

## Self-Care for the Caregiver

You are giving your loved one something no medicine can provide. This guide is about making sure you survive it too.

### 1. The Truth About Caregiving

Caregiving is one of the hardest things a human being can do. It is physically exhausting, emotionally draining, and often profoundly isolating. There is no training for watching someone you love decline.

But here is what is also true: you are giving your loved one something no medicine can — your presence. The comfort of a familiar voice, a gentle hand, the knowledge that they are not alone. That matters more than you know.

You cannot sustain this if you break. Taking care of yourself is not selfish — it is the only way you can continue to take care of them.

### 2. Recognizing Burnout

Caregiver burnout is real and common. It does not mean you are failing — it means you are human. Watch for these signs:

- Exhaustion that sleep doesn't fix
- Irritability or anger that feels out of proportion
- Withdrawal from friends and activities
- Neglecting your own health (skipping meals, doctor appointments)
- Feeling resentful — and then guilty about the resentment
- Loss of interest in things you used to enjoy
- Difficulty concentrating or making decisions
- Getting sick more often
- Feeling hopeless or trapped

If you recognize yourself in this list, you are not weak. You need support — and you deserve it.

### 3. Respite Care: Your Right to Rest

Respite care provides up to 5 consecutive days of inpatient care for your loved one so that you can rest. This is a Medicare hospice benefit — it is already part of the care your loved one is entitled to.

#### About Respite Care

- Your loved one receives professional care in an inpatient facility
- You do not have to be falling apart to use it
- Ask your hospice social worker to arrange it
- You can use it proactively — before you reach the breaking point

Rest is not abandonment. You are not leaving your loved one — you are ensuring you can continue to be there for them.

### 4. Asking for Help: Real Scripts

Most people genuinely want to help but don't know how. Specific requests are easier to say yes to than vague offers. Here are scripts you can use:

#### When someone says "Let me know if you need anything":

"Actually, could you bring dinner Tuesday?" or "Could you sit with Mom for 2 hours Saturday?" or "Could you pick up groceries from this list?"

#### To a friend:

"I need help and I'm not good at asking. Could you...?"

#### To family:

"I can't do this alone. Here's what I need from each of us."

Care Coordination Tools: Consider creating a care calendar so people can sign up for specific tasks. Free tools include: Lotsa Helping Hands, CaringBridge, and Meal Train.

## 5. Anticipatory Grief

You are grieving while caregiving. This is called anticipatory grief, and it is completely normal. You are mourning the loss of the person they were, the future you planned together, and the life you had before caregiving took over.

You may feel loss, sadness, anger, relief, guilt — sometimes all in one day. This is not a sign that something is wrong with you. It is a sign that you love deeply.

Crying doesn't mean you're weak. It means you love them. This grief is real and valid even before the death. You do not need to wait for permission to grieve.

## 6. Your Physical Health

Your body is carrying this too. Caregiving takes a measurable toll on physical health. Here are non-negotiable basics:

### Sleep

- Nap when they nap — this is not laziness, it is survival
- Ask someone to cover night shifts so you can get uninterrupted sleep

### Eat

- Keep easy, ready-to-eat meals available
- Don't skip meals — your body needs fuel

### Move

- Even 10 minutes outside changes everything
- Fresh air and sunlight are underrated medicine

### Medical care

- Don't cancel your own doctor appointments
- Keep taking your own medications

## 7. Support Resources

You do not have to figure this out alone. These resources are available to you:

- Hospice social worker — free, already part of your care team
- Caregiver support groups — available in-person and online
- NHPCO CaringInfo helpline — 1-800-658-8898
- National Alliance for Caregiving — caregiving.org
- Family Caregiver Alliance — caregiver.org
- Area Agency on Aging — eldercare.acl.gov

#### If You Are in Crisis

If you are feeling overwhelmed to the point of hopelessness, please reach out. The 988 Suicide & Crisis Lifeline is available 24/7. Call or text 988. You matter. Your pain is real. Help is available.

## 8. Permission

If you need to hear this from someone, here it is:

### You have permission to:

- Laugh
- Enjoy something
- Feel relief
- Take a break
- Ask for help
- Say "I can't do this right now"
- Cry
- Eat a meal you enjoy
- Watch a show
- Not be available for 2 hours

None of this makes you a bad caregiver. It makes you human.

#### Sources

1. NHPCO CaringInfo — <https://www.caringinfo.org/types-of-care/hospice-care/caregiving/>

2. Family Caregiver Alliance — <https://www.caregiver.org/resource/caregiver-health/>
3. National Alliance for Caregiving — <https://www.caregiving.org/>
4. Hospice Foundation of America — <https://hospicefoundation.org/Caregiving>
5. American Psychological Association — Caregiver Briefcase — <https://www.apa.org/pi/about/publications/caregivers>

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