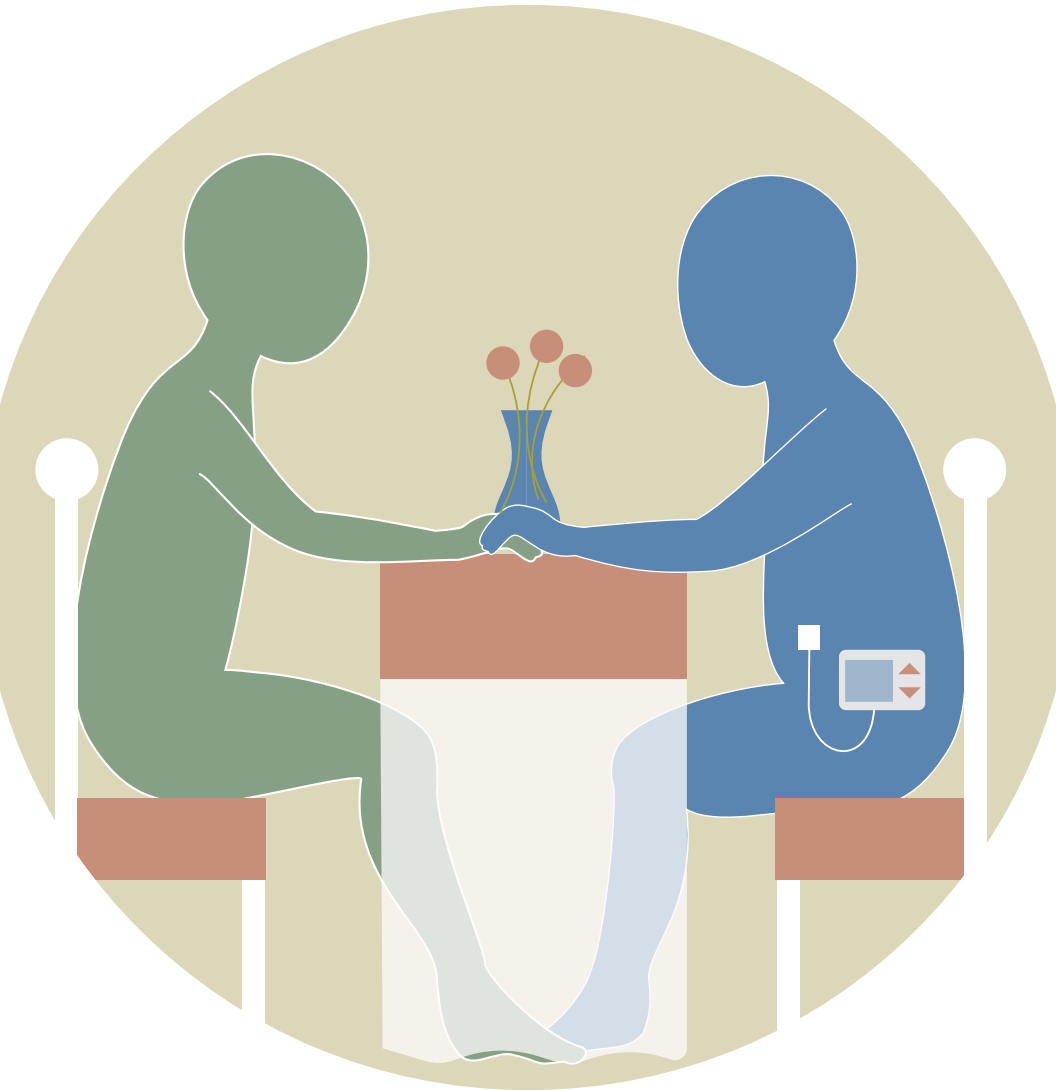
LIVING WITH PH

A GUIDE TO INTIMACY



PHA Pulmonary Hypertension Association
Empowered by hope

ACKNOWLEDGEMENT

PHA gratefully acknowledges the Pulmonary Hypertension Association, U.K., and authors Carl Harries and Iain Armstrong, who wrote the original resource, *It matters to me, A guide to relationships and intimacy for people with pulmonary hypertension*.

DISCLAIMER

This guide has been created for adult members of the PH community interested in or engaged in physically intimate and/or sexual activity and contains sexually explicit information including references to sexuality and sex—both written and in images. PHA respects that it is the parents' responsibility to teach their own beliefs about these topics to their children and it is not the intent of PHA to promote or distribute this guide to children under the age of 18 without parental approval. As part of our mission, however, PHA makes its educational/information resources generally available through our website and store.

This resource is not designed to be a substitute for medical advice. As with any physical activity, you should talk to your doctor about whether you are healthy enough to engage in sex or any of the other activities described in this resource. PHA makes no warranty or guarantee as to the effectiveness of the methods described within this guide or that the activities are safe for all individuals. You assume full responsibility for how you choose to use this resource.

CONTENTS

INTRODUCTION 4

INTIMACY, SEXUALITY AND PH 6

RELATIONSHIPS AND PH 11

PH AND YOUR SEX LIFE 13

RESPONSIBILITY AND SEXUAL HEALTH 21

SUMMARY 22

INTRODUCTION

You have been diagnosed with pulmonary hypertension (PH). Like many other chronic illnesses, PH can affect you in different ways, such as your outlook on life, your sense of wellbeing and/or your mental health.

Living with PH may affect your relationships—whether you are dating or in a long-term relationship. If you find that you have questions about or concerns with intimacy and/or sex, rest assured you are not alone. Questions and concerns about intimacy and/or sex are common in people dealing with a new, serious diagnosis, but having a healthy love life is still possible! Many concerns with dating, relationships, intimacy and sex are common among those with and without an illness. It is important to realize that it's perfectly natural to feel concerned about intimacy and sex and that there are many ways to overcome concerns about continuing your sex life as you live with PH. You may need to find new ways of being aroused, gratified and fulfilled, but don't let PH control your sex life or get in the middle of your intimate or sexual relationship(s). There are creative techniques to be spontaneous, erotic, romantic and flirtatious.

The goal of this guide is to explain how PH and its treatments can affect you and discuss ways of coping and adjusting to the life changes that often accompany serious and chronic illness. Changes in your health due to your PH may happen at various stages of your life. As you move through these stages, PH may affect your behaviors and feelings. Over time, you also may see how different relationships can be affected. By anticipating potential changes and challenges, you may have an easier time confronting them and coping in a healthy way.

Many people, whether they are single or in a relationship, find it difficult to talk about sex and intimacy issues with their sexual partners. This guide has been created to help you talk about subjects of a sensitive matter, and to start conversations at a time in your life when it may not be easy to do so. This guide is for anyone with PH, no matter your age, relationship status or sexual orientation. It also may be helpful to share this booklet with your sexual partner(s).

You may need to find new ways of being aroused, gratified and fulfilled, but don't let PH control your sex life or get in the middle of your intimate or sexual relationship(s).

INTIMACY, SEXUALITY AND PH

Intimacy and sexuality are two ways in which we can express our feelings and desires. It is important to take the opportunity to make the most of your intimate relationships to have a fulfilling sex life.

Healthy intimacy involves feelings and actions of emotional closeness, trust and affection. It offers you the freedom to show and share your emotions, physically or verbally, without fear or embarrassment.

Touching, hugging and kissing are all physical acts of intimacy — these may lead to sex or be part of lovemaking, but aren't in themselves necessarily sexual. They can simply be signs of affection.

It can be challenging to maintain the same levels of intimacy you may have had previously when you are suddenly thrown into a world of hospitals and specialists, tests and medications. PH may lead to changing roles in your family or needing extra help from your loved ones, as well as the uncertainty of levels of functionality in day-to-day life that comes with a PH diagnosis.

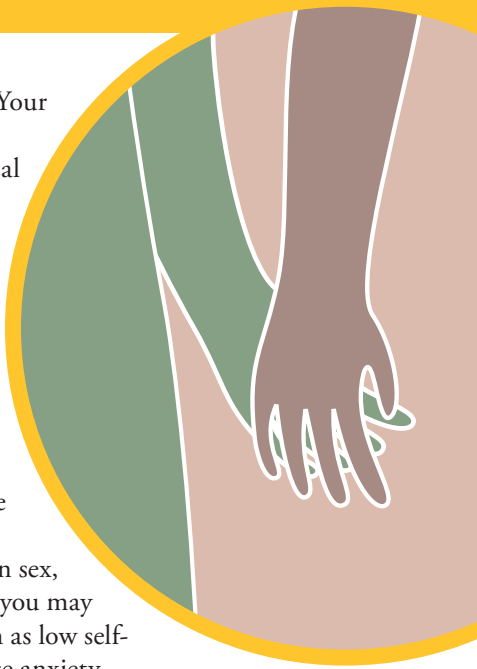
Being able to confide in someone, to rely on their support, or to simply feel their arms around you at a time when you need them most can be very reassuring. Emotional intimacy can be as important as physical intimacy.

SEX AND PH

Sex can be casual and fun, or for the purpose of self-expression or gratification. It also can be an important part of an intimate relationship, which may be the first and most obvious aspect of a love life to suffer as a result of a serious diagnosis such as PH. This diagnosis may be very stressful to both you and your partner(s), and it may have a temporary or permanent effect on one or both of your sex drives. PH itself will not limit your sex drive, but the symptoms and side effects of some treatments may suppress it. Living with PH and managing your health can take a lot out of you. Be ready to accept, at least temporarily, that you or your partner(s) may not want to have sex now or as frequently as you did. Also, the desire for sex may come and go, depending on other factors in your life and health.

It is possible that PH will have a real and lasting impact on your relationships and sexual activity.

There are many reasons why someone may have a low sex drive, including the symptoms of PH and side effects of treatments. However, low sex drive can sometimes be attributed to mental health, hormone levels and/or stress. If you have concerns about your sex drive, it is important to be open and honest with your health care provider(s) — as well as with your sexual partner(s) — to help



identify possible causes and find a solution. Your previous ways of expressing sexual intimacy may need adjusting to meet your new physical limitations from PH. There are ways to successfully do that.

It is possible that PH will have a real and lasting impact on your relationships and sexual activity. In addition, PH can be diagnosed as associated with other conditions, such as congenital heart disease, heart failure and connective tissue disease, which also can impact one's sexual ability and level of intimacy. Common physical side effects of PH, such as breathlessness, lack of energy and fatigue, can affect your interest in sex, which can be very frustrating. Additionally, you may face more challenging emotional issues, such as low self-esteem, poor body image and/or performance anxiety.

Coming to terms with PH can be a challenging roller coaster ride of conflicting anxieties and emotions. When you are coping with medical appointments, new treatments and changes to home and work life, sex and intimacy may be the last things on your mind. Desiring sex and intimacy, however, are very normal and healthy feelings which do not have to be suppressed as you navigate living with PH.

A creative and open-minded approach to overcoming physical and emotional obstacles to sex and intimacy may ultimately lead to a more enjoyable and rewarding love life.

A creative and open-minded approach to overcoming physical and emotional obstacles to sex and intimacy may ultimately lead to a more enjoyable and rewarding love life — maybe as good as or better than you had before the PH diagnosis!

SEXUAL FRUSTRATION AND GETTING "IN THE MOOD"

It is important to let your partner know if you don't feel interested in sexual activity if/when he or she initiates foreplay or sex. Even though it may feel awkward to say, it can be helpful to explain how you feel and what you are experiencing so that he or she does not feel rejected. You may suggest an alternative option, such as, "I don't want to have sex, but I would love to spend

time with you and cuddle (or make out)," or "I don't feel up to having sex, but I'd be interested in trading foot and shoulder massages."

If your partner is feeling sexually frustrated, there may be ways other than sex that he or she can reduce his or her frustration. You can discuss or explore masturbation, either mutual or alone, as a way of achieving sexual satisfaction. Do not be ashamed or hesitant to talk about masturbation; it is a very safe, healthy and natural act for any person—alone or with a partner.

Phone sex is another way to connect with your partner when you are away from one another and want to share your intimate thoughts.

Masturbation can be performed during sex with a partner to heighten your own pleasure, or watching a partner masturbate or masturbating together can be arousing. It can be combined with intimate talk about your arousal, physical feelings you are experiencing, what feels good and/or expressing your sexual fantasies. Masturbation also can involve sex aids, also known as sex toys, to heighten pleasure with less physical exertion.

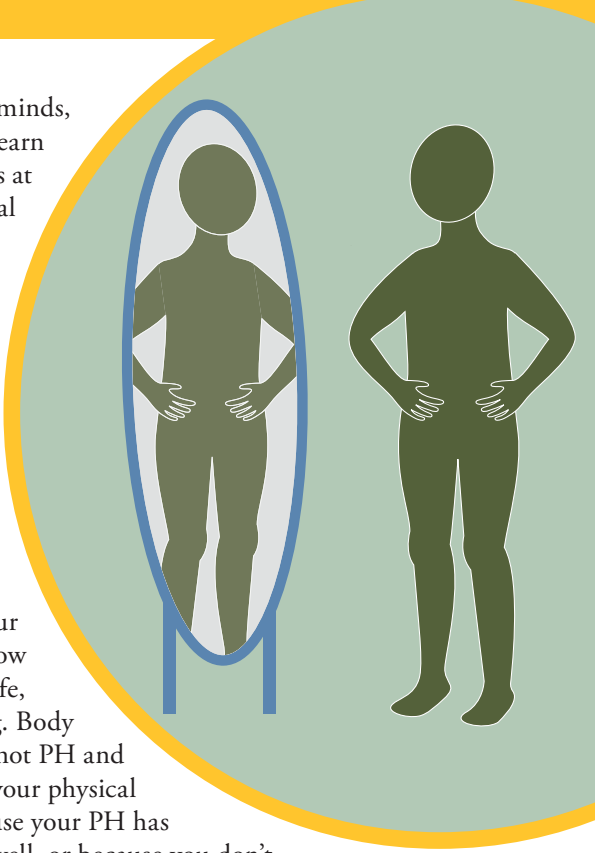
If you're not feeling in the mood to have sex but would like to later, sexting (flirting sexually through texting) or sending email or voice mail messages to your partner throughout the day to build excitement may help set the mood for later sexual play. This can help take the pressure off the expectation of spontaneous interest in sex. Phone sex is another way to connect with your partner when you are away from one another and want to share your intimate thoughts to arouse him or her (and yourself) and to enjoy pleasure together long-distance.

Sometimes, just starting with kissing can lead to making out, and making out can get you and your partner interested in having sex. Literary erotica is just what it sounds like—sexy stories. There are websites and books dedicated to storytelling for sexual stimulation. Additionally, video erotica (or pornography) is something you may explore to discover what interests and arouses your partner and you.

ATTITUDES TOWARDS SEX

Attitudes towards sex and sexuality vary from person to person. Remember that you are a unique individual—when considering sexuality and intimacy, it is important to focus on all of your needs, wishes and desires. Many people worry about what is considered normal. The

reality is that we can change our minds, find new things pleasurable and learn how to communicate in new ways at any time. We all have the potential to feel good about who we are and to choose how we share that feeling with others—emotionally and physically.



BODY IMAGE

Body image is the mental picture you have of your physical appearance as compared to how you think you should look. This image is not drawn from how your body actually looks, but rather how you view yourself. Throughout life, your body is constantly changing. Body image can be altered whether or not PH and its treatments cause a change to your physical appearance. It may happen because your PH has worsened and you aren't feeling well, or because you don't feel confident after your diagnosis.

Changes in body image can cause feelings of distress that go far beyond the physical effects of PH and its treatments. When there has been a sudden and possibly dramatic change in body image, you may feel different both physically and emotionally. You also may experience feelings of shame, embarrassment, inferiority and/or anger. When a change to your body is a visible one (such as having to wear a pump to deliver your PH treatment or nasal cannula for oxygen), these feelings can be made worse by the reactions of other people.

It may help to talk through your concerns with your partner, a close friend, family member or a mental health professional.

Dealing with changes to your body image can be difficult. It may help to talk through your concerns with your partner, a close friend, family member or a mental health professional. Talking to your PH nurse(s) also may help. They have seen many people go through the same thing. In addition, PHA is here to help you find resources. PHA understands the issues involved and can match you with PH mentors who have had similar experiences and who can offer you advice and support.

MYTHS ABOUT SEXUALITY AND PH

Many myths exist about sex and long-term conditions such as PH. When people with PH and others start to believe these myths, it can hinder the sharing of close moments together.

Let's now try to understand and dispel some of these myths.

Myth: BECAUSE I HAVE PH, I AM NOT SEXUAL OR DESIRABLE

Life with PH may have changed a lot for you. You may have oxygen or an IV line, have experienced weight changes or noticeable differences in stamina. These changes can feel like deterrents to your sexuality, but you still are very much worthy of love and affection. Do not let the fact that you have PH discount that you have the body, brain, temperament and libido of an adult. The truth is that you remain a person with your own sexual identity and you are worthy of expressing that in ways that work for you. You should be able to tell your partner what your needs and wants are, whatever your age or physique. To do this, it is important for you to have some idea of what you want and need from your sexual and intimate experiences.

Myth: PEOPLE WITH PH CANNOT HAVE NORMAL SEX OR EXPERIENCE PHYSICAL INTIMACY

There is no such thing as normal sex. Just look at the scenes that exist within film and television shows, where we are told how sex is supposed to work. There, sex is portrayed as progressing from light activity, such as kissing, to a full-blown bedroom scene, sometimes with multiple orgasms, in less than 10 minutes (and typically only portraying male to female intercourse through vaginal penetration). These portrayals frequently present sex taking place in a variety of positions and locations, all in the same session.

The truth is that sex is more than penetration and orgasm. People who cannot or choose not to have penetrative sex still can have real experiences of intimacy and still can express their sexuality in a meaningful way.

Myth: PEOPLE WITH PH HAVE MORE IMPORTANT THINGS TO WORRY ABOUT THAN SEX

This myth originates in a belief that sex is not a priority in life. This myth also evolves from the belief that people with a serious condition such as PH lose the desire for an enjoyable and meaningful sex life and intimate moments.

Believing this myth risks limiting your sex life and could damage your self-worth. Sexual interaction and physically intimate moments can be a good outlet for stress and can distract from the day-to-day worries of living with PH. It also can be a time to feel safe, to be vulnerable and share your feelings about having PH, and for your partner to open up to you.

RELATIONSHIPS AND PH

Many people are single for long periods of their life. Even if you are not in a relationship or choose to never be in one, that doesn't mean you are not a sexual individual. You may be very interested in sex and your sexual wellbeing.

You may decide to engage in sexual relationships as a single person for a while or for the rest of your life. You also may choose to have sexual experiences on your own, through masturbation and/or exploration of erotica.

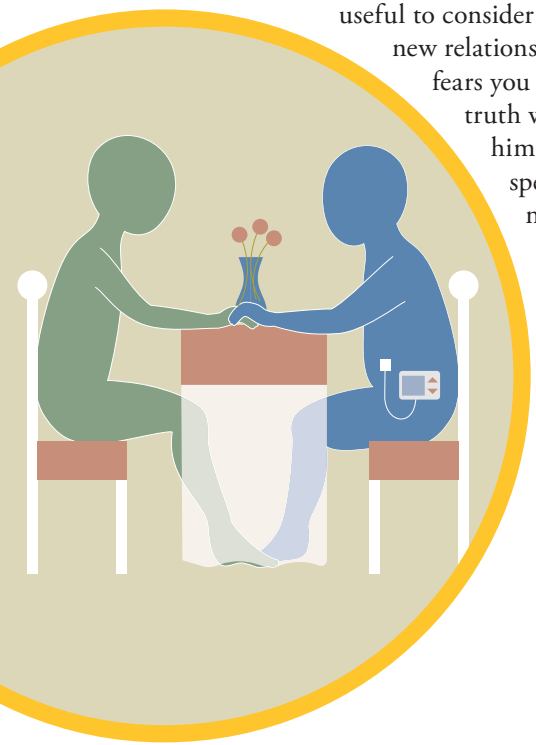
While happily single, you also may be interested in meeting new people and dating. If your diagnosis is a recent adjustment to your life, or if you have been single for a long time, you may experience some nervousness about navigating the dating world with PH.

DATING AND STARTING A NEW RELATIONSHIP

A popular way to meet new people and/or start new relationships is through online dating sites and/or mobile apps. These services vary in how they work, and in the numbers and types of people they attract, so it's worth looking into options before signing up. Sometimes, it is helpful to talk to someone who has used a particular service prior to paying for it. Consider joining a private Facebook group for men or women with PH where you can meet others of the same gender who likely have experienced similar situations and may have great advice.

Creating a dating profile (which generally includes a photo and information about yourself and your preferences) often brings up the question of whether or not to disclose a disability or illness, and when. Should you include that you have PH in your profile, bring it up before a first date or wait until you know if the relationship is going to continue? There is no one right answer to this question. You are in control of how much you tell people about your PH and when you tell them. As you begin to date, it may be useful to consider waiting until you feel safe in your new relationship, and perhaps to talk through any fears you may have about sharing a vulnerable truth with your new partner before you tell him or her about your PH. You also can speak first to a trusted friend, family member or therapist to help talk it through before you decide if you should tell a partner and when. This is particularly important if you have an infusion pump that your new partner does not yet know about and has not seen. You have a right to feel safe and comfortable before sharing information about any medical condition.

You have a right to feel safe and comfortable before sharing information about any medical condition.



PH AND YOUR SEX LIFE

Changes in the regularity of sexual activity can be a normal part of getting older; changes in regularity are also part of the natural cycle of most relationships, no matter your age. Interest and participation in sex may decrease as a relationship matures and strengthens. Sometimes this is due to increased comfort in a relationship and sharing intimacy and feeling fulfilled in other ways. In addition to this, people with PH may find that their condition and treatments or side effects impact their desire and/or ability to have sex.

SMALL CHANGES, BIG RESULTS

Having a fulfilling and meaningful relationship really does start with communication. Although you may know your partner very well, neither of you can read each other's minds. In a relationship, satisfying sex requires sensitivity and vulnerability from each partner. In the context of the physical part of a relationship, it is helpful to take the time to tell your partner what arouses you and makes you feel good. Listen to what he or she likes, too. Making small changes can have significant effects on the quality and frequency of your sexual activity. For example, mix it up by choosing different ways of initiating sex, communicating what turns you on and what you would like to try, and by changing positions and locations to keep things exciting.

Making small changes can have significant effects on the quality and frequency of your sexual activity.

BREATHLESSNESS AND FATIGUE

Breathlessness and fatigue are the most common symptoms of PH and can worsen during sex due to exertion (or sometimes nerves with a new partner). Sex is an energetic activity; during sex, your heart rate and breathing will typically increase, and it may take some time to recover. This process can be exaggerated for people with PH. This may be scary for you and your partner. It may be helpful for you and your partner to agree on a word or phrase that you can say to signal that your breathlessness is more than just from the sexual activity and

you are uncomfortable. This approach may be useful, so your partner is not continually asking, "Are you okay?" or worrying about your breathing while you are trying to relax and be present during your special time together.

If you use oxygen occasionally, you may find that using it during sex is beneficial. If you are prescribed oxygen for use with activity or for continual use, wear it during sexual activity. Talk to your PH specialist or nurse about whether extension tubing to allow for more space between you and your oxygen tank or concentrator may be an option for you.

Sometimes fatigue during sex can be as much as, or more of an issue than breathlessness. Energy levels can become quickly depleted with only a little sexual activity. However, this does not mean that satisfying sex is no longer possible; it just means that you may need to change your approach and take your time.

If you have PH, one thing to avoid during sex is holding your breath for any reason. One way that people hold their breath is called the Valsalva maneuver, which is when you close your mouth and hold your breath as if you were going to blow up a balloon, which fills your abdomen with air and creates pressure in your chest. The Valsalva maneuver also often involves bearing down (like when you create pressure to initiate a bowel movement). You may not associate bearing down with sex, but the Valsalva maneuver can be an instinct with penetration (whether oral, vaginal or anal), especially at the beginning. Additionally, some people hold their breath leading up to or during climax and are not even aware that they are doing the Valsalva maneuver. Sometimes, a man will bear down while attempting to keep an erection longer or to avoid premature ejaculation, but this is dangerous for a man with PH. Remembering to breathe regularly during sex is very important for someone with PH to avoid passing out, dizziness or cardiac arrest.

IT'S ALL IN THE TIMING

Consider having sex at a time when your breathing and energy levels are at their best—perhaps in the morning or early afternoon. Don't be afraid to you let your partner know the times you are feeling at your best.

Consider having sex at a time when your breathing and energy levels are at their best—perhaps in the morning or early afternoon.

When it comes to initiating sex when you are feeling good, be creative! Maybe wearing a special undergarment or sleepwear can be a nonverbal cue to your partner that you are interested in having sex. Sometimes, saying something sexy about how attractive your partner is and that you would like to spend some time with him or her in bed (or naked) will kick things off.

KNOW YOUR LIMITS

There may be times when you choose a great time, place and comfortable sexual position, but you start to feel very short of breath or very tired during sex. It could be on a particularly hot day, if you forgot to take your medication or perhaps enthusiasm just got the better of you. In any case, it is important that you know what your limits are and stick to them. Do not be afraid to try again later when you are feeling better.

You should also let your partner know when you need to pause or stop, so that you can catch your breath. Pausing for a moment should not spoil the moment, but do not be hurried into continuing until you are sure you are ready. Remember, your partner may not be able to tell whether you are gasping with pleasure or because you cannot breathe properly. Often, simply slowing down will allow you to recover enough to continue. If in doubt, slow your activity and control your breathing.

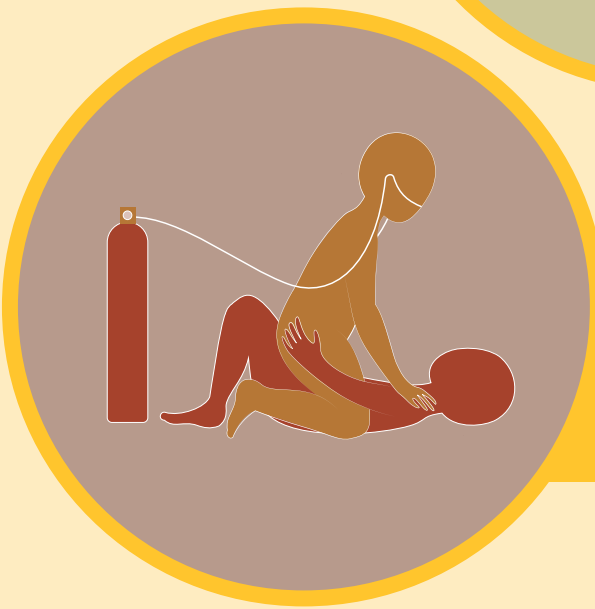
SEXUAL POSITIONS

Some sexual positions may be difficult or uncomfortable for people with PH. It is important that you avoid positions that put weight on your chest. Being able to breathe freely during sex is obviously very important, especially for people with PH who become more breathless during sexual activity. Be patient as you explore with a partner which positions work for you without discomfort.

Some of these positions may work better for heterosexual couples, but the same principles can be applied to same-sex couples. The idea is to ensure that the person with PH has no pressure on their chest and can breathe freely during sex. The following pages show some sexual positions that may be more appropriate. Of course, the best and most enjoyable way to find out what suits you both is to experiment! Trying new positions might seem awkward at first, but just embrace the laughter that might accompany the awkwardness! You may need to try a position on more than one occasion to see if it is a good option for your partner and you. It may take several tries to find positions that you both enjoy and in which you are both comfortable. Remember, you do not have to stay in the same position all the time; you can change whenever you like. Changing positions frequently has the added advantage of avoiding undue stress being placed on any one area of your body and also helps provide some variety to your sexual experiences.

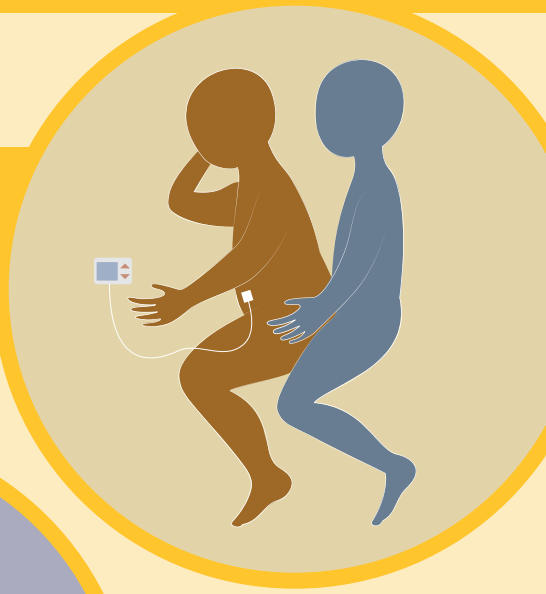
Seated with the receptive partner on top.

Lying down with the receptive partner seated on top.



Lying down with the receptive partner's hips propped up on a pillow to maximize erogenous zones (e.g. "G-spot").

Both lying on your sides, either facing each other or with the penetrative partner behind.



The receptive partner bent (leaning) over and supported by the edge of the bed with the penetrative partner behind.

The receptive partner sitting on the edge of the bed with the penetrative partner kneeling in front of him or her (oral sex).

ORAL SEX

Oral sex is one way to express your attraction to and care for a partner, but it also can be a turn-on for the giving partner to arouse and pleasure the receptive partner. There are many positions in which oral sex can be performed, so experiment to find what works best for you, and for your partner. For instance, if the giving partner is kneeling, putting blankets, towels or a pillow under the knees can help with comfort. Lying down on your sides or having the giving partner lie down between the receptive partner's legs may be more comfortable than kneeling.

When changing penetration between oral sex, vaginal sex and/or anal sex, it is important to take precautions to protect yourself from bacterial infections – specifically from anal sex to oral or vaginal sex. For example, if having both anal and vaginal sex in one session, if going from anal to vaginal, the penetrating partner should wash himself or herself between, and if using a condom, throw that condom away and put on a new condom before vaginal penetration. It is advised to use condoms for oral sex, too (when with a new partner or anytime one chooses).

PROPS

Your bedroom is already full of useful props that can make lovemaking more comfortable, relaxed and enjoyable for both your partner and you. The more comfortable you are, the less energy you have to use to fully enjoy sex and the less likely you are to become very breathless.

Pillows, rolled-up towels or blankets can be used for support during sex. They can be placed to make penetration easier and reduce the weight burden of intercourse. Also, propping up the receptive partner's hips on a pillow for penetration can lead to increased pleasure (particularly for a female partner during vaginal sex, as it may lead to G-spot stimulation). For an even more sensuous experience, especially on a cold day, try warming the towels in the dryer first.

A scarf, bandanna or rolled-up pillowcase can serve as a blindfold for sensual play or soft restraint.

For an even more sensuous experience, especially on a cold day, try warming the towels in the dryer first.

Another tool that can be used is lubricant. A lubricant helps to reduce friction and ease discomfort. Personal lubricants can be used during masturbation alone or with a partner or during sex with a partner. They can be water-based, silicone-based, oil-based, or a combination of water- and silicone-based. More natural options such as coconut oil-based lubricants also are available. If/when using a condom during sex for contraception (pregnancy prevention/birth control), as well as protection against sexually-transmitted diseases (STDs) and infections (STIs), only use a water- or silicone-based lubricant. Oil-based lubricants should

not be used with condoms, as they can cause damage to the latex and break the condom. Lubricants are available at your local drug store, or you can purchase them online if you feel more comfortable.

BE CREATIVE

There are many sex acts you can participate in that may both satisfy your sexual appetite and strengthen an emotional bond between you and your partner. If penetrative sex makes you too breathless, using sex toys, such as vibrators, can be a good way to enjoy sexual acts together. Blindfolding your partner, tickling his or her body with a feather, running an ice cube up and down his or her skin, whispering dirty talk or telling your partner what you'd like to do to his or her body to pleasure him or her while making out are some ideas to explore together and build intimacy.

HELPFUL HINTS IN THE BEDROOM

- Have sex in a position that is comfortable and relaxed for both of you and avoid weight on the chest area.
- Experiment with new sexual positions until you find one—or more—that work for you.
- Have sex when you're feeling at your best, even if this isn't at a time that would normally be described as bedtime.
- Use pillows and rolled-up blankets to support yourself or your partner during sex.
- Talk about sex openly and honestly. If you are clear about what you like, you are more likely to get what you want!

YOUR PH TREATMENT AND SEX

In addition to the symptoms of PH, your PH treatments also may affect your sex life. If you are taking a medicine that requires you to wear a pump and a catheter, you will need to be careful and choose positions where the pump, tubing, etc. will not be in the way. If you need oxygen during sex, you will have to take into consideration the tubing and position of the oxygen cylinder or concentrator.

Some treatments may cause side effects such as nausea, headache, palpitations and generally feeling unwell. These side effects may not be present all the time, but if you have them, sex may be the last thing on your mind. Talk to your PH specialist if the side effects of your treatments are becoming very troublesome and are affecting your quality of life and ability to be sexually active.

PH AND ERECTILE DYSFUNCTION

Sildenafil (Revatio®) and tadalafil (Adcirca®) are two medications frequently used in World Health Organization (WHO) Group 1 PH (pulmonary arterial hypertension, or PAH), and also to treat erectile dysfunction (ED). ED is the inability to attain and keep an erection firm enough for sex. Sildenafil is in Viagra®, a medication prescribed to treat ED; tadalafil prescribed for ED is in a medication called Cialis®. If you are a man who has been prescribed one of these medications to treat your PAH, you might not experience the same erection enhancement effects as men prescribed one of those medications for ED. This is mainly because the medication dosages used for PAH are different than the dosages used for ED. However, medications affect different people differently.

ED is common in men living with diabetes and kidney disease, as well as heart disease. If you are experiencing ED and you have PH, talk to your PH specialist(s) so they can help you meet your personal goals to live your best life with PH, including sexual activity. Proper nutrition, not smoking and limiting alcohol also are important for a healthy heart, lungs and sex life.

If you have WHO Group 2 PH (PH due to left heart disease) or WHO Group 3 PH (PH due to lung disease), talk to your PH specialist before taking sildenafil (Viagra®), tadalafil (Cialis®), vardenafil (Levitra®, Staxyn®) or avanafil (Stendra®) for ED.

RESPONSIBILITY AND SEXUAL HEALTH

Although having PH may affect your ability to have sex, it is important to know that having PH provides absolutely no protection from pregnancy, STDs or STIs. It is crucial that you take your own sexual and reproductive health seriously. The Centers for Disease Control and Prevention (CDC) website (www.CDC.gov/SexualHealth) can help you learn about protecting yourself.

Pregnancy can be dangerous for women with PH. During pregnancy, a woman's blood volume increases tremendously. If you are a woman who has PH, this added volume and pressure can be very risky as your heart and lungs may not be able to safely handle these changes. Pregnancy in women with PH can result in severe heart failure and even death. In addition to the risks to a woman's life in pregnancy, some medications that treat PH may be harmful to a baby developing in the womb. In general, women with PH should avoid getting pregnant; speak to your PH specialist about your individual situation before making reproductive decisions.

If you are a woman planning to have or are having sexual intercourse with a man, first have a plan for contraception (birth control). Contraception means ways to prevent pregnancy. This may be a difficult and embarrassing subject to raise, especially with a new partner, but it should be discussed as soon as possible and prior to having sex. Contraception should be thought about carefully by people with PH. Various PH treatments can make some types of contraception much less effective, and certain types of oral contraceptives could even make your PH worse. Your PH specialist can give you more information about pregnancy and birth control with PH, so do not be afraid to ask him or afraid to ask him or her questions. In some cases, a woman with PH may be required to use more than one method of birth control at the same time, so careful planning is important.

If you are a woman planning to have or are having sexual intercourse with a man, first have a plan for contraception (birth control).

We have emphasized that having PH need not mean the end of your sex life. However, regardless of your gender and sexual orientation, having PH does not reduce your responsibility to take your sexual health seriously. If you have concerns about your sexual health, it is best to discuss these with your health care professional or to visit a local health clinic. Health clinics may offer confidential assessments and treatments that are not shared with your other health care providers without your permission.

SUMMARY

Being intimate and having a fulfilling sex life is an important part of any relationship—with yourself or with a partner(s). Having a serious condition such as PH may affect your intimate relationships and sex life, but there are many ways to overcome intimacy and sexual issues you may face.

The American Association of Sexuality Educators, Counselors and Therapists (AASECT) is a non-profit, interdisciplinary professional organization for individuals that share an interest in promoting understanding of human sexuality and healthy sexual behavior. **www.AASECT.org** can help you find sexuality educators, counselors, therapists and more in your area.

A good rule to follow is the three Cs, which will help you maintain a good, loving and fulfilling relationship.

- Communication
- Creativity
- Commitment

Open and honest communication is an essential part of any relationship and can enhance feelings of trust and confidence (and therefore, intimacy). You may find that you become closer to your partner by talking through any issues and worries you have. Feeling closer emotionally may lead to increased confidence to initiate sex more often or help to get yourself and a partner in the mood.

Creativity is important as you get used to the effects PH has on your body. Remember that there are many ways to give and receive pleasure, and there can be much more to sex than penetration alone. Finding alternatives and new ways to express yourself and play with yourself or a partner can be fun and very sexy.

Commitment to each other—and your relationship—will give you time to discover long-term solutions to even the most difficult of problems. Talk about it, use your imagination and stick with it until you find the solution that works best for you—and have fun practicing! If you are single, a commitment to your sexual wellbeing and exploring pleasure as part of your quality of life is important. Get to know yourself, what turns you on and what fulfills you sexually.

Talk about it, use your imagination and stick with it until you find the solution that works best for you—and have fun practicing!

It is important that you maintain a view of yourself as a whole person, including your sexuality. Focus more on what you can do rather than what you cannot do, and remember that people love you for who you are. With good communication and creativity, you may end up having a better sex life than before!

ABOUT THE PULMONARY HYPERTENSION ASSOCIATION

The Pulmonary Hypertension Association (PHA) is a community of patients, caregivers, families, health care professionals and researchers who work together to empower people battling the disease, pulmonary hypertension (PH), while supporting research toward improved treatments. PHA was the first organization in the world dedicated to providing comprehensive PH patient and caregiver support, medical education, specialty care services that improve patients' quality of life and research.

PHA's mission is to extend and improve the lives of those affected by PH. Our vision is a world without PH, empowered by hope.

PHA facilitates more than 200 active support groups around the country and is a convener of more than 85 international PH organizations. In addition to in-person support, PHA offers a telephone support line, an email mentor program, educational patient programs and a variety of print and online publications. Every two years, PHA hosts the PHA International PH Conference and Scientific Sessions that brings together nearly 1,500 patients, caregivers and medical professionals to share information about the latest research, treatments and lifestyle coping tips.

PHA also has provided nearly $8 million for PH research and offers continuing medical education (CME) programs for medical professionals through the PHA Online University and in-person CME programs.

PHAssociation.org
PHA@PHAssociation.org
301-565-3004

Support Line:
800-748-7274

Copyright © 2019 Pulmonary Hypertension Association

/PulmonaryHypertensionAssociation

@PHAssociation

/PHAssociation

/user/PHAssociation