



CANBERRA
LUNG LIFE
SUPPORT GROUP

October 2019 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 10 October 2019
10:15 am - 12 noon
Weston Creek Labor Club
Teesdale Close, Stirling ACT 2611

Guest Speaker: There will be no Guest Speaker for October. This time will be devoted to discussions and planning for the Anniversary Celebrations.

Dates for your diary

Thursday 14 November 2019 CLLSG Meeting
Wednesday 20 November 2019 World COPD Day

September Meeting

Lyn Morley and Val Dempsey

Discussion and decisions:

- Geoff Cox was welcomed back from Sydney after his double lung transplant. Geoff spoke to us briefly and has been asked by Lyn to speak about his experience in the January 2020 meeting.
- George was welcomed back after his winter trip to a warmer climate.
- Julie, a new member, was also welcomed to the meeting.
- Esther had a fall and is in hospital. I know you'll all join me in wishing her a speedy recovery.
- Lyn has spoken to the functions person at the Labor Club re our Twenty-second Year Celebrations on Thursday 12 March 2020. We are waiting to hear if the club is available for our use for our big day. The cost will be about \$45 for a two course meal with drinks extra.
- Kaye has been to Brisbane for a seminar at Lung Foundation Australia. She said it was very good especially seeing the faces of those who normally communicate by phone, bi-monthly.

- There is going to be an Open Day at Government House in Canberra on 12 October 2019. LFA will have an information booth at this function.
- Xia, the COPD nurse who is responsible for sending the Newsletter by snail mail, has offered to attend our World COPD Day activities and do breathing tests. Time will be spent at the October Meeting discussing plans for World COPD Day.
- Lyn was the guest speaker at the August Sleep Apnea Meeting. She did a presentation and showed an oxygen bottle and portable oxygen concentrator.
- There will be a new Hospital Action Plan with a common sense approach. It will be out in three months.
- Once again some of the group went to the ANU Medical School at The Canberra Hospital to talk to the students about our various lung conditions. This is a yearly event where student doctors are able to gain more knowledge about lung illnesses and how they impact on everyday life.
- Val Dempsey, a relatively new member, will be our guest speaker in November representing St John's Ambulance.

Guest Speaker - Richard Grey (COTA)

Lyn Morley and Val Dempsey

The guest speaker, Richard Grey, is a volunteer with COTA. His talk today was intended to simplify the navigating of the Aged Care System. He described three types of care:

1. Remain at home with support for basic needs.
2. Home Care Package for Independence and Care (which has four levels).
3. Residential Aged Care 24/7 Care Option.

Aged Care Assessment can be accessed through “My Aged Care”. They will assess needs for specific requirements.

The Commonwealth Home Support Program is available and there are also home packages available. To access the system the web address is www.myagedcare.gov.au. There will be an assessment and there will be various packages available. The waiting lists are sometimes very long.

Home Support Packages will have a contribution of money assessed on income. The providers of the services and packages are listed on the web page for the client to select from. Packages are very diverse and sometimes renovations are provided so that client can remain in their own home.

Richard spoke about the different types of care available, eg food preparation, podiatry, maintenance of the home, transport etc. Eligibility of the services is based on need.

Home Care Packages for Complex Care

Personal care and nursing etc., in Level 4, is available for Complex Care needs and is approximately \$50,750 per annum. Funds for this can accumulate. Packages can come as an income tested fee contribution.

A Provider for help at home can be found on the My Aged Care website. These are funded under the government and will incur a waiting list as funding is limited. The website allows for comparison searches between providers. All providers that are funded by the government have to be approved by the government and are held accountable for costing and care.

Happy Birthday to you!

If you'd like to receive a birthday wish from your Support Group send your birthday details to Pam Gaston at peter.olley@grapevine.com.au.

A Reminder about Facebook

Lyn Morley

Did you know that our group has a Facebook Page? If you are on Facebook I would love you to join. To join do a search for "Canberra Lung Life Support Group" and ask to join.

I hope to put interesting articles, jokes, photos and inspirational sayings on this page from time to time, but we need some members. Please join this group.

Here is the link anyway: www.facebook.com/groups/1854434084857617.

My Lung Transplant Journey

Geoff Cox

The event that led to my diagnosis was a severe case of influenza with a very nasty and persistent cough. With this illness I had noticeable breathing difficulties. In 2008, aged forty-nine, I was diagnosed with alpha 1 antitrypsin deficiency, a genetic condition little known outside of medical circles. I had been experiencing a decline in my exercise tolerance for a number of years; however, I had originally put this down to the combined reasons of ageing and not exercising at the same level of intensity as I did when I was a competitive athlete in my twenties and thirties. As an athlete I specialised in road running distances of eight kilometres to the half-marathon. I also competed in triathlons and had completed three full marathons with a personal best of under three hours.

My GP listened to my story of decreasing exercise tolerance and breathing problems and did not hesitate to send me to thoracic surgeon, Dr Mark Hurwitz.

Dr Hurwitz ran a series of tests and then called me back in to give me the news that I had alpha 1, a condition I had never heard of. My parents had been unwitting carriers of the gene. Essentially my lungs have no protection and so over the years they have gradually deteriorated and were no longer working as they should. It was advised that I continue to exercise regularly, try to avoid becoming ill (e.g. hand sanitise, get the flu shot etc) and when travelling stay away from polluted cities. I was also to use asthma style puffers to assist in keeping the airway clear.



2nd in the Esrom Run, Bathurst 1987.

For the next decade my exercise capacity and breathing capability gradually declined. At first I could walk

without problems but running or swimming longer distances was very difficult. Then I began to breath more heavily when just walking or doing light exercise.

In 2015 Dr Hurwitz referred me to Professor Alan Glanville at the Heart and Lung Transplant clinic at St Vincent's Hospital in Sydney. From that point on I was under the care of both Dr Hurwitz in Canberra and the lung doctors at St Vincent's.

As my condition deteriorated, to the point where any moving or light activity (e.g. having a shower) left me breathless, the need to have a lung transplant sooner rather than later became apparent. In mid-2018 I started my transplant workup. This involved multiple tests to see if I was a suitable patient for a transplant. While they knew my lungs were 'rubbish' they needed to see if the rest of my body would hold up to the rigours of a transplant and if I was psychologically able to follow through with the routines I would be required to maintain post-transplant. My listing was held up when a nodule was found following a PET scan. This



nodule could have led to cancer post-transplant, as all transplant patients need to take immune suppressants. I had to wait three months to have a follow up PET scan. This scan gave me the all clear on the nodule in question, but another nodule was evident, so I had to wait a further three months until another PET scan cleared me to be listed.

On 3 May 2019 I was put on the transplant list and from that moment on my phone was with me ready for the call twenty-four hours a day. At 10:30 pm on 14 May 2019 my phone rang to give me the message that they had received lungs that may be suitable for me. I had only been on the list for twelve days. Some people wait months or even years. I was very lucky.

Dianne my wife, Cam our son, and I were soon heading up the Hume Highway to Sydney. We arrived at 2:50 am and immediately started to prepare for the operation. At 5:00 am I was being wheeled to the operating theatre and meeting the anaesthetists (I don't remember meeting the surgeons). Not all transplants go ahead as they must be sure of compatibility. Once again I was fortunate. Dianne was called at 7:15 am to say the transplant was going ahead.

The surgeons completed their delicate work around lunchtime, and I was taken to ICU, still well and truly out of it. I don't recall anything from that day or the next, although apparently, I did begin to respond to the nurse's questions. My first recollections were being in ICU two days post-transplant. As to my breathing, at this stage, I couldn't notice any difference than before the operation. There was no 'Hollywood' like experience of waking up and feeling great. I needed to retrain myself to breathe efficiently again and to regain strength.

The operation, along with problems which developed prior to my transplant, meant that I had problems with swallowing, speaking, and I weighed less than 60 kg. There was work to be done with the speech pathologist and dietitian. It was not a pleasant time. The special food and drinks were definitely not very appetising. I also started regular injections of insulin as the medication played havoc with my blood sugar levels.

On Monday 20 May 2019 I was moved upstairs to a regular ward. I was receiving 'food' through a nasal

tube, as a supplement to what I could eat myself. The physiotherapists joined the team of medical professionals charged with helping me get back on my feet.

I was in hospital for six weeks, which is longer than most transplant patients. The reason for my extended stay was the need to drain fluid and air from around the lungs. This is done by attaching drains to my chest. I had as many as four at one stage, which made it very difficult to move around. Gradually this was reduced to three, then two, then one but it took a long time to get the all clear to finally be free of all the drains.

While in hospital I was very fortunate to have Dianne by my side every day. At first, many basic activities would have been very difficult without her assistance. All transplant patients get the shakes as a result of the medications they have to take, so eating, for example, can be problematic. The staff at St Vincent's were wonderful, right from the lung transplant specialists through to the cleaners and wardsmen.

I was finally released from hospital on 24 June 2019, my first venture outside in six weeks. It is a requirement of getting a transplant that you stay in Sydney for three months post-transplant, so my next move was to Bondi Junction, where Dianne had been staying while I was in hospital. We had an apartment, so our boys could come and go from Canberra and my daughter came for a visit from Scotland for a week.

They monitor you very closely in these first few months after transplant, so I had to go to the hospital most days for tests and to see the doctors. They also run a rehab program at the hospital gym twice a week, and this became one of my favourite times. I gradually got stronger and by the end of my stay in Sydney I was able to walk along the cliff top path from either Bondi to Bronte or Coogee to Bronte. I hadn't been able to exercise like this in years. On 17 August 2019, three months and two days after my transplant, we packed the car and returned to Canberra.

It would be remiss of me not to mention the donor, whom I virtually know nothing about. Without their family thinking of others, at what would have been a very difficult time for them, I would not have received the call that night. I can't thank them enough. Part of the post-transplant process is to communicate anonymously with them, through a letter, to thank them for the 'second life' they have given me.



***1 October 2019 = International Day of Older Persons.
The International Day of Older Persons is a celebration of
the older people in all societies, and a reminder to
continue developing a society for all ages.***

Happy Birthday CLLSG

"*The Canberra Lung Life Support Group*" was established twenty-two years ago to provide a supportive and informative environment for people with a variety of lung conditions and their carers. Twenty-two years is a truly amazing achievement.

We'll celebrate this momentous occasion next year and now is an appropriate time to remember some of those who were around from the very beginning.

Remembering Gordon

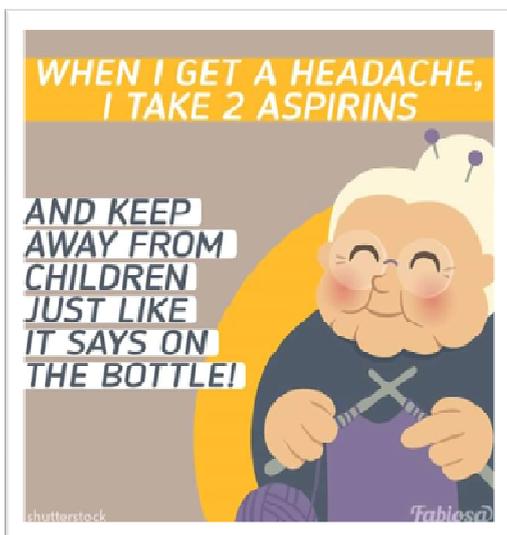
Chris Moyle

Gordon Forrest was with our group from the beginning and used to chair meetings. He was insistent on people wearing name tags. On arrival at meetings everyone would be issued with their badge or a large stick-on label with their name written in text. Gordon would often say, "How can you run a meeting if people aren't wearing their badges?"

He was a good speaker and always stood and made a speech at our mid-winter and Christmas lunches, especially remembering those who'd died. He'd say, "We'll remember them; and we'll keep remembering them."

Before his COPD diagnosis Gordon was a pilot. In Canberra he joined a charter aircraft company, flying single engine aircraft, and also worked as a flying instructor, eventually setting up the "Aircraft Flying School". He also took on the Shell agency for refuelling aircraft at Canberra Airport. By 1983 he'd sold both businesses and had a number of part-time jobs, until his full retirement when poor health finally caught up with him.

Gordon passed away December 2002. His final advice to all who would listen was "Don't smoke!" His obituary read "A life well lived".



POC donations

We've been donated the following items and we would like to continue their use by passing them on to another user. We ask for a donation to the Lung Life Support Group.

You can contact me, Helen Cotter, on: cotterhe@hotmail.com or 02 6281 2988 or reply to this email.

Respironics EverGo SN151369 portable oxygen concentrator

has the following items:

- Trolley
- 2 batteries
- humidifier
- Power cord
- Instruction manual



It gives pulse oxygen from 1 to 6. It weighs 4.5ks (10lbs) with both batteries.

EverGo POCs have now been superseded by others and only limited parts are available. However, their batteries have a long duration time. On level 2 the expected time is 8 hours.

If you have an EverGo, you might like this as a back-up.

Lovego G2 portable oxygen concentrator

Lovego is a Chinese/Hong Kong make and is found in many other countries in the world but is not well known in Australia. The G2 machine was created in 2016.

If you have a Lovego, you might like this as back up.

- It has a continuous flow from 0.5-1.8 LPM, and pulse from 0-5 LPM.
- It has 2 batteries.
- It weighs 6.2kgs (13.7lbs) with battery.
- It has a trolley and a car charger.
- Has an instruction manual.

