



# Living with PH

A Guide for Long-Term Survivors



Pulmonary Hypertension Association  
Empowered by hope

# A Guide for Long-Term Survivors

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## Coping with PH over the Long Term

*“The illness forced me to look at myself and learn what my life was all about.”*

*“I am 47 years old. I have had PH for 14 years. When I ask myself why do I get to survive? — I feel a pang of guilt.”*

*“You have good days and you have bad days and I know each moment will pass and I make the most of each.”*

## How Life Has Changed

Coping with pulmonary hypertension over the long term is like riding a wave of ever-changing emotions. At times, you may feel active and engaged; other times, you may find it hard to get out of bed. The challenges of life everyone faces, such as maintaining a career, nurturing healthy relationships and managing personal finances, become more difficult when you have PH. Meeting the physical limitations and

emotional stress of PH day after day, year after year can also be an extraordinary challenge.

## Looking Back

Looking back on the period following their diagnosis, many long-term survivors describe painful memories of shock, fear, denial and despair. Liz, an eight-year survivor, recounts, “Over my lunch break, my doctor told me that I probably had a year to live. I had a major presentation at work to lead, so I returned to work to lead the meeting. As I began to speak, I just lost it. I cried and cried.” A 14-year survivor, Mark, describes his initial reaction in this way: “The doctor told me I had PH and I just stared at him. He was confused that I didn’t break down emotionally. I was inside my head thinking about what this diagnosis meant for my children and my wife.” Even years after diagnosis, many PH patients can still vividly recall the period of grief and uncertainty that took place in the months after they learned they had PH.

Most long-term survivors also have a second story to tell: the story of their paths to acceptance. After recovering from the initial shock of diagnosis, most long-term survivors learned over time to manage the highs and lows of life with PH and adjust to what some of them now refer to as their “new normal.” Some people

describe experiencing a “waking up” to the things that matter most, like family, nature, spirituality, or giving back to the community. Liz told us, “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.”

## The Physical and Emotional Rollercoaster

While acceptance is a fundamentally important step forward, many long-term survivors come to learn that they may never exit the physical and emotional rollercoaster once and for all. Life with chronic illness can be filled with uncertainties, changes and disruptions to your health. Learning to cope with adversity and then begin again ... and again and again, is one of the major challenges of coping with PH over the long term.

Jeannette, a 35-year survivor, has weathered many storms living with PH. After receiving her diagnosis, Jeannette wanted to end her life. She was placed in psychiatric care to help her process her emotions and address her depression. She had accepted death as imminent, but her husband was not ready to accept that outcome. Over time, with support from

her husband, Jeannette learned coping strategies that allowed her to move forward and live a happy life. Nearly 10 years passed before she experienced another bout of depression. She recalls, “Personal family problems combined with PH caused me so much grief. The stress caused fatigue, increased heart rates and great physical pain.” Jeannette explained that she went into another deep depression, for which she sought professional assistance to help her work through her difficult feelings.

Jeannette has also had frequent hospitalizations due to PH. Recently, she spent nearly 20 days in the hospital with complications due to her illness. “When I was in the hospital I had a meltdown. I was thinking, why am I surviving? Why do I get to live when so many people are passing away from this disease?” she says. Learning to cope with the unexpected physical and emotional upheavals in life, including survivor’s guilt, depression and changes in health status, can be a part of life for long-term survivors.

## Loss of Capacity

Like Jeannette, many long-term survivors learn as time goes on that life with PH is full of unexpected changes, even years after diagnosis. As your health fluctuates and your physical limitations shift, you may lose the ability to work, help around the house, or spend time doing things you

enjoy. Most of us perceive a strong connection between what we do and who we are, so these types of losses can negatively impact self-image and make you question your sense of purpose.

Many people define their life purpose through their careers, but maintaining a vibrant career may become increasingly difficult when living with PH. After working at a major corporation for more than 12 years, five of them with PH, doctors advised Diane to quit her job as a top account executive. She recalls the months after she left: “After my job was taken away from me, I went into a deep depression — I no longer had an identity. I didn’t know who I was. At first, the break was nice, and then as the time passed, I got scared. I thought I was going to die. I thought to myself, who is going to want me? I have no money, no job, nothing to offer.”

Diane had already dealt with the grief of diagnosis, yet five years later she was battling another major change to her identity. Having to give up a job, a volunteer commitment, or even a hobby can take a toll on long-term survivors who may have thought that the most difficult losses were behind them. New losses, much like the losses you experienced when you were first diagnosed, can be jarring life events that change the way you think about yourself and the world around you.

## Changing Personal Relationships

Living with a chronic illness over the course of many years can also impact relationships with friends and family. Many PH patients have noted the challenges of sustaining friends over the long term. Some people find it difficult to relate to someone who is living with a chronic illness like PH, and friends may come and go. Mark reflects, “The friends I did have stopped coming around over time. I would call them to try to get together and they would make excuses. I just felt they didn’t want to be around me. I basically lost all the friends I had before PH.”

PH patients may also find it frustrating to constantly remind friends and family that they have a physical illness. Joanne, a 14-year survivor, says, “Some people will not believe that you are sick because you don’t appear sick. A former close friend told me that I should just go exercise.” Losing a long-term friend in a time of need — when support is so necessary — can be very difficult.

While some relationships change and fall away, many long-term survivors are quick to point out that the relationships they have maintained have become richer and more meaningful. One woman living with PH for seven years told us, “You appreciate friends and family much more. My husband is there for me in every way,

and we’re more of a team than we were before PH.”

## Adapting and Moving Forward

### Prepare for Change

While the life lessons of long-term PH patients vary widely, a common theme that emerges is the importance of accepting not just that your life changed when you were diagnosed, but also that your life will continue to change, many times over, for a variety of reasons.

Even after years of relatively stable health, every long-term survivor needs to be prepared for new health challenges. Many PH patients talk about their “new normal” as an empowered term to describe their ability to factor PH into a foundation for a new life — different from their old life, but no less full or meaningful. If you’ve been living with PH for years, you may have to adjust to a *new* “new normal” on a regular basis. This constant reinvention of self can be draining, and requires an enormous store of *resilience*, the ability to bounce back in the face of adversity.

By building up resilience to change, many long-term patients find that the peaks and valleys of life with PH become easier to traverse. In

*Resilience: A Change for the Better*, Daryl Conner lays out five characteristics of resilient people. His research indicates that resilient people are:

- **positive** — they share the belief that while life is complex, it’s also filled with opportunities
- **focused** — they set goals and take steps to meet those goals
- **flexible** — they are capable of adapting to new conditions and uncertainty
- **organized** — they develop step-by-step action plans to tackle ambiguous situations
- **proactive** — they don’t just react to change; they anticipate it and plan for it

One way of cultivating these characteristics is by mapping out flexible action plans to help you manage change more proactively when it finds you. Make a list of some of the unexpected changes you could encounter in the next year (e.g. health deterioration, loss of capacity, financial setback), and think about what you’d do to cope in each of those scenarios. You’ll never be able to predict the future, but even the process of planning for hypothetical change can flex your resiliency muscles.

Jeannette explains how learning to be flexible and proactive has allowed her to live a full life: “I respect the fact that I have PH and I have limitations, but I plan things, I rest ... I take charge of my life.” Jeannette understands that life can throw you curve balls, but you must be prepared. “Every single time I go into the hospital, I know I have to start over again. I prepare myself emotionally with a pep talk,” she says.

### Make New Connections

Building resilience is also about surrounding yourself with people and tools that make it easier for you to feel positive, flexible and proactive in your daily life. Liz shares that she was in a deep depression for nearly three years. She had received numerous invitations to join a PH support group, but could not fathom the idea of voluntarily spending time with others living with PH. Liz said, “I finally got over myself and decided to attend a meeting. At the support group, there was a three-year-old girl living with PH, and when I saw her and her family that helped me get over my ‘woe is me’ sadness. That family had it so much harder and they were so upbeat ... the support group was upbeat.”

Liz found that connecting with others was the first step to overcoming her depression. Sharing experiences and exchanging information with her new friends in the



PH community also helped her prepare for and manage new changes as they surfaced. Like Liz, many PH patients feel a sense of relief when they meet people who are experiencing similar life challenges due to their illness. If you have yet to explore the PHA community, consider joining a PH support group or connecting with other patients online (see Additional Resources).

### Turn to Loved Ones

New connections are important, but the most resilient long-term survivors have a strong, informed support team that also includes friends and family. While Mark may have lost connection with the friends he had before PH, he benefited from the support of his wife, children and siblings. As he recalls, “My wife found my doctor and she has mixed my meds more than 5,000 times by now. She checks on me throughout the day with frequent phone calls. In addition to dealing with me as the individual, she has to provide additional care and she does it all without a complaint.” Mark has his children and siblings accompany him to doctors’ appointments and support group meetings. He also relies on friends from his PH support group and PHA’s online communities for support and information. Having a well-informed and diverse support team enables Mark to navigate the highs and lows of life with PH.

Many long-term survivors recommend finding ways to maintain relationships with friends and family members during both highs and lows to keep your support system intact. This means recognizing that relationships are a two-way street, and your loved ones sometimes need your support too. Joanne cautions PH patients against talking about PH *all* the time, and she encourages asking friends and family about their well-being too. “Remember, if you are a constant bummer, people will not want to be around you,” she warns. Remembering that everyone has challenges will make it easier to build and sustain balanced relationships.

### Find New Purpose

According to the National Institutes of Health, as you live with a chronic illness over time you may find strength you never knew you had and recognize that when one door closes, another opens. Diane felt a deep sense of loss when she had to choose between her health and her career. Yet after months of reflection and support from her family, Diane was able to move forward. She started volunteering with the Connecticut Board of Education, working in the office and helping to organize events. Contributing her talents to a worthy cause gave her a new sense of purpose. While Diane was unable to reestablish her old identity, she was able to build a new one by focusing

on her interests and abilities and charting a new path.

Other long-term survivors establish new, positive identities by reflecting on what they believe in and carving out a part of each week to work towards a related goal. Some take up community service, others sell jewelry online, and still others throw themselves into writing, painting, or teaching piano. Choosing a goal or mission bigger than yourself can provide forward momentum, even during difficult times.

Coping as a long-term survivor isn’t always easy, but by seeking out support, balance, perspective and things you care about, it is possible to cultivate resilience so you can bounce back from the many challenges you’ll face on your journey. Joanne says, “I try to surround myself with positive people. I love the PHA community, but I also fill my life with other things like books, cooking, spending time with my family and setting personal goals. I am not PH, that’s just something I have.”

### Quick Tips

- **Allow for the highs and lows.** It’s normal to experience periods of sadness and depression when living with a chronic illness over the long term, but they don’t last forever. Give yourself time to grieve,

reflect and then move forward.

- **Prepare for change.** Make a list of unexpected changes that could surface in the next year, and map out an action plan for managing each possibility.
- **Be flexible.** Remember that you’ll never be able to plan for every possibility. Expect the unexpected.
- **Get organized.** Use PHA’s Empowered Patient Online Toolkit to organize your medical paperwork, prepare yourself for emergencies, and help your medical team provide the best care possible.
- **Educate your friends and family.** Teach loved ones about your illness to build a strong PH support network, made up of people who understand your needs. Invite your friends and family to your doctors’ appointments and support group meetings.
- **Connect with others living with PH.** Connect with other people living with PH through local support group meetings, Facebook and PHA email groups.
- **Reflect on your purpose.** Choosing a goal or mission bigger than yourself provides forward momentum, even during difficult times. Find a way to contribute your time and energy to something you believe in, whether it’s community service, a part-time craft business, or a creative pursuit of your

own devising.

- **Be real.** Maintaining a positive outlook is one way many patients try to approach living with a chronic illness. At the same time, it's important to acknowledge that life with PH can be difficult, and it's okay to be sad or even angry at times. Be real about how you feel.
- **Find an outlet.** Many people find solace in meditation, faith, humor, writing, hobbies and more. Find an outlet that you enjoy and that provides relief from life with PH.
- **If it gets to be too difficult, seek professional help.** Talk to your doctors to get a list of mental health professionals in your area.

## Additional Resources

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

PH Email Mentors, Daily Chats  
[www.PHAssociation.org/PHAPHriends](http://www.PHAssociation.org/PHAPHriends)

Local and virtual support groups  
[www.PHAssociation.org/Community](http://www.PHAssociation.org/Community)

"Long-Term Survivors: 10+ Years,"  
an audio recording from PHA's 10th  
International PH Conference  
[www.PHAssociation.org/Classroom/  
LongTermSurvivors](http://www.PHAssociation.org/Classroom/LongTermSurvivors)

"Coping with Chronic Illness," from the  
National Institutes of Health  
[www.nlm.nih.gov/medlineplus/  
copingwithchronicillness.html](http://www.nlm.nih.gov/medlineplus/copingwithchronicillness.html)

"Coping with Job Loss," from  
HelpGuide.org  
[www.helpguide.org/articles/stress/job-loss-  
and-unemployment-stress.htm](http://www.helpguide.org/articles/stress/job-loss-and-unemployment-stress.htm)

"The Road to Resilience," from the  
American Psychological Association  
[www.apa.org/helpcenter/road-resilience.  
aspx](http://www.apa.org/helpcenter/road-resilience.aspx)

Empowered Patient Online Toolkit  
[www.PHAssociation.org/OnlineToolkit](http://www.PHAssociation.org/OnlineToolkit)

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## 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 healthcare 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 differ-

entiating 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 fin-

ish 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:
- **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



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.

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](http://www.PHAssociation.org/Community)

Information on exercise and PH  
[www.PHAssociation.org/Classroom/ELearningGuides/NutritionAndExercise](http://www.PHAssociation.org/Classroom/ELearningGuides/NutritionAndExercise)

Videos and webinars on staying active  
[www.PHAssociation.org/Classroom/LivingwithPH](http://www.PHAssociation.org/Classroom/LivingwithPH)

Body-image resources from the *Our Bodies, Ourselves* Health Resource Center  
[www.ourbodiesourselves.org/book/chapter.asp?id=1](http://www.ourbodiesourselves.org/book/chapter.asp?id=1)

“Fostering a Positive Self-Image,” from the Cleveland Clinic  
[my.clevelandclinic.org/health/healthy\\_living/hic\\_Stress\\_Management\\_and\\_Emotional\\_Health/](http://my.clevelandclinic.org/health/healthy_living/hic_Stress_Management_and_Emotional_Health/)

## [Fostering a Positive Self-Image](#)

*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)

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*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 spe-

cialty 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 reducing mental stress. Avoid smoking, excessive drinking and binging 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, Daily Chats  
[www.PHAssociation.org/PHAPHriends](http://www.PHAssociation.org/PHAPHriends)

Local and virtual support groups  
[www.PHAssociation.org/Community](http://www.PHAssociation.org/Community)

*Pulmonary Hypertension: A Patient's Survival Guide*

[www.PHAssociation.org/SurvivalGuide](http://www.PHAssociation.org/SurvivalGuide)

"Coping with Stress Checklist" and other resources from Mental Health America  
[www.mentalhealthamerica.net/conditons/coping-stress-checklist](http://www.mentalhealthamerica.net/conditons/coping-stress-checklist)

Information on stress management from the Mayo Clinic  
[www.mayoclinic.com/health/stress-management/MY00435](http://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](http://www.nlm.nih.gov/medlineplus/stress.html)

Guided meditations from The Center for Contemplative Mind in Society  
[www.contemplativemind.org/resources/audio.html](http://www.contemplativemind.org/resources/audio.html)

Information on spirituality from the University of Maryland Medical Center  
[www.umm.edu/altmed/articles/spirituality-000360.htm](http://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)

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*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](http://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 experi-

ences). 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 special-

ties. 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](http://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 pervasive 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 experi-



ence 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](http://www.nami.org/depression)

Depression Center on WebMD  
[www.webmd.com/depression/](http://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

[www.suicidepreventionlifeline.org](http://www.suicidepreventionlifeline.org)

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

PH Email Mentors  
[www.PHAssociation.org/Mentors](http://www.PHAssociation.org/Mentors)

Local and virtual support groups  
[www.PHAssociation.org/Community](http://www.PHAssociation.org/Community)

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

Find a therapist: [locator.apa.org](http://locator.apa.org)

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*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 psycho-

logical 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 adjust-**

**ment.** 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](http://www.PHAssociation.org/Classroom/MaintainingRelationships)

Information on dating and relationships with PH [www.PHAssociation.org/Dating](http://www.PHAssociation.org/Dating)

Find a therapist [locator.apa.org](http://locator.apa.org)

Local and virtual support groups  
[www.PHAssociation.org/Community](http://www.PHAssociation.org/Community)

PHA's regional and national education programs: [www.PHAssociation.org/EducationPrograms](http://www.PHAssociation.org/EducationPrograms)

“Building Better Relationships,” from Texas Woman's University [www.twu.edu/downloads/counseling/E-3\\_Building\\_Better\\_Relationships.pdf](http://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)

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

## Grieving a Fellow Patient

*“Today we mourn a woman who inspired so many of us. Although these past few years she was unable to physically attend support group meetings, she was there. We always communicated either by email or phone (when she was able to talk) and she always had a little something to pass on to the group.”*

*“It is always hard to say goodbye to those who are our friends and family. I count my PH friends as both.”*

### What to Expect

The PH community is a tight-knit group. As such, many patients have dear friends who are also living with PH. Patients may have met through PHA’s support groups or online communities, on Facebook, through their PH clinic, or at special events. Some people living with severe PH interact more frequently and in more meaningful ways with their “PHamily” online or by phone than they do with people in their local communities. For people with a rare disease, the connection forged with those who understand what they are dealing with can bring much-needed comfort and relief. For many patients with limited mobility, these friendships provide daily social sustenance, and truly keep them going.

When a member of the PH community

loses their battle, they leave behind not just their own family and friends, but also a network of people with this illness who knew them and loved them. The surviving patients lose a close friend and are faced with the stark reality of their own illness. During these times, surviving patients can feel anxious, depressed, alone and guilty. They might isolate themselves to try and deal with the myriad feelings that emerge. It may feel too hard or overwhelming to attend a support group meeting or participate on PHA’s message boards.

Death is the only thing we are guaranteed in life. It is the cost of living. When we lose someone, it’s normal to feel alone, confused, and a range of other intense emotions. This experience becomes even more complicated when the person lost

was suffering from the same disease with which you live. This resource was developed to help patients grieving the loss of another patient.

### How Grief Happens

Grief is an intensely personal venture and one that can look very different from person to person. Perhaps you’ve known people who don’t seem fazed by loss, while others seem to have their worlds turned upside down. These extremes, and everything in between, are all completely valid ways of experiencing grief. Your grief is your own. It is yours to navigate and process in whatever way works for you. With that said, there are some common experiences with which you may already be familiar.

Perhaps the most famous model of grief was proposed by physician Elisabeth Kübler-Ross, who spent many years working with terminally ill patients and their families. She witnessed grief repeatedly and began to recognize similarities in various individuals’ experiences. The Kübler-Ross model includes the following stages. Keep in mind that not everyone experiences all of these stages or experiences them in the same order.

### Denial and Isolation

For patients, this can look like the general refusal to accept their illness. Perhaps

they choose not to see a PH specialist or take their medication. Friends and family may say things like, “You’re going to be okay. You can beat this,” even when the prognosis is very serious. Isolating is a common strategy for people experiencing something very difficult. It can feel safer and more manageable to focus on your own needs. Maybe you don’t want others to know how much you’re hurting. You may be particularly hesitant to let another patient know that you are hurting because of experiences you have in common.

Denial can help us feel better temporarily. We don’t want to say goodbye to someone we care about or face our own mortality. Denial allows us some time to cope with the practical effects of a loss on our lives before having to acknowledge and work through the way loss makes us feel. Sometimes we stall out in denial and isolation, and that can be harmful. In the long run, reaching out to others is one of the healthiest things we can do. Being supported in times of intense emotion can reduce the negative psychological and physical impacts of grief.

### Anger

When we lose someone we care about, it makes sense to feel angry. No one asks to get PH. It’s not something anyone signed up for, planned on, or looked forward to.

It just happened. And it is unfair. If you want and need to be angry for a time, be angry. Be angry that you have lost your friend. Be angry that you lost the life you had envisioned for yourself. Be angry at the medication and the oxygen and the lack of opportunity to be spontaneous in your life. Be angry, and move through it. Holding on to anger has direct effects on mood and health.

## Bargaining

In this stage of grief, individuals explore feelings of guilt by making deals with the past, the future, or a higher power. Maybe you feel guilty about getting sick in the first place, for feeling like you didn't do enough when you were healthy, or because a friend is suffering or gone while you're doing well. Sometimes these are deals with the intention of shaping the future, such as, "If you keep me healthy until my child's graduation, I'll do volunteer work every week." When someone's passed away, you may bargain with the past, using "What if..." and "If only..." statements. One patient told us after the loss of a friend in her support group, "I kept asking myself, 'What if I had visited her more often in the hospital? What could I have done differently?'"

Bargaining offers a sense of control in the face of something that is largely out of our control. In *When Bad Things Happen*

to *Good People*, Rabbi Harold Kushner wrote, "If the reason for misfortune is moral rather than natural, we can persuade ourselves that we can control it. If guilt is the price to be paid for the illusion of control over nature, many people have seemed willing to pay it. In other words, if we can convince ourselves that we are responsible for sickness, for someone's death, then we can prevent sickness and death by changing our wishes and our behavior."

## Depression

Depression is another common and understandable stage of grief. Whether you're dealing with your own diagnosis, the loss of a loved one, or both, loss can trigger an immense and complex constellation of feelings. PH patients are forced to confront the loss of both life and lifestyle many times over the course of their journeys with PH. Losing someone you care about or witnessing a friend or family member's physical decline can stir up feelings of deep sadness.

When you're feeling sad or depressed, you may be tempted to focus on the bright side to the exclusion of your negative feelings. While the desire to push aside negative thoughts is almost always well-intended, positive thinking can sometimes come at the expense of your true feelings and experiences. Sometimes life is

sad. Allowing ourselves to embrace pain and suffering can help us move through these difficult feelings more quickly and completely.

In some cases, however, intense and enduring reactions to loss 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. For more information, read "Identifying and Seeking Treatment for Depression" on p. 15 of this guide.

## Acceptance

For most people coping with loss, the denial, isolation, anger and depression will begin to lessen over time. Acceptance does not mean that you will feel better and happy immediately. Acceptance is the point at which you can agree that your loss is a reality, in both thought and behavior. Some patients become quiet and reflective when they reach the acceptance stage. While acceptance isn't a magical cure-all, it may be the first point in your grieving process at which you can imagine moving forward from your loss and making new plans for the future.

## Survivor's Guilt

Survivor's guilt is a phenomenon experienced by disaster survivors who witness the multiple deaths of friends and family members. Survivors who watch loved ones die in earthquakes and bombings are often left wondering, "Why not me?" People living with PH may also experience survivor's guilt when they witness the suffering or loss of other patients. Some patients feel guilty that they're feeling healthy or responding well to treatment when they see other patients in declining health. Others feel guilty because they're alive when so many others have fallen to this disease.

Guilt implies responsibility. Why do we feel guilty for the course of our own disease? Why do we feel guilty because someone else passed away? Is it because we feel somehow responsible? If there was something that we could do to prevent the pain, suffering or death of another member of the PH community, chances are we would do it. Yet that nagging feeling of guilt lives on. Often, guilt is irrational, unrealistic and unproductive. What it can do, somewhat counter-intuitively, is allay a type of anxiety. If you are somehow responsible for the course of disease in someone else, perhaps you can control your own health as well. Sadly, this is a fallacy. While there are some things about our health we can control and maintain, often the course of an illness is out of our



control. The illusion of control is comforting, but it's just that — an illusion.

Survivor's guilt can result in a number of very complicated experiences and feelings. It is important to recognize these in order to work through them. If you feel you may be experiencing survivor's guilt, stay on the lookout for the following manifestations:

- **Depression**, guilt and grief are often intertwined and difficult to tease apart. Once caught in a cycle of guilt, it can be difficult to think of much else, which can lead to prolonged feelings of sadness and despair. Depression may present itself as deep sadness, hopelessness, isolation, crying, difficulty concentrating, being unable to find pleasure in pleasurable activities, or a lack of motivation.
- **Anxiety** can arise from some of the misperceptions and distortions that go hand in hand with survivor's guilt. It can be difficult to feel at peace with your daily life when you feel responsible for someone else's suffering or guilty for being alive. Take the time to challenge irrational thoughts when you can identify them. Take the time to learn new techniques for reducing anxiety in your life (see Additional Resources).
- **Psychic numbing** refers to the tendency to tune out emotions in order to

function. Sometimes it just feels easier to shut off feelings and thoughts than to face guilt, anxiety and pain. While this tactic can be temporarily adaptive, it's not generally considered the healthiest option. Sometimes people who bury their feelings also choose to withdraw socially, so it's important to keep an eye on yourself if you start to isolate from friends and family.

- **A search for meaning** is another common manifestation of survivor's guilt. After a loss, it's important to work towards reestablishing a sense of meaning. When you're confronted with death, you may experience a shift in perspective. Some things may matter less than they once did, and you may question the purpose or point of life. In *Prozac Nation*, Elizabeth Wurtzel summed this idea up well: "It all seems pointless in light of the fact that we are all going to die eventually. Why do anything — why wash my hair, why read *Moby Dick*, why fall in love, why sit through six hours of *Nicholas Nickleby*, why care about American intervention in Central America, why spend the time trying to get into the right schools, why dance to the music when all of us are just slouching toward the same inevitable conclusion?" While the struggle to reestablish meaning can feel hopeless at times, over time, it is possible to regain your footing.

## Moving Forward

### Coping with Grief

As you consider and reflect on how these stages affect you as a patient and as someone who cares deeply for others living with PH, it is important to realize the complexity of your position. You are working hard to manage your own physical and emotional health. You are also working hard to provide support and connection to others in similar positions. Don't underestimate the depth of your connections with other PH patients. There are few things that forge friendship and intimacy as quickly as a rare disease. It's hard to find people who "get it." When you do, the bond can be fast and strong.

For these reasons, it is critical that you learn not to judge or criticize your grief experience when you lose a friend to PH. Ralph Waldo Emerson wrote, "Sorrow makes us all children again — destroys all differences of intellect. The wisest know nothing." Though it can feel terrible, confusing and unreal, try to let your grief be what it needs to be. A common misunderstanding about the stages of grief is that they must occur sequentially. This is not true. Grief is messy. You may find yourself depressed, angry, bargaining and accepting all in the same hour. You may think you've mastered one stage and are on to the next when, out of nowhere, you

hear, see or smell something that brings you back to where you were yesterday.

In *A Grief Observed*, C.S. Lewis wrote, "In grief, nothing 'stays put.' One keeps on emerging from a phase, but it always recurs. Round and round. Everything repeats. Am I going in circles, or dare I hope I am on a spiral? But if a spiral, am I going up or down it? How often — will it be for always? — how often will the vast emptiness astonish me...?" This quote captures the confusion and seemingly hopeless nature of grief. Fortunately, while you may never forget or move past your suffering completely, the intensity of grief eventually subsides. Perhaps the author Dodinsky stated it best: "Grieving is a necessary passage and a difficult transition to finally letting go of sorrow — it is not a permanent rest stop." When you find yourself in the throes of grief, take some comfort in the knowledge that you won't feel this way forever.

### Find New Meaning

It may be hard to make sense of life after a loss precisely because loss can be an overwhelming and disorienting experience. There is no reason for one person to fall to a disease that affects another more mildly. How can we find meaning in spite of the apparently random nature of life events? The answer to this question varies from person to person. Some



people choose to engage in activities that help them find meaning externally, be it through volunteering or supporting others navigating rough waters. Others spend time reflecting on and investigating their thoughts and feelings to find internal meaning and acceptance. Still others seek meaning and understanding by turning to their faith or a higher power.

To determine which path will work best for you, reflect on who you are and how you've successfully dealt with difficult situations in the past. Do you cope best with help and support from someone else? Do you cope better on your own? Who in your life do you feel comfortable sharing feelings and vulnerabilities with? What do you believe happens after death? Do you believe your relationship with the deceased is over or that it's taken on a new form? These are some of life's toughest challenges and questions, but they are worth engaging. It can be helpful to find someone you trust to mull these issues over together.

### Quick Tips: Some Do's and Don'ts

(Adapted from Colgrove, et al., 1991)

#### Do:

- Seek support from those who are able to give it. A hug can go a long way.

- Talk to others who have experienced loss.
- Talk or journal about the meaning of loss to you and the things you're going to miss about the deceased.
- Find a routine and stick to your new schedule, even if you feel you're just going through the motions.
- Recognize your feelings for what they are rather than why they are. Acknowledging a feeling can help you work through it.
- Use writing, art and music to express and explore your feelings and thoughts.
- Be forgiving and patient with yourself. It's all right to make mistakes or lose your concentration.
- Be good to yourself. Get the rest you need, do things you enjoy, and offer yourself small rewards for meeting your daily goals.
- Give yourself time. Time does heal, but just how long it takes to heal varies considerably from person to person.
- Seek guidance from someone you trust who can offer both wisdom and empathy.

#### Do not:

- Try to make major life decisions too quickly.

### Additional Resources

*A Grief Observed*, C.S. Lewis (Harper Collins, 1961)

*How to Survive the Loss of a Love*, Melba Colgrove, Harold Bloomfield, Peter McWilliams (Prelude Press, 1991)

*On Death and Dying*, Elisabeth Kübler-Ross (Macmillan, 1969)

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

*Survival Guilt*, Aphrodite Matsakis (New Harbinger, 1999)

*When Bad Things Happen to Good People*, Harold S. Kushner (Avon, 1981)

52 Proven Stress Reducers  
[www.twu.edu/downloads/counseling/F-1\\_52\\_Proven\\_Stress\\_Reducers.pdf](http://www.twu.edu/downloads/counseling/F-1_52_Proven_Stress_Reducers.pdf)

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