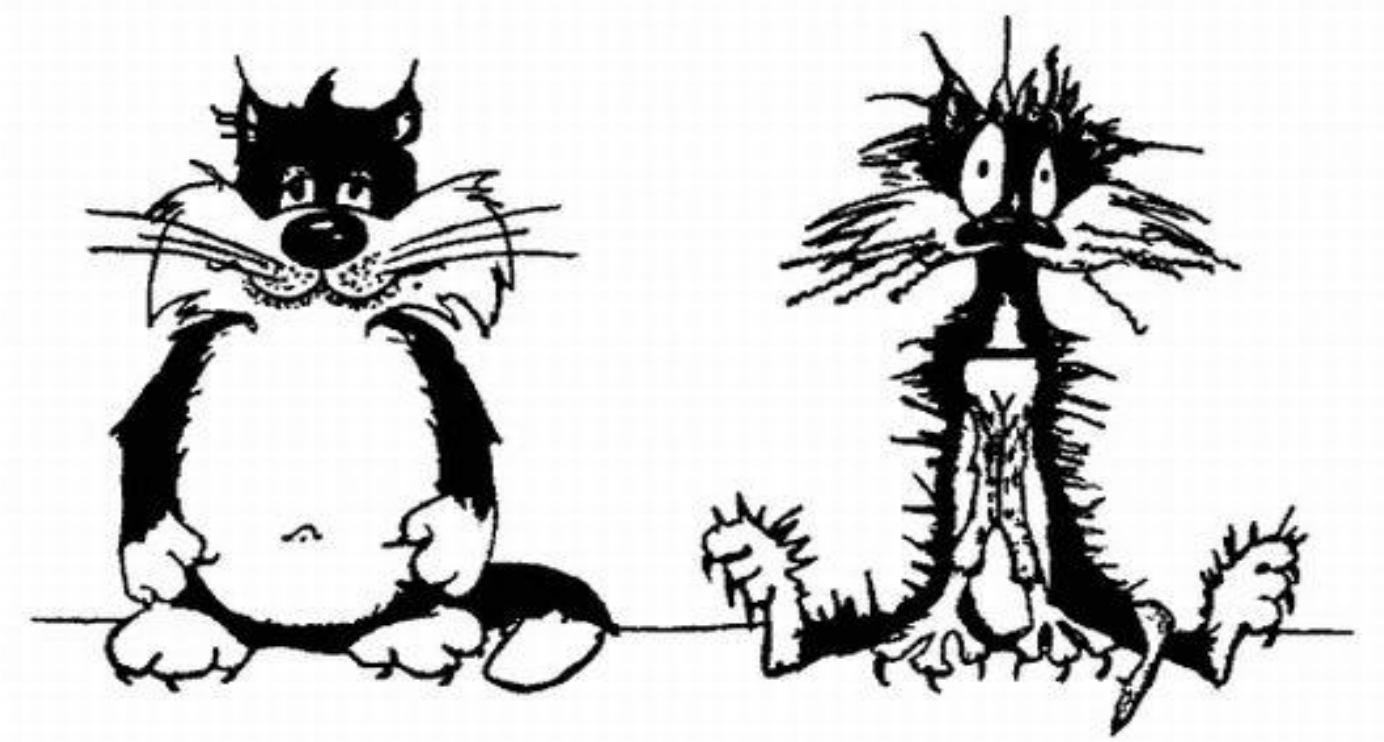


# ... But We're in Denial!



- Seven in ten people in the U.S. will need long-term care at some point after age 65
- Average length of long-term care: 3 years
- Only 24% predict they will need help, though half have already been caregivers!

# Feel familiar?



**Before**

**After**



# The Face of Family Caregivers



# Who Are Caregivers?

Attends to daily needs of another— physical, emotional, and often financial support.



## Caregiver

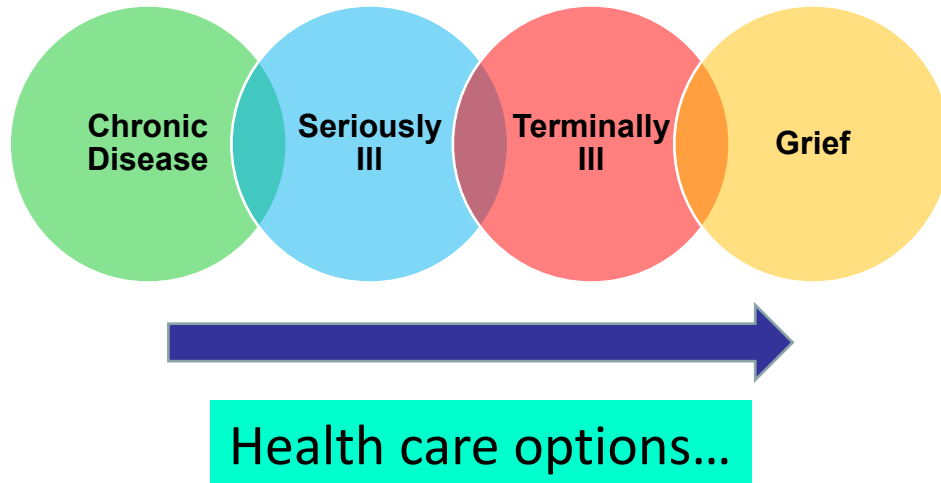


Cares for relatives & loved ones; a member of the caregiver's family of origin or family of choice

Non-professional ("informal") who provides unpaid care for others, in the home.



For many, not all:



# Trajectory of Illness

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# The Basics – An Overview



**Advance Care Planning**



**Palliative Care**



**Hospice**



**Caregiver support**

Self-compassion break  
Practices to build your resilience

# Advance Care Planning

## Go Wish Cards

- What is important to people as they face life's end
- Good for all people, including elders, people with lower-literacy skills or limited English skills
- Play this game with your health care proxy, and ALSO with people for whom you are a caregiver





# Palliative Care

- Specialized medical care for people living with a serious illness
- Focused on providing relief from the symptoms and stress of the illness
- Care is based on the needs of the patient
- Goal is to improve quality of life for both the patient and the family





# Hospice

- For people who are expected to live less than six months
- Focus on comfort care
- Medicare and Medicaid typically cover the full cost of hospice services



# Caregiver Tips

- Preventing Deconditioning
- Encouraging Independence
- Assessing Needs

**BGS** British Geriatrics Society  
Improving healthcare for older people

**Sit Up** **Get Dressed** **Keep Moving**

Preventing deconditioning and enabling independence for older people

**Assess**

- A comprehensive assessment should be completed to determine usual capabilities
- A risk assessment should be completed
- Glasses, hearing aid, clock and calendar should be accessible

**Support**

- Are there appropriate mobility aids available? Ask: Is it the right size and reachable?
- Walking to the toilet helps to prepare for going home. Ask: Is the catheter really needed?
- Sitting in a chair can help you. Ask: Do you need help getting out of bed?

**Encourage**

- Feed and take fluids independently
- Wash and dress independently in own clothes
- Keep arms and legs moving, even in bed or on a chair

**Deconditioning syndrome**

Increased confusion or disorientation

Muscle and joint stiffness, leading to reduced ability to walk

Pneumonia due to prolonged bed rest

Further immobility due to inactivity

Increased risk of falls due to muscle weakness

Increased risk of swallowing problems leading to pneumonia

Constipation and incontinence

Appetite and digestion can be affected

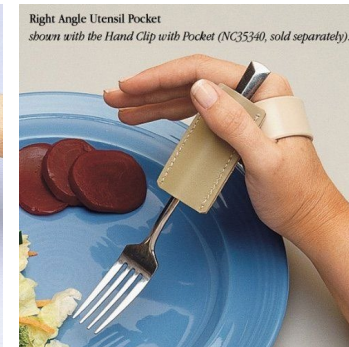
Clots in the legs and lungs

Skin breakdown, leading to pressure ulcers

**#SitUpGetDressedKeepMoving**

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# Caregiver Tips



Right Angle Utensil Pocket shown with the Hand Clip with Pocket (NC35340, sold separately).



# Let's Look Under the Hood

## Caregiver Self-Assessment

**During the last week, I have** *(scale of 1-10)*:

- Felt strained between work and family responsibilities
- Had trouble keeping my mind on what I was doing
- Felt completely overwhelmed
- Been upset that my loved one has changed so much from their former self
- Been edgy or irritable
- Been satisfied with support from my family





# Important Tips for Caregivers, from Caregivers



**Learn to Communicate Effectively** - Communication is key, both with your loved one and their medical team. Learning to communicate with medical staff is essential as a caregiver will help you understand what you need to provide for your loved one, how you can aid in their care, and will allow you to advocate for them if need be. Learning to communicate with your loved one is incredibly important too.

**Take Care of YOU** - Making time for self-care can be difficult, especially when it becomes your first instinct to put the person you are caring for above all. This could mean actively checking in with yourself every day, making sure you see your doctor and reducing personal stress. Caregiving takes a toll on caregivers, but it's important to make sure your mental and physical health are priorities – you won't be able to care for your loved one if you're not healthy.

# Caregiver Tips

**Acknowledge Your Loved One's Limitations** - know that even with their limitations, they are still the person you love and cherish.

**Accept Help from Your Community, Family and Friends** - When your friends, family or community offer support – don't hesitate to accept it! A common worry for caregivers is that they feel as though they are a burden on others when they ask for help – but that's actually the opposite of being true!

**Be Realistic** - It's important to be realistic about what your loved one is experiencing – a memory condition, disease or the process of aging.

**Be Open to New Methods of Care** - ensures that you are pursuing the right path of care for both you and your loved one – and that you're both getting the support you need.

**Stay Connected with the Outside World** - new responsibilities may take over your world which can find yourself feeling isolated. Take some time to stay connected with the outside world – family, friends, colleagues – and talk about something other than your responsibilities as a caregiver.

**Get Organized** - Consider all legal documents, financial obligations and care preferences, and make sure you've spoken to your loved one about them. It may seem like a difficult conversation to have at first – but you'll thank yourself later.



# Moving Forward after the Loss

- Choose One Thing to Do Each Day
- Practice Spending Time With Yourself
- Take Things at Your Own Pace
- Write Down Your Stories & Memories
- Give Thanks to Those Who Have Supported You
- Practice Prayer, Meditation, & Mindfulness

# Resources

## **AARP – Prepare to Care Guide**

<https://www.aarp.org/caregiving/prepare-to-care-planning-guide/>

## **Caregiver Action Network**

<https://www.caregiveraction.org/>

## **Coordinating Caregiver Responsibilities**

[https://www.nia.nih.gov/sites/default/files/2023-04/worksheet-coordinating-caregiving-responsibilities\\_1.pdf](https://www.nia.nih.gov/sites/default/files/2023-04/worksheet-coordinating-caregiving-responsibilities_1.pdf)

## **Five Questions to Ask Your Doctor When You (or a Loved One) are Diagnosed with a Serious Illness**

<https://getpalliativecare.org/five-questions-ask-doctor-loved-one-diagnosed-serious-illness>

## **Get Palliative Care**

<https://getpalliativecare.org/>

Hospice Care – resources for caregivers

<https://www.caringinfo.org/>

## **Go Wish Card Game (free, online resource)**

<https://codaalliance.org/go-wish-game/>

## **Self-Compassion Break**

[https://getpalliativecare.org/n Break](https://getpalliativecare.org/n-Break)