



September 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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NEXT MEETING: Thursday 8 October 2026
11:30 am – 1:15 pm
Weston Creek Labor Club
Teesdale Close, Stirling ACT 2611

Speaker: Alicia from Lung Foundation Australia, talking to us about what it does, the services it offers and, how we can access its many support services.

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

This month's newsletter contains information on two organisations that help you deal with issues related to the Aged Care system or the health system. It's good to know that these organisations exist as sometimes it's difficult to know where to turn to when you are unhappy with a service.

The newsletter has other interesting items that you'll find as you read further.

September Meeting

We had a good roll up today. Marina talked about the following items:

- ✚ Seniors Expo – on Wednesday 24 and Thursday 25 September. Marina was checking some final organisation. By the time you get this newsletter, the Expo will be over but you'll find out how it went in the next newsletter.
- ✚ Our brochures have been reprinted with our new meeting times. They'll be available at the Expo.
- ✚ We are currently deciding on a venue for Christmas Lunch (Friday 11 December).
- ✚ Marilyn will be organising hampers for the Christmas lunch; **so please bring some suitable non-perishable goods to the next meeting to fill the hampers.**
- ✚ We are having a raffle to raffle off two \$100 vouchers for a meal at Vikings; and a beautiful enamel pin. Please contact Marina for some tickets to sell for the raffle.

- ✚ We have two more meetings – one in October; and the final for the year in November. We have the Christmas lunch in December instead of a meeting.



Then on to our Speakers: **Jojo and Thomas from ADACAS**

ADACAS (*ACT Disability, Aged and Carer Advocacy Service*) is an organisation set up to protect and promote the rights of people with a disability, people experiencing mental ill health, older people and carers. Jojo and Thomas are here to talk about older people and aged care.

ADACAS is an independent organisation which provides free advocacy and information. Their focus is assisting the client. If you have an issue with your aged care service or getting your aged care provider to understand your concerns or with the Aged Care system itself, ADACAS can support you with your issue.



They can help you access services or explain options and steps to fix the issue. They can also help you to understand aged care costs, financial statements (eg from your provider) and pay arrangements.

ADACAS is part of the OPAN's national network to ensure that older people have access to safe, high quality care. OPAN (**Older Persons Advocacy Network**) is a national service, funded by the **Australian Department of Health and Aged Care** through the **National Aged Care Advocacy Program (NACAP)**. It operates a network of state and territory advocacy organisations - of which ADACAS is one - ensuring local access to services.

OPAN provides an advocacy line which connects to your local organisation: **1800 700 600**

To contact ADACAS:

Phone the OPAN number – 1800 700 600

Email: adacas@adacas.org.au

Website: www.adacas.org.au .A very user friendly website.

Mary's advocacy story

From ADACAS

Mary is 80 years old, lives in her own home and receives services under a level 2 Home Care Package. Mary saw incorrect charges on her monthly statement. She called her provider but they didn't answer or return her calls, so she called the Aged Care Advocacy number (in Canberra, it's ADACAS). The advocate visited her at her home, reviewed her statement and talked about her services.

With Mary's consent, the advocate contacted the provider, raising the concerns about incorrect charges and poor communication. The advocate asked for a refund and arranged a care plan review meeting for Mary with her provider. The provider reviewed the charges and refunded Mary \$1000 to her package.

Mary's physiotherapist had recommended Mary buy new equipment to help her sleep but Mary didn't know how to get the new equipment. The advocate raised this with the provider who then contacted My Aged Care to request a new assessment for a higher package which would enable Mary to get the equipment.

An Update From The Co-ordinator - Marina Siemionow

Once again, this month, my commitments piled up in the second half of the month. Apart from taking part in my regular Lung Life events (our monthly meeting, the bimonthly Advisory Group Meeting, which is the decision-making body for our support group, the monthly Peer Support Leaders Meeting, and our regular monthly lunch) I became involved in 2 very interesting reviews through the Health Care Consumers Association (HCCA).

Over the month I found myself spending a number of evenings reading and reviewing papers and proposals in preparation for discussions at upcoming meetings.



The Health Care Consumers Association (HCCA): Reviewing the Third Edition of the National Safety and Quality Health Service Standards.

The HCCA is a health promotion organisation working to improve the quality and safety of health services, and advocating for health equity for all of us, living in the Canberra region. Every state has its own version of this organisation but few are as active and involved as ours. HCCA works closely with members, local communities, the ACT Government, service providers, media and non-government and voluntary organisations to improve the quality and safety of health services in the ACT. It receives some federal government funding and donations, to represent the views and priorities of members.

Currently it is heavily involved in reviewing the third edition of the **National Safety and Quality Health Service (NSQHS) Standards**. These standards are designed by the Australian Commission on Safety and Quality in Health Care in collaboration with the Australian Government, States and Territories, the private sector, clinical experts, patients and carers. **The Standards aim to protect the public from harm and improve the quality of healthcare across Australia.** They are used to accredit health services and ensure that all health services deliver safe and person-centred care to all Australians.

This third edition, which is currently under development, is scheduled for release in 2028, and will be followed by a period of transition before assessments against the new Standards begin in 2030. This revised set of standards has a strong focus on Person-Centred Care.

I was involved in a couple of discussions over several meetings, debating the proposed standards. We agreed that the stated aims of the standards were admirable, but we had concerns about how health services would put them into practice. We made numerous recommendations about developing much stronger measures and clear outcomes, to support health services bringing them to life.

The second review I took part in was through a special feedback session on “**Access and Affordability to Private Specialists**” organised by the Chronic Conditions Network, also part of the HCCA. The Australian Government is currently consulting on reform options to make private specialist services more affordable and accessible. We had discussed this issue at our August meeting so I was able to present our members’ experiences and views to the workshop for inclusion in the HCCA submission to the Federal Government.

Finally my last meeting for the month was the **Domiciliary Oxygen and Respiratory Support Scheme (DORSS) Advisory Committee** Meeting, on Friday 28th August. The scheme provides oxygen and respiratory equipment to eligible people in the ACT and I represent consumers on the committee.

Encouraging news for IPF sufferers

From Maureen Bell



To date there have only been two medications to slow down the progression of Idiopathic Pulmonary Fibrosis, Pirfenidone and Nintedanib. Both of these have had side effects for many, although I've had no side effects from Pirfenidone in the 10 years or so that it's been available.

I have been in a clinical trial run by Boehringer Ingelheim for the past two years, and the ongoing trial since the main trial finished, of the drug Nerandomilast. It is now fully approved in the US and has the brand name of Jascayd. It is not curative but slows or stops deterioration of lung function.

The good news is that it has now been approved in Australia by the Therapeutic Goods Administration and it will be considered by the Pharmaceutical Benefits Advisory Committee before long for inclusion in the PBS. They sent me a survey to complete, to tell them of my experience with the drug while on the clinical trial. I was able to give a favourable report as I have had no lung deterioration since taking it, nor any side effects.

I will let you know of the committee's decision.



September meeting

Complaints about health services in ACT? Contact Health Services Commission

[Health Service - HRC](#)

The **ACT Health Services Commission**, under the auspices of the **ACT Human Rights Commission**, handles complaints about the provision of health services in the ACT and complaints about access to and integrity of health records in the ACT.

The role of the Health Services Commissioner also includes:

- Supporting improvements in the provision of health services
- Promoting awareness of the rights of users of health services
- Raising awareness of the responsibilities of providers of health services.

It can deal with complaints about all health services provided by the ACT – public and private, services provided at a hospital, a general practice and all individual registered practitioners.

Complaints about individual practitioners may be dealt with in conjunction with the Australian Health Practitioner Regulation Agency (AHPRA [Australian Health Practitioner Regulation Agency - Home](#)).

The Commission generally tries to resolve health related complaints through **conciliation** with the health service or with the health practitioner. You can contact them online by filling out a complaint form: [Contact Us - HRC](#); or phoning [\(02\) 6205 2222](#) or by emailing human.rights@act.gov.au or by mail: GPO Box 158 Canberra ACT 2601.

Some examples of dispute resolutions

Discharge planning concerns

A man contacted the Commission to raise concerns that his wife, who had suffered a stroke, was about to be discharged from hospital before she was able to talk or move independently. The man told the Commission his wife had not received adequate rehabilitation and her needs for managing at home had not been adequately assessed. He was concerned about the potential impact on his wife's long-term recovery if she were discharged before receiving these supports.

The Commission contacted the hospital to request information about the discharge process.

A review was undertaken and it was decided the woman could stay as an inpatient for a period of time to receive further rehabilitation and to enable appropriate discharge planning. The hospital arranged a family meeting to discuss the family's situation and the range of supports needed to enable her to return home.

Mobility parking permit

A disability advocate lodged a complaint on behalf of their client about disability discrimination in the provision of goods, services and facilities by a government agency. The advocate said their client had received parking infringements because he had displayed a copy of his mobility parking permit on his vehicle rather than the original. The person used a copy of the permit because he found it difficult to reach the permit and transfer it from one vehicle to another due to his physical disabilities. He also said that numerous parking inspectors had told him it was reasonable for him to use a copy of his permit.

In response, the agency explained that it is a strict liability offence for a person to display a copy of a parking permit. After several discussions with the agency to explore alternative options, the agency agreed to provide the person with a second mobility parking permit.

Accessing a restaurant with an assistance animal

A man lodged a disability discrimination complaint against a restaurant after being denied access because of his guide dog.

The matter was resolved in conciliation with the restaurant providing the man with a written apology and providing an undertaking to allow people with assistance animals the choice to dine either inside or outside, in accordance with their preference and in keeping with the choice provided to other customers.

Cystic fibrosis doesn't just affect the lungs. It's a gut disease too

<https://theconversation.com/cystic-fibrosis-doesnt-just-affect-the-lungs-its-a-gut-disease-too-283769>

July 2026 by [\(Keith\) Chee Y. Ooi](#), Professor of Medicine, UNSW Sydney

What exactly is cystic fibrosis?

Cystic fibrosis is caused by mutations in the CFTR gene which would normally produce a protein that helps move water and other contents across the surfaces of organs, keeping mucus and secretions thin and flowing normally. But when genetic mutations lead to a faulty protein, mucus and secretions become thick and sticky which can then become colonised by harmful microbes in the lungs and gut, leading to inflammation.

In Australia and countries with established newborn screening programs, most cases are now detected through newborn screening (via the heel-prick blood test). However, milder forms of cystic fibrosis or people who carry rare mutations can sometimes be diagnosed later in life.

Now let's take a look at three other **common misconceptions** about cystic fibrosis in detail.

Myth 1: cystic fibrosis is mainly a lung disease

The earliest signs of cystic fibrosis begin in the gastrointestinal tract – even before birth. It can be first detected during routine antenatal scans showing bowel changes, or at birth with symptoms of bowel obstruction. As survival has improved, gastrointestinal complications are increasingly being recognised. These include bowel obstruction, severe constipation, stomach pains, gastroesophageal reflux or nausea as well as gastrointestinal cancers.

Myth 2: cystic fibrosis is a death sentence

Today, more adults are living with cystic fibrosis, with a predicted survival age of 64 years for those born in 2019–2023. Introduction of newborn screening, along with earlier support and treatment for nutritional and lung issues, have all contributed to longer life expectancy.

The biggest and most recent transformation has come from a class of medicines called [CFTR modulators](#) which can substantially restore the function of the faulty CFTR protein.

Myth 3: we now have a cure

However, current medicines, including CFTR modulators, do not fully reverse organ damage. Not everyone is eligible for them, and responses vary between individuals. Researchers are now trying to better understand the gut side of cystic fibrosis, including the role of diet, gut inflammation and the gut microbiome (the body's dynamic community of microorganisms).

For now, the story of cystic fibrosis is no longer simply about surviving lung disease. It is increasingly about understanding how a genetic condition affects the entire body – and ensuring people living longer with cystic fibrosis can also live well.