



## July 2016 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 July 2016  
10:15 am - 12 noon  
Weston Creek Labor Club  
Teesdale Close  
Stirling ACT 2611

July's Meeting has been designated Guest Speaker free to give the group the opportunity and the time to discuss topics of interest, questions we'd like future Guest Speakers to address, breathing related items (carried over from last month's meeting) and anything else that is of importance or interest to the group. The meeting is in your hands.

### Dates for your diary

Thursday 11 August 2016 Canberra Lung Life Support Group Meeting

### June Meeting

Margaret and Chris ran the meeting which was attended by about 25 people. Carolyn is still not well with ongoing health issues. We wish her the best.

### Topics discussed:

- About 12 people attended late May's coffee morning at the Jamison Southern Cross Club. The group enjoyed themselves so much many stayed on for lunch. Another coffee morning was discussed but no decision was made.
- The **Flexible Bus Service** (Phone 02 6208 3555) is available to Canberra residents who have limited access to public transport options. It is a free basic bus service which is localized to particular zones. Designed specifically for residents such as the aged or people with a disability, the Flexible Bus Service operates off a basic timetable, picking up residents from their home and taking them to local community service providers such as

local shopping centres and hospitals. The fleet of minibuses are all wheelchair accessible.

The service is assessed on a case by case basis and carers with a valid carers card are welcome to travel. (See [www.transport.act.gov.au/catch\\_a\\_bus/accessible-public-transport](http://www.transport.act.gov.au/catch_a_bus/accessible-public-transport) for more information.)

- Helen Cotter outlined the steps that have been taken in the campaign for the provision of POCs for oxygen users in place of oxygen cylinders. See report later in the newsletter.
- New member, Keren, showed us 3 breathing related items she purchased on eBay (\$35-\$40 each):
  1. Buteyko breathing method DVD, CD and book package (from Ireland)
  2. Expander lung device
  3. Frolov breathing apparatus (from Russia) and/or Brett Slim breathing apparatus (from US - in English).

Time didn't allow for discussion of these and other items that people use so consequently, this topic will be carried forward to the next meeting. Then it was over to our guest speaker, intrepid traveller, David Young.

## Guest Speaker - David Young Chris Moyle

David Young joined Tim Cope, a 35 year old award-winning explorer and adventurer, for a 3 week journey in Mongolia.



The team travelled in September and October, the northern autumn. Most of the countryside was covered by grassy steppe with very little arable land. The local people made them feel very welcome. It was almost obligatory to go into someone's home whenever they stopped. A Mongolian interpreter travelled with them to facilitate communication.

Later they walked in snow for 4 days with ponies and camels to support them. Camels were their beasts of burden and carried everything. It was dry snow so boots didn't get wet. The temperature was a trifle nippy at just minus 19 degrees centigrade. The landscape was expansive with nothing to take your attention except the occasional ger, the traditional Mongolian dwelling.

On an earlier spring/summer trip to Mongolia, however, David saw the landscape covered with flowers from the west growing wild - delphiniums, peony roses and many other varieties.

Between 1162 (date of his birth) and his death in 1227, the Mongol leader **Genghis Khan** conquered nearly 12 million square miles of territory - more than any individual in history. Along the way, he cut a ruthless path through Asia and Europe that left untold millions dead.

He also modernized Mongolian culture, embraced religious freedom and helped open contact between East and West.



Mongolia has a population of 3 million, 45% living in the capital, Ulaanbaatar. The country covers one and a half million square kilometres. On average there are less than 2 people per square kilometre. It is one of the highest countries above sea level in the world, averaging 1500 metres. Mongolians are a nomadic people, yet they have a higher literacy rate than Australians and their education is free. Mongolia is a fascinating place to visit.

## **Dr Saidul Ansary the final speaker at the Lung Foundation Australia's Canberra Education Day.**

**Chris Moyle**

Dr Saidul Ansary, VMO Respiratory and Sleep Physician at ACT Health Care, said we spend about one third of our lives asleep, averaging 3,000 hours of sleep per year. Most people do not get enough sleep which results in health problems and emotional outbursts.



### **Signs of sleep disorders:**

- chronic fatigue
- difficulty concentrating
- snoring or
- stopping breathing.

**Snoring** is a common problem affecting, on a regular basis, up to 40% of men and 20% of women. It worsens with age and weight gain. Factors contributing to snoring are sleeping on one's back; blocked nose; alcohol; smoking; sedatives and pregnancy.

**Obstructive Sleep Apnoea (OSA)** is a sleep disorder that involves cessation or significant decrease in airflow in the person's breathing effort. It is the most common category of sleep disordered breathing. During sleep we are in standby mode and not responding to external cues. Apnoea (cessation of breathing) for 10 seconds or longer is either associated with your brain waking up or you getting oxygen saturation. It is caused by soft tissue collapse in the pharynx and possibly some genetic tendency.

### **Severity is measured by:**

- mild - 5-15 events per hour
- moderate - 15-30 events per hour and
- severe - greater than 30 events per hour.

The severity is diagnosed with a sleep study, either at home or in a sleep laboratory. Anything above 15 can cause bad effect on the heart and carries a risk of stroke. Relevant here are:

- **Anatomic factors:** enlarged tonsils (children); volume of the tongue; soft tissue; lateral pharyngeal walls and length of soft palate

- **Neuromuscular factors:** polio and stroke
- **Non-structural risk factors:** obesity; male gender; smoking; post-menopausal (for women); alcohol consumption and hypothyroidism.

Over a period of time, and after a sleep study, a Continuous Positive Airway Pressure (CPAP) machine may be required. The CPAP machine was invented and refined in the 1980s by Colin Sullivan, an Australian.

**Why bother treating OSA?** It carries an increased risk of cardiovascular disease, stroke, high blood pressure, arrhythmias, diabetes, depression, sexual dysfunction and sleep deprived car accidents. Patients have a decreased quality of life. Consequently, sufferers of OSA must always take their CPAP machine with them wherever they go, inform health providers that they have sleep apnoea, and take their CPAP machine with them when going to hospital and use it as necessary.

**Management:** Correct the potentially reversible factors:

- obesity
- smoking
- alcohol
- sleeping pills
- nasal obstruction
- enlarged tonsils and
- endocrine diseases (hypothyroidism).

Surgery may be required: tonsillectomy; UPPP - surgery removing throat tissue to make airway wider, including removing tonsils and adenoids; bariatric surgery; nasal procedures and sinus operation.

The CPAP machine, if prescribed, should be used during sleep every night and even for that granny nap.

## Questions and answers

**Q:** Is the position of sleep important?

**A:** Often yes. It's better to sleep on your side or your front. In sleep, muscle tone is significantly reduced allowing greater sleep apnoea. Try a device that makes sleeping on your back uncomfortable. Some people use a small ball sewn into pyjama back or kept in a bag tied around the waist.

**Q:** What's your opinion of the Buteyko method?

**A:** It's effective on dysfunctional breathing such as some asthma. It may improve diaphragm functioning but there is no hard evidence that Buteyko works.

## Moving into the 21<sup>st</sup> century

**Helen Cotter**

People who need oxygen for health in the ACT are currently supplied with a home oxygen concentrator and a minimum of two oxygen cylinders per month. Oxygen users appreciate this provision as part of their medical treatment, now, however, cylinders have become ancient technology to our needs. Portable oxygen concentrators (POCs) have been around for about 10 years providing benefits for the user the cylinders don't have.

Unlike cylinders, the POC can be used on batteries, which are easy to change, or plugged into a power point. This means users have more freedom, can do more and go further without their oxygen provision running out. With cylinders, users have to regularly get them changed for new

full ones whereas the POC just keeps going.

Many oxygen users are buying their own POC but they cost between \$4000 and \$5000 so are only available to those who are reasonably well off, resulting in a two tiered system with those not so well off compelled to use oxygen cylinders.

We, the members of Canberra Lung Life Support Group, would like the provision of oxygen cylinders changed to the provision of POCs. We believe the move would be cost-effective once the POC has been provided there is no additional cost whereas each cylinder has to be collected, filled and returned to the user. No-one likes to be dependent on equipment to keep them alive but we should have the most up to date equipment which allows us the best possible quality of life.

This point of view was put to Minister Bourke when he spoke at our last meeting. We have also talked to Lung Foundation Australia and Health Care Consumer Association (HCCA) to see if they can assist. The LFA put it on the agenda for discussion at the Australia wide teleconference; Darlene Cox of HCCA has contacted the Minister for Health, Simon Corbell, regarding the issue and the Canberra Lung Life Support Group have now contacted him as well. We very much appreciate her support and experience in dealing with health issues in the ACT.

As oxygen users and possible future users, we'd love all oxygen users in the ACT to have access to this 21<sup>st</sup> century technology.

## **Sleep Myths**

*From The Chronicle, July 14, 2015*

Don't drink coffee in the afternoon; do have a warm cup of cocoa before bed; try counting sheep - we're all familiar with these sleeping tips and more. But which ones should we be heeding?

Dr Maree Burns, a sleep physician and incoming president of the Australasian Sleep Association, says that it all comes down to what works for you. The most important thing is to be relaxed and comfortable and wound down. Some of the issues she identified were:

- Is hot chocolate sleep inducing? Scientifically, there's no evidence for it. However, if it helps you feel relaxed and drowsy, there's no harm in it.
- Counting sheep? It works as a distraction. It gives you something else to focus on rather than the activities of your life.
- Caffeinated food and drinks? As a rule, caffeinated food and drinks should be avoided for two hours before going to bed though some people will be more sensitive to caffeine than others, in which case Dr Burns recommends abstaining from mid-afternoon onwards.
- Another myth is exercising to tire yourself out. But that's not true if you do it in the evening. Like caffeine, you should avoid it just before going to bed.
- Alcohol, often believed to help with sleep, can actually be a stimulant upon wearing off.

The most important thing is to develop a good sleep routine. Sleep is one of the three pillars of good health along with diet and adequate exercise so we need to take sleep seriously and ensure we have enough.

## **The A-Z of Preventative Health Care**

**Chris Moyle**

**Planning for the future:** One way people can deal with fears of the future is to take control and plan for it. They may never need to put their plans into effect but there is reassurance in knowing they will still be in control if the events they fear come to pass. Becoming helpless and dependent is one of the most common fears among people with a potentially disabling health problem. This fear usually has physical as well as financial, social and emotional components.

As your health condition changes over time you may need to consider changing your living situation. These changes may involve hiring someone to help you in your home or moving to a living situation where help is provided. The first thing you will need to do is carefully *evaluate what you can do for yourself* and what activities of daily living will require some kind of help. Make changes in your life slowly, incrementally. You don't need to change your whole life around to solve one problem. If you think you need help with some activities, hiring help at home is less drastic than moving out and may be enough for quite a while.

You will need an attorney to help you set your financial affairs in order to preserve your assets, to prepare a proper will and perhaps to execute a durable power of attorney for both health care and financial management.

**Source:** Lung Foundation Australia's *Living a Healthy Life with Chronic Conditions*

## **Guinea Pig Pam**

**Pam Gaston and Helen Cotter**

In 2014, Pam Gaston was enjoying a lovely holiday in NZ when she had to make a sudden trip to the Emergency Department of the Auckland Hospital. While there she agreed to participate in a study looking into the different ways oxygen is given to those who need it. Mostly, oxygen is given dry, at room temperature and at about 2-3 litres per minute. The researchers were seeing whether using high flow (up to 60 l/min), humidified oxygen heated to body temperature produced better results. The research subjects were an assortment of people attending the Emergency Department - including Pam.

High flow heated humidified oxygen may improve breathing by flushing the upper airway and improving oxygenation with enriched oxygen. It is purported to have many benefits including reducing harm to patients, shorter stays in the Emergency Department and less need for high dependency beds in hospital.

Pam was given the high flow, heated humidified oxygen for about half an hour, six times a day, for 4 or 5 days. Pam says she was out of it for a while and would have benefited from anything but she felt this treatment was beneficial - especially as her nose didn't dry out. The high pressure of oxygen didn't faze her at all.

The researchers have completed their study, published their results and sent Pam a copy. They found that both methods worked well in the Emergency Department but the heated, humidified oxygen may have resulted in more people getting better sooner after leaving the Emergency Department. However there were some people who couldn't tolerate the new method. This research ended up with a small number of subjects and was unable to be completely scientific in its research methods which limits the interpretation of its results. More research is obviously needed. It has been published in the journal *Respiratory Care, March 2016, Vol 61, No 3*. ([www.rcjournal.com](http://www.rcjournal.com)). Pam's pleased she did her bit for research.

### **Nebuliser available**

We have available a nebuliser for anyone interested. Needs mask and tubing. Please contact Helen Cotter on [cotterhe@hotmail.com](mailto:cotterhe@hotmail.com) or 02 6281 2988