

Caregiving



A Series by:

Real World Health Care
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Caregiving can be both significantly rewarding and tremendously challenging as family caregivers provide a variety of support and care for family members, friends, and neighbors.

Caregiving is a recently published series of articles that spotlights the organizations and efforts dedicated to making sure that those who care for loved ones are getting the support they need. Please accept this complimentary copy as our way of thanking you for your commitment to helping these caregivers and advocating for healthier futures.

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Caregiving Expert: “Fill Your Tank”

The number of Americans providing unpaid care to family members or loved ones has increased since 2015. Today, about one in five is acting as a family caregiver to an adult with health or functional needs, according to a 2020 report by AARP and the National Alliance for Caregiving (NAC). Nearly a quarter of caregivers of adults are providing care to multiple people, stepping up to provide unpaid care to family, friends and neighbors who need assistance.

Who are these family caregivers? They are people of all generations, racial/ethnic groups, income and education levels, family types, gender identities and sexual orientations, although women caregivers outnumber men by about 3:2. Nearly two-thirds of caregivers also work outside of their caregiving duties.

Caregivers Report Physical, Emotional and Financial Strain

According to caregiving expert, author and speaker Amy Goyer, caregiving for a loved one can be a time-consuming and costly initiative, though not without its rewards. Goyer has spent her entire adult life providing unpaid care to family members including her grandparents, parents, a sibling, and other relatives and friends – all while holding down full-time jobs and starting a consulting practice.

“Caregivers spend an average of 26 percent of their annual income on caregiving, and in some cases higher,” she says, noting that her caregiving-related financial challenges led her to file for bankruptcy after more than a decade of caregiving intensively for her parents and her sister. The AARP/NAC research found that 28 percent of caregivers stop saving and 23 percent take on more debt as a result of caregiving. Nearly 20 percent leave bills unpaid or pay them late.



Amy Goyer

Caregiving also can have an impact on the caregiver’s mental and physical health. The AARP/NAC report found that only 41 percent of caregivers report their health status as excellent or very good (down about seven percentage points from 2015). One in four finds it difficult to take care of their own health, and a similar proportion report caregiving has made their own health worse.

“The decline in caregiver self-reported health is concerning, as the stress associated with caregiving may exacerbate declines in health that occur with age,” the report notes. “It begs the question, ‘Who will care for the caregivers?’”

Running on Fumes

Caregivers feel the caregiving push and pull on their time, their financial well-being, their health, their family, their work, and their own personal well-being. Finding the time and the energy to take care of themselves is not always top of mind. Several years ago, Goyer had an “aha” moment as she was pulling out of a service station after filling her car with gas.

"One week, I was so busy working full time and caregiving for family members that I almost let my car run out of gas," she recalls. "As I drove away from the pump, I noticed how much better the car ran on a full tank of gas. I realized that I had been expecting myself to run on fumes all the time and be just as efficient. In reality, my car doesn't run well on fumes, and neither do I. If I don't fill up my physical, mental, and emotional tank, I won't be as efficient."

Goyer discovered four ways in which she could fill up her emotional and physical tank:

- **"Quick tank fillers"** like stopping for a cup of coffee or refreshing drink during the day, having fresh flowers, pausing to hug her parents or pet a dog, doing a few jumping jacks or taking a walk around the block. "Maybe even sitting and doing nothing for a few minutes gives you that quick break you may not even know you need," she says.
- **"Premium fill-ups"** take a bit more time but are just as important to do regularly. For Goyer, this means going to a movie, attending a webinar, or participating in a weekly Pilates class. "I planned fun Friday adventures with my parents when I was caregiving for them," she says. "After their doctor appointments, I took them out for a nice lunch, bit of shopping, or something a little different to fill all of our tanks."
- **"Tune-ups"** are time away from caregiving, even if just for a half a day or a weekend. Goyer would try to schedule a week every year where she wasn't taking care of anyone. "This can be the hardest fill-up due to the time involved and the money required for respite care," she says.
- **"Routine maintenance"** includes the basic self-care everyone should practice – sleep, proper nutrition, exercise – but which may seem like luxuries in the face of competing demands. "Sleep was very important for me," Goyer says. "I also got regular acupuncture to help cope with anxiety and stress."

"As caregivers, it is important for us to do things in all four of these categories; focusing on only one or two categories just won't work to keep us going," Goyer concludes. "We know we need to take care of ourselves, but it's easy to feel guilty when we take time away from our loved ones. Consciously experience things in each category and remember that caring for yourself isn't selfish, it's practical and can help to make you a better caregiver."

Reference

Caregiving in the U.S. (2020 Report), AARP Family Caregiving™ and National Alliance for Caregiving. Accessed 1/16/23.

Nine Steps to Respite Care for Family Caregivers of Persons with Dementia, including Alzheimer's Disease

By ARCH National Respite Network and Resource Center

Caregivers of family members with dementia, including Alzheimer's disease, may face special challenges that result in changing roles within the family and the need for more intensive levels of care. Providing care can be complicated and challenging and requires careful planning. Respite care services can provide family caregivers with a much-needed break from caregiving responsibilities.

The following article is excerpted from the [ARCH National Respite Network and Resource Center's](#) family caregiver fact sheet, which can be [downloaded here](#). Please read the full fact sheet to gain a better understanding of the resources that are available, what caregivers can expect, and how to select a high-quality service that best meets your needs.

Step One: Understand Respite Care

Taking a break allows caregivers to become less stressed, better rested and renewed. Families are encouraged to start using respite care at the beginning of their caregiving experience and on a regular basis to avoid feelings of guilt, exhaustion, isolation, and burnout.

Step Two: Types of Respite Care Available

Respite care is available from a variety of organizations and can be delivered in a variety of locations inside and outside the home. Caregivers can receive a break for a few hours, a few days or even several weeks. Services may be free or offered on a sliding scale, and in some cases, emergency respite services are available.

Step Three: Where to Find Services

There are several ways to find respite. Some programs are for specific populations while others are provided to the general public. [Read the fact sheet](#) for a list of places to contact regarding the respite services available in your community.

Step Four: Paying for Respite

In many cases, respite will be free. In some cases, you may be required to pay a copayment based on the care recipient's medical or disability status and financial information. The [fact sheet](#) lists several public and private funding sources.

Step Five: Deciding What's Right

Once you have decided to use respite care, you want to make sure the service you are considering is right for your situation and family. Careful conversations with family members and the care recipient are crucial when exploring options and how you will use the respite service. After those initial conversations, identify potential respite services or providers and discuss your family's expectations. The fact sheet suggests key questions to ask.

Step Six: Preparing Your Loved One for Respite

Some care recipients may be resistant to respite care because they are uncomfortable in an unfamiliar environment or being with people who are considered “strangers.” Introduce the idea of respite well in advance of when you might want to start using it. Involve the care recipient in respite service planning to smooth the transition and use positive language to show your excitement about the opportunity.

Step Seven: Make the Most of Respite

Use respite early and as frequently as possible. Planning is key to making sure your respite time is enjoyable. Focus on you! The goal is to take care of yourself while ensuring your loved one is safe and secure.

Step Eight: Orienting Respite Providers

Create a checklist of essential information (your contact information, the care recipient’s preferences and needs of daily living, etc.) for the respite provider and summarize key information in a “grab and go” package. If the respite provider is qualified to perform medical tasks, dedicate sufficient time before you leave to demonstrate preferred approaches.

Step Nine: Find Out About Other Helpful Resources

Although being a caregiver is rewarding, it can also be challenging. There are several other types of resources that can help you find the most desirable, safe and appropriate respite options and other useful services. [See the list.](#)

About ARCH Respite

The [ARCH National Respite Network and Resource Center](#) assists and promotes the development of quality respite and crisis care programs, helps families locate respite and crisis care services in their communities, and serves as a strong voice for respite in all forums.

How to Ask for Financial Support During Cancer Treatment

By Courtney McHugh, MSW, LSW, Lead Navigator, Family Reach

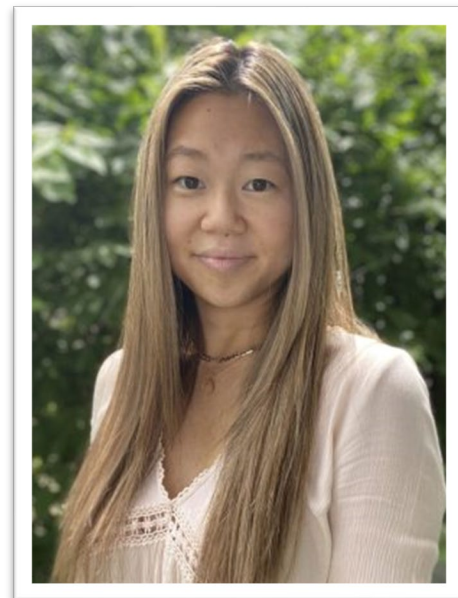
When you're diagnosed with cancer, you may find yourself sorting through a lot of information — treatment schedules, medications, etc. — and it's easy for questions about money to get overlooked.

Even if financial questions are top of mind, we know that asking for help paying your housing, food, and utility bills during cancer treatment can be difficult. Money is personal, and many families aren't sure who to talk to about it. Just remember, you're not alone — up to 73% of cancer patients experience financial hardship as the result of a cancer diagnosis.¹

You deserve the best care and support, regardless of your financial situation. Use the following tips to start a conversation about finances with someone you trust on your care team.

Prepare for the Conversation

- **Write down the questions you want to ask.** What are you the most worried about affording during cancer treatment? These could be treatment-related costs like copays or non-medical expenses like housing, utilities, and food. What bills or payment processes would it be helpful to have someone explain to you step-by-step?
- **Consider who you feel the most comfortable with.** You can talk to someone in your community or anyone on your care team — including your doctor, nurse, social worker, patient navigator, or therapist — about your financial concerns.
- **Be prepared to take notes during the conversation.** You can also ask for written materials to review later or bring along a friend or family member to listen with you.



Courtney McHugh

Bonus tip: Family Reach financial guidebooks are a great resource to help prepare for your conversations and manage your finances during cancer treatment.

Start the Conversation

- **Share your financial concerns.** For example: "I'm worried about missing work and paying my bills." Expressing your worries honestly will allow you to get the best support from your care team.
- **Ask questions.** For example:
 - Can you help me find financial support for my rent/food/transportation?
 - Are there options to help me pay for treatment?
 - What will my insurance cover?

- Can you help me apply for financial support from Family Reach?

Take Steps Toward Financial Relief

- **Follow the steps that your care team shared with you.** This could be contacting a certain non-profit, looking into specific government benefits, or scheduling an appointment with a financial coach.
- **Call, email, or write down questions before your next appointment.** It's okay to ask someone to repeat or clarify information.

Not all of this advice will apply to you, but the most important thing you can do is **ask for help**. While it can be difficult, **asking for and accepting help is a sign of strength and resiliency**. You know the most about your situation, and there's a whole community of non-profits, health care professionals, and federal organizations ready to support you.

View the full tip sheet [here](#).

Reference

1 Thomas G. Knight, Melissa Aguiar, Myra Robinson, Allison Martin, Tommy Chen, Rupali Bose, Jing Ai, Brittany K. Ragon, Aleksander L. Chojecki, Nilay A. Shah, Srinivasa R. Sanikommu, James Symanowski, Edward A Copelan, Michael R. Grunwald; Financial Toxicity Intervention Decreases Mortality in High Risk Hematologic Malignancy Patients. Blood 2020; 136 (Supplement 1): 14-15. doi: <https://doi.org/10.1182/blood-2020-137222>

Two Full-Time Jobs: The Challenges of Being a Family Caregiver While Working

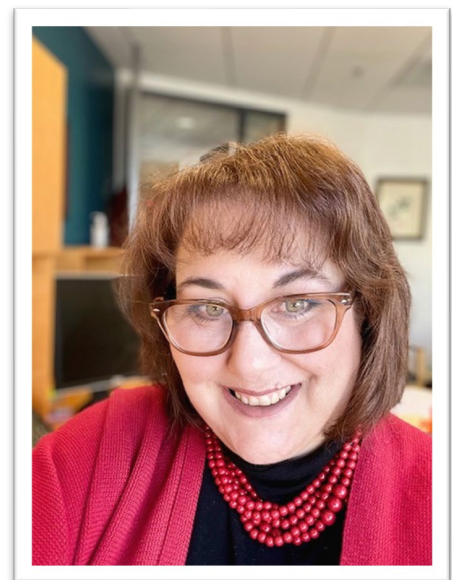
Acting as a family caregiver can be a challenging, full-time job, and it can be even more challenging if you already have a full-time (or even part-time) job. The struggle is a common one: An estimated 60 percent of family caregivers are employed, and two-thirds have had to make some adjustments in their work-life balance because of their caregiving role.

“One of the most common problems facing family caregivers is trying to juggle their job responsibilities with their caregiving responsibilities,” says Lisa Winstel, interim CEO, Caregiver Action Network.

Caregiver Action Network (CAN) is the nation’s leading family caregiver organization working to improve the quality of life for the more than 90 million Americans who care for loved ones with chronic conditions, disabilities, disease, or the frailties of old age. It provides education, peer support and resources to family caregivers across the country, free of charge.

Pandemic-Driven Balances Fade with Return to Work

Family caregiving skyrocketed during the COVID pandemic, as otherwise healthy family members fell ill, elders moved in with their children to avoid the spread of disease in nursing homes, and support organizations paused or scaled back on in-person services. However, according to Winstel, the pandemic had a rare silver lining in that work-from-home mandates helped caregivers find a better balance between working and caregiving by allowing them to spend more time at home caring for their loved ones.



Lisa Winstel

“The return to work was a moment of crisis for caregivers because that balance became more difficult again,” Winstel says.

One of CAN’s strategies for advocating for working caregivers, says Winstel, is to help companies find ways to better support and accommodate their needs. Often, this can be done at little or no cost to the employer, by allowing employees to continue working from home, for example. For employees who can’t work at home, employers can allow them to take short breaks and provide easily accessible locations for private, care-related phone conversations and telemedicine appointments with their loved one and health care providers. They can also allow employees to use their paid sick leave time for caregiving responsibilities like doctor’s appointments or participation in clinical trials.

“We need to normalize the conversation around caregiving,” Winstel says. “Caregivers should feel safe telling employers about their situation and asking for accommodations without being penalized, passed over for promotions, or treated differently by management

and co-workers. Employers should recognize the worker attraction and retention benefits of providing a supportive work environment that allows people to manage their loved one's care."

Can I Afford to Leave My Job?

Winstel says it is natural for caregivers to consider quitting their job to provide care for a loved one, especially if they cannot afford to hire a professional caregiver. She encourages caregivers to carefully consider the pros and cons of leaving the workplace, noting that it can have both short- and long-term financial implications.

In the short-term, it can make it even more difficult for caregivers to help pay for their loved one's out-of-pocket costs related to prescriptions and medical supplies (caregivers shoulder an estimated \$7,000-\$10,000 in costs for items not covered by insurance). In the long-term, leaving a job can reduce social security earnings, resulting in lower payments upon retirement.

"What if, instead of tagging earnings as 'zero' during time away from work for caregiving, the government froze social security earnings at that point in time?" she suggests.

Winstel cautions caregivers from assuming that they can be paid to provide care for a loved one. While it may be possible through certain Veterans Administration and Medicaid programs, the process is complex, requires a lengthy process and must be done following strict tax rules.

To help caregivers manage financial and legal issues, CAN offers a variety of free, [online tools](#) and operates a [help desk](#) to provide caregivers with support and navigation for the challenges they face.

Creative Programs Keep Caregivers Working

CAN works at the policy level to drive changes that will financially and practically benefit caregivers and the loved ones they care for. It also partners with other organizations to develop creative solutions. One example is its work with the Administration for Community Living (ACL) as part of a cooperative program called [Community Care Corps](#). The program seeks to foster innovative local models in which volunteers assist family caregivers, older adults and adults with disabilities with non-medical care in order to maintain their independence.

One of the models under development is a chaperoned rides program in which volunteers drive patients to medical appointments, escort them to the provider's office, get them to the pharmacy afterwards, and deliver them safely back home. Winstel says this type of service can relieve a tremendous amount of stress from a family caregiver who may have difficulty getting time off from work to ferry their loved one to multiple appointments.

"CAN's goal is to improve the quality of life for the growing number of family caregivers in the United States by reducing their day-to-day stress and financial distress through practical solutions and support," Winstel concludes.

Caring for a Loved One with Cancer Can Be Tough: These Two Care Team Providers Can Make It Easier

When someone is diagnosed with cancer, a team of medical professionals mobilizes to coordinate care. Depending on the diagnosis and treatment strategy, patients may be cared for by surgeons, medical oncologists, radiation oncologists, nurses, physical therapists, and other specialists providing hands-on care.

In many cancer centers, patients also have access to two additional team members: psychosocial oncologists and oncology social workers. These professionals provide valuable services to both patients and their family caregivers as they navigate the confusing and uncertain world of cancer diagnosis, treatment, and survival.

What is a Psychosocial Oncologist?

Psychosocial oncologists address the psychological, behavioral, emotional, and social issues that arise for cancer patients and their loved ones. They focus on the emotional response patients and families have to cancer, as well as the emotional, behavioral, and psychosocial difficulties that influence living with cancer.

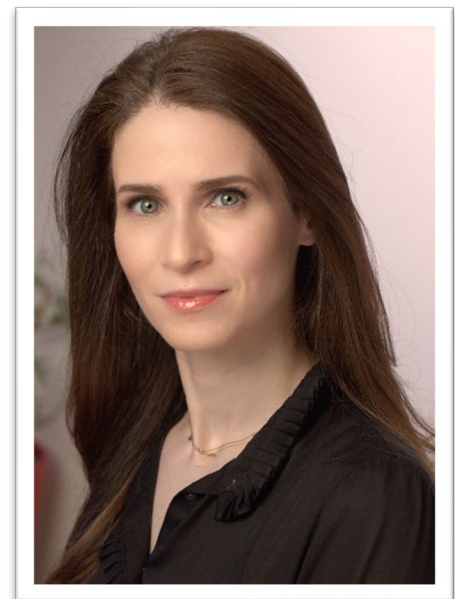
Many psychosocial oncologists are members of the American Psychosocial Oncology Society (APOS), which was formed in 1986 to advance the development and delivery of equitable and evidence-based psychosocial oncology care through research, practice, education, and advocacy.

Why Should a Caregiver Seek Help from a Psychosocial Oncologist?

While psychosocial oncologists most often work directly with patients, they also can help friends and family members who are caring for their loved one with cancer.

APOS member Allison J. Applebaum, PhD, is a licensed clinical psychologist and director of the Caregivers Clinic at Memorial Sloan Kettering (MSK) Cancer Center's Counseling Center. She and her MSK colleagues focus on the well-being of caregivers while they navigate the different stages of a loved one's cancer journey. They provide services such as individual counseling, group counseling, family/couples counseling, and the opportunity to participate in clinical trials for caregivers.

"Caregivers of loved ones with cancer – regardless of the cancer's site or stage – face the common challenge of sitting with uncertainty," Dr. Applebaum said. "They don't know what the next year, month, week, day, or even hour might bring, which makes it difficult to plan for their future and can lead to anxiety and distress."



Allison J. Applebaum

She said many caregivers seek support from her clinic to help them cope with the "existential distress" that results from the challenges of facing an uncertain future, including

having difficult, decision-making conversations with their loved one and the health care team about their loved one's care for which family caregivers rarely receive formal training.

"We have found that anxiety, depression, and other mental health concerns among caregivers are often more significant than they are in the patients they are providing care for," she said. "In fact, they can be at risk for symptoms of post-traumatic stress disorder, especially if they witness their loved one having a significant medical event."

How Can a Psychosocial Oncologist Help Caregivers?

Dr. Applebaum and her team at MSK rely on empirically supported treatments and interventions – evidence-based approaches they know will work – to help alleviate caregiver distress.

One approach they use is cognitive behavioral therapy (CBT), which helps people address both their thought processes as well as their behaviors, to help them adjust to the demands they face. CBT places an emphasis on helping individuals learn to be their own therapists. In-session exercises and outside "homework" help caregivers develop coping skills, whereby they can learn to change their own thinking, problematic emotions, and behavior.

Another evidence-based approach practiced at MSK is Meaning-Centered Psychotherapy for Cancer Caregivers (MCP-C), the first targeted psychosocial intervention that directly addresses existential distress in caregivers. The approach helps caregivers derive benefits from creating, reconnecting with, experiencing, and sustaining meaning in the face of a loved one's illness.

In one study of caregivers caring for loved ones with rare and aggressive tumors, MCP-C was shown to give caregivers a better sense of meaning and purpose in life. They developed a greater sense of spiritual well-being and an enhanced sense of "benefit finding," meaning they were able to acknowledge new inner strength, greater resilience, and an enhanced relationship with their loved one, even as the health status of their loved one was declining.

"MCP-P isn't about negating suffering," Dr. Applebaum said. "It's more about helping caregivers realize that despite profound challenges, they can still have access to the good stuff."

What is an Oncology Social Worker?

Oncology social workers also provide psychosocial services to people with cancer, their families, and caregivers. They connect people diagnosed with cancer, and their families, with essential community, state, national, and international resources as part of the oncology team.

Many oncology social workers are members of the Association of Oncology Social Work (AOSW), created in 1984 and comprised of professionals and students who practice in hospitals, cancer centers, home care agencies, hospice, community-based oncology practices, community programs, patient advocacy organizations, educational institutions and other settings.

Why Should a Caregiver Seek Help from an Oncology Social Worker?

A cancer diagnosis can be extremely overwhelming for patients, and their family caregivers often shoulder at least part of the burden of navigating the complex and confusing health care system on behalf of the patient.

AOSW member Jennifer Dunn is a certified oncology social worker at Washington University's Siteman Cancer Center in St. Louis. She and her colleagues provide support for the anxiety and financial worries a major illness like cancer can entail. While her primary focus is the patient in Siteman's care, she was quick to acknowledge that a cancer diagnosis affects everyone in the patient's life.

"When we meet with a newly diagnosed patient and their family, we ask them to identify who their primary supporters and detractors are," Dunn said. "Caregivers often go unacknowledged as the unsung heroes of a person's cancer journey. Because they can carry the same fears, worries, and hopes as the patient, we want to make sure their experiences are validated, and they get the support they need."



Jennifer Dunn

How Can an Oncology Social Worker Help Caregivers?

Rather than apply a cookie-cutter approach to helping caregivers, Dunn and her team look at the issues from a patient-centered perspective, with the understanding that navigating the cancer care journey is different for every patient and every family.

"Oncology providers – the doctors, nurses and other professional staff – tend to speak a different language, using terms and concepts most people are unfamiliar with," Dunn said. "Therefore, we start by validating the caregiver's individual experience, acknowledging how overwhelming everything is, and letting them know they are not alone."

Dunn helps educate patients and their caregivers on the various personnel, departments, and services available to them at the hospital, then works to get them connected to the right people and resources, both within the hospital and in the community. She helps them sort through insurance issues to determine, for example, if respite care, in-home care, or long-term care is a viable option to alleviate caregiver exhaustion and distress.

She and her team also regularly provide referrals to community, state, and national resources that help patients and their caregivers overcome health disparities driven by social determinants of health (SDOH), including food and transportation insecurity. Examples include arranging free or discounted rides to doctor appointments, helping patients and their caregivers apply for food assistance programs or find local food banks,

and connecting patients and their caregivers with programs that cover out-of-pocket costs for medications.

“Oncology social workers are trained to get to the root cause of problems and then break down any barriers that keep our patients and their caregivers from having their needs met,” Dunn said.

Distress Screening is Important, But Caregivers Should Speak Up Too

Applebaum and Dunn both point to the critical importance of health care providers consistently and adequately screening caregivers for distress.

Dr. Applebaum helped to lead a study on a validated electronic distress screening program designed to address the unique concerns of caregivers, called CancerSupportSource®-Caregiver, developed by the Cancer Support Community. The pilot study also included a follow-up consultation with a nurse five days after being screened.

“One of the unique aspects of this screener is its built-in resources,” she said. “So, when a caregiver clicks a box indicating they are experiencing distress in a certain area – say financial – they are immediately emailed information about financial support services.”

The pilot study found that engaging in the screening process and connecting with a nurse five days later was associated with improved emotional well-being a full six months after the encounter.

When or if distress screening is not offered to caregivers, Dr. Applebaum encourages them to speak up and ask for help – whether that’s asking for help managing their emotional stress and anxiety or requesting instructions for the practical and medical aspects of caregiving, such as the right way to help their loved one get out of bed, administer medications, or change a catheter, tube, or bag.

“Make sure your loved one’s care team knows who you are and has your contact information documented in the patient’s record, so you are acknowledged as an important member of the care team,” she said.

“Caregivers are called upon to do a tremendous amount, and they should be applauded and valued,” added Dunn. “Our objective as social workers is not to do things **for** caregivers, but to give them the tools and empowerment needed to advocate and do things for themselves.”

5 Tips to Manage Caregiver Anxiety and Depression

Caring for a loved one with a chronic illness can be stressful – physically, emotionally, and financially – and burnout among caregivers can be extremely high. [Ruth Lippin, LCSW, JD](#), sees the deleterious effects of caregiver burnout all too often in her therapy practice in New York City. Anxiety and stress among caregivers, she says, exploded during the COVID-19 pandemic and continues, in part, due to aging among the baby boomer population.

“I counsel clients who are living with the behavioral health effects of old age, injury or illness, and in many situations, I am just as or even more concerned with the mental health of their caregivers,” Lippin says. “Whether due to financial barriers or feelings of guilt, caregivers often do not adequately take care of themselves, which can take a significant toll on their mental and physical health.”

According to Lippin, caregiver stress and anxiety can also transfer to the loved one they are caring for – a phenomenon that in its extreme, may lead to abuse of or substandard care for the person needing care.

“Unpaid, family caregivers can only be stretched to a point before breaking,” she says. “Eventually, they can become resentful and angry. Without proper acknowledgement of and treatment for these issues, they in turn may become depressed, anxious, short, angry, or even aggressive with their loved one.”



Ruth Lippin

Anxiety & Depression Association of America Offers Support and Resources

Lippin is a member of the [Anxiety & Depression Association of America \(ADAA\)](#), an international non-profit organization dedicated to the prevention, treatment, and cure of anxiety, depression, OCD, PTSD, and co-occurring disorders through the alignment of science, treatment, and education.

While ADAA is a professional organization of members working in the mental health field, it also offers support and resources to the general population, including family caregivers of aging or ill loved ones. Caregivers can discover many of these resources on [ADAA's Caregivers web page](#), which includes tips on when a caregiver should seek care for themselves, organizations from whom caregivers can access support, and a link to ADAA's online peer-to-peer communities through which caregivers can connect with others, contribute to ongoing conversations, or start their own conversation with a question or post about their journey.

Take a look at one of ADAA's resources below, “5 Tips to Manage Caregiver Anxiety & Depression,” then read on for more insight and advice from Ruth Lippin:

5 TIPS TO MANAGE CAREGIVER ANXIETY & DEPRESSION



CAREGIVER ANXIETY

Caregiver stress and anxiety can be caused by managing too many responsibilities, loss of control, fear of a loved one's well-being, uncertainty about the future or worrying about healthcare finances.



CAREGIVER DEPRESSION



Caregivers often spend more time taking care of others needs over their own. Neglecting your needs to care for loved ones over a prolonged period, combined with strained or overwhelming work environments, can have serious mental health consequences and can result in depression.

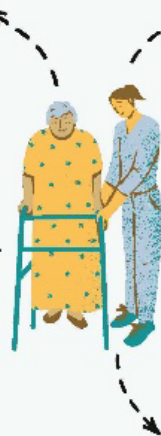
TIPS TO MANAGE CAREGIVER BURNOUT

PRACTICE ACCEPTANCE

When faced with the unfairness of a loved one's illness, practice acceptance and try to avoid the emotional trap of feeling sorry for yourself or searching for someone to blame.

CELEBRATE YOURSELF

Find ways to acknowledge and remind yourself of all the help and effort that you are putting forth. It is important to celebrate the small victories and acknowledge your support as a caregiver.



ASK FOR HELP

Don't be afraid to ask others around for help or support.

FIND A BALANCE

Make sure caregiving doesn't take over your life. Try to incorporate self-care practices into your routine if you begin to feel overwhelmed.

FOCUS ON THINGS YOU CAN CONTROL

Rather than stressing over things you can't control, like wanting more hours in the day, focus on how you chose to react to problems when they present themselves.

Check out these helpful resources to learn more about [Caregivers and anxiety and depression](#). For more information visit:

WWW.ADAA.ORG



Caregivers: Ask for Help

As illustrated above, one tip for managing caregiver burnout is to ask for help – an approach Lippin wholeheartedly endorses.

“The old proverb ‘it takes a village to raise a child’ applies to caregiving for our older adults and chronically ill loved ones as well,” Lippin says. “However, in today’s isolated society, that ‘village’ can be difficult to find or create.”

While Lippin encourages the use of formal, paid caregivers to provide respite care and alleviate pressure on overburdened caregivers, she acknowledges that financial barriers prevent many from being able to afford professional help. In addition, she cautions that for people with generalized anxiety disorder (GAD), using formal, paid caregivers can create additional stress.

“Family caregivers with GAD– known colloquially as “worriers” – may be concerned about how their loved one will be treated, or that something bad will happen, on the paid caregiver’s watch,” she says. “The reality is that bad things can happen at any time, under anyone’s watch. By teaching my clients the skills they need to tolerate the anxious feelings these thoughts provoke they can utilize formal caregivers. This is a game changer for both the caregiver and the person being cared for.”

Contact a Mental Health Provider

ADAA suggests caregivers consult their doctor or contact a mental health provider if they experience any signs or symptoms of a mental health condition, especially if symptoms persist for two or more consecutive weeks and affect their quality of life.

“Some telltale signs that it may be time to seek help from therapist are not sleeping well, irritability, loss of appetite – or conversely, overeating – not paying attention to your own personal hygiene, excessive anger or sadness, or losing control of your emotions,” Lippin says.

Lippin’s preferred approach for treating anxiety and depression is cognitive behavioral therapy (CBT), a structured, goal-oriented type of therapy that focuses on identifying, understanding and subsequently modifying thoughts and behaviors. CBT is a short-term treatment modality that helps one build the skills they need for long-term success.

“CBT can help caregivers balance automatic, negative thoughts with more realistic ways of looking at a situation,” Lippin says. “It allows them to think differently about caregiving and figure out strategies for taking care of themselves as well as their loved one, whether it’s hiring a professional caregiver to provide respite care or taking 30 minutes for a quick nap, a walk outside, or a silly TV show.”

“Caregivers face an objectively hard situation,” she adds. “They should be allowed the time and space to take care of themselves without feeling guilty. I would counsel them to practice self-compassion for their limitations and seek comfort in a way that works for them.”

What is the Cost of Caregiving?

Caregiving for an elderly or ill loved one is a labor of love that can have plenty of rewards for both the caregiver and the care recipient. However, it also can come with some real costs. In fact, AARP estimates that family caregivers spend an average of 26% of their income – about \$7,242 annually – on caregiving activities.

About half of caregivers surveyed by AARP say they used their own money for their loved ones' household-related expenses. Thirty percent covered rent or mortgage payments, while 21% financed home modifications. Medical costs accounted for 17% of caregiver spending.

"Family caregivers are largely unprepared for the costs and amount of money it takes over the long term," says Amy Goyer, AARP's Family & Caregiving Expert. "The strain is compounded when you consider that most family caregivers also work, and about half of them need to make work adjustments that can cut into their income."

The AARP survey found that about one-third of caregivers report two or more work-related strains, such as having to change their schedule or take leave, which leads to an average annual outlay of \$10,525. Goyer says those who quit their jobs to be a full-time caregiver can risk losing about \$300,000 on average in lifetime benefits and wages.

What happens when family caregivers experience financial setbacks related to caregiving? They may have to curtail their spending, dip into personal savings, or cut back on retirement contributions. In Goyer's case – caring for multiple family members over a long period – the result was filing for bankruptcy.

"More and more people are caring for multiple family members," Goyer said. "They're doing more, spending more, and having to make more sacrifices than ever before."

A Plan to Navigate the Financial Challenges of Caregiving

Goyer recommends that caregivers make a plan for their loved ones' finances as well as their own, to help manage the costs and responsibilities of caregiving. Have critical conversations with your loved ones and their financial managers early, she says, so everyone is ready for rising costs as the level of care they need increases.

"People are living longer, even with chronic illnesses, and they often outlive their savings," she says. "Even if your loved one has investment income, a pension, robust health insurance, or even long-term care insurance, it may not be enough."

The financial plan should start by assessing the loved one's income/assets and expenses, including debt. Next, learn about the costs associated with hiring paid caregivers or health aides to provide in-home care as well as costs associated with long-term care or assisted



Amy Goyer

living facilities. AARP offers a [Long-Term Care Cost Calculator](#) to help families compute the costs of long-term care.

“Create a budget that includes their income and all regular and intermittent, fixed, and variable expenses, as well as the cost of care,” Goyer says. “Is there enough to cover the cost of their care, adhering to their wishes for where they want to live and the care they want to receive?”

Goyer stresses the importance of getting a handle on all the legal and financial paperwork involved, including a power of attorney for finances; special powers of attorney for individual banks, investment companies, Social Security, Medicare/Medicaid, and Veterans Affairs, if applicable; as well as documents such as wills, living wills, and living trusts. One power of attorney typically does not suffice for all needs.

“Act only in your loved ones’ best interests, and keep their money, property and assets separate from yours,” Goyer cautions. “Keep good records and be sure to communicate clearly and regularly with your loved ones and other pertinent family members about your loved ones’ financial status.”

Goyer says a bill management service from an accountant, a geriatric care manager, an aging life care expert or an organization like [SilverBills](#) can help ensure that deposits are made, bills are paid, insurance claims are submitted, and taxes are prepared. These services also can help look out for financial frauds and scams.

“As a caregiver, your finances are vulnerable too,” she says. “Consult with a financial advisor, take a money or financial management class to hone your skills, and make a conscious effort to protect your own financial security now and in the future.”

Maximize Income and Resources

According to Goyer, families may be able to access additional income and benefits to help pay for caregiving expenses. Find out if there is a long-term-care insurance policy that can be activated. Apply for any benefits the loved ones may be eligible for, including food, utilities, health, and veterans’ benefits. Get them screened for Medicaid eligibility as well as for [Medicare Part D Extra Help](#) for prescriptions.

Help with prescription copayments may also be available through drug manufacturers and nonprofit organizations like the [HealthWell Foundation](#), which provides grants to eligible individuals living with certain health conditions.

Search out free or reduced-cost services, suggests Goyer. Contact your state and area agencies on aging to ask about eligibility requirements and any services that are free or offered on a sliding fee scale. If you are caring for a veteran, contact the [VA Caregiver Support Program](#) to ask about eligibility for services.

A wealth of financial information, resources, and peer connection groups are available through [AARP’s Family Caregiving site](#), including a [Financial Workbook for Family Caregivers](#), a practical guide focused on health, housing, and money management. Each set of worksheets in the guide is designed to help caregivers capture the essential information needed to manage the complex responsibilities of caregiving. AARP recommends that caregivers make a copy of the completed guide to give to a trusted relative, colleague, or friend in the event you are unable to care for your loved ones.

Goyer also encourages families to get creative in maximizing income and resources by investigating if a reverse mortgage, home equity loan, home equity line of credit, or an income-generating house-sharing arrangement are viable options.

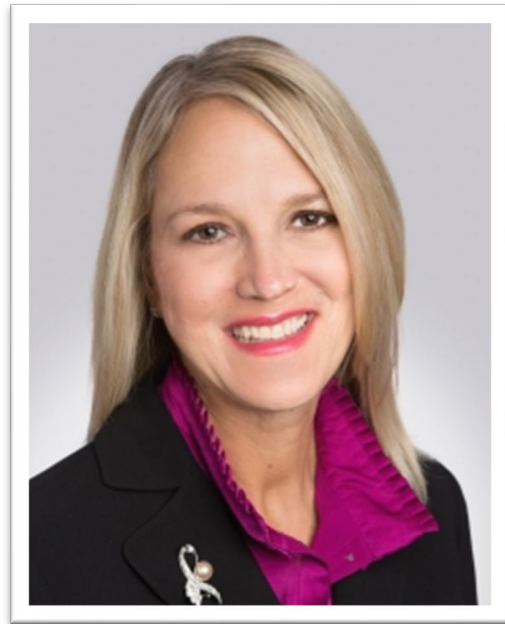
“Recruit volunteers to help where appropriate, including friends, neighbors, faith communities, and volunteer organizations,” she concludes. “And remember that when caring for someone, expenses are about more than their health, they’re also about their quality of life.”

Organization Skills Required: Coordinating Medical Care for Your Loved One

Family caregivers of a loved one with cancer wear many different hats: nurse, chef, driver, financial planner, housecleaner, physical and emotional supporter, and more. Many caregivers also find themselves playing another vital role: care coordinator.

Cancer Support Community (CSC) is a non-profit organization dedicated to uplifting and strengthening people impacted by cancer by providing support, fostering compassionate communities, and breaking down barriers to care. CSC's CEO, Debbie Weir, has personal experience as a family caregiver; she lived with and took care of her brother during the last few months of his life before he died of esophageal cancer, and she is currently helping to coordinate care for an elderly parent on dialysis.

Weir said one of the most important roles a family caregiver can play is to be an advocate for their loved one. "Health care is an incredibly complicated system," she said. "Often, patients don't feel empowered to ask questions or well enough to speak up, and without a loved one by their side to advocate for them, they may not push for answers."



Debbie Weir

Frankly Speaking About Cancer

CSC offers a variety of resources to cancer caregivers, including its *Frankly Speaking About Cancer* series. Here, we summarize some of the common care coordination responsibilities CSC identified in the series:

- **Researching Diagnosis and Treatment Options:** Caregivers may find themselves researching medical information to better understand their loved one's diagnosis, treatment, side effects, and care plan. They may also research doctors, hospitals, and clinical trial opportunities.
- **Scheduling doctors' appointments:** There will be many appointments for checkups, treatments and diagnostic tests. Caregivers may be called upon to provide or coordinate transportation to and from appointments. Keeping a notebook or online spreadsheet with names, contact numbers and a calendar of appointments can help things run smoothly, especially in times of emergency or questions.
- **Meeting with the health care team:** When caregivers attend doctor's appointments with their loved one, they can take notes, ask questions, and be a sounding board. Preparing a list of questions ahead of time will help. Upon your loved one's initial diagnosis, ask their care team for any forms that need to be filled

out in order to have permission to attend appointments and receive information. If your loved one is in the hospital, get to know the nurses who care for them. Meet the attending doctor and explain you want to know about important test results and medical decisions. Find out when the doctor visits patients so you can be there to ask questions.

- **Managing medications:** Your loved one may have many medications that change frequently. Coordinating, filling, and administering prescriptions can be a job in itself. Work with your loved one's pharmacist or healthcare team to understand instructions, refills, and dosing. A pill box or chart may help you keep track of what medication to give when.
- **Navigating insurance and billing concerns:** If your loved one needs help navigating insurance issues, you can offer to contact the insurance company to learn what is covered and what isn't. Pose questions about coverage beyond standard treatment, such as transportation to/from clinics, in-home medical assistance following treatment, out-of-network care, medications, etc. As with health care team access, your loved one will need to give permission for their insurance company to communicate directly with their family caregiver.
- **Making treatment decisions:** Helping a loved one think through treatment options, goals, and priorities may feel overwhelming. You may want to offer help weighing the pros and cons of each treatment option, including elements like time, where treatment will be given and cost. You can also help them think through reasonable short and long-term expectations. Weir noted that it's imperative for caregivers to be flexible and respect their loved one's wishes when making decisions, even if you disagree with them. "Continue to communicate and support your loved one in their choices and help them feel like they have autonomy and control over their lives," she said.

Weir acknowledged that treatment decision conversations can be difficult no matter where the patient is in their cancer journey. Whether finding the best care for the diagnosis or seeking out a second opinion, a caregiver can be a critical part of the patient's experience. Weir recommended that caregivers who are acting as care coordinators work with their loved one to prepare supporting documents including a living will or advance directive; durable power of attorney for health care; financial power of attorney; a do not resuscitate (DNR), do not intubate (DNI), or allow natural death (AND) order if requested or desired by the patient; and a will. These documents will be especially important, she said, if the loved one is no longer in a position to speak for themselves.

Caregivers Can Access Support from Cancer Support Community

"Health care providers are under a tremendous amount of stress these days, and while their main focus should always be on the patient, caregivers need support as well, so they can help their loved one through the experience of having cancer," said Weir, who calls for an increased recognition from the health care system as a whole for family caregivers and care coordinators. "Organizations like Cancer Support Community are here to help and advocate for families living with cancer, and we do it at no cost to patients and their families."

One service is [MyLifeLine](#), CSC's secure, online community where patients, survivors, and caregivers can connect with friends, family, and others like them to receive social,

emotional, and practical support. Caregivers can join their personal network together to keep family and friends informed about their loved one's treatments and other updates. A helping calendar is also available to organize help with events like rides to medical appointments, meals, childcare, pet care, and more. The site also has a 24/7 online discussion forum for caregivers that is moderated by mental health professionals. Here, caregivers share practical tips with others in a place where they can feel safe and supported. Learn more and sign up at www.cancersupportcommunity.org/mylifeline.

Other services include their Cancer Support Helpline, a free telephone (888-793-9355) and web-based chat service, staffed by trained oncology community navigators and resource specialists who can help patients and caregivers get information about cancer and cancer treatment options, identify local support groups, find treatment lodging and transportation resources, navigate financial issues and more.

"Our trained navigators do a lot of legwork to help relieve the burden on patients and their caregivers," Weir said. "They're also there to lend an ear and provide emotional support."

Caregivers can also find support at any of CSC's 190 [network partners locations](#). "Whether in person or online, we've built a compassionate community of caregivers who are all in a similar situation," Weir said. "It is so important as a caregiver to have hope and a sense that they are not alone."