



# Caregivers:

## Who Asked You?

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*During the Pulmonary Fibrosis Foundation's 2018 Volunteer Summit, I was asked to speak on caregiving in the PH community and began my presentation with a question.*

*"Are there any caregivers in the room?"*

*Hands shot up.*

*"Wow, quite a few! So, let me ask you: how do you know?"*

*A pause.*

*I repeated, "How do you know you are a caregiver?"*

*Another pause.*

*"I mean, did anybody ask you? Did you get a certificate? After your loved one's diagnosis, did the doctor take you to the adjoining room for caregiver 101 or sign you up for caregiver bootcamp?"*

*Laughter filled the ballroom. All the caregivers, patients and even a few doctors were in on the joke. Although caregiving often requires tremendous skill and deep emotional reserves, the American health care system has no formalized program to prepare caregivers – indeed, the very notion seems like a fantasy compared to most caregivers' practical experience.*

Like the pulmonary hypertension (PH) community, this audience understood that compassionate, knowledgeable unpaid family caregivers are no laughing matter – and they shouldn't be taken for granted. Caregivers are a pillar of the Pulmonary Hypertension Association (PHA) community – they support their loved ones and play vital roles in the organization, acting as educators, fundraisers, support group leaders and even members of the Board of Trustees. And this is not new; sitting behind the four women patients who founded PHA were their husbands. But just as our understanding of PH and its treatments has evolved over the past decades, so too has our understanding of caregivers and the resources needed to support them.

Before one can even consider these complex issues for caregivers, one encounters a diversity of opinion about the terminology to use. Over the past decade, health care systems have steered away from the term "caregiver" and toward "care partner" because it focuses on the shared responsibility in the relationship. Long-established organizations such as the National Alliance for Caregiving (NAC), of which PHA is a member, may use care partner or even the European "carer" in their work, but "caregiving" is still in the title and, indeed, remains

the most common term in the PH community. Even so, another popular opinion among many caregivers is to avoid any term at all. For these spouses and parents, it is enough to be called “husband” or “mom.”

If the name alone excites this much controversy, you can imagine the diversity of responses when you ask what caregivers *do*. Symptom trackers, chauffeurs, doctor visit buddy, medication mixers, insurance wranglers, emergency managers, oxygen company scolds, errand runners, advocates, listeners – sometimes all of the above. What a caregiver does may depend on the situation, on the state of the health of the patient, on the time of day. For some lucky PHers, multiple family members and friends are engaged as part of the team and take on different roles – a doting son may be the errand runner and chauffeur, a loving wife may be the listener-in-chief and symptom spotter, a neighbor may do the yard work. This cascade of duties is called the “ripple effect” in caregiver research, and it represents caregiving at its best.

There are many terms to describe a person who supports a loved one with a serious condition, including caregiver and care partner. If you are one of those people, what is the right term for you?

In fact, the vital role of caregivers in the lives of patients has become so much better understood and researched that last year Congress passed the RAISE Family Caregivers Act, which calls for the federal government to develop a national family caregivers strategy, and earlier this year PHA joined a national task force to address the role of caregivers in medical device and drug development running in parallel with the larger conversation about patient-focused drug development.

The ideal “village of caregiving” is not the reality for all PH patients, however. Indeed, some patients take care of themselves whether they live alone or not. Most people have heard stories about ignorant strangers harassing PHers for parking in handicap parking spots because they “don’t look sick,” but

imagine when that lack of understanding comes from a spouse, child or parent. There are some who live with others who may be overwhelmed, uncaring or unable to help, making a tough situation even harder.

If you are a PH patient who is your own caregiver – whether by choice or circumstance – please connect with the PHA community. Find in-person, online and telephone support at [PHAssociation.org/Support](http://PHAssociation.org/Support).

“I have been on both sides of this coin – caregiver and critical care provider,” says Marie, an R.N. from Florida. “Once you become a caregiver, the perspective changes dramatically. I found on my journey as mom and nurse, that medical professionals are lacking in knowledge of this disease, myself included. Being an advocate for your loved one while trying not to offend the ‘professionals’ is a delicate dance. I love my profession, and admit that until my daughter’s diagnosis, I, too, was in the dark about PAH. I got my ducks in a row very quickly, and with minimal research was able to get a handle on the day-to-day needs. Even my family ‘didn’t get it.’ She looks fine – until her fingers turn blue and she can’t breathe or lie flat.”

As we have learned more about the complexities of immediate family and friends who run the gamut from doting to negligent, whose duties range from wound care to personal banker, we have evolved our understanding a great deal about the challenges they face. Rare Disease Caregiving in America, a 2018 study by NAC and supported by PHA, found that 90% of caregivers educate medical professionals about their loved one’s disease and two-thirds engage in medical or nursing tasks. To help support these disease-specific responsibilities, PHA provides robust, free education to patients and caregivers through in-person programs, informational videos and a library of topic-based print resources.

The NAC study also showed that half of PH caregivers feel emotionally stressed and isolated. In a survey of its own, PHA discovered that a majority of parent caregivers need additional

<sup>1</sup>*Rare Disease Caregiving in America*. National Alliance for Caregiving. February 2018. [Caregiving.org/rare](http://Caregiving.org/rare).



support opportunities. To address both of these general and parent-specific caregiver support needs, PHA has created new monthly telephone support groups, PHA-administered Facebook groups and pediatric-specific in-person support groups. There are more ways and more places now than ever before for caregivers to learn from one another and offer emotional support on their journeys with PH.

Another telling statistic from the NAC report showed only one in 10 PH caregivers seek professional respite support. Respite is a program or service in which a professional temporarily steps in to take on caregiver responsibilities so that the caregiver can complete another task or get much-needed rest. At a recent PHA support group meeting, the group was asked if anyone had used respite and no one responded, so a follow-up question was asked: Did anyone know what respite was? One person stumbled through a partial response but ultimately conceded they were not sure, so the leader educated the group about respite. The leader talked about home health care and advised attendees to ask their PH care team for information about home health and respite and to contact their insurer for details about what programs or services were covered. In the U.S., respite and home health benefits differ

from state to state — sometimes county to county — and depend upon insurance coverage, but ARCH Respite is a national clearinghouse of free information where you can learn more about respite in your own area ([ARCHRespite.org](http://ARCHRespite.org)).

The need for respite is so great that in May 2019 the National Organization for Rare Disorders (NORD) launched a new financial assistance program to help caregivers pay for some time away. The announcement stated, “Caring for a loved one with a rare disease demands significant time, attention, patience and dedication. NORD’s Rare Caregiver Respite Program is designed to give back to caregivers — the parent, spouse, family member or significant other — of a child or adult living with

a rare disorder and provides financial assistance to enable the caregiver a well-deserved break.” Learn more about the eligibility criteria and apply at [RareDiseases.org](http://RareDiseases.org).

PH is complex and so is providing compassionate care for the people who live with it. Like “caregiver bootcamp,” it is a myth that becoming a caregiver happens only once. Being a caregiver requires choosing to care every day, and that is an awesome, daunting responsibility. It is also untrue that you or your loved one are alone. You may feel isolated, but PHA has a vast community ready to meet you, support you and listen to you. For those who accept the challenge to be a caregiver again and again, you have PHA’s thanks and admiration. For those who struggle or doubt, you can choose to care today and PHA can help. For those who are caring for a loved one or themselves and need support, lean into the PHA community. [👉](#)

Get more information:

- [PHAssociation.org/Support](http://PHAssociation.org/Support)
- Email [Support@PHAssociation.org](mailto:Support@PHAssociation.org)
- Call 301-565-3004 x777

## Education and Support for Caregivers

### Online

- **PHAssociation.org**  
Access dozens of informational pages and downloadable PDFs on PH, treatments, types of PH, testing, grief, lifestyle issues and more.
- **PHA Classroom**  
View free videos of experts in PH discussing WHO groups, insurance, medications, research and more.  
[PHAssociation.org/Classroom](http://PHAssociation.org/Classroom)
- **PHA Facebook Groups**  
Search "PHA Caregivers" or "PHA Parents of Kids with Pulmonary Hypertension."
- **Email mentors**  
Find a caregiver or another parent who understands your issues.  
[PHAssociation.org/Mentors](http://PHAssociation.org/Mentors)

### Telephone

- **Telephone Support Groups** (monthly meetings)  
  
For Caregivers: [PHAssociation.org/Caregivers/Support](http://PHAssociation.org/Caregivers/Support)  
  
For Parents of Children with PH:  
[PHAssociation.org/Parents/Support](http://PHAssociation.org/Parents/Support)
- **Support Line**  
Call the PHA Support Line to ask questions, vent, learn more or connect with a support group. 800-748-7274

### Events

- **PHA's International PH Conference and Scientific Sessions**  
Three days of educational content, networking and support coming to Anaheim, Calif. in June 2020.  
[PHAssociation.org/PHA2020](http://PHAssociation.org/PHA2020)
- **PHA on the Road**  
Day-long free forum of educational talks, support groups and more, 2-3 times annually across the U.S.  
[PHAssociation.org/OnTheRoad](http://PHAssociation.org/OnTheRoad)

### In-Person Meetings

- **PHA Support Groups**  
Hear from medical speakers and other patients and caregivers at one of more than 200 support groups around the U.S. All in-person support groups of PHA welcome and encourage caregiver attendance.  
[PHAssociation.org/LocalSupportGroups](http://PHAssociation.org/LocalSupportGroups)
- **PHA Support Groups for Parents of Children with PH**  
  
DC — DC Pediatric  
FL — St. Petersburg Pediatric  
PA — Philadelphia Pediatric (Children's Hospital)  
TX — Texas Children's Pediatric Group  
[PHAssociation.org/LocalSupportGroups](http://PHAssociation.org/LocalSupportGroups)

