CANBERRA LUNG LIFE SUPPORT GROUP

June 2014 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 12 June 2014** 10.15 am - 12 noon The Burns Club, 8 Kett Street, Kambah ACT 2902
Guest Speaker	Beth Forbes from the Chronic Care Team at The Canberra Hospital will answer all your queries regarding home oxygen plus even more.

Dates for your diary

Thursday 10 July 2014	Canberra Lung Life Support Group Meeting
Wednesday 19 Nov 2014	World COPD Day

May Meeting

Helen Cotter

The May meeting began with business as usual with discussion focusing on:

1. a successful Education Day
2. volunteers for the Expo in mid-May at the Medical School, The Canberra Hospital
3. organising our stand at the Expo and planning our mid-year Christmas lunch in July - Pam will be busy
4. eligibility and application for reduced-cost stamps which was explained by Esther - just go to the Post Office and ask
5. a working party to consider the role of our Support Group's Coordinator and
6. to reflect on /discuss /plan future steps for Lung Life.

Then it was over to our speaker, Wayne Shaw to acquaint us with the roles of the ACT Fire and Rescue.

Wayne Shaw - ACT Fire and Rescue

Helen Cotter

Perhaps because we have respiratory problems, Wayne began his talk with home oxygen therapy and the importance of:

- keeping oxygen away from flame
- always having clean hands when dealing with oxygen as oil and lubricant react with it
- not smoking

- not allowing smoking in your home.

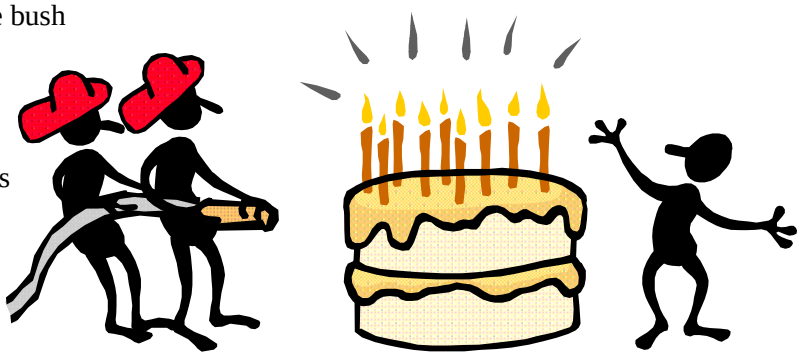
Next came smoke alarms. To ensure the smoke alarm works check fire alarms at the beginning and end of daylight saving. Your local fire station will provide an alarm and change batteries for free.

Operational Matters

The ACT Fire and Rescue Service employs 324 males and 6 females. The application to join has a few layers including a written test, a physical and psychosocial test and a police check. The employees clean their own fire stations, cook their own meals, and have constant drilling and training as well as face to face testing. The Recruit College is at Hume where it has all the facilities for training, including props for different scenarios.

There are nine fire stations in the Canberra area, staffed twenty-four hours a day and responsible for:

- attending fires, in the city and in the bush
- attending vehicle accidents
- providing medical assistance
- assisting with storm damage, eg chopping down trees or putting tarps on houses.

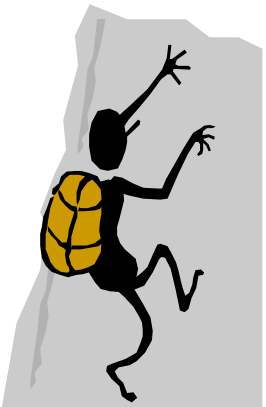


Fires can result from:

- leaving pots and pans unattended
- things boiling over
- things sitting on the stove and catching alight. If this happens, the first step is to turn off the gas or electricity
- clothes drying rack being near a radiator
- an electric blanket
- the lint filter in an electric clothes dryer
- electric arcing from overloaded power points
- frayed cords
- candles near curtains.

Different areas of expertise

- **Investigation service:** This service works with the firefighters to determine the cause of the fire, not necessarily because it is suspicious but to add to their knowledge of fire. It may be that a certain item faults easily and this knowledge can be taken further. Representatives from the ACT can attend further training in NSW such as in detecting arson.
- **Hazardous material section:** They have specialised training and equipment to deal with toxic atmosphere and toxic materials. Recently, there's been a bout of white powder through the mail. The suspect package is checked in a closed box by the Firies wearing safety gloves; and then tested by ACT Health.
- **Vertical rescue service**: Again, have training and all the appropriate equipment including 4 wheel drives to get them into remote areas and abseil down to the victim.
- **Volunteer community fire units:** To be able to protect their own property from ember attack 1000 people have been trained with uniforms, trailers, stand pipes and hoses.



Broader role:

- Task forces to assist with urban search and rescue, national and international eg: the recent Victorian fires, the Christchurch earthquake and the Japanese tsunami.
- International fire fighter exchange for 12 months.

- Do welfare checks on people ie if a person contacts the police concerned about a neighbour etc., the fireman visit the home with the police.
- Worldwide family participating in Police and Fire Games, nationally and internationally.

Wayne was very pleased to hear of good experiences with the Fire and Rescue Service told by club members:

- Esther told how they came and checked her home because of a suspicious burning smell (they didn't find anything).
- Carmel thought she'd left the gas on and was unable to go home and check. The fireman came to the hospital, picked up her keys and checked her home (all was well).
- Pat W's grandson got his knee caught in the bars of his cot. The knee swelled up and the family couldn't remove it. The firemen came, took the cot apart and freed the boy. As they were leaving they sounded their siren, to the joy of all the children.

Lung Foundation Australia (LFA) Education Day

Helen Cotter

Jenny and Juliet from LFA

On Tuesday, 29 April 2014, approximately twenty members of Lung Life along with about forty others, some from Sleep Apnoea, some from Pulmonary Rehabilitation and some from outside Canberra, attended Lung Foundation Australia's Education Day held at the Southern Cross Club.

Juliet Brown started the day off with a welcome from LFA. She outlined the role LFA has played since its establishment in 1990. Based in Brisbane, LFA is the national, not-for-profit organisation that deals with lung health. It provides information, education, awareness campaigns, and support for consumers and professionals. The LFA has established brochures, booklets, fact sheets, telephone support, a lung health check list, a DVD, television commercials, all providing information on a variety of lung conditions.

In Australia, one in ten people have a lung disease: 2.3 million have asthma; 1.4 million have COPD; 11,270 were diagnosed with lung cancer last year and 600 were diagnosed with mesothelioma. Indigenous people die from lung disease three times more than non-indigenous people.

Today's Education Day is one of LFA's programs to inform, educate, raise awareness and support consumers. It's held at different times throughout the year in all the States and Territories of Australia. Today is the ACT's turn. Our speakers spoke on sleep, the latest in lung research and dealing with depression and anxiety.

Grant Willson

How to Get a Better Night's Sleep

Dr Grant Willson, senior lecturer in Physiotherapy at the University of Canberra and Director of Sleep and Lifestyle Solutions, qualified his talk by saying it was a talk with general information only. He said also that, when being treated for sleep disorders, some people get worse before they get better.

There is a spectrum of sleep disorders, including:

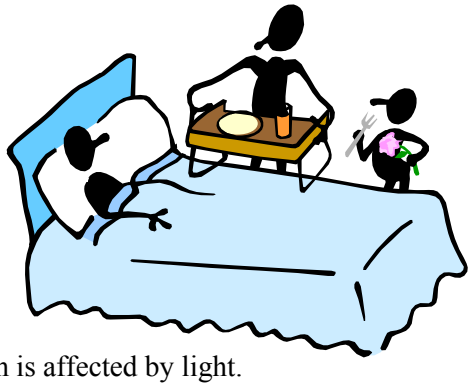
- insomnia and poor sleep
- sleep disordered breathing
- periodic leg movements
- and medical conditions that affect sleep.

Of those with sleep apnoea, 40-60% will have insomnia as well; in COPD, 27-48% report insomnia.

Poor sleep reduces quality of life. The prevalence of insomnia increases if the person has multiple medical conditions. In a definitive longitudinal study of people who indicated they had 'somewhat poor sleep', these people were found to be nine times more likely to die.

What is sleep? Physiologically, sleep is recognised by the action of the brain waves, eye movements and global muscle tone. Sleep has two main stages: 75% of the time is in non-REM sleep; 25% is in REM sleep. Interestingly, in REM sleep, the brain looks as if the person is awake but muscle activity is completely absent. This actually affects breathing as only the diaphragm is working. The deep stages of sleep usually occur early on in the evening.

As we get older, deep sleep decreases, a natural consequence of changing hormones and perhaps mental and physical ill health. How much sleep we need, depends on the individual. Some individuals function well on only a few hours. Studies show that for most people, 6½-7½ hours are best. The belief in the need for 8 hours is unsubstantiated.



Sleep is regulated by two processes:

- the circadian cycle (circadian rhythm) which is connected with the secretion of hormones that promote sleep or wakefulness
- the homeostatic drive ie the drive to sleep. The longer you stay awake, the stronger the drive to sleep becomes.

Both rhythms need to work together to get a good night's sleep. The brain is affected by light.
When it's dark a hormone is secreted that promotes sleep; light in the morning is important for setting the circadian rhythm (body clock). It's important to sleep in a room that allows morning light to show.

If you have a sleep problem, there is a suite of advice depending on the individual:

- You need to fix any physical problems such as sleep apnoea, restless legs, coughing etc.
- You may undergo *cognitive behavioural therapy* to change your mode of thinking and behaving. For instance, worrying about poor sleeping or drinking too much coffee may exacerbate the problem.

Promoting Healthy Sleep

- Don't worry. You will get enough sleep to function. Lie there and enjoy the relaxation; perhaps use relaxation techniques. If you feel too awake, get up for about half an hour, read or eat a snack.
- If you have things you worry about - things you have to do or things you may forget to do, write them down so that you don't have to worry about them.
- If you have a racing mind, you need to switch it off. There are techniques that will help you do that.
- Have regular sleep. Wake up at the same time each morning to assist the circadian rhythm. Sleeping-in any time is a No No. Some exercise after waking helps to consolidate those sleep rhythms.
- Have a regular (perhaps long) bedtime ritual to help you wind down. Keep the bed for sleep and sex, not for other activities.
- Go to bed when you feel tired - not when it's a certain time. Don't go to bed early because you had a bad night the night before - it confuses the body clock.
- No daytime naps. If you do need one, not after 3pm and no longer than about 30 minutes otherwise you'll affect your night's sleep.
- Avoid alcohol before sleep. It may help you get off to sleep but it causes a lighter and interrupted sleep later in the night.
- If you suspect your sleep problem is caused by depression or anxiety, you will need to get professional advice.

This advice from Grant Willson is only for those with poor sleep. If you have no sleep problems, you can do as you like but there are obviously behaviours that help promote good sleep.

Latest Developments in Lung Disease

Mark Hurwitz

Dr Mark Hurwitz, Director Respiratory and Sleep Medicine at The Canberra Hospital; and Clinical Associate Professor, ANU, talked about exciting developments that are occurring:

- new medications on the horizon
- recognition of the importance of looking after people, wholistically
- the importance of pulmonary rehabilitation, keeping active and living a healthy lifestyle.

COPD

Although smoking is closely connected with COPD, the biggest cause of COPD worldwide is exposure from burning biomass such as wood, animal dung, crop residues etc, especially in developing countries and especially for women through cooking and heating often in a one bedroom house. The smoke spreads throughout the house, exposing the whole family to its toxic effects. Having chimneys to take the smoke out of the house is a simple remedy.

Even with chimneys problems can occur. Woodsmoke from woodheaters affects air quality in the developed countries, some area more than others. Tuggeranong has a particular problem with pollution in winter from woodsmoke - which the ACT Government has been trying to reduce. Launceston in Tasmania had a similar problem. They found there was a significant increase in the number of people with COPD experiencing exacerbations resulting in hospitalisation. The polluted air aggravated the lung disease. The Government subsidised gas heaters and there has been a significant reduction of exacerbations.

COPD incorporates both chronic bronchitis and emphysema. In emphysema, the air sacs are destroyed and the lungs overinflate to compensate. They become too big for the chest, which changes shape. This in turn changes the way the chest works and the result is shortness of breath. Some years ago, this was treated through lung volume reduction surgery. This didn't cure the condition but improved breathing and therefore quality of life.

Now, valves have been developed which can be put directly into the lungs - through bronchoscope; not surgery. These valves don't allow air into the bottom of the lungs but lets air out, so the lungs don't over-inflate. This technique should begin in Canberra soon.

In America, there are 15 million cases of COPD. In Australia, the incidence is 7% of the population, about 1.2 million. COPD is mainly caused by:

- Smoking, either actively or passively
- Air pollution, including wood smoke
- Workplace dust and chemicals
- Domestic biomass exposure.

In the past, research had a single focus - ie the lungs - now we realise the interconnection of conditions. For example, research is finding out that anti-inflammatory medication for other conditions such as high blood pressure may inhibit the development of lung disease. The earlier the disease is diagnosed and managed, the better people do. Many people have COPD but are unaware of it. Doctors are being encouraged to perform lung function tests for patients over 35 who have a history of active or passive smoking; a family history of lung disease; or work in dust areas. Many young women unfortunately are still smoking - their smoking rates have not reduced as others have.

Managing COPD

Non-pharmacological

We are now finding that non-pharmacological treatments are equally important to pharmacological ones.

- When we mature, we lose muscle mass and we are not working our bones as well. This makes it more difficult to exercise but it's important to keep active as activity retains muscle health.
- Exercise is also important in maintaining bone health as this reduces osteoporosis and fractures. The active body releases anti-oxidants that assist in health in the lungs, and this improves quality of life. For this reason, Pulmonary Rehabilitation is a significant feature of managing lung conditions.
- A healthy diet is also important in enabling the body to best cope with the disease.
- For those who need it, home oxygen provides a non-pharmacological way of dealing with low oxygen levels, reducing heart stress and improving quality of life.
- It's important also that inhalers are being used correctly to enable the maximum amount of powder to enter the lungs.
- We are finding **multiple risk factors** that are affecting not only the lungs but also the rest of the body. For instance, certain occupations, biomass and smoke, to name a few, can cause brittle bones, cataracts and easy bruising as well as affecting the lungs. Reducing these risk factors will reduce the development of much disease.
- CT scans are proving to be a good diagnostic tool. X rays don't reveal much in the lungs. CT scans are much clearer. However, one CT scan is equivalent to 1000 x-rays so it's important to be cautious in using them. There is a low dose CT with less radiation and this may pick up early lesions.
- Researchers are exploring a genetic connection between smoking and lung disease to find out why airways disease progresses in some smokers but not in others.

Pharmacological

- There is concern with side effects of some of the current treatments with inhaled steroids - for example, people using flixotide have a high incidence of pneumonia - perhaps because it's a little bit more potent. Researchers are just beginning to look at this effect.
- Some new puffers will soon be released. The newer devices seem to be more effective with fewer side effects. These new products are not revolutionary but are improvements. Different drugs suit different people so this gives us more options. One has been approved by the TGA, but after that comes further negotiations between TGA and the company about pricing, marketing etc. Then it goes to the Government to be approved. After approval, it goes on the PBS.
- We are hopeful with Beta 2 agonists (LABA - long acting beta 2 agonists) and anti muscarine agents (LAMA) which combine antibacterial and anti-inflammatory agents as these last longer and are more effective with fewer side effects- although there is some concern that people may develop resistance to the antibiotic. The combination of LABA and LAMA in one puffer seems to work better than separately. No two breaths are the same and the separate puffers may go to different parts of the lungs. If combined, they can be deposited in the same place.
- Flu and pneumonia vaccinations are important preventers. The Australian vaccinations are based on the outbreaks in winter in Europe and America so are well focussed for Australia.

A few words on Asthma

Asthma can occur anywhere between birth and death and has large public health costs. In 2011, there were 374 deaths in Australia relating to asthma. It has many causes, including environmental. There are also many viruses that precipitate attacks and we may need to extend vaccination to cover these viruses. Research is also underway on biomarkers that identify asthma risk; and on preventing allergies.

Conclusion

There have been significant advances in the past few years in treating chronic lung diseases. New medications are becoming available and they all look good. But they relate to controlling lung disease. We still need research for curing the condition.

A little light relief.

Paddy shouts frantically into the phone "My wife is pregnant and her contractions are only two minutes apart!"
"Is this her first child?" asks the Doctor.
"No", shouts Paddy, "this is her husband!"

Paddy spies a letter lying on his doormat.
It says on the envelope "DO NOT BEND. "
Paddy spends the next 2 hours trying to figure out how to pick it up.

Living Positively with Chronic Lung Disease

Rebecca Neilson, Psychologist, Canberra Hospital, talked about recognising symptoms of anxiety and depression and managing these with a lung condition.

It's normal to have an emotional reaction to an illness - friends and family also have an emotional reaction and each person will have a unique reaction. With chronic lung conditions, there is a greater risk of depression or anxiety. It's connected with how much we can get out of life and with our moods and emotional well being. Our emotional well being impacts on our general well being.

Stress

We all experience stress at times. Stress is a response/ reaction to a situation we don't feel we have the resources to cope with. It can be chronic or acute and is more common with an illness. Signs of stress include:

- Poor sleep
- Trouble thinking clearly
- Relationship troubles
- Feeling anxious, irritable or depressed
- Physical changes in the body, including an increase in stress hormones and lowered immunity.

Anxiety

Anxiety is relatively common and has different forms. These include:

- **Cognitive** - we have an excessive amount of fear or worry.
- **Physical** - we have a fight or flight response where our heart and breathing rates rise; our muscles tense; we have nausea or an upset stomach; and we feel sweaty or cold with maybe clammy hands.
- **Behavioural** - we are restless or show avoidance behaviour.
- **Emotional** - we are constantly tense or irritable; we fear the feeling of fear or dread.

People with a lung condition are at increased risk of anxiety. If we are already short of breath, we are predisposed to having a panic attack - ie we are closer to the trigger point when fight or flight occurs. This exacerbates the shortness of breath and increases the anxiety.

Managing changes related to anxiety

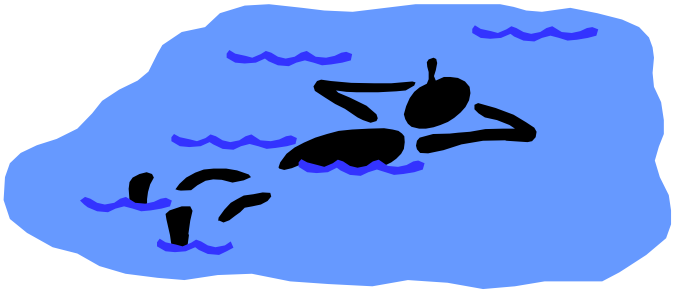
- **Physical** - develop body awareness - being aware of where the anxiety is in the body; use relaxation techniques to relax the body.
- **Thinking** - need to adapt to the situation; to recognise your condition and try to adapt.
- **Behaviour** - need to work out for yourself how to minimise conditions that bring on anxiety; develop a positive lifestyle; try gradual exposure. Cognitive Behaviour Therapy (CBT) is one form of therapy to help reduce anxiety.
- **Social** - develop a support network - this is most important in coping with illness, managing life and managing stress levels. It's good to share experiences and to ask for help when needed.

Depression

Everyone gets down or sad at times. This is not depression. Depression is when you are sad or down **all the time for at least two weeks.** Symptoms differ in different people: some eat less; some eat more; some sleep less; some sleep more.

There is an overlap between depression and COPD. Signs of depression include:

- Feeling **constant** sadness or emptiness
- Loss of pleasure or interest in activities
- Changes in sleep pattern and appetite
- Trouble thinking and concentrating clearly
- Feeling worthless and hopeless about the future
- thoughts of suicide.



Managing anxiety or depression

Use **active self-management**. This means you working to control the situation:

- Use your support network.
- Know your values and reassess what matters. Plan and set goals that fit with these values.
- Take care of yourself: eat healthily, pace your activities, and make time for relaxation and enjoyment
- Participate actively in available programs.
- Ask questions of your doctor. Understand the reasons for your medication.
- Recognise and deal with difficult emotions.
- Practise relaxed breathing - anxiety and depression cause us to breathe faster and shallower, exacerbating the sensation of breathlessness.
- Pace yourself. If you overdo it on good days and need to rest the next day/s, you lose condition and it becomes a cycle of behaviour. Match your level of activity to your ability. Take frequent short breaks; break difficult tasks into smaller bits or do them differently.
- Use helpful self-talk. Ask yourself if it's helpful to think in a negative way. If someone else thought this way, what would you say to them? The aim is to get the best out of your life. We can set:
  - **values** - what for you is worth doing to lead the best life possible.
  - **goals** - an outcome that can be crossed off the list once it's achieved eg exercise 3 times a week. Goals need to be something **you *can achieve*** in the short term and can keep track of; something you ***want to achieve*** in the short term; and have a stated time and duration.

People can create barriers to change:

- they may be uncertain about success
- feel they are too old
- have poor motivation
- maybe have passive involvement in their own care - putting the onus on others
- feel that is just the way they are
- or fear any changes.

It's important to counteract these barriers but if it's too difficult, professional help is available. Don't be hesitant to seek it.

- Your GP can create a mental health plan;
- You can have counselling and/or medication from a psychiatric review, psychologist, mental health nurse, or social worker.
- There are acute services including the local hospital;
- There are support services such as Lifeline 13 11 44; CATT 1800 629 354; or BeyondBlue 1300 22 4636.

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Please be aware that if you receive this Newsletter by post and you have an email address and would like to receive it instead by email you may send your request to Helen Cotter at lung.life1@hotmail.com.