

July 2018 Newsletter

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

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NEXT MEETING: Thursday 12 July 2018

10:15am - 12 noon

Weston Creek Labor Club

Teesdale Close
Stirling ACT 2611

Guest Speaker: Kate Lehmensich, Capital Health Network, who will be talking

about My Health Record, the National Online System that is

expected to start at the end of the year.

Dates for your diary

Tuesday 3 July 2018 Thursday 9 August 2018 Wednesday 21 November 2018 Mid Year Luncheon at the Hellenic Club CLLSG Meeting World COPD Day

June Meeting Lyn Morley

There may not have been many in attendance, even so, it was a lively meeting covering a diversity of topics.

- We celebrated Pam Harris's 70th Birthday by giving her a cake and singing Happy Birthday. Pam's cake was supplied by Esther and we each had a small cake supplied by Marilyn.
- On Thursday 7 June 2018 twenty one Lung Life members plus spouses enjoyed lunch together at the Star Buffet at the Burns Club. The food and the company were very enjoyable.
- The group discussed whether or not we wanted to have a Facebook page on which to put our newsletters and other items of interest to the group. The majority of members don't use Facebook and so we decided not to go ahead with this. There was discussion about setting up a web page for our group which would be available for people to find information about our group. This was thought to be a good idea but someone would have to look after it and also the cost involved with this was unknown. John M said he would check the cost for us.

- Kaye was asked by Lung Foundation Australia to talk about COPD with Over 60. The interview will probably be broadcast on Over 60 in the next week.
- Pam H talked to us about our Mid Year Luncheon to be held on Tuesday 3 July at the Hellenic Club at Woden. We will meet at 12 noon for lunch at 12:30 pm. A \$22 a head Chinese banquet has been arranged with people buying their own drinks. The club has a lift for people who can't climb stairs and there is plenty of parking. We will also be having a raffle. A list of names was taken for those wanting to attend the lunch.
- Helen Reynolds spoke to us about the need for a new person to edit the newsletter as her eyesight is deteriorating.
- Helen R is going to do a bulk order to the Lung Foundation for handheld fans. The fans are \$12 each and have proved to be very helpful for people when they are feeling breathless. Helen will order a few extra in case people who are absent from the meeting would like to buy a fan. The cost will be \$12 plus \$1 postage.
- We had a lengthy discussion regarding 2018's World COPD Day in November. Several places were discussed eg Black Mountain Peninsula, Commonwealth Park, a cruise and lunch on the lake and Fish and Chips at the Yarralumla Yacht Club. For various reasons the most popular was Fish and Chips. This venue is suitable in wet weather as well as sunny. World COPD Day is five months away so further discussion will take place at a later meeting.
- There was some discussion about social outings to Bungendore, Berrima and Marg Wade's tours of Canberra. John M will see how much it would cost to hire a 24 seater bus as he has the licence to drive one.
- During the meeting we had a quiz and played Bingo. Both these were presented by Esther who also donated the prizes. This was something different and very enjoyable.

Canberra Hospital Parking

From Consumer Bites issue 12, 2017

For consumers and carers who have parked at the hospital and are unexpectedly delayed in treatment you may be concerned about getting a fine. You can ask staff to arrange a parking exemption so this doesn't happen. This is also true if you have been unexpectedly called in to visit or care for a chronically ill member of the family.

Staff will phone the parking staff on your behalf. You need to provide the location, make, colour and number plate of your car and the reason you have been delayed. The exemption will only be given for a single day.

Our next social event is ...

What Mid Year Luncheon When Tuesday 3 July 2018

Where Hellenic Club

Woden.

Time 12 noon for lunch at 12:30 pm.

A \$22 a head Chinese banquet has been arranged; drinks you buy for yourself. There will be a raffle.

LiveLife Mobile Alarm with Fall Detect, Hands Free & GPS Helen Reynolds

For anyone looking to buy a personal safety pendant this one is well worth a look as it works outside the home as well as inside it.

The LiveLife Mobile Alarm allows you to go anywhere knowing help is just a press of a button away. It's a simple to use, stylish pendant that works using today's modern mobile network. It's perfect for people who want to feel safe everywhere, not just at home. When the button is pressed it immediately sends the GPS location and starts calling up to 5 people (000 can be a number). At the same time it sends up to 5 help messages showing the wearer's location on **Google Maps** accurate to within 2 metres.



It has unlimited emergency voice calls and texts.

When one of the emergency contacts answers the wearer is able to **talk hands free** through the **shower proof** pendant. Anyone who knows the mobile number of the pendant can call it and it will answer in **speakerphone** mode.

Main features

- Works wherever there is Telstra 3G, 4G & LTE mobile coverage (98.5% of Australia).
- Calls up to 5 friends or family (can call 000) until someone answers.
- Has 2-way "hands-free" voice communication with high quality, easy to hear audio.
- Automatic fall detection. Sends "fall alert" text with location and calls up to 5 contacts.
- Uses GPS and Google maps to send your location to your contacts immediately.
- Family and friends can call the pendant. Pendant can call out to nominated contacts.
- Pendant is shower and rain proof, comfortable and weighs the same as three 20c coins.
- Price includes SIM card, setup and delivery. Completely ready to go out of the box.
- Proprietary customised software: no false alarms.
- Recommended by CHOICE in 2017 and 2018 after scoring best in recent CHOICE tests.
- No contracts or monitoring fees.
- 12 month warranty. 14 day money-back guarantee.

Source: https://livelifealarms.com.au/order-mobile-alarm/

Final talk carried over from LFA Education Day. Breathing and activity

Katie Erwin, Physiotherapist and Pulmonary Rehabilitation Co-ordinator at the Canberra Hospital.

People with lung conditions frequently become breathless. This breathlessness regularly leads to reduced level of activity. The muscles weaken and a cycle develops, reduced breathing, causing weaker muscles and so it cycles on.

It's important to improve muscle endurance and strength as this will improve your quality of life. Exercise helps slow down the progression of the disease with reduced admissions to hospital and fewer exacerbations.

Breathlessness is quite normal. Shortness of breath means there is too much CO2 in the lungs. <u>Breathing out</u> is more important than <u>breathing in</u>. If you take 4 seconds to breathe in it will take 6 seconds to breathe out. If you take 2 seconds to breathe in it will take 4 seconds to breathe out. If you are breathing fast, still make the <u>out breath</u> longer than the <u>in breath</u>. Longer breathing out helps to get rid of CO2. Use the diaphragm and the tummy to help expel the air. Certain relaxed positions can help. Relaxing is also beneficial because muscles often get tight with shortness of breath.

Why do you need to exercise?

- more efficient use of oxygen
- improves strength, flexibility, co-ordination and balance
- helps with weight control
- helps sleep and relaxation
- helps improve your mood
- helps clear your lungs of phlegm/sputum.

Some people find walkers very helpful. You may not need one for walking but it can help with shortness of breath.

When to exercise

about 4 times a week

How to exercise

- you want to get a little bit puffed but can still talk; heart rate 60 80% of your maximum heart rate. You find that by taking your age from 220. Eg 220 72 (say my age) = 148 heart rate.
- On the Borg Scale, you want to be 3 4. The Borg Scale ranges from 0, no shortness of breath, to 10, the maximum.
- You need to do about 30 minutes of moderate exercise looking at aerobic, resistance, endurance and flexibility.

Watch out for blue fingers, nose or ears. They indicate the oxygen level is too low. Avoid extremes of temperature and exercising after a meal. Drink plenty of water before and after the activity. Take your medication.

How to make a long term change

Many of us make resolutions and start off eager but then fade away. To keep on with these resolutions:

- make it fun
- make it routine
- make it fit in with your lifestyle
- get friends to join you.

Gardening and cleaning are exercise; lawn bowls, dancing and swimming are good. Check with YMCA for their classes.

A comment from the floor: "I mark on the calendar what exercise I do every day. In that way I keep a record and it looks and feels good."

Incontinence

This is normal, especially with a large amount of coughing. A leak may occur or you may have a sudden urge to go. It may hinder things you want to do, but you can improve bladder habits.

- Do pelvic floor exercises, men as well as women;
- When you have the first urge, ignore it. It's a warning from the bladder that it is filling. With the second urge, it's probably time to go.

Constipation

Toilet position is important in assisting with easier bowel movements.

- Knees should be higher than hips (squat toilets are the best)
 - Lean on your knees

- Keep your back straight
- Push on tummy.

An easy breathing exercise

Take 3 to 5 deep breaths and hold for 5 seconds. Do some normal breathing, then HUFF. Huff is a breath in and then a strong breath out, but not forced. If there is any wheezing, it's a sign of breathing out too hard and can be dangerous as it can close the airways. To test for huff strength, hold a tissue in front of your face and see how much huff you need to blow it easily.

Questions

- **Q:** With restrictive lung disease, does breathing technique change?
- **A:** No. Should be normal breathing.
- **Q:** With regular walking, do Nordic poles help?
- A: They work your arms better. If you feel they help, then use them.
- Q: How to manage panic breathing?
- **A:** Try to identify early warning signs, and start managing at that point. If it's serious, you can get help from a psychologist.
- **Q**: When I exercise, it's OK, but when I stop, I get breathless. What is going on?
- **A**: When you do something quickly, the muscles use more oxygen and build up carbon dioxide. This may not be realised until you stop exercising. You need to pace yourself and breathe throughout the exercise.
- **Q**: With overseas travel, there is usually lots of walking and climbing steps. What is the best way to manage it?
- A: Pace yourself and monitor yourself. Be aware of what is happening.
- **Q**: Is it better to do Pulmonary Rehab early in the illness or later?
- A: It's better to do it early. Evidence shows that you should start it straight out of hospital or after an exacerbation. In Canberra, the course at the Canberra Hospital is the only one available and there is currently a waiting time of three to four months. If you haven't been in hospital, you need to get a referral from a respiratory specialist.

POC for Loan

We have an InogenOne G2 POC for loan. If you are on oxygen cylinders and thinking of buying a POC, you may like to borrow this one for trial.

If you are on oxygen cylinders and need, for instance, to travel to another city for a break or to visit a doctor, this may help.

The Inogen has all its attachments and has recently been serviced.

We ask for a donation to Lung Life for its use.

Contact Helen Cotter on cotterhe@hotmail.com or phone: 02 6281 2988.

POC Repairs Helen Cotter

It's always been a bother to have POCs repaired. We've needed to pack them up and send them to Sydney. Now we've learnt of two firms who will make it easier for you. They will pick up the POC from your home and return it.

You don't need to have bought it from these firms; however they only repair the machines of the type they sell. I suggest that you check with them to get the latest information.

AirLiquide contact: 1300 36 02 02

They sell: Focus, Freestyle, Inogen, SimplyGo,

autoSAT.

(www.airliquidehealthcare.com.au)

Oxygen Choice contact Dianne Smith: 0414 464 679

or email oxygenladydi@gmail.com.

They sell: SimplyGo. SimplyGo Mini, Inogen G3

and G2 and Eclipse.

(www.oxygenchoice.com.au)

USEFUL NUMBERS AND WEBSITES

ACTION: Phone 13 17 10 Web site www.action.act.gov.au

ACCESS CANBERRA: Staff will be able to answer queries, make a referral or put you through to the right person in the ACT Government. Check the web site www.canberraconnect.act.gov.au or ring 13 22 81 (they can also tell you the location of shopfronts).

MYWAY: Phone 02 6207 7711 Web site www.transport.act.gov.au/catch a bus/myway

COTA ACT Seniors Information Line: Phone 02 6282 3777 (business hours Monday to Friday).

Seniors Information Online: See the website at www.seniors.act.gov.au

Wheelchair accessible taxi centralised booking: 13WATS (13 92 87).

ACT TAXI Subsidy Scheme: 02 6205 1012

Seniors Moving Safely: This is a useful website about road safety for older people, at www.seniorsmovingsafely.org.au.

ACT Engine Immobiliser Scheme: The scheme aims to reduce motor vehicle theft in the ACT by discounting the fitting of engine immobilisers to seniors' cars. For more information call Access Canberra on 13 22 81.

Service Stations Providing Driveway Service: Need someone to fill up your car for you? The Access City Hotline has a list of service stations where staff will (sometimes or always) provide driveway service for people with disabilities (call 02 6257 3077).

Information and Support for People with Disabilities: NICAN provides information about accommodation, travel, recreation and support services for people of all ages with disabilities. You can check their website (www.nican.com.au) or call them on 02 6241 1220.

Lung Foundation Australia has a variety of useful information:

IPF Registry www.lungfoundation.com.au/IPF

Webinar for those with lung cancer: www.lungfoundation.com.au/lung-cancer-connect

Membership of LFA: www.lungfoundation.com.au/lyl or 1800 654 301 (called: Love Your Lungs).

www.altg.com.au: This is the website of the Australasian Lung Cancer Trials Group (ALTG), ANZ's lung and thoracic cancer clinical research group. It collaborates with a number of organisations including NHMRC Clinical Trials Centre (CTC) and Peter MacCallum Cancer Centre. Read more about it in the latest LungNet News, February 2018.

<u>www.australianclinicaltrials.com.au</u>: This website lets you know what clinical trials are being conducted in Australia. You may find a trial that you can volunteer to be part of.