



February 2021 Newsletter

Providing a supportive and informative environment for people with a variety of lung conditions and their carers.

Editor: Geoff Cox 042 990 1131
selaca@bigpond.net.au

Coordinator: Lyn Morley 02 6101 6697
lung.life1@hotmail.com

NEXT MEETING: Date to be confirmed
10:15 am - 12 noon
Weston Creek Labor Club
Teesdale Close, Stirling ACT 2611

All 'get togethers' and any updates on meetings will be advised by email.

From the Editor

Your editor was recently asked to do a video shoot to promote organ donation. Each year there is a **Gift of Life Walk**, which is usually a mass participation event, held at the lake. Owing to the current health restrictions they have had to make this event a 'virtual walk' this year. Participants will walk/have walked their own course any time in the last week of February. You can view your editor in the video by going to the **Canberra Lung Life Support Group** Facebook home page. This is a public page, so anyone is able to view it. You can also look at the **Gift of Life Walk** Facebook page to see other personal stories.

The links are: <https://www.facebook.com/GiftofLifeWalk/videos/905828326912266>
<https://www.facebook.com/groups/1854434084857617>.

COPD Part 5 (continuing our series from 2020)

Coping with a flare-up

A COPD flare-up (or exacerbation) is when your symptoms worsen quickly, usually over a few days. It may be caused by an infection (often due to a virus) or triggered by air pollutants or irritants. Flare-ups are more common during the winter months and can make everyday activities difficult. It is important that you can identify the early signs of a flare-up so you can start treatment as soon as possible.

Common symptoms of a flare-up include:

- Coughing more than usual
- Finding it harder to breathe (increased breathlessness)
- Changes in sputum (more, or thicker sputum)
- Being more tired than usual (less active)

If you are experiencing any of the symptoms below you may need to go to hospital as your flare up may be severe.

Phone an ambulance on 000 if you have any of the following:

- You find it hard - harder than normal - to walk
- You can't sleep because of shortness of breath
- You feel drowsy or confused
- Your lips or fingernails have turned grey or blue
- Your heartbeat or pulse is very fast or irregular.

COPD flare-ups are serious!

If you notice symptoms of a flare-up see your doctor as soon as possible. Getting treatment early will reduce the severity of your flare-up and may prevent the need to go to hospital.

Flare-ups can cause permanent damage to your lungs and make your COPD worse. Reduce your risk of a flare-up by:

- Taking your COPD medicines as instructed by your doctor.
- Supporting your immune system with influenza and pneumococcal pneumonia vaccinations.
- Staying away from people (including babies) who have colds, flu, sinus infections and/or sore throats.
- Avoiding things that can make your symptoms worse such as fumes or dust, or cold or very humid air.

Advice from Ian who lives with COPD.

'I believe in doing what I can and being honest with myself about my condition. Planning is a big part of my everyday living. I do this to make sure I conserve energy and can make each day count'.

For more information see <https://lunghealth.lungfoundation.com.au/>.

Celebrity Quotes – have a go at these before turning over

Name the well-known originators of these quotes. Answers are on page 6.

1. **'I told you I was ill'** is written on which comedian's gravestone?
2. Which US President said, **'There have been times in this office when I've wondered how you could do the job if you hadn't been an actor'?**
3. Which actor said, **'Go ahead – make my day'?**
4. **'Float like a butterfly, sting like a bee.'** This even made it into a song or two. Who said it?
5. **'I'll be back'** - another actor?
6. **'Think not what your country can do for you. Think what you can do for your country.'** Out of the USA.
7. Which late musical star said, **'Do what you like with my music but never make me boring'?**

Christine Moyle (this month Chris has written about herself)

In 1996 I stopped working. I was a casualty of a Liberal government's cut-backs but was actually pleased to be out of the Public Service workforce after using up all my sick leave. A few health problems had caught up with me. I'd had been diagnosed with bronchiectasis at about age 10. It probably occurred after an early childhood bout of Pink Disease, which damaged my lungs. The bronchiectasis hasn't affected me too badly throughout my life. Pink Disease (Acrodynia) was caused by mercury in teething powders and was so named because it caused the extremities to turn pink. Dr Cheek discovered the 'cure', which was to remove the mercury from these products. Some young children died and others, like me, survived, but with various long term effects.

A couple of years after retirement, in 1998, I walked the short distance to the Raiders Club to attend the second Lung Life Support Group meeting. I was welcomed by Esther and Cecelia, who ran the meetings. From then on I attended fairly regularly. It was interesting listening to various guest speakers, and I enjoyed the company.

I tapered off for a while at one stage, after new diagnoses such as pseudomonas aeruginosa. I was told these bacteria had colonised my lungs and I'd never get rid of them. This was because I had bronchiectasis. Very worrying. Then the prescribed nebulised antibiotic caused a kidney problem. An ultrasound revealed I had been born with only one kidney, which was in trouble. I then pictured myself going onto dialysis, which greatly increased my anxiety. I felt so overwhelmed that for a while I even felt incapable of driving the car. It was a bad case of catastrophising. Next I commenced an anti-anxiety tablet and very gradually recovered my composure and mental health. So in 2008 I returned to the Lung Group meetings. The pseudomonas had quietened down and I'd dodged the dialysis. Still surviving.

Around this time Helen Cotter took over as Coordinator and I took over her Treasurer duties. Helen then encouraged me to take notes at meetings for the newsletter. I'd started working life in Adelaide and improved my shorthand speed there before moving to Canberra and becoming a shorthand typist/secretary. Later I moved into the clerical/administrative stream but still found shorthand very useful.

And so I've continued with our Group through all these years. At one stage I chaired meetings and organised guest speakers before Lyn and John Morley came along. I keep archival material which includes organising photos on line. It's confidence-building to be able to help with the running of the Group, and it's important to avoid isolation by keeping in touch with people. This group has helped many people over the past two decades and I'm sure it will continue to do so in the coming years. Most importantly I'm pleased to be coping well with chronic illness and, once again – am still surviving!



**Chris, taken at the 22 Year Anniversary Celebration
12 March 2020**



Chris with Fifi at the 22 Year Anniversary Celebration

Bronchiectasis Part 1 (part 2 will be in a future edition of the newsletter)

Overview

Bronchiectasis is a lung disease that occurs when the walls of the breathing tubes or airways widen due to chronic inflammation and/or infection. This results in irreversible damage to the lungs, which allows mucus to pool in the damaged airways. Infection in these breathing tubes contributes to ongoing inflammation in the airways. It may affect many areas of the lung, or it may appear in only one or two areas. Bronchiectasis is characterised by recurrent chest infections (flare-ups).

Who gets bronchiectasis?

This condition can affect people of all ages and can sometimes begin in childhood. Although the incidence is not accurately known, it is more common in women and the elderly and in certain ethnic groups such as Aboriginal and Torres Strait Islander peoples.

Causes

The most commonly known cause of bronchiectasis is having previous infections that damage the airways such as pneumonia, whooping cough or tuberculosis, particularly in childhood. In many cases, however, the cause is unknown. Some conditions that have been linked to bronchiectasis include:

- Pre-existing lung conditions such as severe Chronic Obstructive Pulmonary Disease (COPD) and asthma associated with allergy to the fungus *Aspergillus*
- Immune deficiencies
- Chronic inflammatory diseases that affect connective tissues such as rheumatoid arthritis and inflammatory bowel disease
- Disorders that affect mucus clearance from airways.

Symptoms

The symptoms and signs of bronchiectasis can present at any age. The most common symptoms include:

- Long-term cough (often described as ‘wet’)
- Increased mucus (sputum) production.

Other symptoms include:

- Feeling tired
- Shortness of breath (breathlessness) or wheezing
- Chest discomfort or pain
- Coughing up blood.

Diagnosis

Bronchiectasis has many symptoms in common with other lung diseases. To get the correct treatment, it is important to have an accurate diagnosis. This may include:

- Blood tests
- Sputum tests: identifies germs present in the mucus
- Chest X-ray
- Lung function tests: breathing tests
- High resolution CT scan (HRCT): looks in detail at the lung tissue and airways - this test is usually needed to confirm a diagnosis of bronchiectasis.

For more information see “Overview | Lung Foundation Australia” at the following link:

<https://lungfoundation.com.au/patients-carers/conditions/bronchiectasis/overview/>.

Digital Health Record

The ACT Government is planning to bring in a **Digital Health Record** system at all ACT public health services. It will record all interactions between you and ACT public health services, including Canberra's major hospitals, community health centres and Walk-in Centres. This will improve your care and reduce errors. You'll be able to access your own **Digital Health Record** through a secure website or a mobile app and you can update your information from home and manage future appointments. You may also be able to access patient education materials tailored to your needs. Work is underway to ensure the **Digital Health Record** is safe and secure.

The Difference

The ACT's **Digital Health Record** is a more detailed record than the Federal Government's **My Health Record**, which only holds a summary of key health information.

The **Digital Health Record** will include:

- Data on observations performed by clinicians
- Details about who administered a medication and at what time
- Information from devices such as heart rate monitors
- Information on what bed you are assigned
- Operating theatre bookings, including surgery staffing information.

Both the **Digital Health Record** and the **My Health Record** are useful and complementary. Relevant data from the **Digital Health Record** will be automatically uploaded to the **My Health Record** (for people who have not opted out), as it is now from our current systems. This is all expected to be available in 2022/23. See www.health.act.gov.au/digital/dhr. If you have any questions, suggestions, comments, concerns, or would like to join a mailing list to keep updated on progress please email DHR@act.gov.au or call 02 5124 9000.

HCCA (HCCA Issue 1, 2021) is interested in exploring this idea from a research perspective, and having on line discussions which include a consumer perspective as well as a range of clinical and information technology experts.

If you have an interest in the Digital Health Record and this research work, please get in touch with Kathryn Briant at kathrynbriant@hcca.org.au or call 02 6230 7800. (HCCA Issue 1, 2021).

2020 the COVID-19 Year!

Page 6 of this edition of the newsletter is a pictorial history of life in 2020. In January Australia's eastern regions were burning and in Canberra bush fire smoke became a regular occurrence. Face masks became a 'fashion' item to shield the wearer from the smoke. Their usefulness continued throughout the year as protection against the coronavirus. Toilet paper and hand sanitiser became two of the most sought after items in the supermarket. We learnt to check-in to venues using our smart phones, and gatherings were held under the rules of 'social distancing'.

On the positive side, the ACT catchment area experienced the best rainfall in a number of years and the dams were full to overflowing, and our group celebrated 22 years of being part of the Canberra community.



The Year that was



2020



Answers to Celebrity Quotes

- (1) Spike Milligan, (2) Ronald Reagan, (3) Clint Eastwood, (4) Mohammad Ali,
- (5) Arnold Schwarzenegger, (6) John F Kennedy, (7) Freddie Mercury