

PULMONARY HYPERTENSION
ASSOCIATION OF CANADA

.....
L'ASSOCIATION D'HYPERTENSION
PULMONAIRE DU CANADA

Emotional Wellness

Handbook for PH Patients

INTRODUCTION

Pulmonary hypertension is an illness with a dramatic emotional impact: in addition to a range of physical symptoms, there can be extensive emotional symptoms depending on the severity. Regardless of its impact, PH leaves the sufferer with daily challenges that can undermine even the strongest individuals.

At a facilitated focus group with PH patients, participants talked about the daily barrage of negative self-talk that frequently erupted in their battle with pulmonary hypertension. Some of the thoughts mentioned included:

- *“I can’t”;*
- *“Will it get me?”;*
- *“Who am I going to disappoint today?”;*
- *“I hate my body sometimes!”;*
- *“I am betrayed”;*
- *“I am trapped”;*
- *and “What will be my battle today?”*

From a counselling perspective, each of these thoughts produces an intense array of emotions.

Given the demands of daily life and the physical strains of managing the illness, many emotions get trapped in the body, creating an enormous build-up of unresolved feelings. This makes daily physical challenges much harder—as we know, our emotional state impacts our physical condition and can lead to emotional crises. In this light, it is helpful to highlight the emotion triggered by the illness and understand the feelings more deeply so we can start emotionally healing.

Emotional Wellness Handbook for PH Patients

One aspect of emotional healing that is profoundly helpful is that it makes us feel more in charge of our life, undermining one of the central aspects of the illness: “feeling out of control.”

According to patients, the negative emotions that are most prevalent in their PH journeys are:

- Fear
- Anger
- Anxiety
- Depression & Hopelessness
- Sadness
- Guilt & Shame
- Invalidation
- Self-Pity & Entitlement
- Grief & Loss

The following sections of the Emotional Wellness Handbook for PH Patients will explore these emotions and others and will provide tools and ideas to learn about emotional wellness and self-healing.

FEAR

Fear can consume our day, make the most minor task seem unattainable, and have us quivering in a corner, wondering who will save us from the torment we are experiencing. Fear builds on fear.

Fear says:

“You can’t! Nothing you can do will take your suffering away. Your old life is gone, and you will never get your identity back.”

Fear encourages us to give in, give up, and give over to the illness and let it have its way with our bodies. Fear loves to be in charge, dominates, and plays havoc with our relationships.

It tells us: *“they don’t care about you,” or “you are a burden to those around you.”*

Fear creates distance from those who genuinely care for you. Fear also wants to convince you that your efforts are meaningless and that you cannot effect any positive change with your struggle with pulmonary hypertension. The truth is fear is a bully, pushing you around, trying to take away your power and making your day unbearable sometimes.

Here’s what we can say back to fear:

- How dare you push me around!
- I am doing everything I can to alleviate the symptoms of the illness.
- I will exercise my power as much as I can.
- I know I am resilient: I can be strong in the face of a struggle and look for small steps of accomplishment when I feel powerless.

Emotional Wellness Handbook for PH Patients

We can also consider the following potential responses/reactions to fear:

- When I struggle to breathe, I will take a break and remind myself that I can pace my day to lessen my symptoms.
- On the days that I can, I will do a little exercise or mindful breathing to help me feel calmer and protect against fear's cruel ways.
- When I feel fear build up in my body, I will write fear a letter and tell it all the ways it tries to manipulate me, educating fear that I am onto its tricks and devious ways, and remind myself that I am in charge.
- I can also write a list of positive affirmations and attributes I genuinely believe about myself. When fear tries to control my day, I can drain its power with reminders of my strength and ability to adapt to change.

Deep down, if I recognize and acknowledge fear, I have already started to minimize its impact on my day and my struggle with Pulmonary Hypertension.

ANGER

Anger is a common human experience in response to loss and change in our lives. When we struggle daily with pulmonary hypertension, it is to be expected that we will experience anger.

Anger reminds us that we can no longer do what we have always done. Anger pays attention to our losses and ratchets them up in our minds, so we are confronted with our illness's physical and emotional limitations. Anger teams up with irritability and reminds us of how unfair life can be.

Anger is a natural emotional consequence of a mass change in our life; however, we also need to pay attention to its dark side.

The dark side of anger says unequivocally: *“You deserve to have an outburst; it is ok to shout or throw things at others because we are suffering.”*

It also says that you must have a meltdown for others to truly understand what you are going through. When it is dark, anger links up with self-righteousness and says we are justified in our response: that we are the only ones battling with the impact of pulmonary hypertension and that we are all alone in our struggle. If we are wise, we can become more alert to the dark side of anger and undermine its temptations.

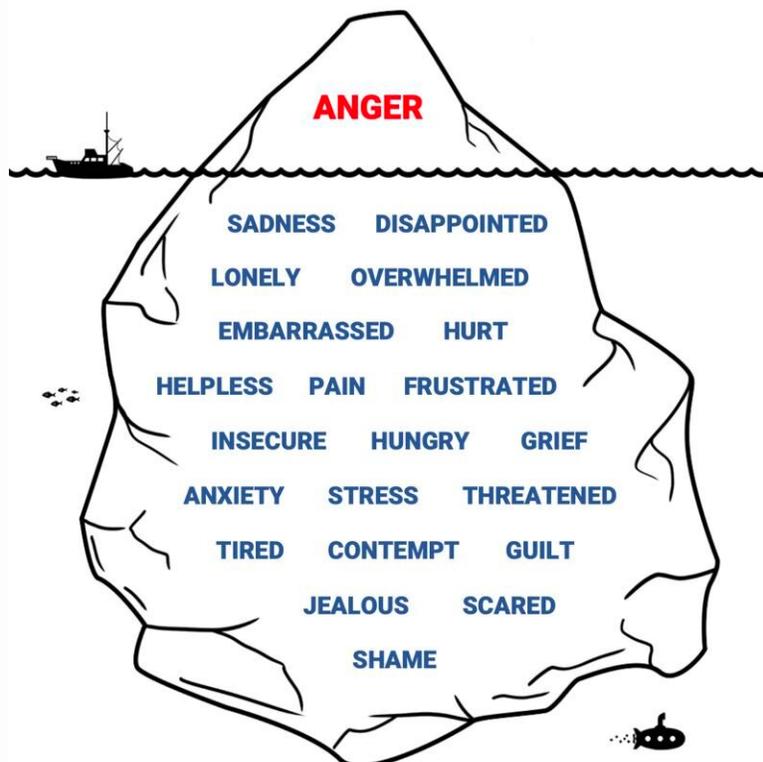
The next time we are angry, we can take a “time out” so we don't inflict our pain onto others in the moment. In the time out, we can write out a list of all our feelings and thoughts, expressing everything on paper and releasing anger's poison so we can become more aware of what lies beneath the anger.

Emotional Wellness Handbook for PH Patients

The most powerful way to think about anger is that it is the tip of the iceberg and that a whole array of feelings lies beneath it. If we discover the feelings underneath the anger, we have found an effective way to drain its power and release it.

Anger is a bit like an onion, we peel one layer, and then another arises. Anger is often fuelled by all the losses we experience due to the impact of pulmonary hypertension on our daily lives.

Anger can provide a path to discover all our emotional pain. By discovering it, we can lighten our emotional load and move closer to experiencing moments of peace.



ANXIETY

Anxiety sits just underneath the surface of our hearts, and with the tiniest change in our world, we are all a flutter. It takes away our ability to focus and makes it challenging to hear what others are saying. It feels almost impossible to get a task done as we are scattered and need clarification about why we feel the way we do. Given our struggle with pulmonary hypertension, it is expected that we would feel a great deal of anxiety. Many questions with few specific answers often torment our life.

For example:

- How much will I get done today without feeling flattened with fatigue?
- Will I cope with the social commitments I have made?
- Am I doing too much or too little?

The list goes on, and the questions collect around our hearts unanswered. Anxiety builds with uncertainty and the expectation that we should know all the answers. Expectation often converts to internalized pressure; the more it builds, the more anxiety rules the day.

An important strategy for anxiety is to look beneath the surface. Anxiety is often the tip of the iceberg; it is all the feelings underneath anxiety that give it power and control. For instance, embarrassment, sadness, shame, bitterness, and despair may all be undiscovered. If they continue to be there collecting as “issues in our tissues,” then anxiety builds inevitably along with unrealistic expectations. An unrealistic expectation may be that we can continue to care for our children, run a household, and buy groceries weekly. This may be unreachable, given the seriousness of our symptoms.

Daily journaling of our feelings can be a powerful way of releasing anxiety. We sit in a quiet place, take some time to be still and breathe the best we can, and then, with a pen and paper, let the feelings out. Sometimes journal writing can be scary; feelings can come out that are tough to face, yet keeping them buried significantly adds to our anxiety.

Emotional Wellness Handbook for PH Patients

Some of the feelings may be:

- I feel sad
- I feel despairing about PH and my ability to manage the illness
- I feel scared of the illness's progression. How will I cope then? I am terrified to die
- I feel angry, confused, ashamed, guilty, bitter, etc.

When feelings are unacknowledged, they build up toxicity in our system. Each challenging feeling also bombards our minds with negative self-talk. Our mind may repeatedly say, “you are not trying hard enough to tackle your illness; you need to try harder.” Honouring and releasing our feelings is the most powerful way to regain our strength. Another key strategy to managing anxiety associated with pulmonary hypertension is to keep bringing ourselves back ‘to the moment.’ Anxiety and worry can build whenever we try to predict the next hour, the next day, the next month and the next year. All our lives are soaked in uncertainty, all human beings will die, and we don’t know when. With PH, the clock is harder to ignore. Each day can feel a day closer to death. Staying focused on death robs us of being alive at this moment. In essence, our lives are made up of precious moments when we bring presence and awareness to now.

Moving into the now can be tricky when our minds are busy. However, one way we can do this is by being aware of our breath; focusing on breathing instantly brings us into this moment. Being in the moment is healing medicine for a terminal illness; the more we can live each moment, the more we can accept the uncertainty around letting go of life as we know it.

With anxiety managed more efficiently, we may still have tough days battling pulmonary hypertension. However, our meagre resources can assist our physical struggle, particularly when our emotional world is more soaked in acceptance of what is and moments of peace.

GUILT AND SHAME

Guilt wants you to believe you are “not deserving.” One example could be guilt telling you that you are unworthy of self-compassion or others’ compassion.

Guilt likes to speak in shoulds; the more shoulds it can terrorize you with, the more you suffer wave upon wave of shame.

Guilt says:

- *“You should try harder even though you are struggling with pulmonary hypertension.”*
- *“Others are managing better than you.”*
- *“You should smarten up.”*
- *“Stop thinking so negatively.”*
- *“You should be able to do more for your family and friends.”*
- *“You have survived with PH, and others have not.”*

Guilt jumps on any deficiency you feel and magnifies it, so you are drowning in self-loathing.

If pulmonary hypertension has you struggling to get out of bed in the morning due to fatigue and feelings of depression, guilt torments you with its negative rant:

“You should have gotten up and made breakfast for everyone by now, and you are using the illness as an excuse to be lazy, quit indulging yourself! You should be making better use of your days; you are just making excuses for yourself; everyone can see that.”

Emotional Wellness Handbook for PH Patients

By the time guilt has ranted, you are even more exhausted to face the day. All your limitations run through your mind—you can't help it—and by listening to guilt rattle on, you now feel a great deal of shame. Shame is guilt internalized. You are convinced that you are the real problem, that others with pulmonary hypertension would be managing better than you, and that something must be wrong with you.

The best way to drain guilt and reduce its tormenting powers is to say out loud every day:

- *“I am worthy of self-compassion.”*
- *“Others may not be able to see the impact of my illness, but that shouldn't take away my ability to honour my struggle.”*
- *“I know this illness is very challenging; it is hard to breathe sometimes, my energy is very low, I feel depressed, I can't exercise in the same way, and I feel dizzy often.”*
- *“I am doing the best I can given my limitations.”*

To be self-affirming, sometimes we need to release the tormenting voices. Writing down all that guilt says can be a powerful way of draining its power. So, get a little PH journal if you don't already have one, or open a new file on your computer. We can recognize “should” as the demeaning tool and retort back with: *“Quit the guilt trip on me! I am doing my best!”* Please write a letter to guilt and let it know you are on to its manipulative ways. Let guilt know how you will fight back.

Instituting a self-care plan (including some of the above ideas) is a great protector. If we treat ourselves well consistently, even if we feel undeserving of self-care, we develop a thick protective armour against guilt and shame and their devious ways.

LONELINESS

Loneliness tears at the heart; it talks to you in sad tones and communicates some of the following:

- *I am battling pulmonary hypertension alone most of the time.*
- *My family and friends don't understand what it is like for me.*
- *I don't feel like socializing when I feel depressed, down and frustrated with my illness.*
- *It is hard for others to hear the depths of despair I sometimes feel.*
- *What's the point of communicating when others just give me advice? They don't understand my illness.*

Loneliness is persuasive; it wants to get its way: it wants you to isolate so that it may intensify. Loneliness knows that it can get so intense that you may feel your very soul has been devoured by it. The lonelier you feel, the more depression can take hold.

In essence, loneliness gives us a choice: we can give in to it and listen to its voice, isolate more, talk less, have our world shrink and then shrink some more, and keep reminding ourselves how utterly alone we are, or we can gradually resist its wily ways. It's not easy to resist, but we can start with small steps and go from there.

Emotional Wellness Handbook for PH Patients

Small steps may include some of the following:

- I will connect with the PH community and tell them how lonely I sometimes feel.
- I will try and sit in public places (i.e. the library or a coffee bar) to feel people around me.
- I will write a list of the people I have in my life and remind myself of any kind acts they have done for me when I am suffering.
- I will think of a small thing I can do for someone else to reduce my lonely feeling.
- I will do some journal writing about how I feel to release the feelings and don't stay focused on them.
- I will write a list of social activities I can do when I feel lonely and focus on doing one of them in the next couple of days.

Loneliness is well aware that the more action you take, despite the lonely feeling, the more likely you will drain its intensity. Challenging feelings like loneliness are a bit like big waves arriving at the shoreline. When they arrive at the edge of our souls, they crash and often feel overwhelmed. However, if we continue our self-care program and take actions that marshal our inner resources, they start to recede little by little until, finally, they have gone for a while. Feelings like loneliness are guideposts letting us know that we have needs that are not being met and that it is wise to address them early before they build into waves of tsunami proportions.

SADNESS

We often have more **sadness** with pulmonary hypertension than others because we deal with so much loss. Sadness is to be expected when grief and loss haunt our days and nights. Sadness remembers clearly what we cherished in our life pre-pulmonary hypertension, and it reminds us that the loss needs to be honoured. Sadness doesn't want things to be brushed under the carpet; that is not its way.

Sadness is determined to be noticed and painful memories to be remembered. It stands firm and refuses to go away. It builds when we try to ignore it and waits patiently in our bodies to be expressed.

When sadness has been unacknowledged, it is stored in tension. One's day can start with the expected array of challenges. Still, built-up pressure will have us overreacting, for example, by being intensely irritable or angry in response to the slightest obstacle. That's how sadness communicates; it gives us that overwhelming feeling as if we can't take another challenge or we will burst. It also interferes with our sleep. Unexpressed sadness has us waking up early, wondering why we cannot get back to sleep.

Repressed sadness also impacts our ability to be with others. We are less present because of feeling overwhelmed. For instance, we meet a friend for coffee, but it becomes hard to focus entirely on what they say when they talk. It is easy to drift off, given that one has limited headspace.

Emotional Wellness Handbook for PH Patients

Sadness wants us to slow down—to take time for stillness and let it rise to the surface. Sadness appreciates when you can take time to do some mindful breathing (when possible), so it can rise with the flow of the breath. Sadness also appreciates when you take time to honour all of your feelings. It is often at a deeper layer, so it can surface when other emotions are expressed. Anger or anxiety can sit on top of sorrow; when we can release them, they allow sadness to rise.

When you don't take the time to honour sadness, sadness has no option but to wait for those moments when you feel overwhelmed and break down. For sadness, that is a massive relief because, finally, it can have a release. The built-up tears can finally flow, and the pain is felt and released—catharsis.

Sadness is confused about why we wait for the build-up. It knows that it would be much more manageable to release it in small doses; you can do this by living a mindful lifestyle where you honour your feelings every day. Practically, this could mean taking time each day to be still and do journal writing—writing out all the feelings you feel at that moment. If you choose, you could also write a letter letting pulmonary hypertension know all your pent-up emotions. Crying is also a powerful way to release sadness as well as talking openly about your feelings to others who are there to support you.

Sadness advises: *“honour me along the way, and I will help you heal emotionally; then all of your inner resources can be utilized to manage the illness as best you can.”*

SELF-PITY

Self-pity and entitlement want you to befriend them, put your arms around them, and treat them like long-lost buddies. It is a trick; both are devious and plan to isolate you and intensify your sense of aloneness. They want you to have unrealistic expectations of others so that you are unsatisfied and feel alienated by those in your life. Self-pity and entitlement both have loud voices, and they like to repeat themselves.

Here are some of the phrases they might say:

- *If other family or friends had pulmonary hypertension, I would always be there for them—how come they are not there for me?*
- *Life is not fair—how come I got this illness? Why am I the only one that has to suffer?*
- *How come I don't get the help that I need?*
- *Can't people see how much I am struggling?*
- *Why don't people ask me questions about how I feel and help me express myself more easily?*
- *Look at all I have to deal with in a day! I should be getting more support and help!*

Emotional Wellness Handbook for PH Patients

The above are some examples, and there are many more because both self-pity and entitlement are creative in how they worm into everyday situations. For instance, it may be a tough day with your illness making it hard for you to breathe and move around freely; you are feeling fatigued already, and the day has just begun. It is as if you are dragging a heavy backpack full of stones on your back. You feel helpless and overwhelmed. This is when entitlement might slip in that you are owed support, that someone else should improve your life. Entitlement says someone else should take over: *“it shouldn’t have to be my entire problem, and so I will just wait for someone to fix me.”*

Entitlement is wrong; every human being is invited to take full responsibility for their situation in life. It is hard, but the best choice we can make as it is only from a place of full self-responsibility that we can grow and heal.

Our healing is frozen when we blame others or wait for them to fix us. We can then experience a lifetime of disappointment waiting to be fixed by someone, whether they are a friend, family member, or therapist. No one else can heal us, not even the best therapist in the world. Only we know our inner world and can effect change by choosing to grow when suffering is high. It isn’t easy; it is unbearable at times, but in essence, it is the only way forward if we don’t want to be stuck in glue for days, months, years, and even decades of our life.

COMPASSION FOR SELF AND OTHERS

Compassion for self and others is one of the most valuable life skills to develop and nurture. It is the greatest threat to judgment. Cruel winds surround judgment and seem to slip into some of the tiniest crevices in our minds. Judgment always has a lot to say about your struggle with pulmonary hypertension.

For instance:

- You will never be able to cope.
- You can't
- You are a loser; you never get it right.
- You are not fighting hard enough; if you did, you wouldn't have so many symptoms.
- You shouldn't have negative feelings.
- You are weak to cry.

Judgment also has a lot to say about others in our lives:

- They don't care about you; if they did, they would do more for you.
- They don't understand what you are going through and never will.
- They are tired of you complaining all the time.
- They think you are faking your symptoms.
- Everybody knows you are using PH to get more attention.
- They should be able to help you more with your struggle.

Judgment's list is endless, and it comes out with its mean-spirited ideas when we are feeling low and vulnerable; that way, it can have the most impact.

The most powerful way to counter judgment is to develop our compassionate selves. Our compassionate self is intent on honouring our efforts and those of others. It knows that the struggle for all human beings is immense and that we are all worthy of compassion.

Emotional Wellness Handbook for PH Patients

Our compassionate self reminds us:

- I am doing the best I can.
- I am a resilient human being and will learn to adapt to my challenging life circumstances over time.
- It is understandable that I would feel a range of challenging feelings, sometimes every day. Struggling with pulmonary hypertension represents an immense emotional and physical load. Some days the grief, loss, anxiety, depression, loneliness, and fear are unbearable. It makes sense that some days I feel buried by the illness and all I can focus on is surviving the day.
- My loved ones are trying hard to cope. They are also experiencing loss and grief, and their lives are undergoing tremendous change.
- I can show self-love by practicing self-care and boosting myself with those actions that make me feel self-nurtured.
 - I am strong, and I am coping well considering my circumstances.
- If there is an unhealthy aspect of my life I have control over, I can make the necessary changes when I feel able.
- I can let others know what would be helpful to me regarding support and let others know my feelings along the way.

When we are compassionate to ourselves and others, our heart expands. We develop our capacity for kindness; we understand all human beings a little more. Also, by honouring ourselves, we are naturally more honouring of others. Compassion is the medicine that can penetrate the depths of our souls and offer immense healing.

PATIENCE

Patience can be a good friend when we are battling pulmonary hypertension.

Patience says:

- You are doing the best you can today, given the PH symptoms you are struggling with.
- Pace yourself. I know you get frustrated at your limitations, but it's important not to push yourself too hard.
- It may take some time to see the benefits of your new medication, dietary, or exercise program.
- Remember that a bit of self-care each day is critical.
- If you are breathless or overwhelmingly fatigued, be patient; hopefully, the symptoms will lessen.

Impatience, on the other hand, can send much stress our way.

It shouts:

- You need to do more if you are going to battle pulmonary hypertension.
- You don't have the time to go slowly today.
- You need to keep achieving something every day; you can't just give in to your illness. It doesn't matter if you feel fatigued or breathless.
- You should be seeing better results from your efforts.
- You must try harder.

Emotional Wellness Handbook for PH Patients

The barrage of negativity from impatience can trigger strong emotions. From its harsh words, we can experience guilt and shame, hopelessness, powerlessness, sadness, anxiety, stress, and self-rejection, to name a few.

So the next time impatience tries to push you around, write a letter to it and tell it what a ruthless tormentor it can be. You know you are doing the best you can.

You are dealing with a massive load of intense physical and emotional symptoms, and the best you can do some days is put one foot in front of another. Honour your efforts, and embrace patience; it is, after all, a profound guide and friend on the road to survival.

INVALIDATION

Invalidation of our struggle with pulmonary hypertension can come in two ways: invalidation by ourselves and invalidation by others. We invalidate our battle with the illness when we say “yes” to others’ requests but know we need to say “no.” By saying “yes,” we educate those around us that we can do more than we can; we ignore our limitations and tell our bodies it will have to take a back seat. We also invalidate ourselves by neglecting our body’s signals.

Over time, if we fall into these traps often enough, our bodies can feel betrayed by us. Our body sends us signals daily; our body speaks to us through the sensations, feelings and intuitions we experience. Some days the communication is intense; for example, you might experience severe shortness of breath, but other days, the communication may be more subtle.

The more we can tune in to all sensations, feelings and intuitions and use them as a cue to guide our day, the more we validate our struggle and honour ourselves. We also honour our body for its ability to manage the moment as best it can.

Specifically, how we do this is:

- We take time to sit still and breathe.
- We check in with how we feel.
- We take time to sense where we feel tension or other sensations.
- We bring mindful awareness to our day and keep checking in as the day unfolds.

The more we get used to noting this information, the more we can use it to validate ourselves and say no when we need to, pace ourselves in a way that works with our illness and not against it, do some vital self-care regularly, and communicate with others about our limitations.

Emotional Wellness Handbook for PH Patients

The other side of invalidation is how others respond to us. Some don't see our illness; they make out that we exaggerate our symptoms and try to trigger our guilt by demeaning or undermining our limitations. If we suffer from pulmonary hypertension, we can feel immense frustration at this lack of understanding.

Also, loud internal conversations such as the following can dominate our minds:

- How come they can't see my struggle and how hard I try to meet my and others' expectations?
- I feel judged, misunderstood, and invisible; no one can see my life's tough!
- If I had a broken leg or something more obvious, I would get more empathy.
- Do I have to have a meltdown for people to get it?

Internal conversations are a natural response to invalidation by others. One choice is to communicate openly and regularly about our feelings and limitations; we then have the peace of mind that we have tried our best to stay close to those around us. If those conversations don't lead to an increased understanding, then we know there is nothing more we can do to bridge the chasm, and we may need to disinvest emotionally for self-preservation.

All of these decisions are tough choices. No one can advise us what to do; in our hearts, we know not everyone can accept the pain and suffering of others, mainly when it takes us to very dark places in life. Others' suffering confronts each human being on Planet Earth, and only they know what they can and cannot handle in others.

SELF-CARE

Self-care is like water is to a desert when dealing with pulmonary hypertension. Each act is so welcome and drunk, with a thirst unquenchable at times.

Every time a self-care act is carried out, the body sighs, the heart sighs, and the spirit sighs. It means that despite the struggle, there will be some replenishment.

We all know that doing some of the following will be good for us:

- Taking some time to breathe and find calm to help deal with the emotional and physical strains related to the illness.
- Saying no when we need to respect our limitations.
- Finding an outlet for our grief and emotional pain as a result of the illness, whether journal writing or talking to a friend or counsellor.
- Pacing ourselves throughout the day; reducing our expectations of what we can accomplish means honouring our struggle with the illness.
- Taking responsibility for seeking out what we need rather than waiting for a friend or relative to persuade us to look after ourselves.
- Doing all those little things for ourselves, like healing balm over a wound.

Being gentle with ourselves, kind, and compassionate creates an emotionally healing milieu where we can start to adjust to the painful reality of living with pulmonary hypertension instead of fighting it and creating more tension in our bodies.

Doing these things makes logical sense. So why are they so hard to do?

- We often don't feel worthy of self-care and find self-martyrdom more attractive. Often our 'need to be needed' is greater than our desire to look after ourselves, so we say yes when our body implores us to say no.

Emotional Wellness Handbook for PH Patients

- We consciously or unconsciously want others to take responsibility for our health. We think it is easier to depend on others and hope they can 'fix' us than step up to the plate and say unreservedly, "my needs are my responsibility, and only I can experience my body and know how I feel." There will be times with the illness when we may be very dependent on doctors, but we can still choose to actively participate in our medical care.
- Our lives need to slow down to make space for self-care. Often a desire to speed things up can be linked to avoiding acknowledging the emotional pain associated with the illness.
- Self-care takes away our ability to blame someone else for our circumstances, which can sometimes be a way of staying in denial regarding our illness that can give us temporary relief.
- If we take full responsibility for ourselves, there can be an unconscious fear of dealing with all the unresolved pain from other times in our lives, which can be frightening.
- If we have a negative view of ourselves, a lack of self-care reinforces it. A regular self-care program would mean we would have to change who we think we are and risk all the consequences of self-transformation.

The reality is that no one can persuade another to 'do' self-care. It is a personal choice, and often it comes from being 'sick and tired of being sick and tired.' Most of us change out of necessity. Change is painful. Change is hard. Change is destabilizing. We don't know where it will lead to. Even if it is positive, it can be frightening. However, despite our fears, it can be a liberating and energizing act and can give us strength in the face of an illness that constricts our lives.

COURAGE

Courage is critical. Courage is needed sometimes daily, sometimes every hour of every day when one struggles with pulmonary hypertension.

For example, courage is required in the following areas:

- It takes courage to 'feel what you feel.' Each day the illness can bring challenges, and at times it seems the best strategy is to ignore one's feelings and hope they go away. It takes courage to admit that you feel scared, overwhelmed with fear at times, angry, powerless, helpless, sad, depressed, or anxious. If we recognize the feeling in ourselves and then share it with others, we must deal with it. Perhaps the feeling is there because our symptoms are increasing, and it feels like we are losing control. Maybe we are grieving our ability to be the partner, friend or family member we want to be. By taking the courage to honour one's feelings, we are choosing to heal ourselves from some of the immense emotional challenges of the illness.
- Courage is also needed when we need to respect our limitations. It appears easier sometimes to pretend to others that we can cope with everyday challenges and demands, but we know our body pays for it. Courage helps us say no, to let others know about our physical and emotional limitations. It helps us deal with the reality of a condition that will impact us for the rest of our lives.
- We need the courage to admit the unpredictable nature of pulmonary hypertension. The illness can sometimes feel like it has taken over our lives; it takes courage to let go and surrender to those times when the illness demands we rest.
- Courage also guides us to take full responsibility for our struggle, not waiting for others to attend to us but rather exercising self-care daily. That way, others don't feel responsible for doing for us what we could be doing for ourselves. Essentially, it reminds us that we are the only person who can heal ourselves emotionally.

Emotional Wellness Handbook for PH Patients

- Courage is also our valued friend when we need to take risks. Perhaps the risk is going to a self-help meeting, knowing it will help us, but we will have to face our fear of opening up. Another risk may be being honest to those that enquire about us. For instance, minor risks include pursuing a new activity or daily journal writing.
- Courage is always by our side when we choose to grow. One of the fundamental tenets of living as a human being is the need to grow, adapt to our circumstances no matter how hard, and become aware of our choices even in the most challenging moments. Every time we shift and expand, courage is like oil on the tracks of our life, making the way a little smoother and helping us to expand our horizons even when we are compelled by our desire to hide and isolate.

We draw on every ounce of our courage when our illness progresses dramatically. It takes immense courage, too, to be honest when we are on the decline and moving toward the end of our lives. Emotional preparation for death is key for ourselves and our loved ones. The more courage we can muster, the more we will be able to face the end of our life with some semblance of peace in our hearts.

One way to build courage is to recognize when we have flexed our ‘courage muscles.’ Each time we honour courage in our hearts, the action it helped us achieve grows a little more. Courage is like an investment that grows, helps ease our lives, and is there when we need to draw on it for any immense challenges we face.