



## December 2018 Newsletter

**Providing a supportive and informative environment for people with a variety of lung conditions and their carers.**

**Editor:** Helen Reynolds 02 6260 4116  
[helen.reynolds5@bigpond.com](mailto:helen.reynolds5@bigpond.com)  
**Coordinator:** Lyn Morley 02 6291 0626  
[lung.life1@hotmail.com](mailto:lung.life1@hotmail.com)

**NEXT MEETING:** Thursday 13 December 2018  
10:15 am - 12 noon  
Weston Creek Labor Club  
Teesdale Close  
Stirling ACT 2611

**This month's meeting will be a social get together with coffee and cake followed by lunch.**

### Dates for your diary

|                           |   |
|---------------------------|---|
| Wednesday 5 December 2018 | Christmas Lunch<br>Hellenic Club's Chinese Restaurant |
| Thursday 10 January 2019  | CLLSG Meeting   |

### November Meeting Helen Cotter

About 25 people attended this meeting. We welcomed back some people we hadn't seen for a few months – most have been travelling!

The following matters were discussed:

- ✚ Finalised our World COPD Day event, being held on the foreshore of the Southern Cross Yacht Club on Wednesday 21 November. See report later in the newsletter.
- ✚ Finalised our Christmas lunch being held at the Hellenic Club on Wednesday 5 December. Information later in the newsletter.
- ✚ On Thursday 15<sup>th</sup> November, Kaye Powell is being interviewed on Valley FM Community Radio for World COPD Day.
- ✚ Maureen Bell has replaced Pam Gaston on the Palliative Care Committee. We look forward to reports from Maureen on the committee's work. We thank Pam for her work on the committee.
- ✚ Next month's meeting will be a coffee and cake meeting in the lounge of the Labor Club – same time as usual – as our room is not available.

Then it was on to our session on Asthma

## How to Live Well with Asthma

*Janine and Diane from ACT Office of Asthma Australia. They are located in the Chifley Health and Wellbeing Centre at Chifley. To contact them, phone 1800 278 462 or [www.asthmaaustralia.org.au](http://www.asthmaaustralia.org.au).*

### What is Asthma?

One in nine people in Australia have asthma. We all need to be aware of the conditions that bring about a flare-up and know what to do in that situation.

Asthma is a chronic long term condition where the airways – which start from the nose and go all the way down to the branches of the bronchi - react to certain conditions by swelling and restricting air intake.

Different people have different triggers:

- ◆ pollen
- ◆ cold wind
- ◆ dust
- ◆ change of weather
- ◆ thunderstorms
- ◆ chemicals
- ◆ perfume
- ◆ grasses
- ◆ exercise and
- ◆ even sex.

In 2015, over 400 people in Australia died from asthma.

From 2015 onwards, the number of women who have died from asthma has doubled.

It's a condition to be taken seriously.

You may have asthma if you have breathlessness or shortness of breath; wheezing; tight chest or a cough. You don't have to have all of these symptoms. And you can get asthma at any age.

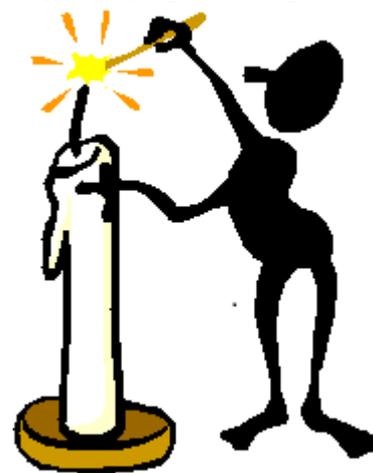
Asthma is different from COPD although often their symptoms seem similar. Both are diagnosed through a lung function test but asthma is a reversible condition and COPD is not reversible. In asthma, the airways constrict - but after using puffers, the asthma symptoms should go away; with COPD the alveoli harden. This is where the transfer of oxygen occurs. Using puffers help the symptoms improve but they do not go away.

### Good asthma control

- ✚ Able to do your usual activities;
- ✚ No symptoms at night or on waking; if you wake at night, you may be on the way to a flare-up.
- ✚ Daytime symptoms not more than twice a week;
- ✚ Need reliever no more than 2 days a week.

Poor asthma control is three or more of the above not happening – that is, you can't do your usual activities; you have symptoms night or day; you need your reliever quite often.

You can get an Asthma Action Plan from your doctor. It includes the medications you need to take and information on how to work out when it's not controlled. For good asthma control, you need both preventers and relievers and use spacers with both of them as spacers help get the medication into the lungs. It's important to rinse your mouth after you take your puffers as puffers can cause a dry mouth and this is not good for mouth hygiene. Dry mouth may bring about dental decay or gum disease. Chewing sugar free gum can encourage saliva.



When it is really bad you couldn't blow out a candle.

## Asthma attack

An attack can be mild or severe. If severe, the person will have difficulty in breathing and will not be able to talk in a full sentence. They will have a tugging in of the skin between the ribs or at the base of the neck. And the reliever doesn't last as long as normal. It's life threatening, if they are gasping for breath, unable to speak coherently; confused; and turning blue.

There is an **asthma app** for your smartphone that gives you information on the daily air quality and pollen count; and helps you to manage your symptoms.

Contact <https://www.airrater.org> or call 1800 322 102.

## Asthma First Aid

It's important to stay calm and to reassure the person having the attack. Sit them down, and get them to take 4 puffs of Ventolin, breathing 4 times between each puff.

Wait 4 minutes. If they are still distressed, call 000.

(If the person is having an anaphylactic attack, you have to deal with that first.)

## Conclusion

Asthma is a controllable condition. Your action plan from your doctor should help you to control it. It's important to get the correct diagnosis to get the appropriate treatment so that you can live your life fully.

*Asthma doesn't go away, it takes a holiday. Dr Mark Hurwitz*

## Christmas Luncheon

Wednesday 5 December 2018

In the Chinese Restaurant at the Hellenic Club, Woden

Time: 12 Noon

Price: \$22.00

Contact: Esther Fitton at 02 6288 7072 or [estheray1@bigpond.com](mailto:estheray1@bigpond.com)



Article printed in *Canberra Times* 14 November 2018

## Access denied: Peter and Pam's new apartment wasn't what they expected

By [Han Nguyen](#)



When Peter Olley and his wife Pamela Gaston looked to downsize almost three years ago, they thought they had found their forever home in a yet-to-be-built apartment block in Tuggeranong.

Ms Gaston, who has emphysema, had struggled to move around their split-level home - so after months of searching for a place that would cater for their needs, the couple bought an apartment off the plan at Greenway.



*Pam Gaston and Peter Olley at their Tuggeranong apartment complex. Despite incorporating ramps for wheelchair access and disabled toilets, the lack of automatic doors makes it impossible for Pam to move around in her mobility scooter by herself.*  
Credit: *Sitthixay Ditthavong*

"When we saw the plans it had adaptable units, disabled parking, larger than normal lifts, slight inclining ramps and everything that we were looking for because Pam relies on a motorised scooter to get around. We thought it was perfect," Mr Olley said.

"But on closer inspection and after settlement we found that she was unable to access these facilities due to manual doors."

The couple were responsible for one of about 60 submissions made to an inquiry into building quality in the ACT, after a parliamentary committee in April announced it would investigate the territory's construction industry amid growing concern about the quality of building work in new developments.

The committee has received 59 submissions ahead of its November 30 deadline.

The submissions have detailed accounts of water leaks at new properties, construction delays and broke builders leaving home owners thousands of dollars out of pocket.

Mr Olley said the plans for their new apartment didn't provide details of the doors.

"Me being a logical person thought if they have a ramp then they'll have electronic doors because the ramp is already recognising that they're dealing with people with mobility issues, but it's not the case," he said.

Instead, the doors needed to be opened manually. This makes it impossible for Ms Gaston to move around the complex in her mobility scooter by herself.

"The frustrating part is that the builders actually complied with the building code, so they didn't do anything wrong ... but there's a building code and there's a Premises Standards guide and the government was supposed to harmonise the building code and the Premises Standards together."

The Premises Standards, issued under the Commonwealth Disability Discrimination Act, came into effect in May 2011 to improve the accessibility and safety of new and upgraded buildings.

In Mr Olley and Ms Gaston's apartment building, the doors prevent access to disabled toilets, lifts and ramps.

"The facilities in here are actually fantastic, they're great ... they've even got a thing in the pool to get people in and out but the whole thing is the accessibility issue with the doors", Mr Olley said.

## **November was *Alpha-1 Anti-trypsin Deficiency* Awareness Month** *Information from LFA and Geoff Cox, a member of Lung Life, who has the condition.*

**Alpha-1 antitrypsin Deficiency** is a rare condition that results in a chronic lung condition. It's a genetic disorder which an estimated 1 in 2500 Australians have inherited and symptoms generally become noticeable about middle age.

**Alpha-1 antitrypsin** is a protein made in the liver, which moves into the lungs to help protect them from damage through inhaled matter such as pollutants and germs. People who cannot make that protein have an **Alpha-1 Antitrypsin Deficiency**. As well as affecting the lungs, the liver can also be affected and, in some severe cases, some children and adults may need a liver transplant. The effect on the lungs can be to bring about COPD.

There is currently no cure for alpha-1 antitrypsin deficiency and treatment is the same as for the COPD with the usual use of puffers, exercise, and living a healthy lifestyle.

In the US and many European countries, augmentation therapy is available. This is a process where the patients are given regular intravenous transfusions to increase the level of alpha 1 protein in the blood. There are currently trials in Australia to see if we should also adopt the augmentation therapy.

In Australia, a lung transplant can help those who have the genetic defect. This only happens when the damage to the lungs reaches such a stage that the person's lung capacity is very low and their quality of life is severely affected.

If you want further information, see the **Alpha-1 Association of Australia** at [www.alpha.org.au](http://www.alpha.org.au) or visit the LFA's website [www.lungfoundation.org.au](http://www.lungfoundation.org.au) or talk to Geoff Cox.

***Just a reminder: this is the last Newsletter of the year.***

# Celebrating our year

## Helen Cotter

As this is the last newsletter for the year, it's a good time to look at Lung Life's activities for the year.

### Our meetings

We have of course our regular meetings where we usually have about 25 people attending. Our talks this year have been on the topics of podiatry, Fair Trading, Mediwatch, My Health Record, palliative care, diabetes, asthma and travelling in far flung places. An interesting variety. I wonder what next year will bring.

We've had a couple of meetings where we talk about whatever we decide to – and we've had a couple of coffee mornings at the club instead of the formal meeting. We usually begin the meeting dealing with business and finish the meeting with a lovely socialising lunch at the club.

### Other activities

Our other activities have included:

- ✚ a stand at the Seniors Expo – always very useful;
- ✚ Education Day at Woden Southern Cross Club – the topics this year were
  - Co-morbidities and lung disease – Dr Mark Hurwitz;
  - Breathing and activity – Ms Katie Erwin, Coordinator Pulmonary Rehab;
  - Psychological Aspects of Living with Lung Disease – Sharon Gavioli, LFA Nurse Counsellor;
- ✚ Visits to the Physio students (UC) and the Medical students (ANU), providing them with live examples of people with chronic lung conditions.
- ✚ World COPD Day which we celebrated this year on the shores of Lake Burley Griffin in front of the Southern Cross Yacht Club.
- ✚ As well, we had the mid-year and end of year lunches at the Chinese restaurant at the Hellenic Club and fish'n chips at the Southern Cross Yacht Club

Such a lovely variety of activities, all supporting and/or promoting the Canberra Lung Life Support Group and chronic lung conditions.

### Significant people

**Lyn Morley** has blossomed in the role of coordinator, not only running the meetings and keeping an eye on everything that's happening, but also keeping us all in the loop via emails. She has been assisted by the following people:

**Helen Reynolds** has edited the colourful monthly newsletter which has items of both interest and information – and lots of photos. She's helped in this by the proof readers Chris Moyle, Lyn Brooks and Helen Cotter who check that there are no errors (hopefully). Helen Cotter also steps in when Helen Reynolds is unable to work on the newsletter.

The newsletters that people receive by mail are sent by Xia Wang COPD and CNC Nurse at The Canberra Hospital. We are ever grateful that she assists the group in this way.

**Chris Moyle**, who unfortunately has been rather sick this year and unable to attend many meetings, is our finance person and our archives person – which includes keeping any photos taken of Lung Life people, our speakers and activities. Chris is also our main minute keeper, which she does brilliantly. Helen Cotter also steps up when the need arises.

**Pam Harris and Esther Fitton** are our activity organisers. With their willing helpers, they organise the expos, the physio and medical students, the lunches and World COPD Day – and often provide many fancy touches to those events.

### **Those on other committees**

Part of any organisation is the need to promote the issues of importance to the group in the wider community. So for Lung Life, it's good to be able to get on committees or be involved in activities where we can make sure the needs and concerns of people with a chronic lung condition are being heard, understood and taken into consideration.

**Kaye Powell** has been a great ambassador for Lung Life and its issues. She is on the COPD Committee, the Diabetes Committee, Health for the Elderly Committee and on the teleconference committee for LFA – known as CPAG.

Kaye has been interviewed on the radio during pneumonia week and for World COPD Day. She also attended an evening at Parliament House organised by LFA where she talked to politicians and trades people.

**Helen Cotter** is also on the CPAG teleconference group with Kaye. These occur every two months with members from all states and territories participating. It's good to find out what LFA is doing and what the other states/territories are doing.

As well, Helen is the consumer representative on the DORSS committee, the committee that looks at the provision for respiratory and sleep patients. Through this committee Helen has been encouraging the provision of POCs instead of oxygen cylinders.

**Pam Gaston** was, for a while, a member of the Palliative Care Committee but has had to resign. We're pleased that Maureen Bell has agreed to take her place.

### **Other organisations**

Lung Life is an associate member of SHOUT, an umbrella organisation for many community groups such as ours. We send through many of the emails that come through SHOUT from other organisations telling about their events in case you are interested in attending.

We are also a member of HCCA – Health Care Community Association – an organisation that works for better health outcomes. Some of our members have completed their Consumer Representative Program which enables them to go on various health committees but also gives them greater awareness of the health system.

We are, by being a support group, a member of LFA, Lung Foundation Australia, the national body looking after lung health issues.

### **Finally**

Looking back over the year reminds us how much we have done. We have had useful information on a wide variety of topics which all helps us with our medical and social issues. And we have a lovely bunch of people, many of whom are involved in helping Lung Life to run smoothly; others in taking Lung Life issues out to the broader world – some do both!

We look forward to extending it next year.

## World COPD Day Helen Reynolds

It was Wednesday 21 November 2018 when the resolute members of The Canberra Lung Life Support Group gathered to mark World COPD Day. On the foreshore of Lake Burley Griffin at The Southern Cross Yacht Club the weather was, unfortunately, most unpleasant. But, as you can see they are prepared for the day, each wearing their green COPD t-shirt to tell the world who they represent. They were ready to enlighten the masses on "What is COPD?" and even to check their lung capacity but the elements were not in their favour. The members lasted for about an hour before the weather got the better of them and they departed for home and a warmer, not so windy place.

The Yacht Club was not a successful venue for the event but it was worth a try. Next year we'll have to pick a place that is open to the public, particularly during their lunch break when they have time for a chat and a testing of their lungs.



*We wish YOU all Happy Holidays, Season's Greetings and Merry Christmas. Plus: A Happy and Healthy 2019.*