BEYOND JUST GETTING BY

A Caregiver’s Guide to Finding Peace Through Tough Times
Before you take off on a plane, the flight attendants tell you that in case of an emergency, oxygen masks will drop from a compartment above you. They tell you to put on your own mask before you try to help someone else. This is because you can’t help anyone if you don’t have oxygen for yourself.

Caregiving works the same way. It is easy to put off your own needs for the more obvious ones of your sick loved one. But over time, doing so may cause you to lose your strength, your health, and your desire to help.

This booklet provides tips on how to care for yourself before giving care to a loved one. Only by this approach can you complete your journey through caregiving with a sense of strength and a measure of peace.
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Beyond just getting by...as a caregiver

You’re not alone
Millions of Americans take care of an ill family member or friend without pay. It’s very likely that someone you know—a coworker, parent, brother, sister, or friend—is juggling priorities, just like you.

The typical caregiver is middle-aged, working, and providing care for more than 20 hours each week. The majority of caregivers are women, but nearly one-third are men.

A growing need
The number of people who can provide care is shrinking, while the need for caregivers is growing. This may be because:

• People in the United States are living longer but have fewer younger family members
• A growing number of Americans have long-lasting health problems that make them less able to carry out their daily activities
• Most people who need care live in their own home or with a caregiver

If family and friends who give free care were paid, it would cost the US economy about $375 billion a year.
Beyond just getting by...at work

The balancing act
More than 7 out of 10 caregivers have to balance working and helping a loved one with health problems.

Employed caregivers may lose time from work, get less work done, quit a job, or pass up the chance for a promotion or more pay in the future in order to give care to a loved one.

Finding solutions
Ask your employer about:
- Telecommuting, “flex” time, or job sharing
- Company programs that support caregivers

Consider taking a leave:
- The US Family and Medical Leave Act allows eligible employees to take up to 12 weeks of unpaid leave to care for an ill family member
- Some states, such as California and New Jersey, allow eligible employees to take paid or partially paid family leave

Look into support programs sponsored by the government:
- The National Family Caregiver Support Program provides caregiver support services
Beyond just getting by... with better self-care

No rest for the weary
Caregiving may tire your body and mind. Many caregivers don’t take the time to do the things that may help them stay healthy and lessen their mental stress.

Don’t wait. Take steps now to care for yourself.

Plan for a healthy body
The work and worry of caregiving may harm your health—higher blood pressure, more heart troubles, more colds and flu, and other problems. Here are steps you can take for better health.

- Get enough rest
- Eat healthy meals at regular times
- Exercise
- Avoid drugs and excessive alcohol
- Get regular medical checkups and care for health problems
- Look into vaccine shots for the flu and pneumonia
- Make time for fun and hobbies
Beyond just getting by…
with better self-care

Check your stress level

The American Medical Association has a quick and easy “distress” test (Caregiver Self-Assessment Questionnaire) that you can take on the Web, at www.ama-assn.org/go/caregiverhealth.
Beyond just getting by…with less stress

When there’s too much mental stress
Taking care of a loved one is often rewarding. But it may also add stress if you feel frustrated, angry, guilty, lonely, or exhausted.

Take control of your stress—don’t let stress control you
You may be able to take better care of your loved one if you find ways to relieve your stress.

- **Ask for help.** Ask for and accept favors from family, friends, and neighbors
- **Set the ground rules.** Let your loved one know what you are willing and able to do for them
- **Let your loved one do as much as safely possible.** He or she will feel more independent and in control
- **Know that there will be hard times.** Be prepared to change your plans to solve new problems
- **Let your feelings out.** Talking to your healthcare professional, family, friends, a counselor, or a support group can be a relief
- **Keep your sense of humor.** Laugh with a friend. Look for the humor in little things
- **Learn to relax.** Take long, slow breaths for 5 minutes to help let go of tension
## Beyond just getting by... with less stress

### Tips for good communication

- Show respect for the person you are talking to
- Really listen, even if you don’t agree
- If you don’t understand, ask the other person to explain further
- Wait for responses to your questions
- Say you’re sorry if you owe an apology

### Look for signs that you are too stressed. You may:

- Feel overwhelmed
- Sleep too much or too little
- Gain or lose weight
- Feel tired most of the time
- Lose interest in things you once enjoyed
- Become easily irritated or angry
- Worry all the time
- Have headaches or body pains
Beyond just getting by... with your emotions

Depression
Your mental and emotional health may be hit the hardest by caregiving. For some caregivers, the stress and worry may lead to depression.

You may be depressed if you have the following symptoms for more than 2 weeks:

- You feel sad, worried, “empty,” hopeless, guilty, worthless, helpless, irritable, restless, tired, or listless
- You lose interest in activities you used to enjoy
- You have trouble focusing, remembering things, or making decisions
- You oversleep or have trouble sleeping
- You eat too much or too little
- You have aches or pains, headaches, cramps, or an upset stomach that don’t go away, even with treatment
- You have thoughts of hurting yourself. You must reach out for help if you feel this way. Call your healthcare provider or a mental health counselor, or go to an emergency room for help right away.

These symptoms don’t result from a lack of love or care on your part. They aren’t due to a lack of inner strength. They are brought on by the stress you can’t avoid as a caregiver.

Don’t struggle alone if you are feeling sad or worried. Seek help from your healthcare professional.
Beyond just getting by… with your emotions

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<th>Where to look for help with depression:</th>
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<tr>
<td>• Your healthcare professional</td>
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<tr>
<td>• Social workers, mental health counselors, psychiatrists, or psychologists</td>
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<tr>
<td>• Community, hospital, or university mental health centers</td>
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<tr>
<td>• Local medical or psychological societies</td>
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<tr>
<td>• Family services or social agencies</td>
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<td>• Employee assistance programs</td>
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Beyond just getting by...day to day

Living life to the fullest
A balanced caregiver is more likely to bring balance to the ill person. Allowing yourself to get run down, missing out on fun activities, and not making time for your own needs will only make your job harder.

Taking regular breaks from caregiving is not selfish. Even short breaks during the day let you be a better caregiver.

- Do things you enjoy. Work in your garden, read a book, go to a movie, take a walk, or do something else you find relaxing
- Spend time with friends and family, or join a support group
- Try yoga. It stretches the body and relaxes the mind
- Practice your religion, explore your spirituality, or try meditation. Some people find peace and meaning in these practices

Enjoy the rewards of caregiving
Caregiving has both challenges and rewards. Some people say that giving care brings them closer to the loved one who needs help. They say they feel needed. They have a sense of accomplishment. Caregivers feel good about themselves and appreciate life more.
Beyond just getting by… for the silent heroes

Your willingness to help another person through an illness answers the call we have as human beings to take care of one another. Thank you for reminding us that true courage doesn’t need credit, and heroes walk among us every day.

A call to care

For some of us, caregiving is easy, even when we are not prepared. For others, the job doesn’t come so easily. For most of us, caregiving becomes a big part of our lives.

Caregiving can bring many rewards. People have come away from the job of giving care to an ill loved one with a sense of:

- A better relationship with the loved one
- Doing a job well
- Feeling that they have given back to the loved one
- Value and self-esteem
- Reward for lost careers
- Purpose in life
- Comfort upon losing the loved one
Beyond just getting by…
for the silent heroes

“Caring for my wife during her battle with cancer gave me a chance to heal parts of myself and our marriage. The hard times I went through caused a shift in my life that, while very painful, brought me peace in the long run.”

—Edward G., caregiver for his wife of 24 years diagnosed with uterine cancer
Helpful contacts for caregivers

**General information**
- American Association of Retired Persons (AARP): Caregiving
  www.aarp.org/family/caregiving
- Family Caregiver Alliance: National Center on Caregiving
  www.caregiver.org
- National Caregivers Library
  www.caregiverslibrary.org
- National Family Caregivers Association
  www.thefamilycaregiver.org
- US Department of Health and Human Services: Administration on Aging
  www.eldercare.gov

**Emotional health and wellness**
- American Medical Association Caregiver Self-Assessment Questionnaire
  www.ama-assn.org/go/caregiverhealth
- Mental Health America
  www.nmha.org