

Caregiving: Benefits and Burden

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More than 53 million Americans serve as **family caregivers**

2.8 million Americans care for someone living with a **terminal illness**

Selfless and one of the most profound act of love and commitment.

A gift of **time, presence, and devotion.**

Yet, a role that is **often unrecognized and underappreciated.**

Video

youtube.com/watch?v=xRMX3xz6X2I
&feature=youtu.be&themeRefresh=1

Caregivers Provide

Physical care

Emotional support

Support with navigating healthcare systems

Coordination of medical care

Treatment administration

Making complex medical and end-of-life decisions

Hidden Strengths of Caregiving

Deeper Connection: Stronger, more meaningful relationships with loved ones

Personal Growth: Resilience developed through navigating difficult moments

Inner Strength: Discovering courage, compassion, and grace

Sense of Purpose: Meaning and fulfillment in caring for another

Clarity About What Matters: A deeper appreciation for life itself

For many, caregiving becomes transformative: *“It makes us more deeply human.”*

Burden of Caregiving

Caregivers often spend 12-16 hour daily

- Physical exhaustion
- Emotional distress- watching your loved one suffer
- Social isolation as your world narrows
- Financial pressures from medical costs and lost work time
- Feeling overwhelmed by medical decisions

Emotions That Often Go Unspoken

Guilt:

- "Am I doing enough?"
- "Should I have noticed their illness sooner?"
- "I feel guilty when I need a break."

Exhaustion

- "I'm so tired I can barely function"
- "I have nothing left to give"

Fear

- "What will happen when they die?"
- "How will I manage without them?"
- "Am I making the right decisions?"

Need for relief - most difficult to process

- "Sometimes I wish it would just be over"
- "I feel terrible for thinking that"

All of these feelings can coexist—and all are valid.

Profound Mental Health Impact

- Studies show that up to half of intensive caregivers experience clinically significant depression
- Anxiety about the future is nearly universal
- Feeling inadequate— not doing enough or don't know what they're doing

Importance of early mental health interventions:

- Improves ability to provide ongoing care
- Improves both current and future mental and physical well-being
- Reduces risk of complicated grief after death

Protecting Caregiver

Ask for and accept help:

- Delegate specific tasks to family and friends
- Use respite care services for breaks
- Consider home health or hospice services
- Join caregiver support groups

Protect your own health:

- Maintain your own medical appointments
- Prioritize sleep when possible
- Eat regularly
- Take short breaks throughout the day

Set boundaries:

- It's okay to say "I need help"
- You don't have to do everything perfectly
- Taking care of yourself is not selfish

Decision Making

End-of-life decisions are among the hardest to face:

Common decisions include:

- Whether to continue or stop treatments
- Where your loved one will spend their final days
- Use of life-sustaining treatments (CPR, ventilators, feeding tubes)
- Hospice care enrollment
- Pain and symptom management

The emotional burden:

- Fear of making the "wrong" choice
- Conflict between what you want and what they need
- Uncertainty about what they would want
- Pressure from other family members

Advance care planning is one of the most important things you can do—not just for your loved one, but for yourself.

When You Must Decide for Them

If your loved one cannot speak for themselves:

Ask yourself:

- "What would they want in this situation?"
- "What did they value most in life?"
- "What did they say about quality versus quantity of life?"

Give yourself permission:

- You're making the best decision you can with the information you have
- You cannot predict the future with certainty
- Using all available information at the time is enough
- You are helping to shape the final chapter of their life story

Avoid promises you cannot keep:

- "I'll never put you in a nursing home"
- "I'll do everything to keep you alive"

Signs of Final Days

Signs of final days:

- Increased sleeping
- Less eating and drinking
- Changes in breathing
- Withdrawal from surroundings
- Focus shifts to comfort

After Loss

- Relief that suffering has ended (this is normal)
- Guilt about feeling relieved
- Exhaustion—physical and emotional
- Identity confusion ("Who am I now?")
- Continued questioning of decisions made

Permission to Feel It All

You may feel:

- Love and resentment
- Gratitude and anger
- Hope and despair
- Connection and loneliness
- Fulfillment and exhaustion

Remember:

- You don't have to navigate this alone
- Your feelings—all of them—are valid
- Asking for help is a sign of strength
- Taking care of yourself is important
- There is no perfect way to do this
- You are doing the best you can

Risk factors for complicated grief

Elevated Risk:

- High levels of anticipatory grief
- Low sense of preparedness
- Perception that your loved one suffered
- Lack of support during caregiving

Protective factors:

- Feeling you did your best
- Advance care planning conversations
- Support during caregiving
- Belief that care matched their wishes

Reflection

What support do I need?

What conversations still need to happen?

How can I care for myself while caring for them?

Moving Forward

Consider:

- Reaching out to one support resource this week
- Having one important conversation
- Accepting one offer of help
- Giving yourself permission to rest
- Scheduling a mental health screening
- Making your own doctor's appointment

Final Thoughts

Caregiving demands

- Physical stamina you may not have
- Emotional strength that gets depleted
- Decisions you're not prepared to make
- Witnessing suffering you cannot fix

And yet:

- You show up
- You love
- You care
- You honor their life

That is enough.

You are enough.