



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

**Guest Speaker:** Joelle Parker  
Senior Cardiorespiratory Physiotherapist  
Pulmonary Rehabilitation

### Dates for your diary

Thursday 12 May 2016  
Wednesday 20 April 2016

Canberra Lung Life Support Group Meeting  
Education Day, Southern Cross Club, Woden

### March Meeting

Chris Moyle

As there were few attendees several matters were deferred to next month's meeting. However, it was decided that the guest speaker for our May meeting will be ACT politician Dr Chris Bourke. Dr Bourke is Minister for Aboriginal and Torres Strait Islander Affairs; Minister for Children and Young People; Minister for Disability; Minister for Small Business and the Arts; Member for Ginninderra. Members who have topics they would like discussed are asked to forward their ideas to Carolyn at [lung.life1@hotmail.com](mailto:lung.life1@hotmail.com) and she will send them to Dr Bourke. In the future we will let everyone know in advance who our speakers will be so members are able to have input into the presentation of the guest speakers.

## Guest Speaker

### Anne Knobel

Anne Knobel, a nurse with ACT Health, gave an informative talk on respecting patient choices and advance care planning. This program originated at Austin Hospital in Melbourne and assists people to express their choices for health care at the end of their lives. If choices are made known then they can be respected and upheld, resulting in a better quality of life. This is especially important if at some future time you can no longer speak for yourself. We do tend to put end of life matters in the closet, and we do it very well. Less than 10% of people die with a plan in place.

**Why plan?** We are very fearful of losing control at end of life, and having a plan in place can allay some of that fear for ourselves and those close to us. It helps to plan for situations where:

- you may become unexpectedly incapable of making your own decisions
- it is clear you will have little or no recovery, and
- the injury or loss of function is significant.

**An Enduring Power of Attorney** (a person you nominate to make decisions for you) is essential for everyone aged 18 years and over. This can be organised with a Statutory Declaration (a legal document) and only comes into effect if you cannot speak for yourself. It means planning for the unknown and helps remove stress from family members.

**A Statement of Choices** is a non-legal guidance document which allows you to state your choices for end of life medical treatments.

**A Health Direction** is an optional witnessed legal document that gives competent adults the legal right to refuse or withhold medical treatment.

### Where do I register these documents?

It is important that you send your Advance Care Plan documents to the ACT Health Respecting Patient Choices (RPC) ACP Program, PO Box 11, WODEN ACT 2606. They will be scanned and placed on your electronic medical record at The Canberra Hospital and the Calvary Hospital.

### Who can help me complete them?

Trained RPC ACP facilitators can assist you with completing the documents or introducing the subject with your family. Please contact the Program if you would like to speak with a trained facilitator.



### Need further information?

If you need assistance or would like more information please contact the **Respecting Patient Choices Program**, HealthCARE Improvement Unit, 02 6244 3344 or email [rpc@act.gov.au](mailto:rpc@act.gov.au).

### A little reminder - injections to discuss with your GP

**Flu injection    Pneumonia    Whooping Cough    Herpes-zoster (Shingles)**

## Points to ponder.....towards a beautiful death.

- to keep my sense of humour
- to say goodbye to important people in my life
- to have my family with me and prepared for my death
- to be able to talk about what death means
- to be able to talk about what scares me
- to be able to help others
- to trust my doctor
- not being short of breath
- to have my financial affairs in order
- to be free from anxiety
- to take care of unfinished business with family and friends
- to remember personal accomplishments
- to feel that my life is complete
- to be free from pain
- to maintain my dignity
- to be mentally aware
- not being connected to machines
- to have someone who will listen to me
- to die at home
- to be kept clean.

## Herpes-zoster (Shingles)

Chris Moyle

Shingles is a viral infection caused by reactivation of the varicella-zoster (chicken pox) virus, which is a member of the herpes group of viruses. It is usually a mild disease characterised by a painful skin rash with blisters involving a limited area.

However, it can be severe in older adults and immunocompromised persons and may cause serious or even fatal complications.

### Causes

Shingles is contagious and can spread through direct contact with the people who are infected. People who have not yet had chicken pox or are immunocompromised are more likely to contract the disease from an infected person.

### Prevention

Shingles is a vaccine preventable disease and vaccination is recommended for adults 65 years and over. Immunisation against shingles is achieved via a one-off, single dose of the Zostavax vaccine which can be given to adults of all ages and whose protection is known to last approximately 10 years.



As of 1 November 2016 the shingles vaccine will be provided free for people aged 70 under the National Immunisation Program Schedule. There will also be a five year catch-up program for people aged 71-79 years. It is important to note that although the vaccine is provided at no cost, a doctor's consultation fee may apply.

Source: [www.immunise.health.gov.au](http://www.immunise.health.gov.au)

## The A-Z of Preventative Health Care

### Chris Moyle

**Ovarian Cancer** (Dr Oz) A genetic disposition can cause ovarian cancer. It is a silent killer - difficult to diagnose. If you have the following symptoms for more than two weeks, see your GP:

- belly and pelvic pain;
- feeling full quickly after eating;
- bloating.
- urinary frequency,
- change in bowel habits and
- extreme fatigue.

A CA 125 blood test can detect ovarian cancer cells. Turmeric in the laboratory kills ovarian cancer cells.

**Oxygen** is prescribed for people with chronic lung disease who have a low blood oxygen level. It is up to your specialist to decide if you need oxygen. You will not be prescribed oxygen if you are still smoking. The ACT Domiciliary Scheme covers the cost of oxygen at home for people living in the ACT who meet the eligibility criteria.  
(ACT Health)

## Past Education Days

### Helen Cotter

Education Day is here again - this year, on Wednesday 20 April 2016. Who do you remember from previous days? Kate Pumpa who exhausted us by energetically talking about the importance and benefit of exercise? Mark Hurwitz who couldn't come one year but made up for it the next in his talk about the latest knowledge and treatment in chronic lung conditions? Samantha Kouris, the Pharmacist, who donned a green t shirt and told us about medicine and what the instructions mean. Grant Willson who kept us awake while telling us how to get a good night's sleep? Or the speakers who did send us to sleep?



We've had 5 Education Days since the inaugural one in 2011 all held in the Southern Cross Club, Woden. This year is going to be the sixth Lung Foundation Education Day in the ACT. Each day has three speakers, two before lunch and one after. Participants get a lovely lunch of sandwiches, fruit, pastries and cakes, provided by the Lung Foundation and the Southern Cross Club to keep us going. We've had many memorable speakers on many memorable topics.

We've had talks by doctors, specialist nurses, physiotherapists, psychologists, university lecturers, a pharmacist and an occupational therapist as well as various other health specialists. We've had talks on:

- asthma
- obstructive sleep apnoea
- lung cancer
- bronchiectasis
- chronic cough
- living with a lung condition
- flying with oxygen
- the benefit of exercising
- using home oxygen
- medications
- breathlessness
- understanding your personal plumbing
- conserving energy
- how to get a better night's sleep
- living positively with a lung disease
- understanding medicines and their instructions from a chemist's perspective
- latest developments in lung disease and
- a talk on the *ACT* chronic strategy.



The topics for 2016 are:

- Fitness to fly
- Am I too sick to exercise
- Sleep apnoea.

## **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.

- That sleep inducing hot chocolate? Scientifically, there's no evidence for it. However, if it helps you feel relaxed and drowsy, there's no harm in it.
- As for counting sheep, it works as a distraction. It gives you something else to focus on rather than the activities of your life.
- 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 on.
- 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.

## **Wheelie Bin Assistance**

**Helen Reynolds**

### **What is it?**

On garbage collection day the garbage collector will retrieve the bin from the designated area, empty it and return the bin to the designated area. This is a free service for eligible people.

### **Who is eligible?**

ACT residents who live in a property where no one is physically able to take their bin(s) to the kerbside for collection due to chronic illness, frail aged or disability can apply for assistance. If an able-bodied person lives at the premises you will not be eligible for this service.

ACT NOWaste may require medical or other information to support your application, and reserves the right to confirm compliance with these conditions, or withdraw or refuse assistance.

### **How do I apply?**

You can apply for this service by phoning Canberra Connect on 13 22 81, or by applying online at <http://www.tams.act.act.gov.au/live/Recycling and Waste>.

**Source:** ACT NoWaste  
Phone: 132281  
<http://www.tams.act.act.gov.au/live/Recycling and Waste>

## **Popcorn Lung**

**From Canberra Times 12 Dec 2015**

Popcorn lung is a disease first recognised in factories that made microwave popcorn. The chemical, *diacetyl*, is used as a butter substitute in flavours. It's been linked to *bronchiolitis obliterans*, a disease with inflammation and scarring of the bronchioles, reducing air flow. There is no cure.

It was believed that *diacetyl* was safe to eat. It's used in butter flavoured popcorn and as well is used in many fruit and alcohol flavours. Now researchers are finding that *inhaling* the vapours of flavouring chemicals is dangerous over a long period.

Researchers are concerned about flavoured e-cigarettes and have found that many of them contain diacetyl, acetoin and 2,3-pentanedione - all flavouring compounds that may pose a health hazard. E-cigarettes also contain some other cancer causing chemicals such as formaldehyde.

The children were lined up in the cafeteria of a Catholic elementary school for lunch. At the head of the table was a large pile of apples. The nun made a note and posted it on the apple tray: ' Take only ONE. God is watching you.'

Moving further along the lunch line, at the other end of the table, was a large pile of chocolate chip cookies. A child had written a note, 'Take all you want. God is watching the apples...'

If you know of any other support that is available to people with chronic lung conditions please forward details to [helenrey@creationcorporation.com.au](mailto:helenrey@creationcorporation.com.au) for inclusion in future newsletters.

### Available support for those with chronic lung conditions

- **Life Support Electricity Rebate for oxygen and CPAP users** provided by electricity providers such as ACTEW, Origin and TRUenergy need a letter from your doctor. For more details, check their websites or phone ACTEW 13 14 93; Origin 13 23 56; TRUenergy 13 34 66.
- **Essential Medical Equipment Rebate** for concession card holders using oxygen or CPAP see [www.humanservices.gov.au](http://www.humanservices.gov.au) or contact Centrelink.
- **Companion card** for those who need a companion with them in order to access theatre, sports and other events. You get two seats for the price of one. See [www.companioncard.gov.au](http://www.companioncard.gov.au).
- **Australian Disability Parking Permit** must be assessed by a doctor. See [www.rego.act.gov.au](http://www.rego.act.gov.au).
- **Pulmonary Rehabilitation** an exercise and life improvement course at Canberra Hospital. Need a referral from a specialist. For more details phone: 02 6244 2154.
- **Lungs in Action** an exercise program for people who have completed Pulmonary Rehabilitation. Needs a referral from a doctor. For more details phone: 02 6201 5843 or go to [www.canberra.edu.au](http://www.canberra.edu.au).
- **Air Liquide** offers a 10% discount to Lung Life members. See <http://www.airliquide.com.au/>. Their EMERGENCY NUMBER for Healthcare/Medical Oxygen is 1300 360 202.
- **NSW National Parks** offer a free annual park entry to concession card holders (not for Tidbinbilla which is an ACT park). See [www.nationalparks.nsw.gov.au](http://www.nationalparks.nsw.gov.au).
- **Wheelie Bin Assistance** phone Canberra Connect on 13 22 81, or applying online at <http://forms.act.gov.au/smartform/public/FormServer?formId=2025>



# Better Living With Your Lung Disease

## Patient Seminar

Canberra 2016



You are Invited

### Seminar Program

- 9.45am Registration — tea and coffee available
- 10.15am Welcome from Lung Foundation Australia
- 10:30am **Fitness to Fly**  
Derek Figurski, Respiratory Scientist and Laboratory Manager of the Department of Respiratory and Sleep Medicine at the Canberra Hospital, will provide an insight into what people with lung disease should consider before flying.
- 11:15am **Am I Too Sick to Exercise?**  
Bethany Crane, Accredited Exercise Physiologist and Clinical Educator at the Student Led Clinics, University of Canberra, will highlight how physical activity and behaviour change can assist in the management of your lung disease, and discuss physiology of the lungs and how they react to physical activity.
- 12.00pm **Lunch**
- 1:00pm **Sleep Apnoea**  
Dr Saidul Ansary, VMO Respiratory and Sleep Physician at ACT Health Care, will explain the diagnosis and treatment options for sleep apnoea.
- 2:00pm **Thank you and close**

### When and Where:

- Date:** Wednesday 20<sup>th</sup> April 2016  
**Time:** 9.45am – 2.00pm  
**Venue:** The Orion Room  
Canberra Southern Cross Club  
92 – 96 Corinne St, Woden  
**Cost:** \$15 payable on the day  
**Parking:** Free undercover parking

To secure your place,  
please call

**1800 654 301**

before Wednesday 13<sup>th</sup> April

Please let us know any dietary  
requirements at time of booking.

The room is air conditioned and may be  
cool.

This seminar is proudly supported by



**LUNG FOUNDATION**  
AUSTRALIA

*"When you can't breathe...nothing else matters"*

[enquiries@lungfoundation.com.au](mailto:enquiries@lungfoundation.com.au)

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