

## September 2023 Newsletter

**Our mission is to provide a supportive and informative environment for people with lung conditions and their carers.**

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**NEXT MEETING:** Thursday 12<sup>th</sup> October 2023  
10:15 am – 12:00 noon  
Weston Creek Labor Club  
Teesdale Close, Stirling ACT 2611

The October lunch is at 12 noon on Friday 27 October at the Mawson Club.

### From the Editor

George is now back in Canberra after his annual pilgrimage to the outback. Here is a little of his journey south to home.

*'Hi from Roma. My holiday is nearly over. I came across sculptures in or out of Roma.'*

This photo opposite is 'Billy' an upcycled billy goat. 'Billy' upholds the traits of being tough and durable while living in outback conditions.

George then continued on to the outback town of St George on the Balonne River, which is part of the Murray-Darling Basin (see photo on page 2).



He then crossed back into NSW where he visited Walgett, the home town of Yorta Yorta man James Oswald Little. You and I know him as Jimmy Little, and he is not forgotten locally (see photos on page 2).

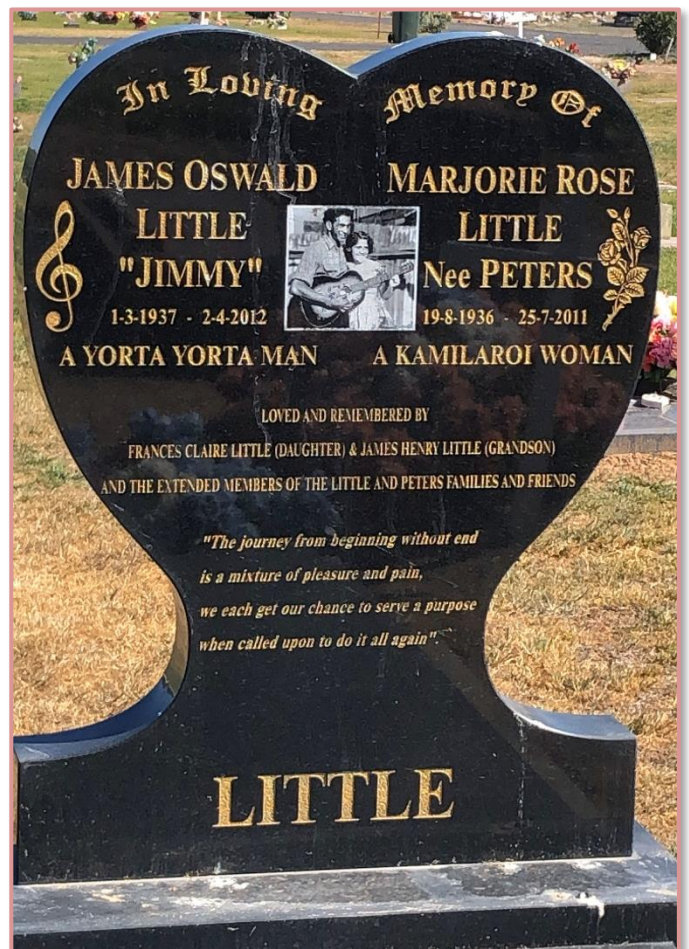


Pictured right is the Beardmore Dam on the Balonne River. While the river flows through the town the dam is located 17 kilometres north-east of St George. The main purpose of the weir is to store water for irrigation.



And below we have 'Jimmy'.

*'Hi, the attached photos are of Walgett's favourite son. One is on the local water tower and the other is of his resting place at the local cemetery across the road from the RV resting area.'*



## **'Meeting' with the medical students**

Prior to COVID, which changed how many chronically ill and immune compromised individuals have had to live, you may recall that volunteers from Lung Life attended the ANU School of Medicine to be interviewed by the first year students. This opportunity for students to hear the story of a 'real person' living with an ongoing condition has always been a valuable one.

You may be pleased to know that this association between ANU and Lung Life has continued albeit in a different form. For the past few years, and most recently in August of this year, your editor has done a Zoom meeting with the students. Dr Matthew Lewis from the School of Medicine has facilitated this by interviewing your editor, who is sitting in the comfort of his lounge room, while the students watched on.

**You may recall from the August edition of this newsletter that George visited Porcupine Gorge on his trip north. This prompted Chris Moyle to compose a little poem.**

George took a trip to Porcupine Gorge.

On sighting a porcupine, exclaimed, 'By George!'

*'Hey Mr Porcupine – on what do you dine?'*

'A few sticky flies will suit me just fine.'

*'They're all round my BBQ. Have some of mine.'*

So ends this tale of traveller George

At an Aussie BBQ at Porcupine Gorge.

**Note from Chris:** This rhyme isn't entirely factual. There are no porcupines in the wild, sociable or otherwise, in Australia, but flies are as Aussie as BBQs and Vegemite.

### **For Sale - Portable Oxygen Concentrator**

*Philips Respironics 'SimplyGo' Portable Oxygen Concentrator purchased new for \$7,000.00 is now being offered for sale for \$3,000.00.*

*It offers the benefits of a continuous flow, or pulse, oxygen output while also being portable. It is in excellent condition and is about 3 years old.*

#### ***Inclusions:***

*1x Carrying case*

*1x Mobile Cart*

*1x Rechargeable Lithium Battery*

*1x DC Power Cord*

*1x AC Power Cord*

*1x Accessory Bag*

*1x User Manual*

*if interested please contact **Lisa on 046 663 9838***

## **Travelling with Oxygen – Alison Torr**

Earlier this year I travelled to Europe for a 'social' cycling holiday. I use an electric bike (both at home and overseas). I still have to pedal, but an electric bike enables me to use the motor when I 'run out of puff'.

I was diagnosed with scleroderma 43 years ago and over time this has mainly involved my heart and lungs. Two years ago this developed into Pulmonary Arterial Hypertension (PAH).

I informed my specialist of my upcoming trip and, as my breathing had worsened, she suggested I undertake a High Altitude Simulation Test (HAST). This is a test whereby you breathe into a mask for 20 – 30 minutes which simulates the lower oxygen levels you'd experience at high altitude. This is to see how well your lungs can handle this reduction whilst flying. Following the HAST, I was advised by my specialist to arrange oxygen for my long haul flights.

I was faced with a few choices on how to go about this. At this stage I do not use oxygen at home. Some airlines will provide medical oxygen for a fee. From my research, this means you have to rely on your order reaching the relevant place/people before your flight and, on some airlines, you have to sit in designated seats. I decided not to risk my order for oxygen being unavailable, and to hire an oxygen concentrator instead which I would carry with me on all my flights. Unfortunately this meant I also had to carry the concentrator with me for five weeks in Europe.

After much searching to locate a company that would hire me a concentrator to take overseas, I found Independent Living Specialists in Sydney. The gentleman I liaised with could not have been more helpful – assisting me with how many batteries I would need for the length of flight time, timing of delivery to Canberra, and the best price etc. I was able to hire an Inogen One G5, with 1 x 16 cell and 2 x 8 cell lithium batteries. As four of my flights were 12 – 14 hours, I wanted to make sure I had enough oxygen for the whole journey if needed. I used an Oximeter to regularly monitor my oxygen saturation level and used the concentrator accordingly. I usually try to break the long haul sections of the journey with an overnight stay, but this time it was essential as I had to allow enough time to recharge the batteries (both the concentrator and mine!).

I was travelling on five different airlines - Qantas, Japan Airlines, British Airways, KLM and easyJet. As it turned out, each airline had different protocols for independent carriage of oxygen. I discovered I had to apply for permission to carry the concentrator and batteries on all airlines. As some flights were not long haul, I was able to obtain email approval for travel on Qantas, KLM and easyJet, as I applied to carry the concentrator as hand luggage only. EasyJet did, however, also require a 'doctor's certificate' to be obtained, to say I was fit to travel. I was hoping I wasn't going to need oxygen on such short flights. As it turned out I did have to use the oxygen on both KLM and easyJet, but no one questioned this.

Approval from Japan Airlines was far more complicated. Numerous questionnaires regarding my health and full details of the concentrator and batteries had to be completed by both my doctor and me. JAL would not accept the forms for approval until 14 days before travel. So the last 14 days before departure was certainly a nail biting time, waiting for them to give me approval.

Once travelling, I carried copies of all the approval emails, medical questionnaires etc. I would declare (and show) the concentrator at all the check-in desks and security. I was amazed at the lack of knowledge regarding concentrators by both airline ground and security staff. I was asked each time what 'this thing' was and had to explain its use. Their main concern was the batteries – lithium batteries are limited to a rating of 100 watts per battery, which luckily mine were. I was held up at each stage of my check-in as supervisors were called and mini conferences were held! Luckily, I was able to board each flight. Although I had notified the airlines and sought approval, with the exception of the last flights on JAL, there was no record of my requests in my bookings; luckily, I had all the paperwork to show them.

All in all it was quite an experience. Would I do it this way again? I think the next time (and there always has to be a 'next time' to look forward to) I would carry out more research on each airline regarding what facilities they have on board to hire.



Although I felt reassured in having equipment that, by now, I was familiar with, and could use whenever I needed, the hassle at the airports and fear they would not let me on board was a bit stressful. At least everyone was very supportive and almost apologetic they were holding me up.

It was a good trip – unfortunately tarnished by COVID on my arrival home!

**Editor's Note:** A number of years prior to his transplant your editor also did a HAST test and oxygen was recommended for long haul flights. After a little bit of research your editor made the decision to always fly Qantas on long haul flights (i.e. over four hours), and to use their airline supplied oxygen. The Qantas flight crew were always helpful and knowledgeable. As a passenger who required oxygen you were allocated a seat near to where the oxygen was located and all you had to do was ask a crew member to get the air flowing for you. They would also periodically check on everything. The end result was a satisfied customer.

## September Meeting – Helen Cotter (pictured)

It was good to see an increase in numbers for our September Meeting and we look forward to seeing even more after the **Seniors Expo** on 21 September. We spent some time during the meeting discussing who would be assisting Chris Gray in setting up, looking after, and packing up our information stall.

Other events on the horizon are:

- On the last Friday of September, the 29<sup>th</sup>, we are meeting at the Irish Club for lunch at 12 noon. No need to RSVP, just turn up.
- Next month's lunch is on Friday 27 October at 12 noon at the Mawson Club opposite Mawson shops.
- We planned our **Christmas Lunch** which we would like to hold at the Hellenic Club on Thursday 14 December – 11:15 for 12 noon. This is instead of our December meeting which would normally be on that Thursday. We will confirm in the next Newsletter.

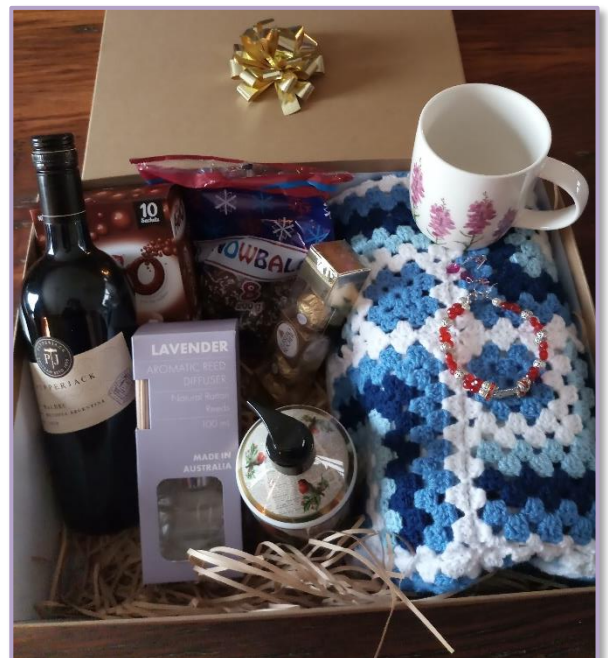
**Please bring some non-perishable donations to the next meeting** for the hampers that we will raffle at the December Christmas lunch.

For any of our lunches, if you want any more details, contact Marilyn:

Phone: 0431 033 825

Email: [zelda2@bigpond.com](mailto:zelda2@bigpond.com)

A month or so ago, we learnt that people who get their newsletters by mail were not receiving them. The mailed newsletters are printed and posted by the ACT Health Service, and we have only recently realised that there has been a problem.



*Here is a photo of the hamper won by Marina in our last raffle at the 'Christmas in July' lunch.*

*Thanks to Val for the photos above and the one on page 6.*

The addresses and other information needed to complete this task had not been passed on to the new person in the job. Hopefully this is now rectified. The newsletter usually goes out around the end of the month. Do let us know if you haven't received yours.

The person to contact is our coordinator, Marina on **042 962 9180** or at [lung.life1@hotmail.com](mailto:lung.life1@hotmail.com).

### Future plans:

We had some discussion about speakers for next year. Marina is hoping to have Raj (the chronic care nurse), and COTA speak at our next two meetings – one at each meeting!

Some suggestions for next year included the police talking about scams, a pharmacist talking about the interaction of drugs, a respiratory specialist, and 'My Aged Care'.

We welcome other suggestions at our next meeting.

In January, our meeting on **Thursday 11 January 2024**, will be a coffee and chat – a catch up on what we've been doing for the past holiday month - followed by lunch for those who wish.

With today's business over we headed for lunch in the bistro.

### August Lunch – Marina and Val Siemionow

Twelve of our members gathered at the *Two Before Ten* in Aranda for our usual monthly luncheon on the last Friday of the month (pictured below). This time we had decided to try somewhere new and were attracted to the cafe by its reputation for showcasing fresh home-grown foods from the cafe's own gardens. What we didn't realise was that the amenities were in the basement, which involved **climbing down 20 stairs** or going outside and walking around the outside of the cafe down a hill! Neither option was possible for a number of our members so we will not be visiting this cafe again. Or at least not until their plans to relocate their amenities upstairs come to fruition. Despite this issue, which did not surface until we were well into our lunch, conversation flowed as usual and for some it continued well into the afternoon.

