



Living with PH

A Guide for Parents

A Guide for Parents

TABLE OF CONTENTS

- 1 Coping as the Parent of a Child with PH
- 7 Helping Your Child with PH Cope
- 17 Co-Parenting a Child with PH
- 22 Caring for Your Relationship with Your Partner
- 26 Helping Healthy Children and Siblings Cope



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

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

Coping as the Parent of a Child with Pulmonary Hypertension

“This hurts as a parent. I am supposed to make the hurt go away. I am supposed to make it all better but I can’t.”

“I want to yell and scream that my child is not even two years old. How dare she be diagnosed with PH. I feel confused, depressed, hurting, almost ... grieving? I don’t know why I’d be grieving. She’s not dead.”

“Some days I’m fine, others I feel like my child has been handed a death sentence. I know that she hasn’t, not really — that there are treatments, and life expectancy has been extended — but it still just bashes me over the head occasionally. I wonder what kind of life to expect for her.”

What to Expect

A child's diagnosis with PH is a life-changing event for both the child and the child's parents. On the heels of the uncertainty, tests and appointments leading up to the diagnosis, some of these changes are positive steps forward. A PH diagnosis can bring answers, explaining symptoms that a child has been experiencing, and treatment, giving a child's medical team the information necessary to introduce medication to relieve symptoms and slow disease progression. Yet PH is a serious illness that can also introduce many difficult changes and challenges. If your child has been diagnosed with PH, it's important to remember that there are no right or wrong reactions. Give yourself the space to feel and respond to this news without judgment so you and your entire family can begin to move forward.

Families of children with PH may encounter a range of daily life challenges. Parents need to cope with the expansion of their parenting roles to include significant health-related responsibilities, including learning new medical terms, coordinating and taking their child to doctors' visits, managing complex medications that require constant monitoring, helping their child through medical procedures, and explaining PH to family, friends, colleagues and teachers. The entire family may face disruptions to daily schedules to accommodate medical appointments

and hospitalizations. The child with PH may be suffering physically and emotionally, taking a toll on parents and healthy siblings, who might feel helpless or guilty. One parent shared, "I wish I could make it all better."

PH may also introduce far-reaching challenges that can alter the fundamental structures of a family's life. In some families, a parent needs to become a stay-at-home caregiver. Some families are forced to move to be at a lower altitude or to be near the child's PH clinic. For others, health care costs and job changes can lead to major financial difficulties. The family may need to make lifestyle changes to accommodate financial need or the child's physical ability. This may mean forfeiting cherished, "normal" activities, like vacations. Stress and shifting roles may also affect the nature of relationships and social interactions within and outside the family. Co-parents may find that worry and stress change their romantic relationship. Children may experience stress in response to disrupted schedules and activities, changes to school and teachers, or frustration with friends or teachers who don't "get it."

Indeed, coping with stress, uncertainty and anxiety can take a toll on the entire family. While as a parent it may feel unnatural to prioritize your own needs, it's important

to stay attentive to all the personal and emotional challenges you're up against. Parents may be anxious about the future in the short-term, worrying about upcoming tests and procedures, and the long-term, fearing for what the future holds for their child with PH. Some parents experience a looming fear of illness and death even when their child is doing well. The losses associated with PH, from the loss of family activities to the loss of professional or community roles, can send parents into a prolonged grieving process. While this is normal, many parents struggle with acknowledging and coping with their grief. One parent spoke to the difficulty of putting on a brave face day-in and day-out. She said, "I have days where I am dealing with everything one minute, and then suddenly, with no trigger, I want to lash out at the world for my child having pulmonary hypertension."

Studies have documented the tremendous stress that affects the child, parents, and entire family when a child is diagnosed with PH. Life changes ranging from small inconveniences to major shifts in a family's organization to profound worries about the future can be scary and overwhelming, especially for parents who feel pressure to remain in control at all times. All the stress can build up and, if left unaddressed, may lead to caregiver burnout, chronic anxiety, or other mental health challenges. While it requires time

and commitment, prioritizing your own emotional health as you face PH can make you more capable of moving forward and beginning to help the rest of your family cope.

Adapting and Moving Forward

PH is a serious illness that many parents find overwhelming, especially in the year following a child's diagnosis. It can be helpful to know that there are hundreds of other families in the PH community who have developed coping strategies that have helped them adapt to PH-related changes and move forward. As a parent, your first priority during this transitional period may be to focus attention on your child. Remember that while this is an important instinct, it's also crucial that you take the time to acknowledge and reflect upon the ways in which this news affects *you*. Staying attentive to your own feelings and needs will make you more capable of tending to your child's needs going forward. Here are a few ideas for coping as a parent of a child with PH:

Know that your child's PH is *not* your fault. Parents sometimes blame themselves for their child's diagnosis. You might feel guilty that you didn't notice the symptoms or take your child to a specialist sooner. Give yourself permission to feel angry, sad, afraid, confused, or

whatever you need to feel, but try not to dwell on “what ifs” and “if onlys.” These are very common responses to a child’s illness but the fact of the matter is that you are not to blame.

Take care of yourself. Data from limited studies suggest that better parental quality of life can directly enhance the quality of life of children with PH. In other words, if you want to care for your child well, you need to care for yourself first. Parents who get enough sleep, exercise, and eat balanced, nutritious meals are in a better position to cope with the stress and demands of PH. Schedule in social time with friends, activities that you find fun and relaxing, and time away from your children to give yourself time to recharge. One mother recommended, “Yoga, church, quiet walks outdoors, journals, candles, music ... explore all the resources to keep yourself mentally, spiritually and physically sound. Start with yourself and the rest will fall into place.”

Ask for and accept help. Parents often want to do everything for a sick child. But the demands of PH can be so profound that it’s crucial that you allow others to help from time to time. In most cases, friends and family are eager to pitch in, but they might not know how to go about it. Here are a few guidelines to help you ask for assistance:

- Consider the other person’s abilities,

interests and availability.

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

Reach out for support. Connecting with other families who have been living with PH for a long time can be a valuable source of information, support and strength. PHA offers email and telephone support groups for parents of children with PH, parent email mentors, and national and regional conferences where you can meet other families face-to-face (see Additional Resources). Many families also benefit from the emotional support of clergy, school teachers, primary care physicians, child-life services, social workers, and psychologists or psychotherapists.

Establish routines. Get in a routine at home to cut back on stress around the house. Having set times for cleaning,

cooking and family time can cut back on indecision, disorder and parental guilt. Routines also allow you to identify high-stress times in your day and make small changes so those pockets of time become more manageable. If mornings are particularly busy or stressful, consider packing lunches and showering at night so you can focus on getting your children ready before school. You can also develop routines around hospital visits to reduce stress. Make plans for meals and snacks in advance, and arrange for visits from friends and family. Familiar faces can take some of the worry out of stressful experiences.

Get organized. You can also cut back on day-to-day stress by taking steps to reestablish influence over aspects of your life that are within your control. Get a detailed calendar or organizer to keep track of appointments, scheduled events, and changes to “normal” school or other activities. Use a journal, notebook or three-ring binder to keep track of medical contacts, instructions, medications, symptoms and other events in your life that are worth recording for your child’s medical team. Visit PHA’s Empowered Patient Online Toolkit to get started (see Additional Resources).

Try new things. Some families need to cut back on sports, travel and other

activities made difficult by a PH patient’s oxygen or medication delivery. But new, shared activities can bring families together and give the child with PH a new focus post-diagnosis. Replace biking trips with board game nights and football games with charades. Creative activities can build self-esteem and nurture life-long family interests. Consider arts and crafts, sewing, woodworking, gardening, collecting, bird watching, music lessons or foreign languages. You can also talk to your child’s doctor about the possibility of introducing sports with lower cardiovascular demands such as golf, bowling, table tennis, or certain video games.

Tend to all your relationships. PH changes life for the child with PH, healthy siblings, parents, and even extended family. While it can be tempting to pour your mental and physical energy into the care of the child who’s been diagnosed, it’s important to pay attention to everyone in your family. Read on for more suggestions for helping your children cope, tending to your relationship with your partner, and communicating with your co-parent about PH. You can also visit www.PHAssociation.org/Parents for more information on coping as a family with pulmonary hypertension.

Additional Resources

Parent-to-parent email group, telephone support group and mentors

www.PHAssociation.org/Parents/Support

PHA's regional and national education programs

www.PHAssociation.org/EducationPrograms

PHA's online classroom for parent-specific webinars and recordings

www.PHAssociation.org/Classroom/Parents

PHA's Empowered Patient Online Toolkit

www.PHAssociation.org/OnlineToolkit

Information on managing caregiver stress

www.PHAssociation.org/Caregivers/Stress

“Stress Management for Parents” from the Child Development Institute

childdevelopmentinfo.com/parenting/stress.shtml

More Than a Mom: Living a Full and Balanced Life When Your Child Has Special Needs, Amy Baskin and Heather Fawcett (Woodbine House, 2006)

By Mary P. Mullen, MD, PhD, Associate Director, Pulmonary Hypertension Service at Children's Hospital, Boston, Mass. and Assistant Professor of Pediatrics at Harvard Medical School.

Helping Your Child with Pulmonary Hypertension Cope

“He is uncomfortable changing into his gym clothes for fear of showing everyone his central line.”

“She’s having a hard time connecting with anyone her own age, maybe because she wants to talk to someone who has gone through the same things she has. Her friends can’t relate to her and she can’t relate to older people from the support group.”

“We wanted to shut her in a big plastic bubble and keep her safe from anything that could cause her to get sick.”

What to Expect

When a child is diagnosed with PH, families face a whole new set of circumstances and challenges. As a parent, it’s natural to want to shelter your child from pain. When parenting a child with PH, this isn’t always easy, and between the symptoms, side effects, treatments, and procedures, sometimes it’s just not possible. Some parents say they feel guilty or resentful that they can’t protect their children from the discomfort associated with this disease. It’s also natural to worry about your child’s emotional well-being. Whether your family has been living with PH for a few weeks or several years, it’s normal to have

lots of questions about raising a child with a chronic illness, and what you can do to help your child cope.

Many parents find that PH quickly assumes a central role in all aspects of their parenting. Decisions about a sick child’s chores, homework, play dates, and bedtime become more complicated than they might be for a healthy child. Parents have to think about how much responsibility and independence they feel comfortable giving their child, how to stay attentive to their child’s needs, and how to talk about the disease with someone so young.

Parents have the ongoing job of identifying and working through not only their own concerns, but their child's as well. Some children will speak up as issues present themselves, while others may need gentle encouragement to articulate their feelings and questions. Children also exhibit nonverbal behaviors that can signal confusion, distress or frustration. Pay attention to your child's moods, facial expressions and body language. Whether or not they're expressing them, many children have questions, either about their illness or about the differences they observe between themselves and their siblings or friends. Children may wonder why they can't run as far as their friends or why they get so much special attention from adults. They might fear pain or assume they became sick because they were "bad." Your child's questions and concerns will change over time. The next section provides a basic overview of developmental stages to help you address your child's needs at every age.

As time goes on, new challenges will continue to present themselves. Just as you're finally adjusting to one aspect of parenting a child with PH, an impending doctor's appointment, a change in your child's health, or a period of transition (to school, college, or adult care) will bring a flood of fresh questions and concerns. While helping your child understand and cope with all these ups and downs

may feel overwhelming, remember that your role as a parent remains constant: to provide the love and support necessary for your child to grow and learn.

Adapting and Moving Forward

John Wilmot wrote of parenting, "Before I got married I had six theories about bringing up children; now I have six children, and no theories." Despite all the books and blogs available on the subject, many parents find that all the experts and advice out there can't compare to the lessons they learn by waking up every day and spending time with their children. Raising a child with PH can be eye-opening, nerve-racking, hectic, physically taxing, emotionally draining, and tremendously rewarding, sometimes all in the same afternoon. By checking in with yourself and your child on a regular basis and trusting your instincts, it's possible to be there for your child through the ups and the downs.

Explaining PH to Your Child

Talking about PH with your child can be one of the most challenging tasks parents in the PH community face. As with any sensitive topic, it's a good idea to plan ahead and anticipate potential questions and stumbling blocks. If you have a co-parent, talk to him or her about how and

when to have these conversations, and how much information you feel comfortable sharing when you do. One mother compared explaining PH to her daughter to "having the sex talk." She went on, "How much to tell is all about age, maturity, and their desire to know."

The established developmental stages, described here, can help guide these talks, but keep in mind that all children are individuals who process feelings and concepts differently.

- **Preschoolers** are concrete thinkers. They aren't able to process abstract information, so they may come to the conclusion that something they did caused their PH. They will need reassurance that this is not the case. Preschoolers process their understanding through play, so dolls, books and toys can be helpful tools to illustrate medical scenarios and parts of the body.
- **Elementary school children** are beginning to visualize on an abstract level, but they may still believe that PH was caused by something they did. If they are articulating questions they are also imagining possible answers, so honest and clear explanations are important. Simple language such as "your heart works harder" can be helpful. Children may need many invitations to talk before they feel comfortable voicing a concern.

Expressing your feelings can encourage children to do the same. Movies, stories and songs can be useful tools in drawing out children who are reluctant to share.

- **Teenagers** have a greater understanding of symptoms, medications and the impact of personal decisions on their health. Still, don't assume an adolescent understands something if you haven't talked about it. At this age, it's ok to ask more leading questions to encourage conversation. Keep in mind that teens have a tendency to turn to the Internet and friends for information. Steer them towards reliable sources to ensure that the information you're providing is reinforced by credible websites and individuals. Teen years are a good time to encourage greater "ownership" of PH and begin the transition to independent adult care.

At every age, try to be gentle, open and honest. If you don't think your child is ready for certain details, that's ok. Some parents find that their children's questions are the best guide for what to tell and when. One parent shared that she didn't tell her nine-year-old daughter very much initially except that "she had to take meds to make her heart stronger." You're the best judge of your child's personality and moods, so you know better than anyone how much information will help your child understand and cope at every stage.

As every parent knows all too well, sometimes children will take you off guard by asking something that you're *not* prepared to talk about. Around the second grade, some children begin asking about death. Keep in mind that this is normal, even in healthy children. It's in elementary school that children begin to develop a curiosity about what happens when a person dies and their own mortality, particularly if someone in your family has recently passed away. Be honest and open, and give your child the space to voice any fears and questions. Try not to rush the conversation because you're feeling uncomfortable. Children can pick up on anxiety in adults, and evasive responses may only add to their fears. If your family has spiritual beliefs that you want to share with your child, this can be a good time to do that.

Above all, reassure your child that your love is unconditional and, if it comes up, that PH didn't develop because of anything he or she did wrong. Offer your child an open line of communication. Be on the lookout for signs of confusion or distress, and turn to your PH team, your child's school counselor, a therapist or clergy member if you or your child need extra support at any point.

Appointments and Hospital Visits

Visits to the doctor's office or hospital, whether routine or not, can be difficult times for children of all ages. They may be afraid of certain tests and procedures, anxious at the thought of interacting with strangers, put off by the clinical atmosphere, or worried about missing school or social activities.

Children have a tendency to feel anxious about the unknown. If possible, prepare your son or daughter for appointments and hospital visits in advance by describing the appointment or procedure, who will be in the room, what devices will be used, and how much your child will feel during any tests or procedures. How much you tell your child and how far in advance will depend on age and developmental stage. One strategy is to wait the equivalent number of days before an appointment as your child's age in years (four days for a four-year-old, two weeks for a 14-year-old), but this guideline will vary from child to child. Talk to your PH team for ideas about how to talk to your child about medical tests, as it's likely they have time-tested strategies for explaining complicated topics to young patients. Some hospitals have pediatric social workers and child life specialists who can help you prepare your child for hospitalizations.

If your child gets a line infection or experiences another unexpected medical emergency, you may not have time to prepare your child for a hospitalization in advance. Unplanned visits to the hospital can be frightening for both parent and child. You can reduce your own stress in these situations by having an emergency plan ready and following it when the time comes. Pack a bag of essentials to keep near your front door. Include a change of clothing for each family member, books and magazines, comfort objects for your child, nonperishable snacks, \$20 in cash for parking, and your child's medication list. Keep a supply of pre-made meals in your freezer and ask two to three neighbors or family members to serve as "on-call babysitters" for your other children or pets if you need to leave the house in a hurry. Children have a tendency to take cues from adults in stressful situations. If you're able to manage your own tension and project a calm demeanor, your child will be more likely to follow suit. On the trip to the hospital, pay close attention to your child, responding to any questions with simple and reassuring language. If possible, use distraction techniques like singing or car games to take your child's mind off any pain or anxiety.

Once at the hospital, stay attentive to your child's body language for signs of discomfort. Keep in mind that it can be difficult for young people to interact

with adults they don't know. Children are sometimes embarrassed to ask nurses for help. Explain that nurses spend time with other kids with conditions like PH every day. Stay at your child's side whenever possible, and work with the doctor and nurse to explain what's happening to put your child at ease. You can actively participate in your child's care during a hospitalization by staying overnight or helping in tasks such as washing. Answering honestly to questions such as "will this hurt?" helps build trust between parent and child and removes the fear of the unknown.

Many parents also try to ease the anxiety their children feel around appointments and procedures by concentrating on the positive. You might focus conversation around how great it will be to feel better after surgery, or all the visitors and games there are to look forward to during a hospital stay. Hannah, now in her 20s, fondly remembers her parents' strategy for relieving her hospital-related stress. After blood draws, IVs, PICC lines, and heart cath, she would always receive a small gift. She told us, "I wasn't spoiled ... I never got money for good grades, but that was something simple that my parents did to keep my mind off the pain. To this day I often go get an ice cream after a less-than-fun doctor's visit."

At Home

With so much already on a young patient's plate, it might be tempting to avoid piling on additional responsibilities. But be wary of protecting your child *too* much. To help a chronically ill child feel as much like a normal kid as possible, professionals recommend that parents set limits and encourage responsibility, just as you would with a child who didn't have PH.

One of the easiest places to establish this sense of normalcy is at home. Talk about your expectations for good behavior and help around the house. One mom, Christine, created a list of chores that she knew her daughter could complete successfully, PH and all. Make sure there are consequences if your expectations aren't met and rewards for jobs well done. Get in a routine and stick with it. Having a predictable home life, with fairly consistent chores, meal times, bedtimes and activities, can counteract the stress and unpredictability of the ups and downs of PH. A well-thought-out routine can also ensure that you make every effort to give every family member, including healthy children and your spouse, the attention they deserve.

As time goes on, you can also encourage your child to take on new responsibilities regarding his or her health and medication management. While parents

sometimes feel the need to control all aspects of their children's health, offering small choices in a predictable environment can ease the inevitable transition to adult care. One parent told us, "We allowed our daughter to choose her own bedtime during the summer as long as she was responsible in taking her oral medications on a daily basis." When the daughter made choices that made her feel worse, she learned to avoid them in the future, and thus slowly developed her own action plan for tending to her health. You can help your child identify activities or behaviors to avoid by verbalizing the circumstances and symptoms when he or she doesn't feel well. You might also encourage your child to mix his or her own medications or fill his or her own pill box occasionally. As children get older, their confidence will grow and they will feel empowered to make more and better choices.

Remember that life with a chronic disease can be extremely stressful for a child, so it's a good idea to keep the home environment as stress-free as possible. While there will be hard times and difficult conversations ahead, try not to argue with your partner about PH or medical bills within earshot of your child. Instead, create a safe and supportive atmosphere by showing your child that you, your partner and the PH medical team are all working together to give the young patient the care he or

she deserves.

School, Friends and Fitting In

Planning for school can be particularly stressful to parents of young PHers because it's a place where they have less hands-on control of their child's care than they do at home. One parent told us that with all the dangers and unknowns she feared, she debated if she should let her daughter attend school at all. She worried, "What if she fell? Her line could get pulled, the kids could pick on her, and she may get too tired!" Yet the knowledge, confidence and relationships children build in school (or, in the case of home-schooled kids, extracurricular activities) are important building blocks in their growth and development. Work through your own fears in advance so you can help your child cope with his or her feelings as they arise.

Speaking to the school in advance in order to prepare teachers for any special needs your child has can help ease some of these anxieties. PHA has a School Resource Handbook you can use to work with school personnel to ensure that your child's classroom environment is as safe and supportive as possible (see Additional Resources). Eventually your child can begin to participate in the process of educating teachers, counselors, and coaches about PH. One high school student

liked to take the lead in the meetings her parents convened of all her teachers at the beginning of every year. She said, "I felt in charge of my PH and my situation at school."

Often parents worry that children with PH will become alienated from their peers because they feel so different. Once children are settled in a new routine, however, most of the stories we hear are positive ones. One mother shared, "Katy has always had a couple of good friends. Her classmates have always protected her and cared about her." Ask the teacher to treat your child like any other student, and students will usually follow the teacher's example. And the more you can do to help demystify your child's illness, the better. Children are naturally curious, so you might consider visiting the classroom to explain the basics of PH, oxygen or an infusion pump to your child's classmates.

One mother was relieved to confide, "Sarah made a ton of new friends and they all wanted to learn about her pump and backpack." A network of informed friends can give peace of mind to both children and their parents. One father said, "Iain has been able to develop very strong friendships with kids who have been with him since diagnosis. This network of friends and their parents helps us to provide a secondary level of protection for him."

The older they get, the more children with PH might dwell on the negative aspects of their disease. Depending on the severity of their symptoms or the nature of their medications, they may be unable to participate in some physical activities. One parent recommended creating “a list of what PHers can do, like watch a movie or play a board game or video games.” While there’s a chance you’ll have to say no to some activities, there may be alternatives that are equally appealing to your child. Remember, for every activity that children with PH can’t do, there’s one they can do. One mom said of her nine-year-old with PH, “She’s a pretty typical kid. She can’t run well or keep up with the other kids, of course. But she’s very bright and typically sassy. She has big plans for her future and to live a long, happy life.”

During the self-conscious teen years it can hurt a lot to feel different from peers. Some young patients have difficulty accepting ownership of the disease as adulthood approaches. Open lines of communication are vital during this time to discuss new responsibilities, drinking, sexual activity and drug use. Periods of denial or some non-compliance are also normal in teens. Talk openly with your child if this occurs. If it continues, speak to his or her PH doctor for advice.

Many kids get through tough times by

making friends with other young people living with PH. Some parents coordinate visits to the PH doctor to coincide with the visits of other children with PH of similar ages. You can use PHA’s email group, message board or support group calls to meet other parents in your area. Attending PHA’s biennial International PH Conference is another great way for children to meet other kids who understand what they’re going through. Online, kids can visit PHA’s website to read interviews with other kids and get advice on school, sports and more. Teens (ages 13 to 18) can visit PHA’s secure social network, *PHA Teens*, to meet other teenagers living with the illness. In the summer, some parents arrange for their kids and teens to attend camps that cater specifically to children with heart disorders and other chronic diseases. See Additional Resources to learn more about all of these options.

Quick Tips

- Before discussing PH with your child, acknowledge and work through your own issues to prevent projecting your own fears or concerns onto the conversation.
- Ask questions such as “How are you handling things?” or “How can I make things easier for you?” to gauge how much your child understands and how he or she is processing and coping with the situation.

- If your child makes a mistake that negatively affects his or her health, try to ask thought-provoking questions (such as, “How do you think your heart is doing if you delay taking your medicine?”) rather than getting upset.
- If you’re worried about giving your child more independence, do everything you can to educate teachers, friends, and others in your child’s life about PH.
- Consider giving your child a cell phone to call you or medical contacts in an emergency.
- Side effects such as facial flushing can be embarrassing, especially during the teen years. Encourage your teen to discuss these issues openly with his or her doctor.
- Work with your child’s school to accommodate his or her PH. If your child tires easily, a shortened school day might be arranged. Gym class could be made easier by arranging in advance for your child to change alone if he or she is self-conscious (of supplementary oxygen or a central line, for example) or signaling to the teacher when he or she is tired.
- If your child has trouble participating in sports and physical play, be proactive about scheduling in plenty of sedentary activities and hobbies (like photography, strategy games and writ-

ing) that appeal to your child’s interests.

Additional Resources

“Explaining PH to Your Child: Developmentally Appropriate Approaches” (webinar recording)
www.PHAssociation.org/Classroom/ExplainingPHtoYourChild

“Children and PH: Babies, Kids, Teens and Family Planning,” in *Pulmonary Hypertension, A Patient’s Survival Guide*, Gail Boyer Hayes
www.PHAssociation.org/SurvivalGuide

PHA’s School Resource Handbook
www.PHAssociation.org/Parents/School

Parent-to-parent support
www.PHAssociation.org/Parents/Support

PHA Teens, a social network for teens 13–18 with PH
www.PHAssociation.org/PHATeens

PH Kids, a place for children with PH to play and learn online
www.PHAssociation.org/PHKids

Information on summer camp planning
www.PHAssociation.org/Parents/Camps

Parenting Children With Health Issues: Essential Tools, Tips, and Tactics for Raising Kids with Chronic Illness, Medical Conditions & Special Healthcare Needs, Foster W. Cline, MD and Lisa C. Greene (Love and Logic, 2007)

Young People and Chronic Illness: True Stories, Help and Hope, Kelly Huegel (Free Spirit, 1998)

Contributions and medical review by Michele Calderbank, Children’s Hospital, Colorado.

Co-Parenting a Child with Pulmonary Hypertension

“We were scared and we really weren’t sure if we could handle it at first.”

“It isn’t always easy, but we don’t talk about it much. I always figured it didn’t affect my husband like it affects me.”

“When our daughter was first diagnosed, he wanted more to do with her medical stuff. Now, because of her medical and developmental delays, he is harder on her. He says he’s preparing her for a normal life. I tend to be more lax, maybe because at some level I feel guilty for all of this.”

What to Expect

Parenting a child who has pulmonary hypertension can feel like riding a rollercoaster with no exit, enjoying some exhilarating highs while also fearing the long, unexpected drops.

On one hand, raising a child with PH can offer unexpected gifts: inner strength, perspective that directs our attention to the “big things,” the support and love of friends and family. It also offers many challenges, including fear for the future, unexpected hospitalizations, emotional highs and lows, disrupted schedules and plans, dynamic priority shifts, and burdensome medical expenses. These challenges

can lead to conflict between you and your partner, even within the strongest of relationships.

It is common for two parents to have different parenting and coping styles. In families with a chronically ill child, these differences can lead to unspoken tensions and assumptions on both sides. One parent may focus primarily on the day-to-day needs of the child, while another may focus attention on concrete tasks during difficult times, such as keeping up with 9-to-5 employment to maintain uninterrupted medical insurance, making repairs around the house to better accommodate the child with PH, or remaining focused

on the future needs of the entire family. While all of these jobs are necessary to sustain family stability, a lack of appreciation for the value of the other partner's approach can lead to conflict.

Similarly, one parent may reach out to family and friends for support, while the other may need time alone to process his or her feelings and reactions. It is important to recognize and accept that everyone copes differently and processes life events at their own speed. While you may be on a loop on the rollercoaster of your family's PH journey, your partner may be on a smooth flat.

As your child grows, you and your partner will encounter new challenges as PH continues to affect your child and your family in different ways. You may find yourself questioning your partner's level of commitment and competence, or entertaining other fears and concerns to emerge in light of your child's illness. Though every family and relationship has its own ways of dealing with chronic illness, communication is critical.

Adapting and Moving Forward

Wherever you and your family are in your journey with PH, there are things you can do to encourage an open dialogue with your co-parent about your concerns, fears,

challenges, and day-to-day responsibilities. If you aren't in the habit of talking about these issues on a regular basis, take the time to prepare for an initial discussion to lay a positive foundation for the future.

- **Don't wait for an emergency to talk.** Sit down with your partner to discuss your child's needs when there is *not* a crisis. You will both be able to think more clearly when you are not reacting to an immediate concern or need.
- **Be honest.** Talk about what the future may hold: for you, your relationship, and obviously, your child.
- **Establish roles and responsibilities.** By talking about who will take responsibility for what, you can save time and avoid miscommunications. Are there strengths that you bring to the table that naturally align with your child's needs? Are there areas where you struggle, but your significant other is a natural and may be willing to take the lead? For example, if you're a born organizer but your partner hates talking on the phone, you might coordinate appointments and medication deliveries while your partner takes on the task of paying bills.
- **Be flexible.** The parenting plan that works in January may not be the plan that works in September. One par-

ent recommends, "Discuss PH and its challenges regularly. Be accepting to the constant changes in care. Acceptance is easier than being irritated."

- **Be sure you *both* know the essentials.** From a practical perspective, be sure that you and your partner both know what to do in a crisis. Review the basics of your child's PH together. Make sure that you're both familiar with your child's medications, what symptoms and side effects demand immediate action, and who to call in the event of an emergency. To stay on the same page regarding these issues, make a point of attending clinic visits, support groups, and related appointments together whenever possible. Attend teacher conferences and sporting events together as well to demonstrate how all of these functions can co-exist.
- **Trust your instincts.** If the conversation is obviously not going well, ask to put it off until another time. Don't put your feelings on the line if you're not both in a place where you're capable of showing one another respect and giving the conversation the time it deserves. Return to the discussion when you both feel ready.
- **Make time for your child *and* your relationship.** Attend to your own emotional needs as well as the practical and emotional needs of your child in this conversation. Your child likely will

not always require complete, undivided attention (and, face it, kids will *want* some autonomy). Your relationship(s) with others are critical to your resiliency and ability to cope. Talk about what it takes for each of you to recharge, and find ways to accommodate your needs during your average day or week. Think about scheduling a standing "date night" for you to spend time together without your child(ren), as well as alone time for each of you.

- **Keep talking.** Make check-ins with one another about your child's PH a regular part of your household routine.

If you are responsible for your child's day-to-day disease management...

- **Come to the conversation ready to accept help.** You likely know the ins and outs of your child's day-to-day needs, and you may feel that you can handle most of the caregiving responsibilities by yourself. Still, it is often helpful and comforting to have someone to share events with. Tell your partner why you want to include him or her, and what you'd like out of this conversation. Your knowledge is bound to instill confidence and respect, and honesty is so often rewarded with the support one needs.
- **Put yourself in your partner's**

shoes. Recognize that while you may have already adapted to many aspects of your child's illness, your partner may still be experiencing feelings of shock, fear, reluctance and grief. You likely had some of the same emotions (and maybe even still do), and needed to take time to process them. Your partner may be at a different stage in processing, accepting and coping with your child's diagnosis, particularly if new health concerns develop.

- **Educate your partner.** Remember, you are an expert on this topic! Give your partner some examples of how you do what you do. Focus on your strengths, and then give him or her a chance to do the same. Remind each other that the qualities that drew you together were likely based on your values, priorities and characteristics that can help you manage your child's PH.
- **Be yourself.** Be the advocate you are for your child, and that will transcend the boundaries of other relationships in ways that are positive and build respect. It may be a challenging series of discussions, but the benefits that result will be invaluable. Your child will have another "expert" in his or her team of supporters, and you will have a renewed sense of confidence as a parent, partner and caregiver.

If you are typically less involved with your child's disease management...

- **Put your child's well-being first.** It's common to be afraid of what you don't know. If you want to be a bigger part of your child's caregiving team, the best way to overcome your fears is to learn everything you can about the child's illness and needs. Make every effort to attend doctors' appointments and meetings with school personnel. One parent of a child with PH advises, "Get involved and stay involved. The level of knowledge you possess will allow you to intelligently discuss pulmonary hypertension with your child and spouse. Participate in doctors' visits and medicine updates. This ongoing training could very well save your child's life."
- **Be supportive.** Many primary caregivers get so wrapped up in the demanding day-to-day responsibilities of caring for a child with PH that they begin to feel drained, overwhelmed and underappreciated. Take the time to express your appreciation for everything your partner does for your little one and your family. Ask your partner what you can do to help, and then make every effort to follow through on your commitments.
- **Ask questions.** Your partner is a valuable source of information about pulmonary hypertension, your child's

needs and your child's medications. There are no stupid questions; don't be embarrassed to inquire about something you feel you should already know. The most important thing is that you know what you need to know to care for and nurture your child. Your partner will appreciate that you're committed to being an active member of your child's caregiving team.

While there is no guarantee of what the future holds, you do what you can to normalize, champion and survive the impacts of PH with each person in your family. With consistent effort, you can learn to sustain yourselves through the ups and downs, and balance the routine stressors of life with the joy and love of family.

Additional Resources

One mother's take on communicating

about PH with a significant other
www.PHAssociation.org/Parents/DiannasStory

Parent-to-parent support
www.PHAssociation.org/Parents/Support

Parenting Children With Health Issues: Essential Tools, Tips, and Tactics for Raising Kids with Chronic Illness, Medical Conditions & Special Healthcare Needs, Foster W. Cline, MD and Lisa C. Greene (Love and Logic, 2007)

By Allyson Rupp, LCSW and Darci Albrecht, LCSW, Vera Moulton Wall Center for Pulmonary Vascular Disease at Stanford.

Caring for Your Relationship with Your Partner

“I’d like to know how other parents of PHers keep this stress from destroying their marriages.”

“We haven’t had a night alone without the kids in three years.”

What to Expect

When a child is diagnosed with pulmonary hypertension, parents must learn to juggle a whole new set of priorities. Many couples find themselves putting their relationships on the back-burner to make room for the new tasks and commitments that a child’s PH introduces to daily life. From paying the bills to medical management to childcare, caring for a child with PH can often feel like two or three fulltime jobs. With everything there is to do, it can be difficult to find time to focus on the fun side of being in a loving relationship. Early on, “date night” may come to mean an evening mixing medications; the “rainy day adventure fund” may be redirected to cover medical bills; and the only “romantic getaways” may be trips to specialty medical centers. Shifting priorities, demanding schedules, and little to no time alone as a couple can take a serious toll on both emotional and physical intimacy.

Working on a relationship while dealing with PH and managing a household is not easy. It’s likely that both you and your partner are dealing with emotions that are difficult to talk about openly and honestly. You might feel guilty about your child’s PH, frustrated by perceived imbalances in the division of caregiving responsibilities, or even in denial about certain aspects of how your lives have changed. On top of these new challenges, some parents report feeling too guilty to take the time to work on their relationship with a sick child at home and so much to do.

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

Adapting and Moving Forward

All the changes that come with PH can make it difficult for you and your partner to focus on the two of you as a couple. But a healthy relationship can be a source of energy and renewal. When life is the most hectic and stressful is when you are in the greatest need of your partner’s affection and support, so take the time to nourish the relationship you have with your “other half.”

Share the Responsibilities

- **While one parent often takes the lead in the caregiving role, try to share tasks so one parent doesn’t feel overwhelmed.** Make sure that you both know how to do all relevant medical tasks so you can provide backup for one another. One mom, for instance, told us that she and her husband took turns mixing their daughter’s medication.
- **Encourage your child to approach both parents for emotional support.** Sometimes children lean on one parent more than the other, but this can prove stressful in the long term. Encouraging open communication with both parents lets children know that they can talk freely to either one whenever the need arises.
- **Both parents should “be present”**

to the disease. Often a parent will, as one of our caregivers put it, “deny things that are not pleasant.” The other parent must then deal with the realities of a situation: from going to doctors’ appointments to accepting and acting on bad news. Another caregiver noted that it took her husband “more than a year to really wrap his head around this ... he doesn’t like to deal with PH, but now I don’t let him sidestep it too much.” If your partner needs some help adjusting to these new circumstances, encourage him or her to speak with other PH parents, to your child’s PH specialist, or to a social worker or counselor.

Talk, Talk, Talk ... and Listen

- “We now have to talk about issues a lot more than we used to and I think we are both a bit more sensitive than we used to be,” revealed one parent. Share your feelings and your worries. Don’t be afraid to ask for what you need from the other. Remember that your partner can’t read minds, so if you need something, you need to ask. Don’t forget that you both have the same underlying priority: the best for your child.
- Questions you might both periodically reflect on include: *How does the illness affect us as a couple? What can we do to improve our relationship? What do we need as couple under our present*

circumstances?

- When conflict arises, try to use “I” messages rather than “you” messages. During an argument “you” may seem judging or accusatory, while “I” expresses your sentiment without judgment. For instance, rather than telling your partner, “You never help with housework,” try, “I need your help cleaning.”
- In difficult times, it’s normal for your physical relationship to be affected. It is important to respect your partner’s pace. Sexual relations are an expression of intimacy. Take time to nourish your intimate relationship.
- If you find it is becoming hard to find common ground with your partner, consider professional counseling.

Reserve Private Time for You as a Couple

- Frequently parents devote *all* their time to their child’s illness, leaving no time for themselves and allow this to become “the new normal.” As one mom put it, the marriage “begins to sit far in the background.” When the focus eventually shifts back to the relationship, she warns, the couple “might be faced with a marriage that is in bad repair or else they feel they no longer know the other person.”

- To avoid this scenario, make time for the kind of activities that you used to do before your child’s illness. Having your child, occasionally, looked after by others is an opportunity to strengthen the bond with your partner. Don’t feel guilty: enjoy this time as a couple. Two of our caregivers try “to have a date at least every couple of months, just the two of us.”
- Leaving your child in the care of a trusted friend or family member can help you and your partner relax during your time alone. Educate this person on the everyday aspects of caring for your child, as well as potential emergency care. Specialty pharmacies can also send nurse representatives out to train family members and friends.

Put the Illness in its Place

- **Don’t give it more time than is necessary, nor less.** Find the balance. Try not to center all your conversations and activities on your child. Your lives are made up of other elements apart from the illness: friends, relatives, hobbies, dreams, etc.
- **It is particularly important that other children do not feel left out.** Make sure there is always a focus on the “family” as a unit, rather than just the sick child. Enjoy shared experiences such as games, vacations, etc. In doing

so you will refocus your roles back to that of “parents” and not only “caregivers” to a sick child.

- **Your relationship with your partner is not defined by PH.** And like any challenge in life, pulmonary hypertension *can* strengthen the family bond. In fact, in a recent PHA survey, the vast majority of caregivers said it had done just that. One caregiver noted, “I think we have both become better people because of everything we’ve been through” while another said, “Pulmonary hypertension has strengthened our marriage.”

Additional Resources

“Nine Psychological Tasks for a Good Marriage,” from the American Psychological Association
www.apa.org/helpcenter/marriage.aspx

Married with Special-Needs Children: A Couples’ Guide to Keeping Connected, Laura E. Marshak and Fran P. Prezant (Woodbine House, 2007)

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

Parent-to-parent support
www.PHAssociation.org/Parents/Support

This resource was compiled from advice offered by parents on PHA’s PHA_Parents email group and adapted from “My Child Has PH: A Guide for Parents,” produced by the National Spanish Association of Pulmonary Hypertension (ANHP). Contributions and review by Allyson Rupp, LCSW, Vera Moulton Wall Center for Pulmonary Vascular Disease at Stanford.

Helping Healthy Children and Siblings Cope

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

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

What to Expect

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

Every child responds differently to the stresses and lifestyle changes imposed on a family by PH. Some children will vocalize

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

Depending on personality, age, developmental stage, and a variety of other factors, some children may not be willing or able to vocalize their stress. One mother said

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

Even children who don’t show signs of stress are likely thinking about PH and how it’s affecting your family. Sometimes the product of these reflections are remarkably positive. A child growing up in a PH household is likely to absorb a lot about the ways in which family members work together and support one another. Many parents in the PH community are proud to report that their healthy children voluntarily take on responsibilities and roles that allow them to advocate for the PH patient and care for parents and siblings. One sibling shared, “I hope someday to find a cure for PH when I am

a doctor and never see anyone go through what my family and PH friends do.” While PH can cause stress for parents and children alike, in the context of a loving and attentive family, children have the capacity to learn, grow and flourish.

Adapting and Moving Forward

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

While there are a limited number of hours in the day, there’s no limit to the amount of love you can share with your children. When your intention is to create an inclusive, healthy and supportive home for your family, mistakes and false starts are ok. In

fact, they're par for the course. When they happen, remind yourself of your love and intention and begin again. Focus on the aspects of parenting you can control, rather than the many chaotic life factors that you can't predict or influence. Here are a few goals to work towards to provide your healthy kids with the structure and support they need:

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

Tell them you love them. Healthy children sometimes wonder whether their parents care about them as much as the PH patient, so make this an item on your daily to-do list. In addition to telling them through words, you can show your love through frequent hugs, tucking them into bed, leaving notes in their lunch bags, singing them songs, and cooking their favorite meals. While you may not have much extra time, displays of love and affection can go a long way towards showing your healthy children how much you're thinking about them.

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

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

can sometimes make life feel chaotic.

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

Encourage open conversation about PH and treatment.

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

on other simple tasks.

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

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

Be prepared for difficult conversations. Not all conversations will lend themselves to easy reassurances. It can be unbelievably hard to talk about the concept of death with a child, and even more difficult to talk about the possibil-

ity of a loved one's death. But questions and concerns in this vein may present themselves, and if they do, you should be prepared to have an open and honest conversation. Do your best to take your time addressing children's concerns, even if the conversation makes you sad or uncomfortable. Children can pick up on anxiety in adults, and evasive responses may only add to their fears. If your family has spiritual beliefs that you want to share, this can be a good time to do that.

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

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

[org](#).

Additional Resources

“Talking to Your Healthy Child About Your PH” (for parents living with PH)
www.PHAssociation.org/HelpYourChildCope

Child and Adolescent Psychiatrist Finder
www.aacap.org/AACAP/Families_and_Youth/Resources/CAP_Finder.aspx

“Where to Find Help for Your Child,” from the American Academy of Child and Adolescent Psychiatry
www.aacap.org/AACAP/Families_and_Youth/Facts_for_Families/Facts_for_families_Pages/Where_To_Find_Help_For_Your_Child_25.aspx

Resources for parents from KidsHealth
kidshealth.org/parent

Parent-to-parent support
www.PHAssociation.org/Parents/Support

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



Pulmonary Hypertension Association
Empowered by hope

801 Roeder Road, Suite 1000
Silver Spring, MD 20910
Phone: 301-565-3004 • Fax: 301-565-3994
PHA@PHAssociation.org

www.PHAssociation.org
www.myPHAssociation.org • www.PHAOnlineUniv.org

This resource guide was made possible through unrestricted educational grants from Actelion Pharmaceuticals US, Inc. and Gilead Sciences, Inc.

Copyright 2016 Pulmonary Hypertension Association