

## June 2017 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 8 June 2017  
10:15 am - 12 noon  
Weston Creek Labor Club  
Teesdale Close  
Stirling ACT 2611

**Guest Speakers:** The speaker this month is Nicole Freene, Physiotherapist from the University of Canberra, who will talk about flutter valves and devices for clearing your lungs.

### Dates for your diary

Thursday 29 June 2017 Mid - Year Get Together Luncheon  
Thursday 13 July 2017 10:15 am - 12 noon CLLSG Meeting

### May Meeting

Helen Cotter

This meeting was a discussion meeting. We talked about the things we needed to talk about; then participants talked about and showed us their hobbies or interests.

- Lyn passed around a permission form for us to sign if we were happy for our photo to be taken and used for publicity purposes, for example in our newsletter or on Lung Foundation Australia's web site. If you haven't already signed this form please do so ASAP.
- Education Day was enjoyed by participants. There was a criticism about not being able to see the bottom of the overhead board unless you were in the front row. This also happened last year and feedback was provided - but nothing had been done.
- We planned a Mid-Year Get-Together Lunch for Thursday 29 June 2017 for noon at the Labour Club at Stirling. Instead of a set menu, this year we have decided to let the individuals order their own lunch.

- We also offered suggestions for speakers we would like to have at the meeting.

Then it was on to hobbies and interests. A number of us had interests in crosswords, reading, gardening and family; some of us in computer games and TV shows; some in crafts such as weaving, knitting, crocheting; some spent their time in looking after their husbands. Ebba talked about her knitting experiences, John talked about his collection of badges, Peta talked about her interest in, and connection with, the history of a very early car and its connection to Canberra.

The ukulele group once again entertained the meeting, playing a variety of well-known songs from the past - Achy Breaky Heart, Paper Roses, Let Me Be There, A World of Our Own and Walking the Floor Over You.

Due to the reports on Lung Foundation Australia's Education Day 2017 the Newsletter is longer than usual. Consequently some reports will be held over until next month.

Chris Moyle, our usual writer of reports did not attend the Education Day as she was not feeling her usual self, so Helen Cotter stepped into the breach. The Group is very fortunate to have two such people who always back each other and give us the benefit of their excellent note taking and report writing. On behalf of everyone, *thank you both* for all your efforts on our behalf.

## Lung Foundation Australia's Education Day 2017

Helen Cotter

We were thrilled that over 100 people enrolled for Lung Foundation Australia's (LFA's) Canberra Education Day held on Wednesday 3 May 2017 at the Southern Cross Club, Woden. It did create pressure on the room but, as some people didn't make it, the only difference was a change of lunch rooms.



The Canberra Lung Life Support Group was very well represented. We all know how important it is to broaden our knowledge and understanding of ways we can better live with our chronic conditions while improving our quality of life. The ALF's Education Days gives us the opportunity to do this and also to keep up with new therapies and thoughts in the management of COPD and quality of life perspectives.

Ashleigh from LFA introduced the session, talking about the work of LFA and reminding us that one in seven deaths in Australia came from lung disease and that lung cancer was the biggest cancer killer. Then on to the first session.

## Living Well with Lung Disease and the importance of being Proactive in Your Care

Claire Mulvihill, Lung Cancer Nurse at Lung Foundation Australia

### Importance of good communication with your doctor

Part of being proactive is having good communication. Communication includes body language, tone of voice and written communication. Underpinning this is the need to have knowledge about the topic, to have a positive mind set and to have a good follow up management plan. It's important to build on what you know.



As a Lung Cancer Nurse for LFA, Claire is on a help line and finds that many complaints patients have are due to a breakdown in patient/ doctor relationships. Breakdown can occur because you're having a bad day or you have your own pre-conceived ideas which come from your past social and behavioural experiences and anxieties; or the doctor talks to you in medical language/jargon without explaining. Doctors are busy and sometimes we feel we should not hold them up. To develop good communication, you need to allow time for the doctor/patient relationship to develop.

Claire then gave us a scenario of a patient visiting a doctor about a cough. The patient has some tests; then comes back to the doctor to hear the results. The doctor gives the patient the results in technical language, using big words to explain the symptoms and also gives a lot of information non-stop. The patient goes away, not fully understanding, thinking the worst and feeling very upset. That was the bad doctor.

The good doctor will have a good 'bedside manner'. The

good doctor will:

- ✓ explain terms
- ✓ allow an exchange of conversation
- ✓ show the patient the information - charts, graphs, diagrams etc
- ✓ use everyday language and explain terminology
- ✓ give a positive explanation of the condition
- ✓ give a clear explanation of what the treatments are and what they will involve
- ✓ set in place the treatments - eg give contacts for follow -up
- ✓ ask questions for feedback on what the patient understands
- ✓ write down information for the patient to take away.

As a patient, you need to be proactive. Take control of the situation. Make sure the doctor does all of the above.

### Proactive tools to use:

- ✓ Ask questions - big or small - every question is important.
- ✓ Let your doctor know if you are feeling apprehensive or depressed or worried - so they can help alleviate these feelings.
- ✓ Write down your questions - and write down the doctor's answers.

- ✓ Find out as much as you can about the condition - LFA has many resources available - information sheets; check lists; booklets such as *Better Living with COPD*. A LFA patient advisory group for people with lung cancer is about to start - keep your eye on LFA's website [www.lungfoundation.com.au](http://www.lungfoundation.com.au) or phone 1800 654 301.

### Be proactive in palliative care

Claire told us that palliative care is not only end of life care. It is another way of assisting those needing extra care. Palliative care looks at the patient as a whole. This extends to family and carers in order to address the patient's needs and challenges. It includes looking at the situation in your home as well as looking at nutrition and exercise. The care can come and go as you need it, providing psycho/social support as well as the physical.

Claire told us proactive means becoming involved in the decision making relating to the process in managing your symptoms. This has been shown to help people live a better quality life.

The patient continues their active treatments as palliative care complements the existing treatments.

A study in 2010 showed that early palliative care lessens depression and improves quality of life with patients living longer. To achieve the best results the patient needs to be in control of their situation - ie use the proactive tools outlined before.

### Summary

It's important to be proactive in your care and use the tools outlined before to provide good communication of the issues and ensure a good quality of life. Empower yourself with knowledge. Ask questions. Write down the answers.

Claire explained that the term 'palliative care' is too closely connected with support for the dying. It is going to be changed soon to 'supportive care'.

### Question: What do you need to do to get palliative care?

**Answer:** Contact The Palliative Care Service at The Canberra Hospital and ask what the referral pathway is or ask your doctor.

### Question: Doctors often don't have the time or are not willing to spend the time.

**Answer:** The patient needs to take control and not leave until all questions have been answered. This is a good reason for going in with questions already prepared. If you think your questions will take some time, you can book a double appointment.

**Comment from the floor:** It's good to ask the doctor to provide a sketch and write the information down as some people are better at taking information in through seeing it rather than hearing it.

### Question: Test results often conveyed in medical terms, where can we find the information to understand these terms?

**Answer:** It's good if you can ask the doctor to explain them. LFA also has information sheets and booklets that explain such terms eg *Better Living Guide with COPD*.

Claire was asked a question about the bronchiectasis register. She said that you can still register. She explained that LFA was organising a doctor in each state/territory to be responsible. As soon as that occurred, appropriate names would be transferred to their list.

As yet, ACT does not have a registry.

Source: [www.lungfoundation.com.au](http://www.lungfoundation.com.au).

## The A-Z of Preventative Medicine

Chris Moyle

**Shortness of breath** means your body is not getting the oxygen it needs. There are many things you can do to manage this problem. When you feel short of breath, *don't stop what you are doing or hurry up to*

*finish, but slow down.* If shortness of breath continues, then stop for a few minutes. If you are still short of breath, take your medication, if it has been prescribed by your doctor. Often, shortness of breath is frightening and this fear can cause two additional problems. First, the hormones that fear itself can release may cause more shortness of breath. Second, fear may cause you to stop your activity and thus never build up the endurance necessary to help your breathing. The basic rule is to take things slowly and in steps. Increase your activity level gradually:

- don't smoke
- use medications and oxygen as prescribed by your doctor
- drink plenty of fluids to help thin mucous and make it easier to cough up, and
- practise pursed-lip and diaphragmatic breathing.

### **Smoking and COPD**

Stopping smoking is the single most important thing you can do to help your chronic lung disease. It will improve your lung health and help slow down worsening of COPD. Do everything you can to give up smoking for good. Your health depends on it. Ask for help from your doctor, pharmacist or nurse. Nicotine replacement therapy and prescription anti-smoking medications may help you quit. If you fail to quit the first time, try, try and try again. It may take several attempts before you can give it up completely.

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

## **The Importance of good nutrition and weight management for Lung Health**

Wendy Valzano, Student Dietitian, University of Canberra, assisted by Julie Priestley, University of Canberra

### **Outline**

There are a variety of lung conditions and nutritional management for each one can be different, so Wendy looked at the main concerns:

- the importance of maintaining a healthy weight, including managing weight loss, avoiding malnutrition and shortness of breath and fatigue
- how to lose weight
- other issues such as calcium and vitamin D deficiency, fatty acids, and vitamin E.

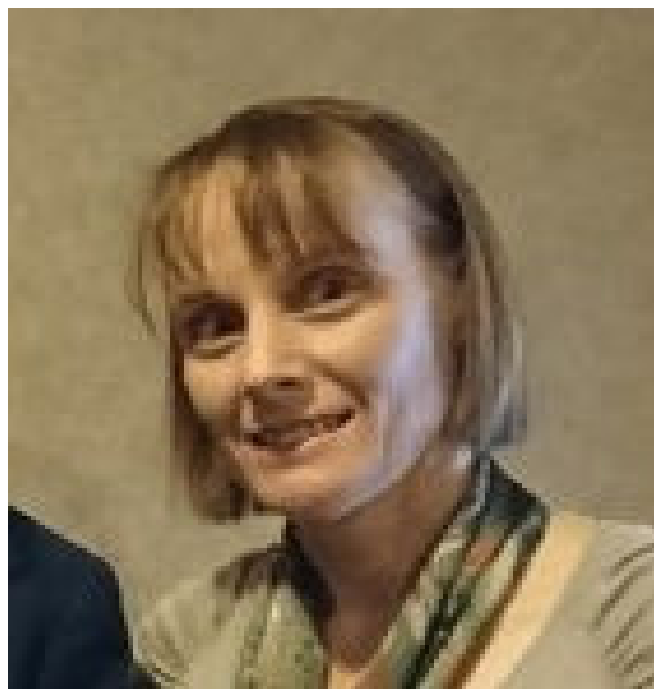
### **Energy requirements**

With a chronic lung condition energy requirements may be increased by:

- the increased work in breathing increases the need for energy
- medical interventions
- inflammation and infections.

If these needs are not met we may lose weight.

It's important to avoid malnutrition. This is common in people with lung disease and malnutrition can also happen in overweight and obese people. Losing weight is not necessarily a good thing. We may lose not only fat, but also muscle and that means we are losing the capacity to be strong and fight infection. If we lose muscle it's more difficult to renew it as we grow older.



Wendy is studying at the University of Canberra to be a Dietitian. The [Faculty of Health](#) offers a range of health clinics at a low cost to the Canberra community and surrounding districts. Staffed by students and their highly qualified supervisors, the clinics offer health services to the public while providing invaluable practical hands on experience to students.

Sometimes, there is a loss of desire to eat:

- medication may reduce the desire
- we may have difficulty in preparing food
- in the morning we may not feel the best or may even feel full
- mouth breathing may affect taste
- medication may reduce appetite or create nausea, diarrhoea etc.

This may lead to malnutrition which affects the ability to exercise and may increase the risk of infection. Low protein and low iron affect the ability to carry oxygen through the body. Other vitamins and minerals may be reduced.

### **How can we prevent weight loss?**

- Have small and frequent meals and eat as much as we can
- Choose foods high in protein and high in energy (calories) such as dairy (full fat), meat, eggs, and nuts. Try to increase the calories
- Add milk powder to soups and stews to increase the calories
- Add cheese on to foods
- Have milk shakes, smoothies, milos etc
- Supplements may help.

**Energy** is the same as **calories** or **kilojoules**. Foods high in calories or kilojoules are high in energy.

### **Managing shortness of breath when preparing food or eating it:**

- Prepare small amounts of food or fluid
- Have a rest before meals
- Have a break in the middle of the meal
- Choose foods that are easier to swallow
- Sit up when eating
- Work out what suits you.

#### **Serves**

A serve of meat = a palm size piece of meat  
A serve of fruit = a cup of diced fruit  
A serve of cooked vegies = half a cup of vegies  
A serve of salad = one cup of salad vegies

### **Managing fatigue:**

- Rest before preparing or eating food
- Work out the time of day when your appetite is highest
- Eat high energy and high protein food first
- Prepare extra portions and freeze leftovers
- Use easy to prepare meals, perhaps use Meals on Wheels or prepared meals from the supermarket.

### **If we are overweight:**

Being overweight increases the load on our heart and lungs and crowds the diaphragm, especially adding excess fat around those areas. Physical activities may decrease and this adds to weight gain.

Steroid medicines also contribute. Steroids as well increase blood glucose and cholesterol levels and increase the risk of diabetes and sleep apnoea (weight loss as little as 5% can have a significant effect on sleep apnoea). However, it's not always advisable to lose weight. Evidence is showing that a little bit of weight can be protective as it increases the good muscle which helps the body to work. And fat may be protective of disease.

### **If we want to lose weight:**

- Focus on maintaining healthy eating habits and choose from the five food groups.
- Try to have protein at each meal such as baked beans for breakfast.
- Look at why we are eating. Is it boredom? Sadness? We need to address this, maybe discuss it with the dietitian.

- Increase physical exercise as it builds up muscle.
- Rather than cutting down on eating make swops. Swop those high in calories/kilojoules such as a hamburger, coke and chips for a meal lower in energy.
- Increase the amount of vegies eaten.
- Use low fat cuts of meat.

### Some other issues:

Steroid use may cause a deficiency in calcium and vitamin D. Vitamin D helps calcium to be incorporated into the bones. This gives strength to the bones. A lack may be connected with osteoporosis. Smoking and lack of exercise may also be risk factors.

Fewer than half of the adult population are getting enough calcium in their diet. Dairy products are the best source of calcium.

- Women need up to 4 serves of dairy a day
- Men need 2½ serves a day up to 70 years of age
- Over 70, men need 3½ serves.

**1 dairy serve equals** = 1 cup of milk or  
 = 2 slices of cheese or  
 = ¾ cup of yoghurt.

If we are using high levels of steroids we may need additional calcium. This needs to be discussed with our doctor if we can't get it from our nutrition. The doctor can prescribe some calcium tablets.

Fish oil may be helpful in COPD rehabilitation but it's better to try to eat fatty fish twice a week to get sufficient omega 3.

Vitamin E supplements may reduce the risk of developing lung disease but the evidence is not conclusive yet.

### Summary:

Being underweight is an issue for many people with chronic lung conditions. You need to work out the best techniques that suit you to assist with your eating. Being overweight is not an issue as long as you are fit and healthy. However, it can lead to conditions like diabetes and heart problems. If you want to lose weight, use the techniques that Wendy outlined in her talk. What is important for everyone is to make sure they are not malnourished but are eating nutritional foods.

**Question:** What are the merits of losing or maintaining weight?

**Answer:** It's important not to lose weight rapidly as it's important not to lose muscle. The focus now is on keeping muscle through exercise and eating plenty of protein. And on maintaining health rather than being in a certain 'good' weight range. With sleep apnoea, it may be good to lose weight. The important aspect is **eating healthily**.

**Question:** Any comments on vegetable oils?

**Answer:** Vegetable oils are healthy but the healthiest seems to be olive oil. There's a current flurry about coconut oil being very healthy but it is high in saturated fat and the evidence is out whether it's beneficial or not.

**Question:** Are there any foods with vitamin D and any comments on vitamin D and sunlight?

**Answer:** There is almost none in food - although a very little in butter. The best is supplements or sunlight. The amount of sunlight is difficult to judge as it is specific to the season and to where you live.

**Comment from the floor:** There is a problem with **quality** in supplements. By the time you buy them, they're often degraded with age. It's better to get nutrition from food rather than supplements.

**Question:** Are there any problems with intolerance and lung conditions?

**Answer:** This is not more common in people with lung conditions than in the general population. But it does increase the difficulty of managing the lung condition.

Wendy gave us many helpful handouts and suggested that if we wanted further dietary advice to contact a Dietitian at The University of Canberra's Health Clinic (there is a small charge) or the Dietitian at the ACT Department of Health. Or you can use one from a private practice.

Dietitians: UC Dietitian Julie Priestly at UC: 02 6201 5843.  
ACT Health Dietitian: 02 6207 9977.

## Exacerbations and Your Lung Disease

Mark Hurwitz, Director Respiratory and Sleep Medicine Physician, The Canberra Hospital and Clinical Associate Professor, The Australian National University Medical School

### What are exacerbations?

Exacerbations are a worsening of a patient's respiratory condition beyond the normal patient variations. It is evidenced by increases in:

- cough
- sputum volume
- sticky mucus
- shortness of breath/ dyspnoea

Each one damages the lungs. Exacerbations can lead to a change in management of medications but also to encouraging pulmonary rehabilitation. The more active we are, the better our bones are. The better our bones are, the better our lungs are also.

### Who is prone to exacerbations?

As we age, we are more likely to have them. The more productive the cough is, the more likely an exacerbation. If we have had antibiotics which kill the good bugs as well as the bad we are susceptible to other infections. If we've been in hospital in the last twelve (12) months, we are more likely to be re-admitted. If we have chronic sputum production, we are susceptible. It is important to clear the secretions in the lungs.

A recent finding has shown that eosinophils, usually connected with inflammation in asthma, have now been connected with COPD. There is an overlap between asthma and COPD and this can affect how inflammation is treated in people with COPD.

Doctors used to isolate each organ in the body and different doctors treated different organs but we've now realised that there is a significant relationship between all of them so that one organ may affect another. This often results in co-morbidity such as heart and lung disease or diabetes. To manage someone properly, we need to look at all their conditions.

### What might make us more likely to have an exacerbation?

- Severity of the COPD.
- Previous history of exacerbations.
- Any hospitalisation.
- Number of times in hospital in the past year. More than two (2) and the risk changes significantly.
- If the disease is mild or moderate, there is low risk of exacerbations; if severe, then high risk.
- Gastro-oesophageal reflux (heartburn) can cause intense coughing which can bring about an exacerbation which can also result in increased reflux. Reflux can sometimes be assisted with a



Dr Hurwitz, is the bringer of good news. The good news being there are new therapies and new thoughts in the management of COPD and quality of life perspective.



treatment for lungs.

- Pulmonary hypertension increases the blood pressure in the lungs. COPD can raise the pressure in the blood vessels and this affects the heart.

### **What sets off an exacerbation?**

- Viral/bacterial infections cause 70% of exacerbations. We are better at diagnosis but not in treatment although we can manage most of the infections a person with COPD can get.
- Pollution makes asthma and COPD worse. It may also increase the lung cancer in people exposed to pollution. India and China are now paying more attention to pollution. It will be interesting to see the effect in those countries.
- Pulmonary embolism - a clot on the lung - may cause a flare up. Scans today make it easier to diagnose.
- Idiopathic - which means that they do not know what causes the exacerbation.

### **Diagnosis of exacerbation**

This is compared with the normal rate (of breathing) and is based on:

- shortness of breath/dyspnoea
- stickier sputum - if we are coughing up coloured mucus, it may be an infection; if it has blood, then maybe it's a blood clot
- how long it's been going on
- oxygen reduction.

If it continues, it could lead to respiratory failure.

### **Treatment of an exacerbation**

Medications today have improved significantly. In the past, with bronchodilators, we had separate treatments for short term and long term effects. Now we have long acting agents in both groups. This has led to significant improvements and may be as beneficial as using cortisone. Some older drugs are less effective but some are now being brought back but used differently. For example, Nuelin, which caused many side effects in the past, now, with a low dose, reduces inflammation and increases sensitivity of the lungs to other inhalers. Antibiotics are useful for infection and some also have anti-inflammatory properties so we can target the infection better.

Steroids are often used in treatment. The evidence now shows that steroids should be used for five (5) days then stopped. Continuing them for longer brings no added advantages. Oral steroids in inhaled puffers are now being looked at cautiously. There is a question whether people with damaged lungs should have steroids. We need to balance the positive effects versus the risks. Now, we are not so sure if the positives outweigh the risks. Inhaled steroids increase the likelihood of pneumonia, cataracts, fragile bones and bruising.

Beta blockers for hypertension and coronary heart disease block the efficacy of bronchodilators but in COPD, if people have underlying heart disease they may well do better with beta blockers. There are currently studies underway to see if all should be on them.

In a significant exacerbation, the considerations are:

- hospital or home
- if they've been at home and not responded, then hospital
- if increasing severity (more than 2 episodes), then hospital
- how good or frail is the person
- if the person is home alone, then hospital may be better.

It depends on judgement of the patient's best interests - what's best for them.

## Oxygen:

We need to be certain it's a benefit in both the short and long term. We know that high levels of oxygen can generate free radicals and this can cause problems. Free radicals fight infection but can also fight the body.

## Supportive care:

More and more we are looking at improving a patient's condition without using drugs. We are trying to lessen the use of drugs although we still need to use them. We use spirometry to get the base results but need to pay as much attention to what people say as to the spirometry results.

- Stopping smoking. Today young women are the biggest group of smokers in Australia.
- Reducing likelihood of blood clots.
- Good mucolytics - help break down mucus. Very good for cystic fibrosis but not so good for other lung disease.
- Devices to clear secretions from the lungs such as Bubble PEP. This involves blowing through water with a tube. This provides pressure as you blow which helps clear the lungs. The bubbles also set up low frequency vibrations that break down mucus. The flutter does the same job.
- Activity is very important and beneficial for people with any type of lung disease. Working the bones generates anti-oxidants which protect the lungs. Exercise also helps the muscle tone - even moving from sitting to standing helps. If you're watching TV, standing up during ads or between programs helps muscle tone - better if you can do it without holding on to anything. There's no need to do gym or hard running - any movement helps.
- Vaccination for flu and pneumonia (every 5 years) helps.
- Having a management plan is important as it can help us keep an eye on the situation and start to manage it before it gets serious.
- Reducing fatigue which often exacerbates a condition so it needs to be better managed both for quality of life as well as for morbidity.

ACT Health is currently undertaking a study looking at the benefits of using portable oxygen concentrators (POCs) instead of gas cylinders.

POCs enable easier use of oxygen giving a better quality of life

## Looking at co-morbidities in treatment:

Many people with COPD also have co-morbidities like cardiovascular disease, osteoporosis, gastro oesophageal reflux and/or sleep apnoea. Anxiety and depression are also significant component of chronic disease. We need to take these into account when dealing with COPD.

## End of the road:

There is a time when we come to the end of the road and don't treat the condition aggressively but select what suits more the needs of the individual. We are improving in the treatment of COPD. It's quality of life that counts.

**Question:** Are steroids useful for inflammation in the nose?

**Answer:** No. There are no anti-inflammatory measures for the nose at the moment.

**Question:** Steroids and pneumonia?

**Answer:** Steroids through inhalers increase the incidence of pneumonia. Steroids have been overused in the past. We are now looking at using other puffers to avoid steroids.

**Question:** What is the 'normal' range of oxygen?

**Answer:** Saturations need to be somewhere between 88 and 92% in Canberra. If you are getting good saturations, it's not good to supplement it with oxygen as too much oxygen can cause problems.