

A Guide for Caregivers



What to Expect and How to Move Forward When Someone You Love Has Pulmonary Hypertension



This resource guide was made possible through support from the Medtronic Foundation and an unrestricted educational grant from Gilead Sciences, Inc.



OTHER GUIDES IN THIS SERIES

- Long-Term Survivors*
- Teens*
- Newly Diagnosed*
- Parents*

A Guide for Caregivers

TABLE OF CONTENTS

- 1 Facing Daily Life as a Caregiver
- 3 Managing Caregiver Stress
- 7 Recognizing Depression in Yourself or Your Loved One
- 14 Caring for Your Relationship With Your Partner
- 18 Helping Healthy Children Cope

Facing Daily Life as a Caregiver

“What I find difficult is the fact that, when you tell others you are a caregiver, they do not understand all that it entails. It is a full-time job. Can you help us explain that to those who have never been caregivers?”

“I occasionally worry that I will not have enough to give to myself, my loved one with PH and others I love.”

Facing Daily Life as a Caregiver

Caregivers are the backbone of the pulmonary hypertension community, offering support and strength to their loved one with PH. Just as PH impacts people from all walks of life, caregivers come in many forms — spouses, parents, siblings, best friends. Caregiver roles may also vary — from offering a shoulder and listening ear to managing housework, mixing medications and coordinating doctor visits.

Pulmonary hypertension is a “whole life” condition that can impact every aspect of one’s day-to-day routine. This is as true for caregivers as it is for patients. As you take on the role of the caregiver, with its new responsibilities and concerns, it can be easy to feel overwhelmed and to push your own needs to the back burner. One caregiver shared, “It’s very easy to give up everything important to you and give all your energy to the PH patient. This leads to extreme stress, physical fatigue, and even anger.”



801 Roeder Road, Suite 1000
Silver Spring, MD 20910
Phone: 301-565-3004
Fax: 301-565-3994

PHA@PHAssociation.org
www.PHAssociation.org
www.PHAOnlineUniv.org

While it can seem best in the moment to focus on your loved one's needs, the reality is that in order to be an effective caregiver, it's important to take care of yourself with the same intention and commitment with which you care for the others in your life. When you neglect your own needs, you put yourself at risk for caregiver burnout and depression. This negatively impacts both your own health and your ability to take care of another person.

By being aware of your needs and risks as a caregiver and building a network of support, you can become empowered to care for yourself and your loved one to the best of your ability.

Be aware of your needs. It can be easy to focus on your loved one's needs, especially when you both are adapting to the PH diagnosis. While you are learning about PH, give some attention to also learning about caregiver needs so you can identify your own. Read the articles in this packet and explore other caregiver resources (see the Additional Resources included with each article), and think through ways you can address those needs. Plan ways to incorporate your needs into your new caregiver routine, and be on the lookout for signs that you're feeling burnt out.

Build a network. We all need someone to turn to for advice and a listening ear from time to time. No one can relate to your experience better than another PH caregiver! Connect with other caregivers via PHA's email, phone and in-person groups at www.PHAssociation.org/Caregivers/Support.

Seek out a mentor. A mentor can be an important resource as you develop your "new normal," offering tips for self-care and living with PH from their own years of experience. Finding a mentor may happen naturally as you build your support network, or you can seek out an experienced member of the PH community through PHA's PH Email Mentor Program at www.PHAssociation.org/Mentors.

Coordinate additional support. "Try to share some of the responsibilities of caregiving with other members of the family or close friends so that you can take some time for yourself in order to recharge your batteries," recommends

one caregiver who responded to PHA's 2011 Family and Friends survey. Another respondent agreed, saying, "If you let yourself become run down — both mentally and physically — caregiving will become increasingly difficult."

Caregiving can be challenging, but the articles in this packet and PHA's community of caregivers can help you be empowered and prepared for the journey ahead. As Nancy shared with the *PHA Caregivers* email group, "Though none of us choose to have PH in our lives, we do, and this group ensures that we don't have to face it alone."

*PH medical review by Mike Hayes, RN, BSN, CCRN,
Pulmonary Clinical Nurse Coordinator at Intermountain
Medical Center in Murray, Utah.*

Managing Caregiver Stress

“He is not able to help as much with the kids as I would like. It stresses me out when they want something or they are fighting and I am trying to work, but he is lying on the couch.”

“When she is sick I worry all day, even while I’m at work.”

“His health went downhill so fast. I’ve had too many days of 12-hour work days and then coming home to the reality of not knowing how many days he has left.”

Understanding Caregiver Stress

Caring for your loved one who has PH can be stressful, and this stress may begin well before your loved one receives the diagnosis of pulmonary hypertension. The journey to diagnosis, understanding your loved one’s condition, and adapting to life as a PH caregiver are each major stages with their own unique stressors. This stress may accumulate, putting caregivers at risk for burnout and depression. Recognizing the stress that caregivers experience at each stage is an important step in understanding and finding ways to cope with caring for your loved one with PH.

Seeking a Diagnosis

The process of diagnosis can be very nerve-racking. It may take several months or years for your loved one to be properly diagnosed. These years are very likely frightening, frustrating and difficult for both the patient and caregiver as they encounter new symptoms, struggle to adapt to an uncertain present and future, and explore a series of possible diagnoses and new medications. When the patient is finally diagnosed with pulmonary hypertension, many caregivers experience a moment of relief at finally being able to put a name to their family’s struggle.

Diagnosed at Last

Unfortunately, a diagnosis of pulmonary hypertension may, in some ways, feel inconclusive in itself. For many caregivers, the cause of their loved one’s PH remains a mystery and there is no clear prognosis. Caregivers frequently report feeling overwhelmed by information as they learn about pulmonary hypertension. It is also common for caregivers to experience grief as they struggle to accept the uncertainty of their loved one’s illness. As one caregiver put it, “It just seems unbelievable to me that in this day and age my wife has this horrible disease with so much unknown about it.”

Returning to Daily Life

Returning to daily life, while incorporating care for your loved one, may be a struggle. Your loved one’s PH may impose significant life changes on you and your family: you may have moved to a new location to be at lower sea level or closer to a PH specialist; you may have become the primary breadwinner if your loved one had to stop working or cut back on work hours; you likely have new medical expenses. If the patient is your parent or adult child, he or she may have moved in with you and your spouse. Other changes may add up as well, and you may have many new responsibilities, including handling chores your partner took care of prior to diagnosis, fitting in appointments and medication management on top of your

regular routine, and explaining pulmonary hypertension to relatives and friends who may not “get it.”

On top of all the changes to daily life, caregivers also experience changes to their world views and future plans that can be disorienting and stressful. The uncertainty of chronic illness requires a shift in outlook that can be a difficult adjustment. One husband to a PH patient shared, “It is sometimes hard to plan in advance because she could have a ‘bad PH day’ and not be able to leave the house.” Many caregivers are also forced to reconsider plans for retirement or family trips. “My wife is just shy of 50 and was just diagnosed with PH,” said one caregiver. “After killing ourselves for so long and finally getting to the ‘us’ time, now this. Our younger son graduated college recently and we were looking forward to spending some time and money on us for a change.”

The Myth of the Super Caregiver

For some caregivers, the biggest source of stress comes from within. Many of us have a sense of the person we’d like to be, and for caregivers who are wearing many hats (spouse, parent, employee and caregiver, just to name a few), it’s not uncommon to set lofty expectations that can be difficult to meet. A sister of a PH patient told us that she feels disappointed in herself when she fights with her sister, because that’s “not how a good caregiver would act.” A husband of a PH patient told us he never goes out with his friends because it would make him feel too guilty. The wife of a PH patient said she feels stress because she needs to take so much sick time to accompany her husband to his PH appointments. Even when she’s able to meet her expectations for herself as a wife and caregiver, she’s not able to meet her expectations for herself as an employee.

All of these caregivers feel stress because they are comparing themselves to a mythical creature, the “Super Caregiver.” The Super Caregiver is everything to everyone at all times. The Super Caregiver works full time, makes meals, takes care of all the shopping and household chores, pays the bills, spends lots of time playing and chatting with everyone in the family, and does it all with patience and a smile. The Super Caregiver never yells, nags

or gets frustrated. Everyone’s idea of the Super Caregiver is a little different, but the thing that all Super Caregivers have in common is that they aren’t real.

Take the time to think about the expectations you’ve set for yourself and whether they’re realistic given everything on your plate. Many caregivers beat themselves up for normal and necessary reactions to stress, like expressing frustration or prioritizing one task at the expense of another. Rather than making stress go away, this type of negative self-evaluation can actually send your stress levels through the roof.

Risk for Caregiver Burnout

Stress can be cumulative. The long path to diagnosis, the adjustment to a diagnosis of pulmonary hypertension, and the strain of adjusting to a new life as a caregiver can all add up to make you feel like you’re on a never-ending roller coaster with no opportunity to step off. Many caregivers experience “caregiver burnout,” a state of mental and emotional exhaustion that results from ongoing levels of stress and suboptimal self-care. Burnout may be accompanied by increased anxiety and can be an early sign of depression.

Adapting and Moving Forward

Providing care for your loved one includes self-care. It’s important to recognize the early warning signs of stress so you can make changes before you become overwhelmed. Our emotions are great teachers, but some, like anger, guilt and depression, can be very uncomfortable. It can be helpful to see such emotions as signals that your stress level has increased and that you need to make a change or ask for more help. Read on for tips for coping with caregiver stress. If you think you may be depressed, contact a medical professional or read more about recognizing signs of depression (see “Recognizing Depression in Yourself or Your Loved One” on page 7 of this guide).

Allow yourself to grieve. Grief is a normal reaction to loss — including the loss of your plans, expectations and former lifestyle. Caregivers sometimes express bafflement and frustration that they are grieving, but this is a normal,

healthy response. Acknowledging your grief is healthier than locking it away.

Live for today. While you and your loved one do need to make plans for a wide array of possible scenarios, don't spend time dwelling on your loved one's prognosis. "My loved one had a very poor prognosis from the doctors," says a caregiver. "He lived five more years with PAH than the doctors predicted, and we did a lot of living. So don't give up hope. Live your life to the fullest so you don't have to *wish* you had."

"You can't base your day on thinking about how much time she has here," another caregiver adds. "Let it be more like, 'Where should we go out to dinner today?'"

Stop trying to be the "Super Caregiver." Think critically about the standards to which you hold yourself and if they're not realistic, adjust them so they are. When you fall short of your expectations, cut yourself some slack. Nobody's perfect. Even the best caregivers occasionally find themselves getting impatient, stressed or frustrated. Learn to think about these feelings as cues that you need some time to yourself, not as evidence of failure.

Schedule some you-time. "It's very easy to give up everything that's important to you and give all your energy to the PH patient," describes a caregiver. "This leads to extreme stress, physical fatigue, and even anger. Try to find a few hours per week that are just for you. For me I have a few hours on Saturday and Sunday mornings before my husband gets up and I sit, drink my coffee, watch my reality shows, and cross stitch. This re-energizes me and I am doing something I love that I can't do when my husband is awake."

Take five-minute breaks. You might feel like you have no time to practice stress-relief. The good news is that a little goes a long way! Even five minutes can be enough to help you de-stress and return to your day feeling stronger and refreshed. Try these quick five-minute stress relief exercises whenever you need a boost:

- Breathe deeply and slowly, in your nose and out your mouth. When we're stressed, we breathe poorly and

receive less oxygen. Breathing exercises increase our oxygen intake, which helps us relax.

- Yoga has been shown to have a beneficial effect on stress levels, and it's easy to do in your office or living room. Look up a quick YouTube video and spend a few minutes in downward dog!
- Take a brisk walk. We all know that exercise is good for us, but when someone becomes a caregiver, it may be one of the first things to go. If you don't already exercise or if you've given up your routine, the Family Caregiver Alliance recommends walking because, in addition to its physical benefits, it can reduce tension.
- Exchange a laugh with a friend. Nothing resets your mood like a good laugh. Are you all by yourself? Hop online and find your favorite comic strip, or sign up to receive a daily joke via email.

Set self-care goals. Are you having trouble fitting in even five-minute breaks? Set goals and take immediate action to put them into practice. Your goals can include taking a break from caregiving, getting help with your caregiving tasks and doing things that promote your own good health. You can start with a small goal, such as taking five minutes at lunchtime to practice breathing, or a larger goal, such as taking a night off or planning a vacation. Either way, lay out action steps to make your goal attainable. Put your break on your calendar or call a friend to schedule your night out.

Maintain a support network. Family, friends and other caregivers can all play an important role in helping you manage stress. Schedule in regular coffee dates and phone chats with people you enjoy spending time with, and encourage your loved one to do the same. Friends and family can be an important source of support when you and your loved one need a break from the "PH world." Other times, it can be helpful to talk to someone who can relate to your experience as a PH caregiver. Connect with other PH caregivers at a local support group, via email, or on PHA's monthly Caregivers Telephone Support Group (see [Additional Resources](#)).

Ask for and accept help. As one caregiver put it, "PH is

an uphill battle. Sometimes PH requires more than just one person to help a patient accomplish what would be an easy task for healthy people.” People really do want to help you, but they need to know how. The following guidelines can help you effectively ask for help:

- Consider the other person’s abilities, interests and availability.
- Don’t ask the same person for help repeatedly.
- Prepare a list of things that need to be done and let the other person choose what suits him or her best.
- Be prepared for a “no,” or hesitation. Accept it, but if the person gives you an opening, ask another time.
- Don’t weaken your request — be clear about what you need, including how important it is to you and the amount of time that help would be needed.

Keep in mind that even small things add up! Some things that may seem minor don’t take much time but can make your day go more smoothly. Ask your neighbors to add a few items to their grocery list for you, take your trash cans to the curb, or double a recipe so half of it can go into your freezer for a busy week.

Be prepared. “Think through the potential emergencies you may encounter at home and consider in advance how you will deal with them,” suggests a caregiver. “For example, if your PH patient needs oxygen and you live where ice storms, snowfall, or other things can close roads and cut power for extended periods, consider contacting your power company about obtaining a standby generator.” Being prepared will help you cut down on “what if” thinking and anxiety.

Communicate with your loved one’s medical team. As a member of your loved one’s healthcare team yourself, it is important that you build a relationship with his or her medical professionals. PH-treating doctors and nurses want to understand what they can do to help train you on your loved one’s complex PH therapies. They also want to know how caregiving is affecting your own health and well-being so you can be the best PH caregiver you can be.

Additional Resources

“Care for the Caregiver” (webinar recording)

www.PHAssociation.org/Classroom/CarefortheCaregiver

The Family Caregiver Alliance

www.caregiver.org

Caregiver Self-Assessment Questionnaire, from the American Medical Association

www.ama-assn.org/ama1/pub/upload/mm/433/caregiver_english.pdf

Caregiver Stress Check, from the Alzheimer’s Association

www.alz.org/stresscheck

Caregiver Stress: Tips for Taking Care of Yourself, from the Mayo Clinic

www.mayoclinic.com/health/caregiver-stress/MY01231

When Someone You Love Has a Chronic Illness: Hope and Help for Those Providing Support, T.M. Greenberg (Cedar Fort, Inc., 2012)

Email a caregiver mentor

www.PHAssociation.org/Mentors

Connect with other PH caregivers by telephone or online

www.PHAssociation.org/Caregivers/Support

Attend a local support group

www.PHAssociation.org/FindaSupportGroup

Reviewed by Allyson Rupp, LCSW, of the Vera Moulton Wall Center for Pulmonary Vascular Disease at Stanford.

Recognizing Depression in Yourself or Your Loved One

“My wife told me she feels like her life is over. I don’t know how to help anymore.”

“I have been dealing with overwhelming depression and anxiety. My husband is my very best friend and the person I turn to when I am most scared or upset. So when the person you usually look to is the one you can’t, it is the scariest and most helpless feeling. I know I need to probably get help for this as I imagine the fear and anxiety are not going to just ‘go away’ because my husband’s PH is not going to just go away either.”

What to Expect

Pulmonary hypertension patients and caregivers face a host of daily challenges that put them at increased risk of depression, from the financial strain of medical bills to the isolation and loneliness of living with a rare illness. Recent studies indicate that while the majority of people affected by PH suffer from periods of depression, with treatment, most of these patients and caregivers go on to live full and meaningful lives.

In families living with PH, it’s not uncommon for more than one family member to be depressed. The emotional effects of chronic illness can make people act differently than they did before diagnosis, and these changes inevitably affect other members of the household. If you have noticed changes in your loved one or yourself, you are not alone. One husband to a PH patient told us, “I feel overwhelmed by my wife’s condition and her actions toward me and others.” Another said, “My sister’s diagnosis came with a lot of questions and definitely shock, and it was kind of crazy watching my family go through all the emotions.”

As the caregiver of a PH patient, it’s important to become familiar with the warning signs of depression and learn about the resources available if anyone in your family

needs help. Depression is a serious but treatable illness, and research suggests that the earlier depression is treated, the greater the likelihood of a positive outcome.

Identifying Depression

Depression is an illness that affects millions every year, but there’s no blood test for depression and no virus that scientists can study under a microscope. Depression can affect how a person acts, feels and thinks, and yet many people don’t realize they are depressed until they’ve been living with the symptoms for a very long time. It’s also unusual for someone suffering from depression to go to loved ones to ask for help. That’s why it’s so important for everyone in a family affected by PH to understand depression and stay alert to the symptoms in the patient, the primary caregiver and other family members.

As you watch for symptoms of depression you are looking for *changes in behavior* that present themselves over an *extended period of time*. If the person you are caring for has always cried during sad movies and continues to do so, this might be less significant than if this behavior developed after being diagnosed. If the crying lasts only for a few days, this might be less significant than if this behavior continues on a near-daily basis for a period of several weeks or more.

A few of the key symptoms of depression are:

- **Feelings of sadness, numbness, or emptiness nearly every day.** Depression may feel like a dark cloud that can make everything seem hopeless. Be aware of any irritability or lack of humor. Not everyone expresses these feelings in words. Pay attention to non-verbal cues, such as crying or shutting off from family more often than is normal compared to past behavior.
- **Markedly diminished pleasure in almost all activities.** Be particularly aware of a loss of interest in things your loved one used to enjoy such as exercising, cooking or hobbies. Sexual interest may also decrease.
- **Significant weight loss or weight gain, or decrease or increase in appetite.** In children, consider failure to make expected weight gains.
- **Insomnia or excessive daytime sleeping nearly every day.** Recent research shows that about 80% of people with depression also suffer from insomnia and that 15% of people with depression sleep too much.
- **Fatigue nearly every day.** Depression can make the activities of daily life almost impossible because it consumes an enormous amount of energy. Be aware of changes in the amount of energy or number or intensity of tasks your loved one seems able to handle. This may present itself as an inability to keep up with everyday grooming, work, shopping and household chores. Keep in mind that in patients, increased fatigue, weight changes and sleep trouble related to depression may be mistaken for worsening symptoms of PH.
- **Feelings of worthlessness or excessive guilt nearly every day.** These feelings are often inappropriate to the situation. Someone who is depressed might feel guilty for things they have no control over, including getting ill in the first place.
- **Diminished ability to think, concentrate or make decisions.** Depression can make it hard to think clearly or pay attention to tasks and conversations. Even simple choices can feel overwhelming. Notice if there is difficulty completing tasks such as deciding which medication to take or if there is frustration built into even simple decisions, like which sweater to wear or magazine to read.

- **A feeling of being completely alone.** People suffering from depression frequently isolate themselves and pull away from loved ones. Take note if your loved one begins avoiding conversations and wants to be alone more than usual.
- **An inability to relax.** More than half of the people diagnosed with depression also suffer from anxiety. Someone who is depressed may find it difficult to kick back and stop worrying, even for short periods of time.
- **Thoughts of death and suicide.** Some people wish that they were dead, feeling that the world would be better off without them. Others make very explicit plans to hurt themselves. One of the best ways to prevent suicide in someone who is depressed is to recognize the warning signs of suicide and always take them seriously. If you or a loved one is thinking about self-harm or suicide, visit your local emergency room or call the National Suicide Prevention Hotline at 1-800-273-TALK.

Depression in Your Loved One

As a PH caregiver, you may be the first to recognize that your loved one is in need of help. In some cases, however, the opposite is true. Caregivers and other family members sometimes find that they are too close to the patient to recognize the symptoms of depression and take action. It's common to confuse symptoms of depression with irritability, laziness, fatigue related to the patient's PH, or sadness that's "to be expected" in someone with a serious disease. If your loved one is newly diagnosed, you may assume that this is the way life with chronic illness has to be. This is simply not the case. Many PH patients have overcome periods of depression brought on by diagnosis, changes in health status, and other environmental and circumstantial factors.

Many loving and concerned caregivers are distraught to find that it does not always come naturally to be supportive when a loved one is exhibiting symptoms of depression. Some worry that if they interact with a depressed person too much, they will slip into a depressed state too. Others simply find themselves frustrated and unable to relate. Human beings want to respond to the suffering of

others by listening and providing physical and emotional support. This support may come naturally when the suffering is due to clear and observable symptoms, such as those experienced by a person suffering from a physically debilitating illness. When we can actually see the suffering, it is easier to relate and respond to that suffering.

With clinical depression, however, much like with pulmonary hypertension, an individual's suffering happens mostly on the inside, with few visible outward signs besides exhaustion. It's much more challenging to relate to the suffering a person experiences when depressed. Because you can't always see depression, it is frequently confused by friends and family members with laziness or self-pity. Some caregivers will find themselves telling their loved ones to "snap out of it." But expecting someone with depression to "snap out of it" is like asking someone with PH to "just breathe easier" or a person with diabetes to "just stop having high blood sugar." Recovery is not a matter of will power. These are illnesses that take place at a cellular level and typically require the intervention of a health care professional in order to improve.

If you notice any of the symptoms of depression in your loved one, it's important to take action. As with any other illness, depression can compromise an individual's physical health. It can cause physical pains and aches, digestive problems, fatigue, sleeping problems, changes in weight and appetite, dizziness and light-headedness, all problematic side effects that may interfere with a PH patient's already compromised quality of life. Furthermore, people suffering from depression are sometimes less likely to follow their medication regimens, which can seriously compromise a PH patient's treatment plan. A PH patient suffering from depression must be treated for depression *as well as* PH and any other illnesses they may be living with. If the symptoms have been apparent for some time, talk to your loved one and your loved one's PH-treating physician at the earliest opportunity.

Depression in Caregivers

PH patients aren't the only ones at increased risk of depression. While caregivers don't have to personally manage the physical symptoms of PH, a 2011 study

revealed that their lives are just as affected in all other areas, including the practical, social and emotional arenas. In a PHA survey of PH caregivers, 42% reported that they sometimes felt sad or depressed. When caregivers are depressed, they often neglect their own needs due to the inherently unequal nature of the patient/caregiver relationship. In a recent survey, one caregiver wrote: "I am in therapy and I try not to let myself get too fearful, but I panic through every PH doctor appointment. I try to be strong for her, but I am losing it."

To be an effective caregiver and to notice signs of depression in your loved one, you must take care of yourself with the same intention and commitment with which you care for the others in your life. In fact, since you are taking care of (at least) two people, the effort to keep yourself physically and mentally healthy may be twice as challenging. Remember the flight attendant's instructions as the airplane takes off: "*In case of emergency, first place the oxygen over your face and then your child's...*" Caregivers who don't pay attention to their own needs can experience caregiver burnout and be too exhausted, stressed or unfocused to help their loved ones. Try to develop a routine that includes exercise, stress management, a healthy diet, sufficient rest and time with family and friends who can support *you*.

If you suspect that you may be suffering from depression, anxiety or chronic stress, give your symptoms the attention they deserve. Read on for tips to help you and/or your loved one overcome depression.

Moving Forward

Treating Depression

Depression, though sometimes difficult to identify and understand, is an illness like any other, and symptoms will not go away on their own without attention and intervention. For stomach pain we can't ignore, we go to the doctor. When depression begins to interfere with an individual's everyday functioning (sleeping, eating, working or socializing), that's a good indicator that it's time to seek the help of a mental health professional.

Mental health professionals (psychologists, social workers and psychiatrists) use therapy, lifestyle changes and sometimes medication to help people identify and overcome difficult issues and negative thinking patterns. The goal of treatment is to help an individual reclaim a sense of control and rediscover pleasure and fulfillment in daily activities. Many people start by seeking out a psychologist or social worker, as these are the front-line therapists who can provide short- or long-term treatment. As therapists get to know their clients, they sometimes refer them on to psychiatrists who have the ability to prescribe and track medications.

The search for the right therapist can take time. Ask your loved one's PH doctor, primary care physician, support group members, friends and insurance company for recommendations for good therapists in your area. Some therapists specialize in chronic illness and health-related depression, areas of expertise that may prove particularly helpful to PH patients and caregivers. Seek out a professional who you (or your loved one) feel comfortable with and who's willing to get to know you before deciding on a course of treatment. This may mean interviewing multiple therapists in person or by phone. This process can be a bit like dating — not everyone is compatible, and the right match is worth the effort.

Lifestyle Changes

While professional help is a crucial component of depression treatment, you can also make lifestyle changes on your own to deal with symptoms between therapy appointments. Make every effort to treat yourself with the same compassion that you would treat a loved one. Remember that depression is an understandable response to a very difficult situation. Here are some suggestions for incorporating self-compassion and self-care into your life:

- **Get into a routine.** It's common for a caregiver to feel overwhelmed after their loved one's diagnosis because their old routines no longer accommodate their PH-related responsibilities and reorganized priorities. Rather than living in reaction to the tasks and stresses that present themselves day in and day out, try to establish a new routine that incorporates your work,

chores, meals, caregiving responsibilities and fun time. By structuring your day with pre-planned activities, it's possible to slowly regain a sense of control over many aspects of your life.

- **Take up good habits.** Maintain consistent sleep patterns, eat nutritious meals and exercise on a regular basis. Try stress-relief techniques like breathing exercises, muscle relaxation and yoga. If you're having trouble finding the time, talk to your therapist about ways to incorporate small self-care activities into your daily schedule.
- **Break the cycle of negative thinking.** You may find yourself experiencing feelings of self-reproach and shame as you come to terms with your depression. One PH caregiver told us that a year after her adult son was diagnosed, she found herself lying awake every night ruminating about what a bad mother she was. Over time, with the help of a therapist and a supportive family, she realized that these thoughts weren't based in reality. Try to take notice when your mind starts to fixate on negative and unproductive thoughts. You may notice that these thoughts often come in a chain, with one leading to another and another after that. Some people find it helpful to recite a self-accepting statement, something like, "I'm trying my best, and that's the best I can do," to break this cycle.
- **Build a network of support.** The support of family members and friends can make a big difference in the speed and success of your recovery. It's also a good idea to connect with people who can relate to some aspects of what you're dealing with. You might consider joining PHA's online email group for caregivers or a depression support group (see [Additional Resources](#)).
- **Reach out for help.** One PH caregiver told us, "I feel like I have to be there, every moment, everywhere, 24/7." If you're holding on to similar superhuman standards, do yourself a big favor and let go of them now. Not even the most loving and supportive caregivers are with their loved ones all the time. You owe it to yourself and your entire family to schedule in "me time" to tend to your own needs. Assemble a core group of trusted friends and family members to be a part of your "PH team." Assign your helpers clear and specific tasks like

grocery shopping, transportation to medical appointments and cooking the occasional meal.

- **Be patient.** It takes time to see the benefits of therapy, medication and lifestyle changes. Don't give up after a few weeks just because you haven't seen dramatic changes. Keep putting effort into your recovery and all your hard work will eventually start to pay off.

Supporting a Loved One with Depression

For most people, knowing how to respond to someone with a serious illness can be very challenging. We don't want to say the wrong thing. We don't want to appear insensitive. We don't yet know what is helpful and what isn't. On top of all that, seeing a person we love dealing with pain and suffering often reflects back to us our own mortality and this can be very frightening. For many, this proves too difficult to handle and they simply become unavailable.

Yet part of being an effective caregiver is being open to many of the same emotional challenges your loved one will confront. This means a willingness to be present with the fears, anxieties and range of questions that will arise. No matter how loving and diligent you are, you will never be the "perfect" caregiver. You will make mistakes, and that's ok. With caregiving there is a very steep learning curve and like any learning process it will take practice, patience and commitment to get through.

Here are some suggestions for communicating with a loved one who is depressed:

- **Listen without judgment.** Most people underestimate the value of listening. Try to get a sense of what this experience is like for your loved one. Put aside the need to fix, advise, criticize or react. Most caregivers will wrestle with their desire to be in control. After all, it's your attention to detail and willingness to help that makes you such a capable PH caregiver to begin with. But for someone who's depressed to truly heal, "answers" often need to come from within, not from their family or friends. Rather than offering advice, make yourself emotionally available and allow your loved one the space to share.

- **Accept the reality of this moment.** Acknowledge that this situation is what it is. You don't have to condone your loved one's feelings or give up hope that they'll change in order to accept them in this moment. Meet your loved one where he or she is, not where he or she was yesterday or where you think he or she should be, and take every moment as it comes.
- **Be reassuring.** Remember that someone suffering from depression might have a distorted perception of the world around them. By pointing out realistic options, honest observations that emphasize the positive aspects of situations, and the admirable qualities your loved one possesses, you can play a part in countering the hopeless and negative thoughts your loved one may be feeling.
- **Practice the art of gentle encouragement.** If you get an invitation for a party and your loved one declines, don't force the issue. Feeling pressured to socialize can make someone who's depressed withdraw further. But don't give up on your loved one either. Give it time and ask again.
- **Be true to yourself.** Don't ignore your own feelings or pretend that you're not affected by the changes brought on by PH, depression or other household stresses. In the long run, trying to disguise your true feelings can take a toll on both you and your relationship. Acknowledge how you're feeling, first to yourself and, if you'd like, to your loved one. When you're talking about your feelings, try to speak from an "I" perspective. For example, rather than saying, "You're not listening to me," try, "I feel unheard." This acknowledges to your loved one that you're taking responsibility for your emotions and will make it easier for them to listen to what you're saying without feeling humiliated or attacked.

Even with these tips in your back pocket, many caregivers find it challenging to offer the support they want to provide. One caregiver told us, "Some days it feels like everything I say is wrong, everything sends her further down her dark spiral. I don't know what to do for her when she gets like that." Keep in mind that there's no magical pep talk or solution that will make a depressed person perk up. The biggest gift you can offer your loved one is a stable environment and your caring presence.

Bob and Sharon

Here's an example of a conversation between Sharon, a woman living with PH, and her husband, Bob. Bob can't change Sharon's feelings, but in this conversation he is able to provide patient and persistent support without losing his temper or putting pressure on her to "snap out of it."

Sharon: (*tearfully*) I don't want to go out tonight.

Bob: (*neutrally, trying to understand what's motivating Sharon's feelings*) Ok...

Sharon: I just don't think I am very good company. I feel exhausted all the time, and I just want to go to bed.

At this point in the conversation, Bob just listens for a bit before responding to make sure there is nothing else Sharon needs to say. Being comfortable with silence and resisting the urge to offer advice can be healing for both patient and caregiver.

Bob: (*after a while, emphatically, without judgment...*) Sounds like you're having a hard time right now.

Sharon: I just don't know how I am going to get through this.

Bob: Well, there's a lot going on and you have a very full plate right now. It's no wonder you're feeling some self-doubt.

Sharon: You have no idea.

Bob: That's probably true. (*After a while...*) I do have to tell you that I have a lot of faith in you and in us to get through this. You have to try and remember that you are not alone in this.

Sharon: That's what it feels like. You're not ready to pass out after a walk to the mailbox, Bob. You haven't had to give up your job. I know you mean well, but you really just don't know what it's like.

Bob: You're right. I can't imagine what it must be like for you. Can I hug you?

Sharon: (*tearfully*) Yes.

Bob: (*after a pause...*) So, listen. We can do a few things. If you'd like to get into bed, I can rub your back a little and we can play it by ear as to whether we go out or not. Either way is fine with me. I don't want you to feel pressured. I think you may be a little depressed and it's just important that you take care of yourself right now. But I do want to tell you that things are going to get better. When we see Dr. Smith, maybe he can suggest some ways to deal with the exhaustion and difficult feelings. What do you think?

Sharon: I guess that sounds ok. Thank you, Bob.

Of course all conversations won't go this smoothly, for Bob or for you. Depression is a very difficult illness to come to terms with. But the main ingredients of healthy conversations are almost always the same: a willingness to listen without judgment and an acceptance of the present moment for what it is. Sometimes conversations will go well, and sometimes they won't. One caregiver recalls the moment that his persistence finally started to pay off. He shared, "[The emotional challenges] were very hard to address, but when I heard the words from her, 'Thank you, you have been so good to me in this ordeal,' the challenges started to melt away." It may not happen overnight, but over time it's possible for your presence and support to play a central part in your loved one's healing process.

Additional Resources

Recognizing and Coping with Depression as a PH Caregiver (webinar recording)

www.PHAssociation.org/Caregivers/DepressionWebinar

Depression Screener

www.depression-screening.org/depression_screen.cfm

National Alliance on Mental Illness

www.nami.org/depression

Depression Center on WebMD

www.webmd.com/depression/

Depression and Bipolar Support Alliance:
Find a Support Group

www.dbsalliance.org/site/

[PageServer?pagename=support_findsupport](http://www.dbsalliance.org/site/PageServer?pagename=support_findsupport)

Caregiver-to-caregiver virtual support groups

www.PHAssociation.org/Caregivers/Support

Email a caregiver mentor

www.PHAssociation.org/Mentors

Family Caregiver Alliance

www.caregiver.org

When Someone You Love Has a Chronic Illness: Hope and Help for Those Providing Support, T.M. Greenberg (Cedar Fort, Inc., 2012)

National Suicide Prevention Lifeline: 1-800-273-TALK (1-800-273-8255)

National Crisis Help Line: 1-800-SUICIDE (1-800-784-2433)

Depression Hotline: 630-482-9696

Para obtener asistencia en español llame al:
1-888-628-9454

By Charles Leighton, LCSW, CGP. PH medical review by Keith Swetz, MD, Associate Program Director of the Palliative Medicine Program at Mayo Clinic in Rochester, Minn.

Caring for Your Relationship with Your Partner

“After killing ourselves for so long and finally getting to the ‘us’ time, now she has PH. We were looking forward to spending some time and money on us for a change.”

“My hubby said that he felt like it was his job to ‘FLX’ everything for me, and he gets so upset with himself because he cannot fix my PH. That really opened my eyes to why he sometimes acts the way he does or says the things he does.”

“It is hard for a caregiver to watch what PH does to their loved one. I think for some (like me), there is safety in denial.”

What to Expect

Few couples stop to consider the implications of the words, “in sickness and in health,” but a diagnosis with pulmonary hypertension quickly calls this marriage vow to action. Whether you’re young newlyweds or settled into retirement, when a partner is diagnosed with PH, it’s common to encounter difficult feelings, fears and challenges. There’s no way to plan for a diagnosis with PH, for the hospital visits, complex treatments, shifting priorities or uncertain future. PH is a “whole life” condition that can bring major changes to household finances, family roles and responsibilities, and daily life. In short, if your partner is living with PH, then so are you.

Many couples find themselves putting their relationships on the back-burner to make room for the new tasks and commitments that PH introduces to daily life. As a caregiver to someone living with PH, it’s likely you’ve taken on a host of new and unfamiliar responsibilities. When their partners are diagnosed, many caregivers rise to the occasion, attending doctors’ appointments, learning everything they can about PH, and ordering medications. Some find themselves taking on chores and roles that once fell to their partner.

From paying the bills to housework to childcare, caregiving can often feel like two or three fulltime jobs. With everything there is to do, it can be difficult to find time to focus on the fun side of being in a loving relationship. Early on, “date night” may come to mean an evening mixing medications; the “rainy day adventure fund” may be redirected to cover medical bills; and the only “romantic getaways” may be trips to specialty medical centers. Shifting priorities and demanding schedules can take a serious toll on both emotional and physical intimacy.

Time isn’t the only challenge couples living with PH face. When two partners who once operated relatively autonomously begin to rely on each other in new ways, it’s common to experience major shifts in your marriage or partnership. Depending on the severity of your partner’s PH, you may be called upon to support your loved one financially, physically and emotionally. Many caregivers find that taking on all these new roles can throw off the delicate balance that once kept their relationship afloat. It can be difficult to adjust to new relationship dynamics, particularly if you have yet to give up hope that life will return to the way it was before PH. Many couples find

themselves moving in and out of denial, anger, bargaining, depression, and acceptance as they grieve for the relationship they've lost. These responses to loss and change can begin to feel like very real parts of your current relationship. You and your partner may grieve at different paces, putting your relationship to yet another test of endurance.

Working on a relationship while dealing with PH and managing a household is not easy. It's likely that both you and your partner are dealing with emotions that are difficult to talk about openly and honestly. Some caregivers feel guilty that they aren't sick. Others have so much on their plates they feel overwhelmed, ashamed, or even resentful. Your partner is likely experiencing difficult emotions too, which may make it more difficult to communicate your own feelings and concerns. The caregiver is often called upon to be the voice of reason, the "rock," the constant, and the receptacle of their partner's sadness, pain and fear. While you may have leaned on your life partner for support before PH, it's common to want to protect your partner now that he or she is sick. Yet trying to handle everything on your own can lead to isolation, dissatisfaction and blame. The tendency to hold back can affect both the caregiver, who has lost a primary source of support, and the patient, who may miss feeling relied upon and being perceived as strong and independent. Trying to protect your partner from difficult topics can sometimes backfire, leaving him or her feeling dependent or isolated. One patient asserted, "Just because I have PH, doesn't mean that I can't think. Sometimes I think my wife believes PH has affected my brain ... actually, my brain is the healthiest part of me now, and I really want to be asked to use it."

All of these feelings and challenges are normal, but over time, without attention and effort, they can take a toll on even the most loving and devoted relationships. By taking the time to acknowledge and talk about the challenges you're both up against, you can begin to work on your relationship so you and your partner can face this journey as a team.

Adapting and Moving Forward

We've all heard the advice: "You can't take care of anyone until you take care of yourself." But is it really possible to devote time to yourself and your relationship when your

partner's illness requires so much daily attention? The answer is yes, but it's not easy. Read on for some suggestions for prioritizing your relationship in an already hectic life.

Review. Talk about your needs, your partner's needs, and your relationship. It might feel most natural to begin by talking about what your partner is looking for from you as a caregiver. Listen openly and without judgment to what your partner has to say, and be prepared to step back in certain areas if you're asked to do so. One caregiver told us, "I found out from my wife that I was taking away her independence. I didn't realize I was [doing that] ... I was [simply] very concerned for her." Also discuss your needs, and the ways in which your loved one can better support you. Even couples who have been living with PH for years can make changes. Your roles will likely evolve over time. Use changes — especially good changes, like stability on a therapy regimen or reaching a milestone — to prompt discussion of how you are working together and what you need from each other in your roles. Prepare for emotional reactions — both yours and your partner's — and recognize that emotional vulnerability is both normal and the foundation of empathy, change and healing.

Reflect. Take an inventory of the things that you loved and admired about your partner and relationship before PH. While you may not think about this list as much as you did when you first fell in love, reflecting on the things you see in your partner can remind you of why your relationship is worth your time and attention. Think about the things you enjoyed doing together as a couple before your partner was diagnosed. Which of those activities do you still make time for? Consider the factors that led you to give some of these activities up. Your loved one's physical limitations? Lack of time? Simply acknowledging the ways in which things have changed is an important first step towards accommodating those changes in your relationship.

Innovate. If you're unable to do all the things you enjoyed prior to your partner's diagnosis, work with your loved one to find new ways of spending time together. Take the core characteristics of your shared interests and work on integrating new fun and feel-good activities into your routine. Think about hobbies you haven't tried in the past because

you were too busy with other activities. Re-create special memories with an updated twist.

Take breaks. It's a good idea for both you and your partner to rely on people outside of your relationship for some of your support. If your partner occasionally asks a friend or family member to accompany him or her to a doctor's appointment, try not to take it personally. Going outside of the relationship for connection and help doesn't mean that your loved one doesn't appreciate everything you do. Take these opportunities to catch up on the news, read a book, or do something creative. If these opportunities don't present themselves naturally, seek them out by asking a close friend to help out with an item on your to-do list while you take some time for yourself. Taking a break from your partner does not make you insensitive or less devoted. Think about life before PH. Chances are good that you didn't spend every moment together. The most loving partners spend time apart so they have stories to share at the end of the day.

Schedule. Taking time for yourself as a PH caregiver isn't always easy, but it is important. Find time (even just an hour a week) to do something you enjoy, without your partner, and have your partner do the same. Formally scheduling independent activities into your routine ensures that you'll get the alone time you need, without the guilt you might otherwise feel doing something fun without your partner. Go for a run, spend time with friends, or take a class. Activities that involve physical activity and socializing can keep you feeling energized, both physically and mentally.

Explore. If you and your partner have struggled to reestablish physical intimacy, there are steps you can take to begin to overcome many of your fears in this area. Begin by talking to your partner's PH medical team, who may be able to offer specific recommendations and assurances. Some couples find that they're able to reintroduce physical intimacy relatively quickly after the patient is on medication and in stable health. But even if physical acts need to be mellowed or altered, they are generally still possible. Talk to your partner's doctor about positional changes to accommodate for medical devices or pain. Over the long run, it's also useful to broaden your definition of intimacy.

Gentle touch, massage, verbal and non-verbal expressions of love, foot rubs, laughing, sharing memories, watching intimate movies, and simple physical closeness can be welcome substitutes when other types of physical intimacy aren't possible.

Share. Open communication is critical to a healthy relationship. Even on busy days, make an effort to stay conscious of your mood, as well as your partner's. Talk about small problems and gaps in communication as they come up. You might also consider scheduling times to touch base about how you're both feeling. Many of us wait for a crisis or argument to talk about what's working or, more often, not working in a relationship. But putting check-ins on the calendar will give you the chance to talk when you're not worked up, when you and your partner are both more likely to listen and respond with a clear mind. Getting in the habit of listening and sharing in your everyday life will also help you communicate more effectively when you do argue.

Get support. Find people to talk to about PH and caregiving, as well as about your "non-PH" life. Participate in support groups with your partner to understand his or her experiences from a new vantage point. Get involved in caregiver groups so you have a safe, confidential place to share your story and vent frustrations with people who can relate (see [Additional Resources](#)). One caregiver credited the support she received from others in the PH community as a critical factor in helping her reach a place of acceptance: "My way to battle my denial was to join PHA and become a part of the community." If you feel overwhelmed, burnt out, or depressed, you might also consider speaking to a therapist, physician, or clergy member. Being honest with yourself when you need help and reaching out to get it can only make you stronger.

Accept. Acknowledge to yourself that you will never be perfect in every role. Reflect on your expectations for yourself and for your relationship. Make an effort to honestly assess how important each expectation is to your happiness. Prioritize them and get rid of expectations that are unnecessary, redundant or unrealistic. Then make a plan for meeting those that remain. Recognize there are factors outside of your control (like PH), and try to focus,

instead, on taking charge of how you respond to new challenges as they present themselves.

Thrive. Many couples find that once they've adapted to new roles and expectations, PH actually brings them closer. They're reminded of the qualities that attracted them to their mates in the first place, and they discover new traits (like resiliency, courage and faith) that help them reconnect. One caregiver said of his wife, "She is a fighter. I have learned to trust in her." Another caregiver told us, "In sickness and health, for better or worse, we have each other and are stronger for it. We take care of each other and battle PH every day, trying always to make the best of it we can." With patience and commitment, your relationship will continue to change and grow. Over time, it will become easier to see yourself as not just a caregiver, but as an advocate, partner and friend.

Additional Resources

Maintaining Healthy Relationships, an article for PH patients with helpful tips on communicating, intimacy and independence

www.PHAssociation.org/Patients/HealthyRelationships

Maintaining Healthy Relationships webinar (January 2012)

www.PHAssociation.org/Classroom/MaintainingRelationships

PHA resources for PH caregivers

www.PHAssociation.org/Caregivers

Family Caregiver Alliance

www.caregiver.org

"Building Better Relationships," from Texas Woman's University

www.twu.edu/downloads/counseling/E-3_Building_Better_Relationships.pdf

When Someone You Love Has a Chronic Illness: Hope and Help for Those Providing Support, T.M. Greenberg (Cedar Fort, Inc., 2012)

Email a caregiver mentor

www.PHAssociation.org/Mentors

Connect with other caregivers by telephone or online

www.PHAssociation.org/Caregivers/Support

Attend a local support group

www.PHAssociation.org/FindaSupportGroup

By Allyson Rupp, LCSW, of the Vera Moulton Wall Center for Pulmonary Vascular Disease at Stanford. Medical review by Mike Hayes, RN, BSN, CCRN, Pulmonary Clinical Nurse Coordinator at Intermountain Medical Center in Murray, Utah.

Helping Healthy Children Cope

“We have been through a lot and I try to help my parents but they say I need to focus on being my own age and doing what kids my own age do. I have to share a room with my sister ... she has on her oxygen machine and cries many times at night, and that makes it hard.” —Sibling of a PH patient

“I worry about our kids. There’s so much weight I feel to keep them from being affected by my wife’s PH.” —PH caregiver

What to Expect

Pulmonary hypertension affects everyone in the family, including healthy children. When someone in the family is sick, many parents find it difficult to make time for everything and everyone that needs attention. This can leave children feeling stressed, angry or anxious, and parents feeling drained, guilty, and unsure about how to make things better. While there’s no magic formula for resolving healthy children’s PH-related stress, recognizing their feelings and experiences is an important first step in providing them with the support they need.

Every child responds differently to the stresses and lifestyle changes imposed on a family by PH. Some children will vocalize stress directly. Parents report that some healthy children worry aloud about their sick sibling or parent. Some kids express guilt or distress that they can run and play when the PH patient can’t. Others display visible anger or resentment that they need to go to school or help with chores when the PH patient doesn’t. Some parents also report that their children pick up on the stress of other family members in the house and ask questions that reflect worries related to “adult” problems like marital arguments, hospitalizations and finances. They may even ask about difficult topics like death.

Depending on personality, age, developmental stage, and a variety of other factors, some children may not be will-

ing or able to vocalize their stress. One mother said that her healthy daughter refused to talk about PH and left the room whenever family conversation turned to doctors’ visits. More commonly, children may not articulate specific questions or concerns about PH, illness or the concept of death, even when invited to share their feelings. In such cases, children may present stress through behaviors or physical symptoms. Some children may act younger than their age, falling into old habits they had previously outgrown, such as sleeping with the light on or clinging to you in public. Siblings may compete with one another, vying for a parent’s attention. Children who feel everyone is focusing on the PH patient may act out or sulk. The external symptoms of stress can include bad behavior, low moods, stomachaches, headaches or trouble sleeping.

Even children who don’t show signs of stress are likely thinking about PH and how it’s affecting your family. Sometimes the product of these reflections are remarkably positive. A child growing up in a PH household is likely to absorb a lot about the ways in which family members work together and support one another. Many parents in the PH community are proud to report that their healthy children voluntarily take on responsibilities and roles that allow them to advocate for the PH patient and care for parents and siblings. One sibling shared, “I hope someday to find a cure for PH when I am a doctor and never see anyone go through what my family and PH friends do.”

While PH can cause stress for parents and children alike, in the context of a loving and attentive family, children have the capacity to learn, grow and flourish.

Adapting and Moving Forward

No matter how busy and overwhelmed you feel, there are things you can do to help your healthy children cope with PH in the family. These are not to-do items to check off a list once and for all, but rather activities to help guide your family's ongoing journey of coping and acceptance. For a non-patient parent in a PH household, there are lots of things you may struggle to accept, from your loved one's diagnosis to the way PH affects your family to your limitations as a parent. Acknowledge to yourself now that you'll never be the "perfect" mother or father. Between caring for a PH patient, paying the bills, getting food on the table, and your own stress, you have a lot on your plate. You can't be everywhere at once, and you can't be everything to everyone.

While there are a limited number of hours in the day, there's no limit to the amount of love you can show your children. When your intention is to create an inclusive, healthy and supportive home for your family, mistakes and false starts are ok. In fact, they're par for the course. When they happen, remind yourself of your love and intention and begin again. Focus on the aspects of parenting you can control, rather than the many chaotic life factors that you can't predict or influence. Here are a few goals to work toward to provide your healthy kids with the structure and support they need:

Keep healthy children healthy. Kids cope best when they're well rested, eating regular and nutritious meals, and getting plenty of exercise. Siblings of PH patients are sometimes hesitant to run and play when their brother or sister with PH can't do the same. If that's the case in your family, try scheduling in sports and outdoor activities for healthy kids when your child with PH is busy with other activities, like music lessons or art classes.

Tell them you love them. Healthy children sometimes wonder whether their parents care about them as much as the PH patient, so make this an item on your daily to-do list. In addition to telling them through words, you can

show your love through frequent hugs, tucking them into bed, leaving notes in their lunch bags, singing them songs, and cooking their favorite meals. While you may not have much extra time, displays of love and affection can go a long way toward showing your healthy children how much you're thinking about them.

Be attentive on *your* terms. Children need lots of attention. When someone in the family has PH, it's likely that they're not getting as much as they would otherwise. It's common for kids who want to be noticed to act out. Experience has taught them that when they misbehave, parents will stop what they're doing and focus on them. One strategy for showing children you care without reinforcing negative habits is to give them extra attention when they're playing nicely. Give your children small and specific compliments throughout the day. For example, "You put your glass in the sink, thank you," or "I love the way you're concentrating on that homework." While this tactic may not eliminate bad behavior entirely, it will give you the opportunity to actively communicate your love to your children on a more regular basis.

Set rules and enforce them. While it's a good idea to be patient with some regressive behavior in kids who are struggling to make sense of their emotions, make sure your children know there are repercussions if they hit, scream or bully. Sometimes setting and enforcing rules can be difficult, especially if you're already feeling guilty that you're not giving your kids enough attention. Keep in mind that discipline is as much for them as it is for you. Clearly defined limits can give children a comforting sense of structure in a world in which PH and other curveballs can sometimes make life feel chaotic.

Keep a routine. Children feel safe and secure when they have a predictable day-to-day life. If every day looks different because of doctors' appointments or your work schedule, make a weekly schedule rather than a daily schedule. Try to build pockets of dependable repetition into an otherwise complicated routine. Saturday morning chores, Sunday Fun Day, and Mexican food Monday can give children things to focus on and look forward to throughout the week.

Encourage open conversation about PH and treatment. If

PH isn't specifically addressed by a parent, young children will try to make sense of the illness by using their imaginations, while older children may turn to incorrect information from the Internet. Offer children clear, honest and brief explanations. Share more depending on age, capacity for understanding, and interest level. Ask them to explain back to you what is happening to the family member who's sick. This will give you the chance to correct any misunderstandings or misconceptions. Some healthy children will blame themselves for the family member's illness and, if that's the case, they need to be reassured that PH was not caused by anything they said, did or thought. If they're interested, give children the opportunity to take part in the patient's PH care by marking the medication calendar or taking on other simple tasks.

Make time for them. When you can, schedule one-on-one time with each of your kids. Do something you both enjoy, share jokes and stories, and give children the opportunity to talk about whatever they care about most. These can also be good times to talk to your children about any questions or worries they have related to PH. They may need many invitations to talk before they feel comfortable voicing a concern. If kids aren't ready to talk, that's ok too. Some children process and cope best by simply spending time with a parent or doing something fun.

Anticipate potentially stressful situations. Pay attention to when your children exhibit symptoms of stress, and look for patterns. Some healthy children are most prone to moodiness or acting up when the PH patient is sick or hospitalized. Others feel anxious when the time comes for their own doctors' appointments. Talk to children to determine what's at the root of these anxieties, and correct any misconceptions that may be causing undue stress.

Be prepared for difficult conversations. Not all conversations will lend themselves to easy reassurances. It can be unbelievably hard to talk about the concept of death with a child, and even more difficult to talk about the possibility of a loved one's death. But questions and concerns in this vein may present themselves, and if they do, you should be prepared to have an open and honest conversation. Do your best to take your time addressing children's concerns, even if the conversation makes you sad or uncomfortable. Children

can pick up on anxiety in adults, and evasive responses may only add to their fears. If your family has spiritual beliefs that you want to share, this can be a good time to do that.

Talk about stress. As children get older, they can become more active participants in managing their stress. In late elementary school you may consider talking to children about stress and what may be causing it. You can work together to come up with strategies for alleviating the stress. Some children around this age enjoy keeping a journal to record their thoughts and feelings.

Turn to a counselor. If a child's stress has become unmanageable, it might be time to talk to a school counselor or therapist. Don't see this as a failure in parenting on your part. In fact, sometimes being a good parent means giving your child the opportunity to talk to a professional who's trained to help them work through problems. Ask your child's teacher or doctor for recommendations, or visit the American Academy of Child and Adolescent Psychiatry at www.aacap.org.

Additional Resources

Talking to Your Healthy Child About Your PH
(for parents living with PH)

www.PHAssociation.org/HelpYourChildCope

Pulmonary Hypertension Handbook for Families

www.PHAssociation.org/ParentResources

Child and Adolescent Psychiatrist Finder

www.aacap.org/cs/root/child_and_adolescent_psychiatrist_finder/child_and_adolescent_psychiatrist_finder

"Where to Find Help for Your Child," from the American Academy of Child and Adolescent Psychiatry

www.aacap.org/cs/root/facts_for_families/where_to_find_help_for_your_child

Resources for parents from KidsHealth

kidshealth.org/parent

*Medical review by Debra Hudock, RN, MSN, CNS,
Akron General Medical Center.*