

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

Editor: Helen Reynolds 02 6259 7737
helenrey@creationcorporation.com.au

Contact: Helen Cotter 02 6281 2988
lung.life1@hotmail.com

Next Meeting Thursday 10 October 2013
10.15 am – 12 noon
Burns Club, 8 Kett Street, Kambah

No speaker this month. We will have time for discussion and some activity.

Dates for your diary

Thursday 31 October 2013	National Botanic Gardens' Tour and lunch
Thursday 14 November 2013	Canberra Lung Life Support Group Meeting
Wednesday 20 November 2013	World COPD Day – Canberra Centre
Thursday 28 November 2013	World COPD Day – Black Mountain Peninsular

September Meeting

Helen Cotter

Names for the Botanic Gardens' Tour on Flora the Explorer, were taken. There are a few seats left which, hopefully will be filled at the next meeting. After the hour long tour lunch will be partaken at the restaurant at the Gardens. If you haven't given Helen Reynolds your name and would like to come, please let her know on the contact numbers above.

World COPD Day is on Wednesday 20 November. Negotiations to hold it in the Canberra Centre between 11am and 2pm are underway. Volunteers from the Canberra Lung Life Support Group will join Beth Forbes and others from the Chronic Care team to increase awareness of lung problems in the community. This event won't involve all of us so we are holding our own event, probably on Thursday 28 November at Black Mountain Peninsula. More details in the next newsletter.

Electronic Health (eHealth) Record System -Eleanor Pritchard

Chris Moyle

The Australian Government's personally controlled Electronic Health (eHealth) Record system will help you take control of all your health information thus helping your doctors provide you with the care you require. If you have an eHealth Record and need medical treatment – after hours, in an emergency or from a different doctor – important health information such as current medications, allergies or tests can be quickly accessed. The system means you will suffer less stress as better connected health records mean you will not have to remember every medication or health-related incident, or repeat unnecessary tests. Another plus for eHealth: it will not matter where you are in Australia, with your authorisation, your eHealth record can be accessed.

Computer or computer skills are not required for someone to have an eHealth record. If you wish you can nominate a trusted person, such as a carer or family member, to view or manage your eHealth record.

People can register with eHealth in one of four ways:

1. Online – visit www.ehealth.gov.au
2. Over the phone – call 1800 723 471 and select option 1
3. In person – visit a Medicare office
4. In writing – complete a registration application form, available from a service centre offering Medicare services or from www.ehealth.gov.au, and post it to:
Personally Controlled eHealth Record Program
GPO Box 9942
Capital City.

Can I travel?

People who have COPD can travel. Some people, however, are advised to avoid travelling at high altitudes (for example, flying) because of decreased oxygen levels at high altitudes. If you are planning to travel at high altitudes, you should discuss your oxygen needs with your doctor and the airline you plan to fly with.

Source: *Better Living with Chronic Obstructive Pulmonary Disease*

Australian COPD Patient Task Force

Helen Reynolds

The Task Force has undergone some rather radical changes.

- * The name has been changed to **Australian COPD Patient Advocate Group (C-PAG)**.
- * Meetings will be held bi-monthly.
- * Skype will be used beginning next meeting.
- * There will be a dedicated page on the Lung Foundation Australia website for use by C-PAG with a link to a site where support groups will be able to share their newsletters.
- * Recommendations were put forward to broaden the eligibility to include “a person with COPD/carer of someone with COPD or a person friend or family member who has been personally impacted by the disease”.
- * It was also recommended that C-PAG include indigenous representation from any state or territory.

Plans for World COPD Day are well underway and members will soon be able to access them via the Lung Foundation Australia website.

A message from Esther:

Laurie Kent who, with his wife Cecilia, were part of the original founding group members died on Monday 16 September. Although Cecilia was the one with COPD and Laurie was her carer they were both very much involved with the group. Until recently, Laurie attended our Christmas lunches so newer members of the group may remember him from the lunches.

NARI Research Study

Chris Moyle

The National Ageing Research Institute, which is affiliated with The University of Melbourne and Melbourne Health is recruiting participants for their research into the effect of telephone support on anxiety or depression in people with COPD. The aim is to help gain an understanding of how best to support people with COPD.

After completing some questionnaires relating to self, anxiety and depression participants are telephoned each week, the calls lasting one hour approximately.

There are two groups:

1. participation in social interaction. The participant is phoned each week and spends the time simply chatting about anything and everything and
2. telephone-administered Cognitive Behaviour Therapy. The participant is given psychological support and therapy.



I contacted Debra Osborne on toll free 1800 088 823 (also on email d.osborne@nari.unimelb.edu.au) with regard to joining the study. We had a long conversation and I was deemed suitable and agreed to participate. All very easy.

Recruitment closes at the end of October 2013.

Meeting our future GPs

Chris Moyle

On 15 August eleven of our members visited the ANU medical students at The Canberra Hospital. Complimentary taxis took us there and home if we wanted them. Each of us sat in a separate room with about 10 – 12 students and a medical doctor. In my group the females outnumbered the male students by 8 to 3.

The Doctor introduced me by saying I'd given up my time to be there. One student was nominated to take my medical history with medications, doses etc. and they all asked questions about how I coped with a chronic illness. There was time to look at my X-rays and they all listened to my lungs. It's the best run session I've been to.

Hopefully we've been of help to these doctors of the future. Thanks to all who attended.

Quotes from 11 year old students' science exams

(For those on oxygen) Water is composed of two gins, Oxygen and Hydrogin. Oxygen is pure gin. Hydrogin is gin and water.

When you breathe, you inspire. When you don't, you expire. *(There's some truth in that).*

Respiration is composed of two acts, first inspiration, and then expectoration. *(Sounds like a bronchiectasis patient).*

The body consists of three parts – the brainium, the borax and the abominable cavity. The brainium contains the brain, the borax contains the heart and lungs, and the abominable cavity contains the bowels, of which there are five – a, e, i, o and u.

Priority assistance for consumers with diagnosed life-threatening medical conditions

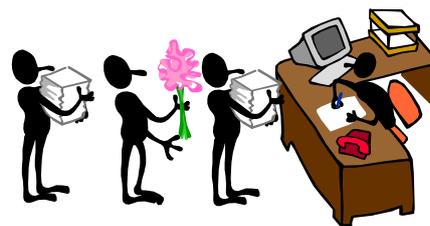
Priority Assistance is a service designed to help people with diagnosed life-threatening medical conditions who depend on a reliable, fixed-line home telephone service to be able to call for assistance when needed.

Priority assistance customers are entitled to priority connection and fault repair of their telephone service. The time frames for connecting a service or repairing a fault for a priority assistance customer is 24 hours in urban and rural areas and 48 hours in remote areas. If a priority assistance customer experiences two or more faults in a three month period, the phone service must be tested by the carrier.

Eligible Medical Conditions (Telstra Priority Assistance Form)

Those relevant to us include:

- Patients at high risk of respiratory emergencies;
- Technology dependent patients who are at high risk;
- Patients at risk of life-threatening hypoglycaemia or epilepsy;
- Patients at high risk of cardiovascular emergencies;
- Other dependent patients who live alone, without support or in remote locations.



If you're unsure whether your medical condition would qualify for Priority Assistance, please talk to your doctor.

Who offers priority assistance?

Telstra: Telstra is the only carrier required to provide priority assistance services to its customers as a condition of its licence. Under its licence condition, Telstra is required to have an effective policy for offering priority assistance services to persons with a life-threatening medical condition. General information about Telstra's priority assistance service is available on Telstra's website www.telstra.com.au/homephoneservices or call 13 22 00.

Additional PA providers: Other carriage service providers/carriers such as Primus may also provide PA services to their customers. Contact your carriage service provider/carrier to check if it offers PA services.

Providers that do not offer priority assistance: Carriage service providers/carriers have to either offer a priority assistance service or inform customers of the names of carriage service providers/carriers which do offer priority assistance services.

Further information

If you feel that you are eligible, you need to call your carrier or Telstra and check. You will need to get your doctor to sign a form about your condition.

Source: www.dbcde.gov.au/telephone_services www.acma.gov.au www.telstra.com.au/homephoneservices

A nebuliser Ventalair MAX - Nebuliser Sytem - Model AE 65044 free to anyone interested. Please email Matt on the address below if you are interested. Email address:

mattandali@internode.on.net

A POC concentrator which we will on-sell to anyone interested, with the money going to the Lung Life Support Group. Please let Helen C know - not Matt and Ali - if you are interested in the POC.

COPD Working Group

Helen Cotter, Consumer Representative

The group met in mid-August at the Canberra Hospital under the chair of Mark Hurwitz and the auspices of Beth Forbes. Included in the Group are representatives from Pulmonary Rehabilitation, MedicareLocal, GP Liaison, Calvary Hospital, and Chronic Disease Management.

- We received updates on such issues as quality assurance and patient discharge efficiencies in the Canberra Hospital. The plans for starting the Hospital in the Home expansion project (HITH) are almost complete whereby some suitable people will be able to receive support at home rather than in the hospital.
- We discussed and endorsed the proposal that portable oxygen concentrators (POCs) replace oxygen cylinders for use by those who need the extra oxygen.
- Beth reported that there are currently 173 patients on the COPD nurse program with 25 patients accessing the smoking cessation clinic and 31 on care co-ordination. There are also one off educations on the ward which are not counted in these numbers.
- We discussed World COPD Day to be held on Wednesday 20 November. Louise, from Chronic Disease Management, is working with the Lung Life Support Group to raise awareness of the issue. The group is

negotiating with the Canberra Centre to hold an event in the Centre between 11am and 2pm on World COPD Day.

The representative from MedicareLocal reported that MedicareLocal was very supportive of the need for COPD education of its client base, the primary care professionals such as doctors, nurse practitioners and other health professionals. The group next meets on the 30th October.

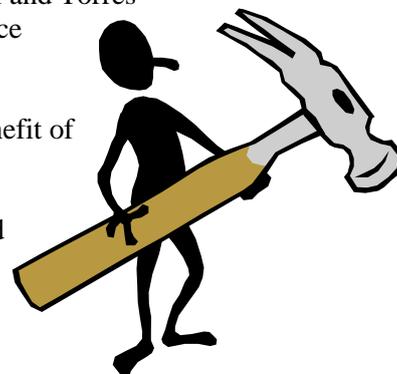
What is Medicare Local?

Helen Cotter- Community Representative, Chris Moyle

Medicare Locals make up the national network of 61 primary health care organisations, responsible for meeting the primary health care needs of their communities and helping ensure that the range of primary health care services required by their communities are available and work effectively for patients. They update doctors and other health professionals on the latest issues such as disease management; dealing with new drugs, tests and infections; professional requirements, ehealth and so on.

ACT Medicare Local will improve primary health care services for ACT residents by:

- Making it easier for patients to access the services they need, by linking local general practitioners (GPs), nursing and other health professionals, hospitals and aged care, Aboriginal and Torres Strait Islander health organisations, and maintaining up-to-date local service directories.
- Working closely with the ACT Local Hospital Network Council to ensure primary health care services and hospitals work collaboratively for the benefit of their patients.
- Planning and supporting local after-hours face-to-face GP services.
- Identifying where local communities are missing out on services they need and coordinate services to address those gaps.
- Supporting local primary care providers, such as GPs, practice nurses and allied health providers, to adopt and meet quality standards.



Here's your chance to get involved

Survey - Consumer Experience and Expectations of General Practice in the ACT

This survey, being carried out by the Health Care Consumers' Association (HCCA), aims to build a picture of people's wants and needs in terms of general practice in the ACT. The information will inform future work carried out by the Health Care Consumers' Association in their advocacy for better healthcare in the ACT. The survey is open until 4 October and can be found online at <https://www.surveymonkey.com/s/3HLC8LC> The survey will take 10 minutes to complete but the material we get from this is valuable and will inform our work with the ACT Medicare Local as well as ACT Health.

Please contact Health Care Consumers' Association Inc on 02 6230 7800 should you have any questions.

The A to Z of Preventative Health Care – Exercise

Chris Moyle

Exercise is among one of the simplest and most effective ways to improve your ability to live a full life with a chronic lung disease. Physical activity strengthens muscles, improves mood, increases energy levels, and improves the way the heart and lungs work. Make it a daily habit but start slowly.

Joining a gym or club is a good way to get motivated.

- The follow-on maintenance program from pulmonary rehab is "Lungs in Action". This is held at the University of Canberra, Belconnen. Ph: 6201 2936.
- The YMCA of Canberra runs community fitness programs on both the Northside and Southside of Canberra. Ph: 62811 0124.
- Southern Cross Health Club runs rehabilitation classes that are targeted for people who have completed pulmonary rehabilitation. Ph: 6283 7340. Advice from Australian Lung Foundation.



Exercise for people with severe lung disease is especially important. Move slowly, breathing as you go,. Everyone who can get out of bed can exercise 10 minutes a day. Every hour, get up from what you are doing and **walk slowly** across the room or around your chair **for 1 minute**. Doing this 10 times a day will give you your 10 minutes of exercise.

After you have done this for a week or two and are feeling a little stronger, then walk 2 minutes every hour. You have just doubled your exercise and are now up to 20 minutes a day. When this feels comfortable (in another week or two), change your pattern to walking 3-4 minutes every other hour. Again, wait a week or two and try 5 minutes 3 or 4 times a day. Next, try 6-7 minutes 2 or 3 times a day. You now have the basic idea. Most people with severe lung disease can build up to walking 10 or 20 minutes, once or twice a day, within a couple of months.

The rules are the same as for any exercise. Start with what you can do now and as you feel stronger and more able slowly increase the activity.

Source: *“Living a Healthy Life with Chronic Conditions”*

Better Living with Your Lung Disease – a ten part DVD series for people with chronic lung disease. Karen Wright - COPD National Program – Projects

Lung Foundation Australia has launched a new Self-Management 10 part DVD series for people with Lung Disease. *Better Living with Your Lung Disease* supports people living with a lung disease through a series of educational patient DVDs focused on giving patients the ability to ‘self-manage’ their disease with an objective to increase the knowledge and confidence of people with lung disease to enable them to better manage their condition and their overall wellbeing. They are an excellent opportunity for patients to learn the importance of managing their disease and techniques on how they can implement these strategies in their homes.

You can get them from online shop at <https://lungfoundation.net.au/shop/>, or contact the Lung Foundation on 1800 654 301 to order a FREE copy now. The DVDs are also available to view on the Lung Foundation YouTube at <https://www.youtube.com/user/thelungfoundation>

If you would like to borrow the DVDs our Support Group has a copy. Simply contact Helen Cotter at the address at the front of the Newsletter.

Traffic and Woodsmoke Pollution and COPD

Am J Respir Crit Care Med Vol 187, Iss. 7, pp 721–727, Apr 1, 2013 www.atsjournals.org

This study investigated the association of long term exposure to elevated traffic-related air pollution and woodsmoke pollution with the risk of COPD hospitalisation and mortality.

COPD, a leading cause of death worldwide, is characterized by progressive airflow obstruction related to a chronic inflammatory response in the lung. Although smoking has been regarded as the most important risk factor for COPD, accumulating evidence has demonstrated that many COPD cases cannot be explained by smoking history.

COPD is also a common chronic disease among never-smokers; worldwide about 25–45% of patients with COPD are never-smokers. In most studies, the population-attributable fraction for smoking as a cause of COPD is less than 80%. It has been suggested that nonsmoking risk factors may also play important roles in the development and progression of COPD. There is sufficient evidence that exposure to indoor wood smoke, originating from household cooking in developing countries, is associated with COPD morbidity and mortality. This research showed that long-term exposure to outdoor woodsmoke pollution was associated with COPD hospitalization in a developed country setting AND that ambient air pollution*, including traffic-related fine particulate pollution and woodsmoke pollution, is associated with an increased risk of COPD.

**Ambient air pollution is the pollution that is in the air all around us*

Given the substantial social and economic burden of COPD, ambient air pollution as a widespread environmental risk factor deserves more attention for prevention and control of COPD.