

Caregiving: Exploring the Special Needs of Friends-and-Family Caregivers



A Series by [REALWORLDHEALTHCARE.org](https://www.RealWorldHealthCare.org)

2019

More than 90 million Americans care for loved ones with chronic conditions, disabilities, disease or the frailty of old age.

Caregiving: Exploring the Special Needs of Friends-and-Family Caregivers 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.

founding sponsor



HEALTHWELL
FOUNDATION®

www.RealWorldHealthCare.org

CONTENTS

Along the Caregiving Journey	4
<i>Real World Health Care Editorial Staff</i>	
Lung Cancer Caregivers in the Spotlight at COPE Summit	8
<i>Real World Health Care Editorial Staff</i>	
Sjögren's Syndrome: Reflections of a Caregiver	10
<i>Jonathan Morse, National Board of Directors, Sjögren's Syndrome Foundation</i>	
Talk about your Health Care Choices before you're Faced with a Crisis	13
<i>Jon Radulovic, Vice President, Communications, National Hospice and Palliative Care Organization</i>	
Lung Cancer: Being a Better Caregiver	15
<i>Real World Health Care Editorial Staff</i>	
The Cascading Effect of Migraine Disease	18
<i>Jim Carleton, Association of Migraine Disorders</i>	
Calling for A Culture of Caring	20
<i>Real World Health Care Editorial Staff</i>	
Help for Pediatric Cancer Patient Caregivers	23
<i>Julie Komanetsky, Vice President, Patient and Family Services, The National Children's Cancer Society</i>	
From CancerCare: The Importance of Cancer Caregivers in Medical Settings	26
<i>Mary Hanley, LMSW, Oncology Social Worker, CancerCare</i>	
Understanding the Voice of Cancer Caregivers	28
<i>Alexandra Zaleta, PhD, Senior Director, Research, Cancer Support Community</i>	

Maintaining Control with Parkinson's Disease Through Palliative Care . . .	30
<i>Provided Courtesy of GetPalliativeCare.org</i>	
Caring for a Child with Migraine	32
<i>The American Migraine Foundation</i>	
Understanding Chronic Heart Failure: Advice for Caregivers	34
<i>Real World Health Care Editorial Staff</i>	
How To Support a Friend with Heart Disease	37
<i>Provided Courtesy of Go Red for Women</i>	
The Many Moods of Heart Failure and the Caregiver Challenge	39
<i>Real World Health Care Editorial Staff</i>	
What People with Migraine Attacks Hate to Hear	41
<i>National Headache Foundation</i>	

Along the Caregiving Journey

By Real World Health Care Editorial Staff

In our first interview for our 2019 caregiving series, Real World Health Care spoke with [Susan Reinhard, RN, PhD, FAAN](#), senior vice president and director of AARP's [Public Policy Institute](#) and chief strategist, [Center to Champion Nursing in America](#).

We talked with Dr. Reinhard about the many challenges facing people who are caring for loved ones with chronic illness and how [AARP](#) can help them along their journey as a caregiver.

Real World Health Care: AARP is well known as an organization that empowers people to choose how they live as they age. How does that mission extend to people caring for a loved one with a chronic illness such as multiple sclerosis, cancer or Parkinson's disease?

Susan Reinhard: Our mission at AARP is to help family caregivers by giving them what they need, when they need it and where they need it. The journey is different for every individual caregiver and every individual loved one, and it can change over the trajectory of an illness.



Susan Reinhard, AARP

Acting as a family caregiver for someone with a chronic, long-term condition may be a completely different experience than caring for a loved one with an acute condition like a heart attack, stroke, or even cancer – all of which are shocking but are treatable. On the more chronic end of the disease spectrum, consider Parkinson's disease, a progressive disease that a person can live with for 20 or 30 years. Diseases like Parkinson's, as well as MS, are typically difficult to diagnose and lead to many questions about how to treat the disease, how living with the disease will impact the person's life and how to navigate the health care system.

Caregiving is not a one-fits-all-and-at-all-times role. AARP recognizes that and our [caregiving resources](#) reflect this vast range of experiences.

The Changing Face of the Family Caregiver

RWHC: Given the increase in professional services available to people with chronic diseases, why are more and more family members being called on to act as caregivers for a loved one?

SR: Advances in medicine have led to people living longer with chronic illness than in the past, and the trend from a health system perspective is for patients to move out of the acute-care hospital setting and into ambulatory, home-based care. While patients may prefer to be at home instead of the hospital or a long-term care facility, they often need help with both complex medical tasks like changing a wound dressing, as well as activities of daily living like bathing, shopping and cooking.

Tasks that used to fall to providers such as nurses, physical therapists or dieticians are now performed by family caregivers. For example, someone with motor skill issues due to multiple sclerosis may need a family member to administer medications or nutrition. Our research, which we plan to update in April, shows that a good percentage of caregivers who perform these complex medical tasks lack adequate training to do so, often learning by trial and error. As a result, they worry about making mistakes, and that anxiety can affect their emotional well-being.

Moreover, the proliferation of professional services often adds to the burden. There are more appointments to coordinate and travel to, more medications to administer, more provider and insurance systems to navigate, and more paperwork. Someone with a chronic illness can't do these things all on their own.

RWHC: Is there a “typical” family caregiver who shoulders most of the responsibility?

SR: Most people are familiar with the concept of the “sandwich generation” – the middle-ager who is taking care of both dependent children and an aging parent. Indeed, the “average” family caregiver is a late 40s white woman caring for her elderly mother. However, family caregivers are of all genders, ages, ethnicities and cultures. You may be surprised to learn that one in four family caregivers today is a millennial. In order to care for a loved one with a chronic, long-term illness, these millennials are forced to put their own lives on hold, delaying decisions about their careers, relationships and even where they live. They often feel isolated because their peers can't relate to the complex issues they face, like managing medication schedules, sorting through Medicare coverage or changing a feeding tube. They are thrust into a confusing world that most people are unprepared for, let alone someone in their 20s or 30s.

Advocating for Caregivers

RWHC: How is AARP advocating for family caregivers?

SR: AARP is working closely with caregivers and patient support organizations nationwide to push for laws that support caregivers. We are proud to note that since 2014, about 300 state laws have been enacted to help family caregivers. As an example, the CARE Act is now in place in 40 states and territories. Under this law, every time a person is admitted to the hospital – regardless of their age or condition – they must be asked if they have a family member who will be helping them. If yes, the patient is asked whether the family member should be added to their electronic health

record as part of their care team. If the caregiver will be providing medical care, they must receive proper instruction. Moreover, the caregiver must be informed of when the patient will be discharged in a timely manner.

We're now in the process of studying how the CARE Act is being enacted at health systems across the country. How do hospitals identify caregivers? It's not always a spouse or next of kin. How are they training staff to make sure caregivers are connected to the care team? How do they anticipate what a caregiver might need? In the fast-paced hospital environment with an overload of forms and charting to manage, it's easy to lose sight of the family caregiver.

We're promoting best practices when we find them. For example, one hospital gives family caregivers a badge like their staff wears, with the caregiver's name and the title of Caregiver. With that badge, the caregiver is eligible for discounts in the hospital gift shop and cafeteria. It seems like a small gesture, but it really means a lot for caregivers to be acknowledged as an integral part of the care team.

RWHC: Are there other ways in which AARP supports caregivers?

SR: We have a wealth of information on our web site, including a series of [Prepare to Care guides](#), which help to make the job more manageable.

We are in the process of working with a few other organizations and the UC Davis College of Nursing as part of [The Home Alone Alliance](#) to develop a series of evidence-based instructional videos and tips sheets to help family caregivers learn how to do complex medical tasks such as administer an injection, change a wound dressing and do a tube feeding.

AARP also is acutely aware of the financial stresses related to being a caregiver. Our research shows that about 80 percent of family caregivers spend money out-of-pocket to help defray their loved one's medical costs. Those out-of-pocket costs range on average from \$7,000 a year to \$12,000 a year for long-distance caregivers who must travel to be with their loved one. Often, caregivers are forced to leave their job or cut down on hours, which has a long-term effect on their whole family in terms of the impact on social security earnings and pensions. To help, AARP offers a range of [financial tools](#) and information.

We are also encouraging employers to step up and help employees who are caregivers. We partnered with the Northeast Business Group on Health to create a [guide](#) to help HR and benefits leaders support employees, and we teamed up with the United Way to launch a [Do You Care Challenge](#) to help raise awareness about millennial caregivers and their need for more caregiving-friendly workplaces.

Through the vast array of caregiving-related advocacy efforts, education, partnerships, and resources AARP offers, we want family caregivers to know that they are valued as an essential part of their loved one's care team. At the same time, they need to take

care of themselves as well. I often liken my message to the crew member instructions when flying: “Be sure to put your own oxygen mask on first before assisting others.”

Categories: [Caregiving](#), [General](#)

Tags: [AARP](#), [caregiving](#), [family caregiver](#), [Multiple Sclerosis](#), [Parkinson's Disease](#)

Lung Cancer Caregivers in the Spotlight at COPE Summit

By Real World Health Care Editorial Staff

This April marks the [LUNGevity Foundation](#)'s second [COPE Summit](#), held during its 9th Annual [International Lung Cancer Survivorship Conference](#), April 26-28 in Washington, D.C. Directed toward caregivers of loved ones with lung cancer, the COPE Summit is one of three simultaneous summits at the Conference, which features a full weekend of information, networking and support designed to educate, connect and empower anyone who has been impacted by lung cancer.

“Lung cancer caregivers often report that they feel isolated and unsupported in their communities,” said [Katie Brown](#), OPN-CG, vice president of Support and Survivorship Programs, LUNGevity Foundation. “Lung cancer is a disease with many misconceptions and stigmas. Because of that, there may be a sense of guilt, shame or anger associated with the disease. Unfortunately, practical services and emotional support for patients and their families is lacking in most communities.”

The COPE Summit was created to help bridge that gap, with sessions focusing on relationship issues, practical issues, and caregiver roles and needs. Caregiver burnout and “lone soldier syndrome” will be two of the topics covered. Caregivers and their loved ones will also be able to take advantage of large panel discussions with lung cancer experts.



Katie Brown, LUNGevity Foundation

Lung Cancer Caregiver Resources

The COPE Summit is just one of the many services and resources the LUNGevity Foundation provides for lung cancer caregivers. LUNGevity also offers an online [Caregiver Resource Center](#) with articles, videos, caregiving tips and other resources. A toll-free Lung Cancer HELPLine (844-360-5864) connects caregivers directly with oncology social workers and caregiver mentors. Caregiver-specific [Twitter chats](#) are held several times a year.

The online Caregiver Resource Center also provides detailed information on [end-of-life planning](#), including legal and financial considerations, hospice decisions, how to prepare when death is near, and tips for coping with grief and loss.

“Many of legal and end-of-life issues should be addressed by all adults, regardless of whether or not they are ill,” Brown said. “If these conversations are too difficult for families, they may want to enlist the help of an oncology social worker, patient navigator or therapist.”

Self-Care for Caregivers

“It is crucial for caregivers to become educated about their loved one’s diagnosis, and their type and stage of lung cancer,” said Brown. “Our resources will help them help their loved one and will also help them practice self-care, which is equally important.”

Brown added that caregivers need their own practical and emotional support system. She encourages caregivers to ask for help and accept help when it’s offered. She also advises caregivers to take breaks from caregiving when they can and get as much rest as possible.

Editor’s Note: The LUNGeVity Foundation’s mission is to make an immediate impact on increasing quality of life and survivorship for people with lung cancer by accelerating research into early detection and more effective treatments, as well as providing community, support and education for all those affected by the disease. LUNGeVity’s ultimate goal is a world where no one dies of lung cancer. For more information, visit www.LUNGeVity.org.

Categories: [Caregiving](#), [General](#), [Non-Small Cell Lung Cancer](#)

Tags: [caregivers](#), [caregiving](#), [lung cancer](#), [survivorship](#)

Sjögren's Syndrome: Reflections of a Caregiver

By Jonathan Morse, National Board of Directors, Sjögren's Syndrome Foundation

April is Sjögren's Awareness Month. This article is reprinted with permission of the Sjögren's Syndrome Foundation. It was originally published in The Moisture Seekers, Volume 37, Issue 03.

Today is not terribly different from any other day. It begins....slowly.

There is no way to know how my wife will feel. Will it be a sick day? Will it be a pain day? Will it be both?

I know these questions are not helpful. Instead, I need to know what to do and what to say. Instead of questions, I need to project happy thoughts and find the sunshine.

The role of Caregiver is demanding, unselfish and ever-present. The role requires an ability to not just listen, but to hear and then measure the appropriate response. Because my wife does not want help with everything. She still wants to preserve whatever bit of independence she can, because she has already lost so much. My tendency is to react, to offer to do everything.



Jonathan and Nancy Morse

It was not always like this. She used to be able to do so much more: clean the house, go for a run, take an exercise class, take a spin class, work in the garden, have a job, have a schedule – get up and go.

Over the many years of battling Sjögren's, so many therapies and medications have been tried. And while the disease chose its own paths of advancement, the therapies and medication side effects have imposed their own blend of affect, interaction, ineffectiveness and ultimately uselessness.

The search for better and more effective treatment is endless. I spend an infinite amount of time reading blogs, web sources and drug explanations. Visits to specialists have become routine. The challenge in every encounter is to both cram as much background in as possible to set the table (mindful of the allowable 11-minute interval) then mine for gems that are actionable and deliver hope.

Difficulties managing the total body sickness are trumped by overcoming crushing fatigue, containerizing and filing pain, and the sense of loss: the feeling of what *was*

this body, what activities *used* to be possible, time spent with friends and family, and possessing the energy to live are all different.

To look at my wife you may think “but....she looks fine.” Yes, she *looks* good. But I know the depth of the battle, the dimension of sickness, the crush of pain that no one else can see. I know the extraordinary effort it takes for her to simply get up and get ready to go. Everything hurts. The shower water hurts. Standing on bare feet hurts. Food hurts.

And still we get up and go places. We see people. And when she’s asked how she feels or told she looks and sounds better, she replies, “I’m fine.”

So many things have been taken away by Sjögren’s. Friends and even family members don’t know what to say, so many stay away. They simply can’t listen, comprehend, or empathize. They assume she is a burden, so they don’t include us in their plans. Sadly, family is precisely what my wife and I need — they serve as fuel to flush away the fatigue, silence the body sickness, and file the pain away.

So we come to a fork in the road. Should we be honest with friends and family as to the level of sickness and the level of life’s change? Or, should we withhold, internalize, and privatize as insulation to prevent any further pain and loss?

Loneliness has set in. For my wife, the loneliness comes from the thought that few — maybe no one — understands what living with Sjögren’s is like. No doctor, no specialist, no pharmacist...no one knows.

The same holds true for me, her caregiver. Dare I even say, “what about me?” Does anyone know what it’s like to watch a person you love slowly disintegrate? Does anyone understand the feelings we caregivers have — the helplessness, fear, hurt, sadness, guilt and loneliness? In a sense, we are bystanders with a close-up view of the tick-tock, tick-tock disease progression, treatment side effects, discomfort, and pain. Yet, we are powerless without tools to help.

I use the term ‘right-size’ to describe the types of activities we can do. The plans I make (suggest) are ‘right-sized’ to my wife’s daily ability level. I push aside the things we used to do, or more accurately stated, can no longer do. Instead I suggest, “let’s go shopping,” “let’s go for a walk,” “let’s go to a movie.” As caregiver, I have ‘right-sized’ my activity to the mutually acceptable level of the patient.

Through it all, we caregivers stay positive, strong, and resolute because there is no other choice.

To all the Caregivers out there, you possess the power to instill the seed of possibility, of promise and of hope. Smile.

Sjögren’s Syndrome Foundation is an organization driven to educate patients and their families, increase public and professional awareness and encourage research into new

treatments and a cure. For more information, visit www.sjogrens.org.

Categories: [Caregiving](#), [General](#)

Tags: [caregiver](#), [caregiving](#), [family caregiver](#), [Sjogrens Syndrome](#)

Talk about your Health Care Choices before you're Faced with a Crisis

By Jon Radulovic, Vice President, Communications, National Hospice and Palliative Care Organization

A family is gathered by the bedside of a loved one who has been seriously ill, and now is likely near the end of life. Each member of the family has a different idea of what should be done and what their loved one would have wanted. That's the point when the loved one and their family caregivers realize they should have planned ahead and talked about the care they would want in a medical crisis.

Heartbreaking scenes like this happen far too often.

The National Hospice and Palliative Care Organization encourages families to spend time talking about the care they would or would not want long before a medical emergency is at hand. This is particularly important when family caregivers are coping with a serious or life-limiting illness of a loved one.



Jon Radulovic, National Hospice and Palliative Care Organization

Advanced Care Planning

Having discussions about one's health care wishes is part of advance care planning.

Advance care planning involves making decisions about the care you would want to receive in a medical crisis that might be the result of a serious illness or an unexpected accident. Advance care planning also involves deciding who will speak for you if you are not able to speak for yourself.

An essential part of advance care planning involves having these important conversations with your loved ones – and then completing the documents that will reflect your wishes.

Advance care planning also includes:

- Deciding what types of treatment you would or would not want should you be diagnosed with a life-limiting illness or faced with a serious medical crisis. For some people this might include all possible medical interventions while others would prefer to make quality of life a priority.
- Sharing your personal values and beliefs with your loved ones, caregivers and your health care professionals. Additional people to talk with might include a

leader of your faith community or close friend.

- Completing an advance directive to put into writing what types of treatment you would or would not want.
- Designating a person as your health care power of attorney (sometimes called a health care proxy) to speak for you if you cannot speak for yourself. In some states, the advance directive form includes the health care proxy, other states make this an additional form.

Resources for Caregivers

NHPCO's [CaringInfo.org](https://www.caringinfo.org) offers free state-specific advance directive forms and free information to help families talk about the care they would want. Visit [caringinfo.org/planningahead](https://www.caringinfo.org/planningahead).

Hospice and palliative care providers see how difficult it can be for families that have never talked about care choices and are in a crisis situation. Similarly, they see how beneficial it can be when the priorities at life's end have been discussed and are clearly understood.

Not only is it important for each of us to clearly make our wishes known through advance care planning but it is one of the most important gifts we can give to our families and loved ones.

Categories: [Caregiving](#), [General](#)

Tags: [caregivers](#), [caregiving](#), [hospice](#), [palliative care](#)

Lung Cancer: Being a Better Caregiver

By Real World Health Care Editorial Staff

This week, Real World Health Care continues our series on [caregiving](#) by speaking with [Deborah P. Brown](#), Chief Mission Officer of the [American Lung Association](#). Brown oversees strategic planning and implementation of the Association's health promotions programs, advocacy efforts and research programs. We talked about lung cancer programs and services offered by the Association for both patients and their caregivers.

Lung Cancer a Top Priority

Real World Health Care: The American Lung Association has a broad lung-health mandate. Where does lung cancer stand in terms of your overall mission?

Deborah Brown: The American Lung Association envisions a world free of lung disease. Our mission is to save lives by improving lung health and preventing lung disease, as well as to reduce the burden of lung disease on patients and their families. Lung cancer is a priority for the Association, and supporting caregivers is an important aspect of what we do.

Support for Lung Cancer Patients and Their Caregivers

RWHC: How does the American Lung Association help lung cancer patients and their caregivers?

DB: Being diagnosed with lung cancer is difficult. It quickly becomes overwhelming as people process their diagnosis, cope with their emotions and try to navigate the health care system.

We support lung cancer patients and their caregivers by providing comprehensive educational content at www.lung.org/lung-cancer. Our content navigator tool tailors information to each person's journey, whether they're a patient, caregiver or health professional. We also offer a toll-free Lung HelpLine at 1-800-LUNGUSA that provides expert bilingual guidance from nurses and respiratory therapists.

Because lung cancer patients and their caregivers value being able to speak directly with others who are in their shoes, we offer a [free online support community](#). It's a wonderfully caring and kind community of people facing similar challenges.



Deborah P. Brown, Chief Mission Officer, American Lung Association

We also offer a number of resources dedicated to caregivers, including articles, videos, tips sheets and more. These resources cover everything from how to talk about lung cancer and cope with your emotions to self-care tips and how to prepare for the future.

Caregiving is Emotionally and Physically Draining

RWHC: How can family caregivers address the challenges they face when caring for a loved one who has lung cancer?

DB: Being a caregiver in any capacity can be emotionally and physically draining. We believe that family and friends can be better caregivers and advocates by understanding their loved one's journey and their needs throughout the ups and downs of treatment. Because lung cancer patients are often immuno-compromised, it's important for caregivers to stay as healthy as possible and up-to-date on their flu shots and other vaccines. And it almost goes without saying: they should never smoke around a lung cancer patient.

When caring for a loved one with lung cancer, it's important to keep in mind that *anyone* can get lung cancer, regardless of prior smoking history. However, if the patient has smoked in the past, they may feel guilty and ashamed. Caregivers should reiterate that they are not to blame for their cancer and that they need to let those feelings go.

Caregiving Tips

RWHC: What sort of advice would you give to family caregivers?

DB: Let your loved one know you love them, you are there for them and you are ready to help them, no matter what. Learn as much as you can about lung cancer so you are better able to advocate for them and help them navigate the health care system. The priority is making sure they get the best possible treatment they can.

Understand your loved one's boundaries. Some patients want their lives and activities to go on as normal and don't want a lot of help, while others may feel overwhelmed and need assistance. Respect the wishes of your loved one so you can give them both the assistance and the space they need. Open communication is key. However, be mindful of your role. Your loved one may or may not want to tell people about his or her cancer. Do not share information meant to be kept private.

We offer a full range of [caregiver tips](#) on our web site, and I encourage your readers to visit the site to get more detail. They can learn about the importance of:

- Keeping appointments and following treatment instructions.
- Getting to know the patient's care team.
- Letting the patient speak first during doctor appointments.
- Helping the patient stay organized.

Taking Care of the Caregiver

RWHC: How can someone be a better caregiver?

DB: Accept that it's normal to feel a wide range of emotions. While a positive attitude can improve both your and your loved one's moods, it can be easier said than done. If you have a hard time staying positive, confide in someone you can trust. Talking about your feelings with a therapist or social worker specializing in cancer may be beneficial.

As mentioned before, stay healthy by staying up to date on your doctor visits and vaccinations. Get plenty of sleep, eat a balanced diet and try to do some form of physical activity every day. Allow yourself to take breaks from caregiving to recharge yourself.

Ask for help if you're overwhelmed. Use your support system to help you run errands or do chores. Stay in touch with family and friends. Join a support group for caregivers. Some people find strength and support in religion and faith-based organizations.

Remember that every question you have is worth asking. Sometimes medical providers don't bring up topics because they aren't sure you want to hear about them. Don't wait for the doctor to start all of the conversations. Ask all of your questions and make sure they get answered in a way you understand.

Categories: Caregiving, Non-Small Cell Lung Cancer

Tags: American Lung Association, caregiver, caregiving, lung cancer

The Cascading Effect of Migraine Disease

By Jim Carleton, for the Association of Migraine Disorders

Editor's Note: June is National Migraine and Headache Awareness Month. Medical experts don't fully understand what causes migraines, making the condition difficult to diagnose and treat. This week, Real World Health Care brings you insights from the perspective of a family caregiver supporting a loved one with chronic migraine.

"I never signed up for this"

Quote from a migraine sufferer's fiancée when he ended the engagement.

How is it possible that such a devastating illness in all its expressions could not have far-reaching, negative effects in all related areas of a migraine sufferer's life? It's not, of course. Only recently have we begun to see research that looks at subjects like family burden and the corollary disruption that episodic and chronic migraine causes in the lives of sufferers. Very few of us lead totally isolated lives, devoid of familial connections and other work and relationship associations. More often, the opposite is true. The vast majority of people are interconnected with others through family, relationships and work; these relationships are all compromised by migraine suffering. That's a lot of people.



Jim Carleton

Migraine Affects More Than the Patient

In the United States alone, we estimate that there are 36 million migraine sufferers. If we allow ourselves some statistical latitude and cede that each sufferer has two relationships affected by their migraines, the numbers grow exponentially. For the purpose of this argument "collateral" means a person in some level of a relationship with the migraine sufferer. Following this line of reasoning, there are about 108 million people, including the sufferers, whose lives are negatively impacted in a variety of ways. The population of the United States is 319 million at last count. Again, following our assumptions, 34 percent of the U.S. population has their lives disrupted to some degree, by migraine disorders. Remember, this assumption is based on two collaterals only. Most people have more than two relationships. So, if that is the case, the number affected would rise accordingly.

Admittedly, that is a pretty astonishing number. One may question what does "disruption" mean? Migraine sufferers and those that live and work with them would

Table of Contents

not have any problem answering that question. So, in deference to the two-thirds or so of the U.S. population that may not understand the nature and level of problems caused by migraine attacks and experienced by collaterals, what follows is a less than a complete list. Broken relationships, lost jobs and income, family arguments, emotional distance, canceled family events and vacations, friendships lost, loss of self-esteem (both sufferers and collaterals), anxiety and a host of depressive symptoms, constant worry, and feelings of inadequacy. This list could be expanded greatly, I am sure. But one consequence stands out for me personally in my life with an episodic migraine sufferer: the frustration experienced when I am forced to stand by and watch my loved one's anguish while being unable to help her in any way.

This brings us to the bottom line: migraine suffering is not limited to the migraine sufferer alone. The misery spreads throughout the lives of associated individuals, not unlike other chronic, disabling conditions. At present, with about one-third of our country's population touched negatively by this neurological illness, why is so little being done to search for a cure? What will it take?

Some interesting research has been done in the area of caregiver stress. If you would like to read some interesting articles as a follow-up, consider:

Caregiver stress focusing on self-care

<http://adrenalfatiguesolution.com/caregiver-stress/>

Family support essential to surviving migraines

<http://www.practicalpainmanagement.com/patient/conditions/headache/family-support-crucial-surviving-chronic-migraine>

CaMEO research studies the burden of migraine on families, among other variables

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4430584/>

The [Association of Migraine Disorders](#) strives to expand the understanding of migraine and its true scope by supporting research, education and awareness.

Categories: [Caregiving](#), [General](#), [Migraine](#), [Pain Management](#)

Tags: [caregiver](#), [headache](#), [migraine](#)

Calling for A Culture of Caring

By Real World Health Care Editorial Staff

When someone becomes ill with a chronic disease such as cancer or multiple sclerosis, theirs is not the only life that changes. Indeed, their illness can impact friends, co-workers, and most particularly, their family members. Nowhere is that impact felt more strongly than by the family caregiver: the person whom the sick loved one counts on to provide the aid, comfort and care they need to supplement the professional care they receive from their health care providers.

According to Ruth Lippin, LCSW, JD, the role of the family caregiver has evolved over the past century. Lippin, a cognitive behavioral therapist who also runs a geriatric care management company, said that in previous generations, extended families lived together longer, making it easier for individual family members to “pitch in” when help was needed.

“Today, our country places a higher value on individualism,” she said. “We’re no longer a culture in which we take care of each other. Asking for or needing help is often seen as a sign of weakness instead of being embraced. People with chronic illnesses are vulnerable, and they need the protection of our society.”



Ruth Lippin

Reluctant Patients, Resentful Caregivers

Taking care of a loved one with a serious illness changes the family dynamic, especially when the caretaker is an adult child, said Lippin.

“It’s a complete transformation of the relationship from one of being cared for to one of having to be the caretaker,” she explained. “The ill parent may be reluctant to be taken care of, and the adult child often isn’t used to asserting their authority or conducting the type of care tasks that aren’t part of the ‘normal’ course of development for a parent/child relationship.”

“Consider an adult child whose parent has Parkinson’s disease and should no longer be driving,” she offered. “How do they cope with the worry that their parent may hurt

themselves or others while driving? How, as their child, do they assert authority to take away the keys?”

Lippin said that it’s not uncommon for caregivers to feel guilty, stressed, anxious and depressed while caring for a loved one. Resentment also can grow quickly, especially if the family caregiver feels “forced” into taking care of their loved one or does not receive the support they need from siblings or other family members.

“Caregivers face an internal conflict about exactly what one owes another person by virtue of being a blood relative or having loved them, in the case of a well spouse caring for an ill spouse,” Lippin explained.

Financial stress also can take its toll if the ill family member can no longer work, or if the caretaker has to leave their job or cut back on hours to provide the care their loved one needs.

“I had a client with a thriving freelance business who ended up on Medicaid while taking care of her elderly mother because she could no longer work the hours she needed to support herself financially,” Lippin said. “I would much rather have a loving, doting aide caring for me than a resentful family member. Unfortunately, a family caregiver is often the only solution because hiring a live-in caretaker or full-time aide is cost-prohibitive for most people.”

Setting Boundaries and Seeking Help

Lippin said that it’s crucial for family caretakers to set boundaries to avoid emotional burn-out and the negative biological affects that too much anxiety and depression can have on their central nervous system.

“I often see caretakers who stop taking care of themselves while they are taking care of a loved one,” she said, noting that 30 percent of caregivers die before their ill loved one. “They may skip doctor’s appointments because they can’t or won’t leave their loved one alone. Or, they may stop taking their own medications if finances become an issue. One client’s very ill spouse outlived her by many years because she stopped taking care of herself to care for him.”

Lippin is adamant that caregivers need to take care of themselves as well as their sick loved one.

“Do something for yourself a couple times a week,” she suggested. “Meditate, take a yoga class or join a support group with people who understand exactly what you’re going through. Realize that you aren’t in this alone and that you shouldn’t be expected to give and give without receiving some care of your own.”

“Caretakers also can benefit from professional help available through a therapist,” she said. “A professional therapist will provide a compassionate ear and listen to their concerns without passing judgement. Together, the therapist and caretaker can

formulate a plan to help them decrease their stress, anxiety, depression or other mood disorders.”

Even if seeing a therapist or hiring an aide for their loved one is not an option financially, there are a range of free online and in-person support groups and self-help information available said Lippin, pointing to resources available through her professional society, the [Anxiety & Depression Association of America](#).

Through the ADAA website, caregivers can learn more about [mental health signs and symptoms](#), read [tips for restoring mental wellness](#), and join a free, anonymous [online support group](#).

“Seek help,” Lippin urged caretakers. “As a caretaker, you need someone caring for you too.”

Categories: [Behavioral Health](#), [Caregiving](#), [General](#)

Tags: [behavioral health](#), [caregiver](#), [caregiving](#), [therapist](#)

Help for Pediatric Cancer Patient Caregivers

By Julie Komanetsky, Vice President, Patient and Family Services, The National Children's Cancer Society

By definition, parents are their child's number one caregiver. However, when that child has cancer, "caregiving" takes on a completely new meaning and many new challenges.

Consider the journey: A child is born, and the proud parents wait for a little cry. They count ten fingers and ten toes and they give thanks for the healthy addition to their family. Cancer is the farthest thought from their minds. After all, cancer is something that happens to adults—not children, or so they think.

The symptoms are different based on the child and the type of cancer, but parents tell us stories of trusting their intuition when their child ends up sick and doesn't seem to recover after a few days. They push for testing beyond what's normal. They know something isn't right. Still, when the doctor walks into the room to tell them that their child has cancer, parents are devastated.

Caregiving Takes on New Meaning

Cancer is a diagnosis that impacts the entire family, oftentimes sending them into a tailspin as they adapt to their new role as cancer patient caregivers. One mom, whose son Zach was diagnosed with rhabdomyosarcoma at age 2, told The National Children's Cancer Society. (NCCS):

"Those first few days after his diagnosis, I couldn't eat, couldn't sleep, and couldn't think. I was afraid he wouldn't live to see age three."

Her reaction is common. Parents are faced with the immediate need to learn about their child's cancer and treatment plan. They are further challenged with maintaining their households, taking care of their other children, missing work and ensuring the family's financial stability. And one of their most difficult struggles, yet most basic needs, is simply getting their child to and from treatment.

And then they find NCCS. Most often, they are referred by a social worker at the hospital for help with the financial burden of childhood cancer, but soon discover we can also help with their emotional struggles through our **Family Support Program**.



Julie Komanetsky, The National Children's Cancer Society

Supporting Family Caregivers

The NCCS works tirelessly and compassionately to support families making their way through the daunting world of childhood cancer. We know how to navigate this world, helping families get where they need to be—physically, financially, and emotionally—to give them hope, and to give their children the best possible shot at survival.

Our dedicated staff is here to provide practical and emotional support to parents, caregivers and survivors. Once a family is referred to the NCCS, a case manager is assigned to them who stays by their side throughout their cancer journey. Our case managers are trained professionals who help during difficult times, encourage parents to advocate for their child, provide referrals, and perhaps most importantly, they listen when a parent just needs to talk, and they comfort when a parent just needs to cry.

Our support is critical for families like Hazel's. Hazel is the youngest of four and was diagnosed with leukemia when she was two. She recently turned four years old and continues to receive chemotherapy at a hospital two hours from home during the maintenance phase of her treatment. Hazel's dad, Nat, recalls the past year as the toughest of his life, describing it as excruciatingly hard for his entire family, as cancer changed their lives entirely but never destroyed their family bond.

Nat shares:



Hazel

“My family is stronger today because of our journey with cancer, and here’s why: people. The people we have met during this process have been unforeseen blessings, providing comfort, support, love and respect at every turn. We have met doctors, nurses, administrative staff, individuals and professionals from all walks of life that helped provide the stilts to prop my family up as we struggled to manage our situation. Some of the most cherished people have been representatives from The National Children’s Cancer Society.”

At The National Children’s Cancer Society, we create a clear path through the maze of childhood cancer and survivorship to help families stay strong, stay positive and stay together. Because no family should have to go through childhood cancer alone.

About the Author

Julie Komanetsky has tirelessly and compassionately served with The National Children’s Cancer Society (NCCS) for more than 20 years. She is currently the Vice President of Patient and Family Services, overseeing all NCCS programs, taking a “no

matter what” approach, to create a clear path through the labyrinth of childhood cancer and survivorship to help families stay strong, stay positive and stay together. She is a member of both the Association of Pediatric Oncology Social Workers and the Grant Professionals Association.

Categories: Caregiving, General

Tags: cancer, caregiver, caregiving, pediatric cancer

From CancerCare: The Importance of Cancer Caregivers in Medical Settings

By Mary Hanley, LMSW, Oncology Social Worker, CancerCare

Being the primary caregiver to a cancer patient is a long, intense experience both physically and emotionally. The cancer caregiver often experiences all the highs and lows of the patient's cancer journey and is there to observe every detail, for better or for worse. This makes the caregiver a beacon of information on the patient's physical and emotional well-being during cancer treatment. Yet, caregivers often express feeling ignored by their loved one's medical team or excluded from the patient's treatment planning. Considering that cancer caregivers often play second-fiddle to their loved one with cancer in other areas of life, it is imperative that the caregiver feels included for continued success in their role.

A qualitative study of patients and their caregivers suggests that fostering appropriate involvement of caregivers and family members is an important factor for a strong provider-patient relationship.¹ Doctor's visits can be overwhelming and the patient may forget to ask a question. Caregivers are able to observe external signs of illness and can improve communication with their loved one's health care team. It is crucial for accurate medical treatment of the patient that the caregiver is given the space to report any observations and to be fully acknowledged by medical personnel.



Mary Hanley, LMSW, CancerCare

The caregiver also brings their own issues and concerns into the room with them. The average caregiver is 53 years old and 60 percent of cancer caregivers are caring for someone who is 65 years old or older.² The caregiver is more than likely dealing with age-related health changes in addition to the physical and emotional demands placed on them through caregiving. Furthermore, while the average caregiver is in good physical health, the impact of their loved one's diagnosis has an equal, sometimes even greater, emotional impact on the caregiver as the patient. When a caregiver isn't acknowledged by medical personnel, it also can lead to the caregiver feeling ignored or undervalued. One nationwide study in 2015 found that only 29 percent of caregivers are asked about their own care by medical professionals.²

There are a few simple steps to bridge the gap between the medical team and the caregiver. Acknowledgment of the caregiver is the first and most important step. Being respectful of and being genuinely engaged in discussions of the caregiver's wellbeing

can help the caregiver feel important and needed. Such moments are good opportunities for doctors to assess if the caregiver is experiencing any physical complications from caregiving activities, showing any signs of burnout or emotional distress, or needs help navigating extended time away from work. If any of the aforementioned issues are presented, caregivers can often benefit from a referral to the treatment center's oncology social worker, a patient navigator, a financial coordinator or to mental health services.

About CancerCare

Founded in 1944, CancerCare is the leading national organization providing free, professional support services and information to help people manage the emotional, practical and financial challenges of cancer. Its comprehensive services include counseling and support groups over the phone, online and in-person; educational workshops; publications; and financial and co-payment assistance. All CancerCare services are provided by oncology social workers and world-leading cancer experts. To learn more, visit www.cancercare.org or call 800-813-HOPE (4673).

References

1 Kimberlin, C., Brushwood, D., Allen, W., Radson, E., & Wilson, D. (2004). Cancer patient and caregiver experiences: Communication and pain management issues. *Journal of Pain and Symptom Management*, 28(6), 566-578.

doi:10.1016/j.jpainsymman.2004.03.005

2 National Alliance for Caregiving (2016). Cancer caregiving in the U.S.: An intense, episodic, and challenging care experience. Self-published. Retrieved from

https://www.caregiving.org/wp-content/uploads/2016/06/CancerCaregivingReport_FINAL_June-17-2016.pdf.

Categories: [Caregiving](#), [General](#)

Tags: [cancer](#), [caregiver](#), [caregiving](#)

Understanding the Voice of Cancer Caregivers

By Alexandra Zaleta, PhD, Senior Director, Research, Cancer Support Community

At the [Cancer Support Community](#), we have always strived to serve everyone who has been affected by cancer. For us, this means providing support to patients as well as their family members, who often play a critical role in providing support and care. It also means conducting research that prioritizes cancer [caregivers](#) in order to understand their greatest needs and to develop better support programs.

Caregiver Research

One of the two key initiatives of our [Research and Training Institute](#) is [CancerSupportSource®-Caregivers](#), a tool that captures caregivers' concerns and links them, automatically, to the information and support they need most. The program was developed by working closely with cancer caregivers. Our affiliates across the country use CancerSupportSource®, and we continue to grow the program through our research efforts.



Alexandra Zaleta, Cancer Support Community

Since 2014, we have also been enrolling caregivers into our [Cancer Experience Registry](#), a web-based research survey that allows patients and caregivers to share their experiences and provide insights into the impact of cancer. The Cancer Experience Registry has allowed us to collect valuable information around caregivers' priorities, needs and experiences when caring for someone with cancer. This project is ongoing, and our goal is to increase knowledge and improve outcomes for caregivers in the cancer community. We encourage caregivers to join at www.CancerExperienceRegistry.org.

Caregiver Resources

In addition to research, Cancer Support Community offers a number of resources that provide support to caregivers and patients, including our [toll-free Helpline](#), our [Frankly Speaking About Cancer](#) educational series, the direct services offered to caregivers through our [Affiliate network](#), the [MyLifeLine service](#) (which connects cancer patients and caregivers with their family and friends for support), and the [Cancer Policy Institute's Grassroots Network](#), a place to make your voice heard to local and national policymakers.

***Cancer Caregivers* Book Highlights Research and Resources**

In service of our commitment to caregivers, we are excited to share that we have authored a book chapter in *Cancer Caregivers*, published by Oxford University Press. The book is dedicated to the science of cancer caregiving and the support that is available to caregivers in their community.

Learn more about our book chapter in *Cancer Caregivers* [here](#).

Categories: [Caregiving](#), [General](#)

Tags: [cancer](#), [caregivers](#), [caregiving](#)

Maintaining Control with Parkinson's Disease Through Palliative Care

Provided Courtesy of GetPalliativeCare.org

Editor's Note: This week, we share some advice for caregivers of those living with Parkinson's disease on how palliative care can help, from a post reprinted with permission from www.GetPalliativeCare.org. We encourage our readers to visit this site for more useful tips and insights on palliative care for people with serious illnesses.

If you or someone you love is living with Parkinson's disease, there are ways to improve your quality of life. While there is no cure for Parkinson's disease, there are medications and treatments that can reduce the symptoms. A medical specialty called palliative care can help.

Palliative care is specialized medical care for people living with serious illnesses like Parkinson's disease. It treats the pain, symptoms and stress of the illness, with the goal of improving quality of life.

The Caregiving Team

Palliative care is provided by a team of palliative care doctors, nurses, and other specialists who work together with the patient's other doctors to give them an added layer of support.

Palliative care teams are experts in complex symptom management. Parkinson's disease is a progressive illness that damages the system of nerves that the brain uses to direct the body's muscles and movements. The illness results in hand tremors, muscle stiffness, slowing and jerking. People living with Parkinson's can experience sleeplessness, fatigue, constipation and low blood pressure. The disease can also affect the brain in other ways, may result in depression and anxiety, difficulty concentrating and dementia. The palliative care team will work with the patient's neurologist to be the first line of defense against any of these physical and emotional symptoms, always communicating preferences and making sure treatments are in line with your goals.

If you or someone you love is living with Parkinson's disease, don't wait to ask for a palliative care referral. Early involvement of palliative care can give you the added layer of support to help you and your family enjoy quality of life.

Almost all large hospitals have palliative care teams, and it's also available in outpatient clinics and for home visits, depending on your area. At GetPalliativeCare.org you can learn more, look for palliative care in the [Provider Directory](#), and take a short [quiz](#) to see whether you or your loved one might need palliative care.

About GetPalliativeCare.org

Getpalliativecare.org provides clear, comprehensive palliative care information for people coping with serious illness. Key features of the site include a [Palliative Care Provider Directory](#), a [definition](#) of palliative care, and detailed descriptions of what palliative care does and how to get it. It also provides an interactive [quiz](#) to assist you in deciding whether palliative care might be right for you or a loved one. The site is provided by the Center to Advance Palliative Care (CAPC).

Categories: [Caregiving](#), [General](#)

Tags: [caregiver](#), [caregiving](#), [palliative care](#), [Parkinson's Disease](#)

Caring for a Child with Migraine

By The American Migraine Foundation

Editor's Note: The following is reprinted with permission from the [American Migraine Foundation](#). Visit the American Migraine Foundation web site to [download a copy of the full guide](#), which includes additional information on pharmacological and non-pharmacological treatments.

Nothing hurts more than seeing your child in pain. Between four and ten percent of children experience migraine, and kids display different symptoms than adults. Early diagnosis, an open dialogue and specialized treatment plan can equip you and your child with the tools to best manage their migraine.

Maintain a Dialogue

An ongoing dialogue with your child is critical to getting an accurate diagnosis and finding a treatment plan that works. Your child's migraine management plan will evolve as they grow older and their daily routines change. Being able to talk about migraine openly will help you adapt as a team.

Find a Common Language

Younger children might have a hard time describing their symptoms. Use non-verbal cues, like pointing to your tummy or making pained facial expressions, to find out where and how severe their pain is.

Keep Your Focus on Them

It can be scary when your child is having severe pain or other migraine symptoms, but kids will pick up on your anxiety and it can add to their stress. Put on a brave face, offer your child reassurance and empathy, and seek the consolation you need from your own support systems.

Work Together to Find Solutions

Involve your child in the process of finding a headache specialist and devising a treatment plan. It can be as simple as asking them what they thought of a new doctor after a first meeting, or keeping track of healthy behaviors and rewarding them for practicing good headache hygiene.

Leave the Conversation Open-Ended

A diagnosis and treatment plan are only the beginning. Encourage your child to keep you informed about their symptoms, and invite any questions or concerns they have

about their medication or daily routine. Then, work together to find alternatives, and get the whole family involved in following through.

Establish Healthy Habits

Establishing a healthy routine is essential for the migraine brain, so it's recommended that parents sit down with their children and discuss fundamental healthy habits.

Children should be sleeping a minimum of nine hours a night, while teenagers should get at least eight hours. Discourage your child from taking naps or staying up past their bedtimes.

Work with your child to make sure they don't skip breakfast and have access to three well-balanced meals a day. They should also drink enough water; eight 8-ounce glasses a day is a good rule of thumb.

Get the whole family involved: track how much water each family member is drinking, sit down for dinner together every night, and establish regular bedtimes for everyone.

Finding a Headache Doctor

When it comes to caring for your child with migraine, you are not alone. A headache specialist plays a critical role in any migraine management strategy and can help you and your child explore your options and find an effective treatment plan. Visit americanmigrainefoundation.org to find a headache specialist near you to get your child the treatment and care they deserve.

About the American Migraine Foundation

The American Migraine Foundation provides education, support and resources for the millions of men, women and children living with migraine. Our mission is to advance migraine research, promote patient advocacy and expand access to care for patients worldwide. Migraine, and other disabling diseases that cause severe head pain, impact more than 37 million people in the United States alone. By educating caregivers and giving patients the tools to advocate for themselves, we have cultivated a movement that gives a collective voice to the migraine community. For more information, please visit www.americanmigrainefoundation.org. Together we are as relentless as migraine.

Categories: [Caregiving](#), [General](#)

Tags: [caregiver](#), [caregiving](#), [headache](#), [migraine](#), [pediatrics](#)

Understanding Chronic Heart Failure: Advice for Caregivers

By Real World Health Care Editorial Staff

Are you caring for a loved one with chronic heart failure? Being a [family caregiver](#) can feel overwhelming and isolating, but you are not alone. According to the [American Heart Association](#), more than six million American families have an adult member dealing with heart failure. And while living with any chronic disease can be difficult, many people with chronic heart failure learn to manage their symptoms and enjoy full lives, with help from their family and friends.

“One of the biggest challenges people face when caring for a loved one with chronic heart failure is understanding the disease,” said John Osborne, MD, PhD, FACC, FNLA, director of cardiology for [State of the Heart Cardiology](#) in Dallas. “Many of us in the medical world tend to use jargon and abbreviations, which can be confusing to patients and their families. But it’s crucial for everyone to know exactly what the disease is, what it means, how to monitor it, and how to manage and treat it.”

Simple Language for a Complex Disease

Dr. Osborne said he and his team act as educators to help patients and their families better understand chronic heart failure. Instead of using technical terms like [reduced ejection fraction](#) and [preserved ejection fraction](#), he communicates using simple language and analogies – referring to the heart as a “plumbing” system that needs to pump properly to give the body the blood flow it needs.

“With some patients, I may talk about their heart as being ‘big and baggy,’ which makes it hard to squeeze to pump blood in and out,” he explained. “With other patients I may tell them that their heart squeezes properly, but it’s too ‘stiff’ to sweep blood in and out efficiently — like the difference in pressure between blowing up a balloon and blowing up a hot water bottle.”

According to the American Heart Association, [open communication](#) between patients, their families and their care team is important, especially to help with shared decision-making. They advise patients and their loved ones to be prepared for appointments by writing down concerns, asking questions, taking notes and clarifying what the health care team says.

Managing Chronic Heart Failure

About 10 percent of adults living with heart failure have advanced heart failure, in which the condition has progressed to the point where traditional therapies and symptom management no longer work. However, the vast majority of heart failure patients can improve their symptoms with behavioral and lifestyle management strategies.

Table of Contents

“Maintaining a healthy weight and monitoring it daily are important as heart failure patients can quickly hold onto fluids, which causes pulmonary edema and difficulty breathing,” Dr. Osborne said. “One of the simplest ways to empower patients and give them something they can control is getting them to focus on the Rule of Twos: Gaining more than **two** pounds in **two** days is **too** much.”

In addition to weight management, the American Heart Association suggests a number of lifestyle changes that can help alleviate heart failure symptoms, slow the disease’s progression and improve everyday life:

- Quitting smoking
- Tracking daily fluid intake
- Avoiding or limiting alcohol and caffeine
- Eating a heart-healthy diet
- Being physically active
- Managing stress
- Monitoring blood pressure and other symptoms
- Getting adequate rest

“Family caregivers play a critical role in helping their loved one adopt and maintain healthy living practices,” Dr. Osborne said. “In some cases, patients may brush off their symptoms or slack off on recommended diet and exercise. It often falls to family caregivers to hold the patient accountable and advocate for them with their health care team.”

Emotional Health for Patients and Caregivers

In addition to helping manage the physical symptoms of heart failure, healthy living can also help patients manage stress and other mental and emotional complications that come with having a chronic disease.

“Chronic heart failure causes severe limitations in daily functioning and may lead to a shortened life span,” explained Barry J. Jacobs, Psy.D., a clinical psychologist, health care consultant and long-time AHA volunteer. “Patients don’t feel well and can’t do much, which leads to a high degree of depression, anxiety and frustration.”

Dr. Jacobs added that if patients allow chronic heart failure to limit their lives, they are more likely to become hopeless and depressed. On the other hand, if they are proactive in managing their symptoms and remain active and engaged, they can attain a higher level of physical functioning and a more positive outlook.



Barry J. Jacobs, PsyD

“Caregivers have a direct influence on helping their loved ones maintain a positive attitude,” he said. “That influence is most effective when the caregiver acts as a coach, guiding the patient to make better choices, instead of nagging them.”

Dr. Jacobs cautions family caregivers to not fall into the trap of blaming the patient when they backslide or when inevitable exacerbations occur.

“Heart failure is different from other chronic diseases like cancer because so much of it is behaviorally based,” he explained. “One would never think to blame a cancer patient for winding up in the emergency room due to exacerbated symptoms. But those guilt trips are more common when dealing with a heart failure patient who decides to ‘cheat’ and have a high-sodium meal, for example.”

The blame game and other family conflicts between patient and caregiver can lead patients to feel they’ve lost control over their own lives. They can also lead to stress for the caregiver.

“It’s easy for caregivers to get frustrated when their loved one tries to assert control and does something they shouldn’t – sometimes just for spite,” Dr. Jacobs said. “It’s also easy for caregivers to get worn out, because heart failure is a disease in which demands go on indefinitely, for years, instead of for weeks and months as with other diseases.”

Drs. Jacobs and Osborne recommend that caregivers stay on top of their own physical health and mental well-being so they can provide the best possible support for their loved one. They suggested that caregivers reach out to their primary care physician if they start to feel stressed or depressed. Their doctor can evaluate them, develop a treatment plan, and put them in touch with resources such as therapists, respite services and support groups to help them avoid burnout. The American Heart Association’s Rise Above HF initiative offers [caregiver tools and resources](#) as well.

The Rewards of Caregiving

“Caregiving for a heart failure patient can be challenging, frustrating and tiring,” Dr. Jacobs admits. “But it can also be tremendously gratifying, especially when caregivers realize the significant difference they can make in their loved one’s life. There’s a sense of purpose derived from caregiving that can help sustain caregivers over time.”

“The good news is that with proper treatment from a patient’s health care team, good life habits and the support of family caregivers and other loved ones, heart failure patients can dramatically extend their lives and enhance their day-to-day existence,” concluded Dr. Osborne.

Categories: [Caregiving](#), [General](#)

Tags: [caregiver](#), [caregiving](#), [chronic heart failure](#), [heart disease](#)

How To Support a Friend with Heart Disease

Provided Courtesy of Go Red for Women

Editor's Note: When a family member or friend is sick with a chronic disease like heart failure, the role of caregiver often falls to women. However, more than one in three women is living with some form of cardiovascular disease themselves: It is the number one killer of women in the U.S.

Go Red For Women is a global community whose hearts are united against heart disease. The following article is reprinted with their permission. Learn more about heart disease in women. Read the original article [here](#).

You want to support a friend with heart disease or be part of a support system. Your support can help her feel better about her diagnosis and can even help her make healthier life choices.

Listen

When discussing her heart diagnosis with you, one of the best things you can do is listen. While it may be tempting to tell her all the ways she can eat healthier or exercise more often, focus instead on hearing her concerns before rushing to give advice.

“Just listening is a really easy way to show someone you care,” says Carol D’Anca, a Chicago-based clinical nutritionist and owner of Foods Not Meds, who has helped to support several women friends struggling with heart disease.

Get Informed

Chances are, your friend is going to the doctor quite a bit these days and may feel overwhelmed by the barrage of information given to her. Lighten her load by doing some research yourself, suggests D’Anca.

“Go online and help her with research about her condition and treatment options,” she says. “Work together to dig deeper and gain an understanding of what she is going through. Your willingness to help will go a long way.”

Socialize

Depression is an unfortunate byproduct of heart disease for many women. Upon receiving bad health news, they tend to shut themselves off from activities they once enjoyed. If this describes your friend, set up a regular social outing for the two of you (or invite others) – maybe a Tuesday afternoon tea hour or a movie night once a week.

“She will start to feel better emotionally when she feels love from others,” D’Anca says. “I also recommend helping them find a support group of others who are going through the same thing. Several of my friends have done this and it has brightened their moods tremendously, just knowing that they aren’t suffering alone.”

Get Active

Help improve your friend’s heart health by scheduling time to do activities together. Based on her likes and capabilities, organize a regular walk around the neighborhood or take a dance or step aerobics class together. Not only will the physical activity help your friend’s heart health, but it will improve her mood too.

Categories: Caregiving, General

Tags: caregiver, caregiving, chronic heart failure, heart disease

The Many Moods of Heart Failure and the Caregiver Challenge

By Real World Health Care Editorial Staff

Caregivers play an important role in the well-being of chronic heart failure patients. In addition to helping their loved one manage the physical and medical aspects of heart failure, they are called on to help with the patient's emotional health.

According to Ann Laramee, APRN, Cardiology Nurse Practitioner in Cardiology and Palliative Medicine at the University of Vermont Medical Center, the heart is very sensitive to mood stressors like anxiety, fear, loneliness, anger and depression. She says that mood changes in heart failure patients can result in reduced compliance with treatment plans, longer recovery times and an increased risk of additional cardiac events.



Ann Laramee, APRN-BC

Caregiving: A Burden or a Blessing?

Studies have shown that improved social support has been associated with better outcomes for patients living with heart failure. But often, caregivers themselves suffer from physical and emotional symptoms, according to Laramee, who notes that most caregivers of heart failure patients serve in that role for an average of 50 hours a week over 53 months.

“At the same time, caregiving can be very gratifying,” she says. “People say it brings fulfillment and meaning to their life. They feel appreciated.”

She encourages caregivers to take care of themselves so that they can be there for their loved one. She recommends many of the same self-care tips as she does to patients, including getting enough sleep, exercising regularly, eating a well-balanced diet and asking for support when needed.

Webinar for Caregivers

Additional insights from Laramee are available in a [free webinar](#) “Moods in HF and Caregiver Challenges” from the [Heart Failure Society of America](#) that's perfect for caregivers, patients and families alike.

In the webinar, Laramee reviews the various moods that may affect a heart failure patient, how to recognize mood changes, when to seek help and the treatment options

available. She also addresses the important role a caregiver plays, the challenges and rewards of caregiving, the importance of self-care and finding support when needed.

The HFSA Patient Education Webinar Series is provided to patients, caregivers and families through a collaboration between the Heart Failure Society of America and Mended Hearts. The series covers topics including heart failure diagnosis, therapies, clinical trials and diet and therapy advice. For more information, please visit www.hfsa.org/patient/webinarseries.

Categories: [Caregiving](#), [General](#)

Tags: [caregiver](#), [caregiving](#), [chronic heart failure](#), [heart disease](#)

What People with Migraine Attacks Hate to Hear

By National Headache Foundation

Editor's Note: Real World Health Care is pleased to close out our 2019 series on [migraine](#) by sharing an article originally published by the [National Headache Foundation](#). Here, they share advice for helping patients respond to caregivers and others when faced with stigma associated with migraine disease. You can read the original article [here](#), and learn more about migraines from the National Headache Foundation [blog](#).

It can be difficult to explain the excruciating pain of a migraine to those who don't experience it. In fact, there's a stigma attached to this disorder stemming from a lack of knowledge on the severity of symptoms associated with migraine and headache. Migraine is not just a headache, and the attack may include nausea, vomiting and sensitivity to light and sound. Anyone who experiences migraine attacks has surely been frustrated with well-meaning friends and family offering dismissive advice that's not only unhelpful but can make the situation worse.

We took to social media to discover the most common comments and advice that people with migraine hear when they discuss their condition. We compiled the 10 most common in a list below.

1. Take some Advil
2. Did you take something?
3. Have you been drinking enough water?
4. You've got another headache?
5. Again?
6. I get bad headaches too.
7. It's just a headache.
8. I have some Tylenol if you want it.
9. Just push through it!
10. I think you just want an excuse.

Chances are, you've heard one or more of these pieces of "advice" at some point in your life. One comment in particular—"It's just a headache"—encapsulates the popular misconception about a disorder that affects around 40 million Americans. It's frustrating to feel that no one understands what you're going through, and some, out of their own lack of knowledge, may even think you're faking symptoms.

In order to demystify the stigma surrounding migraine disease, here are a few steps you can take to educate those around you about this debilitating neurological disorder.

Explain the Migraine Triggers

While **migraine triggers** differ from person to person, there are a few common causes that will bring about symptoms in many sufferers. For example, a naturally-occurring compound called Tyramine—often found in aged, smoked or cured meats and vegetables—has been found to be a major trigger of migraine attacks. If friends, family and coworkers have a better understanding of your migraine triggers, they're more likely to notice when you're experiencing an attack and can respond accordingly.

Provide Migraine Resources

Of course, you don't need to justify your condition to everyone with whom you interact, but migraine symptoms can cause a strain on certain close relationships. For example, a boss or supervisor doubting the severity of your condition may cause you additional stress, which can negatively impact **work performance** or compound the pain. Fortunately, the National Headache Foundation has an abundance of **resources** that help skeptics and allies alike get a better understanding of migraine and headache. Sharing these informative sources with those closest to you can help alleviate the burden of constantly explaining your condition.

Seek Migraine Treatment from a Headache Specialist

Understanding the specifics of your condition makes it far easier to explain them to others. **Seek out a headache specialist** to receive an appropriate diagnosis. The health care practitioner will likely diagnose you based on your medical history, symptoms and a physical and neurological examination. This could include blood tests, magnetic resonance imaging (MRI) or computerized tomography (CT) scan. (It is critical to visit a medical professional who specializes in headache and migraine, as they will be able to **best diagnose and treat the pain.**)

There will always be those who doubt the severity of migraine symptoms. However, by educating yourself and those around you, you can help tear down the stigma associated with migraine disease and, in the process, make living with migraine attacks a bit easier.

Categories: [Caregiving](#), [General](#), [Migraine](#)

Tags: [caregiver](#), [caregiving](#), [headache](#), [migraine](#)