CANBERRA LUNG LIFE SUPPORT GROUP

August 2026 Newsletter

Our mission is to provide a supportive and informative environment for people with lung conditions, as well as their families and carers.

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Web Sites: Canberra Lung Life Support Group | Web Site
Canberra Lung Life Support Group | Facebook

NEXT MEETING: Thursday 10 September 2026
11:30 am – 1:15 pm
Weston Creek Labor Club
Teesdale Close, Stirling ACT 2611

Speaker: Jose (Jojo) Sibayan, the Community Engagement Officer, for ADACAS (ACT Disability, Aged & Carer Advocacy Service) will talk to us about the new aged care system.

NOTE: arrival for meetings is now 11:30. We continue until 1:15.

August Meeting

Our speaker today, Alicia from Lung Foundation Australia, was unable to come so we took the opportunity to discuss a topic dear to our hearts: **medical specialists: their access and affordability**.

Marina gave us the background to this discussion: o*ver this next year the Australian Government is undertaking an inquiry into access to, and affordability of, medical specialists. This is a real issue for us in the ACT as we pay some of the highest out of pocket costs for access to private specialist care - especially those with chronic conditions! The HCCA will be drafting a submission to this inquiry and will be running a workshop to hear thoughts and experiences from their members. As I will be attending this, I would really like to hear what our Group's experience has been around access and affordability of specialist care.*

We talked about some of the following aspects that Marina had set out:

1. **Access to medical specialists in Canberra**
    - How would you describe your experience?

- After getting your referral, how long did you have to wait before you were able to talk to a specialist?
- What did you have to do to get to see the specialist?

2. **What was the experience like?**
    - Were you satisfied with your visit?
    - Were you treated with dignity and respect?
    - Were you informed about services, treatment options and costs?
    - Did the specialist address your concerns?

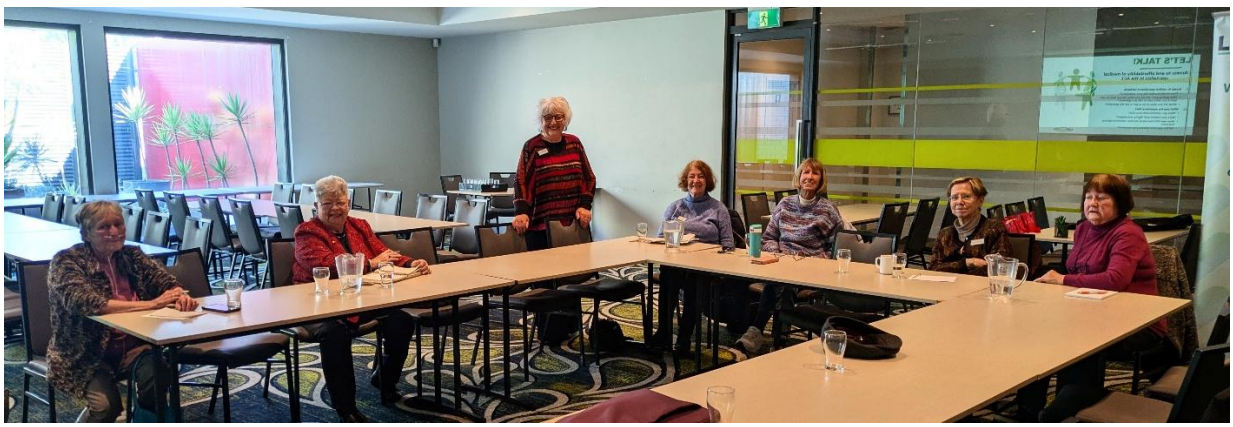
We all spoke about our experiences, with the following issues emerging as quite common:

- **Length of time waiting**: after initial diagnosis and referral by the GP, the wait for an appointment was often about 2 months. More significantly, there was often a longer waiting time after that for the follow-up treatment. For instance, one member had a stroke, with an MRI not until 3 months later and the follow-up appointment a year later.
- **Poor communication 1**: There were a variety of experiences here such as: no communication between specialist and GP; requests for information such as referrals, blood tests and so on from the specialist when these have already been sent; lack of information about, for example, the necessity to have a blood test before a procedure.
- **Poor communication 2**: often, the specialist did not seem to take on board some of the issues the patient felt important.
- **The cost**: hospital specialists are free but often have long waiting times; visits to private specialists are expensive plus the cost of any follow-up treatment.

We felt that some aspects of this resulted from:

- Pressure of time on the Specialist and their staff with maybe insufficient number of specialists to meet the number of patients.
- Complexity of the system – length of time waiting depends on whether you are a public or private patient. One story was told of a specialist who saw you in emergency but wouldn't treat you further unless you became his private patient.
- The pressures in the hospital – seeming to want a quick turnover of patients. Some told of the hospital wanting to discharge them when they still had some issues. They felt they were not being listened to.

It was a good discussion which clearly showed some of the issues. If you would like to make a comment on any of them, let Marina know: lung.life1@hotmail.com



Some participants at the August meeting.

From Lung Foundation Australia:

We wanted to share an important update that may be relevant to you or someone you know. From the 1st of July, the **National Immunisation Program** has expanded access. The updated program protects against more disease strains.

A new **one-dose pneumococcal vaccine** is recommended and free for people aged 65+, First Nations people 25+, and for the first time, 18+ living with COPD. Eligible people who previously received an adult pneumococcal vaccine are also recommended to be revaccinated for free.

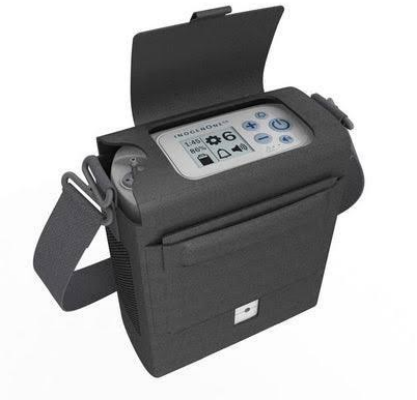
Talk with your healthcare provider about pneumococcal vaccination. You can find out more here: Pneumonia - Lung Foundation Australia

An Update From The Co-ordinator - Marina Siemionow

Looking through my diary for July I did not have a single free day but on looking back, more of my time was spent accompanying Val on his medical appointments than on 'Lung Life stuff'. I was interviewed by the communications officer for HCCA for an article in their Newsletter and I did spend a bit of time setting up our new **Facebook** page. This slower month also gave me the space to review all our marketing materials to prepare for our stall at the Seniors Expo in September.

1. **Wednesday 8th July: BREATH Project Team Meeting**. The project presented at the Lung Foundation Symposium in Melbourne on 12-13 June at which it was described as a major success. Currently the project is testing the 'Breathlessness Recovery Plan' in three, real live sites and will soon be bringing two more sites on board. The project has been extended for a further six months to allow the new sites time to test the plan. We also discussed the latest version of the app which will be going out for feasibility testing soon after we change the narrator on the tutorial from an AI to a real health care professional. Given that I was unable to take part in the co-design workshops for the app, as they were held in person in Sydney, this was my first look at the app, and I was amazed.
2. **Wednesday 29th July: Chronic Conditions Network Meeting**. This was one of our on-line meetings at which we had a fabulous speaker, Jennifer Faerber, who gave us some insights and tactics into how to influence Government decision makers. In her talk she covered some change management approaches and had us mapping the people with the power and influence to help - or hinder us - achieve what we want.
3. **Wednesday 22nd July: Better Together - Peer Support meeting - Lung Foundation.** During the hour-long, on-line meeting we discussed how to share the load and build sustainability within the support groups. It was great to hear that the Lung Foundation is planning a range of improvement projects to enhance the Peer Support Programs, over the coming years. They are asking for input from current peer support leaders to help these improvements reflect the needs and experiences of members.
4. **Friday 31st July: Christmas in July lunch**. We had a very chatty, lunch. We manage to sell lots of raffle tickets. Six people each went home with a beautiful box of 'Goodies', provided by Marilyn. Another person won a stunning hand-quilted, quilt made by Val, and one further person won a basket of 'Goodies' prepared by Val. It was wonderful to have Margaret join us again after a long stint in hospital and rehabilitation.

Inogen One G5 (16 cell) for sale.



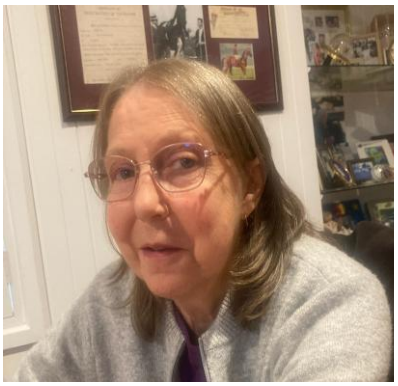
Inogen One G5 is a POC for patients with higher oxygen requirements. It has:

- 6 pulse flow settings;
- a double battery (16 cell) which lasts up to 13 hours (based on setting of 2);
- power cords for home and for car.

Price: $2000 (new: $ 4000 - $5000, especially with the 16 cell battery)
Contact: Jenny Keen at djkeen1@bigpond.com or
ph: 0411 438 659

Jenny's lung transplant journey

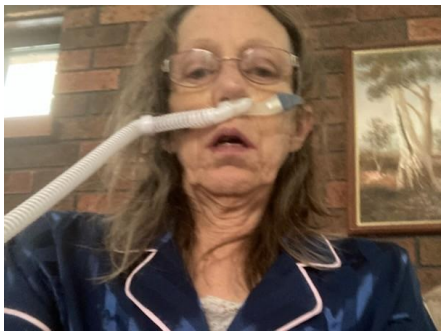
Jenny Keen, a long-time member of Lung Life, had a lung transplant at St Vincent's Hospital in July 2025 – last year – and feels a new woman. The journey to the transplant was long, tortuous, and not for the faint hearted.



Jenny today

In 2022, she wasn't feeling the greatest. Her breathing wasn't good. She often spent the day, lying on the couch, feeling lousy. Jenny finally had some tests and was diagnosed with pulmonary hypertension which stresses the heart. She then went on oxygen to help her breathing.

So with these and other complications, the doctor suggested she think about having a lung transplant, the suggestion catching Jenny by surprise - but she gradually warmed to it and began the journey.



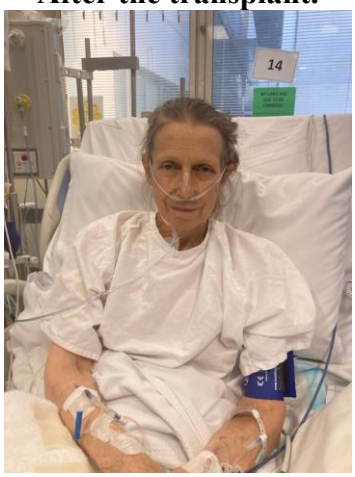
Waiting for the transplant. Note the large tube, allowing for greater oxygen delivery

First, you have to be well enough to get on The List for a transplant. There are a huge number of criteria to meet to get on The List, walking 150 metres being one of them. Jenny found this quite difficult. She also developed a blood clot; so for a while she was on The List, then off The List, then on The List.

It was a real catch 22: would benefit from a transplant but was too sick to undergo it.

For Jenny, it also involved travelling many times to Sydney for appointments and tests. Mostly, she travelled up and down in one day but sometimes she had to stay there – for early morning appointments – or late afternoon ones. A real trial for a rather ill person.

After the transplant.

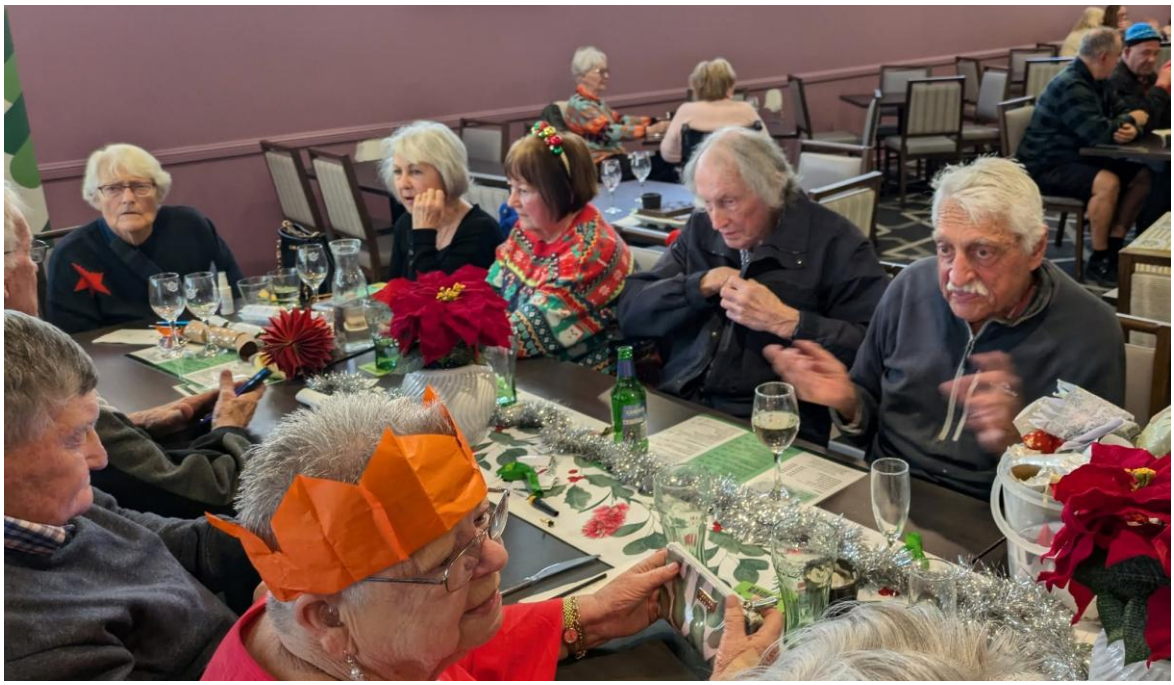


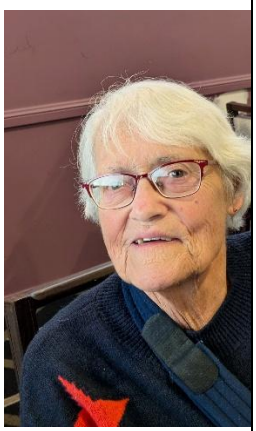
Finally, she was On The List, and three weeks later – July 2025 - was at St Vincent's Hospital in Sydney having her transplant. She then spent 3 weeks in hospital; then 3 months in Sydney while they monitored her condition.

Now she's home, off oxygen, exercising at the Canberra Hospital gym, and visiting St Vincents Hospital every three months for check-ups.

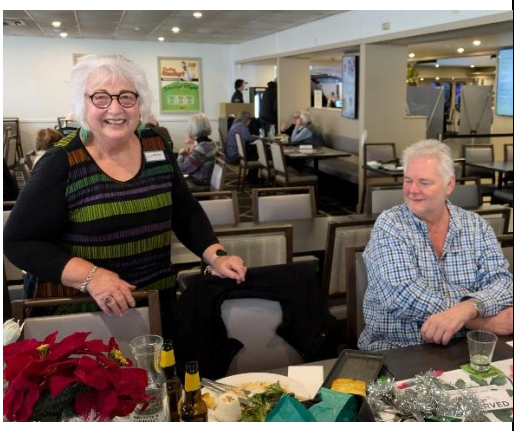
But living a quiet life as her immunity is compromised and she has to be beware of infections. As with all transplant patients, she will be on immunosuppression drugs for the rest of her life. For Jenny, a new freedom to her life – such a great feeling.

Christmas in July Lunch: Raiders Club Weston

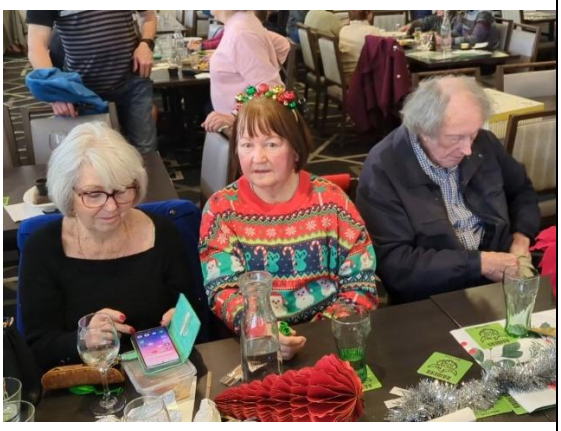




Margaret



Marina and Richard

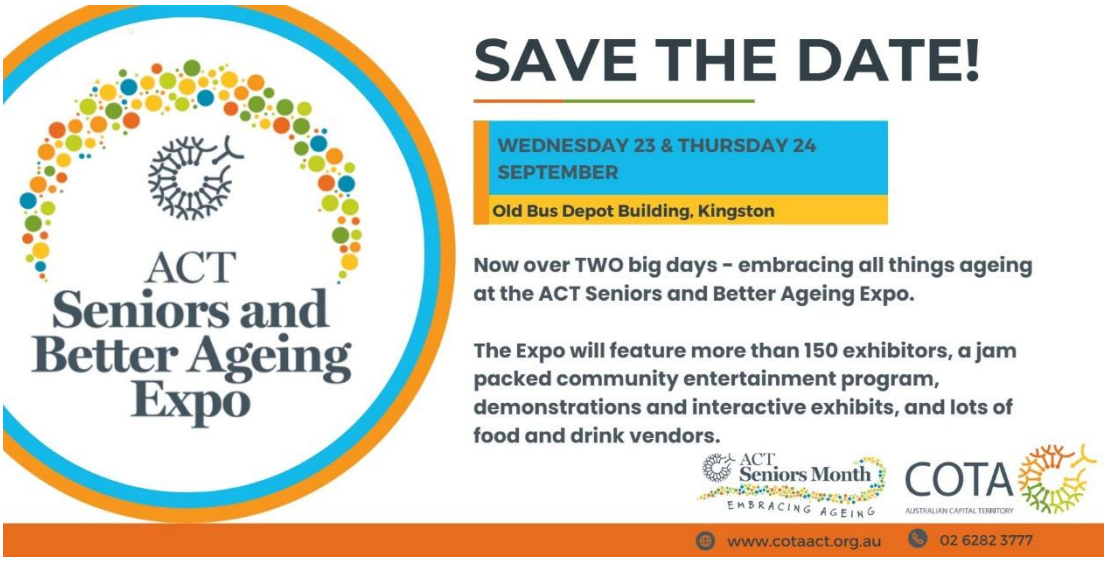


Linda, Win and Barry

St Vincents Hospital has performed 910 lung and heart/lung transplants since 1989 and is currently performing about 60 transplants each year. Transplants are also performed in Brisbane, Melbourne and Perth

Respiratory Medicine - St Vincent's Hospital Sydney

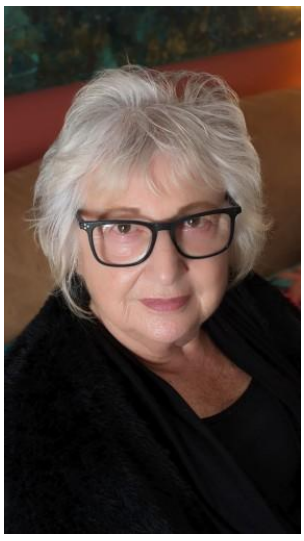
Come and visit our stall as well as looking at everyone else's



Here's an extract from HCCA newsletter issue 16/20 August: Members Spotlight

If you'd like to read more, join HCCA (free) and get the newsletter. It will help HCCA in their advocacy for your health care.

Marina Siemionow



Marina has been coordinating Canberra Lung Life Support Group for the past five years, helping to raise awareness and advocate for people living with lung conditions in the community.

Lung Life is one of Canberra's longest-running support groups, celebrating 27 years this year. With around 70 members, it provides connection, support and practical information for people living with a range of lung conditions. While many support groups have moved online, Marina believes face-to-face support remains essential.

"*People need understanding and connection, especially when they're unwell*," she says.

For Marina, Lung Life is about much more than in-person meetings with members. Advocacy, education and community awareness are at the heart of the group's work.
Through Lung Life, she has been involved in several co-design projects aimed at improving support for people living with chronic lung conditions, particularly those experiencing breathlessness.

Marina became an individual member of HCCA two years ago after being involved in the Chronic Conditions Network through Lung Life, which has been an organisational member of HCCA for many

We have run out of room. You can read the rest in the HCCA newsletter.