

A Guide for the Newly Diagnosed



Dealing with Change, Loss,
and the Emotional Impact
of Pulmonary Hypertension



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Coping When You're Newly Diagnosed

"When I was diagnosed with PH, I cried thinking I would never know my future grandchildren."

"It hit us all hard. My husband was planning retirement, we were about to book the trip of a lifetime for three months overseas, but I was told travel was out of the question. Our world was turned upside down in one minute."

"I had a lot of time to think while I was in the hospital; I was angry, sad, frustrated, and I guess even relieved to some extent. I had been telling doctors for years that I wasn't feeling right and finally I knew why."

What to Expect

No one plans to get sick. Learning that you have pulmonary hypertension can turn your whole world upside down. Every new patient, when learning that they have PH, responds differently. You may feel angry, frightened, lonely, frustrated, worried, numb, or some combination of these feelings. It's important to remember that there are no right or wrong reactions. Give yourself the space to feel and respond to your diagnosis without judgment so you can begin to move forward.

One thing that most newly diagnosed patients do have in common is that even before they were diagnosed, they were experiencing breathlessness



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and other symptoms of PH. One patient told us, “In the beginning, it was *very* difficult. I couldn’t walk very far without getting short of breath. I couldn’t bend over to tie my child’s shoe without getting dizzy. My heart would sometimes race dangerously fast if I overexerted myself. I was so fatigued that I would fall asleep at the drop of a hat.” Whether your symptoms are mild or severe, it’s likely that you have been dealing with physical limitations, exhaustion and a compromised quality of life for some time. Many patients find that these physical symptoms can take a serious mental and emotional toll. Some find that breathlessness can lead to feelings of anxiety and panic. Others report that their inability to keep physical pace with friends, family and co-workers leaves them feeling frustrated, left-out and lonely.

Another thing that almost everyone with PH has in common is that by the time they’re diagnosed, they’ve been through the medical ringer. One patient said, “I went to six doctors and had been living with symptoms for 15 years before being diagnosed. The most difficult thing about trying to get my diagnosis was people truly believed I pretended to be ill just to gain attention.” Even if you’re one of the lucky few diagnosed in a matter of months, chances are good that you’ve donned your fair share of hospital gowns and filled out a lifetime’s worth of complicated medical paperwork. Many patients were feeling confused and overwhelmed by medical jargon long before they ever heard the words “pulmonary hypertension.” After all the appointments and tests, some people report feeling a sense of relief when they finally learned they had PH. One patient said, “I was thankful to finally know what was wrong with me. Now I knew what we were dealing with.”

While your diagnosis marks an ending, it also marks a beginning. Finding a PH-treating doctor, getting on PH-specific treatment, making accommodations for PH in your everyday life, and acknowledging your fears and feelings are all parts of a journey that begins now.

Grieving Your Losses

While learning you have PH can bring relief, it can also disrupt your life, forcing you to put goals and dreams on

hold, and changing how you think about yourself and the world around you. In the beginning, learning that you have a chronic illness can be profoundly painful. One woman described the time following her PH diagnosis as a time filled with difficult losses: “The life I once had was taken away from me. I lost my old life, my friends, my job, my car, my home, and my dignity.” Whatever losses you may face, it’s normal to need time to come to terms with them and what they mean to you.

For many patients, this healing process is similar to the grieving process you experience when a loved one dies. Instead of grieving for an external loss, a PH patient may grieve for a part of his or her identity that feels lost, for a body that no longer does what it once could, for a life that no longer feels predictable or safe, or for a world view that is no longer sufficient to explain your daily life. Feelings of loss can be frightening and overwhelming, and many people who are diagnosed with PH struggle to find balance and direction in the weeks and months following diagnosis.

The grieving process typically unfolds in stages. In 1969, psychiatrist Elisabeth Kübler-Ross identified five key stages individuals may experience as they process grief: denial, anger, bargaining, depression and acceptance. Not everyone experiences all of these stages or encounters them precisely in this order. How you grieve and for how long depends on many factors, including your personality, support system, culture, coping style, faith, life experience, and the severity of your illness. Grief is a profoundly individual process that everyone experiences in their own way and in their own time. While some may only need to grieve for weeks, others may need a year or more. Read on to learn more about some of the ways you may find yourself grieving, struggling and ultimately surviving when you’re first diagnosed.

Shock and Denial

The shock of learning you have PH can be overwhelming. Cancer physician Michael Lerner compares being diagnosed with a serious chronic illness to parachuting into a war zone behind enemy lines. You are surrounded by potentially life threatening danger in completely unfamiliar territory. Your mind may go into “fight or flight” mode,

your body's natural response to extreme stress. When you're feeling threatened, your body sets in motion a series of physiological responses, including increased adrenaline flow, heart rate, breathing rate and blood pressure, to improve your chances of escaping danger. You may have experienced some of these responses when the doctor first told you that you had PH. For many newly diagnosed patients, the body and brain's natural reactions to stress are the forces that propel them forward in the days following diagnosis.

Everyone deals with these emotional and physiological responses differently. Some people describe feeling consumed with their diagnosis, unable to talk or think about anything else. Others describe "walking around in a fog" after learning they have PH. They go through the motions of daily life, but aren't ready to seek out more information about the disease or tell friends and family members what's going on. This "fog" is their brain's way of protecting them from too much pain and anxiety all at once. Combat veterans, who encounter intense stress on the front-line, are often surprised to discover their wounds following a battle. Their denial allows them to keep moving and carry out their missions. For many people who have just been diagnosed with PH, initial denial gives them a buffer to deal with important tasks and priorities before turning their attention to their illness and sorting through the impact of PH on their lives.

While denial can play a useful role in the grieving process, the apathy associated with *prolonged* shock and denial can sometimes prevent patients from seeking timely access to life-saving medical care. No matter where you are on your journey, it's important to see a PH-treating physician and get on PH-specific medication as soon as possible after your diagnosis. PH-specific therapies can help relieve symptoms, improve your quality of life, slow disease progression, and play a crucial role in helping you adjust to life with PH, both physically and mentally. See [Additional Resources](#) to learn more about finding a doctor to treat your PH.

Frustration and Anger

With time, you may find that the "fog" or numbness you felt immediately following your diagnosis will give way

to emotional pain. Pain often presents itself as anger. At some point in their journeys, many PH patients report feeling anger towards strangers, loved ones, doctors, or just life itself. You may question, "Why me?" or ask, "Who's to blame?" Keisha, diagnosed in 2006, said, "I had dreams for my life. I wanted to jump start my career in a new city, get married, and have kids. After my visit to the doctor, I felt that all of my aspirations were being taken away from me. So I got angry, angry at everyone, angry with the world, angry with God. I felt I was a walking time bomb just waiting to explode."

Anger can take many forms. You might resent people on the street who appear healthy and carefree. You might experience frustration with the medical system for misdiagnoses and painful tests. You might even find yourself harboring feelings of anger and disappointment with close friends and family members who don't respond to your illness in ways that feel supportive. While anger can be uncomfortable and difficult, it can serve an important function in your grieving process. According to Elisabeth Kübler-Ross and David Kessler in their joint work, *On Grief and Grieving*, "At first grief feels like being lost at sea: no connection to anything. Then you get angry at someone ... Suddenly you have a structure — your anger toward them. The anger becomes a bridge over the open sea, a connection from you to them. It is something to hold onto; and a connection made from the strength of anger feels better than nothing." Recognizing the role of anger in your grieving process can make it easier to eventually move past that anger towards acceptance.

Guilt and Bargaining

Guilt is another common feeling among newly diagnosed patients. Some people feel guilty about getting sick, about not taking better care of themselves or going to the doctor sooner. Others feel responsible for imposing new responsibilities, financial obligations and stress on family members and friends. This sense of responsibility, while misplaced, offers the comforting illusion that patients have or had some direct control over their illness.

Some people go through a bargaining stage to explore these feelings of guilt without having to directly confront

or engage with them. They find themselves bargaining with the past: “What if I hadn’t taken so long to go to the doctor?” or, “If only I hadn’t taken Fen-Phen, I wouldn’t be dealing with this today.” “If only…” and “What if…” statements may offer a temporary sense of command to individuals whose illness has stripped them of power and control.

Sadness, Fear and Depression

At some point in the process of adjusting to life after diagnosis, it’s common to experience deep sadness. In this phase, you may wrestle with feelings of emptiness, loss and pain head-on. You may worry about facing daily life with PH symptoms or going out into the world with an oxygen tank and new medications in tow. You may be afraid for your future or the future of your family. You may feel isolated and alone as you come to terms with living with an uncommon, life-changing illness. Debra, diagnosed in 2006, told us, “I was so depressed when I was diagnosed all I did was cry all the time.” Thousands upon thousands of PH patients have dealt with similar feelings of despair. Depression, while deeply painful, is a normal reaction to illness and a healthy part of the healing process.

In some cases, intense and enduring reactions to a diagnosis with PH can turn into major depression. Someone suffering from major depression may feel afraid, isolated, hopeless, anxious, powerless, or incapable of carrying out everyday tasks for weeks and months at a time. Manifested over the long term, depression is a serious illness that requires professional assistance to overcome. Read “Identifying and Seeking Treatment for Depression,” beginning on p. 18 of this guide, to learn more.

Acceptance

For most people with PH, the fear, anxiety, sadness, isolation and other strong feelings that emerge in response to diagnosis will begin to lessen over time. Once on PH-specific medications, many patients find that their physical symptoms lessen, and the “fog” they experienced post-diagnosis starts to lift. As you become more functional, you may find yourself more capable of seeking realistic solutions to new challenges. Over time, most PH

patients are once again capable of tackling practical and financial problems and developing a daily routine in which PH is a part of life but not the defining factor.

Acceptance does not mean you will feel better immediately. Given the loss, suffering and disruption that can accompany diagnosis, you may never return to the more carefree version of yourself you were before PH. Yet most people living with PH do find their way forward. Many patients get to the point where they are ready to begin making new plans for the future and, over time, reawaken a sense of joy in their daily lives.

Adapting and Moving Forward

No matter how intense and enduring the grieving process, every PH patient is capable of healing and moving forward in the months and years following diagnosis. Medical treatment is just one component of healing. While physical healing has an external focus, with the intention of improving your physical symptoms and slowing your disease progression, healing can also be an internal process in which you work through your grief to rediscover a sense of meaning and purpose in your life. Healing literally means “to make whole,” and refers to the process of exploring and accepting all dimensions of your physical, emotional, mental, social and spiritual self. Regardless of how your medical treatment is progressing, you can still heal.

What follows are some practical tips and coping strategies that have helped other newly diagnosed patients move forward. This is not a list of shoulds but a list of suggestions. Use only what works for you and feels right. Do what you can, but don’t create unrealistic expectations. A diagnosis with PH can be physically and emotionally draining, and it’s important that you let yourself grow into your choices slowly. By doing so you send a message to yourself that doing something is enough to begin.

Physical Healing

Medical treatment is an important and time-sensitive component of the healing process, especially for PH patients. Ken, a caregiver in New York, recommends,

“Seek out a PH center ... this is no common cold you are dealing with. Go find the best PH doctor, even if it means traveling!” PHA’s Scientific Leadership Council encourages everyone who’s been diagnosed with pulmonary hypertension to seek immediate medical treatment from a PH-treating physician who can prescribe PH-specific therapy. Getting on treatment can make a huge difference in how you feel, both physically and mentally. In the words of PH patient Shana, “The right medication can change your life!” Visit www.PHAssociation.org/FindaDoctor or call PHA’s Patient-to-Patient Support Line at 800-748-7274 to learn more about finding a doctor to treat your PH.

In addition to seeking PH-specific treatment, there are steps you can take to prioritize your physical health by relaxing, energizing, strengthening and nourishing your body. Here are a few places to begin:

- **Be mindful of what you put in your body.** Eat nutritious, low-sodium meals every day, and do your best to avoid things you know are bad for you. Drinking, smoking and binging on junk food may feel good in the moment, but these short-term fixes do long-term damage to your health, especially if you have PH. Talk to your doctor to make a plan to cut out bad habits for good.
- **Get lots of rest.** Doctors recommend at least eight hours of sleep a night, and PH patients may need even more than that. Don’t feel guilty about taking naps when you need them.
- **Get moving.** Low-impact resistance training and light to moderate aerobic exercise such as walking or swimming can increase strength and endurance. Just 20 minutes of exercise a day can benefit your mind, body and outlook. Talk to your PH medical team to develop an exercise plan that works for you.
- **De-stress.** Consider setting aside 30 minutes a day for chair yoga, meditation, aromatherapy, massage, or just some time to yourself to unwind. If quiet time isn’t your thing, make time for any activities that make you feel good, like funny movies or coffee dates with friends.

Social Healing

While healing is an internal process, it doesn’t need to be a solitary experience. It’s important to reach out and ask for help. Talk to your family, friends, medical team, and other people living with PH. Research indicates that people with strong support systems often have better clinical outcomes because they’re less stressed, isolated and depressed than people who don’t have family and friends they can count on.

Social healing can begin as soon as you’re diagnosed. Ask a spouse, sibling, parent or close friend to accompany you to medical appointments. Remember that you may be operating in “fight or flight” mode for the days and weeks following diagnosis, which means all of your decisions are about survival with little thought for details. This can make it difficult to pay attention or process information. With that in mind, many patients benefit from having a close friend or family member with them at all of their early appointments as an extra set of eyes and ears. It can also be enormously comforting to have someone to hold your hand, chat with in the waiting room, and decompress with on the drive home.

As time goes on, it can be helpful to build a team of loved ones you can count on for physical and emotional support. It’s likely that your illness will have a profound effect on your loved ones, and they’ll appreciate the opportunity to contribute during your hour of need. One patient recommends, “Let your friends and family help when they offer. They love you and are probably feeling helpless. With PH, you truly find out who your precious angels on earth are!” Consider asking friends and family members to run errands, drive you to appointments, prepare meals and help you with household chores. It’s usually during the challenging times we come to see and appreciate all the support and love we have in our lives. By reaching out to friends and family and talking about the ways in which PH is affecting each of you, it’s possible to empathize and connect in new ways.

While a diagnosis with PH has the potential to strengthen your existing relationships, you might also find that you need new sources of support to cope with the many ups and downs in the months following diagnosis.

Many newly diagnosed patients find it enormously helpful to connect with other people living with PH through PHA's Email Mentor Program, online communities, or local support groups. Ruth Ann advises other PH patients, "Join a support group! The knowledge you will gain from others is tremendous. Take you, your caregivers and your family." Indeed, many new patients credit support groups for helping them feel less alone and overwhelmed. Support groups provide a safe place to talk about and process feelings, collect information on managing day-to-day, and share stories. Other PH patients understand what it's like to grieve for an old way of life, adjust to complicated medications, and navigate shifting personal relationships. Consider visiting PHA's website for online connections or joining a PH support group to tap into the wisdom of other patients, many of whom have been living with this disease for many years (see [Additional Resources](#)).

Mental and Emotional Healing

A lot of the healing to be done as you move forward will happen in the realm of your feelings and thoughts. Being diagnosed with PH can fundamentally challenge your belief system and force you to confront your ideas about illness, suffering and how the world works. Paying attention to your feelings and thoughts as they surface can make it easier to acknowledge the various ways in which PH is affecting your outlook and help you regain influence over your daily life.

Here are some suggestions to help you begin to acknowledge and shape your mental and emotional responses to PH-related challenges:

- **Practice self-compassion.** Some newly diagnosed patients believe they did something wrong to cause this illness. While it may be difficult to accept at first, *no one* deserves to have PH, even if you developed the disease due to diet pills or other drugs. Unchecked self-blame can lead to depression and chronic anxiety, while higher levels of self-compassion have been linked to happiness, optimism and curiosity. Consider choosing a phrase to repeat to yourself when your inner voice begins to criticize or blame. Simple, kind sentiments like "May I be gentle with myself in this moment" or "May I give myself the compassion that I need" can serve as reminders that you deserve the same love and understanding from yourself that you give to others.
- **Accept the present moment.** The many changes that accompany a diagnosis of PH may be too overwhelming to accept all at once. Some newly diagnosed patients find it's more manageable to concentrate on accepting just one moment at a time. Focus on what's in front of you rather than ruminating on what you were capable of doing last year or worrying about where you'll be next year. Showing up for the present moment and appreciating the challenges and joys of your immediate situation can help you function in the face of uncertainty and rediscover the pleasures of everyday life.
- **Turn challenges into opportunities.** Learning you have a chronic illness can raise difficult questions and feelings. While some of these feelings may be new and in direct response to PH, it's also common for big life changes to stir up existing issues. Keep in mind that this is normal. Most of us have anxieties or insecurities that bubble to the surface during times of stress. Over time, many patients come to see their diagnosis as a turning point, as a catalyst for positive change.

One patient told us that before she was diagnosed, she wasn't close with her family. Her parents had both passed away before she graduated from high school, and she saw her brother and sister-in-law only twice a year. When she learned she had PH, she found herself on the phone with her brother several times a week. They spoke about the years immediately following their mother's death, and connected over their shared grief in a way they hadn't had the opportunity or courage to do as teenagers. When you stay open to the possibility for personal growth during difficult times, it's possible to zero in on the things you value most.
- **Know pain from suffering.** Pain is a part of life, especially when you're living with a chronic illness. PH patients sometimes experience site pain due to intravenous medications, pain associated with related conditions, or other types of physical discomfort related to PH. Pain is made up only of various physical sensations like pinching, sticking, heat and pressure. But when anxiety in the mind converts pain into thoughts ("This is

going to kill me” or “It’s never going to stop”), pain can begin to take on new meaning, often converting physical sensations into mental suffering. Psychotherapists believe that assigning negative meaning to your physical pain can actually make the pain worse. One strategy for coping with physical discomfort is to begin thinking of pain as no more and no less than a series of sensory experiences. Focusing on your physical sensations rather than worrying about how pain might progress can make it easier to take pain at face value and reduce feelings of apprehension and resentment.

- **Beware the myth of the positive attitude.** While there are benefits to “looking on the bright side,” putting pressure on yourself to *always* keep a positive attitude can be counterproductive if it means not accepting how you sincerely feel in the moment. Give yourself permission to experience the full range of your feelings. In many cases, only by acknowledging our pain, disappointment and suffering are we able to grieve our losses and move forward with renewed purpose. One patient, Erica, reminds us that acknowledging difficult feelings can build strength and perseverance: “A healthy mind is as important as a healthy body. Don’t try to be a superhero. It’s ok to break down, and when you do, just pick yourself back up. Remember that every day is a fight you’re capable of winning.”
- **Remember that you are more than your illness.** PH may take up a significant amount of your time, but it doesn’t have to define you. Members of the PH community like to remind one another, “You have the disease; the disease doesn’t have you!” Life is still what you make of it. Take the time to do things you enjoy and stay up-to-date on news, causes and interests that have nothing to do with PH.
- **Talk to a therapist.** When difficult feelings begin to interfere with 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 use therapy, lifestyle changes and sometimes medication to help people identify and overcome difficult issues and negative thinking patterns. Ask your PH doctor, 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 as you adjust to life with PH.

Spiritual Healing

Many PH patients also turn to spiritual practice to cope with their diagnosis. For some, this means attending church, temple or mosque. But spirituality has many meanings. Generally speaking, you don’t need to be religious or have a special vocabulary to be spiritual. Spirituality is about seeking meaning and purpose in your existence.

Reflecting on your core beliefs can be one way to reestablish your sense of self and find new purpose after a diagnosis with PH. Liz, a PH patient in North Carolina, says, “Those of us who have been diagnosed with PH have the opportunity to take a good hard look at the ‘whys’ of our lives and how we want to really live. For me, this disease has been a gift of sorts. I have been given the opportunity to look deeply at my life and make something out of it.”

Many spiritual practices are about deepening your awareness and acceptance of whatever is happening in the present moment. Practices such as meditation, prayer and yoga can quiet the mind and make it easier to take every moment as it comes. You may find that by reflecting on your inner-self and your place in the world around you, it becomes easier to cope with the complexity of daily life and adapt to rapid changes. The Center for Contemplative Mind in Society recommends a range of activities to encourage contemplation and spiritual healing. Here are just a few suggestions:

- **Stillness practices**, such as sitting in silence or meditation
- **Movement practices**, such as walking or yoga
- **Creativity practices**, such as journaling, singing or sketching
- **Activist practices**, such as volunteering or community service work
- **Devotion practices**, such as prayer or repeating mantras

- **Ritual practices**, including worship services and cultural traditions
- **Relational practices**, such as listening or storytelling

Once you find coping strategies that work for you, create a routine and put your daily practices on your calendar. Try to do these activities on an ongoing basis, as routine creates healthy habits and a healthy lifestyle that can become second nature over time. Coping and healing in the months and years after diagnosis can be a long and difficult journey, but by tending to your physical, social, mental, emotional and spiritual needs, you'll be able to put one foot in front of the other and rediscover a life worth living. By seeking medical treatment and acknowledging and tending to your needs, it's possible to move forward with a renewed sense of passion and purpose.

Additional Resources

PHA's Patient-to-Patient Support Line: 800-748-7274

PH Email Mentors

www.PHAssociation.org/Mentors

Local and virtual support groups

www.PHAssociation.org/Community

Information for new patients

www.PHAssociation.org/NewlyDiagnosed

Find a Doctor Directory

www.PHAssociation.org/FindaDoctor

Webinars and videos for new patients

www.PHAssociation.org/Classroom/NewlyDiagnosed

Pulmonary Hypertension: A Patient's Survival Guide,
Gail Boyer Hayes (4th Edition, July 2011)

www.PHAssociation.org/SurvivalGuide

The Center for Contemplative Mind in Society

www.contemplativemind.org

*On Grief and Grieving: Finding the Meaning of Grief
Through the Five Stages of Loss*, Elisabeth Kübler-Ross and
David Kessler (Scribner, 2005)

When Things Fall Apart: Heart Advice for Difficult Times,
Pema Chodron (Shambhala, 2005)

*By Charles Leighton, LCSW, CGP, psychotherapist and stress
management educator. Medical review by Landra Slaughter, RN,
University Hospitals, Cleveland, Ohio.*

Maintaining a Positive Self-Image

“Ten years ago I was hiking, raising a son and working full-time. I held myself to a high standard, but when PH hit hard and heavy I couldn’t meet that standard any longer. I speak from experience when I tell you that when your body goes to hell in a hand basket, it can easily take the rest of you with it.”

What to Expect

Pulmonary hypertension is a “whole life” condition that can influence everything, from how long it takes you to shower in the morning to your social life. Changes to your body, both real and perceived, can be difficult to adjust to, practically, intellectually and emotionally. In a society that celebrates youth, fitness and health, it can be challenging for people living with a chronic disease like PH to figure out how they fit in.

PH and Self-Image

Our self-image is made up of all the ideas we have about ourselves, including how we look, how intelligent we are, how connected we feel to those around us, and how hopeful we feel about the future. Being diagnosed with PH can affect every aspect of an individual’s self-image. Many patients describe feeling isolated, either because they can’t get out much or because strangers, friends and family don’t understand their disease. One young woman described how being house-bound has limited her social circle with far-reaching effects: “I used to know lots of people my age at church but now no one is around. They are all either married, have kids, or moved away. Their lives are full of adventure but mine stays here.”

Others find it difficult to maintain a positive self-image with so many of their old “feel good” activities and plans for the future suddenly stripped away. Tiffany said, “Everything I do, my efforts and ability are limited. Cooking, cleaning, working, shopping and decorating my

home are all things I love and need to do to enjoy my life. I cannot do these, or I’m limited in how I can do them.” Some of the activities that PH patients have to give up are the very things they did to maintain a healthy self-image before diagnosis, such as running, dancing or staying up late chatting with friends and family. Cut off from self-affirming activities, it can be difficult to reestablish a positive sense of self after diagnosis.

PH and Body-Image

Many PH patients also struggle with one central aspect of self-image: body-image. Physical symptoms of PH and associated conditions, including chronic breathlessness, low energy, weight fluctuation, fluid retention, skin rashes, facial flushing and sweats, can make patients feel like they’re “starting over” in a body that feels totally foreign. Teresa told us, “It’s like a body transplant! You’re the same person inside, in terms of personality, interests, hobbies. But you’re presented with a body that doesn’t do those things anymore.”

Some patients on supplementary oxygen and intravenous medication find that the discomfort and conspicuous nature of their medical devices can take a toll on their self-confidence. One woman with a Flolan pump confided, “People stare at me and my self-esteem has been lowered. I cry all the time.” Others report feeling self-conscious even in front of their spouses, particularly in the bedroom. A woman in her late 20s described the “horror” of having to go on a date for the first time with an oxygen tank in tow.

Loss of Perceived Identities

Between all the symptoms, medical equipment and life changes, people diagnosed with PH often find themselves experiencing what one support group leader called “the loss of who they once were.” A 42-year-old former cyclist told us that he didn’t know who he was if he wasn’t an athlete. A 65-year-old mother of three told us that after she was diagnosed she thought she’d “never feel like a woman again.” After being told that pregnancy can be life-threatening for women with PH, one young woman was surprised to find herself grieving the loss of a “future mother” identity she didn’t realize she was holding onto. Loss of perceived identities is just one more way PH can alter your self-image.

Yet it’s important to keep in mind that self-image isn’t static. Over time, people with the intention of changing the way they think about themselves are capable of doing just that. According to Dr. John Wynn, medical director in the Department of Psycho-oncology at Swedish Cancer Institute of Swedish Medical Center, “A healthy body-image is a sense of one’s physical self that feels easy and acceptable. What it comes down to is how do you think of yourself and do you accept who you are?” For many living with PH, the answers to these questions change from one day to the next, and the path to a more positive self-image is ongoing.

Adapting and Moving Forward

While everyone deals with changes to their self-worth and body-image differently, there are strategies that have helped others with PH reflect and improve upon their self-image over time. Here are a few approaches to get you started. Some also find it helpful to seek out professional counseling to work through some of these issues. Talk to your health-care team about finding a therapist in your area.

Demystify Your Thinking

A negative self-image can feel the most isolating and overwhelming when you can’t put your finger on what you’re feeling and why. Without an awareness of the situations and circumstances that trigger negative thoughts, it’s easy to believe that you’re the only one who feels the way

you do. By developing a critical awareness of the expectations you feel, however, it’s easier to recognize that your negative thoughts are just that — thoughts — and not direct reflections of reality.

Think about the expectations you encounter as you move through your day. For example, what expectations do you feel as a result of television, magazines and movies? What images do you see of people with chronic illness in the media, and how do these make you feel? What expectations do you feel because of your family or background? Many people grow up in families or cultures where illness and disability are stigmatized. Sometimes without realizing it, these individuals carry around the unrealistic expectation that they should feel and look healthy, energetic and upbeat at all times, even when they’re sick.

One way to develop critical awareness of your expectations is to make a list of all the elements that make up your self-image (the picture you have in your mind of your personality, your body, your ability to connect with others, etc.). How has your thinking in each of these areas changed since you were diagnosed? When do you feel the most vulnerable? When do you feel the most confident? Look for patterns. One PH patient, Lisa, found that she felt the worst about herself when she thought she was letting her family down because of her illness, like when they dropped her daughter off at college and she couldn’t help move boxes into the dorm. This simple act of recognition helped her see that she was unfairly clinging to expectations that were no longer attainable. It also helped her work up the courage to talk to her husband and daughter about how she felt in these situations.

By talking to her family, Lisa realized that when she couldn’t move boxes, mow the lawn, or cook a meal, she felt like a bad mother and wife. She was experiencing the “loss of who she once was,” a mother who showed her love for her family through actions. By identifying the root of the problem, she was able to start expressing her love in ways that she *was* capable of. She started spending lots of time with her husband and daughter when she was feeling well, folding laundry and doing other sedentary chores, and being vocal about how much she appreciated their help. Demystifying her thinking helped Lisa distinguish

reality (she couldn't move boxes) from her perception of reality (she was a bad mother). This helped her begin to accept her limitations without putting herself down.

Accept What You Can't Change Today

While research has come a long way in the past two decades, PH is still a life-altering disease. Allow yourself to grieve for the dreams and activities you've had to give up. For some, accepting limitations and life changes can take a long time. Teresa told us, "My acceptance has been in fits and starts. It was prolonged grief for me because I didn't know what was wrong with me at first. I felt guilt. I thought I was lazy. I kept thinking, "This isn't who I am." Yet over time, Teresa got better at differentiating between things she could change and things that she couldn't. She said, "At the end of the day, PAH is beyond my control. But how I choose to live with it is definitely within my control."

Keep in mind that acceptance doesn't mean giving up. By accepting what you absolutely can't change today, you're less likely to tire yourself out fighting unwinnable battles, and you'll be left with more energy to take a fresh look at what you can change tomorrow. According to Diane, life with PH "is a balancing act of knowing what you can and cannot do. Each day is different."

Make Positive Changes Where You Can

Once you've accepted what you *can't* change, it gets easier to zero in on areas of your life where you are willing and able to take control. Here are some suggestions for implementing positive changes to improve your self-image:

- **Call in reinforcements.** Surround yourself with friends and family who make you feel good about yourself. And don't limit yourself to two-legged friends either. One patient told us, "The thing that helped me the most was going to the humane society and getting a dog. My dog loved everything about me. He saved my life."
- **Be good to your body.** Rather than focusing on the body you think you should have, focus on the body you do have. One patient told us, "When I was stuck on how fat I was, it didn't matter what I ate because I

was already overweight. What helped me was when I started putting my health at the center of every decision I made. Instead of stuffing potato chips down my throat, I started eating less sodium and feeling better." Work with your PH team to develop a nutrition plan, make sure you're getting plenty of sleep, and don't push your body too hard when it's telling you it needs rest.

- **Stay active.** Talk to your PH doctor about developing an exercise plan. Low-level aerobic exercise, even just a daily stroll around your neighborhood, can be good for your body and mind. One patient started by walking out the back door to the end of her alley and back. Over the course of several months, she extended the walk bit by bit, and today she walks three miles a day. She said, "That was the thing that helped me cope emotionally with my body. Being out in the fresh air, moving my body, having my muscles respond, all these things helped changed my body. Everything happened together. I centered myself."
- **Celebrate your accomplishments.** When you reach a personal goal or finish a project, take the time to recognize your achievement. If you like to write or scrapbook, consider keeping a journal of your milestones. You could take yourself out to dinner, take pictures that remind you of the accomplishment, or make an announcement to friends and family. Finding ways to formally recognize your successes can help you build new, positive identities post-diagnosis.
- **Change the way you talk about yourself.** If you find that you're putting yourself down a lot ("What's the matter with me?" or "I'm hopeless!"), challenge your negative thoughts by replacing them with kind words that don't reflect unrealistic expectations. For example, on low-energy days, many PH patients will tell friends and family that they are feeling lazy. *Lazy* is a loaded word that implies that you should be capable of doing more. Instead, try using judgment-free language that acknowledges a more basic truth: *your body needs rest*. Using your feelings and needs as guideposts can be a helpful way of translating negative self-talk into language that's more compassionate and realistic. Here are some more examples:

| Negative self-talk | Realistic self-talk |
|--|--|
| I'm too fat to go out. What will people at the party think? | My body has been through a lot in the past year. My friends know how much I've been through and accept me as I am. |
| I'm a terrible person because I can't plan my mother's retirement party. | I feel badly that I can't help out as much as I'd like because of my PH, but I need more time to rest these days. |
| No one will ever want to date me with this tube coming out of my chest. | I feel self-conscious about my disease and my medication, so I'm going to take this dating thing one day at a time. I can hold out for the kind of person who will make me feel at ease, PH and all. |

- Stay in the moment.** Your self-image, like life with PH, will have ups and downs. Your body, your health status, your outlook: none of these will stay the same forever. It can be helpful to think about every day as a new beginning, and appreciate each moment for what it is. According to Dr. Tiffany Stewart of the Body Image Project, “The more we hold on to what should be, the less we can see what is and what can be. Opening up to this possibility is a shift in perspective and the essence of acceptance ... acceptance of constant change. It takes realizing that the journey is about the journey, and not about certain preconceived expectations and outcomes. When we are able to cultivate this vision for ourselves, we unlock our own ability to let go of judgment and find a genuine appreciation, not just of the body, but of the whole person.”

Additional Resources

Local and virtual support groups

www.PHAssociation.org/Community

Information on exercise and PH

www.PHAssociation.org/Patients/ExerciseandPH

Videos and webinars on staying active

www.PHAssociation.org/Classroom/LivingwithPH

Body-image resources from the *Our Bodies, Ourselves* Health Resource Center

www.ourbodiesourselves.org/book/chapter.asp?id=1

“Fostering a Positive Self-Image,” from the Cleveland Clinic

my.clevelandclinic.org/healthy_living/mental_health/hic_fostering_a_positive_self-image.aspx

The Chronic Illness Experience: Embracing the Imperfect Life, Cheri Register (Hazelton, 1999)

Good Days, Bad Days: The Self in Chronic Illness and Time, Kathy Charmaz (Rutgers University Press, 1991)

Contributions and review by PH patient and former social worker Teresa Asselin-Hayes. Medical review by Debra Hudock, RN, MSN, CNS, Akron General Medical Center.

Managing Stress

“Stress as a patient with a chronic disease is different from the stress I enjoyed as an architect.”

“I divorced my husband because I was tired of defending myself about not being able to have children. My pressures were increasing from the stress of my relationship with him, and I had to go up on my medicine.”

“I have found that stress will aggravate my sickness and symptoms. Unfortunately, stress is a major factor in my life. Today, I am trying to minimize the amount of stress I feel and improve the way I handle it.”

What to Expect

Stress is a part of the human experience. It accompanies life changes happy and sad, from the excitement of planning a wedding to the devastation of losing a loved one. We all experience some levels of stress in our day-to-day lives. However, when combined with a chronic illness like pulmonary hypertension, stress can be especially difficult to manage. Without proper attention, stress has the potential to take a toll on your physical health and quality of life.

For some people living with pulmonary hypertension, PH-related stress begins *before* diagnosis. Some report feeling stress related to their breathlessness and fatigue, which can make it difficult to complete ordinary tasks like running errands or cooking dinner. Others experience years of misdiagnoses and the uncertainty of knowing that something is wrong, but not knowing what. Still others deal with the stress that comes from friends and family members who may not believe they are truly sick.

Upon diagnosis, patients experience stress associated with the range of challenges that come with living with a chronic illness. Some of these challenges are directly related to their physical health and disease management, as they adjust to unique life-sustaining medications and,

in some cases, supplemental oxygen. While physicians and nurses at PH centers and specialty pharmacies are available to answer questions, the onslaught of information can be overwhelming for patients without any prior medical background. Some of the unique medications used to treat PH require preparation before administration, which can be burdensome for patients who are accustomed to more common medications taken by mouth, drops, sprays or topically.

The cost of medication may also cause stress, especially for the uninsured or underinsured. Between treatment costs, hospital bills, and a sometimes compromised capacity for full-time work, a number of patients report experiencing major stress around bills, insurance, and their families' long-term financial stability. While very few patients actually pay for their medications out-of-pocket thanks to Patient Assistance Programs (PAP), sorting through all the questions and paperwork can take a lot of time and energy.

Many patients also experience stress related to household and family responsibilities given their physical symptoms. Alex, a mother of three, recounted the stress she felt when her former husband was deployed to Iraq: “When I was first diagnosed, my PH doctor warned my former husband

not to let me worry or stress over anything, including bills. Stress and worry are especially difficult for me as it increases my heart rate as well as my pulmonary artery pressures. I had to take on all the responsibilities my husband had previously handled. Managing the checkbook for me was mentally trying, but dealing with the day-to-day activities of running our home was most trying overall.”

This host of new challenges can make it more difficult for people with PH to continue to juggle *old* causes of stress, like challenging relationships or work pressures. Doug worked for many years in a high-stress profession. He thrived on meeting tight deadlines, satisfying clients’ needs and facing many other challenges involved in running an architecture firm. However, his capacity for handling stress changed upon being diagnosed with PH. In order to manage his levels of stress and his overall health, Doug ultimately had to quit his career as an architect. Others report having to make similar sacrifices to find time to rest and deal with PH-related responsibilities, from cutting ties with less-than-supportive friends to cutting back on hobbies that had once been sources of “good stress,” like volunteering for time-consuming committees.

Complicating matters further, the activities you’ve used to cope with stress in the past may no longer be available to you after you’re diagnosed. Traditional forms of exercise and other physical stress-busters, such as deep-breathing exercises, are out of the question for some patients. Doug shared, “Before I got sick I went to the gym three to four times a week. I released so much stress through physical exercise.” Post-diagnosis, Doug was unable to maintain his rigorous workout regimen, causing him additional anxiety. Others find that they are unable to turn to old support networks to de-stress because friends and family can’t understand the magnitude of what they’re dealing with. Joanne, a patient in New York, told us, “I’ve lost friends due to diagnosis because they were uncomfortable with my illness.” With old support systems out of the picture, bouncing back after a stressful day can feel more difficult than ever.

“Chronic disease is an internal stress with so many unknowns and what you do with them can become a crisis,” said Doug. Developing new methods of coping is

essential to adapting and moving forward. Researchers at Mental Health America say that, over time, stress can weaken the body’s ability to fight disease, decrease already diminished energy levels and raise the risk of depression. Managing your stress is very important for your physical health and your overall quality of life.

Adapting and Moving Forward

The first step toward moving forward is recognizing that your life has changed and that the way you handle stress may have to change as well. Most people living with PH learn to manage stress better over time by developing coping strategies that tend to their mind, body and spirit. What follows are a variety of coping methods that have worked for others. Stress is very subjective; what causes stress in one person may bring joy and pleasure to another. What relieves stress also differs from person to person. Don’t be afraid to explore a few stress relief techniques before settling into a routine that fits for you and your situation.

Expect the Unexpected

It may seem counter-intuitive, but one way of coping with stress is by learning to accept its inevitable presence in your life. Even the most laid-back among us encounter occasional frustrations. Rather than trying to eliminate stress entirely, accept that you’ll face some unexpected hurdles every day. Some of these challenges may be everyday annoyances and some may be much larger obstacles. However, if you can adjust your thinking to acknowledge that challenges are bound to present themselves, it’s easier to interpret potentially stressful situations as challenges to be overcome or changes to be accepted. Learning to accept those things you can control and to let go of those that are outside of your control can make it easier to move forward when things break down, fall apart, or deviate from schedule.

Consider taking stock of the things in your life that cause you stress. You can even make a list of common stressors you experience: work commitments, a particular relationship, having only 20 minutes to grab lunch during the day, etc. Be as specific as you can. Then review the list and determine which stressors are within your control and

which are outside of your control. Underline everything within your control. Think about how you can adjust all of the underlined items to reduce your stress. While you may not be able to control a deadline at work, you *can* control how often you speak to an emotionally draining acquaintance. Then go a little deeper — maybe there are pieces of items beyond your control that you can influence. For example, while you might only have 20 minutes for lunch, is there something you could pack in your lunch that you would look forward to? Finding creative and simple solutions can make a difference in the amount of stress you experience on a daily basis.

Trim Down Your To-Do List

Make a personal commitment to treat yourself well by setting realistic goals and prioritizing tasks that truly matter to you. After a PH diagnosis, it's important to adjust your goals to make sure they're realistic. Many people hold themselves to high standards, and not reaching a goal can leave them feeling discouraged. Be forgiving of yourself in regard to meeting self-imposed expectations. Imagine a close friend in your position. Would you chastise her for not accomplishing everything on her to-do list or would you understand that she is working hard to do the best she can? Extend this same kindness to yourself.

Consider prioritizing the tasks in your life. Make a list of everything you want to do and rank the activities in order of importance. Ask yourself if the items at the bottom of the list are truly necessary. If they aren't, cross them off the list. If they are, recognize they are not *as* important as other things on the list and allow yourself some extra time to get them done. Prioritizing helps you cut back on unnecessary stress and focus on activities that make your life more meaningful. One patient recommended setting just one main priority per day, and adjusting your list as necessary based on your energy level.

Part of adjusting goals and prioritizing tasks can include having to tell people “no” sometimes. This is easier for some to do than others. If saying no is something you have trouble with, take some time to understand why. Are you afraid of letting people down? Are you having a hard time accepting a slower pace of life post-diagnosis? Do

you feel it's unfair that you can't do everything you used to? Identifying what is behind your inability to say no may help you develop realistic strategies for asserting yourself. Saying no takes practice, but those close to you will understand if you communicate directly and honestly with them. If a friend or colleague asks you to do something that you feel isn't currently within your bandwidth, don't be afraid to politely decline.

Schedule in Stress Relief

It might seem a little strange at first that we would need to schedule time for stress relief, but when you think of all the requirements of your daily life, finding time to relax is usually one of the items that falls quickly to the bottom of the list. This is why it makes sense to schedule specific time for it. A clear mind can help alleviate stress, so consider incorporating relaxation techniques into your daily routine. Taking a few moments out of your day to meditate or reflect in a quiet place can help you get in touch with your thoughts. Some people enjoy gardening, a nice nap, yoga, or spending time with a loved one. Think about what leaves you relaxed, but also recharged. Energy is finite, as anyone living with PH can tell you. We spend lots of time devoting energy towards other people. What can you do that directs energy towards you and helps you feel rejuvenated?

Mental exercises such as crossword puzzles or Sudoku can keep your mind sharp. Many patients also find that writing in a journal every evening can reduce stress by providing a safe venue to explore their feelings. Jotting down life events as they happen can make it easier to acknowledge your challenges and reflect on your options. Over time, you may find patterns in how you approach difficult situations and develop methods for reducing future conflicts.

Be Good to Your Body

Remember, reducing stress means being proactive about things in your life you can control. To an extent, your physical health is one of those things, even though there are major pieces of your physical health you can't control or predict. Cultivating habits that directly affect and support your physical health can do wonders for reduc-

ing mental stress. Avoid smoking, excessive drinking and bingeing on junk food. Eat filling, nutritious meals and take your medication as directed so you feel your best. Get enough sleep at night and take naps when you need them to ensure that you have the energy to deal with stressful situations when they present themselves.

Physical exercise is another well-known stress buster. Over time, many patients are able to reincorporate low-impact exercise into their daily lives to energize and relax. While Doug was unable to sustain his rigorous workout schedule after his diagnosis, he recognized that physical fitness was still an important part of his stress management routine. Rather than giving up exercise altogether, he started going to a local pulmonary rehab center. Doug found that exercise at the pulmonary rehab center was the best way for him to alleviate stress. He felt comfortable working out in an environment with professionals who understood his condition and could provide recommendations based on his limitations. Consult with your medical provider to determine the most appropriate exercise regimen for you.

Nurture Your Spirit

In moments of crisis, many find comfort in finding connection to something larger than themselves. For some, this is their spirituality or faith. According to researchers at the University of Maryland Medical Center, “Spiritual practices tend to improve coping skills and social support, foster feelings of optimism and hope, promote healthy behavior, reduce feelings of depression and anxiety, and encourage a sense of relaxation.” Anna, who’s living with PH, lupus and scleroderma, told us, “In the beginning I would not address the issues that were causing me stress and then they would start to just snowball. Now I meditate and study Buddhism to cope.”

Another way people can connect to something greater than themselves and relieve stress is to cultivate meaningful connections. Often as the patient, you are the one being helped or even coddled. Some patients find fulfillment in building relationships that allow them to counter this patient-caregiver dynamic by helping others in need. Volunteering, tutoring, or even caring for a pet can make you feel good and help you develop a new sense of

independence. Over time, cultivating meaningful connections can help you approach stressful situations with new perspective.

It’s also important to nurture relationships with friends and family members. Sylvia told us, “Dealing with a chronic illness will reveal those people in your life who you can rely on and those you can’t. Don’t dwell too much on those who are having difficulty dealing with your diagnosis. Focus on those who are your advocates. Their support will help you through rough times and raise your spirit again.” The simple act of talking about your experiences and frustrations with family and friends can provide a tremendous amount of relief. You might also consider joining a PHA support group or contacting a PH Email Mentor to connect with others living with PH (see [Additional Resources](#)).

Sometimes talking to family and friends just isn’t enough. If stress is getting in the way of everyday functioning, talk to a therapist, clergy person, or your PH doctor.

Quick Tips

- **Prioritize.** Make a list of your goals for this week and put them in order, from most important to least important. Cross off 2-3 items at the bottom of the list.
- **Put yourself first.** Remember, you need more rest than you did before you were diagnosed. It’s ok to say no when friends and family ask you to do things you don’t have the energy for.
- **Meditate.** A clear mind helps to alleviate stress. Take a few moments out of your day to find a quiet place to reflect and clear your thoughts.
- **Exercise your mind.** Crossword puzzles and Sudoku games allow your brain to relax and refocus.
- **Exercise your body.** Talk to your PH doctor about incorporating physical exercise into your schedule to release the tension that builds up in your body due to stress.
- **Volunteer.** Some people find that taking a moment to help another person allows them to approach stressful situations with fresh perspective.

- **Nurture your spirit.** In moments of crisis, many find comfort in relying on spirituality, faith, or a connection to something larger than themselves to cope with stress.
- **Write.** Keep a journal so you have a safe place to blow off steam, reflect on your day, and develop strategies for avoiding or addressing stressful situations in your daily life.
- **Find and maintain a support network.** When you're feeling stressed, reach out to friends and family. Talk to them about how they can help to ensure you're getting the support you need.
- **Ask for help.** If you're dealing with unmanageable, chronic stress, it may be time to seek assistance from a mental health professional.

Additional Resources

PHA's Patient-to-Patient Support Line: 800-748-7274

PH Email Mentors

www.PHAssociation.org/Mentors

Local and virtual support groups

www.PHAssociation.org/Community

Pulmonary Hypertension: A Patient's Survival Guide,
Gail Boyer Hayes (4th Edition, July 2011)

www.PHAssociation.org/SurvivalGuide

"Coping with Stress Checklist" and other resources
from Mental Health America

www.nmha.org/go/stress

Information on stress management from the Mayo Clinic

www.mayoclinic.com/health/stress-management/MY00435

Information on stress from Medline Plus (a service of
the U.S. National Library of Medicine)

www.nlm.nih.gov/medlineplus/stress.html

Guided meditations from The Center for
Contemplative Mind in Society

www.contemplativemind.org/resources/audio.html

Information on spirituality from the University of
Maryland Medical Center

www.umm.edu/altmed/articles/spirituality-000360.htm

*How to be Sick: A Buddhist-Inspired Guide for the
Chronically Ill and their Caregivers*, Toni Bernhard
(Wisdom Publications, 2010)

*Medical review by Landra Slaughter, RN, University Hospitals,
Cleveland, Ohio. Mental health review by Virginia Maril,
MPsy, Texas Woman's University.*

Identifying and Seeking Treatment for Depression

“People stare at you and my self-esteem has been lowered. I cry all the time. But then there are moments when you feel so uplifted and hopeful. Your faith is so strong and nothing can stop you from keeping on, pushing through whatever comes your way.”

What to Expect

Living with pulmonary hypertension can introduce a host of daily challenges that may put you at increased risk of depression, from the stress of shifting family relationships to the uncertainty and loneliness of living with a rare illness. Whether you’ve been living with PH for months or years, feeling sad, anxious or scared is completely normal. It’s important to remember that depression, though very serious, is a treatable diagnosis that many people have experienced and successfully managed.

Recent studies show that the majority of people affected by PH will suffer from periods of depression. Because of its high incidence in the PH community, it’s important for you and your family to become familiar with its warning signs. Being prepared can make it easier to identify depression early so you can take steps to find treatment and move forward with your life.

Depression or the Blues?

While people are often hesitant to talk about depression, it can happen to anyone. In fact, some professionals believe that all of us will suffer from depression at some point in our lives. Despite its being very common, some people have misconceptions about depression that stigmatize people affected by it. Depression, like PH, is a nearly invisible disease, with internal symptoms that are difficult for onlookers to observe. Because it’s difficult to see, some people don’t believe it’s real. They have the false perception

that if we are depressed, it means we are weak. They can’t understand why a person who’s depressed can’t just “get over it” or “shake it off.”

In reality, depression is a real illness — just like PH — and it can be a dangerous one. Depression is associated with higher rates of mortality, pain and physical illness. Pains and aches, digestive problems, fatigue, trouble sleeping, and changes in weight and appetite are all problematic side effects of depression that may interfere with a PH patient’s already compromised health.

While depression is common, it can be difficult to detect. There’s no blood test to identify depression, and we can’t see it under a microscope. So how do we know if we’re experiencing a temporary bout of the blues or something more serious? This is an important distinction to draw, as treatment for depression typically requires professional intervention. If you suspect that you may be depressed, a psychologist or physician will look for a collection of symptoms that are present over a significant period of time. You and your loved ones can also keep an eye out for these symptoms to determine whether you should seek treatment.

As you monitor yourself or someone you love for depression, it’s important to look for *changes in behavior* that last for *more than a few weeks*. For example, if you know that you’ve always cried during sad movies and continue to do so, that might be less significant than if this behavior developed after you were diagnosed. If the crying lasts

for only a few days, this might be less significant than if it continues on a near-daily basis for a period of several weeks or more.

Here are some key symptoms of depression:

- **Feeling sad, empty or numb.** Depression may feel like a dark cloud that can make everything seem hopeless. Pay attention to how long these moods last and how often they occur. People suffering from depression typically experience feelings of sadness or hopelessness on a near daily basis.
- **Diminished interest in activities.** Depression can make you lose interest in activities that you once enjoyed. While it's normal to be less interested in activities that have become more difficult because of PH-related physical limitations, take note if you find yourself less interested in activities you *are* still capable of doing, like socializing or sedentary hobbies.
- **Significant change in weight or appetite.** When depressed, some people find comfort in food, while others lose interest in eating altogether. Be aware of your tendencies and pay attention to weight losses, gains, and fluctuations in appetite.
- **Sleep disturbance.** Most people suffering from depression report unusual sleep patterns. Some people sleep much more than they normally would, while others sleep much less. Others experience a disturbed sleep cycle, staying awake all night and sleeping all day.
- **Fatigue or loss of energy.** Depression can make the activities of daily life almost impossible because it consumes an enormous amount of energy. Be aware of changes in the number or intensity of tasks you're able to handle. Fatigue may present itself as an inability to keep up with everyday grooming, work, shopping and household chores. Keep in mind that when you have PH, increased fatigue, weight changes and sleep trouble related to depression may be mistaken for worsening symptoms of PH. It's important to consider your energy levels within the context of your personality and your illness.
- **Feelings of worthlessness or excessive guilt.** 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.
- **Inability to concentrate.** Depression, like PH, can make it hard to think clearly or pay attention to tasks and conversations. Even simple decisions can feel overwhelming. Notice if you have trouble completing tasks such as deciding which medication to take or if you are frustrated by simple decisions, like what to wear in the morning.
- **A feeling of being completely alone.** People suffering from depression frequently isolate themselves and pull away from loved ones. Take note if you find yourself avoiding conversations or wanting to be alone more than usual.
- **An inability to relax.** More than half of the people diagnosed with depression also have anxiety. Someone who is depressed may find it difficult to kick back and stop worrying, even for short periods of time.
- **Recurrent thoughts of death.** This symptom can look very different from person to person. Thoughts about death may be very explicit or they may be more covert. People might engage in risky behaviors, like not taking medications as prescribed, or make passing statements that indicate they wouldn't care if they weren't alive. If you or someone you love is thinking about suicide, visit your local emergency room, call the National Suicide Prevention Hotline at 1-800-273-TALK, or visit www.suicidepreventionlifeline.org.

Who Becomes Depressed and Why?

Anyone can suffer from depression. While the reasons for depression remain a bit of a mystery, most experts believe it is a combination of nature (your DNA) and nurture (your environment and experiences). Nature is thought to play a large part in an individual's likelihood of becoming depressed. In other words, it's likely that vulnerability to depression is passed down genetically. The most widely accepted theories point to an imbalance of certain chemicals in your brain, including the neurotransmitters serotonin and norepinephrine. Most medical treatment of depression attempts to regulate these chemical levels.

Your environment and life experiences also contribute to your likelihood of becoming depressed. Undergoing major life changes like divorce, job loss, grief, or a major medical diagnosis can increase your chances of becoming depressed. High levels of stress can contribute to and complicate depression. People who have histories of abuse or trauma are more likely to be depressed, especially if that trauma has gone untreated. Substance abuse can initiate or complicate depression, as can prescription medication. When being evaluated for depression, make sure you share your current medication list with your mental health professional and physician to help them determine whether your medication could be a contributing factor.

Depression and PH

As someone living with PH, you are much more likely to suffer from depression than someone without a chronic illness. Whether you're newly diagnosed or you've been living with PH for years, the challenges of daily life and health changes can lead to guilt, grief, sadness, disappointment, uncertainty, lowered self-esteem, and emotional fatigue.

Many PH patients experience intense feelings of guilt, one of the cardinal symptoms of depression. Some patients feel guilty because they can't do as much as they did before they were diagnosed. Others feel guilty because they have to rely on friends and family to support them physically, emotionally or financially. One patient shared, "After being a caregiver most of my life, I now have to depend on others more. Not an easy thing for me to do." Some even feel guilty because they are doing better than other patients in their support group. Unaddressed and unresolved, prolonged and intense feelings of guilt can lead to depression.

Another common experience among PH patients is loss. The sadness and disappointment tied to the loss of goals, plans and identities can be shattering. No one builds becoming ill into their plan. As one patient shared, "Having PAH is soooo hard. ... The life you once had is now taken away from you and you experience a lot of loss: Loss of the old life, loss of friends, loss of job, loss of car, loss of home, loss of dignity." All of this loss can compound and manifest as depression.

Fear and uncertainty are also common psychological features of PH that can contribute to depression. Many newly diagnosed patients are informed of the worst possible outcomes by under-informed doctors or, worse yet, Internet searches. Diagnosis is a scary and uncertain time, and unfortunately, the uncertainty never subsides entirely as health changes can also affect long-term survivors with little warning. As one support group leader told us, "People with severe PH are faced with some daunting tasks. You feel just absolutely totally out of control. And when you feel out of control when you're trying, it makes you wonder why you should go on trying at all."

While all of these feelings are normal, when guilt, hopelessness and sadness begin to take over your daily life so you're no longer able to function, you may be depressed. Read on to learn more about taking the first steps towards finding treatment and managing depression in your everyday life.

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 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. As Teresa, a PH patient who sought treatment for her depression, put it, "There are enough struggles when you have PH without struggling with your emotions. You don't have to live with depression."

Mental health professionals (psychologists, social workers and psychiatrists) use psychotherapy, lifestyle changes and sometimes medication to help people identify and overcome difficult issues and negative thinking patterns. The goal of treatment is to help you reclaim a sense of control and rediscover pleasure and fulfillment in daily activities. Psychotherapy, also known as talk therapy, may sound intimidating if you've never been to a therapist. Movies lead us to believe that going to therapy means lying on a

couch and confessing our inner demons to a gentleman with a beard. In reality, talk therapy is the opportunity to spend a confidential hour with a professional trained to listen to what you have to say and help you find resolution or solutions to life challenges.

Just like physicians, different therapists have different qualifications and specialties. It may be important to you to find someone who works with people with chronic illness, though this specialization isn't always necessary. The most important thing is to find someone you connect with and trust. Ask for recommendations from friends and family, your medical team or PH support group members, or visit locator.apa.org to locate a therapist in your area. Speak with a number of professionals on the phone and ask questions about their approach and style. Don't be afraid to meet with several people before settling on someone you feel comfortable with. Finding the right therapist for you is a process, and it's worth the time and effort.

Your mental health professional may also recommend medication to treat your depression. There are a number of medications that have proven very successful for individuals suffering from depression, particularly when coupled with talk therapy. If you are considering medication, remember to put your psychiatrist in touch with your PH doctor. One patient shared that encouraging communication between her doctors paved the way for successful treatment: "I told my psychiatrist about pulmonary hypertension right away. She was in touch with my PH doctor, and went over the medications. I try to always be very upfront with my psychiatrist, my PH doctor and my family doctor about what medications I'm taking, and I've never had problems with drug interactions."

Managing Depression by Practicing Mindfulness

While professional help is a crucial component of depression treatment, you can also make lifestyle changes on your own to manage symptoms between therapy appointments. One of the most useful methods for managing difficult thoughts and feelings is a strategy called mindfulness. Mindfulness asks you to pay attention to the present moment purposefully and nonjudgmentally. It requires a dramatic shift in the way many of us think. There is a per-

vasive idea in the West that happiness is the natural state of emotion. This implies that pain, suffering and other difficult feelings must be avoided or tamed. Mindfulness derives from a more Eastern way of thinking that proposes that suffering is an integral part of the human condition, one that cannot be avoided or controlled. It is not our place, in this way of thinking, to avoid or master the suffering, but to accept it and move through it. Mindfulness requires nonjudgmental acceptance of your true feelings and the strength to stay with your feelings rather than trying to push them aside.

In the beginning, mindfulness practice may feel risky. You may worry that asking yourself to acknowledge and fully experience strong and uncomfortable emotions will send you spiraling out of control. You may fear that if you allow yourself to feel truly vulnerable in this moment, you'll feel vulnerable forever. The important thing to remember about emotions is that no matter how intense they feel in the present moment, they come and go. Most people can't sustain high levels of emotional intensity for very long. In fact, accepting your true feelings in the moment can actually help you move forward more quickly and completely than you would if you chose to resist or fight against your suffering.

Picture yourself standing in the surf with your feet planted firmly in the sand. The waves are crashing around you and you are being pushed and pulled in many different directions. You are pushed off your feet and struggle to get back up. What would happen if you leaned into the wave? What would happen if you let yourself float over the wave and, after it passed, placed your feet back on the ocean floor? Riding the wave would leave you with more energy than resisting the ocean's force. When you feel overwhelmed, remember this lesson. Try leaning into the wave. This way of thinking takes practice, but over time, it's possible to retrain your brain to accept the present moment, making you more attentive, clear-minded and calm.

Some patients choose to couple mindfulness with meditation or relaxation techniques and report positive effects on their mental and physical well-being. These practices can be spiritual or non-spiritual in nature, and may include prayer, modified yoga, or whatever feels right for you.

Managing Depression by Building Resilience

Another method for managing the symptoms of depression is by building resilience. Resilience refers to an individual's ability to bounce back from adversity, stress or trauma. It's not something that you have or don't have. Resilience encompasses a series of traits that can be learned and cultivated to help alleviate the effects of depression. Here are some things you can do to build resilience and improve your overall emotional health:

- **Build a caring support network.** Research shows that one of the most important factors in building resilience is maintaining caring and supportive relationships. Reach out to friends and family to get support. Many patients also benefit from connecting with people in the PH community who understand what they're going through. Consider reaching out to a local or online support group through PHA's website (see [Additional Resources](#)).
- **Be kind to yourself.** Resilient people try to be as kind to themselves as they are to others. Remind yourself what you like about yourself. Forgive yourself. Set realistic goals. Perhaps pre-diagnosis, you were able to pop up out of bed, run a couple miles, make breakfast, pack a lunch, and head off to work. This may not be a realistic goal for you now that you have PH. Maybe a realistic goal now is preparing lunch the night before, slowly waking, and doing your physician-recommended exercises. When you set goals you can achieve, you'll feel better about your abilities.
- **Expect and accept change.** Change is one of the few things we are guaranteed in life, yet we often work very hard to resist it. Resilient people are capable of adapting to new conditions and uncertainty. One way to become more accepting of change is by anticipating it and planning for it in advance. While you won't be able to anticipate every possible change to come your way, you can become more accepting of change by imagining what you'd do in a variety of scenarios, from dealing with financial trouble to coping with relationship stress.
- **Control what you can.** Research also shows that resilient people are focused. They take stock of what they can control and then take steps to actively improve

those areas of their lives. Eat regularly and nutritiously. Exercise. Go to doctors' appointments and follow your medical team's directions. If something prescribed isn't working for you, call your doctor or nurse. Get massages if you like. Get enough sleep. Wear clothing that makes you feel comfortable and good. Even simple things can make a difference in your outlook and how you feel.

- **Integrate more of what you love into your life.** Resilient people share the belief that while life is complex, it's also filled with opportunities. Brainstorm things that bring you peace, joy and happiness and incorporate those activities into your daily life. Take steps to reduce your exposure to people and things that make you feel badly. Maybe you can't completely cut ties with your nosy neighbor or a taxing relative, but you can choose when you want to answer the phone.
- **Reflect on your coping skills.** Another practice that builds resilience is to look at how you have coped with challenges in the past. What worked? What wasn't helpful? What strategies that have proven effective in the past could you employ in the current situation to help you through? Dedicating time, thought and energy to your emotional health can make an enormous difference in your ability to ride and survive the ups and downs of life with PH.

Additional Resources

National Alliance on Mental Illness

www.nami.org/depression

Depression Screener

www.depression-screening.org/depression_screen.cfm

Depression Center on WebMD

www.webmd.com/depression/

National Suicide Prevention Lifeline:

1-800-273-TALK (1-800-273-8255)

Para obtener asistencia en español llame al:

1-888-628-9454

Or visit: www.suicidepreventionlifeline.org

PHA's Patient-to-Patient Support Line: 800-748-7274

PH Email Mentors

www.PHAssociation.org/Mentors

Local and virtual support groups

www.PHAssociation.org/Community

How to be Sick: A Buddhist-Inspired Guide for the Chronically Ill and their Caregivers, Toni Bernhard (Wisdom Publications, 2010)

By Virginia Maril, MPsy, Texas Woman's University. Medical review by Tania Von Visger, APRN, MS, CNS, CCNS, PCCN, The Ohio State University Medical Center.

Maintaining Healthy Relationships with Family and Friends

“I don’t feel like my family truly gets it, even though I think they really want to. Part of me spends a lot of time and effort protecting them because most reacted so strongly to the diagnosis. Another part of me wants to keep reminding them of the reality of the disease because they have clearly become complacent about it. Part of me wants them to be at peace and accepting and part of me feels like they need to keep paying attention. But I get annoyed with too much attention and fuss. It’s complicated.”

What to Expect

Building and maintaining relationships is one of the most important things that we do, yet something that we are rarely formally taught. More commonly, we approach our relationships through a process of trial and error based on what we learned about relationships from the adults who raised us. We then bring the patterns and strategies they used to our new relationships as we grow up. Sometimes those strategies work well, but sometimes they meet resistance because new friends and partners are raised with different ideas about what a relationship should mean.

Given this complexity, it can be especially challenging to manage various relationships while also managing a complicated and life-changing disease like pulmonary hypertension. While maintaining strong relationships isn’t always easy, by taking the time to identify some of the potential challenges, it is possible to find ways to ensure that you’re getting the support you need in high stress situations and feeling the love you deserve year-round.

Shifting Relationships

No one person’s experience with illness is identical to another’s, but there are some common frustrations and concerns reported by people affected by PH. One patient told

us, “Even if you’ve got the most loving friends and family, there’s a part of it they just don’t comprehend.” If you have PH, chances are your relationships have changed since you were diagnosed. Relationship challenges such as poor communication and conflict exist in most relationships to some degree, whether or not you’re sick. As a PH patient, not only are you expected to deal with these “normal” challenges, but also with the complications that come with chronic illness: the stress of medical appointments and bills, the difficulty of making plans when you don’t know how you’ll be feeling next week or next year, the guilt of imposing life changes and responsibilities on loved ones, and the need for new kinds of support, just to name a few.

It’s a good idea to be prepared for a wide range of reactions to your illness from friends and family. Some people living with PH report that loved ones become over-involved after diagnosis, worrying too much and insisting on taking on responsibilities that the patients still feel capable of doing on their own. Other loved ones may have the opposite response. They may pull away when they learn that you have PH. Serious illness evokes feelings of fear and apprehension in some people for a number of reasons. Some feel uncomfortable because illness reminds them of mortality. Some people find it easier to withdraw from relationships to avoid getting hurt. Others may feel unsure about how to act around you, or guilty

that they don't know how to make things better. There are many potential reactions to a diagnosis and many of these reactions can be addressed with clear and empathic communication.

Sometimes people, even people who care about you, may doubt that you are sick. One patient said, "I have a family member who just doesn't get why I can't walk as fast or as far when she beat cancer and now is running marathons." Another said, "My boss had a talk with me regarding my tardiness. She has no empathy or understanding." Because PH patients don't always look sick in the way that people expect, you might get the sense that others assume you are "faking it," or that they don't understand why you are unable to keep up with the crowd. This can feel terrible — as though others are questioning your honesty or work ethic. Friends may begin to perceive you as unreliable because you cancel plans at the last minute due to health concerns. While these types of reactions are unwarranted and unfair, acknowledging the injustice may offer little in the way of comfort.

Patient and Caregiver Intimacy

Many PH patients with spousal caregivers find that a diagnosis with PH brings about real challenges to physical and emotional intimacy. As caregivers take on new responsibilities like household chores, caring for children and mixing medication, both patient and caregiver may begin to view their relationship as unequal. One PH patient admitted that she often felt like her husband treated her "like a baby." A caregiver told us, "It can be difficult seeing each other all day long." These types of changes can be difficult to talk about because they frequently run counter to an individual's ideals about what their relationship "should be" like.

For some couples, an important component of intimacy is their sexual relationship. Like other aspects of life with PH, this may change post-diagnosis. It can be intimidating for either member of the couple to initiate intimacy if the patient is frequently short-of-breath or on intravenous medication. The patient may worry about stamina or tubes getting in the way in the heat of the moment. The caregiver may be concerned about hurting the patient. On top

of specific concerns, there can be a social stigma related to illness that may play a part in tempering sexual activity. If PH changes the ways in which a couple is intimate, a ripple effect can occur. Both partners may begin to feel alienated, distant and unsupported.

The Physical and Mental Stress Continuum

Relationship changes and challenges can be exacerbated by the fact that PH patients are often operating at depleted energy levels. Anyone who has ever been sick will recognize that when we do not feel physically well, our mood is affected. On a down day, one woman living with PH said she felt, "limited, frustrated, powerless and alienated from others." People describe having "shortened fuses" and being quicker to anger or snap. Irritability, sensitivity and hostility can emerge quickly within relationships. Generally, we end up snapping at those closest to us because they are the ones who are there. Sometimes it also feels safer to snap at someone who loves us because we know they won't leave us. Yet even in "unconditional" relationships, the stress of chronic irritability can take a toll on you and your loved one. Hostility often provokes hostility, leading to escalation and hurt feelings on both sides.

Some patients also observe a connection between relationship stress and physical symptoms. Elise told us, "A year ago, I went through a very stressful time with our daughter, and I was so short of breath and had so much chest pain from the stress that I thought my disease was getting worse." As in other disease states, recent medical research involving PH patients shows that physical and mental health are indeed interconnected. The strain and anxiety of arguments and tensions, when left unaddressed, can take a very real toll on your energy levels and general health.

Adapting and Moving Forward

There are all sorts of complex situations and conversations that come up in relationships when you're dealing with health issues, stress, uncertainty, insecurity and irritability. But with time and patience, it's possible to help ease tension and work towards more authentic and meaningful relationships with the people you care about.

Making Meaningful Connections

Even the most independent human beings crave connection. While it can be tempting to pull back from people when relationships begin to cause stress, spending *too much* time alone is likely to make you feel disconnected, lonely, or even depressed. No matter how busy you get, set aside time to spend with family and friends. Acknowledge the ways in which your life has changed and take steps to accommodate those changes in each of your relationships. If you're unable to participate in the same activities you enjoyed prior to diagnosis, work with your loved ones to find new ways of spending time together. Connecting with the people we care about on a daily basis can provide much needed stress relief and remind us of why we fight to get through the tough times.

It's also important to find *new* sources of positive support. Many patients find that after they're diagnosed with pulmonary hypertension, they need more support than they're getting. This might mean that your poker buddies aren't the people you want to talk to about your illness. It might mean that your best friend, while a great listener, can't provide the 24/7 phone-a-friend service you're looking for. It might even mean calling someone to talk when that's the last thing on earth you want to do. Sometimes finding the support we need means reaching out when it feels easier to be alone.

Challenge yourself to make new connections beyond your immediate family and circle of friends to ensure that you're getting all the support you need. Many people in the PH community find great comfort in talking to people who understand what it's like to live with pulmonary hypertension by attending local support group meetings, PHA educational conferences, or connecting online (see [Additional Resources](#)). Connecting with new people who can relate to you in different kinds of ways can provide a number of very real physical and psychological benefits. Encourage your family members to do the same.

You might find that when all is said and done, some friends just aren't capable of providing you with the friendship and support you need right now. Taking the time to grieve for these relationships can make it easier to come to terms with these losses. By allowing yourself to

let go of relationships that are no longer positive sources of support in your life, you will make room for new and better relationships with the people who are here for you in the present. One PH patient said several years after being diagnosed, "My relationships are being tested more than ever. I lost some friends, but some friends actually came back once they found out I was sick."

In addition to relying on support from family, friends and the PH community, there may come a time when it makes sense for you or a loved one to speak to a mental health professional. Psychotherapists are trained to help individuals, couples and families navigate the inevitable challenges that arise in life. While the thought of going to see a therapist is anxiety-provoking for some, years of research have supported the idea that speaking with a trusted and competent professional can increase your quality of life.

Communicating

Learning to communicate openly and respectfully can strengthen relationships old and new. But open communication doesn't always come easily. It requires practice, patience and self-compassion. In some difficult situations, we don't want to accept (to ourselves) how we feel. Sometimes our feelings are confusing, painful, embarrassing, or just don't match up with the person we think we should be.

You can plan for conversations with friends and family members by reflecting on your feelings and needs before sitting down to talk. One PH patient found herself snapping at her family when they were painting the living room. While she had trouble communicating with her husband about her frustration in the moment, she was later able to reflect on the situation: "I was listening to my body, which was telling me to take it easy, but I felt like a slug not helping when everyone else was painting." She realized she was angry because she felt embarrassed by her physical limitations, and needed her husband's assurance that he understood why she couldn't help more.

Honest conversations require the willing participation of both parties. Once you have a sense of how you feel and what you need, invite your loved one to talk. Find a time

to do it when you're both in a calm and non-defensive frame of mind. Sometimes this will mean walking away from a tense situation and returning to the conversation when you're both ready for it.

Open, respectful communication requires two crucial ingredients: a willingness to listen without judgment and an acceptance of the present moment for what it is, imperfections and all. Here are some tips to help you incorporate these elements into your conversations with friends and family members:

- **Think about your intention.** Before you begin, think about how you'd like to be there for your loved one throughout the conversation. Even if you're the one initiating the talk, it can be very helpful to imagine how you'll show empathy and strive for connection. Remember that you're in this relationship because you care about this person. Relationships aren't about being right or proving someone else wrong. They're about listening, understanding and connecting.
- **Set ground rules.** Name-calling, insults, bringing up the past, and pushing personal hot buttons are not allowed. Also be aware of your volume, tone and body language. These are part of the message you're sending your loved one too. Agree in advance to take a break and step away if either of you find yourself getting angry.
- **Try to speak from an "I" perspective.** For example, rather than saying, "You're totally inconsiderate — you never slow down to my pace when we're walking together," try, "I feel like I'm always trying to catch up with you and it wipes me of energy for the rest of the day. I'd like for you walk slowly when we're together so I know you appreciate how much this illness affects me." This approach acknowledges to loved ones 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.
- **Listen actively.** When it's your loved one's turn to talk, make a conscious effort to listen attentively. Don't start to formulate your responses in your head until the other person is finished speaking. Part of active listening means putting aside the need to criticize or react. Make yourself emotionally available and allow your loved one the space to share. When he or she is finished, repeat back what you think you heard to ensure that you haven't missed anything important.
- **Look for realistic paths forward.** Many of us are eager to problem-solve when we're faced with challenges. Don't agree to a solution that you know won't work for you, even with the noble intention of making your loved one happy. It can be tempting to agree to "try harder not to argue," but it might be more realistic to talk about the circumstances that typically lead to arguments so you and your loved one can focus on meeting each other's needs more intentionally in the future. Not all situations have easy solutions. Sometimes the best you can do in the moment is talk about your experiences and agree to talk again when you've had more time to think the situation over and appreciate the other person's perspective.
- **Practice, practice, practice.** Sometimes these conversations will go well, and sometimes they won't. Even conversations that don't leave you feeling warm and fuzzy are worth the effort. Practice communicating honestly and thoughtfully as much as possible and it will soon become second nature.

Reclaiming Intimacy

Open communication is especially important if you have an intimate relationship with your primary caregiver. When two partners who used to operate independently begin to rely on each other in new ways, it's common to experience major shifts in your marriage or partnership. Here are some tips from PH patients whose partners are also their primary caregivers:

- **Allow for a period of adjustment.** One patient told us, "If someone had told me how difficult the first year with PH was going to be on our marriage, I think I would have been better equipped to handle the fighting. I wouldn't have taken it so personally. Looking back, I can see it wasn't that *we* were broken. It was that we were both worried out of our minds. Now, four years later, we take things one day at a time, and we're closer than ever."
- **Find ways to care for your caregiver.** When her husband has the stomach flu, Val stops at the store to pick up juice and soup. She told us that while his sick days

are more infrequent than hers, “It feels good to take care of him when I can.” While you might not need to care for your loved one the way that he or she cares for you, it can be helpful to identify places where your caregiver needs and appreciates your help and support. This can help reestablish a sense of balance in the relationship.

- **Do what you can for yourself.** When you’re feeling up to it, do the chores you’re capable of. Helping out around the house when you’re able can offer a sense of independence and contribution that many patients miss when they’re feeling sick.
- **Know and respect your limits.** Talk openly and honestly about what you can and can’t do. Listen to your body and encourage your caregiver to listen to you when you communicate your limitations.
- **Work up the courage to talk about physical intimacy.** Many PH patients and their partners have active and fulfilling physical relationships. If you or your caregiver is concerned about your physical limitations in the bedroom, raise your concerns with your PH doctor and nurses. They’ve heard it all before, and may have recommendations from other patients. With a catheter in her chest, Geal says she and her husband are more careful when they’re cuddling or being intimate, but it hasn’t changed their love for each other.

Caring for Yourself

While it may seem counterintuitive, self-care is absolutely critical to maintaining healthy relationships with others. Most of us think about taking care of those around us before we think to take care of ourselves. Remember the instructions you receive on an airplane — if the oxygen masks deploy, put your mask on first before helping those around you. This lesson is all the more important if you’re living with PH, as your physical health requires constant, mindful attention.

Control what you can when it comes to your health — take your medications, keep your doctors’ appointments, eat a nutrient-packed and low-sodium diet, develop an exercise plan with the help of your PH physician, and get plenty of rest. These seemingly simple steps can contribute

to overall well-being exponentially. The better you feel, the more patient you’ll be with yourself and others, and the more positive attention you’ll be able to offer your loved ones. No one’s relationships are perfect, but with time and perseverance, most people affected by PH are able to develop rich support networks that provide them with love, understanding and connection.

Quick Tips

- Take care of yourself before you turn your attention to others. Get plenty of rest, eat healthy, take your medications and keep a reasonable schedule.
- Be forgiving of yourself. You are adjusting to a new life every day. Cut yourself some slack; you'd likely do so for others. You deserve it too.
- Make time to do things you enjoy with friends and family.
- Practice open and honest communication. Take the time to remember that you value those around you and that being in a relationship means taking time to work things out.
- Reflect on your own feelings and needs so you can better articulate them to loved ones.
- Be prepared for ups and downs. No relationship is perfect.
- Don't be afraid to ask for help when you need it. Therapists can provide help for individuals, couples and families, and may even have groups for people living with chronic illness.

Additional Resources

"Maintaining Healthy Relationships" (webinar recording)
www.PHAssociation.org/Classroom/MaintainingRelationships

Information on dating and relationships with PH
www.PHAssociation.org/Dating

Find a therapist
locator.apa.org

Local and virtual support groups
www.PHAssociation.org/Community

PHA's regional and national education programs
www.PHAssociation.org/EducationPrograms

"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, 2012)

How to be Sick: A Buddhist Inspired Guide for the Chronically Ill and Their Caregivers, Toni Bernhard (Wisdom Publications, 2010)

By Virginia Maril, MPsy, Texas Woman's University. Medical review by Landra Slaughter, RN, University Hospitals, Cleveland, Ohio.