

## March 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 14 March 2019  
10:15 am - 12 noon  
Weston Creek Labor Club  
Teesdale Close  
Stirling ACT 2611

**Guest Speaker:** Simon and Arthur  
Lungs in Action - CIT Bruce Campus

### Dates for your diary

Thursday 21 March 2019	Seniors' Expo at Exhibition Park
Thursday 28 March 2019	9:30 am - 11:30 am UC Physiotherapy Students
Wednesday 3 April 2019	1:30 pm - 3:30 pm UC Physiotherapy Students
Friday 5 April 2019	Education Day Seminar, Southern Cross Club
Thursday 11 April 2019	CLLSG Meeting

### February Meeting

**Helen Reynolds**

After Esther marked the roll and we checked among the members present on the health of those absentees we moved into business.

#### Topics discussed:

- The Seniors Expo on Thursday 21 March 2019 at Exhibition Park, an event well worth attending with stands from many government and non-government organisations. Names of members willing to assist on the Canberra Lung Life Support Group stand were taken.
- LFA's Education Day at the Southern Cross Club Woden on Friday 5 April 2019. There will be three speakers giving us the benefit of their knowledge and expertise on informative health topics. More information at later meetings and in later newsletters.

- The list went around the room asking for volunteers for the University of Canberra's physio students. An interesting couple of hours where we get to talk to a captivated audience about our health conditions with an emphasis on respiratory matters. And we get to socialise with the students over morning or afternoon tea.
- All the handheld fans have gone but if anyone is interested in buying one the group decided we should make another bulk order so there will always be fans available.
- On Thursday 21 February 2019 The National Strategic Action Plan for Lung Conditions will be launched at Parliament House by the Minister for Health The Hon Greg Hunt MP.

## Guest Speaker - Claudia Cresswell Lyn Morley

Claudia's presentation was aimed at preparing ourselves for a visit to our GP or specialist. Information is what we need and asking questions is the way to get answers and understanding. This can be done by writing a list of questions to ask the doctor or specialist, mainly so you don't forget what you would like to know about your medical condition. Asking questions puts the patient in a better position to make the best healthcare decisions for themselves.

### **5 questions to ask your doctor or other health care**

**provider before you get any test, treatment or procedure.**

**Some tests, treatments and procedures provide little benefit.**

**And in some cases, they may even cause harm.**

**Use the 5 questions to make sure you end up with the right amount of care - not too much and not too little.**

#### **1. DO I REALLY NEED THIS TEST OR PROCEDURE?**

Tests may help you and your doctor or other health care provider determine the problem. Procedures may help to treat it.

#### **2. WHAT ARE THE RISKS?**

Will there be side effects? What are the chances of getting results that aren't accurate? Could that lead to more testing or another procedure?

#### **3. ARE THERE SIMPLER, SAFER OPTIONS?**

Sometimes all you need to do is make lifestyle changes, such as eating healthier foods or exercising more.

#### **4. WHAT HAPPENS IF I DON'T DO ANYTHING?**

Ask if your condition might get worse - or better - if you don't have the test or procedure right away.

#### **5. WHAT ARE THE COSTS?**

Costs can be financial, emotional or a cost of your time. Where there is a cost to the community, is the cost reasonable or is there a cheaper alternative?



Claudia works for Health Care Consumers Association (HCCA) in the Health Promotions Arm. She teaches people how to better understand and use the health system.

### Some more questions a patient may ask are:

- What is the name of the condition?
- How serious is it?
- What causes it?
- Is it likely to get better?
- What treatment is required?
- Is there anything I can do to improve it myself?
- Are there support groups for people with this problem?
- What are the possible side effects?
- How much will the treatment cost?
- How long will the treatment be?
- Does Medicare, a Private Health Fund or any concession cards cover the cost of the treatment?

There are many questions a patient can ask about medicines and tests the doctor may want the patient to have as well. Remember be prepared! Write down your questions. Write down the answers.

Claudia also counselled us to keep a copy of our own health records, reports and test results for future reference as eHealth records only basic general health information about the patient.

Claudia's talk was so informative it was decided we should invite her back later in the year to be our guest speaker. On that occasion those of us who have a laptop will be asked to bring it along so we can have a morning of "hands on" experience navigating safe and relevant medical information on the web.

**Source:** [www.choosingwisely.org.au/resources/consumers/5-questions-to-ask-your-doctor/](http://www.choosingwisely.org.au/resources/consumers/5-questions-to-ask-your-doctor/)

## National Strategic Action Plan for Lung Conditions February 2019 Helen Reynolds

Professor Christine Jenkins AM, Chair, Lung Foundation Australia, writes in the Foreword of the *National Strategic Action Plan for Lung Conditions February 2019* and reiterated her belief when she spoke at the launch of the document: "You only need to look at the facts. Seven million Australians - that is almost one in three people - live with a lung condition" and "Of the leading causes of death in this country, lung disease is the second biggest, following closely behind heart disease."

This **Action Plan**, commissioned by the Department of Health and launched on 21 February 2019 by Minister for Health The Hon Greg Hunt MP articulates six high-level national priorities that together aim to improve the lives of all Australians through better lung health.



Minister for Health The Hon Greg Hunt MP officially launching the Action Plan.

The **Action Plan** outlines a comprehensive, collaborative and evidence-based approach to reducing the individual and societal burden of lung conditions and improving lung health. The plan addresses the broad spectrum of lung conditions, ranging from the common cold which impacts the health of many Australians and their participation in the workforce, education and social activities, to lung cancer which

is Australia's biggest cancer killer with an estimated 9,020 deaths in 2017, more than breast, prostate and ovarian cancers combined.



The Canberra Lung Life Support Group was well represented by Helen and Kaye in the front row and Jan, Terry and Helen in the second row. Peter was there too but he wasn't sitting with us.

The **Action Plan** has a strong focus on:

- Addressing health determinants and risk factors for lung conditions to enhance the lung health of the Australian community.
- Optimising quality of life for people with lung conditions.
- Redressing areas of poorer health outcomes and unmet needs.
- Action at the wider health-system level to ensure real and lasting improvement for all Australians.
- Delivering tangible improvements in health outcomes, equity and economic benefits.

The **Action Plan** articulates a goal supported by *six high-level priorities* that together aim *to improve the lives of all Australians through better lung health*. Each priority has a number of *recommended actions* informed by evidence and these actions are detailed within this Action Plan. Below is an outline of the goal, six high-level priorities and a key objective for each priority area.

**Goal: To improve the lives of all Australians through better lung health.**

Priority Areas	Objectives
1. Prevention and risk reduction.	Prevent lung conditions and reduce the risk of lung disease.
2. Awareness and stigma.	Raise awareness about lung conditions and reduce stigma, discrimination and social isolation.
3. Diagnosis management and care.	Translate science into quality diagnosis, management and care of lung conditions.
4. Partners in health.	Support people with lung conditions to participate in shared decision making and self management.
5. Equitable access.	Ensure equitable and timely access to evidence based diagnosis and management of lung conditions.
6. Research and monitoring.	Increase research capacity to redress under resourcing of research into highly prevalent lung condition.

An evaluation framework is proposed to assess progress of the **Action Plan** over a five year period.

Together with lung health experts, health professionals, and over 500 patients and family members who provided feedback, Lung Foundation Australia put together this **Action Plan** to help make lung health a priority.

The **Action Plan** outlines how, together, we can reduce the individual and societal burden of lung conditions and improve lung health for all. It addresses the broad spectrum of lung conditions, ranging from the common cold to lung cancer.

## Why does it matter?

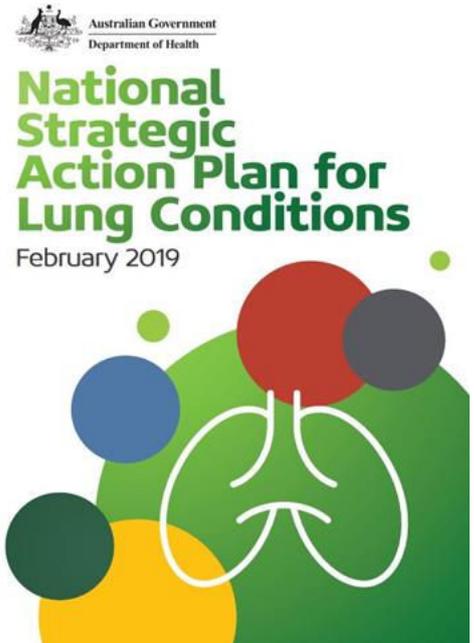
Over the past decades, conditions like breast and prostate cancer have received funding, but many lung conditions continue to be stigmatised and drastically underfunded. In Australia, seven million people (almost one in three) live with a lung condition. That's why we're advocating making lung health a priority.

## What's next?

Thanks to a \$4 million funding commitment from the Federal Minister for Health, The Hon Greg Hunt, we can start work on three of the 21 recommendations outlined in the **Action Plan**. But we need your continued support to champion the need for increased funding, and to encourage politicians to adopt all of the recommendations from the **Action Plan**. We must continue to remind Australians that lung conditions are devastating, and they need our utmost care, diligence, and focus in the weeks, months and years to come.

*Source: National Strategic Action Plan for Lung Conditions February 2019*

[www.lungfoundation.com.au/news/what-is-the-national-strategic-action-plan-for-lung-conditions/](http://www.lungfoundation.com.au/news/what-is-the-national-strategic-action-plan-for-lung-conditions/)



## The future is coming: stem Cell treatment

Adapted from: [www.choice.com.au](http://www.choice.com.au)

Researchers are looking into many different ways to cure our illnesses - one of these is by using the body's stem cells. Stem cells are cells that can divide and multiply indefinitely. Stem cells from embryos (**embryonic stem cells**) change into all the different cells that make up our body - skin, bones, organs, nerves etc. We've known for years that these embryonic stem cells are useful for replacing any type of faulty cells. But there are ethical issues about using stem cells from embryos and this has limited the development of treatments.

Stem cells from adults (**adult stem cells**) are being increasingly investigated in the treatment of many diseases and conditions. Adult stem cells can divide to make more of the same type of cells. They have been used for years to treat leukaemia and other blood disorders, some cancers and some auto immune disorders. For these treatments, the stem cells have been taken from blood in the bone marrow or cord. But recent developments have enabled use of specialised cells, such as fat, blood or skin cells and this has opened up the field in stem cell treatment - also called **regenerative medicine**.

### If you want more information:

Stem Cells Australia is a multidisciplinary team of experts in bioengineering, nanotechnology, stem cell biology, advanced molecular analysis and clinical research, conducting research in stem cell science. It's also involved in public education and research into ethical and legal aspects of stem cell science.

[www.stemcellsaustralia.edu.au](http://www.stemcellsaustralia.edu.au)

The Therapeutic Goods Administration (TGA) has a question and answer guide for consumers on stem cell therapy and regulation. [www.tga.gov.au](http://www.tga.gov.au)

CHOICE has a detailed article on **stem cell therapy** that much of this information was taken from.

See [www.choice.com.au](http://www.choice.com.au) last update 28 December 2017.

There are some clinical trials in process and many private clinics offering treatment for a wide range of diseases and conditions. Some people are even going overseas for treatment - 'stem cell tourism'. People from Canberra need to go to another city such as Sydney or Melbourne for treatment. The treatment is quick: they take cells from your fat or blood, extract the stem cells and transfuse them into your body. Then you go home and wait for the effect. The improvement may only be small - perhaps about 20% - but it can be repeated to try for further improvement. As it is private treatment - apart from the trials - it adds up to being quite expensive.

## **Lesley Lee's experience**

Lesley has bronchiectasis and a cavity in the lung, has lost a lot of weight and has found doing things quite a challenge. She finally decided to give stem cell treatment a go. She had an initial consultation at home via Skype; then flew to Melbourne in late October 2018 to undergo the therapy.

Her respiratory specialist, Dr Hurwitz, has supported Lesley in her decision and has spoken by phone to her treating doctor in Melbourne. In the Melbourne clinic, Lesley had three separate appointments over a weekend:

- The doctors took 16 vials of blood, 4 to check the blood; and 12 to separate the plasma from the blood
- Three hours later, the plasma extracted from the spun blood was injected via a muscle
- The next day, the stem cells were introduced into her body via a drip.

Then, she returned to Canberra, somewhat exhausted after the whole process.

At home, Lesley had to be careful about what she did, at least for a month. She felt no different for a while but then began to put on more weight and felt generally better in herself with a little more energy. She looked a different person.

In January 2019, Lesley had a second treatment in Melbourne. This time she borrowed the POC we loan out - we were pleased the POC was being used for such a reason. Unfortunately, she has - up to this time - felt no noticeable improvements after the treatment and has lost some of the weight she had gained. However, there's still hope things might improve with the cooler weather - fingers crossed.

Lesley has found the Melbourne Clinic to be very supportive and available - even on the weekends. The Clinic doctor has emphasized that this is experimental treatment with no guarantees. But every treatment also helps to further knowledge about how to use stem cells to treat many conditions effectively. It's an exciting area of research. As a support group for people with lung conditions, we hope stem cell therapy becomes successful soon.

### **10 Facts about you.**

- 1. You're reading this right now.**
- 2. You're realising that is a stupid fact.**
- 4. You didn't notice I skipped 3.**
- 5. You're checking now.**
- 6. You're smiling.**
- 7. You're still reading even though it's stupid.**
- 9. You didn't notice I skipped 8.**
- 10. You're checking again smiling about how you fell for it again.**
- 11. You're enjoying this.**
- 12. You didn't realise there's only supposed to be 10.**