



August 2018 Newsletter

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

Editor: Helen Reynolds 02 6259 7737
helen.reynolds5@bigpond.com

Coordinator: Lyn Morley 02 6291 0626
lung.life1@hotmail.com

NEXT MEETING: 10:15 am - 12 noon
Weston Creek Labor Club
Teesdale Close
Stirling ACT 2611

Guest Speaker: Marian Kosatz, a retired school teacher, talking about travelling and teaching in far flung places around the world.

Dates for your diary

Thursday 14 September 2018
Wednesday 21 November 2018

CLLSG Meeting
World COPD Day

July Meeting Helen Cotter

We had about 20 people for this meeting – a good turnout for a winter month. We spoke about:

- **the mid-winter lunch** held at the Hellenic Club and enjoyed by twenty two of our members and friends.
- Helen Reynolds organised to buy some **hand held fans** for people. These fans help when you are breathless. They have arrived and she will bring them next month. Those on her list: make sure you have your \$13 to pay her. Helen will have a few spare if you want one and your name wasn't on her list. (You can also buy them from LFA.)
- **Personal alarm:** Ebba reminded us how important it is to wear our personal alarms *at all times* – and not to take it off for baths or showers as it is waterproof. It is easy to slip in the bath or shower and a bit useless if you're not wearing your alarm. It is also good to wear it in bed as you may not be capable of reaching it if it's on the bedside table.
- **The Newsletter:** We are still looking for a new editor. We see the Newsletter as an important means of communication for members and friends who attend meetings as well as those who rely on the Newsletter to keep them up to date with the Club's activities while reminding some and letting others know about various health and other matters. It would be a pity to no longer have the Newsletter.

The editor doesn't have to attend the meetings but needs to have a modicum of computer skills. There are three or four people who can assist the editor by providing information and proofing the newsletter. If you would like to volunteer please contact Helen Reynolds on the address at the top of this newsletter.

Guest Speaker

Kate Lehmensich,
Community Engagement Officer
Capital Health Network

My Health Record, the national digital on-line health record system, a record of your health information, was created five to six years ago. The Government is now expanding the program to facilitate the inclusion of information from additional health providers to be on the one site so that it can be accessed, when necessary, nationwide.

The information on this site is **personally controlled by the individual** who can say what goes into it. It has a section for privacy: you can choose who you share it with. The information will include:

- clinical documents
- medical and pharmacy information
- organ donor
- immunisation information and
- an advance care plan
- emergency contact details.

The information will come from hospitals; specialists; pathology such as diagnostic imaging and blood tests; allied health such as psychiatrists, dentists, chiropractors etc; pharmacy; and aged care

The main **benefits** are seen as:

- avoiding allergic reactions
- reducing time gathering information and
- avoiding duplication of services.

There are all sorts of **rules to ensure security** of information so that it is seen only by the people you want to see the information. However in an emergency, it can be over-ridden. You are able **to link your record** to someone else, either an authorised representative such as a parent looking after their children or a nominated representative such as assisting aged parents (or being assisted by family).

For the next three months, 16 July 2018 to 15 October 2018, you can **opt out** of the system otherwise records will be created for all Australians by about mid-November 2018. You can actually opt in later or opt out later – it's the individual's decision.

When the record is created, it will have two years worth of information from the MBS and the PBS but you will **need to add the other information** that you see as necessary. This includes emergency contact details.



Kate Lehmensich,
Community Engagement
Officer

Capital Health Network is part of the nationwide Primary Health Networks set up by the Federal Government originally to support the doctors and nurses in general practice to better meet the needs of the community. But now it's been broadened to service the gaps that fall between the hospital and the doctors. For example, the mental health services, transition care program, indigenous care program, child health, aged care community groups and other health organisations. It provides educational events and clinical resources to the health professionals to enable the best health services possible in the ACT.

There are **apps available for your smart phone** which will access the My Health Record web site. These are good for travelling, even overseas.

Your health record could contain:

- medicines you are taking or have taken prescribed by your doctor
- your Medicare claims history
- your organ donation decision.

Doctors and other health care providers may be able to see and add information including:

- a summary of your medical history, conditions and treatment
- hospital discharge information
- diagnostic imaging reports
- pathology reports.

You can add:

- information about any allergies and adverse reactions you may have
- personal contacts and their details
- personal health notes
- advance care planning information
- information about other medicines or vitamins you might be taking like over the counter medicines.

You can customise access to your record by setting access controls including restricting who can see your information.

Check out the site: www.myhealthrecord.gov.au

Progress on the POC Trial

Helen Cotter

On Thursday 19 July, Lyn Morley, Pam Gaston, Peter Olley and I met with Dr Paul Dugdale, Acting Executive Director of the Department of Rehabilitation, Aged and Community Care, to talk about the POC trial to see if it is feasible for the Government/Health Directorate to supply POCs instead of oxygen cylinders to oxygen users.

The POC trial has been completed and the question is: what is the next step?

Paul comes from a background of chronic care so is concerned with people being able to have a good quality of life – but that needs to be seen against the cost of providing this quality of life.

One aspect of the trial found that POCs do not suit all people. Our Lung Life Group oxygen users all prefer the POCs but not all people like them. The trial also found that the POCs do not necessarily provide the same level of oxygen at the same amount as the cylinders - that is, 2 litres of oxygen from a POC may not be the same as 2 litres from an oxygen cylinder. These aspects need to be taken into consideration – and the cost - when looking at the best way to provide POCs. Consequently the first step is to look at the policy for the provision of oxygen in order to incorporate what has been learnt from the trial.

My impression from the meeting is that we will be moving forward on the provision of POCs but that it will be small, cautious, economical steps that will happen slowly.

Mid-winter Lunch Helen Reynolds



The Hellenic Club was a change of venue and apart from inadvertently choosing the busiest day on the Hellenic Club's monthly calendar which meant parking was somewhat easier said than done. The venue itself was most satisfactory. The lovely Chinese buffet, the service and the company compensated for any shortfall.

As usual our thanks go to Pam Harris for organising the lunch and to Esther and friends for organising the raffle – it all helps with Lung Life's funds. After today we have an additional \$113.00 in the bank.

Raffle Winners: Margaret, Lyn M, Pam G, Barry, Lyn B, Sharon, Ann and Stephen

