CANBERRA LUNG LIFE SUPPORT GROUP

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

Newsletter September 2011

contact: Helen Cotter ph: 6281 2988
lung.life@hotmail.com

Next Meeting

Thursday 8 September
10.15am – 12 noon
(NOTE NEW STARTING TIME)
The Weston Club,
1 Liardet St
Weston

Caroline Manning from *Mobility Matters* will be showing us some of the latest items that can assist our mobility in everyday life

August Meeting

This month we began our new starting time of 10.15 so that people can get tea/coffee and talk to others before the meeting begins at 10.30. It was lovely to see most people there about 10.15. The main issue we discussed was the portable oxygen concentrator donated to us recently. Thrilled to have received it, we want to ensure we put it to the best use possible. Currently we are having it serviced and will decide at our next meeting.

After our business, we listened to and quizzed Jim Thornton on computers and computer technology. He clarified the meaning of some terms and successfully answered any questions we asked. It was a useful session and we hope to have Jim back again sometime next year to continue the discussion.

Welcome Donation

Lung Life was thrilled recently to receive a donation of an InogenOne portable oxygen concentrator. We are currently having it serviced and will discuss how to best use this donation at our next meeting. If you have any suggestions, please let me know on lung.life@hotmail.com

Another donation

We have received an offer of a donation. This time a large oxygen concentrator and unused masks and tubing. If you are interested, please contact Helen on 6281 2988 or lung.life@hotmail.com .

Conference Report from Caroline Polak Scowcroft

I attended a very interesting international conference in Melbourne for two days in July run by the Health Issues Centre which is Victoria's Health Consumer Organisation.The conference was entitled **consumers reforming health** –details can be found on their website at www.consumersreforminghealth.org. The priority conference themes were:

- **The case for participation:** a viable strategy to develop, maintain and better address consumer and communities needs, allocate resources and develop health priorities, health services and programs, improve health outcomes and reduce costs;
- **Consumers and health services as equal partners:** examining successful partnerships with patients, families and communities and the implementation of person-centred approaches including patient-centred care;
- **Consumers in research:** consumer involvement in collaborative research activities; consumer involvement in prioritizing topics; consumer-led research in health; the future for consumers in research;
- **Human rights, health and health care:** The links between human rights, health and health care and participation; understanding consumer/communities rights and responsibilities; non-discrimination and attention to vulnerable population groups; improving the responses of the health system to emerging challenges;
- **Strategic Partnership Between Consumers and Communities and Quality Improvement:** Consumer involvement in quality improvement to enhance health programs and processes; organizational benefits and project outcomes; patient safety and satisfaction.

There were over 450 participants and the presentations were excellent – engendering many questions and debates. The noise during the tea break-outs was phenomenal as people greeted old friends and made new ones and valuable new connections. On the first day I wore the blue polo shirt of the Health Care Consumers' Association and on the second the green 'What is COPD?' T-shirt. Both gave an easy entrée into answering questions about the relevant organization. It's still amazing how little people know about lung disease, and there was no-one amongst the participants on supplementary Oxygen. Why am I surprised?

Networking breakfast for chronic disease self management

The Chronic Care Alliance is holding another networking breakfast on Tuesday 6 September (buy your own breakfast) at Woden, 8am. This is a good time to learn about the organisations dealing with chronic care, to meet the people, and to learn what they do that is useful for us. It's also a good time to spread the word about our support group. Anyone interested in attending, let me know: my contact details are at the top of the newsletter

Travelling with Oxygen

The following information comes from the American College of Physicians so relates to American information. However, much (most?) of what it says applies to us in Australia.

Effects of Altitude and Air Travel: The Basics

At sea level, the air we breathe is rich in oxygen. At higher altitudes, the atmosphere becomes increasingly thin as a result of decreasing air pressure. The thinner the air, the less oxygen it contains. Most commercial airline flights maintain an average cruising altitude between 30,000 and 40,000 feet. At these levels, the air outside the cabin is extremely thin. Airplanes must, therefore, be pressurized at these altitudes to protect passengers from

dangerously low levels of oxygen. Regulations established by the US Federal Aviation Administration (FAA) require that air pressure in commercial aircraft be maintained at a level equal to or lower than 8,000 feet above sea level. For most passengers, this provides enough oxygen to breathe comfortably. For passengers with lung disease, however, this level may not be suffcient to meet their needs.

In some cases, your doctor may order an altitude simulation test to determine if you need portable oxygen for your trip. This test measures oxygen levels in your blood while you breathe a mixture of gases similar to the atmosphere inside a pressurized airplane cabin at cruising altitude.

Use of Oxygen on Commercial Airlines

Policies concerning the use of in-flight oxygen vary substantially among airlines. Contact your airline or check your airline's Web site to obtain its specific guidelines on oxygen use during flight.

Airlines require a minimum of 72 hours advance notice before your flight if you plan to travel with oxygen. Airlines generally require a "Physician's Statement"—a written authorization signed by your doctor—that verifies your need for oxygen therapy. This document also outlines any specific oxygen delivery instructions that you and the airline need to know. Many carriers have their own airline-specific medical forms that must be signed and dated within a certain period, (eg, 10 days or less) before travel. Be sure to check with your airline about its specific policies.

Air carriers typically offer two basic options for oxygen therapy during flight: 1) carrier-supplied compressed oxygen or 2) use of a personal portable oxygen concentrators (POCs).

Carrier-Supplied (Compressed) Oxygen

Various airlines provide compressed oxygen during flight as a service to passengers who need oxygen therapy. Fees for this service vary based on the duration of the flight or the number of flight segments in the trip. Your insurance policy may cover some of the costs associated with your in-flight oxygen needs. Check with your insurance carrier to determine the specifics of your coverage. Maximum flow rates and available equipment, such as masks, vary among airlines.

Also, be mindful that oxygen provided by the carrier will be available only while you are onboard the aircraft. Airlines do NOT provide oxygen for passengers when they are in the terminal either before or after a flight. If your trip includes connecting flights with a different airline, you must make separate arrangements with each carrier before your departure.

If in-flight oxygen service is not available, in most cases you will be able to use a personal oxygen concentrator (POC) during your !ight. Travelers who choose this type of equipment are responsible for supplying and operating their own POC unit which may be rented or purchased from suppliers. All airlines require a Physician's Statement from patients traveling with POCs which verifies that the patient is knowledgeable and capable of operating the POC unit. Always check in advance that the POC you intend to use is approved by your airline for your specific flight.

POCs offer several advantages over other oxygen delivery systems for travelers. Unlike carrier-supplied oxygen, these devices can be used by passengers during long layovers or delays. Travelers can also use this lightweight and convenient equipment at their final destination without making any additional arrangements.

CPAP Machines for Sleep Apnea

CPAP machines were developed primarily for use at home. Advances in CPAP technology now make it possible

for patients with sleep apnea to use their CPAP devices during long-duration flights that span normal sleeping hours. Like POCs, CPAP machines are classified as medical assist devices. They are, therefore, permitted on most domestic and international flights. Remember that an external power source may not be available during your flight. Check with your airline ahead of time to make arrangements for any electrical power you will need.

Disabled Parking

Recently, Albert Richards emailed accesscity@citizensadvice.org to complain about the removal of a disabled parking space at Jamison by the painting of yellow lines on one of the two spaces.
The reply from Adrian Nicholls (Access City Project Officer, Citizens Advice Bureau email accesscity@citizensadvice.org.au Phone 02 6257 3077 Web www.accesscity.org.au.org.au) Included the following:

Dear Albert, I have just received some feedback from Roads ACT on the issue you raised. They advised that changes have been made to the disabled parking spaces at the car park to comply with **new Australian Standards for the design and size of disabled parking bays.**

I understand that this has resulted in the combining of two bays that you referred to and marking of a shared zone that is intended to provide adequate access to the parking place.

Albert responded with some questions: may disabled drivers park in the area covered by yellow diagonal lines? May the general public or tradesmen park in that area? When is a notice going to be installed to state who may, or may not, park in that area as confusion reigns at present.

Adrian emailed: I followed up your questions with Roads ACT. They advise that the Australian road rules prohibit parking on areas marked by diagonal lines. I will formally notify them about the problem that you raise about current confusion and request appropriate signage.

COPD stories

The Lung Foundation has stories from people affected with COPD on its website. You can still input your story – see if there are any from Canberra already.
Check out the site: www.lungfoundation.com.au

Deadly Healthcare by Caroline Polak Scowcroft

At one of the airports I picked up a copy of 'Deadly Healthcare' by James Dunbar, Prasuna Reddy and Stephen May. I read it in a sitting – WOW! I'll just copy from the back cover: 'The story of Australia's own 'Dr Death', Jayant Patel, is symptomatic of a tidal wave heading towards all modern healthcare systems. In this absorbing book, the authors have ploughed through the mass of public inquiry data, interviewing key figures in the affair to reveal in gripping detail how it happened, who was to blame, and how it can be avoided. Drawing on international cases and experiences, they reveal how institutional weaknesses are able to be exploited by individuals with serious personality problems. Hospitals worldwide are facing increasing pressures from staff shortages and the need to manage financial considerations that impact directly their ability to adequately manage patient care. This is a story relevant and timely for all who are a part of a modern complex healthcare network, from hospital administrators to doctors, nurses, ancillary staff and the patients themselves. The case of Bundaberg Hospital and its infamous 'Dr Death' could be happening again right now in your own overburdened healthcare system.' As I said - 'WOW!' – an engrossing book, but severely worrying.

The International Coalition Against Wood Burning Pollution

www.coalitionagainstwoodburning.com

This site is a gathering place for people around the world to come together to help clear our neighborhoods of wood smoke pollution.

Many investigations of wood smoke complaints are due to the continuing efforts of CAWB.

If you can see or smell debris smoke, there is a health problem!

One of its articles is by **Dr Dorothy L Robinson,** Snr Research Scientist, Adj A/Prof, University of New England, Armidale. Below is an extract of what she says.

Woodsmoke is not just an outdoor problem. The particles are very small, ranging from .2 microns at the start of the burn period to .05 microns as the burn cycle progresses. Particles of this size behave like gases. The only way to keep them of houses out is to make our homes airtight and risk dying from lack of oxygen. When emitted on cold, still nights, woodsmoke builds up outdoors and then seeps into our houses. A study in Vancouver (Intake Fraction of Urban Wood Smoke, Ries et al.. Envir Sci Tech, 2009) reported that woodsmoke particles are 7 times more likely to be breathed into our lungs than the average PM2.5 particle in Vancouver's air.

Once breathed in, woodsmoke particles are much more dangerous than environmental tobacco smoke. In human cell lines, woodsmoke caused more DNA damage than traffic-generated PM per unit mass and was found to induce lung cancer in mice. Oncogene mutations in human patients with advanced non-small cell lung cancer have been associated with exposure to wood smoke as well as active tobacco smoking.

Predominant wood (fuel) users in North America and Europe had a 21% higher risk of lung cancer. In developing countries, exposure to woodsmoke is associated with lung, mouth and throat cancers, and even cervical cancers in women who test positive for the HPV virus.

In OECD countries, lung cancer increases by 14% for every additional 10 ug/m3 of annual PM2.5 exposure. It is the largest single-source of PM2.5 emissions in most Australian cities - 67% of PM2.5 emissions in Canberra (where 3.9% of households have woodheaters) and 34% in Sydney (where 4.3% use wood as the main form of heating). The situation is similar in Canada, e.g. Quebec, where wood heating is responsible for 61% of fine particle emanations.

IDIOT SIGHTING.

My daughter and I went through the McDonald's driveway window and I gave the cashier a $5 note.

Our total was $4.25, so I also handed her 25c.

She said, 'you gave me too much money.'

I said,'Yes I know, but this way you can just give me a dollar coin back.'

She sighed and went to get the manager who asked me to repeat my request.

I did so, and he handed me back the 25c, and said 'We're sorry but we don't do that kind of thing.'

The cashier then proceeded to give me back 75 cents in change.

Do not confuse the people at McD's.

Help for the Disabled at Airports

The following has been taken from the recent U3A newsletter

Help for the Disabled at Airports

Many of our older members, not to mention younger disabled travellers, find difficulty in coping with airline travel. Those with walkers, for instance, have to hand them in at the counter and unless help is available, have to manage as best they can or not travel at all.

The 2010 autumn issue of the *U3A News*, published by the UK Trust, the umbrella organisation of U3As in the UK, had an interesting feature stating that an EU law on disability has made it a winner for such people. Passed in July 2008, the law is designed for the benefit of anyone with any kind of disability, physical or otherwise, and regardless of whether it is temporary or permanent.

'This is how it works,' the feature says. 'When you make your booking, either through a travel agent or direct with an airline you tell them of your disability and the assistance you require. It is then the responsibility of the airline and airport to ensure you get the help you need.'

Cyril Selby, chairman of Worthing U3A, applauded the help he and his wife, both in their 80s, received when they arrived at Gatwick. Cyril wrote that he has 'a dodgy hip' and they were directed to a particular seating area to await transport, saving them both a long hike across the airport to the south terminal.

They were then loaded onto an electric buggy with their luggage and driven to the appropriate gate. When their aircraft was ready they were taken to the head of the queue for boarding. On arrival at Pisa they were met by members of the Italian Red Cross with wheelchairs and their luggage and taken to the front of the terminal.

On the return trip the Italian Red Cross again helped them to their aircraft and once back at Gatwick were duly assisted through customs and quarantine and helped to the exit. 'Should airports or airlines fail to provide the service you require, the EU will take action against them through the Department of Transport,' Cyril writes. They can be very punitive. The service is free throughout the EU. A free booklet sets out the whole thing in simple language; it can be obtained by phoning 08456 046 610 or online at www.equalityhumanrights.com

While some Australians have high praise for the help they've received, especially if they are in wheelchairs, plenty of others, not so fortunate with the problems they've experienced, would welcome a similar law.

Last year the Belconnen current affairs group had an official from the Canberra airport speak to them about the new facilities being provided. One member approached him about the provision of walkers being made for passengers who have to give their trolleys over at the check-in. The suggestion of airport ones then being made available until the passengers boarded the aircraft was well received - but does anyone know whether such assistance has been offered?

Dorothy Braxton

Dates for your diary

Wednesday 16 Nov World COPD Day

If you no longer wish to or need to receive this newsletter, please send an email saying you no longer wish to subscribe.

lung.life@hotmail.com or return the mailed newsletter