PHWA INTRODUCES "We are PHamily"

"The PH Patient Pack"

"The PH Puzzle"
Putting the Pieces Together

"The Invisible Diseases"
Project
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Hello PH Family and welcome to the Winter edition of PHan Mail magazine, helping you to live well with Pulmonary Hypertension! This edition is packed full of really good articles that we hope will help you cope and manage your chronic disease day by day.

What an incredibly busy time it has been this year. This edition will highlight the incredible work tirelessly carried out behind the scenes by our fabulous Grants & Development Coordinator Helen Blanchard and her work on the all new patient resources for people living with pulmonary hypertension. These written resources in the shape of a "PH Patient Pack", or the "3-P-Pack" as we affectionately call it, has been researched, compiled and written exclusively by PHWA for anyone living with or caring for someone with pulmonary hypertension.

We are really pleased with the outcome of our two projects "We are PHamily" & "Invisible Diseases" and look forward to sharing these new resources with everyone. At our launch luncheon on June 21st when CEO Connect Groups Association Antonella Segre officially launched our new products we were humbled to be told that they were able to further fund us for our next projects "GP Aware" & "Living Well with PH - Live & Personal" miniseries. We will share more about those with you in the coming editions.

I would like to extend my deepest thanks to our support group members for listening tirelessly and joining in for the last year on with the planning and development of our new PH resources. Often these planning sessions over took our support group meetings as we nutted out exactly what we wanted to achieve for people living with PH. It has been our honour to work with you all on your behalf and now it is time for you to enjoy the fruits of our combined labour. Be kind to one another, your PHWA Editor Melissa and team.

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RIP PH Angel Joyce Willis
Our sincerest condolences to the family and friends of Joyce who will be sadly missed.
Mission Statement
Provide information and resources about pulmonary hypertension to people living with PH, medical and health professionals, and the wider community.
Provide support to people living with pulmonary hypertension, their carers, family, and friends.
Raise awareness about pulmonary hypertension where ever it is needed!

“The PH Puzzle”
Putting the pieces together towards an early and accurate diagnosis.

Proud Sponsors & Supporters of PHWA

**PH Clinical Trials:** The Institute for Respiratory Health is currently running a clinical trial into Pulmonary Hypertension. If you would like to get involved please contact the recruitment officer, Leisa Wilson, on 93464482 or leisa.wilson@resphealth.uwa.edu.au Leisa will be able to explain the trial in more detail with you and see if are suitable to participate. If you would like to volunteer with the Institute for Respiratory Health please contact the Administration Officer Janet Pesce on 9346 3198 or admin@resphealth.uwa.edu.au

**Donations & Fundraising** Donation from Margaret Nunn $10.00.

**Thank You’s & Shout Out’s** Wyllie Arthritis Centre who generously provide their function room to us for each meeting. This is invaluable to us and we are very grateful. PHWA Sponsor Gabrielle Worthington from Dependable Laundry Solutions. She is very generously sponsoring us for the support group "PHan Mail" magazines to be printed. The team at Weigh n Pay Woodvale, business sponsor and IT management. Connect groups who continue to support and guide our group. Carers WA who are there to offer assistance to our carers wherever they can, and to our Volunteers, family & friends who work tirelessly to support our team and its members; we greatly appreciate your assistance, kindness & reliability.

**Support Group Meetings - PHWA** Please advise if transport is needed we’ll do our best. Meeting Dates for 2016 - Tuesday’s 11.00am - 2.00pm, registration 10.45 DATE Below under Save the Date! Catered Lunch cost per person $12.00 pp now with $2.00 price increase as of 2016. (subject to change. please advise dietary needs) - Menu will consist of a Roast dinner with a dessert to finish. Catered by the Nourished Cafe Wyllie Centre. Morning tea supplied by PHWA.

To all those who have access to the internet please be aware that you can log onto our new website at www.phwa.info and go to the PHWA Support Group page to see the meeting dates and to RSVP. You can also get access to the latest PHan Mail magazine (under magazine) by downloading it directly.

Quote: Being brave isn’t supposed to be easy!
It’s wintertime and there is nothing more appealing on a cold and chilly winter’s eve than curling up with a good book or a movie and savouring some of these amazing gooey and decadent no bake chocolate fudge brownies. I should tell you it’s going to be very hard to stop at just one, so cut them into little squares and try to be good!

**No-bake Fudgy Choc Brownie**

Description
A super fudgy chocolate brownie without even turning on the oven! It’s a cross between a brownie and fudge!

How to Make
Grease and line a 20cm square pan with baking paper.

In a medium saucepan combine x1 packet NESTLÉ dark choc melts and tin 395gm Sweetened Condensed Milk. Stir over medium heat until it comes to the boil. Reduce heat and continuously stir for a further 2-3 minutes or until mixture becomes slightly thickened. Removed from heat and stir in 1 teaspoon vanilla.

Meanwhile place 200gm plain biscuits in a food processor and process until fine crumbs form. Add to saucepan and stir until combined.

Press into prepared pan; if desired top with 65gm pistachios or white choc bits chopped. Refrigerate for 10 – 15 minutes. Cut into 18 squares and serve.

_TIP: Top with Nestlé BAKERS’ CHOICE White Choc Bits for a rich double chocolate fudge brownie_

I watched Karen make this with her gorgeous sister who is a pastry chef and has generously shared her recipe in Karen’s latest cookbook. I sliced banana over the top and also trickled maple syrup over the top of that before I baked it. It was so moist and fragrant and especially decadent with the whipped maple butter, yum!

**Sisterly Banana Loaf with Maple Butter**

Description
This is a moist and deliciously banana scented cake topped with creamy butter, what could be better!

How to make
Grease a large loaf tin and line with baking paper.

Into a food mixer pour 100ml vegetable oil, 50gm yoghurt, 110gm caster sugar, 1 egg, generous pinch of salt, 200gm mashed bananas, and combine well (mixture is quite wet). Add in 170gm sieved plain flour, 1 tsp bicarb, 1 tsp baking powder, combine well and add to mix, blend well pour into large lined, greased tin loaf.

If desired you can layer slices of banana cut on the diagonal across the top of the loaf. Bake in a preheated oven at 170 degrees for 30-35 mins.

**Whipped Maple Butter**
125gms butter unsalted, sweeten with about 2-3 tbls of maple syrup and a pinch of salt. For an added kick put in a touch of white miso paste, combine well and spread across your slices. Yum
Health Professionals

Results from a retrospective study based on a claims database of U.S. patients with pulmonary embolism indicated that physicians are failing to recognize and diagnose thousands of cases of a serious lung disease, chronic thromboembolic pulmonary hypertension (CTEPH). The study, “Monitoring for Pulmonary Hypertension Following Pulmonary Embolism: The INFORM Study,” was published in the American Journal of Medicine and funded by Bayer.

CTEPH, a rare form of pulmonary hypertension characterized by progressive dyspnea, is commonly seen as a long-term sequela of acute pulmonary embolism. It can lead to right heart failure if unrecognized and left untreated.

In many patients with CTEPH, dyspnea is attributed to other conditions, leading to a delayed diagnosis. The mean duration from onset of symptoms to a CTEPH diagnosis was estimated to be 2.7 years. Effective diagnosis is crucial as CTEPH is a treatable condition.

In the INFORM (Investigating the role of disease monitoring in incident pulmonary embolism patients using a Managed care claims dataset) study, researchers performed a retrospective claims database analysis of incident pulmonary embolism (PE) cases, and extracted data for one year prior and two years post the incident PE event. The aim was to determine the prevalence of pulmonary hypertension following incident pulmonary embolism, and the disease monitoring patterns in 7,068 incident PE patients.

Of the total patients, 87 percent had a claim for a pulmonary hypertension-related symptom, and 7.6 percent had a claim for pulmonary hypertension during follow-up. Only 55 percent of all pulmonary embolism patients had diagnostic procedural claim(s) post-pulmonary embolism:

- Echocardiogram in 47 percent, computed tomographic angiography in 20 percent, ventilation-perfusion scan in 6 percent, and right heart catheterization or pulmonary angiography in less than 1 percent, suggesting that the incidence of CTEPH could be 3.8 percent. The mean time from pulmonary embolism diagnosis to first screening test was 131 days.

“Between 300,000 and 600,000 Americans experience a pulmonary embolism every year, and our study shows that up to four percent of those patients may later go on to develop CTEPH,” Victor Tapson, MD, director of the Venous Thromboembolism and Pulmonary Vascular Disease Research Program at Cedars-Sinai Medical Center in Los Angeles, said in a news release. “Furthermore, the results demonstrate that the risk of developing CTEPH after pulmonary embolism remains substantially under-recognized.”

“These results demonstrate that if respiratory symptoms are nonspecific and persistent in a patient with a history of pulmonary embolism, you have to have a high index of suspicion for pulmonary hypertension,” said David Platt, MD, director, U.S. medical affairs at Bayer, and co-author of the INFORM study. “The implications are particularly important for the subset of pulmonary embolism patients who go on to develop CTEPH. Increased awareness and use of recommended diagnostic methods, such as V/Q scans, could dramatically improve prognosis, given the availability of potentially curative surgery.”

The researchers indicated that future studies should investigate how patients with pulmonary embolism, both with and without pulmonary hypertension, may differ in the way they are treated and managed to gain additional insights into prevalence, treatment patterns, and costs associated with CTEPH.
PHWA
New "PH Patient Pack" resources COVER ART, WINS National Art Award!

About the Artist - Helen Blanchard

Helen is the Coordinator Grants/Development & Design for PHWA. Amongst her many talents she is also a budding artist and writer. Her artwork is mainly abstract and impressionistic in nature and has been a source of great therapy for her as she deals with multiple chronic conditions herself and those of her family members. Helen has a long history in the Health Care profession starting out at Royal Perth Hospital training as a Registered Nurse then advancing into multiple fields in the medical arena both in health, education, and training in the public and private sectors. She is passionate about health management and education and has spent the last year researching and writing the new PH patient booklet, "Understanding and Living with PH", which will be released June 2016 as part of the PH Patient Pack (3-P-Pack).

Helen created the artwork below initially as a series of graphics and we chose one as a bookmark for PHWA which has now been adapted to suit our new PH patient packs booklet "Living with and Understanding PH". The chance to promote both her artwork and pulmonary hypertension awareness came up earlier this year through the Avant Card Postcard Media Advertising Company. An Australian based company which has an "Australian Artist Project" that encourages artists from all over the country to participate in the competition.

The application for the artwork into the competition included an artist bio which included Helen’s work with PHWA and on pulmonary hypertension. The judges were really touched by her story "Pulmonary Hypertension - A lung disease that’s Breathtaking". The prize includes 10,000 free postcards distributed nationally to various participating venues across Australia. The post card will include our PHWA website, and will also be advertised on all of their social media sites so that people anywhere can look us up online! She will personally receive 500 printed copies for her own collection and we look forward to sharing those with you later this year.

Artwork by Helen Blanchard
Inspired by the images of the echocardiogram given to PH patients.
Ok, so I really get how mind-numbingly annoying it is that Easter eggs start filling supermarket shelves from Boxing Day, but please don't switch off when I'm here to tell you about preparing for flu season right after you've downed that chocolate egg. While flu season usually doesn't start before autumn it's unpredictable, so don't wait until your partner brings it home to consider vaccination.

I hear you ask, "But I had a flu jab last year, why do I need it again?" Aha, glad you asked. Unlike some other vaccine preventable infections, influenza is a wily virus with a big family and new member's joining the clan frequently. Some are meaner than others. Indeed, it is said more people died from the Spanish flu in 1918 than World War 1.

Although that sort of pandemic is rare, we simply can't predict when the next stealth bomber flu will arrive and it's best to be prepared. The vaccine needs updating every year and a special group of health experts have been beavering away, brainstorming the best combination of our 2016 influenza vaccine since the Northern Hemisphere winter, it will be ready to roll our soon.

To have the best chance of protecting against flu you need an annual vaccine. Not only because of the new flu types, but also your resistance has likely faded since your last jab.

I hear you protest, "I don't need that jab", but we all know that translates as you're scared of needles, so toughen up!

**Most healthy people who get the flu may be laid up for two weeks and make a complete recovery, but not always. Then again, flu can lead to devastating complications, including death, especially in vulnerable people. For example, the very old, young and those with chronic diseases, such as lung conditions or diabetes, or lowered immune systems.**

While the Government provides a free vaccine program for high-risk groups, it's worth considering the vaccine for yourself if you mix with those who might be at risk. Sure, you might feel you can soldier on through flu, but you don't know whether that person sitting next to you on the train is on chemo. Flu's not a nice gift to give them.

What's that? Your bestie's bro claims he got the flu from the vaccine. Hmm, sorry his claim is simply wrong. Either he was already infected before the vaccine took effect (hence my advice to get in early) or it was something else. (I'm biting my lip, resisting the sexist temptation to mention Sunday morning "man-flu").

You can't get flu from the vaccine. There are simply no live viruses in it. Yes, some people get a sore arm or maybe some transient aches and pains, but these are way fewer symptoms than the flu. Of course, if you have had a reaction in the past, or have concerns, do speak to your doctor, and, of course, those genuinely allergic to eggs should **NOT** have the vaccine as the vaccine prep process involves eggs.

Ok, here's the big one - the latest recommendation is that pregnant women should have the flu vaccine, too. Research from Stanford University has shown that it's safe in pregnancy.

Flu can trigger an over the top immune response that can cause devastating lung complications. Certain flu vaccines are not recommended for children but others are available for babies over six months.

In short, chat with your GP about your individual risks and whether you qualify for a freebie flu vaccine.

Check your workplace has a program. And ask your pharmacist when the 2016 vaccine will be in stock.
Magnesium is the eighth most abundant mineral on earth and the third most plentiful in sea water. In the human body it is the fourth most abundant mineral and is involved in over 300 reactions in the body.

Magnesium is important in so many of the body's regulatory and biochemical systems that deficiencies can be extremely detrimental to overall health. Magnesium is used by every organ in our body, especially our heart, muscles, and kidneys. Unfortunately, it is estimated that up to 80% of adults are not getting enough magnesium and therefore may be deficient.

Although there are blood tests available to assess for magnesium status, these are notoriously unreliable. Serum blood can be used to measure magnesium status but the body has a mechanism to keep blood magnesium levels within normal ranges. If blood levels drop, our body removes magnesium from tissues to prop up levels in the blood. This makes it look like our levels are normal, but in fact our tissues (e.g., heart, lungs, kidneys) may have insufficient levels.

The alternative is to consider signs and symptoms of magnesium deficiency to predict your magnesium status.

Below are 10 signs of magnesium deficiency (you may experience one or several if you are deficient):

1. Unexplained fatigue or weakness
2. Abnormal heart rhythms, heart "flutters" or palpitations
3. Muscle soreness or spasms
4. Eye twitches
5. Anxiety, depression, or restlessness
6. Inability to sleep or insomnia
7. Infertility or PMS
8. Headaches
9. Fuzzy brain or difficulty concentrating
10. Thyroid problems

"How To Increase Your Magnesium Levels"

Eat foods high in magnesium. Some examples of foods high in magnesium include dark green leafy vegetables, nuts, seeds, fish, beans, whole grains, avocados, yoghurt, bananas, dried fruit, and dark chocolate.

Limit your intake of caffeine, sugar, and alcohol. These foods tend to deplete magnesium levels so it is imperative that you limit your intake of them.

Learn ways to manage stress. High stress levels deplete magnesium levels in your body so you must find ways to reduce your stress levels.

Relaxation techniques, meditation, or taking supplements to help your body deal with stress more effectively, are all good examples of how to reduce stress levels in your body.

Improve gut health. We absorb magnesium from the foods we eat so it is essential that you have good digestion to help breakdown the food components and effectively absorb the magnesium.

Supplement with a high quality, well absorbed form of magnesium. If you are low in magnesium, supplementation is likely essential to help restore levels quickly. However, some forms of magnesium are poorly absorbed (e.g., magnesium oxide). BCN's Rest & Replenish contains magnesium glycinate, a highly bioavailable, great tasting form of magnesium (plus other nutrients to reduce stress and support healthy sleep) and is a good option for increasing the level of magnesium in your body quickly.

PHWA Editors Note:
(While this article recommends a natural approach to increasing your magnesium as a pulmonary hypertension patient you must follow your treating PH doctor’s instructions strictly and take the medication they recommend. Slow K is generally the medication of choice. If you want to boost your magnesium or supplement it further please discuss with your doctor first. Thank you.)
Coping with loss

Losing a loved one can be a very painful experience. You may experience many emotions such as shock, sadness, anger, guilt, and despair. You may also feel relief, hope and acceptance. All these feelings are normal and natural when you are grieving the loss of a significant person in your life regardless of your age, gender or culture.

_Grief_ can also bring on feelings of helplessness, sensitivity and vulnerability; a longing to fill your day with activities to take your mind off it or not wanting to do anything. You may experience good days and bad days. This is how grief works. It can be very chaotic in nature - an 'all over the shop' experience.

In conjunction with the emotional responses, you may experience physical reactions such as loss of appetite, inability to get a restful night's sleep, lack of motivation to do the things you once enjoyed or to be around friends and family, panic attacks, memory loss as well as experience symptoms of depression.

It is important that during your journey of grief, you do not isolate yourself but find support with family and friends whom you feel comfortable sharing your grief with. There is no right or wrong way to grieve and over time these painful emotions decrease in their level of intensity. You may never be able to get over the loss of a loved one; you can learn to manage and live with it.

_Talking things over_ - "How can I access emotional support at Carers WA"? Talking things over with a Carers WA counsellor can help a carer to feel less overwhelmed and relieve potential isolation. It can also help a carer gain new perspectives, problem solve, and assist in exploring respite and time out options. Free telephone counselling line 1800 007 332.

Some suggestions that might be helpful:

1. Try to establish a new routine, one that works for you. Make plans for the future even if that means just planning next week.
2. Engage in activities that interest you, those which give you a sense of meaning and purpose.
3. Maintain social connections.
4. Look after yourself. Visit your GP regularly, exercise, plan a holiday for yourself or with a group of friends.
5. Maintain a journal. Journaling may not appeal to everyone but it can be a very valuable means of support if you are struggling to sleep or if you feel you cannot reach out to your family or friends. It is a good way to pour out your thoughts and feelings.
6. Access Counselling. Reaching out for help is a hard thing to do for so many people. You may feel as though you do not want to burden your family and friends with your problems. Counsellors are there to listen and help you manage your grief in a way that works for you.

Tip: Get adequate amounts of sleep and try to eat healthily.

Forms of counselling available through Carers WA - Free over Telephone - Email - Face to Face - Skype

Information courtesy Carers WA - Carers Quarterly Magazine
The facts about Sleep Apnoea!

Tired of feeling tired?

Do you suffer from:
- Excessive daytime sleepiness?
- Poor memory function?
- Short concentration?
- Depression?
- Snoring?

It's time for a check up

Your symptoms could be hiding a more serious condition. Obstructive Sleep Apnoea (OSA) is a common sleep disorder that can have severe effects on your health and lifestyle. OSA occurs when you stop breathing during sleep because your airway has completely closed. This can happen hundreds of times during the night, while each apnoea (period of no breathing) can last anywhere between 10-60 seconds.

Epworth Sleepiness Score (ESS)

This score is a way of evaluating how sleepy someone is during the day. It is used internationally by sleep clinics, research groups and sleep physicians. For each situation listed below, record a number from 0 to 3 that best reflects how likely you are to fall asleep. Then add your total score up out of 24.

- Sitting and reading
- Watching TV
- Sitting inactive in a public space
- As a passenger in a car for an hour
- Lying down in the afternoon
- Sitting and talking to someone
- Sitting quietly after lunch without alcohol
- In a car stopped while in traffic

0 : No chance of falling asleep
1 : Slight chance of falling asleep
2 : Moderate chance of falling asleep
3 : High chance of falling asleep

Did You Know?

Sleep apnoea is usually hereditary.

OSA is diagnosed through a sleep study which can be done in the comfort of your own home! Simply take the survey (right) today and discuss the answers with your GP if you have concerns about daytime energy levels and alertness.

If your total score was more than 5, you have mild sleepiness and may not be getting the proper sleep you need. If your score is 10 or more you should talk to your Doctor about a diagnostic sleep study.

www.tiredoffeelingtired.com.au
Pulmonary hypertension is a serious and hard disease to live with, especially if we’re talking about young patients. Being diagnosed with a lung disease like PH as a child or a teen, can be really complicated. We’ve put together some tips on how to parent your child while she/he is living with pulmonary hypertension (source: PHWA website).

Story shared with you by PULMONARYHYPERTENSIONNEWS.COM

1. Rest assured that your child developing pulmonary hypertension was not caused by you or anything you’ve done.
2. Don’t forget to take care of yourself. Even though your child is sick and you have to care for them, you also have to look after yourself.
3. Look for answers and ask for help. It’s ok to feel overwhelmed with everything, but it’s also ok to seek help and to accept it when offered.
4. Establish routines for your own tasks so you can reduce the stress at home, at work, or even in your social life.
5. Find yourself some good support among your family, your friends, or even in a support group (where you will find people in the same situation you are).
6. Get organised and always keep track of your child’s appointments, your own appointments, events and other activities you may have.
7. Step out of your comfort zone and try new things. Look out for some new activities you can do as a family and especially with your child after being diagnosed with PH. Arts, crafts, music or even cooking lessons can help you and your child to cope with this together.

FINDING A SPOT TO SIT!

Deidre Sabine is one of our PHWA members, who also takes part in the pulmonary rehabilitation classes, held in Wembley, has some great ideas about where to take a rest when out shopping. If you take a wheeled walker with a seat you cannot manage a shopping trolley as well, and you still may need to sit down sometimes.

Shopping centres are huge and, while there are sometimes seats in the central malls outside large department stores, what if you’re getting breathless and tired inside a store?

If you are in stores like Big W, K-Mart or Target here are three places you may be able to sit down to catch your breath:

- Where they sell outdoor furniture
- The shoe section has seating
- The area where you upload and print photo's

Great ideas Deidre!

Thank you to LIFE’s Breath of Life Winter Edition for this great instant read. If you have any ideas you would like to share just let us know.
"The Invisible Diseases" Project

A colour, A5 card was designed and made especially for people with pulmonary hypertension who use Acrod bays. We designed our own triangle and used wording adapted from the USA based Pulmonary Hypertension Association with our own layout and graphics. To make the card multi use we included our PSA (public service announcement) on the reverse side. This will enable the user to show anyone who is curious or questioning their use of the Acrod bay and raise awareness while educating about PH. We have continued this range into an A3 sized magnetic car decal, which market research has shown to be very effective. In our range we have included other chronic conditions, all of which are available through PHWA.

"What if it's PH" & "The PH Puzzle"
Public Service Announcement (PSA)

This public service announcement has been used both as the reverse side to our disability sign (above) and as our first PSA launched on 5th May World PH Day!

Two new PHWA slogans were born with this project, one being "What if it's PH" and the other "The PH Puzzle", putting the pieces together for an earlier and more accurate diagnosis. The puzzle pieces reflect the many different types and causes of PH.

The advert screened on the Medical Channel over a two week period and reached up to 40,000 people across Western Australia.
The PH Puzzle
Putting the pieces together

The all new "PH Patient Pack" or (3-P-Pack) for short!
A resource for newly diagnosed and long term survivors of pulmonary hypertension.
Their carers, family, and friends. Written by patients, for patients.

What will you find in your new 3-P-Pack?

☑️ PACK HOLDER
White PVC A5 folder.

☑️ ORGANISATIONAL PAMPHLET
Inside dual pockets on either side with business card holders.

☑️ SUPPORT GROUP PAMPHLET
PHWA organisational and support group network pamphlets.

☑️ EMERGENCY I HAVE PH PAMPHLET
An Emergency pamphlet for Ambulance through to the ED and ward.

☑️ UNDERSTANDING & LIVING WITH PH BOOKLET
Understanding and Living with Pulmonary Hypertension - Booklet.

☑️ PHWA PEN
The periwinkle purple pen with PHWA logo.

☑️ PHWA CONTACTS MAGPAD
Fridge magnet with PHWA contacts and attachable writing pad.

☑️ PATIENT HEALTH PROFILE CARD
A double sided card ready for you to complete with essential information.

☑️ INVISIBLE DISEASES ACROD CARD
A5 double sided card to be used in conjunction with Acrod permit and the PHWA PSA (public service announcement on the reverse).

☑️ PHWA BUSINESS CARD
PHWA Business card with PSA on reverse.

☑️ EXTRA SERVICES PAMPHLETS FYI
Carers WA - Magnet & pamphlet, Connect Groups Association Support Groups WA for all your support group needs, Lung Foundation Australia pamphlet & "Travelling with Oxygen" pamphlet from Respiratory Supplies.
Pulmonary Hypertension Western Australia

What if it’s PH?

"The PH Puzzle"
Putting the pieces together to an earlier and accurate diagnosis.

Pulmonary Hypertension is a rare and serious lung disease that can lead to heart failure.
PH can affect people of any age, gender, and ethnic group.

Symptoms may include:
- shortness of breath
- fatigue
- dizziness
- fainting
- fluid retention
- irregular heartbeat
- chest pain
- cough

Some people may be at higher risk of developing pulmonary hypertension.

For information, support and resources please go to
www.phwa.info
THE CHALLENGES OF LIVING WITH A LONG TERM CHRONIC CONDITION

PHWA WORK SHOP - Guest Speaker Jenni Ibrahim LIFE Support Group Coordinator

This is a summary of discussion at the workshop held with members of the Pulmonary Hypertension WA Support group April 2016 meeting.

What we did at the workshop

- Write down three things that are challenges for you, living with a long term condition. If you are a carer write down the things that are challenges to you as a carer (not the challenges facing the person you care for).

- (In pairs - but not with the person you came with) explain the challenges you wrote down with the other person. The other person listens to you. Then, listen while the other person reflects back to you what they understood you to say. Clarify as necessary. Then swap roles. The first speaker becomes the listener etc.

- (As a large group) Share the challenges each person heard the other person explain. Discuss common thread & ideas for dealing with them.

Perhaps you can identify with many of these issues yourself or can think of others more relevant to your life. Maybe you could share things you find helpful for addressing some of them? We’d love to hear from you.

People with one or more long term conditions said...

- Managing my condition with family life (and for some, work life). Others do not take account of my condition and still expect me to do everything I used to do. Or, I feel I should contribute more to family life but I just cannot do as much as I want to. I feel bad about this.

- Managing the multiple conditions I have, all day every day. Sometimes the conditions or their treatments interact with each other and are very hard to balance.

- Caring for my own long term condition as well as the long term conditions of others. I can manage now, but I am worried that when I get worse I will not be able to manage caring for another family member with a serious long term condition.

- Thinking about my long term prognosis. Even though I’m not very ill yet, I look at others worse off than I am and worry about my future.

- Took a long time to be correctly diagnosed. I still feel frustrated about this.

Mobility...

- Managing oxygen on a holiday. Have never done it and would like to.

- Transport, getting around, especially when I cannot drive and public transport is difficult to use. Leads to isolation, feeling lonely, missing out on events I’d like to take part in. Managing a walker in and out of the car, public transport.

Social and Mental Health Issues...

- Aloneness, especially those who live alone.

- Staying positive, keeping going.

- Dealing with other people who don't understand my long term condition.

- Socialising.

- Living within the limitations of my condition.

- Admitting my frailty and limitations.

- Putting my thoughts and feelings into words with family, friends and health care professionals.

Carers Said...

- Taking guilt free carer breaks.

- Encouraging the person I care for to be more active.

- Always having empathy for the person I care for, whether as a family member or a paid health care worker.

- Staying positive, keeping on going for the person I care for.
Practical ideas and resources available...
(Some of these came from the group discussion and some were added later).

Managing Condition(s):

Make a list of the issues you need to discuss with your doctor, most important ones first. Some GP clinics allow you to email or phone requests for repeat prescriptions so you don’t need to waste valuable discussion time on that. Or hand the doctor a list of the repeats you need so he/she can get them printing while you talk.

Speak to your GP about balancing out treatment for your different long term and short term conditions. It’s their job to help join the dots, not your sole responsibility. Specialists are usually focusing only on their specialty.

Draw up a care plan for yourself, with help from the doctor if needed.

List your usual care, as well as signs of something flaring up and what you can do before making a medical appointment (sometimes you may forget some of these things).

Speak to your doctor about taking part in pulmonary rehabilitation classes, which strengthen muscles for daily activities and keep you out of hospital.

Use the resource "Living life to the full with a chronic condition", brochure (handed out at meeting, copies available directly from PHWA).

Mobility...

Taxi vouchers may be an option. If you contact HACC (Home and Community Care) the ACAT team or your local Council there may be various options available to you with assessment.


Visit an independent living centre to find out what aids and equipment could help you manage things more easily. Identify which activities are of most concern to you. Make an appointment first to get personalised assistance from an Occupational Therapist there (free). Independent Living Centres are located at The Niche, near SGH in Nedlands and at the Cockburn Integrated Health and Community Facility, 11 Wentworth Parade, Success, T: 1300 885 866.

Communication...

Role play. How to speak to others about my condition. (This will be an activity held at a future support group meeting).

General...

Ring WA Aged Care Framework to find out about paid and subsidised services in your area, including transport options.

Carer...

Go for a gentle walk with the person you care for, drive to a place they really like to visit, e.g. Kings Park or a local park, beach etc. Start with a short distance and gradually work up walking time. Discourage the person you care for from chatting while walking as this increases breathlessness, try deep steady breathing instead.

More...

Contact Carers WA, Red Cross or Commonwealth Respite and Carelink to access some subsidised carer time out.

www.carerswa.asn.au T: 1800 242 636
www.respite.redcross.org.au T: 1800 422 737
My Aged Care Framework T: 1300 785 415
www.myagedcare.gov.au
Connect Groups T: 9346 6909
Beyond Blue 24/7 T: 1300 22 46 36

What about you? What are your challenges in living with one or more long term conditions? Do some of these issues resonate with you? What different ones would you have recorded? What strategies do you use to deal with them? Other readers would undoubtedly love to hear your tips and experiences. (Article courtesy of LIFE Winter Edition).
Pulmonary hypertension is high blood pressure in the arteries going to the lung. In healthy individuals, the blood pressure in these arteries is much lower than in the rest of the body. In a healthy individual, the blood pressure of the arteries going to the rest of the body is around 120/80 millimetres of mercury (mm Hg) and pulmonary artery blood pressure is about 25/10 mm Hg. If the pulmonary arterial pressure exceeds about 40/20 mm Hg or the average pressure exceeds 25 mm Hg, then pulmonary hypertension is present. If pulmonary hypertension persists or becomes very high, the right ventricle of the heart, which supplies blood to the pulmonary arteries, unable to pump effectively, and the person experiences symptoms that include shortness of breath, loss of energy, and oedema, which is a sign of right heart failure. Many diseases and conditions increase the pulmonary artery pressure.

**Whom does it affect?**

Epidemiology, prevalence, economic burden, vulnerable populations.

The exact prevalence of all types of pulmonary hypertension in the USA and the world is not known.

In Australia Pulmonary Hypertension is a relatively rare disease considered to be present in between 15 – 55 patients per million people of the general population in its rarest form of Pulmonary Arterial Hypertension (PAH).

This has substantively increased from historical data suggesting only 1-2 patients per million in the general population. Pulmonary Hypertension is however more of an ‘umbrella’ disease encompassing more common forms of associated Pulmonary Hypertension affecting much larger numbers of patients.

Recent Australian data suggests that pulmonary hypertension, in all its forms, may affect up to 5,000 people per million or 500 in every 100,000 people in Australia.

(Above information shared with you by the Pulmonary Hypertension Society Australia & NZ).

**Causes of Pulmonary Arterial Hypertension**

PAH Diagnoses
- Other - Idiopathic PAH
- Familial PAH - Associated PAH

**Diseases Associated With Pulmonary Arterial Hypertension**

PAH Associated with other diseases (APAH)
- Connective Tissue Disease
- Portal HT (Liver Disease)
- Congenital Heart Disease
- Other - Drugs/Toxins - HIV

Most medical references are to left heart failure; pulmonary hypertension causes right heart failure and affects all races, genders & socio economic groups.

The most common cause of pulmonary hypertension in the developing world today is Schistosomiasis, a parasitic infection in which the parasite’s eggs can lodge in and obstruct the pulmonary arteries. Another risk factor for pulmonary hypertension is high altitude. More than 140 million persons worldwide live 10,000 feet or more above sea level. In African Americans, sickle cell anaemia is an important cause of pulmonary hypertension. A specific type of PH in which the disease process occurs in the pulmonary arteries themselves is called pulmonary arterial hypertension (PAH). This condition generally affects young and otherwise healthy individuals and strikes women twice as frequently as men. The average age of diagnosis is 36 years, and three-year survival after diagnosis is only about 50%.

Each year, between 10 and 15 people per million population are diagnosed with the disease.
PH Feature

With improved treatments and survival, the number of USA patients living with the disease has increased to between 10,000 & 20,000.

Because so many disorders can result in severe pulmonary hypertension and treatments may vary dramatically, it is important for a thorough evaluation to occur when pulmonary hypertension is detected or suspected. For instance, pulmonary hypertension related to blood clots in the pulmonary arteries (pulmonary embolism and thromboembolic pulmonary hypertension) requires anticoagulation and, in some cases, surgical removal of the clots. Because about 250,000 cases of pulmonary embolism occur each year in the USA, thousands of patients are annually at risk of residual pulmonary hypertension from this disorder. The actual number is not easily determined because most cases of pulmonary embolism go undiagnosed.

What are we learning about pulmonary hypertension?

Pathophysiology, causes: genetic, environment, microbes

The last 20 years have witness an explosion of clinical and research advances in pulmonary arterial hypertension (PAH) that have resulted from better understanding of the mechanisms of the disease.

A genetic cause of PAH was found by two groups in 2000, and it has led to research and increased understanding of the condition. Mutations in an oddly named receptor, bone morphogenetic protein receptor type 2 (BMPR2), are the cause of heritable PAH in over 85% of afflicted families.

BMPR2 mutations are found in about 10 to 20% of people with PAH who have no other family members with the disease. It is now known that multiple biological pathways lead to PAH, and, therefore, different drug treatments may ultimately benefit specific types of patients. In addition, PAH has been associated with connective tissue diseases (especially scleroderma), liver disease (portapulmonary hypertension), human immunodeficiency virus (HIV) infection, congenital heart disease, and stimulant drug ingestion. However, the most common type of PAH is idiopathic - with no known cause!

Little is known about the effect of the environment or microbes on pulmonary hypertension, although molecular mediators of inflammation interact with many molecules that affect changes in pulmonary blood vessels. Stimulants such as amphetamines, the erstwhile diet pill fenfluramine/phentermine (Fenphen), methamphetamine, and cocaine can cause or exacerbate pulmonary hypertension.

How is it prevented, treated, and managed?

Prevention, treatment, staying healthy, prognosis.

There is no way to prevent pulmonary hypertension, although drugs and toxins that cause or worsen the disease should be avoided.

Because it is best detected and measured by echocardiography or right heart catheterisation - tests that most patients do not undergo - pulmonary hypertension is generally not diagnosed until the disease is advanced and the right heart begins to fail. By then, the disease is usually incurable.

In some patients with pulmonary arterial hypertension (PAH), vasodilator drugs, such as calcium channel blockers, reduce pulmonary hypertension and improve quality of life. Unfortunately, only a minority of patients - less than 10% - benefit from this therapy. Also, PAH usually involves the accumulation of fibrous tissue in the pulmonary arteries, a problem not amendable to vasodilatation.

Understanding the physiology of the blood vessels in the lungs has led to the development and testing of several new classes of drugs. These drugs have vasodilator potential but also other beneficial characteristics, including platelet inhibition, anti-smooth muscle proliferation, and improved cardiac function. The overall survival of patients with idiopathic PAH has doubled with these drugs, and quality of life has markedly improved.

In addition to calcium channel blockers, three other classes of vasoactive drugs are used to treat pulmonary hypertension: endothelin receptor antagonists, phosphodiesterase-5 inhibitors, and prostaglandins (of which prostacyclins is the most important). Endothelin receptor antagonists block the endothelin effects of vasoconstriction and smooth muscle growth. Phosphodiesterase-5 inhibitors address the relative lack of nitric oxide in patients with PAH. Nitric oxide is a potent relaxer of the blood vessels. There are minimal side effects with this class and, similar to the endothelin receptor antagonists, these drugs are moderately effective in treating pulmonary hypertension.

The first fully effective treatment for PAH was the prostacyclin derivative Epoprostenol, which was approved in 1995. It has been shown to improve survival in this disease, but it has many side effects, like flushing, jaw pain, and nausea to name a few.

Although each of these classes of drugs is a major advance in the therapy of PAH, a proportion of patients will continue to worsen despite treatment with the best drugs. These patients may be candidates for lung transplantation or, very rarely, for a procedure called atrial septostomy, which creates a...
connection from the right side of the heart to the left side to allow blood to bypass the lungs.

Staying healthy with most forms of pulmonary hypertension can often be challenging. Patients must work with their healthcare team. Drug regimens often require frequent dosing adjustments and have many side effects. In addition, patients with heart failure are usually asked to follow a low salt diet and to limit the amount of liquids they drink daily. Because patients with pulmonary hypertension cannot tolerate the stress of pregnancy, women of childbearing age are generally told not to get pregnant and encouraged to be sterilised. Patients whose pulmonary artery pressure significantly improves with a vasodilator have a much better prognosis.

Are we making a difference?
Research past, present, and future

The accurate diagnosis and effective management of pulmonary hypertension is a medical triumph made possible by the development of right heart catheterisation in the 1940’s. In 1951, the entity “primary pulmonary hypertension” was accurately described. A major advance was the development of Doppler echocardiography, which allowed non-invasive imagine of the right ventricle and estimation of pulmonary artery pressure. The discovery that calcium channel blockers improved quality of life but also doubled survival stimulated research into the development of other agents. The genetic revolution, funded by the National Institutes of Health and other agencies, led to the discovery of the genes responsible for heritable pulmonary hypertension and is leading to the identification of other genes that may permit or modify disease. These discoveries have resulted in more awareness of the intricate and complicated interactions of various cells and their metabolic pathways. The biological revolution in intracellular signalling and cell-to-cell communication has led to insights into the mechanisms of disease.

New drugs are being developed and tested for beneficial effects. Because of the hope engendered by these advances, patient - and family-centred associations, such as the USA based Pulmonary Hypertension Association, have become forces for education, research, and service to people affected by pulmonary hypertension and professionals dedicated to defeating the disease.

What we need to cure or eliminate pulmonary hypertension?

Better tests are needed to make an early diagnosis. The tests should be convenient for screening and could identify persons at risk or give a measure of how severe the disease is. They could be in the form of genetic markers, which could identify risk, or of blood hormones or mediators, such as brain natriuretic peptide, that might rise with worsening disease. What is currently available, however does not adequately assess either risk of severity.

Further research will be needed to produce safer and more effective drugs that one day may be used in presymptomatic patients at high risk for pulmonary hypertension, such as those with scleroderma or those who have family members with pulmonary hypertension. Although there is much more to be done, the future has never been brighter.

For article references and websites of interest see www.thoracic.org or go to phwa.info/education/ph-puzzle for the complete article.

Pulmonary Hypertension by mechanism of disease

- Left ventricular pump failure (heart attack, cardiomyopathy).
- Left ventricular stiffness (hypertension, diabetes, metabolic syndrome)
- Valve diseases (mitral or aortic stenosis or regurgitation)
- Decreases affecting the whole lung (lung diseases obliterate blood vessels)
- Chronic bronchitis and emphysema (combination of loss of lung plus hypoxia)
- Interstitial lung diseases
- Destructive diseases that obliterate vessels, such as pulmonary fibrosis, sarcoidosis and many others
- Hypoxia Related (decreased oxygen constricts pulmonary blood vessels)
- High altitude dwelling
- Sleep apnoea and other hypoventilation syndromes
- Hypoxia or chronic bronchitis and emphysema (chronic obstructive pulmonary disease, or COPD)
- Pulmonary arterial hypertension (changes in the structure and function of the pulmonary arteries)
- Idiopathic (formally primary PH)
- Heritable (formally familial, due to BMPR2 or Alk-1 mutations)
- Drug and Toxin induced (stimulants)
- Connective Tissue Diseases (especially scleroderma/lupus)
- HIV infection (rare occurrences <1%)
- Portal hypertension (cirrhosis & other advanced liver diseases)
- Congenital heart disease (that allows blood to shunt around the lungs)
- Pulmonary Veno-occlusive disease & pulmonary capillary hemangiomatosis (rare)
- Primarily obstructing diseases of the pulmonary vessels
- Pulmonary thromboembolism
- Schistosomiasis
- Sickle cell anaemia
- Tumour emboli
- Fibrosing mediastinitis (obstruction by fibrosis related to histoplasmosis).
Pulmonary Hypertension Western Australia

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T: 08 9302 3078 - M: 041 893 0291
E: pulmonaryhypertensionwa@gmail.com
FB: facebook.com/pulmonaryhypertensionwa
W: www.phwa.info

Lung Health Support Groups in WA

All affiliated with Lung Foundation Australia - www.lungfoundation.com.au

<table>
<thead>
<tr>
<th>NAME OF GROUP</th>
<th>CONTACT PERSON - TELEPHONE &amp; EMAIL</th>
<th>TYPE OF GROUP</th>
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<tbody>
<tr>
<td>Everyone (LIFE) Support Group</td>
<td>Jenni Ibrahim - Coordinator 9382 4678 - <a href="mailto:life@resphealth.uwa.edu.au">life@resphealth.uwa.edu.au</a> (Facebook)</td>
<td>All Respiratory Diseases</td>
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<td>Pulmonary Hypertension Western Australia (PHWA) Support &amp; Information Team</td>
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<td>Respiratory</td>
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<td>Rockingham Respiratory Support</td>
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<td>Heavy Breathers - Midland Walkers!</td>
<td>Bernice &amp; Greg - 0418 415 200 - 9250 7006 <a href="mailto:heavybreathers@outlook.com">heavybreathers@outlook.com</a></td>
<td>Respiratory</td>
</tr>
<tr>
<td>Huffers &amp; Puffers</td>
<td>Meets at RPH, contact Sandra, Respiratory Educator T 9224 2903 E <a href="mailto:sandra.daly@health.wa.gov.au">sandra.daly@health.wa.gov.au</a></td>
<td>Respiratory</td>
</tr>
<tr>
<td>Northern Easy Breathers Support Group</td>
<td>Meets Heathridge Leisure Centre, Contact John M: 0412 017 789 E: <a href="mailto:john.neale43@gmail.com">john.neale43@gmail.com</a></td>
<td>Respiratory</td>
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<tr>
<td>South West Impaired Lungs Support (SWILS)</td>
<td>E: <a href="mailto:imaginegriffiths@bigpond.com">imaginegriffiths@bigpond.com</a> Janelle &amp; Barry M: 0429 631 559 E: <a href="mailto:imaginegriffiths@bigpond.com">imaginegriffiths@bigpond.com</a></td>
<td>Respiratory</td>
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<tr>
<td>Wheat belt Wheezers</td>
<td>Contact Colin Easther 0468 452 962 <a href="mailto:avoncopd@gmail.com">avoncopd@gmail.com</a></td>
<td>Respiratory</td>
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<tr>
<td>Yarraly Midwest Group - Geraldton</td>
<td>Contact Michelle T: 0432 580 613 E: <a href="mailto:yarraly@yahoo.com.au.com">yarraly@yahoo.com.au.com</a> Facebook</td>
<td>Respiratory</td>
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<tr>
<td>Rockingham Respiratory Support</td>
<td>Contact Jan T: 9528 2965 E: <a href="mailto:janthair@yahoo.com">janthair@yahoo.com</a></td>
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<td>Australian Online Groups Search for group at groups.yahoo.com</td>
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Useful Contacts

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<tr>
<td>Carers WA</td>
<td>T: 1300 227 377 - <a href="http://www.carerswa.asn.au">www.carerswa.asn.au</a></td>
</tr>
<tr>
<td>Arthritis Osteoporosis Foundation WA</td>
<td>T: 9388 2199 - <a href="http://www.arthritiswa.org.au">www.arthritiswa.org.au</a> - Scleroderma Support Group</td>
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