

August 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 11 August 2016
10:15 am - 12 noon
Weston Creek Labor Club
Teesdale Close
Stirling ACT 2611

Guest Speaker: Mary Perkins and/or Juleen Schiefelbein
Relationships Australia
Including a Q&A on topics like "Maintaining Partnerships and Intimate Relationships", "Dealing with reduced physical capabilities", and "How to get family and friends to understand your circumstances".

Lung Life Support Group Members are invited to bring their family and/or friends to this meeting (as is always the case anyway).

Dates for your diary

Thursday 8 September 2016 Canberra Lung Life Support Group Meeting

July Meeting Helen Cotter

Numbers were down for this meeting. We were in the middle of a cold snap with snow in Canberra the day before and the weather playing havoc with our health. Even so, sixteen members braved the elements. As we had no speaker, we were able to spend the time discussing Lung Life issues.

New coordinator

Our coordinator, Carolyn, feels unable to continue as coordinator as her health has not been A1 for most of this year. We are sorry about this and wish her well. But we are now looking for a new coordinator.

The Lung Life group is both a support group and an advocacy group. The coordinator position involves overseeing the activities of the group, keeping an eye on membership, and advocating for the group and for those with chronic lung conditions outside the group. Like all positions, it involves learning on the job - the coordinator is not expected to know everything at the beginning.

Roles of members

Much of the meeting was spent looking at the roles members of the group already undertake to assist our group:

- finances
- newsletter
- entertainment
- organising speakers
- sending cards when needed
- representatives on, and contacts with, other groups and so on.

We were looking for new people to assist in these roles and were pleased that some have volunteered. Many thanks to those people.

We do know that some have worked hard for the group in the past and now are letting others have a go; and some are too up and down with their health to do more than attend the meetings - and we are pleased to see them. We know that people do what they can.

Other items

- We organised a lunch at the Burns Club on Thursday 28 July at 11.45 am.
- Chris Moyle will step down from organising speakers at the end of the year but she will organise two more for this year. We have a speaker for next month so we will be able to have two meetings without speakers. We are happy to have ideas on what to do in those meetings.
- Helen Reynolds spoke about a diabetes research study she is involved in. We look forward to hearing more about it.
- Kaye Powell is now on an Aged Care Committee and we look forward to finding out more about aged care.
- Helen Reynolds is unable to be in the CPAG group for the rest of the year - CPAG is an interstate group that has a teleconference every two months discussing relevant issues. Wyn Thomas is also leaving CPAG but Helen Cotter is joining it so we will still have a representative on it.
- Helen Reynolds is also unable to be on the COPD Committee which meets at The Canberra Hospital. We hope that she can be replaced by Kaye.
- Peta Rees spoke about a recent holiday she had to Uluru and the lack of ramps in the tourist resort, making it difficult to get around on her scooter. This is something we need to be aware of when we go on holidays, perhaps checking with the destination beforehand.
- Helen Reynolds read a letter from Richard White, a long time supporter of Lung Life, thanking us for all the work we do and donating \$100 to the group. We thank him very much for that lovely gesture.
- Helen Cotter spoke briefly about the issue of getting POCs to replace oxygen cylinders. She contacted Simon Corbell, the Minister for Health, about a month ago regarding the issue; then followed that up before our meeting, asking if they had any information to report to our meeting. Sadly no.

It was indeed a worthwhile meeting. We have a lovely cooperative where many people do what they can. It was good to be able to talk about that and to explore the variety of roles people have undertaken. Next month, we have a speaker from *Relationships Australia*.

Oxygen Update **Helen Cotter**

On 12 June 2016 I emailed Simon Corbell, Minister for Health, about supplying POCs to oxygen users instead of oxygen cylinders. I followed this up a couple of weeks later, hoping for feedback for our Lung Life meeting. No feedback came. However, now we have received a letter from Minister Corbell indicating that there will be a trial in 2016/2017 to look at introducing POCs with, as Minister Corbell

writes, 'a sample of oxygen users contacted to establish interest in participating in the trial before the end of 2016'. This is lovely news. We look forward to some of our members being involved in the trial and hopefully, in the not-too-distant future, POCS being provided routinely.

Thinking of having a lung transplant?

Helen Cotter

In March this year, 2016, Patrick Harris had a double lung transplant. He is now feeling fighting fit and as a consequence has donated his Inogen POC to Lung Life to lend to others for temporary use - such as travel to Sydney for medical reasons or trying before buying one. We are most appreciative of such a decision.

Prologue

Patrick's story is an incredible one. Usually a very healthy person, in August last year (2015), he developed flu symptoms which included being very breathless. He finally ended up in Emergency, was admitted to hospital and underwent all possible tests to discover the cause. He was by now using oxygen - first the oxygen cylinders; then a POC - to help him in his daily life.

The diagnosis was Idiopathic Pulmonary Fibrosis (IPF). This was most unexpected. He had had no previous hints of anything wrong, apart from a cough. Because it was acute, it would probably progress very quickly so The Canberra Hospital referred him to the heart/lung clinic in St Vincent's Hospital in Sydney for a possible lung transplant.

Pre-op

In October, 2015, Patrick was assessed at St Vincent's as probably being suitable for transplant but he needed to undergo extensive testing:

- blood tests
- X-rays
- scans
- sleep study
- dermatology tests and
- anything else you can think of to show he was fit and healthy.

Patrick has nothing but praise for the medical staff at the St Vincent's Heart/Lung Clinic.

Their care was high quality. They explained every step clearly, what was involved in the operation, and that it was not a cure but extended life and gave a better quality of life.

Patrick felt that it was really personal care.

He is also appreciative of the ongoing assistance by the medical staff at The Canberra Hospital.

St Vincent's provides shared accommodation for:

- patients and their families when needed,
- the family when the patient is in hospital,
- the patient and family when the patient is in recovery mode but needs to stay at the hospital.

The cost is covered by Medicare.

He walked regularly (with his POC) and attended the Pulmonary Rehab sessions at The Canberra Hospital, keeping himself as fit as possible. He was getting more and more breathless and finding it harder to get around.

In early March 2016, he was given the OK by the St Vincent's specialists - he was suitable for a transplant and was put on their list. This meant he waited for a call, for a set of lungs to become available. He was cautioned that there could be false alarms - the lungs might not be suitable. The lungs need to be in good condition but also have a matching blood group and be a suitable height and size for the recipient.

The op and post op

Patrick was lucky - he only waited a few weeks. The call came at 4.00 am in the morning in March, 2016, and he was in Sydney by 9.30 am. All day they prepared him for the transplant. This involved meeting with a physician and a member of the surgical team. Blood, an

X-ray and an echocardiogram were taken. Patrick was taken to the pre-operation area at 5.30 pm and then, at 7.30 pm, they started operating, finishing at 2.00 am.

The next few weeks were in hospital but no rest: physio daily; X-rays daily; medical team daily; training to take a myriad of tablets. After that it was staying in accommodation at St Vincent's Hospital for three months - again no rest! Mondays and Thursdays were seeing the triage team, lung function tests, X-rays, blood tests etc. Tuesdays and Fridays were seeing the doctors. Gym/physio was every second day. Wednesday was the day off. During this period, there was constant checking to see that everything was going well - this included four bronchoscopies within 12 weeks - after an anaesthetic, a tube was inserted into the lungs and a biopsy taken to check how the insides were going.

After three months, home and happy with renewed vigour! Patrick now has appointments with St Vincent's once a month for twelve months; and for the rest of his life he will be on a fair amount of medicine to help prevent rejection or infection, maintain bone density and calcium levels, and some to counteract the side effects of others. But that's a small price to pay for getting his active life back.

Epilogue

From August 2015 to the end of April 2016, Patrick and his wife Ann have been on a physical and emotional roller coaster; from diagnosis of a life threatening lung condition; to assessment for a transplant; to having the transplant and recovering from it - all in less than 10 months, not to mention the battery of tests Patrick constantly and repeatedly took. Now Patrick and Ann look forward to getting on with life.

Lung transplant program at St Vincent's Hospital, Sydney

St Vincent's Hospital in Sydney has performed over 870 lung and heart transplants since 1987. Approximately 50 patients undergo lung or combined heart-lung transplantation at St Vincent's each year, and the number is increasing annually. The procedures are performed on patients aged between 12 and 65 with severe lung failure.

POC for Loan

We now have an InogenOne G2 POC for loan. If you are on oxygen cylinders and thinking of buying a POC, you may like to borrow this one for trial.

If you are on oxygen cylinders and need, for instance, to travel to another city for a break or to visit a doctor, this may help. The Inogen is only 6 months old and has all its attachments.

We ask for a donation to Lung Life for its use. Contact Helen Cotter on cotterhe@hotmail.com or phone 02 6281 2988.

ACT IPTAS (*Interstate Patient Travel Assistance Scheme*)

People who need specialist medical or oral surgical treatment in another city are eligible for partial reimbursement of costs under the IPTAS scheme (Interstate Patient Travel Assistance Scheme) for travel and accommodation costs.

It's available to permanent residents of the ACT where the access to inpatient or outpatient medical treatment and/or specialist oral health surgical treatment is not available in the ACT.

Patients who think they may be eligible to apply for assistance under ACTIPTAS should contact the ACT IPTAS Office to clarify their eligibility before undertaking travel.

To apply, you need to fill out an application form which has three parts:

1. your details
2. the referral details filled out by the referring doctor and
3. the specialist and treatment details filled out by the specialist.

Full details for the scheme and its guidelines are available at www.health.act.gov.au/iptas. Contact can be made by phone (02 6244 2234), fax (02 6244 3453) or email (IPTAS@act.gov.au). NSW also has an IPTAS scheme and NSW residents need to contact: ENABLE NSW on 1800 362 253 or internet: NSW IPTAS (www.enable.health.nsw.gov.au/home/iptaas).

A-Z of Preventative Health Care

Chris Moyle

Prayer can be helpful in managing both the physical and emotional symptoms of disease. For some, it is a form of relaxation that helps reduce tension and anxiety. For others, it may be their method of distraction whereby they refocus their attention away from their symptoms. Regardless of the rationale, prayer is an important part of many people's self-management programs and remains the oldest of all symptom management techniques. (From *"Living a Healthy Life with Chronic Conditions"*.)

Could prayer actually improve your health? (From *"The Doctors" - The TV Show.*)

In California women receiving IVF treatment were divided into two groups. Half were prayed for and half were not. The group who received prayers had double the implantation rate and double the pregnancy rate. Not that we all want to become pregnant. A similar study with heart patients in hospital showed greater improvements in the group who received prayers.

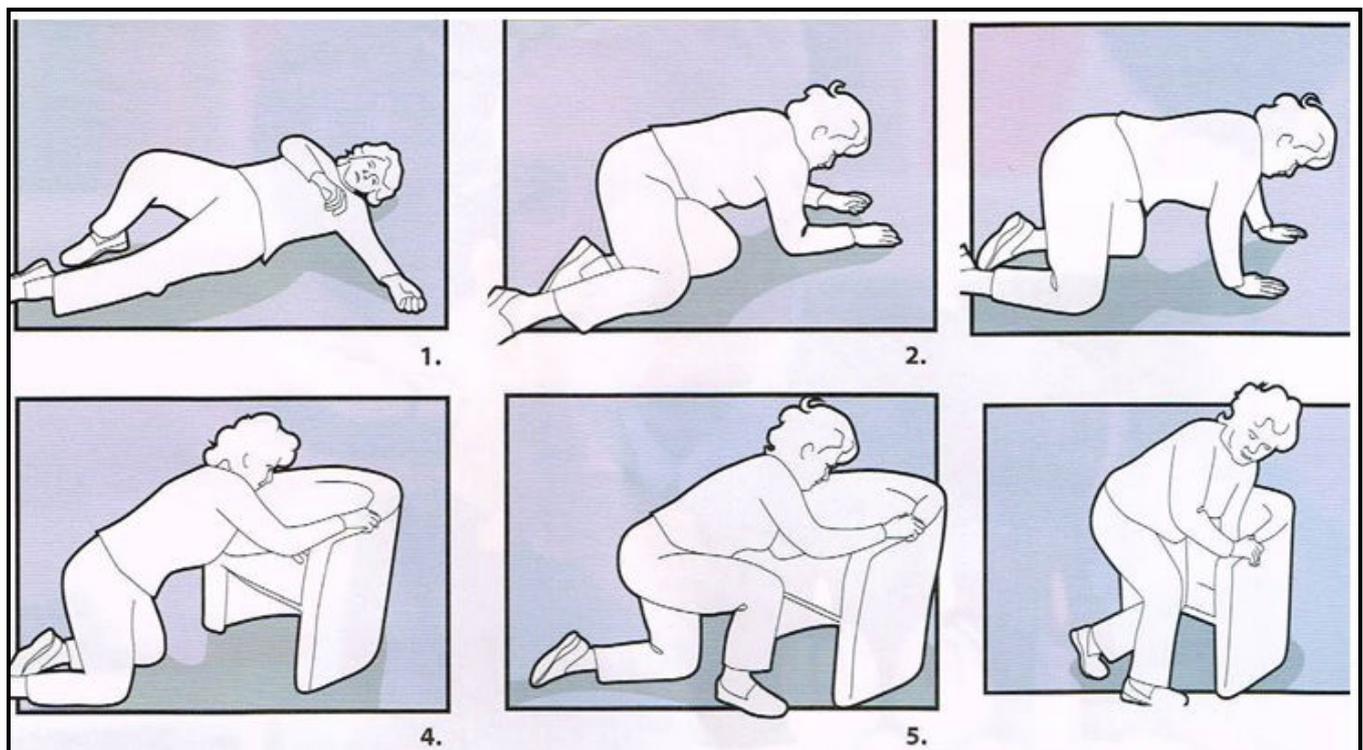
Prayer connects us to a higher power and can put us in a positive state of mind. Faith and hope helps heal.

A word of warning: don't pray to manipulate the situation. It isn't what happens to you that matters but what you do in the midst of that situation. It's knowing you can pray and get help to deal with problems. You need to have faith and believe in something bigger than the problem at hand.

Don't Wait For A Fall

Helen Reynolds

Learn to get up now. Practise these at your convenience.



Check out more at www.activeandhealthy.nsw.gov.au/.

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 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.
- **Australian Disability Parking Permit** must be assessed by a doctor. See 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 rehab. Needs a referral from a doctor. For more details phone: 02 6201 5843 or go to 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.
- **ACT IPTAS** provides reimbursement for medical or oral surgical treatment in another city. Full details of the scheme and its guidelines are available on the internet at www.health.act.gov.au/iptas or you can telephone 02 6244 2234, fax 02 6244 3453 or email IPTAS@act.gov.au.

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All the Canberra Lung Life Support Group newsletters since December 2009 are available at:

<http://www.creationcorporation.com.au/Canberra-Lung-Life-Support-Group-Newsletters.htm>.