Spring 2020
Sep- Nov

Breath of L I F E

Lung Information & Friendship for Everyone

People with long term lung conditions, their family & carers

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Read it online here

SPRING

The last issue of Breath of L I F E was packed with information about the Covid-19 virus. The world pandemic has been going on for six months now! Who would have believed we could last this long? But we have. And spring has come. Spring is usually an optimistic time - if not for the situation on the east coast of Australia.

Now it's time to look forward to a future together as L I F E. **We plan to meet face to face on Wed 7 Oct!** More on page 2.

This issue looks more like our old Breath of L I F E with the usual sections plus information about keeping safe from Covid-19.

We have news from the L I F E leadership team and the regular Shorts column, featuring respiratory research news from across the world, including some local research projects. Pulmonary poetry makes a re-entry thanks to a contribution from member David Payne and there are some easy exercise videos that will get you up, moving and keeping warm. Member Frances Hills, who was stranded on a cruise ship off the coast of South America in April, gives an update on their recent Covid adventures. As usual there are some lung laughs. All in all, almost a return to the old Breath of L I F E that you are used to.

This issue is available online, except for members who don't have email. You can revert to a posted copy if you wish, provided you are a financial community member. Just let us know. Contact details on page 28. Click on a blue underlined link to take you to a webpage or another part of this issue.

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Please consider…

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Up to two-thirds of annual membership fees get absorbed by printing & postage.

An e-copy – gives you a full colour magazine with clickable links, saves trees, and lets more of your membership fee support L I F E and the Institute for Respiratory Health.
Contact us
life@resphealth.uwa.edu.au

Breath of L I F E Archives

A digital copy of each issue of Breath of L I F E is lodged with the State Library of WA and the National Library of Australia, via their E-Deposit Scheme. Our digital record number (ISSN) appears in the top right corner of the cover.

Started as LISA News in 1993, we became the Breath of L I F E in 2009.

WHAT'S INSIDE

L I F E EVENTS

Recently

Meetings and Social Events

L I F E has still not met as a group since Wed 4 March although the leadership team of Sal, David, Gaye and Jenni have been meeting by Zoom monthly to review the situation. We have also been joining in virtual (online) meetings with other support group leaders from around Australia, hosted by Lung Foundation Australia.

Coming up!!

We are pleased to announce we will resume face to face meetings on

Wed 2 October at 12 noon

Social meeting – no speaker. Let's catch up at last!

New conditions to make it safe for everyone

- All meetings are subject to change if the Covid-19 situation changes in WA. Confirm with Sal, Gaye, David or Jenni, contacts below.
- If you are feeling unwell, please stay home and get well soon.
- Please bring your own mug and your own food. No shared food.
- Please bring your own hand sanitiser. Use it every time you leave a bus or train and in the meeting room.
- If your mobile phone has the capacity please download, and turn on

the Covid-Safe app.

- You can have a contactless temperature scan at the Perkins building entry and can sanitise your hands before entering the lift and room the meeting room 612A.
- While in 612A please observe 1.5 metre physical distancing at all times.
- Wearing a mask is optional but encouraged, especially when on public transport where distancing is often difficult. L I F E member Tom says sitting up the front of the train often allows better distancing. Avoid public transport if you can. If you can't, take all precautions.

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Jenni Ibrahim 9382 4678 life@resphealth.uwa.edu.au

On 4 November we'll have hospital pharmacist Jo Armstrong speaking about medicines and on 2 December our traditional **(Covid-19-safe) Christmas party** (more details, next issue). Meeting details on page 28.

Join our L I F E Telephone Tree - get the latest news and keep in touch.

L I F E NEWS

Subscriptions fell due for many (but not all) members on 1 July 2020. Others will receive a letter or email reminder to renew just before the anniversary of the month they joined. On page 28 (para 4) you can read how to renew – online or by phone with a credit or debit card. At present there's no way to renew by cash - until the October meeting. If your membership is due now and you want to pay by cash when we meet, just let Alison know T 6151 0797 or E alison.harvie@resphealth.uwa.edu.au .

We recently received a small grant from ConnectGroups to have our L I F E logo digitally enhanced so it will look more professional in merchandise and publications. So we have revamped our magazine masthead. We're sure you'll still recognise it.

Many thanks to ConnectGroups!

L I F E'S RESPONSE TO THE PANDEMIC

In March we established the L I F E Telephone Tree to keep members in touch and to help combat the aloneness of enforced isolation, especially for those who live alone. Everyone who wanted to join, gets a phone call from another member, currently about once a fortnight or so. Many who receive calls also call one or two others. Currently there are almost 30 people on our phone tree.

In addition to supporting members over the time when we couldn't meet, the L I F E Telephone Tree should ensure that, when we finally get to the end of the pandemic, we'll still have a group. After all, our group is built on the relationships we share.

If you are not part of our phone tree and would like to have an occasional or regular chat with a phone buddy, contact Jenni at T 93824678 M 0413 499 701 or E life@resphealth.uwa.edu.au.

We've also produced a short video about managing during isolation and some home exercise suggestions. Both are also available from our L I F E Facebook page.

In between issues of our quarterly Breath of L I F E magazine we have issued one Puff of L I F E, a short newsletter to keep you up to date.

There will changes to the way our group functions in the longer term, especially if there remain protective restrictions for people with chronic conditions like us, and no vaccine available. The new meeting conditions are on page 2.

FRANCES'S STORY

Member Frances Hills's adventures on a cruise ship in the high seas at the beginning of the pandemic were published in the last issue. Here's an update.

I just thought you might be interested in some new developments regarding our cruise adventure.

After our return from America and quarantine in a Melbourne hotel, and having isolated for the required two weeks back in Perth, we continued to live our lives within the restrictions of the time.

My husband was asked to do a Covid-19 test because he was due to have surgery on a wisdom tooth. We thought nothing of this until he had the test on 3 June.

Much to our surprise, later that day he received a call from the Health Department to say that his nasal swab had come back positive. A second test showed negative - and a third test was inconclusive. He was told to isolate and the next day a nurse from CliniPath in full PPE came to our home and took nasal, throat and blood samples from both of us.

We were on tenterhooks all the morning of 5 June, until eventually a doctor from the Health Department called to explain. We both had antibodies in our blood which showed that we had both had had the virus. My nasal swab test was negative but my husband's was still very slightly positive. This did not seem to be a problem and he was not infectious. We were classified as historic cases numbers 598 and 599.

My doctor is so surprised, she has asked if she can share my case with her colleagues. I am of course happy to help with any research and I thought my experience might give others hope if they do catch the virus.

I still am not sure when I caught it. At first I suspected it might have been while locked down on the ship, when I had a bad headache and painful sinuses. We are both in good health and it is a mystery to us where and when we caught the virus. I have since been advised that it was most likely in Melbourne which I think is quite ironic given our extensive travels.

I would like to say to all to stay safe and enjoy life as much as you can in these troubled times. We are so blessed to live in Australia and in particularly to be here in the West.

Stay safe and I look forward to meeting you all again in person.

Frances Hills

Thank you Frances!

PULMONARY POETRY

Yes, this much-loved column has returned with a verse from member David Payne, who grew up in England, as you'll guess.

Back in the days of tanners and bobs,
When Mothers had patience and Fathers had jobs.
When football team families wore hand me down shoes,
and T.V gave only two channels to choose.

Back in the days of threepenny bits,
when schools employed nurses to search for your nits.
When snowballs were harmless; ice slides were permitted
and all of your jumpers were warm and hand knitted.

Back in the days of hot ginger beers,
when children remained so for more than six years.
When children respected what older folks said,
and pot was a thing you kept under your bed.

Back in the days of Listen with Mother,
when neighbours were friendly and talked to each other.
When cars were so rare you could play in the street.
When Doctors made house calls; Police walked the beat.

Back in the days of Milligan's Goons,
when butter was butter and songs all had tunes.
It was dumplings for dinner and trifle for tea,
and your annual break was a day by the sea.

Back in the days of Dixon's Dock Green,
Crackerjack pens and Lyons ice cream.
When children could freely wear National Health glasses,
and teachers all stood at the FRONT of their classes.

Back in the days of rocking and reeling,
when mobiles were things that you hung from the ceiling.
When woodwork and pottery got taught in schools,
and everyone dreamt of a win on the pools.

Back in the days when I was a lad,
I can't help but smile for the fun that I had.
Hopscotch and roller skates; snowballs to lob.
Back in the days of tanners and bobs.

Author unknown

LUNG LAUGHS IN THESE STRANGE PANDEMIC TIMES

A woman in a supermarket is following a grandfather and his badly behaved grandson. He has his hands full with the child screaming for sweets, biscuits, and all sorts of things.

The grandfather is saying in a controlled voice: "Easy, William, we won't be long".

Another outburst and she hears the grandfather calmly say, "It's okay William. Just a couple more minutes and we'll be out of here. Hang in there".

At the checkout the little horror is throwing items out of the cart. Grandfather says again in a controlled voice, "William, relax buddy, don't get upset. We'll be home in five minutes, stay cool William."

Very impressed, the woman goes outside to where the grandfather is loading his groceries and the boy into the car.

She says, "It's none of my business, but you were amazing in there. I don't know how you did it. That whole time you kept your composure, and no matter how loud and disruptive he got, you just calmly kept saying that things would be okay. William is very lucky to have you as his grandfather."

"Thanks," says the grandfather, "but I'm William, this little bastard's name is Kevin!

L I F E CARD CLUB

If you're celebrating a birthday during the lockdown you'll welcome a card from L I F E to help make it special. Editor Jenni reached her 70th on 30 July and was thrilled to receive two cards from L I F E.

L I F E member **Jan Mairorana** looks after our card club. We send a card for birthdays - or if we know someone is going through a tough time with a bereavement or illness. Let us know about other members. Please let Jan know - T 9339 3617 or E janjohn1968@bigpond.com

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WHAT'S THE CURRENT COVID ADVICE?

Health advice varies all over the world in response to local risks of Covid-19. It can be hard to work out what's applicable to where you are. Not only that, things change on a weekly basis, making it hard to spell out the restrictions here for you as you read this. As we can see from the rapidly-changing situation in Victoria, things may have changed again by the time the Breath of L I F E reaches you.

So here is a list of places to find the latest advice – what the current rules are, what is recommended for older people and for people with certain conditions. In the end we each must decide what is legal and what we feel safe with. What is safe depends on the level of risk we can accept - low or zero? Just because you are permitted to do something, it doesn't mean you should.

1. Get updates on the Western Australian Government's Covid-19 restrictions click here
2. For the latest Covid-19 health advice from WA Health click here
3. Have you had a WA consumer transaction (purchase, rent etc) affected by the Covid-19 restrictions? Find out your consumer rights here
4. See the Australian Government's Covid-19 advice for older people here
5. Read the Australian Government's Covid-19 advice for people with chronic conditions here

There are two kinds of risk to consider and they are not the same:

- **Infection risk**: What is the risk that you as, an older person or someone with a chronic condition is infected by Covid-19? That depends on what you do, where you go, who you see, where you are,

etc.

You can catch Covid-19 by touching a surface contaminated by the virus or by breathing in air containing fine breath particles from an infected person. Using the recommended preventions reduces this risk.

- **Severity risk:** What is the risk that you as, an older person or someone with a chronic condition, gets the more severe form of Covid-19, requiring hospitalisation and perhaps, intensive care, with a much higher risk of death? If you do get infected, the risk of getting the severe form of Covid-19 is higher for people of any age with a range of chronic conditions or a compromised immune system. The risk of severe Covid-19 increases with age over 60 (but is not limited to older people).

Remember the Basics

The government advice for those of us with a higher risk is to still stay home as much as possible and follow all the other hygiene basics. People with chronic conditions or compromised immune systems are at greater risk of more serious illness if they are infected with coronavirus (COVID-19).

1. practise **physical distancing** (keep at least 1.5 metres or two arms' lengths from each other)
2. practise good **personal hygiene** (wash hands often with soap and water, or hand sanitiser and cover coughs and sneezes with a tissue or use your elbow)
3. **stay home if unwell** and, if you are experiencing flu-like symptoms, **get tested** for COVID-19
4. if you have a smartphone **download the COVIDSafe app** (external site)
5. make sure you continue to go to any **usual or scheduled appointments** with your doctor.
6. **stay away from people who are sick** or in isolation;

Sources *Australian Government Department of Health*

US Centres for Disease Control

HealthDirect has a *symptom checker tool* you can use

National Coronavirus Health Information Line open 24/7 T 1800 020 080

Call your GP clinic if you think you may have symptoms of COVID-19

HealthDirect Helpline 1800 022 222if you become unwell and cannot reach your doctor

If you become seriously unwell at home call an ambulance on 000

If you have a confirmed case of COVID-19 (or are awaiting results of a Covid-19 test), you **must** isolate yourself to stop the virus spreading to other people.

Source Australian Government

LIVING WELL IN A COVID WORLD

By now it's obvious that our lives have changed, most likely for ever. It's quite possible that an effective vaccine against Covid-19 will never be found. In the meantime we cannot just keep waiting for things to go back to the way they were.

As a community group we must start to think about how we can adapt to the new circumstances we are faced with. We have made a plan to re-start face to face meetings on 7 October, with some changes.

Some members it may never feel safe to meet face to face. They may feel unsafe travelling on public transport to the meeting or sharing a room with others who have been on the bus. But what about those people? Do they simply drop out of the group because they cannot access face to face meetings? Hopefully some can attend by video-conferencing or phone.

Becoming an online only group and "meeting" only by video-conferencing platforms like Zoom would disadvantage another set of members without suitable technology and skills.

What about those who live alone? They too face big challenges. We cannot miss out any of these groups. What about the relationships we have developed at L I F E? How can we sustain them? We aren't really a group unless we address these issues.

We hope to offer audio (phone) and video-conferencing participation at all future face to face meetings. The platform we use has not been decided yet, but Zoom is under consideration, as well as MightyNetworks, which is being provided by Lung Foundation Australia for support groups to use.

On 10 August we extended an invitation to any member with an email address to join the L I F E leadership team's monthly Zoom "meeting" and bring their own views to this important subject. We have been deciding on restarting face to face meetings on a month to month basis. And we welcome your thoughts and views on these important matters about the future of L I F E.

This column is about how we have been and can live a good life in a Covid-19 world. Your ideas and contributions are welcome. Here's a few ideas to kick things off.

Taking up activities you've enjoyed before

Member Raema returned to crochet and knitting and has donated a few baby blankets to charity as a result. Great giving, Raema.

What have you taken up again during Covid? Have you learned any new skills during the pandemic or taken up any new activities? Did you keep a diary or start exercising more regularly?

Exercise

We all know exercise is one of the main things recommended for people with lung conditions. Although community pulmonary rehabilitation classes have returned in a modified form, not everyone can get to classes. Some are still on the waiting list or have transport difficulties.

With spring on its way it's important to get the blood flowing again, and fill our lungs with deep breathing. Two members David Payne and Gaye Cruikshank share their favourite YouTube exercise videos to keep active at home.

David says these four exercise videos for older people are fun and easy to follow. Follow them from your computer or tablet, even from your smart phone (if you have very keen eyesight). He says you just need to tolerate the American accents!

Choose one that seems to be at your fitness level. If you have a heart or other relevant condition ask your GP or physiotherapist if it's safe to start these exercises.

Ten Balance exercises - strengthen those core muscles and prevent falls. Stay independent and on your feet for longer.

Good 30 mins exercise - standing and seated exercises for seniors, obese, plus size and those with limited mobility, including some you can do from your chair

Go4life exercises: Learn How You Can Go4Life. (This one has the least annoying accent, in my view Ed.)

Senior/Beginner 1-hour workout. - easy to do exercises at home. A bit more vigorous - Jenny McClendon (US trainer). Pretty good, David says.

Member Gay Cruickshank has some more easy exercise videos to recommend. Both presenters have Australian accents ☺.

15 Minute Indoor Walking Workout - Low Impact!

Breathing practices to reduce worry and stress in seated yoga

My Covid story

How have you been feeling over the Covid-19 period? Probably a range of emotions at different times. At first we were all quite anxious about the potential threat to our wellbeing, even though there were not many Covid-19 cases in Australia at that stage.

That was made worse by the limited information about this initially unknown disease, which can be asymptomatic. Now there's more Covid-19 in certain

parts of Australia. But after a lengthy lockdown period there some people are becoming less cautious in trying to avoid getting infected.

Please share your Covid-19 story with us. Jenni's contact details on page 28

SHORTS

VENTOLIN NOW WITH A DOSE COUNTER!

If you use a Ventolin inhaler (containing salbutamol) for asthma there's some great news. The manufacturer has finally introduced a dose counter. That means you know how many doses are left in the canister you are using and don't have to be worried about using an empty one when you have a flare-up. Health consumers and health professionals have been calling for this for years. Don't forget that for maximum effectiveness, always use a spacer with your Ventolin, now with dose counter. (Inhalers with the same drug, salbutamol, are Airomir (no dose counter) and Asmol (dose counter available).

Thanks to Dr John Blakey for drawing this new development to our attention. This is such hot news you cannot even find an image of the new Ventolin with dose counters.

STAYING CONNECTED THROUGH TELEHEALTH

This is more of an intervention than a research project. The Australian Government is funding a project to promote telehealth, especially among people living with chronic conditions during the Covid-19 period. ConnectGroups, the WA peak body for self-help groups is running the project in Western Australia by inviting self-help groups to champion telehealth by surveying members both before and after

an information kit is distributed. You will have seen information both about the surveys (by post, Facebook or email) and also about the kit which can be viewed here .

L I F E joined the project in early July, a week or so behind other groups, such as endometriosis, prostate cancer, and diabetes.

Here is the link to the Telehealth information sheet for people living with chronic lung conditions. Also available are:

Managing chronic conditions with Telehealth

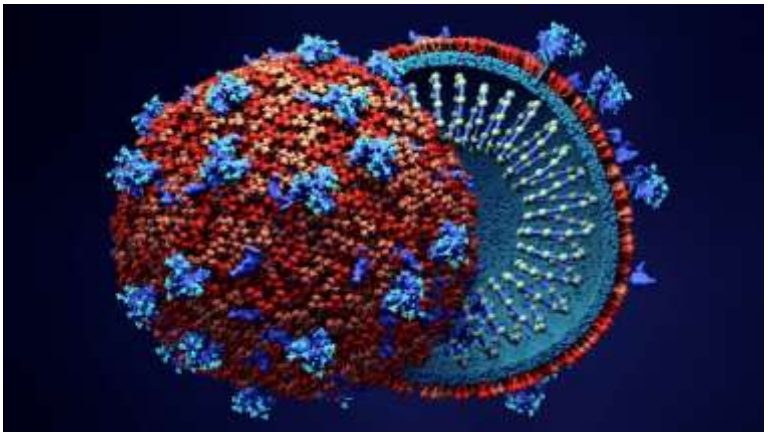
Easy steps to manage your condition using Telehealth

Telehealth experiences of others at the testimonials and videos page.

ConnectGroups is hoping that evidence from this project may help the Australian Government decide to retain the availability of telehealth for people in metropolitan areas with chronic conditions. Even before Covid, it was an option for people living in rural; and remote areas.

SIX TYPES OF COVID-19

British scientists analysing data from a widely-used COVID-19 symptom-tracking app have found that there may be six distinct types of the disease, each characterised by a cluster of symptoms.



A King's College London team found that the six types correlated with levels of severity of infection, and with the likelihood of a patient needing help with breathing - such as oxygen or ventilator treatment - if they are hospitalised.

1. **'Flu-like' with no fever:** Headache, loss of smell, muscle pains, cough, sore throat, chest pain, no fever.
2. **'Flu-like' with fever:** Headache, loss of smell, cough, sore throat, hoarseness, fever, loss of appetite.
3. **Gastrointestinal:** Headache, loss of smell, loss of appetite, diarrhoea, sore throat, chest pain, no cough.

4. **Severe level one, fatigue:** Headache, loss of smell, cough, fever, hoarseness, chest pain, fatigue.
5. **Severe level two, confusion:** Headache, loss of smell, loss of appetite, cough, fever, hoarseness, sore throat, chest pain, fatigue, confusion, muscle pain.
6. **Severe level three, abdominal and respiratory:** Headache, loss of smell, loss of appetite, cough, fever, hoarseness, sore throat, chest pain, fatigue, confusion, muscle pain, shortness of breath, diarrhoea, abdominal pain.

Patients with level 4, 5 and 6 types were more likely to be admitted to hospital and more likely to need respiratory support, the researchers said. That said this study had not been reviewed by other expert researchers. So it's not definitive and is included here for interest only.

Source Reuters News Service

THE GENETICS OF VITAMIN D ABSORPTION IN COPD

Doctors and researchers have long known that COPD is a conglomerate of conditions, rather than a single condition. The main ways to reduce flare ups have been with corticosteroids to reduce inflammation or specialised antibiotics.

Vitamin D deficiency is associated with chest infections and COPD flare-ups.

Vitamin D supplements can be helpful in reducing these episodes in people who are deficient. This paper by a Belgian group, suggests that the distribution of enzymes and receptors is different in COPD lungs from those without COPD. This difference suggests that inhaled vitamin D might be a helpful treatment for some people with COPD in the future.

Source Mathyssen et al 2020

ALPHA1- ANTI TRYPSIN DEFICIENCY (AATD) DIAGNOSIS &TREATMENT

Position statement by the Thoracic Society of Australia and New Zealand

AATD is a common inherited disorder associated with an increased risk of developing pulmonary emphysema and liver disease. Several L I F E members have been diagnosed with this. However, many people with AATD-associated pulmonary emphysema remain undiagnosed and therefore without access to care and counselling specific to the disease. AAT augmentation therapy is available and consists of intravenous infusions of exogenous [1]AAT protein harvested from pooled blood products. Its clinical efficacy has been the subject of some debate and the use of AAT augmentation therapy was recently permitted by regulators in Australia and New Zealand, although treatment is not presently subsidised by the government in either country.

The purpose of this position statement is to review the evidence for diagnosis and treatment of AATD-related lung disease with reference to the Australian and New Zealand population.

The clinical efficacy and adverse events of AAT augmentation therapy were evaluated by a systematic review. The GRADE process was used to move from evidence to recommendation. Other sections address the wide range of issues to be considered in the care of the individual with AATD-related lung disease: when and how to test for AATD, changing diagnostic techniques, monitoring disease progression, disease in heterozygous AATD and pharmacological and non-pharmacological therapy including surgical options for severe disease.

Consideration is also given to broader issues in AATD that respiratory healthcare staff may encounter: genetic counselling, patient support groups, monitoring for liver disease and the need to establish national registries for people with AATD in Australia and New Zealand.

Source Dummer et al 2020

CHILDHOOD & ADULT ASTHMA

About 30% of children with asthma keep on having asthma into adulthood. The longer duration of asthma in these people is a risk factor for poor asthma

[1] Here exogenous means, coming from someone other than the person with AATD

control. However, the characteristics of adult patients with asthma that has persisted since childhood are not well documented.

This Japanese study sought to compare the clinical characteristics of people with adult-onset asthma, those who appeared to outgrow childhood asthma, and those with persistent asthma since childhood.

Researchers studied a cross-section of adult patients with asthma who visited their Tokyo hospital. They classified them into three groups: those with adult-onset asthma (adult-onset), those whose childhood asthma went away but then came back (relapsed), and those who had asthma that had persisted since childhood (persistent). The clinical characteristics of these groups were compared.

A total of 1443 patients were enrolled in the study. The persistent group was younger and included fewer patients with a smoking history. There were statistically significant differences among the three groups in the percentages of patients with a family history of asthma (and comorbidities of allergic rhinitis (hay fever) and atopic dermatitis).

The proportion of patients with severe asthma differed among the three groups (31% in the adult-onset group, 34% in the relapsed group, and 40% in the persistent group; significantly different at p=0.015).

The values of FEF [2]75 were lower in the persistent group than the relapsed or adult-onset group. A multivariable logistic regression analysis in each group revealed that the factors associated with severe asthma differed. Their overall model suggested that also having hay fever (allergic rhinitis) affected the severity of asthma differently in the relapsed group compared to the two other groups.

The clinical phenotype of asthma that stays from childhood to adulthood seems to be a distinct phenotype of adult asthma.

Source Masako To et al 2020

[2] FEF is the flow (or speed) of air coming out of the lung during the middle portion of a forced exhalation, a measure of lung function.

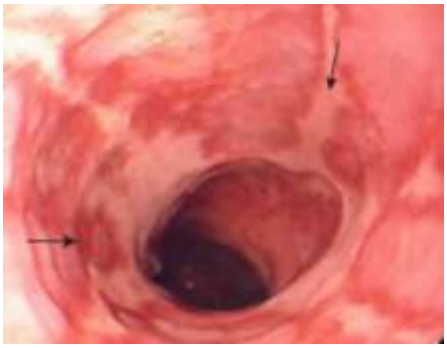
Comment from our medical reviewer, Dr John Blakey:

Almost everyone with childhood asthma goes on to have adult asthma. Those that don't were usually misdiagnosed initially or the asthma hasn't shown itself again (yet). It's a common misconception that children "grow out of asthma". Asthma seems to wax and wane over time, and can occur at any age.

The overwhelming majority of the study population had adult-onset asthma. Asthma is not a disease just of childhood.

Based on previous studies, adult onset asthma in Caucasian populations tends to me more severe than childhood onset disease. The results are interesting, but it's not clear how applicable results of this study are outside Japan.

COPD FLARE-UPS & REFLUX – A REVIEW



It's been suggested that having reflux (gastroesophageal reflux disease, or GERD) is associated with flare-ups of chronic obstructive pulmonary disease (COPD). This study looked at the links between them through a meta-analysis.

A total of 13,245 patients from 10 observational articles were included in the meta-analysis. The meta-analysis indicated that GERD is associated with increased risk of COPD flare-up. People with both COPD and GERD had an increased number of flare-ups compared with those with only COPD,

The meta-analysis suggested that there was a significant correlation between GERD and COPD flare-ups.

Source Huang et al 2020

Comment from our medical reviewer, Dr John Blakey: People with reflux were about five times more likely to have a flare up. That, on average was an extra exacerbation every two years. That's a major increase in risk. However, it isn't clear whether being on a protein pump inhibitor drug like Losec (PPI) for reflux helps or makes this worse, which is frustrating for people with COPD and for clinicians trying to keep them out of hospital.

LYING PRONE IN ARDS TREATMENT

In TV coverage of severe Covid-19 you may have seen people apparently lying face down (prone) in intensive care and wondered how on earth can that be any good? This systematic study of people with moderate to severe **Acute Respiratory Distress Syndrome** (ARDS) looked at positioning and

non-invasive ventilation [3]. It has implications for clinicians caring for people with severe pneumonia, including severe Covid-19 pneumonia, even though the study was carried out before the Covid-19 pandemic began.

Since the 1970s lying ICU patients face down for periods established as an effective part of treatment for people who have been intubated, are on

ventilators, and in an induced coma. Lately there has been interest in seeing whether "tummy time" helps people who are not on ventilators, but using non-invasive ventilation, such as wearing a mask and using CPAP machines.

Previous studies suggest that **prone positioning** (PP) can improve an important measure of the oxygen level in your blood, and reduce mortality in moderate to severe **acute respiratory distress syndrome** (ARDS). The aim of this Chinese study was to determine whether the early use of PP combined with **non-invasive ventilation** (NIV) or **high-flow nasal cannula** (HFNC) can avoid the need for intubation in moderate to severe ARDS patients.

This prospective observational cohort study was performed in two teaching hospitals. Non-intubated moderate to severe ARDS patients were included and were placed in PP with NIV or with HFNC. The efficacy in improving oxygenation with four support methods—HFNC, HFNC+PP, NIV, NIV+PP—were evaluated by blood gas analysis. The primary outcome was the rate of intubation.

Between January 2018 and April 2019, 20 ARDS patients were enrolled. The main causes of ARDS were pneumonia due to influenza (nine cases, 45%) and other viruses (2 cases, 10%). Ten cases were moderate ARDS and 10 cases were severe. Eleven patients avoided intubation (success group), and nine patients were intubated (failure group). Blood oxygenation was lowest in those on the high flow nasal cannula, followed by those in the prone position

[3] Non-invasive ventilation is the use of breathing support through a face mask, nasal mask, or a helmet. Air, usually with added oxygen, is given through the mask under positive pressure; generally the amount of pressure is alternated depending on whether someone is breathing in or out. Use of a CPAP machine is an example. In contrast invasive ventilation involves intubation, putting a breathing tube into your trachea through a hole in your throat.

with HFNC as well and then those having non-invasive ventilation, followed by those with prone position as well. The average duration in the prone position was 2 hours twice a day.

Early application of the prone position with high flow nasal cannula, especially with moderate ARDS and baseline oxygen saturation over 95% may help avoid intubation. The prone was well tolerated. Severe ARDS patients were not appropriate candidates for HFNC/NIV+PP.

Source Lin Ding et al 2020

Comment from our medical reviewer, Dr John Blakey: Studies like this are beginning to help us understand who might benefit from prone lying whilst awake, but we still have a way to go to be sure.

REDUCING BREATHLESSNESS WITH MORPHINE WITH PULMONARY FIBROSIS

This Danish randomised placebo-controlled trial looked at using morphine to try to improve chronic breathlessness in people with fibrotic interstitial lung disease, such as cryptogenic pulmonary fibrosis.

People with **fibrotic interstitial lung diseases** (fILD) have a poor prognosis and a high symptom burden. Palliative treatment includes relief of symptoms such as breathlessness. There is no evidence-based treatment for chronic breathlessness, but opioids are often used, despite concerns about a potential risk of depressing the respiratory system. This study investigated the effect of oral morphine drops in patients with fILD on chronic breathlessness and safety.

In a double-blinded [4]placebo-controlled study, 36 patients with fILD were randomised to either four daily doses of 5 mg of oral morphine drops or placebo for 1 week. Endpoints and safety parameters were obtained at baseline, at follow-up after 1 hour and 1 week.

[4] In this double blinded study, neither the people with lung disease nor the clinical trial staff knew whether a particular person had received the real drug or the placebo. This ensures a more objective outcome.

The primary endpoint, the **visual analogue score** [5](VAS) of breathlessness was reduced by 1.1 ± 0.33 cm in the morphine group at follow-up compared to baseline ($P < 0.01$), whereas the reduction was 0.35 ± 0.47 cm in the placebo group. However, the difference between the two groups was not statistically significant ($p = 0.2$). Oral morphine drops did not affect respiratory frequency, pulse rate, blood pressure, peripheral saturation or the 6-min walk test. More patients treated with morphine reported constipation, nausea and confusion.

Morphine drops, 20 mg a day, in people with fILD did not significantly reduce shortness of breath VAS score during 1 week compared to placebo. Oral morphine did not induce respiratory depression, but was related to an increased risk of constipation, nausea and confusion.

Source Kronberg-White et al.2020

Comments from our medical reviewer, Dr John Blakey: These findings differ from those from studies on other lung diseases. So we can't just assume that if something works for COPD it will work for interstitial lung disease. It also highlights the potential side effects of morphine, something that's important for people to factor into their decision whether to use it. Finally, there are effective non-drug interventions for reducing breathlessness – such as breathing exercises and handheld battery-powered fans. We shouldn't just jump straight to opiates.

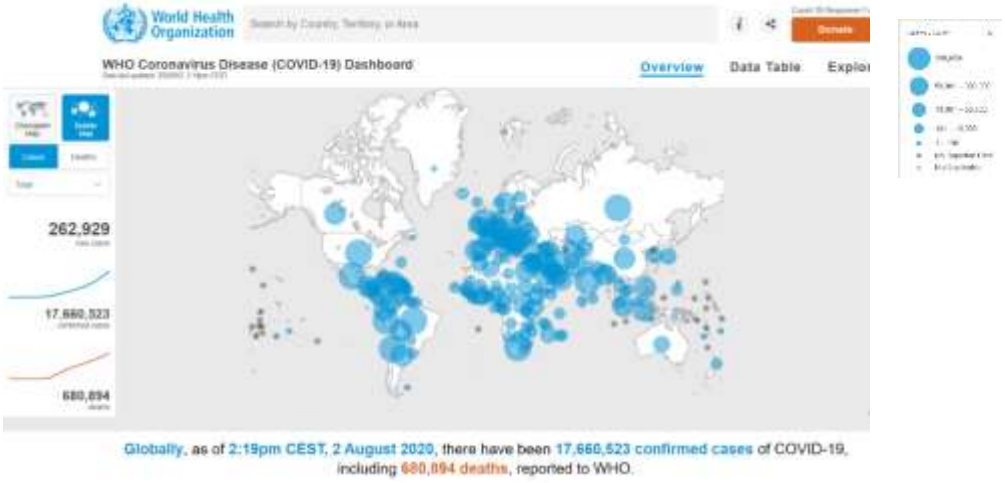
Thank you to this issue's guest medical reviewer Dr John Blakey, respiratory physician at Sir Charles Gairdner Hospital and Curtin University adjunct professor in respiratory medicine

THE WORLD AND COVID-19

In just three months Covid has spread extensively as these two WHO graphs demonstrate. The first was published in the winter issue and reflected the current situation on 3 May 2020. The second is current for early August, three months later.

[5] The **visual analogue** scale (**VAS**) (see image above) is a validated, subjective measure for acute and chronic breathlessness. Scores are recorded by making a handwritten mark on a 10-cm line that represents a continuum between "no shortness of breath" and "maximum shortness of breath."

One dot per country, size related to number of cases on download date.
https://Covid19.who.int/ downloaded 3 May (above) 3 Aug (below) 2020



LOCAL COVID 19 RESEARCH PROJECTS

The new virus Covid-19 has sent health researchers seeking answers to many clinical and scientific questions. New Covid-19 research funding has attracted a great deal of interest, including here in Western Australia. Our Institute for Respiratory Health researchers are among those putting up proposals to help address knowledge gaps about Covid-19.

In April researchers with COVID-19 research proposals contacted L I F E. They sought input from us as regular users of health services, health consumers. Since then L I F E has been approached to take part in or provide a consumer view on several more research projects, in addition to those mentioned in the last issue.

Staying Connected Through Telehealth –described in Shorts column above

Remote monitoring people with lung diseases

A group of researchers approached L I F E to comment on a research proposal to refine a system to remotely monitor people isolating at home with Covid-19. Small sub-samples of people with COPD or Cystic Fibrosis will be assessed to prove the concept works before testing it on people diagnosed with Covid-19. The aim is to reduce the need for hospitalisation of everyone with Covid-19, while at the same time as picking up on people whose condition suddenly worsens. Of course it will also be useful to keep an eye on people with other lung diseases. The project is called EDICT = Early Digital Intervention for Covid-19 Community-based Treatment. L I F E has already provided feedback to researchers about the need to ensure the technology is suitable for older people.

If you would like to be involved in any future research discussions that may arise contact Jenni E life@resphealth.uwa.edu.au T 9382 4678.

HOW CAN I GIVE BACK?

Doing something that helps make the world a better place, feels good too. There's always something you can do - no matter how advanced your condition.

1. **Volunteer** for L I F E - help our L I F E group. Or another community organisation near you. Help in the Breath of L I F E mail out or join the L I F E working bee which helps the Institute for Respiratory Health's Clinical Trials Unit. Just speak to Sal at the next L I F E meeting or call her T 0409 336 639 E salhyder1@gmail.com
2. **Spread the word** with family and friends. Tell them about L I F E, the Institute for Respiratory Health and respiratory conditions. We have brochures, old issues of Breath of L I F E and business cards which have a space for your name and phone number. Contact us for some.
3. **Register with the Clinical Trials Unit** of the Institute for Respiratory Health to take part in the trial of a new respiratory medication. T 6151 0838
4. **Volunteer to be a research subject** in a medical research project described in Breath of L I F E or in your local paper
5. **Donate** to the work of the Institute for Respiratory Health. Call 6151 0815 or donate online. Mention the Institute's important research into lung disease to friends and relatives who also might be interested to make a donation. Or make a bequest in your will.

USEFUL CONTACTS

Please let us know of any others you have found helpful. Click on the blue underlined links to go to the organisation's website.

COVID-19

HealthDirect Helpline T 1800 022 222.

Coronavirus Health Information Line T 1800 020 080

WA Department of Health

WA Health - Frequently Asked Questions

Australian Government

Australian Government - Frequently Asked Questions

HealthDirect COVID-19 symptom checker tool

Respiratory

Flying with Oxygen - L I F E's own practical guide endorsed by Prof P J Thompson, Respiratory Physician, Lung Health Clinic.

Lung Foundation Australia T 1800 654 301 (Queensland time zone)

Pulmonary Rehabilitation programs (scroll down to WA) or T 1800 654 301 Need referral from a respiratory specialist who has admitting rights to a WA public hospital (even if you see them privately).

Pulmonary Hypertension Network Australia – a sister support group to L I F E

Alpha-1 Association of Australia for people with Alpha-1 Anti-Trypsin Deficiency – has an online forum, and on Twitter, Facebook, M 0410 108 104 T (07) 3103 3363 (Qld time zone)

HealthyWA - lung condition information from the WA Health Department

BetterHealth – lung condition information from the Victorian Health Department

Asthma Foundation WA T 1800 278 462

Bronchiectasis Toolbox for health professionals

Active Cycle of Breathing Technique (video) helps you clear your airways of phlegm

Asbestos Diseases Society of Australia (WA) T 1800 646 690 (08) 9344 4077

National Quit line – help to quit smoking T 13 78 48

Exercise

Mall Walking groups COTA T 08 9472 0104

Living Longer Living Stronger programs in many areas conducted by physiotherapists, evidence based. Contact your local council or physiotherapist.

Strength for Life programs in many areas, endorsed by COTA. Need GP referral. T 08 9472 0104

Stay On Your Feet information and resources to prevent falls and keep Western Australians active, because falls are preventable no matter what age T 6166 7688 or Country callers 1300 30 35 40. Level 2, 297 Vincent Street, Leederville, WA

Pulmonary Rehabilitation programs (scroll down to WA) or T 1800 654 301 Need referral from a respiratory specialist who has admitting rights to a WA public hospital (even if you see them privately).

Mental Health

Connect Groups – peak body for support groups in WA T (08) 9364 6909

Act Belong Commit- activities to promote mental health T (08) 9266 3788

Beyond Blue mental health support service T 1300 22 4636

Australian Men's Shed Association – find a men's shed near you T 1300 550 009

Lifeline 24 hour personal crisis support and suicide prevention association T 13 11 14

PORTS (Practitioner Online Referral Treatment Service) referral by GP or other health practitioner, phone or online assessment, start 4-6 week face to face therapy, 2-4 week phone counselling or 8 week online course. Referral is free. T 1800 176 787 E contact@ports.org.au.

Mental Health Care Plan for those with a diagnosed mental health problem. Referral by GP, Medicare rebates, gap payment needed, by allied mental

health care providers. Covers up to 10 individual and 10 group sessions per year.

General Health

Health Direct look up reliable health information or speak to a registered nurse T 1800 022 222

Better Health Channel Victorian Government's health information website

Cancer Council WA T 13 11 20

Health Report with Norman Swan ABC Radio National (810 AM), listen to past programs on your computer or smartphone

ABC Health Online find reliable health news and information

Independent Living Centre T (08) 9382 0600 Country callers 1300 885 886 choose and access equipment, technology and services for independence and wellbeing of people with disability and older people throughout WA. Centres at Nedlands, Westminster and Busselton.

Seniors

Council on the Aging (COTA) voice of older Australians T (08) 9472 0104

MyAgedCare aged care services you may be eligible for. Speak to your GP

National Seniors voice of older Australians T 1300 76 50 50

Seniors Services guide database of services and activities for older Australians

Seniors Recreation Council WA T (08) 9492 9773. Runs Have A Go Day each year.

The Move Into Aged Care tools and resources supporting you and your family. Advocare is the WA contact.

Advocare advocating for Western Australians receiving aged care services at home or in an aged care facility T (08)9479 7566 Country callers 1800 655 566

WA Elder Abuse Helpline (operated by Advocare) 1300 724 679

CentreLink 13 24 68

HaveAGoNews read seniors' news online

Computer basics guide for seniors (free)

Aged Care Navigator trials across Australia, incl. WA T 1300 025 298

Seniors Housing Advisory Centre free Government service T 1300 367 057 (cost of a local call)

Health Consumer and Carer Rights

Carers WA supporting friends and family who care for others T 1300 227 377

Health Consumers Council an independent voice advocating for patients in WA T (08) 9221 3422 and 1800 620 780

Patient Opinion Australia share your experience as a patient an d ensure the message gets passed on to the right people T 1300 662 996

Voluntary Assisted Dying – new WA laws explained by WA Health. Proposed to come into effect from mid 2021. Ask your GP for more information.

Other

TED Talks watch videos of great speakers on a topic that interests you. Free

Recycling in WA - tips from South Metro Regional Council T 9329 2700

Do Not Call Register – stop unwanted marketing calls to your home phone or mobile, renew every 2 years, market research, charitable organisations and political organisations excepted T 1300 792 958

The Australian Bereavement Register stop unwanted mail to a family member who has passed away T 1300 887 914

INSTITUTE FOR RESPIRATORY HEALTH

The Institute for Respiratory Health is a collaborative research organisation. It aims to improve the life of Australians living with respiratory conditions by bringing together world class researchers and dedicated clinicians to investigate, diagnose, treat and prevent respiratory conditions.

The Institute conducts and fosters innovative basic and clinical research and translates their work into improved treatments for people with respiratory conditions in Australia.

The Institute includes a Clinical Trials Unit and the community support group – L I F E for people living with chronic respiratory conditions.

Membership is open to community members, researchers, health professionals and research students and subscriptions fall due each 1 July.

Your tax deductible donation to the Institute or bequest supports respiratory research.

About Lung Information & Friendship for Everyone (L I F E)

L I F E - a group for anyone with a chronic lung condition, their family and carers. It's run by, and for, people with chronic lung conditions. Started in 1992 as LISA, our name changed to L I F E in 2009. L I F E is the community support group of the Institute for Respiratory Health. More about the Institute on page 27.

L I F E is also a member of Lung Foundation Australia's network of respiratory self help groups T 1800 654 301. L I F E is extremely thankful for the support of the **Department of Respiratory Medicine** at Sir Charles Gairdner Hospital.

institute for RESPIRATORY HEALTH

Breath of L I F E magazine

Our magazine is published 4 times a year - March, June, September & December. It is distributed to all community members of the Institute, including L I F E members. Send your contributions to the editor, Jenni Ibrahim E life@resphealth.uwa.edu.au 7 Ruislip St, W. Leederville, WA 6007. Read it online.

Seeking information about your lung condition and how to cope with it?

Like to meet others in a similar situation?

Join L I F E!

L I F E Membership

Join **L I F E** by becoming a community member of the Institute. Come to a meeting or contact Sarah at the Institute T **6151 0815** or E life@resphealth.uwa.edu.au. Membership fee of $20 a year (incl. GST) is **due each 1 July or on the anniversary of your joining**. Members' help and ideas are always welcome - magazine, speakers, social events. Please be sure to tell us if you change address.

Contacts

Phone Coordinator **Jenni Ibrahim** T 9382 4678 M 0413 499 701 life@resphealth.uwa.edu.au
Deputy Coordinators **Sal Hyder** T 0409 336 639 salhyder1@gmail.com
and **David Payne** T 0439 048 897 perthmillwall@yahoo.com.au

Postal L I F E c/- Institute for Respiratory Health, QEII Medical Centre, level 2, 6 Verdun Street, Nedlands WA 6009

Email life@resphealth.uwa.edu.au **Web** L I F E on the Institute website L I F E is also on Facebook

Meetings (suspended April-September 2020 during the COVID-19 restrictions)

1st Wednesday of the month from February to November from 12 - 2.30pm. Speaker from 1.00pm.

Level 6, Meeting Room 612A, Harry Perkins Institute Building, Queen Elizabeth II Medical Campus, Nedlands. Directions here. Wheelchair and gopher accessible. Light refreshments. Please bring your own food and mug. Buggy pick-up from the car park or bus stop, M 0481 438 731 (Mon-Fri 9am-4pm) or ask at Gairdner Voluntary Group Enquiries Desk just inside the main entrance in E block.

COMING UP (subject to change)

Wed 3 Sep	No face to face meeting	Hold tight, we're nearly there
Wed 7 Oct	**Getting back together meeting!**	See the new conditions on page 2
Wed 4 Nov	My medicines and me	Jo Armstrong, pharmacist at Sir Charles Gairdner Hospital
Wed 18 Nov	World COPD Day	Share the word about COPD with friends and family
Wed 2 Dec	**Christmas party, Covid style**	Details in the next issue. **Save the date!**