

# **August 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 8 August 2019

10:15 am - 12 noon

Weston Creek Labor Club

Teesdale Close, Stirling ACT 2611

Of particular interest to the males in the Group is the Men's Shed. At the meeting there will be a representative from the Tuggeranong Men's Shed to answer everyone's questions regarding this important social outlet.

## Dates for your diary

Thursday 12 September 2019 CLLSG Meeting Wednesday 20 November 2019 World COPD Day

# July Meeting Helen Cotter

#### Discussion and decisions:

• Today Lyn reminded us of the very successful mid-winter lunch we had at the Irish Club. Over twenty people enjoyed their pre-ordered lunches in a room to ourselves. Ebba recently turned 99, so we had a lovely cake for her – which took Ebba completely by surprise. As Helen Reynolds said at the meeting, Ebba is an inspiration to us all. With her compromised lung capacity she is still able to blow out her birthday candles.



Happy Birthday Ebba. You are absolutely remarkable.

- Esther ran a lovely raffle and door prizes with many people winning a prize. We raised \$127. It was a lovely event.
- Lyn updated us on how Geoff Cox is faring. After his recent lung transplant he is still in Sydney but is now out of hospital.
- Then we moved on to planning our celebration of 22 years of Canberra Lung Life Support Group.
  - ♦ Lyn and John reported on their findings relating to possible venues.

Members Lyn, John and Chris are having a wonderful time.

- After a somewhat lively discussion
  the Group voted and the decision was made to take advantage of what was offered by the
  Weston Creek Labor Club, the venue for our monthly meetings.
- ♦ After discussion the date for the event was agreed upon Thursday 12 March 2020, commencing at 11:00 am and followed by lunch.
- ♦ Chris and Helen volunteered to collect photos and write the history. Marina, a relatively new member, volunteered to do the Power Point Presentation.
- Planning for Anniversary Celebration will be included on the agenda for all monthly meetings.

# **Celebrating 22 Years of Lung Life Support Group**

At the Weston Creek Labor Club, Stirling Thursday 12 March 2020 From 11:00 am followed by lunch

For members, family, friends and interested others

As the event is eight months away we are still planning. We hope to have:

- photos of the people and events over the past 22 years
- some of the early members talking about those days
- a look at what Lung Life has been involved in over those 22 years
- a lovely lunch.

It's a great opportunity to celebrate what Lung Life has achieved and the people who helped it along.

Early next year, we will be asking you to let us know if you are coming. At the moment, we want you to make sure you are available on that date. If you know already or want to make sure you are kept up to date, let our Coordinator Lyn Morley know on the Lung Life email address: <a href="mailto:lung.life1@hotmail.com">lung.life1@hotmail.com</a> or phone her on: 02 6291 0626.

# Lauris Andrew Helen Cotter

In late June we were saddened to learn that Lauris had passed away. Lauris had been on oxygen for many years but recently hadn't been feeling well at all. She went into hospital and a few days later, died.

Lauris was very musical and artistic – as well as a good organiser. She was dux of her school in music and went on to become a teacher. During her life, her family had a farm in Victoria and a sheep property in Bombala. Upon moving to Canberra she continued her music teaching at various Canberra schools. Also during all that time, she raised five



sons of whom Stewart is the oldest and James the second youngest, both known to us here in the Canberra Lung Life Support Group.

While I was Coordinator, Lauris was one of the members who provided ideas and suggestions – or was a good sounding board – for submissions and input on other issues. It is always good to have people like that.

Despite having difficulty getting around, Lauris attended as many meetings as she could, assisted by one of her sons – either Stewart or James. She was a lovely lady – always very positive. A sad loss.

## A Little Light Relief

Here is a little light relief to put a smile on your face and a song in your heart, with thanks to the *Nepean Puffers and Wheezers*.

#### The Burglar

A burglar has just made it into the house. His intention is to ransack the house and he's looking around for stuff to steal. Suddenly, a little voice pipes up, "I can see you, and so can Jesus!"

Startled, the burglar looks around the room. No one is there at all, so he goes back to his business.

"I can see you, and so can Jesus!"

The burglar jumps again, and takes a longer look around the room. Over in the corner by the window, almost obscured by curtains, is a cage in which sits a parrot, who pipes up again, "I can see you, and so can Jesus!"

"So what?" says the burglar. "You're only a parrot!"

To which the parrot replies, "Maybe, but Jesus is our Rottweiler!"

# Home Care Package Services - Part 1 Helen Reynolds

A Home Care Package provides Government funded services that can help you to live independently in your own home for as long as is feasible. The benefit of a home care package is that your home care provider will work with you to:

- choose care and services that best meet your needs and goals
- manage your care and services
- provide choice and flexibility in the way that the care and support is provided.

Home Care Packages (HCP) are one of the ways that older Australians can access affordable care services to get some help at home. They are designed for those with more complex care needs that go beyond what the Commonwealth Home Support Programme can provide. Home Care Packages can be an option if you need a coordinated approach to the delivery of your help at home - perhaps because you need help with many everyday tasks, or the care you need is more complex or intensive.

### What help can I get?

Depending on the level of Home Care Package you receive, you can get assistance with services such as:

## Services that keep me well and independent

Personal care	Help with showering, self-care, hygiene and grooming
Nursing	Wound management or help with medicines
Allied health and therapy services	Health and therapy services e.g. podiatry, physiotherapy, and occupational therapy
Specialised support	Help for people with a particular condition e.g. vision, dementia
Meal preparation and diet	Help with feeding, meal preparation, and using eating utensils

## Services that keep me safe in my home

Domestic assistance	Help with basic chores around the house
Home maintenance	Help with keeping your home and garden safe
Home modifications	Changes to your home to improve safety and access e.g. ramps and rails
Goods, equipment and assistive technology	Items to help you get around or adapt e.g. walking frame, shower chair

#### Services that allow me to interact with my community

Transport	Community transport, transport to GP
Social support	Social activities in a community-based group setting or accompanied activities

## Who provides these services?

Services are provided by a variety of organisations across Australia. You choose a service provider that is right for you. The government then pays your provider a subsidy to arrange a package of care services to meet your needs. As everyone's care needs are different, there are four levels of Home Care Packages with different funding amounts. These cover basic support needs through to high care needs. The package level assigned to you is based on your needs.

Package level	Level of care needs
Level 1	Basic care needs – approximately \$8,750 a year
Level 2	Low care needs – approximately \$15,250 a year
Level 3	Intermediate care needs – approximately \$33,500 a year
Level 4	High care needs – approximately \$50,750 a year

<sup>\*</sup> These figures are rounded.

You work with your chosen provider to identify your care needs and decide how best to spend your package funding. Your service provider coordinates and can manage your services for you on your behalf.

#### What will it cost me?

You're expected to contribute to the cost of your care if you can afford it. Your contribution is made up of three types of fees:

- 1. Basic daily fee (up to \$10.54 per day from 1 July 2019)
  - This is up to \$9.44 per day for Level 1, up to \$9.99 per day for Level 2, up to \$10.27 per day for Level 3, and up to \$10.54 per day for Level 4. Your provider may ask you to pay a basic daily fee based on your home care package level.
- 2. Income-tested care fee (up to \$30.25 per day from 20 March 2019).

Some people may also have to pay an income-tested care fee. Whether you pay it, and how much of it you pay, is determined through a formal income assessment from the Department of Human Services. If you have to pay this fee, there are annual and lifetime limits on how much you can be asked to pay.

#### 3. Additional fees

Any other amount you have agreed to pay for extra care and services that wouldn't otherwise be covered by your Home Care Package.

#### Am I eligible?

Eligibility is based on your care needs as determined through a face-to-face assessment, but you must also be:

- an older person who needs coordinated services to help them stay at home, or
- a younger person with a disability, dementia or other care needs not met through other specialist services.

Your financial situation won't affect your eligibility. However you will need a financial assessment to work out exactly how much you may be asked to contribute. If you think you only need a low level of support - perhaps only one or two services - you may not need a Home Care Package. You may be more suited for help at home through the Commonwealth Home Support Programme. Details are at <a href="https://www.myagedcare.gov.au/node/21">www.myagedcare.gov.au/node/21</a>.

### How long will it take to get a Home Care Package?

After you have been assessed as being eligible, how long it takes to get a Home Care Package depends on what package level you are eligible for. The expected wait time for approved Home Care Package levels to become available is:

Package level	Approximate wait time
Level 1	3 - 6 months
Level 2	12+ months
Level 3	12+ months
Level 4	12+ months

<sup>\*</sup> Last revised 31 May 2019

How urgently someone needs services can also impact on how long it may take to receive a Home Care Package. Those with higher or more urgent needs are prioritised to receive services.

Sources: www.agedcareguide.com.au/home-care-packages

www.myagedcare.gov.au/help-at-home/home-care-packages

# Lesley Lee and Stem Cell Therapy Helen Cotter

In late June we read of the death of **Lesley Lee** in the newspaper. Last October, Lesley borrowed our POC to go to Melbourne to undergo stem cell therapy for her lung condition. Lesley had bronchiectasis and a cavity in the lung, had lost a lot of weight and found life challenging, and so she decided to give stem cells a go.

Stem cells are cells in our body that can divide and multiply indefinitely and are increasingly being used in the treatment of many diseases and conditions. They've 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 although this work is still experimental with varied results. Blood cells were used in Lesley's case. The doctor took her blood and on the next day gave her, via a drip, the stem cells taken from the blood.

It seemed to work – Lesley felt better and put on weight - so in January this year, she returned to Melbourne for a second treatment. However, this time, there was no improvement and, sadly, Lesley passed away in late June.

Stem cell therapy is still experimental for lung conditions with no guarantee of success — which Lesley knew. We were sorry to hear of her death. It would be lovely to know that stem cell therapy was now a successful form of treatment — but it's also good to know that it's a possible form of treatment in the future — hopefully in the near future.