



Living with PH

A Guide for Teenagers



Pulmonary Hypertension Association
Empowered by hope

A Guide for Teenagers

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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
www.PHAOnlineUniv.org

Coping as a Teenager with Pulmonary Hypertension

“It’s a hassle remembering what times I have to take my meds now, and cleaning all of the equipment and whatnot. I really hope that this medicine helps ... I just find it a huge distraction.”

“It makes me upset that pulmonary hypertension is holding me back from doing things I love, like baseball.”

“Everyone asks me about my pulmonary hypertension bracelet lately. It’s nice to be able to explain but it’s a bittersweet feeling. After they hear that I’m sick the way that they look at me is forever changed.”

What to Expect

Being a teenager is all about becoming more independent, meeting new people, figuring out how to fit in with your friends, thinking about who you are, and making plans for the future. These years can be rough for anyone, but for teens with pulmonary hypertension they can sometimes feel especially unfair and stressful. You may be trying your very best to do it all: hang out with friends, keep up with homework, and come up with answers to big questions like: “What do I want to do with my life?” And then, on top of everything else, you’re expected to deal with PH. Between all the medications, missed school, and doctors’ appointments, it can feel like a lot.

We talked to some teenagers living with PH and asked them to tell us about what they had to deal with. We also asked them what they wanted other teenagers with PH to know. What follows are some of the things we heard.

“We’re not freaks! But we are different.”

Lots of teens with PH talk about looking and feeling different. Some feel different because of all the medications and side effects they’re dealing with. Some get out of breath in gym class when everyone else is just warming up. Some worry about

fitting in because they can’t play on the soccer team or try out for cross-country. While lots of the teenagers we spoke with were lucky enough to have close friends who knew about their PH and stuck by their sides, the pressure of trying to fit in with classmates who don’t know about PH can be a source of stress.

Things that everyone else gets excited about can be harder to plan for if you have PH. Shopping for clothes and makeup can be trickier if you need to think about a pump, facial flushing or a surgery scar. Lots of high school students look forward to asking someone to prom or finding the perfect dress or tux. But teens with PH told us they also have to plan to find a dress that works with their pump, find a date who doesn’t mind that they’re on oxygen, or convince their parents to stop worrying enough to let them stay out late with friends for one night. Lots of teens with PH are looking to find a balance between their “PH life” — symptoms, medications and doctors’ visits — and their high school life — school, parties and friends.

“Everything’s up in the air ... but change can be good.”

Teens with PH also deal with a lot of change. They say they’re becoming more independent from their families (although their parents don’t always make it easy!),

they’re setting goals for the future, and some are thinking about moving out of their parents’ houses in the next few years.

Some teens are frustrated to find that the plans they’re making all need to be adapted to accommodate their PH. If you’re planning on attending college, you may have to consider finding a college close to home or near a PH center. You may also need to request a private room or seek accommodations from your school to make your college experience successful. You might need to start thinking about transitioning to an adult PH doctor. This can be a pretty intimidating step, especially if you’re close with your current PH doctor and nurses. You may also have to start taking on more of your medical responsibilities, from managing your medications to ordering prescription refills.

Life changes, even good ones, can cause stress. Keep in mind that stress looks different in everyone. When you’re feeling overwhelmed you might find yourself crying, wanting to be alone, or snapping at family members for no good reason. One teen told us, “PH is on my mind all the time. I have friends, but sometimes I just want to be by myself.” You may also experience physical symptoms, like upset stomachs or trouble sleeping. While it can sometimes be difficult to identify symptoms as they’re happening, it’s important to start paying attention to your emo-

tional and physical ups and downs. These changes can influence your PH and your overall health, so talk to your parents and your PH doctor if you notice any symptoms or changes in behavior.

Lessons to Live By: Teens Share Their Wisdom

Learning how to deal with all these changes is a process that takes time and practice. While it’s not always easy, understanding more about PH and starting to take responsibility for your own health can help you feel healthier and more confident. How you view yourself will influence how others view you. If you are happy with who you see in the mirror, your friends and classmates will be too.

Lesson #1: When it feels right, be open with your friends.

Take time to talk to your friends about PH. You are a survivor and you deserve the love and support of the people closest to you. Most teens are amazed at how supportive true friends become once they understand how complicated life with PH can be. One teen recommends being honest about the challenges you face and straightforward in your request for support. She tells her friends, “Life as a chronically ill teen and young adult

is not what people think it is. It is a sad, miraculous, triumphant, disheartening and frightening life that we live ... please try to be understanding.”

Lesson #2: Remember that everyone has a story.

You are not the only one with a hidden story. You may be surprised to discover what you don't know about your friends. One young adult with PH told us, “I've learned that if you're willing to open up, let your friends in and tell them your story, it makes them feel closer to you. They are dealing with something, you're dealing with something, and it might be different, but it's a way you can connect. Letting them in, giving them the chance to go through the good times and bad times with you, is really important.”

Lesson #3: Get creative.

Since self-esteem and appearance often go hand-in-hand, consider getting creative in how you dress. For special events such as prom, shop for a dress or tux that makes you feel good about yourself. If hiding your scar is important to you, find an outfit that does the trick. Some teens use ace bandages or cute purses to conceal their pumps in discrete places for special events. But most importantly, don't hide who you are. If how you look is okay with you, it will be ok with your classmates

too.

Lesson #4: Believe it: all eyes aren't on you.

If you have an obvious physical difference due to your PH, you may feel like that's the only thing people see when they look at you. It can be difficult to believe, but it's true: most people are not staring at you ... they're far too busy thinking about themselves!

Lesson #5: Be ready for questions.

Most people have never heard of pulmonary hypertension, so at some point you're bound to get questions. Think about how you'd like to respond if someone asks you about your PH, oxygen or medication. Becca, a teen living with PH in Arizona, advises, “Having PH, I know that there are people out there who get comments about the IV tube coming out of their shirt. I know the pain, sadness and self-consciousness that come from these insensitive comments. However, when people ask questions or say something that seems rude or insensitive, I remind myself that they most likely did not mean to be rude. I tell myself that if I answer their questions with a smile, then I can help bring awareness to PH. I urge all of you, the next time someone makes a rude or insensitive comment ...

kindly turn to them and explain what is going on with your body. We can make a difference in the way the world sees those who are different by sharing our stories of survival.”

Lesson #6: Know your rights.

If you are planning to attend college, contact the university's disability center and explore what accommodations they can offer you given your PH. All universities must have some type of disability program that can offer students appropriate academic accommodations. These may include a single dorm room due to your need to mix IV medications, early registration for classes, assistance getting to classes if walking long distances is difficult, extended time on exams or excused absences. Many young PHers manage to succeed in college by learning their rights and advocating for accommodations.

Lesson #7: Take charge of your health.

It's going to be really hard, if not impossible, to leave your parents to go to college or start a career if you're still relying on them to prepare your medications, remind you to take your pills, or call your doctor when you're not feeling well. It's never too early to begin preparing yourself to transition to an adult PH doctor or take on more responsibility for your daily medical

management. You are your best advocate, so make yourself aware and responsible. Begin by learning your medications and doses. If you are on IV medications, learn to mix and do this 1-2 times a week, slowly increasing your responsibility. If you take oral medications, fill your own pill box, take your medications without prompting from your parents and learn how to request refills.

Lesson #8: Speak up at the doctor's office.

Start speaking directly with your medical team. You know your body and symptoms the best — be your own voice. You'll be amazed at how taking a little responsibility for your PH helps you to feel more independent, mature and capable. Plus it will demonstrate to your parents that you're ready for more responsibility in other areas as well.

Lesson #9: Get to know other people your age with PH.

Being a teenager with pulmonary hypertension is sometimes hard, but it can be helpful to remember that you're not alone. Talking to other teens with PH is one way to get support from people who understand what you're going through. To meet other young people living with pulmonary hypertension, visit PHA's social network for teenagers,

PHA Teens at www.PHAssociation.org/TeenSocialNetwork.

Lesson #10: Have fun.

Hang out with friends, listen to music, study, play video games, read books and watch movies. Find time to try something new every couple of weeks. Seek out causes you care about and activities you love. You're only in high school once. Remember, pulmonary hypertension is something you have, not who you are.

More to Explore

Meet Other Teens with PH

PHA Teens, PHA's secure social network for teenagers 13-18

www.PHAssociation.org/TeenSocialNetwork

My Life As a Chronically Ill Teen, a blog by Becca, a teen with PH

www.lifeasachronicallyillteen.blogspot.com

Consider attending a summer camp for kids with health conditions

www.PHAssociation.org/Parents/Camps

Read More about Coping with PH as a Teenager

Coping with High School and PH

www.PHAssociation.org/Teens/PHandHighSchool

I Love My Life! Living Strong with Chronic Illness, from WebMD

<http://teens.webmd.com/features/i-love-my-life-living-strong-chronic-illness>

Taking on your own care

Teen Transition Guide

www.PHAssociation.org/Teens/Transition

Planning for College

Planning for College with PH

www.PHAssociation.org/Teens/College

Contact a Young Adult Mentor for advice on planning for college with PH

www.PHAssociation.org/Mentors

Students with Disabilities Preparing for Postsecondary Education, from the U.S. Department of Education

<http://www2.ed.gov/about/offices/list/ocr/transition.html>

By Darci Albrecht, LCSW, of the Vera Moulton Wall Center for Pulmonary Vascular Disease at Stanford. Medical review by Debra Hudock, RN, MSN, CNS, of Akron General Medical Center.

Living with PH ... and Your Family

"Our families love us and when we are sick, it affects them because of how much they love us. Don't ever feel guilty but realize that your family is just as scared as you are. They are just as nervous, as worried, as sad, as upset as you are."

"I will never be able to show my mom or my boyfriend just how grateful I am to them for all that they've done for me in this past year alone."

Living with PH ... and your family?

Your teenage years are an exciting and sometimes confusing time as you transition from being a child to being an adult. During this time, you learn more about who you are and who you want to be as an individual. As this happens, you naturally become more independent and it is normal to be less interested in spending time with your family and more interested in spending time with your friends. You may also find yourself challenging your parents' ideas or values as you work toward figuring out who you are. Dealing with family can be really hard for any teen, and living with PH can make your relationships with your parents, brothers and sisters a lot more complicated. Even though it might be frustrating, it's worth the effort to work on

these relationships. At the end of the day, family is an important part of our lives, providing us with the support and love we need to make it through challenges like living with PH.

"Mom, I'm not so different!"

Being a teenager is hard and being a teenager with PH can be even harder. Sometimes this ends up making relationships between teens and their parents more stressful than they might otherwise be. Becca, a 19-year old living with PH, told us, "Just like with any regular teen, the parents are scared to let go. With us it's just a bit more complicated." Your parents may want to help you with your medications or check in with you all the time. On one hand, that might feel a little annoying sometimes, and on the other

hand, it is also nice to know that we are cared for. Sometimes you might feel like you are getting too much attention when it comes to being sick and you might want a little space. Other times it might feel like you need a little extra help with some of the stuff that is going on for you. It's ok to want to be more independent and to still want your parents' help. The important thing is to find a balance and to remember that each person in the relationship should try hard to be respectful of where the other person is coming from.

If you have had PH since you were little, it may be just a part of how your family relates to each other. Your parents and siblings might not know how to treat you any other way. This can be really frustrating when you want to be seen as more than someone with PH. It can be hard to develop who we are when so much focus is put on one aspect of ourselves. It can be a different experience if you were diagnosed with PH as a teenager. If that is the case, you need to know that it is normal to feel sad about how much your life has changed. You were probably used to having some freedoms, like getting to go out with friends and do things on your own, that your parents may no longer want you to do. You might find that people suddenly treat you very differently — even parents and siblings — and that can be tough.

Your parents may worry about your getting sick when you are away from them, and this can impact their willingness to let you stay out late or go out with your friends. You may find yourself arguing frequently with your parents about what you can and cannot do by yourself, like driving, going to parties, or spending the night out with friends. Kiah, now 20 years old, was diagnosed at age 10. She shared, “Balancing your parents’ fears and preparing yourself for facing obstacles on your own is hard.” She’s right — just like a lot of parts of your life, this is a balancing act. Luckily it is one that gets easier with time, patience, and practice.

You may also worry about the impact your PH is having on your parents. You don't want to be a burden to them. One teen with PH we talked to wondered, “What if I have to go on my parent’s insurance and their premiums sky rocket? Will they have to sell their home? Will we have to move out of state just to get better insurance? Will my mom have to get a job?” It can also be confusing to see your parents sad, upset, or worried. Many teens with chronic illnesses feel a need to protect their parents from feeling this way. This is a lot of extra stress and not one that most teens have to worry about. This might feel unfair, because it isn't fair. You did not choose to develop PH and it is important to remember not to take on so much worry and responsibility. If you

find yourself worried about some of these big issues, share that with your parents. They will likely be able to give you some insight into their situation and help you feel better about it.

“Love them or hate them, siblings are for life.”

As you probably know all too well, living with PH can also impact your relationships with your siblings. Siblings might not understand why you have to take so much medication or undergo certain tests. They may also be worried about you and not know how to act around you while they get used to your diagnosis. Older siblings may try to act like they know what's best for you. Younger siblings may be upset with you for getting extra time and attention from your parents and not really understand what is going on. Kiah told us, “Sometimes parents give more toys, gifts and time to the sibling with the illness and this can cause jealousy.”

On the flipside, you might feel a little resentful or envious of your siblings for being healthy and not having to deal with PH. You might even feel guilty for having these emotions, but that is a completely normal way to feel. You might be watching your siblings get to do things that you are not able to participate in as easily. You might also feel that your parents give your siblings certain freedoms that they don't give you.

What Now?

Like others your age, you have to prove that you are capable of handling greater independence in order to gain the trust of your parents and the freedom that you want. One way you can show your parents that you are responsible is by talking to them about everyday things, not just PH. This creates an open line of communication so that your parents have some insight into what is going on in your life. One teen suggested, “Showing your parents that you are more than your health can help them to realize they need to let you do normal teen stuff like field trips and shopping with friends.” Keeping that open line of communication can also help because when you do need to talk about your health or other serious things, it will feel less awkward starting the conversation. Keep in mind that this is a gradual process and it may take some time for your parents to recognize and trust that you are mature enough to be more independent.

Also remember that it is natural for your parents to want to take care of you and that with some planning and open communication, you will achieve more control, independence, and freedom over your life and your PH. Here are some steps you can take to get that independence and maintain healthy relationships with your parents and siblings:

Moving Forward with your Parents

Take charge. Show your parents that you are comfortable taking on aspects of your PH care and that you're thinking through how you can manage your PH in day-to-day situations. Taking charge shows them that you are taking your health seriously and that you can manage it responsibly. Here are a few ways you can do this:

- Speak up when you are at the doctor's office. Know all of your medications by name and know their doses. Learn what they are for and pay attention to how often you are taking them if they are prescribed on an as-needed basis. Pay attention to any side effects that you may experience and share those with your physician. Also, share openly about how you feel your health is when speaking with your physician. Ask your PH provider about any test results and what to expect before your next visit. If you have questions about your health, you should ask them. This is your health and you have the right to know how you are doing from a professional's perspective. Speaking up at the doctor's office will show both your parents and your doctor that you take your PH seriously and are ready to take on some of the responsibility for managing your illness yourself.
- Talk to your parents about what aspects

of your PH care you are ready to take on for yourself. When you feel ready, you may want to take care of your central line, mix your medications, or order your oxygen therapy. When you need a prescription refilled, let your parents know that it is time to request one. If you have a refill available through your pharmacy and do not need to see your physician, take the initiative to call the pharmacy and order it. You do not need to do all of these things at once, but each time you are able to successfully take on a new aspect of your PH care, you are showing your parents that you are more ready for independence.

Think it through. You'll have to negotiate curfews, responsibilities and freedoms just like any other teen. Think through your requests in advance so you can anticipate what your parents might be worried about and have solutions ready. Though it might feel like a lot of work, demonstrating responsibility and the ability to make good decisions works wonders when it comes to gaining your parents' trust.

- Negotiate with your parents about things like curfew and activities with friends. Be reasonable with your requests — if you are sick, it is probably not the best time to be going out anyway, and, if you are well, you will still have rules and restrictions to follow just like other teens.
- Think about how what you are asking

to do will affect your PH. Be prepared to tell your parents how you anticipate your PH impacting the activity — for instance, if you are asking to spend the night at a friend's, do you need to set an alarm for your medication? Does your friend understand what activities are safe for you to do? Do your parents trust you to say something when an activity is not safe? Showing them that you are aware of your health and can take the initiative to be assertive and make good decisions goes a long way towards being given more freedom. Having a plan and talking your parents through how you plan to accommodate your PH will show them you are ready to take on the new activity.

- Offer to check in with your parents at frequent intervals at first. If they see that you are doing well, they will be more likely to let you go out in the future and you can gradually reduce the need to check in and reassure them. Texting your parents is a great way to check in without drawing attention from your friends.
- Write down or text your parents the address of the place(s) where you will be going with friends. Let them know if your plans change. Knowing where you will be can help your parents feel more comfortable with your going out.
- Even though it might be annoying, embarrassing, or inconvenient, always

answer the phone when your parents call. Ignoring their calls increases the chance that they will worry more than they already are. It also sends the message that you do not want to be bothered by them. While this might be true to an extent, try to accept that these phone calls are coming from a place of care and love. Talk to your parents if you feel that these calls are excessive and negotiate a way to check in that feels comfortable for all of you. It is also important to let them know if you will be somewhere where you will not be able to check your phone. For example, if you are going to see a movie, let them know ahead of time when you will be inaccessible. Chances are that once your parents realize that you are able to handle this responsibly, they will give you a little more freedom and require you to check in with them less frequently.

Think ahead. As a teenager, you're probably already thinking ahead — to the college you want to attend or the job you want to have, to moving out of the house or traveling.

- For big decisions about your future, give your parents time to adjust to the changes you want to make. "Be open with your parents about what you want your future to look like regarding things like college, moving out, etc.," recommends Anna, a 15-year old PH

teen. “If you’re clear with your parents early on about how you want to slowly make these changes in your life, they will be less resistant and it gives them time to get used to the idea.”

- Don’t hide symptoms from your parents. They will be more likely to trust you to do things when you say you are feeling well if you are honest with them when you aren’t feeling well. Demonstrating this in smaller instances, like not going out if you aren’t feeling well, is a good way to show your parents that you will also be smart when it comes to bigger decisions like traveling or attending college.

Focus forward. At times it can be easy to get caught up in the struggle over what you want for your future versus what your parents want. Most schools have professionals who can meet with you and your parents to help you understand different career paths and help you decide what colleges, occupations, or professional school might be a good fit for you.

Back to center. Remember that if your parents restrict your activities, it is because they want to know you’re safe. Just like you may feel at times that your parents are being unfair or unresponsive, they probably also feel frustrated at times and unhappy with being the “bad guys.” When you’re feeling like you and your parents are on opposite sides of an issue,

remember that your parents want what’s best for you. Remind them that you appreciate them, even when you disagree.

Gain outside perspective. You may feel like the impact of PH on your family is overwhelming, but it’s important that you don’t try to shoulder these concerns on your own. Think of a trusted friend, teacher, or mentor who you can talk to openly. Maybe your sister or brother would understand. If you ever feel like you need a safe and unbiased place to talk, ask your parents about talking to a counselor. Often someone outside the situation can offer you a fresh perspective.

Be open with your parents. Tell your parents if you have any worries about how PH is impacting them. Let your parents know if they are saying things about you and your PH that are hurtful to you. Remind them that you love and appreciate them when they do things that help you, and forgive them when they do things that aggravate you. Expect the same from them. You can both help these conversations go smoothly by giving and receiving information in a calm manner.

Moving Forward with your Siblings

Be a friend. Discuss and share everyday things with your siblings, like activities you both enjoy. Ask about their day at

school. Care about what is important to them. Your siblings will likely look to you for cues on how to act. You can set the tone for them to treat you like any other brother or sister.

Be open with your siblings. If you’re worried that your PH is impacting your siblings, ask them. Similarly, if your siblings say things about your PH that are hurtful to you, be honest with them about it. Remind them that you appreciate them when they do things that help you, and be forgiving when they do things that annoy you.

Keep your cool. Sometimes when we feel frustrated or jealous, it is easy for us to lose our cool. Maybe you snap at your sister or maybe you all out tear into your brother. Instead of losing your temper, practice calming yourself. Take a moment to step aside and focus on the problem at hand. Are you mad at the person or at the situation? If it’s at the situation, is there something you can do to change it? If it is at the person, how can you share what you are feeling without yelling or fighting? If you are having trouble calming down, go to a quiet spot where you can reflect and calm down. Being angry can affect your mood and your body. You might notice yourself breathing faster and more shallowly. You might feel your heart rate increasing. It is especially important to monitor this and try to calm down.

Expect things to go wrong sometimes. Siblings argue and sometimes say hurtful things to each other. This is a completely normal aspect of being a part of a family. Don’t expect perfection from anyone, including yourself. We all make mistakes and we all need to be forgiven. If you say something hurtful, apologize. If your sister or brother says something hurtful to you, tell them and help them understand why it was hurtful.

Friends for life. Though it can be hard to imagine at times, your siblings might end up being some of your closest friends in life. Treating them with love and respect helps build that relationship. You are also entitled to love and respect from them and are allowed to share when you are not feeling loved or respected. Many adults share a special bond with their siblings unlike any other. That bond comes from going through good times and hard times with them. Keep in mind that it is all part of the larger process of growing up.

More to Explore

Meet Other Teens with PH

PHA Teens, PHA’s secure social network for teenagers 13-18

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

TeenSocialNetwork

My Life As a Chronically Ill Teen, a blog

by Becca, a teen with PH

www.lifeasachronicallyillteen.blogspot.com

Read More about Coping with PH as a Teenager

Coping with High School and PH

www.PHAssociation.org/Teens/PHandHighSchool

I Love My Life! Living Strong with Chronic Illness, from WebMD

<http://teens.webmd.com/features/i-love-my-life-living-strong-chronic-illness>

Dealing with a Health Condition, from TeensHealth

http://kidshealth.org/teen/your_mind/problems/deal_chronic_illness.html

Taking on your own care

Teen Transition Guide

www.PHAssociation.org/Teens/Transition

Planning for College

Planning for College with PH

www.PHAssociation.org/Teens/College

Contact a Young Adult Mentor for advice on planning for college with PH

www.PHAssociation.org/Mentors

Students with Disabilities Preparing for Postsecondary Education, from the U.S. Department of Education

<http://www2.ed.gov/about/offices/list/>

[ocr/transition.html](http://ocr.transition.html)

By Holly Gooding, MD, MSc, of the Division of Adolescent and Young Adult Medicine at Children's Hospital Boston. PHA is grateful to all the teens who shared their experiences to make this resource possible. Additional review by Virginia Maril, MPsy, Texas Woman's University.

Friends, Peers and PH

"I have to take my treatment at school, which means I have to do it between classes. I get to class late every day now, and everybody asks why I'm late. I want to explain to them that I have to take medicine, but I'm afraid that they will make remarks."

"I've made new friends, and these new girls are more concerned about body image than my old group. It's hard to explain everything about PH all over again."

"My friends act like I'm normal, which is nice until I'm in a situation where I can't run, swim, or be extremely active. I wish they would show more sensitivity to my disease and accept the fact that I am different."

The Balancing Act

Being a teenager means that you have entered a stage in your life when you want to try new things, be more independent, and develop your own identity. This is a time in life that is both exciting and challenging. As a teen with PH, the fact that you have a chronic illness will be added to the usual issues and challenges that many teens face, such as peer pressure, body image and sometimes even bullying.

Spending Time with Friends

Going to the movies, a school sporting event, or hanging out at someone's house — all fun activities, right? Doing these things might mean bringing your medication or oxygen along with you. At times it may also mean that you can't join in on the activities with your friends. One teen shared, "If I want to go out, I will have to bring my treatment equipment with me, and I'm afraid of what my friends might say when I need to take my medicine."

Being with your friends means that you

have to balance your health needs with your social life. This means feeling independent enough to take your medication and also feeling comfortable enough with letting your friends see you take care of your PH. Some teens may feel embarrassed to the point that they decide to stay home rather than go out with their friends.

Peer Pressure

Peer pressure occurs when your friends are pushing you to do something or act in a certain way in order to fit in. Sometimes this isn't a big deal, but other times you may be uncomfortable with what your friends are asking you to do. Many teens give in to peer pressure because they worry about losing their friends. Friends might pressure you to try drugs or alcohol, stay out past your curfew, or lie to your parents about where you are going. You might feel compelled to take part in activities that can put your health at risk including running, swimming or playing active sports. One young adult described, "I found that the times I felt the most pressure, particularly when I didn't want to tell someone about PH, was when my friends or acquaintances took off running, or wanted to go hiking, bike riding, etc. I was always tempted to go ahead and try."

As a teen with PH, these things can actually put your health — and your life — at

risk. It can be hard to tell your friends that you can't or don't want to do something. You might worry that your friends will not want to hang out with you anymore. But remember, if they are good friends, they do not want to put your health in danger and will not pressure you to do anything you do not want to do.

Bullying

Another challenge that many teens face is bullying. Bullying is unwanted, repeated aggressive behavior such as spreading rumors, making threats, physically or verbally attacking someone, or purposely excluding someone from a group. These things can happen in-person or online. Sometimes people don't take bullying seriously or they think that the victim should "get over it" or "toughen up," but bullying is a serious and dangerous situation that can result in severe consequences for the bully and the bullied.

Teens with PH may get picked on for their medical equipment, scars from surgeries, or just because they have different health needs than the teens around them. Becca, a 19-year old teen with PH, shared, "I even had someone look at a picture of me, put her hand over my scar and say, 'You'd look way better if you didn't have that.'" Bullying is a very hard thing to go through. No one has the right to make you feel bad about yourself. If

you are being picked on or bullied, let your parents and school administrators know what is happening. You can also visit stopbullying.gov to learn what you can do to prevent, respond to, or help stop bullying.

Self-Image and Dating

Your teenage years are a time when your body and your tastes are changing. It might feel important for you to begin to express yourself through the clothes you wear. Teens with PH sometimes worry about how they can dress like other teens while still accommodating their PH. You probably want to fit in with your friends, but most likely you are the only one of your friends who has a catheter or an oxygen tank.

You may also be interested in starting to date. Dating can be stressful at any age. For example, it's hard to have feelings for someone and not know if they like you back. You might start to be particularly aware of what you look like, what you say, and how you interact with your romantic interest. For teens with PH, this can be especially stressful. Not only do you have the typical worries that are a part of dating, you also may worry about whether your PH may impact how a romantic interest may relate to you. One teen told us, "Having PH can definitely make you feel undesirable, especially if you are

already self-conscious about treatment equipment and oxygen." If you have a significant other, you may feel pressured to be physical in ways that you are not comfortable with or that could put your health at risk.

Adapting and Moving Forward

Being a teen with PH can be tough, but it does NOT mean that you can't have great friends, feel good about yourself, and fit in with your peers!

Tip #1: When you feel ready, talk to your close friends about PH

If you have close, supportive friends, you may want to explain to them what PH is and how it impacts your life. Choose to tell friends who you trust and who you feel will be supportive and understanding. You could even practice with a parent, if you feel nervous. Your friends are probably curious about your PH, but may be afraid to ask you about it for fear that they will offend you. So start the conversation yourself! If you need to take your medication while you are hanging out with your friends, this may be a good place to start. Show them your treatment equipment and explain to them why you need it. This will likely spark a conversation about what PH is. You can explain to

them what kinds of activities you can and cannot take part in. If your friends know what PH is and see your equipment, it becomes familiar to them and less awkward for you. Shannon, a 17-year old with PH, even brought her best friend Jen to PHA's 10th International Conference.

Explaining PH will hopefully make your friends more sensitive to planning future activities that you can take part in. If they do make plans that you can't take part in, you can remind them of your conversation. This will hopefully make it easier for you to hang out with your friends and feel comfortable with them. This will also allow your friends to get to know you better. Carson, a young adult with PH, told us, "I've learned that if you're willing to open up, let your friends in and tell them your story, it makes them feel closer to you. They are dealing with something, you're dealing with something, and it might be different, but it's a way you can connect. Letting them in, giving them the chance to go through the good times and bad times with you, is really important."

Tip #2: Don't let peer pressure put your health (and life) at risk!

Not giving into peer pressure can be very hard. Rather than taking that sip of alcohol or going on a strenuous hike, explain to your friends how doing those

things could put your health and life at risk. They will understand and be less likely to pressure you to do anything that could be harmful to you. If people don't know about your PH and try to pressure you, be calm and take their questions or comments as an opportunity. Becca told us, "When people ask questions or say something that seems rude or insensitive, I remind myself that they most likely did not mean to be rude. I tell myself that if I answer their questions with a smile, then I can help bring awareness to PH."

If you feel uncomfortable explaining the risks to your friends or other teens, then practice saying no or have a reason ready to use to leave early. You can have a pre-arranged signal with a friend, sibling or your parents for them to text, call or pick you up. Being prepared will help you feel safer.

Tip #3: No one deserves to be bullied

You should never be bullied or made fun of. If this is happening to you, talk to a teacher or a school administrator you trust. Tell your parents. While you might feel like you are "telling on" a peer, this is actually a way of standing up for yourself. You can also talk to your close friends about what's going on. Being able to share your pain with trustworthy friends will feel good, and your friends may even

help you to stand up to the bullies. If you are being bullied because of your PH, reach out to other people who have PH and talk to them about their experiences with bullying. You can connect with other teens who have PH at *PHA Teens*, a secure social network for teens living with PH, at www.PHAssociation.org/TeenSocialNetwork.

Many people who are bullied end up becoming bullies themselves. Don't let that happen to you! One PH teen says it perfectly, "I believe my heart condition has made me a better person. I have been picked on because of my scar, my extraordinarily long hospital visits, and the way my medications have affected me. This is why I'm never the bully." Use your experience with adversity to stand up for others who aren't able to. Setting an example for others to stop bullying is a powerful gift.

Tip #4: Get creative with your PH equipment!

If your PH makes you feel embarrassed about your body and how you look, get creative! Find ways to hide your pump and catheter. Decorate your oxygen tank. Put your medications in a cool looking bag. If you are confident about how you look, other people will respect you and you will feel better about yourself. Shannon emphasizes, "Just be yourself and don't worry about what other people

think."

Tip #5: Dating

If you worry that your romantic interest might not want to date you because of your PH, remember the many aspects of yourself that you like and all that you have to offer. PH may be a major part of your life, but it doesn't mean that it makes up all of who you are. If you are worried about your PH equipment being a "turn-off" to your romantic interest, get creative with your clothing. If you are in a romantic relationship with someone you trust, you may want to consider explaining to this person what PH is and how it impacts your life (see Tip #1 for some additional guidelines).

You have the right to feel comfortable and safe in a relationship. If your significant other is pressuring you or making you feel uncomfortable, speak to your parents or a counselor. If you have questions about what love is, what it isn't, and what you should expect from a relationship, check out the Bill of Dating Rights at http://www.twu.edu/downloads/counseling/E-2_Bill_of_Dating_Rights.pdf.

If you are considering exploring a sexual relationship with your significant other, be sure to speak to both your PH specialist and your primary care doctor. Pregnancy can be dangerous for women

with PH. The worst thing you could do is decide “in the moment” and not be prepared. If you are feeling pressure from your significant other — either to go farther physically than you are comfortable with, or to not use protection — speak to your parents, a school counselor, or another adult whom you trust for advice on how to explain to your significant other what you want and need. No one has the right to make you feel like you “have to” do something that you are uncomfortable with or that puts your health at risk.

More to Explore

Meet Other Teens with PH

PHA Teens, PHA’s secure social network for teenagers 13-18

www.PHAssociation.org/TeenSocialNetwork

Consider attending a summer camp for kids with health conditions

www.PHAssociation.org/Parents/Camps

My Life As a Chronically Ill Teen, a blog by Becca, a teen with PH

www.lifeasachronicallyillteen.blogspot.com

Read More about Coping with PH as a Teenager

Coping with High School and PH

www.PHAssociation.org/Teens/PHandHighSchool

I Love My Life! Living Strong with Chronic Illness, from WebMD

<http://teens.webmd.com/features/i-love-my-life-living-strong-chronic-illness>

By Nicole Vengrove Soffer, MSW, LCSW, of the Division of Adolescent/Young Adult Medicine at Children’s Hospital Boston. PHA is grateful to all the teens who shared their experiences to make this resource possible. Additional review by Virginia Maril, MPsy, Texas Woman’s University.

Creative Expression as a Coping Tool

“I feel left out because I can’t participate in most of the activities that others can. I feel as if most people would think I was a freak. I don’t share my emotions easily so nobody knows how I feel.”

“Art was my passion; it’s who I was. Then, in a heartbeat, everything changed. I found out I was in the ‘severe’ stage of PH and was ‘knocking on death’s door.’ When I first got out of the hospital, I lost everything, including my desire to do so much as pick up a pencil.”

How Has Life Changed

It is not easy to be a teenager: Your body is changing, you are learning to be your own person independent from your parents, you might be feeling the tug of peer pressure and you probably have a million things on your mind. If you have a chronic illness like pulmonary hypertension, you may feel fear and anxiety when the needs of your illness intrude on all the other things you are trying to juggle in your teen years.

So, what challenges do you face as a teen with PH? Independence is a big one. You are learning to be your own person separate from your parents, but you still need

to rely on them for help in managing your disease, and sometimes your parents might be afraid to let you be too independent because they want to protect you and take care of you. Parents of teenagers with a chronic illness often find it harder than other parents to let their children be independent, and this can feel frustrating.

Fitting in with other teenagers can also present many challenges. You feel different: You might not be able to play sports, you might have to wear a pump, you may have lots of medication to take, and you may have to miss school or plan activities around doctors’ appointments. Trying to fit in with other teenagers who do not face the same obstacles can add a lot of

pressure to your life.

You can probably think of lots of other things that are difficult about your life as a teen with PH, and they can all add up to stress. The signs of stress can look different in everyone. Some people get irritable or moody, others get stomach-aches or headaches. Lots of people feel sad or depressed, and when you are stressed, it can be difficult to sleep at night.

On the other hand, sometimes stress can encourage us to get something done (like when we're stressed out about a school assignment, so we pay extra close attention to it and work really hard to complete it). Stress is an emotion we may feel when our bodies are responding to different demands in our lives. It's our body's way of rising to a challenge and preparing to meet that tough situation with focus, strength, stamina and heightened alertness. A little of this type of stress can help keep you on your toes. You are ready to meet whatever challenge comes, and then afterwards, your nervous system quickly returns to normal and you can relax.

Other times, stress can be really bad for us. Long-term stressful situations — like situations where you are constantly dealing with the demands of a chronic illness — can produce a lasting, low-level stress that's hard on you and your body. Your nervous system remains on high alert, and

you can't relax.

Since our bodies are not meant to be on high alert all the time, we need to find ways to deal with the stress and relax. What can we do?

Moving Forward: Finding Ways to Relax through Creative Expression

Think of stress as a boiling pot on a hot stove. The steam is building up, and you need to find a way to release the steam before the water boils over or the pot explodes. That's what we need to do with stress — find a way to release it before we find ourselves with a stress overload. Keep in mind that sometimes we do need to look to others like our parents or our doctors to help us deal with stress. If you are about to boil over or explode with too much stress, you might need to ask for help.

At other times, however, we can deal with stress on our own. Many teenagers in the PH community turn to creative activities to help them blow off steam and clear their minds. You can listen to or create music, journal and write about your feelings, meditate, create artwork or write poetry. You can be as creative as you want to be! Studies show that any type of creative expression can improve your physical, mental and emotional well-



"Human Spirit" by Katie Tobias

being by helping you to relax. When you engage in calming activities, you trigger your body's relaxation response; it's your body's opposite of stress, and it creates a sense of well-being and calm.

Here are some examples of creative techniques that you can use to help you get started and trigger your body's relaxation response:

Music: Music can be therapeutic and stress relieving, whether you listen to it or create it yourself. Jack, age 15, loved to play baseball, but when he received his PH diagnosis in 2009, he had to give up the sport. "I thought my whole life was over," Jack says. "I thought I was really restricted." Instead of focusing on what he could not do, Jack discovered music

and began taking guitar lessons. He wrote his first song and uploaded it to YouTube in May 2011. "I was surprised how easy it was to express myself through lyrics," he says. "It was pretty easy to come up with lines." The song, "You Are My Everything," became a hit, and Jack was asked to perform it live in November 2011 in New York City alongside hip hop artist Proclaim. You can check out Jack's music at www.YouTube.com/user/JackkLarsenMusic.

Journaling and writing: Becca, age 19, finds writing to be a therapeutic form of expression. She says, "I want to take my feelings and gift for the written word and transform lives and bring awareness to this disease." Through her writing, she has even found ways to educate her classmates about PH and the way she feels as a patient: "For English class we had to write a poem about food. I chose my favorite place to eat, which is Kentucky Fried Chicken. Since I am on a low salt diet because of my PH, I decided that it would have a lot of emotion behind it, along with the memories of when I used to be able to eat it." Becca writes regularly on her blog, *My Life as a Chronically Ill Teen*, at www.liferasachronicallyillteen.blogspot.com.

Artwork: Expressing yourself through art — such as painting, drawing and sculpting — can give you an outlet for feelings that

you just cannot put into words. Katie has always been an artist. When she received her PH diagnosis at age 19, she discovered that art could also be therapeutic for her: “Art has a way of freeing the spirit and bringing peace and tranquility to the soul. It is a non-judgmental form of expression. It accesses the parts of our brain that feel but cannot use words. Everyone can experience the amazing healing qualities that come from making art, whether you consider yourself an artist or not.”

Cartoons: Nicole, age 17, created a cartoon character named Alfie to help her deal with her PH. She says, “My message to all is that even though you’re sick, that doesn’t mean you can’t do anything. It doesn’t mean that you have to isolate yourself. It doesn’t mean that you are a freak. It doesn’t mean you have to give up. When I feel alone, I think of those others who have chronic illnesses, and I feel better knowing that they know how I feel and that gives me hope.”

Photography: Julie, age 15, has been living with PH for four years. She enjoys taking pictures and finds photography to be both relaxing and therapeutic: “By doing photography, I forget about PH and the difficulties of life, and I focus on what’s in front of the lens. I’m capable of pausing time and capturing the wonders of the world.”

Meditation: While meditation is not an outward form of creativity in the same way as the previous examples, meditation can help calm your mind and allow you to refocus your energy to tap into your creative side. Try to make meditation part of your daily routine (like washing your hair or brushing your teeth). Sit quietly for a few minutes each day. Take deep breaths and try to clear your mind. If thoughts come into your mind, that’s okay. Acknowledge them, and then send the thoughts back out again. If music helps you, turn on some quiet, soothing tunes as you meditate. Sometimes, when you are first learning to meditate, it might be helpful to follow along with a meditation recording. Your local library may have meditation recordings.

These are just a few of the many ways you can use creative outlets to express yourself and relieve stress. There’s no wrong way to be creative. As long as you are enjoying the experience and feeling more relaxed, you are doing it the right way. What types of creative activities do you participate in? Join the conversation at www.PHAssociation.org/TeenSocialNetwork.

More to Explore

Read More About Stress and PH

PHA Teens, PHA’s secure social network for teenagers 13-18

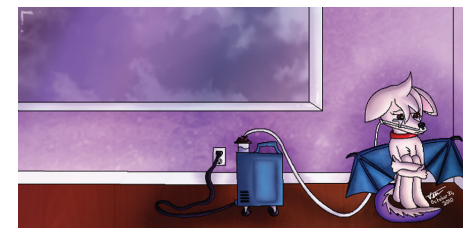
www.PHAssociation.org/TeenSocialNetwork

Learn more about stress on TeensHealth http://kidshealth.org/teen/your_mind/emotions/stress.html

Read Kiara’s post on the Generation Hope blog for young adults on using creative expression as a coping tool <http://PHAGenerationHope.blogspot.com/2012/02/put-your-headphones-on.html>

Check out [Writing out the storm: Reading and writing your way through serious illness or injury](#) by Abercrombie, B. (2002).

PHA is grateful to the teens who shared their experiences and artwork to make this resource possible. PH medical review by Mike Hayes, RN, BSN, CCRN, Pulmonary Clinical Nurse Coordinator at Intermountain Medical Center in Murray, Utah.



Nicole created the character of Alfie to help her express her feelings about having PH.



Otter, photographed by Julie



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

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