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# phan mail

Edition 27  
Spring 2017  
www.phna.info

magazine

## Step into Spring

Improve your mental health,  
wellbeing & stress less!

## OXYGEN

Young adults use oxygen too!

## BANISH

those negative  
body image ideas

## HAPPINESS

is an  
Inside Job

## Getting Stuck

when asking  
for help

PAH MEDICINE UPDATE  
DELIVERY TO YOUR  
DOOR FOR FREE!

MONTHLY  
MENTAL HEALTH  
MOMENT

PHAWARE PODCAST  
5 THINGS A PATIENT  
SHOULD ASK



A publication from Pulmonary Hypertension Network Australia  
*A lung disease that's Breathtaking*

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Edition?  
SPRING 2017

### Introducing PH Ambassador Chloe Temtchine

Award Winning International musician and pulmonary hypertension patient, Chloe is the Ambassador for the PH USA association. Find her at [www.phna.info](http://www.phna.info) Magazines & Blogs - "Breathless not Hopeless"



Shine a light on  
Pulmonary Hypertension  
Awareness



## SUPPORT GROUPS RECOGNITION AND GOOD PRACTICE

### CONGRATULATIONS

*PHNA on your  
nomination as a finalist  
in the Innovation Category.*



## Awards



PARMELIA HILTON PERTH

FRIDAY 8 SEPTEMBER 2017



# EDITORS LETTER

Hello PH family and welcome to the Spring edition of PHan mail magazine 2017.

**Hello PHamily**, where is the year going? As I sit here and type I can hardly believe we are more than half way through 2017 already. I feel like one of those little mice on the running wheel trying to catch up or keep up, I haven't decided yet... The Spring edition of PHan Mail is packed full of great articles and information ready for you to read and enjoy.

Our yearly PH November Awareness fundraising events calendar is finalised and our new posters and fundraising kit are ready to be distributed to anyone who orders them within Australia. *We have two amazing posters and a Get Breathless for PH - 60 Second Straw Test Challenge kit that will be launched at our November events.* Save the Dates will be advertised very soon so check out our FB and events page on our website to stay connected or request your awareness items. *Hold your own straw test challenge* at work or with friends and family and make a day of it and share your photos with us on Facebook.

We are pleased to share with you a *new PAH resource* has been released through the Better Living Series at the Lung Foundation Australia. Its a great booklet on living with pulmonary hypertension and we highly recommend you contact us for your **FREE** copy if you haven't already received one. (Available only to newly diagnosed through LFA).

Recently *phaware.global* approached us to share their podcast series with our members on our website so please check that out on the Home page and if you would like to be interviewed they are interested in speaking to PH patients, carers and health professionals. This innovative and connected organisation are at the forefront of awareness raising for our disease and we welcome this partnership. They also have a great *phone app* you personalise your selfies with, which is a lot of fun.

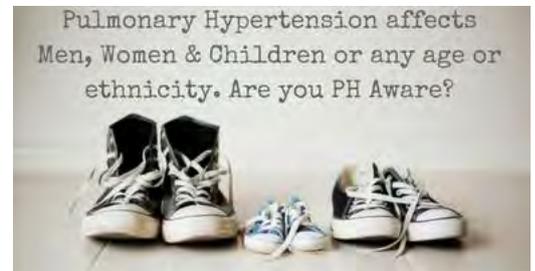
We love to share with our members stories and blogs that help them to feel less isolated, see what is happening around the world or just have a good laugh. You will find that we feature several within our magazine especially from *pulmonaryhypertensionnews.com* who write the most amazing PH and related articles. Please check them out and more on our website under Magazines & Blogs. My personal favourite is Australian transplant and CF patient Lauren Rowe and her morning and evening YouTube routine clips, *get ready to laugh hard* at her hilarious take on daily life as only people living with chronic disease would perhaps understand!

Finally, we would like to acknowledge the sad loss of two of our precious members, Jean Gawthorn and Pamella Mork. Pamella passed away in August. We are going to miss her and her beautiful daughters very much and wish both the families our heartfelt warmest wishes for their loss. I know that it can be distressing to others when we lose a fellow PHer, but please know that you are not alone, we are all here for each other.



**Be kind to one another  
From your Editor & CEO**

*Melissa Dumitru x*



## NOTICE BOARD - NOTICE BOARD

### Donations & Fundraising

June Support Group gathering (WA) Raffle \$79.00. August raffle \$80.00. Donations \$20.00.

### Acknowledgements

To our members, sponsors, volunteers, & sister organisations we thank you for your ongoing commitment and generosity with helping us to grow our network by bringing together our community for some amazing events, fundraisers, education days and support group gatherings. Our PH community spirit is alive and thriving and we love working with you all.

### Special Mention

Thank you to those sponsors who have offered special member discounts on goods and services. Without the valuable support from our community we could not promote PH awareness or build on our educational resources to help those living with pulmonary hypertension.

Thank you to the following peak groups for their ongoing support of our small but valuable organisation. **The Arthritis Foundation Wyllie Centre, Connect Groups Association, and the Lung Foundation Australia.**

Any funds raised and education grants received go towards ensuring the continuation of our organisation and its goals to help people living with PH to have better lives, more support and great resources. Our board thanks you for entrusting us with these funds and the decisions that go into the future planning of patient education projects, support group gatherings and special events. From the Team at PHNA.



# FRESH, FAST & PHABULOUS



## INTRODUCING

Jessica Sepel: a nutritionist, health blogger and author. Find her on our website [phna.info](http://phna.info) under Education/Cooks Book Club.

## GOOD HEALTH STARTS IN THE KITCHEN

*Hi I'm Jessica and I am a shameless foodie. I love cooking and eating, so I spend a lot of time in the kitchen, whipping up delicious and nutritious dishes, drinks and snacks for myself as well as my family and friends. If you ask me, nothing beats sitting down to a healthy meal and feeding your body and soul with amazing food and conversation. I don't keep my recipes under lock and key I want everyone to know that being healthy doesn't have to be boring! I want you all to treat your taste buds daily. On my website you'll find a bunch of my recipes, most of which are free of refined sugars, gluten and processed foods. I use fresh, seasonal whole foods – a.k.a. real food – that not only taste great, but also nourish the body from the inside out. (See more bottom page).*



## Healthy Recipe for Chicken San Choy Bow - Serves Two

This is one of my absolute favourite dinners to make on weeknights – so simple, so easy (it literally takes 10 minutes to cook and serve!) and so tasty.

I'm obsessed with the tamari-mustard dressing I created for this too, it really completes the dish. You can use turkey or beef mince too, even some sautéed tofu would work in this recipe!

### Ingredients:

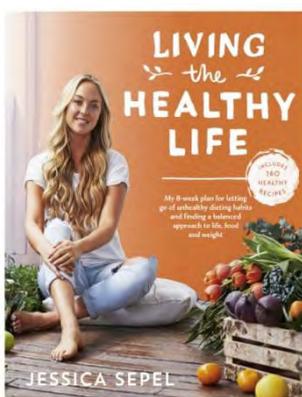
- ✓ 1 tsp coconut or olive oil, for frying
- ✓ 2 garlic cloves, minced
- ✓ 1 red onion, finely diced
- ✓ 1 tsp sea salt
- ✓ 150g organic chicken mince
- ✓ 1 tbsp tamari sauce
- ✓ 1 tbsp olive oil
- ✓ 2 tbsp parsley, finely chopped
- ✓ 1 head of iceberg lettuce
- ✓ 1/2 avocado, smashed
- ✓ 1 tbsp sesame seeds
- ✓ Extra sesame seeds, chopped spring onion and parsley, to garnish

### Tamari-Mustard Dressing:

- ✓ 2 tbsp Dijon mustard
- ✓ 1 1/2 tbsp tamari sauce
- ✓ 1 tsp sesame oil
- ✓ 1 tbsp spring onions, chopped
- ✓ 1/4 cup water

### Method:

1. Heat coconut oil in a large non-stick frying pan.
2. Add the minced garlic cloves and sauté until golden.
3. Add the chopped red onion and a tsp of salt, sauté until golden.
4. Add the chicken mince, tamari and olive oil and sauté until brown and well-cooked. Set aside.
5. Prepare lettuce cups by chopping off the stem of the lettuce and carefully pulling each lettuce leaf/cup away from the head of lettuce. Set aside and repeat until you have 5-6 lettuce cups.
6. In another small bowl, smash the avocado and add 1 tbsp sesame seeds. Set aside.
7. To make the dressing, add the mustard, tamari, sesame oil, spring onions and water to a small bowl and whisk until combined.
8. To serve, add 2 heaped tbsp of the cooked chicken mince to each lettuce cup and top with dressing, spring onion and parsley.



After overcoming years of struggle in my relationship with food and body image, it is now my passion to help you heal, too. I understand the dangers of chronic dieting and over-exercising, because I've been there. I want to teach you how to eat with a deep sense of peace and enjoyment by choosing nourishing foods that suit your individual needs. Together, we'll explore a more gentle approach in taking care of your beautifully unique body.

Jessica Sepel, a young Sydney-based nutritionist, is following in the footsteps of health bloggers such as Lee Holmes, Lola Berry and Sarah Wilson. Jessica is a trained nutritionist with a burgeoning private practice and a hugely popular health blog. Her philosophy is simple: good health starts in the kitchen. Her focus is on fresh produce, prepared simply and with love. The Healthy Life is fully photographed, and has 100 recipes, meal plans, and a kind approach to creating better health and stress-free living. [www.jessicasepel.com](http://www.jessicasepel.com)



# STAY UP TO DATE!



FB: [facebook.com/pulmonaryhypertensionna](https://facebook.com/pulmonaryhypertensionna)

## #SocialMedia & PH

WHAT DOES SOCIAL MEDIA MEAN TO YOU?



PHNA social networking is huge in the world of people living with pulmonary hypertension. Across the globe a vast network has been created throughout the organisations dedicated to PH and as such there are more ways to connect than ever before. With over 600 members we have a great network of our own and we hope if you are on FB you give us a like and start following us too. We provide some great educational information, the latest news from the network and some light relief and warm fuzzies to enjoy.

PHNA is currently incorporating as a National Network. As such our new Board is being formed and all our membership application processes have been updated. We need you to go online to update your membership using the electronic format provided. You can also apply for membership if you are not already a member, it is currently FREE. You will also find our National Registry (info back page) where we ask current PAH patients to participate in a questionnaire to assist in the growth of the pulmonary hypertension industry.

# Online!

Renew or Apply for Membership Today!

[phna.info](http://phna.info)



PHNA strive to stay up to date with providing information and resources for people living with PH in Australia. As a non profit and NGO (non government org) we have to raise all our own funds for our operations, events, awareness initiatives and patient projects. We rely on donations from members, community and other organisations as well as respected PH pharmaceutical companies. See what we have planned for the financial year 2017/18 and beyond on our website [phna.info](http://phna.info) under the Home page, Strategic Plan.

## Seeds to Sustainability

PHNA Strategic Plan



PHNA offer the only PH Patient Pack for newly diagnosed and existing patients living with PH in Australia. Due to our expansion into a National Network, we are currently in the process of updating our pack to be utilised as a national educational tool and are constantly adding new information to the pack to assist you in your PH journey. The existing pack is suitable for everyone with only a few areas being concentrated in the state of WA. To order your FREE PH Patient pack today go to our website home page.

## The PH Patient Pack and The Invisible Diseases Resources

A welcoming and informative pack with great information and education about your disease, with some tips on how to cope and live better with PH.

Available Now!



[phna.info](http://phna.info)

THE PH PUZZLE

PUTTING THE PIECES TOGETHER FOR AN EARLIER & ACCURATE DIAGNOSIS

PHNA have some amazing new resources ready to distribute for November Awareness Month. We also have general information posters you can request and ask your GP and specialist to display in their rooms or anywhere you would like to raise awareness. We are currently working on a new Fundraising Kit for our "Get Breathless for PH - 60 Second Straw Test Challenge" which will be released in time for awareness month too. See our website [phna.info](http://phna.info) and get involved in our PH Community today!



Get Breathless for PH!  
60 Second Straw Test Challenge

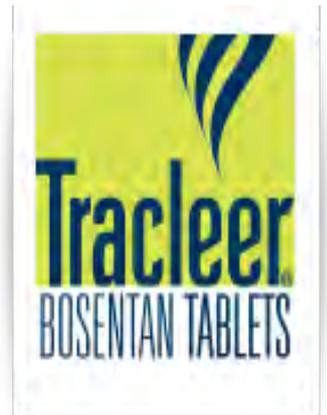
# PAH MEDICINES UPDATE

## Tracleer® Home Deliver Program

It's now possible to have your Tracleer (Bosentan) medicine home delivered rather than collecting it from your hospital or local pharmacy, at **no additional cost**.

Actelion Pharmaceuticals Australia (the manufacturers of Tracleer) and Inservio (a specialised medicine distribution company) have worked together to introduce this program based on patient feedback highlighting the value of home delivery.

If you are interested in home delivery, or want more details, please contact Inservio on 1300 799 832. Further information is provided below.



### Details of the Tracleer home delivery program:

WHAT WILL HAPPEN	WHAT IT MEANS TO YOU
<ul style="list-style-type: none"> <li>Direct delivery to your nominated address.</li> </ul>	<ul style="list-style-type: none"> <li>No need to go to your local pharmacy or hospital to collect your Tracleer (Bosentan).</li> <li>No need to call beforehand to check it's there.</li> <li>Inservio's speciality pharmacy partner will liaise with you to ensure you get your medicine.</li> </ul>
<ul style="list-style-type: none"> <li>Scheduled dispensing.</li> </ul>	<ul style="list-style-type: none"> <li>Ensures you always have a sufficient quantity of Tracleer at home.</li> </ul>
<ul style="list-style-type: none"> <li>Inservio hold onto your prescription.</li> </ul>	<ul style="list-style-type: none"> <li>No problems with lost prescriptions. Inservio's partner pharmacy will alert you and your PAH clinic when your Tracleer repeat is about to run out.</li> </ul>
<ul style="list-style-type: none"> <li>Other medicines can be dispensed and delivered with your Tracleer if you wish.</li> </ul>	<ul style="list-style-type: none"> <li>No need to go to the pharmacy for your other medicines.</li> </ul>
<ul style="list-style-type: none"> <li>SMS or phone call communication.</li> </ul>	<ul style="list-style-type: none"> <li>Opportunity to manage the schedule and delivery of your medicines by SMS or 1300 phone number.</li> <li>Opportunity to speak to a pharmacist if you need to.</li> </ul>

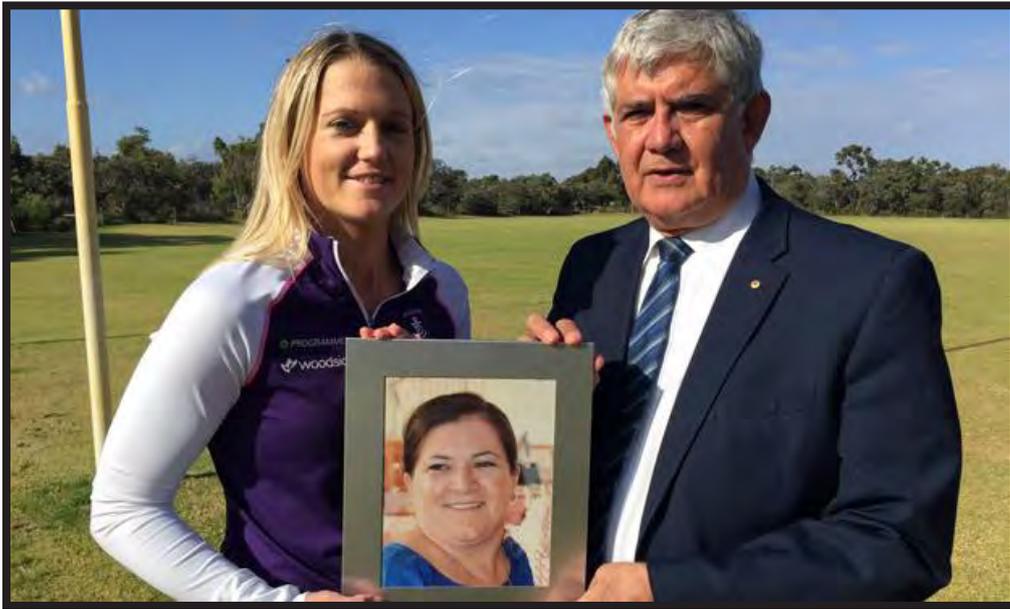
Inservio is a specialised medicine distribution company that works with specialty pharmacies, like iCare Pharmacy, to provide a best-in-class service for patients with PAH. They have been working with PAH centres around Australia since 2014 and have been home delivering other PAH medications to patients for some time. Their goal is to support better patient outcomes by improved patient access to prescribed treatment regimes and their services aim to minimise hassle and increase convenience for patients.

**Once again, if you are interested in home delivery, please contact Inservio on 1300 799 832.**



# Legacy Lives on through Lavell

Source: Rosie Duffy - West Australian News July 14, 2017



Amy Lavell is taking on an ambassador role for organ donation in memory of her close friend.

- **AFL and all 18 AFL clubs to support DonateLife week AFLW U18s: WA Falls to Allies**

Being drafted into the inaugural Freo Dockers AFLW team was a moment Amy Lavell won't forget, but after the initial joy of realising her AFLW dream, Lavell's mind shifted to a close friend. The same year the 30-year-old had one of the biggest highs of her life, was also the same year she watched a close friend pass away due to an unsuccessful double lung transplant.

On Thursday morning Lavell spoke at the AFL's announcement of its partnership with the Organ and Tissue Authority and their joint support of DonateLife Week. "My friend **Linda Franklin** passed away last year, she was unsuccessful in surviving the surgery from a double lung transplant," Lavell said. "She was on and off the register for 10 years and she was on oxygen for most of that time. "She was a huge advocate for DonateLife and also the Organ and Tissue Authority in WA and she continued her volunteer work right up until her transplant surgery in 2016."



Lavell and Aged Care Minister and Indigenous Health Minister The Hon Ken Wyatt with a photo of Linda Franklin.

Lavell said **Franklin** was a phenomenal woman and a mad Freo Dockers fan who had been a member of the club since its inception in 1995.

"When I got drafted into the Freo Dockers AFLW team one of the first things I thought was that I wanted to continue her legacy," Lavell said.

Lavell is now an ambassador for DonateLife and the Organ and Tissue Authority of WA, and is passionate about ensuring more people talk to their families about their wishes when it comes to organ and tissue donation.

The key forward played in all seven of Freo's AFLW games in the league's inaugural season, and wore the number seven on her guernsey. "I chose the number seven because that was **Linda's** favourite number, I really wanted to do that to honour her and I think she continues to watch over me while I'm playing football," Lavell said.

"It is so important that people are given the opportunity to live their lives to the fullest and the opportunity to continue their lives if they can. "When **Linda** passed it was her aim to be able to offer that opportunity to others. "Registering with DonateLife is so easy to do and it only takes a short period of time to complete. **"If we can get more people on the register and talking about organ and tissue donation that would be fantastic."**

## Phaware Podcast: Dr. Peter Leary Lists Five Things Patients Should Ask About

*Dr. Peter Leary is a specialist in pulmonary and critical care medicine. He focuses on treating and doing research on pulmonary vascular disease. Here he breaks down the five points every pulmonary hypertension patient should discuss with their specialist during follow-up visits.*

I'm Peter Leary, a pulmonary hypertension physician at the University of Washington, and I wanted to talk to you just a little bit today about follow-up.

So, what do I mean by follow-up? There is a lot of focus rightly so at the beginning of a pulmonary hypertension work-up. You're a patient, you've just come into the hospital, or you come into an out-patient clinic, and there are a lot of tests. There are a lot of conversations and there are a lot of discussions about what drug do I take? How much drug do I take? What are my options? What's the prognosis?

What is hugely important, though, is not just that first experience, but all the ones afterwards. Everyone's heard the phrase "take two aspirin and call me in the morning." I've always felt like the most important part of that phrase is the **"and call me in the morning."** Everyone focuses on the "take two aspirin." That's what we do a lot in medicine, too. What drug are we going to give you? What dose are we going to give you? Do you have a disease for which that drug works?

What is hugely important is the **"and call me in the morning."** Particularly early in the course of follow-up, we may find that we've given somebody a drug for pulmonary hypertension and they've gotten worse. Sometimes that means we didn't give enough medication. Sometimes it means we didn't give the right medication. Sometimes it means they don't have pulmonary arterial hypertension or a disease that's treated by these drugs.

So early in the course of follow-up, it's very important to kind of take stock, keep an open mind both as a patient and as a doctor to say, "Is the disease that we think I have the disease that I actually have?"

Medications are a great way to test that idea and check and see whether that's true. It doesn't mean that just because you feel worse after you started a PAH drug that it's not the right drug. There are a lot of side effects, which most people can progress through and are left with the benefits of the drugs and not the side effects, but it should be a good jumping off point to say we need to keep an open mind as we go through follow-up.



Then, as a physician, what my goals are after I feel pretty confident in what the diagnosis is, is to kind of hit at least five points during any visit that I see for a patient with pulmonary hypertension. One of those is, is there evidence of disease progression? When I see a patient, I want to know are their good days slipping?

**Everyone has good days and they've got bad days, and a bad day can happen for a lot of different reasons.** It can happen because you had a Big Mac and a salt and two gallons of water and you feel terrible. You got a bad night's sleep, the dog was barking, whatever it happens to be, but if the good days are slipping, when you say, "Hey, you know I had a good day last week, but I couldn't go quite as far as I did before," that worries me that the disease is progressing.

So as a pulmonary hypertension doctor, I want to take the information and say, "If I think the disease is progressing, do I need to be more aggressive in how I treat it? Do I need to increase the dose of the drugs my patient's already on or start a conversation with them about whether or not it's time to add a new drug or think about a different approach?"

This is where a lot of the routine things that happen, the blood work, the six-minute walk [test], the echo, the conversation, all of these things go into that impression of is the disease progressing or is it staying still on the regimen that we have?

The second part of any visit that I'll have with a patient is to think about adverse drug events. Are you having side effects from your PH drugs?

**We know that pulmonary hypertension drugs are part cure and part poison.** We know that they've got some side effects with them, and I try and make a point of explicitly talking about the side effects in every visit. Because sometimes people will ignore the side effects of a PH drug, they won't bring them up at the visit. And then an opportunity is missed to really sit down and think about whether or not we have other medications that can treat the side effects, whether or not the pulmonary hypertension is under such good control that we can pull back a little bit and get rid of some of the side effects, make somebody feel better without compromising on their pulmonary hypertension control.

Or to really sit down and say, "Well, is this symptom you're having, is this new problem you're having, is it actually related to pulmonary hypertension or actually related to the drugs? Or are we missing the opportunity to treat a completely different medical problem that could make you feel better?" Did you get kidney stones along the way? Do you have something like that that really would be in your best interest to treat and could make you feel a lot better completely independent of pulmonary hypertension?

The third thing that I spend a lot of time with on every visit is how is it going with fluid? Are you carrying around a lot of extra fluid? Does your physical exam look like you have a lot of extra fluid? Is your weight going up? I think taking time to say ... All the patients in our clinic keep a diary. Every day they write down how much they weigh and just a quick 1 through 10, how are they feeling that day. If people's weight is consistently going up, are they carrying around too much extra fluid? Is it time to take a visit to the nutritionist to think about, hey, what are some more ways that we can cut salt out of the **diet**? What are some more ways we can focus on not getting too much **fluid** in? What are some tricks that work for some people? Sucking on a lemon drop, things like that that may take away that feeling to go get a big glass of water without getting a big glass of water. Do we need to increase medicines to make you pee out some of that extra fluid?

So I find that oftentimes when people are feeling worse with pulmonary hypertension, it may be just a problem with all that extra fluid. If the heart gets stretched out, it is hard to squeeze a good solid beat out because it's too stretched to do it. If you can get rid of that fluid, the heart comes into a much happier place and can beat much more strongly.

The next thing that we think about on almost every visit is lifestyle modifications. So part of that is the things that I was talking about, making sure we cut back salt, making sure we cut back fluid. We keep revisiting these over the course of the years that we work together, because it's easy to go off the rails there at some point, but there are other things that are important, too.

So **exercise** is incredibly important. It used to be that we would say exercise will teach your body how to do more with less. There's even some research that's come out of Germany in the not too distant past that shows that exercise is changing the disease. It's making the resistance to blood flow less. It's allowing your heart to pump more. Doing structured exercise is important in this disease. Not only does it make people feel better and do more, it can actually potentially impact the disease itself.

So different exercise is different for everybody with PH. For some people a structured exercise program is five minutes every day being more active and then building that up over time. Some people, it's much longer than that and so it's very individualised, but whatever level it is I think that it's important. So we spend some time talking about those kinds of lifestyle adaptations and changes that are not drugs, but are still hugely important in feeling good with pulmonary hypertension.

Then the last thing we do is we just run through any symptoms, any new symptom that a patient is having. As a pulmonary hypertension doctor, all my patients also have a primary care doctor, and it's not my intention to kind of take over the role of a primary care doctor. But what I do want to make sure is that it's very easy for patients and the entire healthcare team alike to say everything I feel is related to my pulmonary hypertension or the drugs that I'm on for pulmonary hypertension.

By going through those symptoms we can say, "Oh that may be pulmonary hypertension that may be a pulmonary hypertension drug. Oh, that symptom probably is not related to pulmonary hypertension." So as a healthcare team, and by healthcare team I mean patients, families, doctors, primary care doctors, this allows people to help keep an open mind and find where the other problems are that we can help correct.

We're always going to be focused on the pulmonary hypertension. We're not going to forget about that, so one of the key aspects of this is if somebody has a bunion on their foot and we blame it on their pulmonary hypertension drugs; we're never going to fix that foot pain. But if we instead call a spade a spade and treat the bunion, they're going to feel a lot better than if we just blame it on their PH drugs.

My name is Doctor Peter Leary, and I'm aware that I'm rare.



**EVERYBODY HAS A STORY. WHAT'S YOURS?** phaware wants to share your pulmonary hypertension story with their engaged global audience. Whether you are a patient, caregiver, or medical professional, they are enlisting PH community members from across the globe. Visit [www.phaware.global/podcast](http://www.phaware.global/podcast) to share your story and to be considered for a future episode. And *learn more about pulmonary hypertension at [www.phaware.global](http://www.phaware.global). #phaware #phawarepod*



# Your Life Talks

Our foundation website [Your Life Assist](http://www.YourLifeTalks.com) is an independent source of free resources to inform, support & connect people, and to encourage greater participation and a wider range of choices in their decision-making about significant lifestyle transitions. It covers many life topics including:

- ✓ **Putting Your Affairs in Order**
- ✓ **End of Life Planning & Care**
- ✓ **Arranging & Personalising a Funeral**
- ✓ **Post Funeral Advice for the weeks & months following a funeral**

Our latest initiative is to raise community awareness of the importance of having meaningful conversations within families to recognize our loved ones' intrinsic need to remember and celebrate their life and achievements, and share their plans for their future. These conversations are meaningful for our loved ones, their families and for generations to come.

We have designed 2 sets of Conversation Starter cards to help families break the ice and start these conversations. Please take a moment to visit our new [website www.Your Life Talks](http://www.YourLifeTalks.com). There are multiple resources for you to access both online and directly from the "your life talks" organisation.

We also have an Australia wide register of speakers available to talk with community groups about a variety of topics, so please let us know if you would like us to come along to your Support Groups. See [Your Life Talks - Speaking Requests](http://www.YourLifeTalks.com).



## 'Your Life Story'

50 Conversation Starter cards – Sharing your life story encourages families to have conversations about life and what matters most. The cards are a wonderful way for us to reaffirm to our loved ones how much they have impacted our lives, and how much they have meant to us.



## 'Your Life Wishes'

50 Conversation Starter cards – We talk about and share most things with our family, but there's probably one 'chat' we haven't had, and the reason may be because it's difficult to start. The cards are an easier way to kick-start 'the conversation' about how you want to live out the final stages of your life, including how you'd like to be remembered.



**JOLENE HILL** Founder & Director

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Website: [www.yourlifetalks.com](http://www.yourlifetalks.com)

PHNA are pleased to share this information with you about a wonderful new resource we have found for planning for a subject matter that we are all faced with but perhaps would rather not start the conversation for.

Having PH means facing a future that could be shortened due to progression of our disease process and as such it's important that you have **"the talk"** to make sure all your wishes have been heard and you have said what you need to say. It's amazing how much comfort and reassurance doing this can bring to you and your loved ones.

PHNA will have these resources available at our website shop [phna.info](http://phna.info) or you can go straight to the foundation for more information. We welcome Jolene the Founder & Director to our PHamily. Editor

# Monthly Mental Health Moment



## Mental Health Moment: 10 Tips to Staying Mentally Healthy

The Western Australian Association of Mental Health (WAAMH) has developed a one-page tip sheet with some easy to adopt suggestions for maintaining a good life balance and mentally healthy activities.

Improve your mental health  
and wellbeing - stress less!

### 10 tips to help you stay MENTALLY HEALTHY

#### Have an early night

When your car runs low on fuel - you fill it up. When you run low on fuel make sure you do the same. Sleep is a great reviver. Late nights drain the energy reserves. Top up whenever you can.



#### Reach out and help others

Connect with people around you who will support and enrich your life. The quality of our personal relationships has a great effect on our wellbeing. Put time, effort and energy into building strong relationships and reap the great rewards.

#### See the funny side of life

Laughter is a wonderful medicine. Life isn't all work and no play. We get stuck in patterns and sometimes need to break out and ask ourselves - when did I last have a good laugh?



#### Learn something new

Learn a new skill or take on a challenge to meet a goal. Whether at work or at play, there is always so much more to learn. The process of learning improves your mental fitness and what you learn makes you a better person with more to offer yourself and those around you. Learning is achieving and with it comes a great sense of accomplishment.

#### Organise your day

Being disorganised can build stress and anxiety. You may be able to avoid some of the triggers and learn to prepare for or manage others. A balanced, organised lifestyle can help you manage stress better. Take time to organise and plan your life and avoid being constantly on the treadmill.

#### Eat healthy

Rest and exercise have limited use if you aren't eating well. We all know what is right and wrong to eat. Rushing around nearly always means making the wrong food options; why else is it called 'fast food'? Take time to plan your diet, and cook meals that are nutritious and full of energy. The whole process of planning and cooking is therapeutic - and that's even before you get to eat it!

#### Take time out

Allow yourself some unfocused time each day to refresh, for example, let your mind wander, daydream or simply watch the clouds go by for a while. It's OK to add 'do nothing' to your to-do list! You deserve some time to yourself.

Find more information at  
[www.waamh.org.au](http://www.waamh.org.au)

#### Go for a walk

There is no better medicine than exercise. And it is not always easy to put on your joggers and head out for a walk. It takes an effort sometimes. But once you have made the effort, the reward is huge. Exercise clears your head and places you outside the environment that is causing you concern. And it's good for mind and body. *(There is evidence now that patients living with PH benefit greatly from gentle regular exercise. Don't forget to speak to your clinic physio about an exercise program that is suitable just for you! PHNA Editor).*

#### Be a friend

Your friends are your friends because you enjoy shared interests. They care for you. So spend time doing the things you do well with them.

#### Ask for some help

This can be as simple as asking for a friend to babysit while you have some time out or speaking to your doctor (GP) about where to find a counsellor or community mental health service. The perfect, worry-free life does not exist! Everyone's life journey has bumpy bits and the people around you can help. If you don't get the help you need first off, keep asking until you do.

# Modified Functional Classification System May Help Predict Paediatric PH Morbidity and Mortality

*By Phyllis Hanlon, Contributing Writer  
Article Courtesy PHAssociation.org USA*



Adults diagnosed with pulmonary hypertension (PH) are frequently assigned a functional classification during a clinic visit. The functional classification is a way to classify how limited patients are by their disease, and has been used by many physicians and scientists to track disease progress. The [scale ranges from functional classification I to IV](#), and identifies the severity of disease and the urgency for intervention.

However, the WHO functional classification, while useful for adults, was not intended for use in children and infants. [A 2016 study](#) noted that since the WHO functional classification does not take into consideration variations in growth and development in children, this classification system is not ideal for medical decision-making or for use in measuring treatment outcomes in young children. Additionally, PH in children is often present in association with conditions other than PH that can affect their symptoms, which makes it harder to assign a functional class.

Emily Morell Balkin, MD, and Roberta L. Keller, MD, were part of a team of University of California, San Francisco researchers [who studied children with PH using a child-specific classification system](#). The Pulmonary Vascular Research Institute (PVRI) Functional Classification of Pulmonary Hypertension in Children (also known as the “Panama Paediatric Functional Class”) is a modified version of the WHO’s classification system. This system assigns patients to one of five categories (I, II, IIIa, IIIb or IV) that are defined slightly differently for different age groups (0-6 months; 6 months-1 year; 1-2 years; 2-5 years; or 5-16 years).

The definition for the [Panama Functional Classification](#) specifically takes into account differences in severity of symptoms, limits to physical activity and abnormalities directly related to growth and development considered appropriate for their age group. According to the authors, this system aims “to standardize the assessment of a child’s functional limitations and symptoms,” potentially providing insight into the patient’s quality of life.

The study examined data on 65 infants and children with a diagnosis of PH who were treated at one medical centre; 25 (38 percent) had WHO Group 1 PH (PAH, pulmonary arterial hypertension); 1 (2 percent) had PH due left heart disease (WHO Group 2 PH); and 39 (60 percent) had PH as a result of respiratory disease (WHO Group 3 PH).

The main measures the author assessed were the Panama Paediatric Functional Class (FC) at diagnosis, at last visit and any changes noted in FC during follow-up. Dr. Balkin and her colleagues found that the initial FC at diagnosis was not associated with higher mortality and morbidity. However, the last two measures – FC at last visit and changes in FC during follow up – were “strongly associated with mortality and morbidity in children with PH.” They noted that as FC increased, more therapies were used to address PH.

According to the authors, this study did have some limitations. For instance, patient data was retrospectively drawn from just one centre so the results might not be applicable to the general population; although they pointed out that the patients were relatively diverse. Also, the study involved a small group of children, which might make the results harder to apply to a larger group.

However, despite these limitations, Dr. Balkin and her colleagues asserted that their findings could be useful as a tool to establish a baseline and evaluate outcomes related to research, providing other studies can duplicate these results in other patients.

Finally, the authors pointed out that “...it will be important to better understand these emerging patient populations of infants and children with PH, so strategies and therapies to improve outcomes can be investigated.”

CHANGING  
PERSPECTIVES

# BANISH those negative body image ideas when weight fluctuations occur.

An article from [pulmonaryhypertensionnews.com](http://pulmonaryhypertensionnews.com)



*“The scale can only give you a numerical reflection of your relationship with gravity. It cannot measure beauty, talent, purpose, life force, possibility, strength, or love.” Dr. Steve Maroboli.*

*Please enjoy this article from Brittany Foster a fellow PH patient and writer for PHNews.com. Please remember these are her thoughts and experiences only. Consult and follow your treatment centre and doctors advice always. Editor*

Seven years ago, while in the depths of my eating disorder, if you had told me that I would be working toward having a healthy relationship with a scale, I would never have believed you. Recently, I have struggled with ignoring eating disorder thoughts that arise because of weight fluctuations of more than a few pounds. Many in the PH community have talked to me about their own struggles with body image, particularly on days when they notice extra weight from fluid retention. My body image may not be where I want it to be, but there are things I remind myself of when I am struggling.

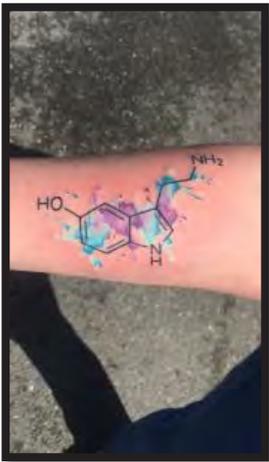


## My Words of Wisdom:

1. Know your baseline weight. Weigh yourself at the beginning of the day on the days you feel water retention. Keep track of the number by writing it down. Call your doctor to report any abnormal weight fluctuations (get a reference to know what is normal vs. abnormal at your next visit).
2. If you see the number on the scale increase, don't assume that you are "fat" or "got fat" overnight. This isn't the case and is just your mind playing tricks on you. Obsessing over body image acts as a distraction from a health concern, but it's not a healthy distraction.
3. Throw on something comfortable for days when you have more fluid retention. I prefer something with an elastic waistband, leggings, or just walking around my house in an oversized T-shirt and underwear. Trying to fit into those skinny jeans is **NEVER** a good idea. Also: Who actually enjoys jeans?!
4. Don't stare at yourself in the mirror and pick yourself apart. I've squeezed my sides, pinched my legs and poked at my swollen knees. You will not get rid of your fluid retention or swelling by pinching it.
5. Ask your doctor if you should avoid certain foods and if you should adjust any particular medications to help with extra water weight. Sometimes some extra weight is "normal" for someone with PH. Know your "normal" and learn to accept that it will be uncomfortable.
6. No one likes to appear heavier and no one is overjoyed when the number on the scale goes up. Don't put yourself down for being upset about it. Feel upset and acknowledge your emotions, but try not to let it ruin your entire day.
7. Distract yourself in positive ways. When your body image isn't great, don't do something that will make you uncomfortable. Maybe this isn't the best day to try on your favorite bathing suits or go clothes shopping for a formal dress. Do things that don't involve focus on your body.
8. On a hot day, even with the extra water weight, don't feel like you need to hide from the pool. If you are comfortable with wearing a bikini, GO FOR IT! But if you aren't (like me) just wear your favorite cover up, put on an adorable one-piece, and cool off in the pool or at the beach. Don't hide in fear of what other people might think of your weight gain. You notice it more than others will.
9. Do things you enjoy. Read, watch a movie, have a friend visit, go out for a special treat, journal, blog, chat with friends online, and ask for support from people who understand.
10. Remember that this weight fluctuation will most likely happen. It is up to you and your doctor to establish what is "normal" and what isn't.

**Living life with a chronic illness is ridiculously hard. Your body may seem awful, but it's yours. It can be triggering for anyone with pulmonary hypertension to see the numbers on the scale increase. It triggers worries, fears, anxiety about our condition, and anxiety about weight. A scale causes lots of anxiety, but it can be a crucial part of monitoring our condition. Don't pick on yourself for things that you have no control over. Don't let a number on the scale stop you from living.**

# HAPPINESS IS AN INSIDE JOB



I got a tattoo today. It's actually my sixth tattoo, but this one is definitely a good one. I decided to get a tattoo of the **serotonin molecule**. Serotonin, the chemical that helps your brain feels happy.

I got it because I haven't been happy lately. I've felt heavy, a bit sad, scared and restless. The weight of loss, and the unknown of this disease called pulmonary hypertension, refuses to leave my heart and brain alone.

**Happiness is an inside job.** People may add to that happiness, or subtract from it. You can add stuff to your life, thinking it will make you happier, fuller. You may define happiness by your career, your success, the amount of people who admire or love you. But at the end of the day, it's up to you to make yourself happy. That's why this serotonin molecule is so important to me.

Every day, my body is **succeeding** a little bit more. Filling me with happiness. I don't have to drown under the heaviness of life. No, I instead allowed myself to feel those feelings, and then set them out to sea. Then I get to fill myself back up with happiness. This comes from knowing my own worth.

**I am worthy of love.** I am strong, smart and brave. I'm excellent at board games, and a pretty decent cook. I'm a good listener and good with kids. I'm a wife, a sister, a friend, a daughter. I am proud of every part of me, even my flaws, because they have made this body. And this body has fought wars with itself. It's read thousands of books, and walked down an aisle to get married. This body has rocked many babies to sleep, hugged hundreds, and laughed until it cried. It has made meals for people who didn't feel good, and popped the corks of bottles of champagne to celebrate with people who felt amazing.

I have **LIVED**. And with this body, I'll continue to do so.

Our illness is not what **defines** us. It's not who we are as people. You are so much more.

I'm working harder to be happier. Some days it's hard. But happiness is out there. **Go find it!**



## Ways to lighten the weight of expectations around the house

Before I was diagnosed with pulmonary hypertension I was a real go-getter. Now, don't get me wrong, I loved a day in my sweats and a good Netflix binge as much as anyone, but I worked hard. I was a nanny and worked more than 50 hours a week, cooked every night, and easily kept up with household chores. I loved doing a good load of laundry and going grocery shopping. *When I got sick, I couldn't even wash my hair. I could barely dress myself. Going to the grocery store became impossible. My husband and I lived off grilled cheese sandwiches, and anything that he could BBQ.*

Over the past two years, I've improved, but I've had to accept that I'll never be at my "pre-PH" level of ability. It was a hard pill to swallow. I wanted so badly to be able to take my pills, cut out salt, and bounce back to who I used to be. But it didn't happen. And now, that's okay.

So, today I've come up with a list of ways to make your life a little easier that have helped me.

- ❖ **Meal plan:** There's nothing worse than beginning to prepare dinner and realizing you have no food in your house. Going to the grocery store can be overwhelming and tiring. Every Sunday, I make a list of meals I plan to make that week. I write out every single ingredient, and include household items as well.
- ❖ **Take your time:** move slowly, and try not to forget things. (I forget things every single time, no matter how slow I go. My husband, Matt, runs to the store for me at least once a week, picking up one lone item.) *Go to the store, and walk slowly. You're not in a rush, friend!*
- ❖ **Meal prep:** This one is just as useful. Bake and cut-up all your meats. Chop all your veggies. Sometimes I even measure and divide up my seasonings, and store them in ready to go Ziploc bags. Then all you have to do is dump it all together that night.
- ❖ **Laundry:** This one is tricky. It involved lifting heavy baskets, bending, going up and down stairs, etc. I usually have Matt bring the laundry basket downstairs before he leaves for work. I'll take a day, or two, and slowly do a load. When it's all done, I'll pile it back in the basket and wait until he's home so he can carry it upstairs for me. Do I wish I could do it all myself? Sure. Is that always reasonable or realistic? Nope. Adjust those expectations.
- ❖ **Showering:** Few things wear me out more than taking a shower. I do have a shower chair that I use. Now I tend to wait a couple of days between showers. It's easier on my lungs, and better for my hair! Also, baths. Lifesaver.
- ❖ **Sleeping:** Get a wedge pillow. Seriously. They have them at amazon.com and they're incredible. I used to just bunch up a pile of pillows, and slowly slide off of them by the middle of the night. Now I just have my wedge pillow, and it makes night-time much easier.
- ❖ **Cleaning:** There are certain things I can do with no problems. Vacuuming is an easy one for me. Doing dishes, and loading them in a dishwasher? Much more difficult. So, I'll do the sweeping and vacuuming, and I delegate the dishes to Matt.



This little list may seem silly, and some of it may seem obvious. But it has taken me a couple of years to remind myself that I can't do it all myself anymore. I have to ask for help. I have to rely on people more than I'm used to, more than I ever did before. My ego took a giant hit, but now I just keep reminding myself that I am worth more than how much laundry I can get done. At the end of the day, does it really matter that I need to ask for help doing dishes? No.

Pulmonary hypertension is a disease that seeps into every aspect of your life. But it doesn't have to ruin your life. Just adjust those expectations, friends. **Readjust your sails, and set sail.** Our next story is from the same writer and talks about her journey into doing Yoga...

# A PH Patients Journey with Yoga

## Here's how I got started on my journey with yoga: story cont...



When I first got diagnosed with pulmonary hypertension, I was physically unable to do anything. Showering was a chore. I could hardly walk from my bedroom to the kitchen.

I stopped leaving the house. But eventually, with the help of my medications, I began to do more and more. I finally talked to my doctor about what sort of exercises I could start doing, and how to live a healthier life. We talked a lot about different options, and we finally agreed on yoga.

I created a yoga room. My husband Matt and I had an extra room in our house. It basically became a catch-all for our junk, clothes and holiday decorations. After being fed up with it all, I cleared it out. I actually put our laundry away, stored our decorations in a spot that made sense, and cleaned it up. Then I picked a soothing colour, and bribed Matt with all the baked goods he could handle to paint it. I created a space where I could "just be" with the yoga.



I found the right person to teach me. I looked into books, and YouTube starts, and decided on [Yoga with Adriene](#). She's on YouTube, and she has hundreds of [videos](#), ranging from easy to difficult. She has videos for everything you can think of! Toning, digestion, hangovers, aching backs, headaches, bad moods. You name it, she's got it. She can teach you how to do a proper downward dog, and forward fold. She has a positive attitude, and can either energize you in the morning, or help you unwind in the evening.



Be dedicated. At first, I was averaging about four or five minutes at a time. I would do one downward dog, and immediately start gasping. My muscles had atrophied, and my lungs refused to cooperate. I wanted to quit. I wanted to throw my yoga mat in the garbage can, frustrated that my body wouldn't do what I wanted. But I persevered. Every day I pushed myself a little bit more. My doctor saw the results before I did, and urged me to keep going. So, I did.

Be proud of yourself. I can now do 45 minutes to an hour of yoga at a time. I'm stronger, healthier, and happier. I look forward to yoga every day. My doctor is proud, and the time I've put into this journey obviously has paid off. My six-minute walk tests have improved by more than 150 meters, and I'm not as winded. Be proud of the results you see, no matter how small they may be. Can you do five extra minutes? Are you feeling less anxiety? Do you have tiny baby muscles poking through? Hooray!

Of course, be sure to check with your doctor to see if yoga is the right choice for you. It's not for everyone, and it won't work for everyone with pulmonary hypertension. Sometimes I can feel a little bit dizzy if I push myself too far. You just have to find the right moves and trainer for you. Namaste! [Check out phna.info Exercise page for PH Yoga ideas and links.](#)

# goodhealth.

## Getting Stuck when Asking for Help



Shared with you from [PHNews.Com](http://PHNews.Com) and Author [Brittany Foster](#)

There is an inner dialogue that often goes on in the mind of someone who is chronically ill when asking for help. Ultimately, the outcomes of these inner conflicts are feelings of guilt, shame, and uselessness. It is hard to break out of this mental ping-pong of feelings. I'm sure if people could actually see what goes on inside my brain, they would laugh at the ridiculousness of it all. The truth of the matter is, it is difficult for many people, even those with able bodies, to ask for the help they need. It is especially difficult for those with chronic illness.

**Below** is a list of examples of some of my inner thoughts and the problems with these thoughts. *"Try to do this on your own. Maybe if you nap for an hour you will feel more energized."*

**Problem:** Usually naps don't make me feel more energized. If I am tired in the beginning of the day, most likely this will stay with me the entire day.

**Advice:** On days when you are feeling especially fatigued and worn down, don't try to "nap it off."

*"Just shake it off, you will be OK. You need to get this done."*

**Problem:** Realistically, I can't "shake off" having PH. As much as I would like to think I can, it's impossible.

*"I can't do anything! I'm just going to sit around all day being bored. My body stinks!"*

**Problem:** Just because it is hard to do things one day, doesn't mean I can't do anything at all. Sometimes my body tells me to rest in bed, but that doesn't mean I'm lazy. That means I'm taking care of myself.

**Advice:** Saying negative things about yourself will just make you feel worse mentally and doesn't help the physical aspect of it. Don't get caught up with your bad day. You will make it worse by putting yourself down.

*"People will think I'm lazy! I need to do this myself. I don't want my family to think I am trying to get out of something."*

**Problem:** The people who I trust enough to ask for help definitely don't think I am lazy. They are probably in admiration of the fact that I try to manage the best I can.

**Advice:** Remember that the majority of people WANT to help you in any way they can. They feel helpless seeing someone they care about go through so much.

*"I already asked this person to help me a few days ago. She is going to think I'm taking advantage of her."*

**Problem:** This is the guilt side of my feelings. I get caught up in feeling guilty about my need for help.

**Advice:** If you ask someone for help, either they will do it because they want to and know you need the help, or they won't. If they don't, it's probably because they are too busy with something else. Always have a few people to turn to!

*"Today I need to clean the entire house and go grocery shopping."*

**Problem:** There is no need for me to do everything all at once. It will just make me more tired.

**Advice:** Only do what you can manage. If you absolutely have to clean the entire house and go grocery shopping, make sure to bring someone with you to the grocery store and split up the house chores with someone who can help. It is not worth wasting all of your energy and spoons on one trip to the market.

**What keeps someone who is chronically ill from asking for the help they need?** Why do we feel such shame when those who will help us know how much energy we are putting in just to get through a day?

For me, it is a very long list of feelings, fears, and worries that keep me from getting the courage to ask. I'm sure those with PH can add many thoughts and inner dialogue to this list. **Writing** out my inner dialogue helps me to evaluate it when I have a clear mind. When I am able to think logically about it, I can work on changing how I view getting help. **Why don't you give it a try too?**

# Oxygen in Real Life

YOUNG ADULTS USE OXYGEN TOO



## PHNA EDITOR'S PICK RECOMMENDED READING

Although pulmonary hypertension caused me to give up my fancy grown-up job, I have been lucky enough to work part-time from home. I actually work for [BioNews Services](#), the company that runs [Pulmonary Hypertension News](#). One of my favorite tasks is browsing through stock images, trying to find the perfect image to accompany a column.

From time to time, I have to try to find images that depict patients, and the various types of medical equipment they use, like supplementary oxygen. I was browsing through the images available for supplementary oxygen and noticed how none of them accurately depict me, or other pulmonary hypertension patients.

All of the images that were available showed frail elderly people using supplementary oxygen in a hospital bed. I think that society has this general belief that oxygen is an “end of life” therapy for “old people,” when that isn’t necessarily the case. I’ve actually had strangers ask me if I was dying when they saw me wearing oxygen at a bank. I had never seen anyone else my age use oxygen before my diagnosis, so I understand that some people are curious about why I use it.

I found their questions really intrusive, however. Even if you are curious, there is no polite way to ask a complete stranger if they are dying.



### Normal things with extra O2

Truthfully, I hated being asked why I use oxygen. Often, strangers would come up and make a rude comment or ask a personal question while I was out doing very normal things; working, shopping at the mall, waiting at a chiropractor appointment, grabbing a smoothie, or — my least favorite — while I was out on a date.

I once had a waitress ask me about my oxygen when I was out for dinner on a date with my boyfriend, Spencer. We’re in our 20s, and it took a lot of courage for us to finally try to plan normal dates after my diagnosis. I got really depressed, cut myself off from the world, and felt too hideous to leave the house; it made it difficult for us to regain any sense of normal. It took some time, but we finally started to go out for nice dinners. I remember spending that warm afternoon trying to do my hair and makeup, and picking out a cute outfit for our date.

When we sat down at our table, I was so focused on our date that I wasn’t thinking about all of the insecurities that were eating me alive. I wasn’t consumed by my anxiety until the waitress asked me about my oxygen. Spencer rolled his eyes and I let out a heavy sigh. It felt strangely invasive to have someone ask me about medical equipment, especially while I was doing something so normal.

Although I try to raise awareness for PH, I like to try to enjoy my normalcy when out and about. Wearing oxygen or a piece of medical equipment isn’t equivalent to wearing a sign that says, “Ask me about my disability/disease!”

***Some pulmonary hypertension patients need oxygen to accomplish various tasks. Some patients may need oxygen simply for an airplane flight, or maybe just for sleep. Others may need it just for heavy exertion, while others may need it 24/7. Some patients use oxygen the same way someone would use a wheelchair; simply put, it helps them get around!***

# Oxygen in Real Life

YOUNG ADULTS USE OXYGEN TOO

## Representation for young adults

### Kayla riding her bike



So where are the images depicting me, and patients like me? Where are the fashion-forward, 20-something-year-olds, who just happen to need oxygen as an extra accessory? Where are the images showing friends going out for ice cream, one of whom just happens to need oxygen? Where are the people using oxygen at cafes, concerts, working, and going out on dates? I know these people exist because these are all things I have done while using oxygen. (Well, the line about me being fashion-forward is a lie. I dress like a retired poker player.)

Perhaps the problem is that most people aren't educated on oxygen use. Most assume that young people don't need it, and many others don't understand that oxygen is medical equipment that can help us function better.

## Meet my PHriends: Young adults

I would like to introduce you to my friends [Jenny](#) and Kayla, who are young adults who just happen to have PH and use supplementary oxygen. Kayla went to college, started her own [PH fundraiser jewelry line](#), and enjoys riding her bike — all with her oxygen in tote. Jenny also went to college, enjoys exploring the world around her for her photography, writing poems, and going to concerts. She also happens to use oxygen to help her get around.

### Jenny with a new "friend"



### All kinds of people use supplementary oxygen, including young adults with busy lives!

Supplementary oxygen not only helps some patients breathe better, but also it enables some patients to do certain activities like climb stairs, work, sleep, or shower. Oxygen isn't just a [treatment](#) you get at the hospital, nor is it just for the elderly. Oxygen therapy needs to be better understood by society as a piece of medical equipment for people of all ages and abilities.



## Just some of the young adults wearing and living with oxygen supplementation as part of their PH treatment

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# Community Spotlight



## The PHNA National PH Patient Registry

### REGISTER

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