



June 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 14 June 2018
10:15am - 12 noon
Weston Creek Labor Club
Teesdale Close
Stirling ACT 2611

There is no speaker for this meeting. So it is time to talk about all the things you want and need to talk about

Dates for your diary

Thursday 7 June 2018	Lunch at the Burns Club
Thursday 14 July 2018	CLLSG Meeting
Wednesday 21 November 2018	World COPD Day

Your Newsletter

We need a new editor for the newsletter. I am having problems with my eyesight and can no longer work on it easily. It's not an onerous job:

- Most of the items and photos are sent to you;
- You need to organise them onto the newsletter template;
- You send it to the three people who check it for errors;
- Then you forward it to be sent to our readers.

That's all there is to it. There's help and back-up if you need it.

If you want to know more or to offer to do the newsletter, please contact me on:
helen.reynolds5@bigpond.com ph: 6259 7737 or

Helen Cotter on:
cotterhe@hotmail.com or ph: 6281 2988

May Meeting

Helen Cotter

Numbers were down for this meeting – maybe the cold snap had something to do with it. We first had the talk on Palliative Care; then dealt with business. But here is the business first:

- We had a delightful Fish'n Chips at the Yacht Club during April. The weather was windy to begin but then settled down and the afternoon was very pleasant.
- Thursday 7 June 2018 is earmarked for our lunch at the Burns Club. Meet there at 11.45am.
- A number of us attended the funeral of David Jarvis – a quiet event with lovely talks about David and his life – including one by Carmel. In her talk, she mentioned how they enjoyed coming to our meetings and how supported they were by the group.
Carmel has told us she will come to the meetings and will continue to do our condolence cards.
- We reported on the recent CPAG teleconference that Kaye Powell and Helen Cotter took part in. See later in the newsletter for the details.
- Kaye Powell attended her first meeting with the Diabetic Service Group where they talked about a new pump for small children to better regulate their diabetes.
- We held a raffle to help raise money for our group. The winners turned out to be everyone in the group who wanted a prize as our meeting numbers were small. We raised \$95.
- Next month's meeting is a talk fest. Some topics may include:
 - Pam Gaston is part of a project about Palliative Care in hospital and would like feedback on what sort of help we would like when we're in hospital.
 - Lung Foundation Australia (LFA) would like to know what we want from LFA. How best can it serve us.
 - Our newsletter will need a new editor soon.

Our talk for the meeting was on palliative care.

Palliative Care

Anne Booms Nurse Practitioner, Palliative Care, Oncology, assisted by Julie Griffin, Palliative Care Nurse Specialist, Palliative Care Team, The Canberra Hospital.

The Palliative Care Team at Canberra Hospital has seven (7) members which include doctors, nurses, pastoral care workers, a psychologist, and a social worker. You can be referred by a doctor or can self-refer. The team mainly works with in-patients and oncology. There is another team at Calvary Hospital which mainly works at Clare Holland House (Canberra's hospice) and does home visits.

Anne explained that palliative care is not just about end of life but is also about living well. The sooner you get palliative care, the better quality your life can be. The palliative care nurse will review all your medications which can often be simplified. For instance, some medication - such as anti-cholesterol or steroids - are for long term benefit and are no longer necessary.

The nurse will also look at other aspects of your life – for example, you may be constipated, have nausea, shortness of breath or be anxious and the nurse will help you deal with that. They can also help to navigate the numerous decisions that have to be made at this time. It is often very positive just to have someone there to help.

Clare Holland House is not only for end-of-life but also for pain management. Some patients come in to get their pain managed; then go home.

You may not need to see the nurse regularly but you can call them up when you need them. They can incorporate morphine into the treatment as it can help with anxiety and with shortness of breath.

Palliative Care Nurses can help with an Advance Care Plan where you delineate the treatment you want or do not want in hospital. Once it is lodged with the hospital, the information comes up on the screen when you go to Emergency. The Nurse can help advise the family at end-of-life if there is no Advance Care Plan.

Anne talked about the benefit of hand held fans which have been shown to help with breathing.

They would prefer not to get called in at end-of-life - but earlier where they can help improve the quality of life and the length of life.

BENEFITS OF HAND-HELD FANS

Mary Roberts, Clinical Nurse Consultant, Respiratory Ambulatory Care, Department of Respiratory and Sleep Medicine, Westmead Hospital

From LungNet News, May 2018



Shortness of breath is one of the most common challenges for people living with a lung disease. It can be frightening and distressing when you feel like you can't get enough air into your lungs. Many people find using a battery operated fan can help control breathlessness, and research has shown that a cool draft of air from a hand-held fan can be very effective. Hand-held fans are a great option because they are cheap, quiet and easily portable. A free-standing fan, a desktop fan or the breeze through an open door or window may also help.

How to use a hand-held fan

Follow these steps below and you should start to feel a benefit in a few minutes:

- ◆ Hold the fan about 15 centimetres from your face so you can feel the air on your top lip.
- ◆ Slowly move the fan from side to side so that the breeze covers the bottom half of your face.

Remember to use your controlled breathing techniques and try and relax your shoulders. To find out more about controlled breathing techniques talk to your health professional.

You can use your fan as often and for as long as you like. Keep it handy when at home and also take it with you when you go out. You may find it helpful to use your fan if you stop for a 'breather' after doing an activity that makes you breathless, such as walking, climbing stairs or for sudden breathlessness when you are still.

Not all fans are the same; some are hard to turn on and others make a lot of noise but don't blow air very well. Lung Foundation Australia has tested hand-held fans available via our online shop at www.lungfoundation.com.au/fans. Funds raised from the hand-held fans will go towards our Respiratory Nurse telephone service fundraising campaign. So far, we have raised \$60,000, almost half of our \$150,000 target. The cost of the fans is \$12.00.

We will be asking everyone at our next meeting if they are interested and we will purchase the fans in bulk.

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 on cotterhe@hotmail.com or ph: 6281 2988

Come one, come all to our mid year social get together.

Where?
When?
What Time?

At The Burns Club in Kambah
Thursday 7 June 2018
11.45 am

Remember bring:

- your appetite, it is a smorgasbord
- money for the raffle tickets and
- plenty of good Cheer and Chit Chat

Supporting you to live better with your lung disease

Sharon Gavioli, registered nurse and LFA's Information and Support General Manager

This is the third talk from our Education Day in April. The second talk on Breathing and Activity will be in the next newsletter

Most people find it hard to sustain good intentions. One way of managing it is to care for your whole self not just your lung disease. You need to listen to your whole body and give your own well-being and self-care high priority.

One of the key things is the quality and intention you bring to your activity – you must want to - or like to - do it. The things that support you include:

- food choices – this is not about diet. Some foods may not suit you and may cause bloating or moodiness – avoid them. The wrong foods put a strain on your body and immune system.
- rest and sleep. The quality of sleep is important – it's a time for your body and mind to regroup. Important to get enough sleep and a rest during the day will do wonders. Sometimes the food you eat affects sleep – or you may be pushing yourself too hard. It's important to listen to what your body is telling you. You need to prepare for sleep – have a wind down time; don't eat too much or too little food; don't be too busy in the evening. The best sleep actually comes between 9pm and 1am.
- activity and movement – we're not talking exercise classes but any activity and movement - in the home or out of it - helps your body to put all its functions to use. The quality of your movement is important too – put all of your body to use and be conscious of your body's movement.
- staying warm – important as being cold uses up more of your body's resources and puts a strain on your system – makes it harder to fight off infection.
- responding to situations – there are times when someone's words or actions will get to you – make you cranky or cross or agitated. It's your decision to react or respond. **Reaction** is where your body goes into fight or flight response. It increases your hormones to prepare you. This increases your stress and affects your immune system. Too much of that is not good for you.
Response is where you have increased awareness about your reactions and try to reduce them. If you have a strong reaction, there is psychological support to help lessen unnecessary reactions.
- breath - a gentle breath technique is good to use in a stressful situation
 - ◆ sit comfortably with eyes closed;

- ◆ notice your breath coming in and out of your nose;
 - ◆ make the breath as gentle as possible (feel like a butterfly on your nose that you don't want to disturb);
 - ◆ breathe out and hold for a little while;
 - ◆ then breathe gently in.
 - ◆ on the next breath, let go of any tensions in the body;
 - ◆ then open your eyes.
- accept support (from others) - this is sometimes difficult to do. We are often brought up to see this as a sign of weakness. But, most of us like to support and do things for others – give them a chance to do things for you.

The benefits of looking after your whole self are many but the main one is you get a much better quality of life.

We have available

- two (2) batteries suitable for a SimplyGO POC – as new, costs over \$300 each
- a charger with power cord for those batteries – charges the batteries out of the POC – as new, costs over \$300.
- a variety of power cords.

We ask for a suitable donation to Lung Life.

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

CPAG Teleconference May 2018

Kaye Powell and Helen Cotter recently took part in the LFA's bi-monthly teleconference with representatives from all states and territories. We talked about many things, but of significance to us are the following:

- We discussed how best get air quality index information to those who need it. We mentioned how we get forwarded information about burn off from the Fire Department forwarded by Lyn, our coordinator;
- The LFA wants to know what our members want from LFA (what do you want?);

Every teleconference has a members update where each State/Territory says what it's doing – it's good to hear what people are doing in other places – things like talking to Men's shed – taking the lung Health Check list for them to do; fund raising with sausage sizzles; visiting other support groups; having various speakers at their meetings. If we like the ideas, we can follow suit.

We told them about the successful Education Day; the various speakers we've had; the visit to the Physio students and how worthwhile they are; the POC trial and how we have contacted the Minister for Health for a meeting.

Caroline Scowcroft (who some of you know and who is now in Queensland when she is not travelling the world) mentioned our wonderful newsletters and how it would be good for people to receive each other's newsletters. That seems to be going ahead – Lyn has sent out a couple from the Nepean Puffers and Wheezers – an interesting read.

Juliet from LFA suggested that LFA would set up a drop box and our newsletters could go there. Sounds good.

Then we talked about:

- update on what LFA is doing: raising money for a respiratory nurse – will be available on LFA phone for all your questions and concerns. They have one for lung cancer;
- World COPD Day now November 21st (changed from the week before);
- Suggestion for things we could do – visiting local organisations to talk about COPD and LFA; go on media; spread the word to other organisation; especially take the Lung Health Check List to those other organisations so the people can do a simple ticking of boxes on their lung health – Kaye is going to be sent many copies to share out.

And that was our one and three quarters hour teleconference. Next one in 2 months' time.

The 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.

A big thank you to Xia and her team for their efforts in sending the Newsletter out by snail mail – and to Joanne who is doing it while Xia is away. It is greatly appreciated.

