



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

Newsletter June 2011

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Next Meeting

Thursday 9 June
10.30am – 12 noon

The Weston Club,
1 Liardet St
Weston

In this meeting, Emma Awisen will take us through an Advanced Care Plan workshop. Advanced care planning involves stating your wishes for your health and personal care should the time ever come when you are not able to communicate because of illness or injury.

Here are some questions you might like to consider:

- What constitutes quality of life for you?
- What types of invasive medical procedures do you consider to be undesirable?
- If you had multiple physical problems, at what point, would you want the doctors to stop trying to prolong your life?
- Are you a religious or spiritual person, what are your values and beliefs?
- When your time eventually comes, what would constitute a "good death" for you?

May Meeting

We had an interesting May meeting where we combined information about our lung conditions, doctors, medication and other remedies. We were lucky that Beth Forbes from the Chronic Care Team had attended the meeting to talk with us about a Canberra focussed COPD pamphlet. We seconded her into writing on the butcher's paper for us – and she was able to answer queries we had about our medications etc – an extra bonus for us.

Results of our discussion

The largest group of members have COPD; but we also have members with Pulmonary Fibrosis and Bronchiectasis as well as some with fungal and other lung infections and poor breathing caused by scoliosis.

The discussion showed that we see about 6 different specialists and use over 10 different sorts of prescribed medications plus an assortment of antibiotics. Some of these are used regularly; some on standby. The same with oxygen that many use – some on standby, some for a certain number of hours, some at night, and some 24 hours a day.

As a combined group, we do all the right things. We exercise, at home, by attending the gym, walking or through other activities such as singing, gardening, lawn mowing, swimming. We practice breathing techniques. We are aware of the benefits of good nutrition – some avoid red meat; some maintain a high fibre diet; some believe in coffee and a glass of red wine or beer. Many of us use fish oil for its Omega 3 and take vitamin and mineral supplements. And some firmly believe in the importance of a siesta and good sleep at night.

The details of our research are attached at the back of the newsletter for members. If anyone else would like a copy of the details, please let me know on the email address above.

Chronic Care Expo

The Chronic Care Expo **Living a Healthy Life – See, Feel, Touch, Do** - was held on May 14th at pleasant venue of the Southern Cross Club, Woden.

Laurelle and Caroline set up our table, and soon after Helen, then Pam and Pat came to assist.

It was good to see the variety of organisations assisting in and providing information on self management techniques in all sorts of areas.

We could also view the results of Albert's photojournalism experience (detailed below) on the wall – it looked good.

I hope you took advantage of the massages being offered



Pam & Pat at the Expo

ALF COPD Patient Taskforce Teleconference May 9, by Caroline Scowcroft
Caroline is our representative on this taskforce which is part of The Australian Lung Foundation (ALF). Each month, she participates in a teleconference with representatives from around Australia. Here are some of the issues they discussed in the May teleconference.

One issue discussed is the banning of smoking in common outdoor areas of residential housing. In Queensland, residents need to request the Body Corporate to change a by-law. The other reps will investigate the situation in their States and Territories.

Queensland Health is looking into the feasibility of having pulmonary rehabilitation programs in regional centres conducted by physiotherapists in private practice. One of the arguments being canvassed is that a large proportion of COPD patients have private health insurance and could receive a rebate for attending such rehab programs.

A tabled report showed that 1 in 3 families had a member with a lung condition.

The reps gave their report about their local activities. Caroline talked about the successful Education Day recently held in the ACT.

ALF and Asthma Australia will work together on an **International Men's Week Men's Shed initiative**, mentoring and using skills (for more information on the Men's Shed movement you can Google it). 'Spanner in the Works' is a health initiative booklet (50 pages).

A reminder - World No Tobacco Day – always held on 31 May.

Photojournalism experience

Recently, Susan Abbott from the Centre for Health Stewardship at ANU asked for volunteers to record on camera the effects of their illness on their daily life, with the camera being loaned by the Centre. Albert Richards was one of those who volunteered.

Albert was given a camera and encouraged to interpret the topic "the impact that living with chronic disease has on your use of time". He also made audio recordings of the stories behind his photographs. Albert's photographs represent previous experiences that have enabled him to adapt a number of his life support systems.

The recordings of other participants showed the diversity and complexity in the lives of people with chronic diseases.

The main point of difference was their understanding of effective self-management strategies and their advocacy skills.

This project shows that consumer perspective highlighting the impact of chronic illness are in many ways more vivid than the spoken word alone.

Albert's comments on his Project

I thoroughly enjoyed the project as I learned how to produce a Power Point presentation. It was not hard work for me with a technical background but time consuming, a commodity of which I have in excess.

My only problem was that the NEW camera I was loaned repeatedly requested I insert new batteries but new batteries failed to satisfy its insatiable thirst.

I began to cynically wonder if the camera was made by *Ever Ready!* Even my recommended remedy of a damned good thrashing secured no improvement.

I did not wish to add my recorded commentary as I often run out of breath before completing a word but Susan said it was in keeping with a person suffering from COAD (COPD) so I complied.

Susan also promised to give me a copy of the audio recording that will be a challenge to synchronise with the slides in the project. There is also a copy of the composite poster being prepared from my Power Point slides.

**Live with intention, play
with abandon; laugh; do
what you love; live as if
this were all there is**



**Albert Feeling a Little
Ho(a)rse**

One of Albert's PowerPoint slides

Vitamin D Improves Exercise Outcomes in Patients With COPD

From www.sciencedaily.com 15 May, 2011

Vitamin D supplements may help patients with chronic obstructive pulmonary disease (COPD) get more from their pulmonary rehabilitation programs, according to a study conducted by researchers from Belgium.

COPD has important non-respiratory consequences such as osteoporosis, cardiovascular disease and muscle weakness which are influenced by physical inactivity along with exercise intolerance. Vitamin D deficiency is common among patients with COPD, and is often associated with lack of exposure to sunlight and diet.

The researchers enrolled 50 COPD patients with a history of exacerbations who had been referred for rehabilitation and randomly assigned them to receive either a monthly dose of vitamin D or placebo.

Patients in the vitamin D group were given 100,000 IUs (international units) of vitamin D in their monthly dose; the U.S. recommended daily allowance of vitamin D is 600 IUs daily for adults up to age 70 and 800 IUs daily for adults over age 70.

All patients participated in a pulmonary rehabilitation program for three months. At the beginning of the study and again at the completion of the rehabilitation program, peripheral and respiratory muscle strength, exercise capacity and vitamin D levels were measured. Patients were also asked to complete a quality of life survey both before and after rehabilitation.

At the end of the study, researchers found that patients treated with vitamin D had a significant improvement in exercise capacity and respiratory muscle strength compared to those in the placebo group. Future studies should focus on the specific mechanisms by which vitamin D affects patients with COPD.

Music for Your Lungs from www.sciencedaily.com

Research has shown that learning the harmonica is a good exercise for people with lung conditions. The repeated pattern of pushing air from the lungs into the instrument, and then sucking air back into the lungs helps patients learn to control and boost their breathing. Blowing out against resistance helps to strengthen the respiratory muscles. Learn some catchy tunes while you are exercising.

Senior Health Care Solution from Lorna

So you're a sick senior citizen and the government says there is no nursing home available for you - what do you do?

Our plan gives anyone over 70 years or older, a gun and 4 bullets. You are allowed to shoot 2 Federal MP's and 2 State MP's - not necessarily dead! Wounding is fine!

Of course, this means that you will be sent to prison where you will get 3 meals a day, a roof over your head, central heating and all the health care you need! New teeth - no problem. Need glasses, great. New hip, knees, kidneys, lungs, heart? All covered - (And your kids can come and visit as often as they do now)

And who will be paying for all of this? The same government that just told you they cannot afford for you to go into a home.

Plus, because you are a prisoner, you don't have to pay any income taxes anymore!!!!

Overcoming Anxiety - A Trip to the Theatre by Chris

This isn't about a trip to the hospital theatre (thank goodness!) but a visit to the Canberra Theatre to see a show.

Last year I did the Living with Chronic Conditions course and have consequently made a few changes in my life.

In December I decided I'd like to try something different, such as booking a seat in advance at the Theatre and seeing whether I could actually get there. There'd been several occasions in the past where I'd paid for a ticket in advance and felt unwell on the day, so I didn't go and lost out financially. For years it was easier not to bother going anywhere. The car might break down and I could be stranded on a lonely road at night and, if I really thought about it, I could even be abducted and murdered. Or I could be unwell on the day, which was my main worry.

But this time I was very courageous and booked a ticket.

Six weeks before the show I became unwell and had a course of antibiotics. Then a fortnight before the show I again became unwell and had another course of antibiotics. I was now quite run down and started worrying about the car.

"It's all right," said the mechanic. "You don't need another service. You just need to drive it!"

I started to settle down and make a plan for the outing. I checked out a road map and made a test trip from home to the theatre. Now I knew how long the trip took, what time to leave home and where I'd park. What's more the car hadn't broken down so it would probably be OK on the night.

The day before the show I prepared my handbag - with a fully-charged mobile phone, NRMA card, tissues, purse and, most importantly, my ticket. Alas that evening the sinusitis headache started, so I took 2 Panadol and an anti-histamine tablet.

The next morning, the day of the show, the thumping headache continued. I decided to continue calmly throughout the day, as though I was going out - as planned - and make a final decision at the last minute. I took 2 Panadol at breakfast, 2 Panadol at lunch and finally 2 Panadol at dinner-time (the maximum dose) before the headache miraculously lifted, just in time to leave for the show.

I was very pleased I'd done the pre-planning and the practise-run beforehand as the trip was easy, no troubles parking and the show was magnificent. There were no worries driving home, my headache had gone, and the best thing is - with my new-found skills, and a little bit of luck - I might even do it again!

Information for people covered by Vet Affairs

Due to a change of suppliers plus some other changes, Michael Reid of **Pegasus Healthcare** is now able to supply people covered by the Dept of Veterans Affairs with all their requirements. He can update them on any changes.

Pegasus Healthcare, Dundas Court, Phillip Ph: 1300 303 603;

email:pegasuscanberra@bigpond.com

Lung Cancer weakened CT May 12, 2011

Scientists at University of NSW have developed a technique for switching off protein cells that are resistant to chemotherapy, making the cancer more sensitive to the chemotherapy. The next step is to find a way to deliver the treatment to the tumor without the body rejecting it. Prof Maria Kavallis hopes to begin human trials late next year.

The Wood Heater Replacement program is on again. A partnership between the ACT Government and ActewAGL encourages people to remove, recycle and replace their wood heater with a new mains-supplied natural gas heater. Since the program was launched in 2004, 894 wood heaters have been replaced with cleaner heating alternatives. The rebate for replacing wood heaters with ducted gas systems remaining at \$800, and \$600 for new flued gas installations.

For more information, or to apply for the Wood Heater Replacement Subsidy, please visit <http://www.environment.act.gov.au/> or call Canberra Connect on 13 22 81.

We would still like to see the program broadened to include other types of heating.

Ready & Able – *Keep your brain active* by Chris

Last month's word unscrambled was "notable", so the sentence read:

"The notable surgeon was not able to operate as he had no table."

Here's an Elimination exercise.

All but two of the listed words fall into one of the four categories. Put these leftover words together, and what word or phrase do they make?

CATEGORIES: Words following 'water' : Punctuation marks : Emotions : Types of nut

Happy Scared Full stop Frustrated Mark Apostrophe

Resistant House Fowl Opera Angry Sad

Cashew Pistachio Pistol Colon Hyphen

Comma Level Pecan Macadamia Brazil

Answers in next newsletter.

Dates for your diary

Wednesday 16 Nov World COPD Day

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

Our Research

COPD

Doctors – initially and current	Prescribed medications	Antibiotics	Other therapies	Other remedies
Nogrady Nicholls Burke May Miller Hurwitz Jones earliest date of diagnosis: 1987	Ventolin (10 people) Atrovent (5) Seretide (9) Pulmicort (2) Flixotide (3) Spiriva (5) Onbreeze (1) Qvar (1) Bricanyl (2) Symbicort (3) Prednisolone (9) Nuelin SR (4)	Rulide Amoxycillin\Avlox Klacid Keflex Zithromax Doxy 50	from the doctor: oxygen Vpap from the physio: bubble PEP tri-flo flutter Parry PEP humidifer	gym breathing exercise cycling; walking talking; singing mowing the lawn splitting wood gardening sleeping well good nutrition coffee; red wine beer; coffee vitamins overtraining therapy (for elite athletes) Omega 3 (fish oil) Zink Butekyo breathing techniques

Comment

- Hurwitz treating many of our members until his accident, causing them to move on to other doctors.
- Most people taking a combination of medications.
- Of the Prednisolone, 3 take it regularly; 6 have it for emergencies.
- A reminder that people taking those medications containing steroids such as Seretide and Symbicort need rinse their mouths out after a dose to prevent infection such as thrush
- The member who mows lawns is on 24 hour oxygen. He has set up a basket on the handles of the mower where the oxygen bottle sits. He is careful about this.

Pulmonary Fibrosis (Interstitial Lung Disease)

Doctors – initially and current	Prescribed medications	Antibiotics	Other therapies	Other remedies
Burke Wee Hammett Nicholls earliest diagnosis 2001	Spiriva Seretide Prednisolone		Oxygen	Walking gym table tennis siesta breathing exercises fish oil yoga

Comment

- comment from one member that the prescribed medications have no proven efficacy.
- comment from one member that yoga is not advised for lung diseases. *We are following this up.*
- Comment from one member that problem of maintaining an exercise program due to recurrence of asthma.

Bronchiectasis

Doctors – initially and current	Prescribed medications	Antibiotics	Other therapies	Other remedies
Burke earliest diagnosis 1975	Pneumovax	Nilstat	Flu vaccine flutter valve posturage draining daily	Astragalus 8 armaforce women's multivitamin & mineral Vit B complex Vit C Healthy eating

Other lung conditions

Condition	Prescribed medications	Antibiotics	Other therapies	Other remedies
Aspergillosis? Dr Loh (Newcastle) 1995	<i>As for COPD</i>		Oxygen on standby	High Fibre diet
Hypersensitivity pneumentis? (collapse of immune system – TB as a baby) Dr Cooke (immunologist)	Methatextrate (need constant blood tests to check eg liver) folic acid (needs to be taken in conjunction)			
Sinusitis (connected with bronchiectasis)			Clarotyne COTC anti-histamine panadol	Nasal spray nasal rinse allergy desentisation
(type of) Asthma (connected with bronchiectasis) (diagnosed 1990)	Seretide 250 with spacer			As for bronchiectasis above fish oil exercise: swimming; walking; weights; stretching
(chronic) pseudomonds aeruginosa (bacterial infection) goes with bronchiectasis (colonises in the lungs) (diagnosed 2006)	Klacid Ciproxin (antibiotics) Gentamycin (nebulised antibiotic)			
Poor breathing due to scoliosis Dr Farnback Dr Huang (earliest diagnosis 1930)	Spiriva		Oxygen back support	Gym breathing exercises Tai Chi walking

- One member commented that the following didn't work for her: 'Butekyo breathing method; acupuncture; natural remedies; juicing; fasting; enemas; Reiki.