

## October 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 13 October 2016  
10:15 am - 12 noon  
Weston Creek Labor Club  
Teesdale Close  
Stirling ACT 2611

October's Meeting has been designated *Guest Speaker free*. In its place let's learn a little about the chronic conditions that affect us. What conditions do you have? What are your symptoms? What is the treatment? What medications do you take? Do you suffer from side effects of the medications? How does your health impact on your quality of life?

### Dates for your diary

Thursday 10 November 2016	Canberra Lung Life Support Group Meeting
Wednesday 16 November 2016	World COPD Day
Thursday 8 December 2016	Christmas Lunch, Weston Creek Labour Club, Stirling

### September Meeting

Chris Moyle

Lyn Morley, the new meeting coordinator, joined Chris in chairing the meeting. One of their main tasks was to welcome several new members to our support group.

### Business discussed:

- Pam Harris talked about our commitment to the ANU medical students on Thursday 15 September 2016. She was able to recruit more people to fill her quota and ensure our volunteers will have small groups with whom to share their medical history.
- New pamphlets are available from Helen Cotter. Our thanks to Pam Harris and her son, whose firm, "Millenium", donated the money to print the pamphlets.
- The POC (portable oxygen cylinder) has been lent out again.

- This year's World COPD Day is Wednesday 16 November 2016. A space is booked at the Canberra Hospital for our display and testing of people's lung capacity by a lung care nurse. We need volunteers to operate the stall; the more volunteers the shorter the time each person will be needed.
- There was discussion about trips to the Tulip Farm and to the Botanic Gardens. These ideas were put on hold, particularly as Helen Reynolds, who organises the Flora bus trip through the Botanic Gardens, is hoping to go overseas.
- A fish and chips luncheon at the Southern Cross Yacht Club was organised for noon on Thursday 22 September 2016.
- A Christmas lunch has been organised at the Weston Creek Labour Club, Stirling for Thursday 8 December 2016, our usual meeting day. Names and numbers will be taken at future meetings.
- Helen Reynolds discussed future memorials going in the newsletter for deceased members. Family, friends who knew the deceased are invited to write something about them for inclusion in the Newsletter.

### Christmas Hamper

There are two meetings before our Christmas luncheon, plenty of time for people to bring along and donate items such as non-perishable foods/drinks etc. suitable for the Christmas Hamper.

### Guest Speaker - Richard Gray AM Chris Moyle

Our guest speaker from COTA was Richard Gray AM, a Senior Aged Care Adviser who has been involved with aged care for 25 years. He was made a Member of the Order of Australia (AM) in the 2014 Queen's Birthday Honours for his contribution to policy direction in the not-for-profit aged care and disability services sectors.

There have been a number of changes made to the government subsidised Home Care Package Scheme. Since July 2015 all home care packages are delivered under a Consumer Directed Care (CDC) framework. This gives consumers more choice on the services and supports available and more control in the management of their Home Care Package.

There are two types of home care packages, one with more complex support at home, and a residential aged care package. The range of care and services available under a Home Care Package includes, but is not limited to:

- **Support services:** such as help with washing and ironing, house cleaning, gardening, basic home maintenance, home modifications related to your care needs, and transport to help you with shopping, visit your doctor or attend social activities
- **Personal care:** such as helping with showering or bathing, dressing and mobility
- **Nursing, allied health and other clinical services:** hearing services and vision services
- **Care coordination and case management.**



There are four levels of Home Care Packages ranging from Level 1 - basic care needs, to Level 4 - high-level care needs.

**My Aged Care** on 1800 200 422 or [www.myagedcare.gov.au](http://www.myagedcare.gov.au) is the first point of call for all your aged care needs.

### **Step 1: Check your eligibility**

You first need to contact My Aged Care who will refer you to an Aged Care Assessment Team (ACAT) to complete an assessment. This assessment will identify whether you have high or low-level care needs and the ACAT member (usually a nurse, social worker or other health care professional) will come to your home or hospital. The ACAT will write to you to let you know the outcome of your assessment, the level of care you are eligible for and approved to receive, as well as an overview of that care. Keep a copy of these documents to show you are eligible to receive Australian Government-subsidised aged care services.



### **Step 2: Find a Home Care Package provider**

Once you receive your ACAT approval you will need to find a home care provider in your local area who can provide a Home Care Package to you. Your ACAT member can help you find a home care provider, or you can contact My Aged Care. Each provider is different, so meeting them will help you understand what you can expect. You'll also be able to see what types of care, services and activities they offer.

### **Step 3: Work out the costs**

There are two types of fees that you can expect to pay:

- A basic daily fee. The maximum basic daily fee is 17.5% of the single person rate of the basic Age Pension.
- An income-tested care fee (if your income is over the maximum income for a full pensioner, you may be asked to pay this fee).

My Aged Care can give you more information about home care fees, as well as an estimate of your likely fees.

### **Step 4: Accept a Home Care Package**

Once you have a home care provider you will enter into a *Home Care Agreement*. This is an agreement between you and the home care provider that sets out how your package will be provided to you. There should be enough time for you to look at the Agreement, and to seek independent legal advice, if you wish, before you sign the *Home Care Agreement*.

Your care plan may include:

- The care and services you will receive and who will provide which services.
- How much involvement you will have in managing and coordinating your services.
- When your services are delivered (for example, which day of the week).
- How much you will pay.



You can have another person, such as a carer or family member, with you to help while your care plan is being made, or an advocate can be made available through the National Aged Care Advocacy Programme (NACAP) by calling 1800 700 600.

### **Step 5: Begin your services**

Once you have a *Home Care Agreement*, a care plan and an individualised budget, your care and services can begin. Your package starts on the day your *Home Care Agreement* is signed, not from the day you receive care and services.

At present Home Care Packages are allocated to your home care provider, not to you, but from February 27, 2017 **you** choose the care you want. From that date it becomes your package, not the provider's package.

## **Lung Transplant**

**Helen Cotter**

The world's first successful lung transplant, a combined heart and double lung transplant, was performed at Stanford University Medical Centre in 1981. Since that time there have been over 40,000 lung transplants performed throughout the world. In Australia, lung transplantation began in 1986 with well over 1000 patients receiving these operations since that time.



Until the early 1990s it was much more common to have a combined heart-lung transplant than a lung transplant, but now the reverse is true - only 2 or 3 heart-lung transplants are performed in Australia each year, while well over 100 lung transplants are performed. This approach now allows many more patients to be transplanted while not compromising outcomes.

Over ten years, a double-lung transplant is slightly better, but a single lung transplant is still an excellent treatment option, especially for those patients with idiopathic pulmonary fibrosis (IPF) where, due to the

scarring nature of the disease and contraction of the chest wall, it can be very hard to find a suitable double lung donor. In this situation we can place a large single lung transplant, leaving the other diseased lung in place.

A new piece of technology called ex-vivo lung perfusion (EVLP) allows us to resuscitate organs that are not immediately suitable for transplantation. The organs are placed on our EVLP machine, warmed back up to body temperature, ventilated to mimic breathing and perfused with a special solution which removes toxins and excess fluid. Over a few hours these lungs are restored to near normal function. This technology allows doctors to use lungs that would never have been able to be used in the past.

### **Who needs it?**

Only people who are dying from their lung disease, or who have very significantly impaired quality of life, may be suitable candidates for this type of surgery - people with severe lung diseases such as cystic fibrosis, chronic obstructive pulmonary disease (COPD), or pulmonary fibrosis as well as certain forms of congenital heart disease and pulmonary hypertension. Lung transplantation is not a suitable operation for patients with lung cancer.

Lung transplantation is a high risk procedure, and age itself increases that risk, particularly after the age of 60. By the age of 70 the risk of having a transplant has usually increased to such an extent that it

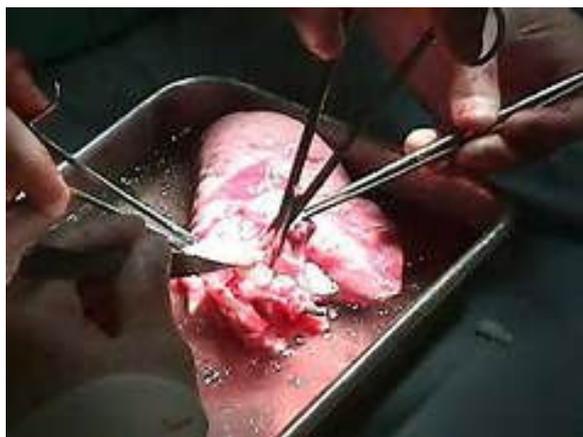
becomes prohibitive. However, as people are now healthier at an older age, there is no doubt that in the future, older patients who are in every respect ideal candidates other than for their date of birth, will be undergoing transplantation.

### **How many people receive a lung transplant each year?**

Only about 140 patients a year get a lung transplant in Australia.

### **Where is it done?**

There are four centres which are able to provide lung transplantation services to the Australian community. These are The Alfred Hospital Program in Melbourne, St Vincent's Hospital Program in Sydney, The Prince Charles Hospital Program in Brisbane and the Royal Perth Hospital Program in Western Australia.



### **How successful is it?**

Survival after a lung transplant is higher in Australia than anywhere else. Regardless of the form of transplant (single lung, double lung or heart and double lung) the majority of patients (approximately 93%) will live at least a year or more following their transplant, with 70% living five or more years. Quality of life as measured by the ability to exercise, attend educational courses, work or manage a household is usually excellent. Most patients return to a relatively normal life after a lung transplant.

**Source:** *Lung Foundation website*  
*10 Myths about Lung Transplantation* by A/ Prof Daniel Chambers, Queensland Lung Transplant Service, The Prince Charles Hospital, Brisbane.  
<http://www.lungfoundation.com.au/wp-content/uploads/2013/12/LungNetNewsFeb2013web.pdf>

## **The A-Z of Preventative Health Care**

**Chris Moyle**

### **Problem Solving**

Learn to recognise when you have a problem. When you do have a problem, then decide if you need to do something about it. Resist the urge to act impulsively. Take time to sit down and look at your options before acting. Tackle the problem in manageable steps.

When you are stressed, the tendency is to look at all your problems at once, throw up your hands and say, "That's too much to cope with ... I give up!"

Break the problem down into smaller steps and take one step at a time. Prioritise. Work out what is most important for you at this stage. Write down your problems. Your problems will appear clearer when they are on paper.

Reward yourself. Even if you don't solve the problem the first time, at least you have tried. Accept that the problem may not be solvable now.

**Source:** *Better Living with COPD - A Patient Guide*



## **Pulmonary Rehabilitation**

The Canberra Hospital (Ph: 02 6244 2154) and the Queanbeyan Hospital (Ph: 02 6298 9306) both run a Pulmonary Rehabilitation Program which is one of the most effective and important treatments you can do for COPD. The Program consists of an eight week program of low impact aerobic exercise e.g., walking, balance and strength training. Education sessions are also provided once a week covering a range of relevant topics including medications, nutrition, relaxation and breathing. A referral from a respiratory specialist is necessary.

## **Visit to ANU Medical Students Chris Moyle**

On 15 September 2016 eleven members visited the ANU medical students at The Canberra Hospital. The students were keen to learn about our ailments and how they affect our quality of life. As a thank you for giving up our time and our histories we each received a \$30 Coles voucher. The benefits of such an experience are felt on both sides: the students are exposed to a real live person who lives with chronic respiratory conditions and the Support Group Members are able to interact with future members of the health profession. Thanks to all those who attended and a special thanks to Pam Harris who once again organised the visit.

### **God's Plan For Ageing Esther Fitton**

Most seniors never get enough exercise. In His wisdom God decreed that seniors become forgetful so they would have to search for their glasses, keys and other things thus doing more walking. And God looked down and saw that it was good.

Then God saw there was another need. In His wisdom He made seniors lose coordination so they would drop things requiring them to bend, reach & stretch. And God looked down and saw that it was good.

Then God considered the function of bladders and decided seniors would have additional calls of nature requiring more trips to the bathroom, thus providing more exercise. God looked down and saw that it was good.

So if you find as you age, you are getting up and down more, remember it's God's will. It is all in your best interest even though you mutter under your breath. So in that context here are **Nine Important Facts To Remember As We Grow Older:**

- #9 Death is the number one killer in the world.
- #8 Life is sexually transmitted.
- #7 Good health is merely the slowest possible rate at which one can die.
- #6 Men have 2 motivations: hunger and hanky panky, and they can't tell them apart. If you see a gleam in his eyes, make him a sandwich.
- #5 Give a person a fish and you feed them for a day. Teach a person to use the Internet and they won't bother you for weeks, months, maybe years.
- #4 Health nuts are going to feel stupid someday, lying in the hospital, dying of nothing.
- #3 All of us could take a lesson from the weather. It pays no attention to criticism.
- #2 In the 60s, people took LSD to make the world weird. Now the world is weird, and people take Prozac to make it normal.
- #1 Life is like a jar of jalapeno peppers. What you do today may be a burning issue tomorrow.

Please share this wisdom with others while I go to the bathroom.

\* Images on page 3 are courtesy of Bing.com.au Aged Care Images.