



# Breath of L I F E

Lung Information & Friendship for Everyone

People with long term lung conditions, their family & carers

Summer 2020-21

Dec- Jan



institute for  
RESPIRATORY HEALTH

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[Read it online here](#)

## SUMMER

This is the last issue of Breath of L I F E for 2020 and what a year it's been!

Wishing you all the best for a joyful Christmas with family and friends in WA and online. And we hope you'll have a healthy and happy New Year.

Have you booked for our Christmas party on Wed 2 Dec? More on page 3.



Bookings for Christmas lunch close **20 November**.

We have news from the L I F E leadership team and the regular Shorts column, featuring respiratory research news from across the world. There are lots of lung laughs, a book review, and a reminder about meeting guidelines under Covid-19 restrictions.



This issue is available as an e-copy, 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. With an e-copy you can click on a [blue underlined link](#) which takes you to a webpage or another part of this issue.

## E-COPY

### Please consider...

We can email **Breath of L I F E** to you - or you can [read it online](#) on the L I F E webpage

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](mailto:life@resphealth.uwa.edu.au)



institute for  
RESPIRATORY HEALTH

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.

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## L I F E EVENTS

### Recently

#### Meetings and Social Events

At last we have got back to meeting face to face (F2F)! In October we made tentative steps into our meeting room 612A, with one member joining us via Zoom. We were careful with social distancing, hand sanitisation and cough hygiene. We spent most of our time together sharing our Covid stories, and there were some really interesting ones.

Again in November we met F2F, this time to hear inspiring speaker Charlie's pharmacist Jo Armstrong speak on Me and My Medicines. She covered: the various roles of different types of pharmacists, tips and tricks, use of inhalers, My Health Record. And Jo shared some useful resources with further information. Everyone enjoyed the question and answer part of this presentations too. See under [SHORTS](#). Thanks to member Elaine who organised for Jo to come to speak to us.

Social events for 2021 will appear in the next issue of Breath of L I F E.

Do you have an idea for a topic or speaker? Let us know or come to our planning meeting and raise it there:

#### L I F E Telephone Tree

Even though we've recommenced face to face gatherings you can still join our L I F E Telephone Tree - get the latest news and keep in touch with a phone buddy. Contact us to get involved! Contact details for L I F E are on pages 5 and 28.



## Coming up!!

In October members decided to hold our Christmas lunch at a hotel so we could all relax and not worry about catering or sharing food as before. L I F E Christmas elves Elaine and Sal have negotiated an excellent deal for L I F E members. With Telehealth project funds L I F E raised this year we can subsidise the cost for members.

We are pleased to announce that our special Christmas 2020 party will be held on

**Wed 2 December 2020, from 12 noon**

### **HYDE PARK HOTEL**

331 Bulwer Street, West Perth (corner Fitzgerald).

Plenty of parking. Public transport accessible (the #960 bus stops nearby). Fixed price festive menu (right): \$25 (members); \$45 (non-members). Drinks not included.

### **What you need to do now**

We circulated the Puff of L I F E, our occasional newsletter, in late October because we needed your urgent response to this invitation. Unless you receive this magazine by email, the time for responding is probably over! If not, you would have to reserve a place immediately. Reservations and payments **close Friday 20 November.**

We also need to know of any dietary requirements by 20 November - not your menu choices - just whether you require a gluten free, vegan, vegetarian meal, etc. Sorry, no cancellations after 20 November.

### **Ways to pay**

- Pay by credit card over the phone to Karen at the Institute Respiratory Health on 6151 0844



### **HYDE PARK FESTIVE MENU**

#### **MAINS**

Christmas plate of turkey & ham, roast butternut, mustard potato, beans, cauliflower, broccolini & cranberry

Rolled pesto pork belly, cauliflower puree, prosciutto wrapped beans with red wine jus (GF)

Honey lime sriracha basted salmon, kipfler potato & broccolini (GF)

Marinated tofu, mushroom poke bowl (V, VEGAN, GF)

#### **DESSERT**

Plum pudding anglaise with fresh strawberries

Fruit tart with apricot glaze (GF, V, VEGAN)

- Pay online to Westpac BSB 036-083 Account no: 119959. **Don't forget to include your name and LIFEXmas as reference. Please email any dietary requirements to [elainewells1952@gmail.com](mailto:elainewells1952@gmail.com)**

### On the day

- Don't forget your bottle of hand sanitiser and use it frequently, including getting on and off public transport
- Even though it's a festive occasion, please keep your distance from other people and avoid physical contact. It's easy to forget when we are with friends
- Make it a fun day by donning some Christmas gear – a tinsel tiara, your Christmas T shirt or earrings
- Though we won't do crackers this year, feel free to bring a Dad-joke or two to share with your table neighbours
- If you are unwell on the day, please don't come. Unfortunately we cannot issue a refund but we may be able to help you find someone else to take your place
- If you have the CovidSafe app on your phone, make sure it's turned on when you leave home



**1** MANY WILL RECALL LATE MEMBER SHIRLEY SHEHAN, WHO REALLY KNEW HOW TO DRESS FOR CHRISTMAS

### January 2021

Each January we plan for the rest of the L I F E meeting year. Come along to the planning meeting if you like, or wait till February for the first regular L I F E meeting.

Our planning meeting will be held as in 2020, at Rejuven8 café 8<sup>th</sup> floor G Block (blue lifts) on Wed 20 January. All welcome.

Events we had to cancel during the Covid-19 restrictions included:

Speakers on: the role of humour in living well with chronic conditions, Alpha-1 Antitrypsin Deficiency (now scheduled for March 2021), clinical trials with a visit to the Institute's new Clinical Trials Unit premises on level 2 of the Perkins Building, seniors housing options. Social events: lunch at the New Norfolk Hotel, Fremantle, lunch at Mandurah (and train trip). Focused discussions: recycling.

We will consider them again for 2021 but are open to your ideas as well.

## February 2021

Always a social meeting with no scheduled speaker or discussion topic. Come and have a chat over tea or coffee. A great opportunity for new members to get to know others.

### L I F E Covid-19 Plan - meeting conditions to make it safe for all

- All meetings are subject to change - if the Covid-19 situation changes in WA. If you are uncertain, 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 sanitise your hands before entering the lift and should do it again on entering the meeting room 612A.



- While in 612A please observe 1.5 metre physical distancing at all times. Please do not hug or shake hands. Don't feel offended if someone asks you to step back a bit. It's easy to forget.

• Wearing a mask is optional but encouraged, especially when on public transport where distancing may be difficult. Member Tom says sitting up the front carriage of the train often allows better distancing. Avoid public transport if you can. If you can't, take all precautions.

#### Contact our L I F E leadership group

Sal Hyder 0409 336 639 [salhyder1@gmail.com](mailto:salhyder1@gmail.com)

Gaye Cruickshank 0417 908 647 [gmcrick@bigpond.net.au](mailto:gmcrick@bigpond.net.au)

David Payne 0439 048 897 [perthmillwall@yahoo.com.au](mailto:perthmillwall@yahoo.com.au)

Jenni Ibrahim 9382 4678 [life@resphealth.uwa.edu.au](mailto:life@resphealth.uwa.edu.au)



## LUNG FOUNDATION AUSTRALIA GUIDELINES FOR GROUPS



These are similar to ours but we need to make you aware.

### Peer Support Group Guidelines

#### **COVID safe strategies**

Lung Foundation Australia has developed a Road to Recommencement COVID Safe plan for face to face peer support activities. As part of this COVID Safe plan, your peer support group leader and co-members will need to follow the strategies listed below to minimise the risk when engaging in group activities and meetings.

#### **Pre-meeting information**

All members informed of the COVID Safe plan.

If any members are unwell with any new symptoms that may be related to a virus, they should not attend group meetings and/or activities.

Group members will be asked who can bring hand sanitiser and anti-bacterial wipes to the meeting.

#### **Meeting space**

Follow the COVID-19 guidelines for the meeting venue.

The venue will be reviewed prior to meeting to ensure it is sufficient in size to meet social distancing requirements<sup>1</sup>.

Follow social distancing requirements in communal facilities such as the kitchen and bathroom.

#### **At the meeting**

A record of attendance is completed for each meeting for contact tracing in the event a member tests positive for COVID-19.

Prior to the start of the meeting, wipe down any surfaces at the meeting venue with anti-bacterial wipes that may be touched by members such as tabletops, chairs, and door handles if the venue is not cleaned in between uses.

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<sup>1</sup> Our meeting room 612A can hold up to 24 people at 2 sq m per person, as applies in WA October 2020

## Hygiene measures

Wash hands with soap and water and/or use hand sanitiser before and after each meeting and/or activities.

Avoid using other member's digital devices such as mobile phones, laptops, or tablets.

Try to avoid touching your eyes, nose, or mouth.

Additional strategies may be required e.g. wearing a mask depending on the state or local COVID-19 regulations / recommendations at the time.

## Social distancing

Abide by the 1.5m social distancing and 4 m<sup>2</sup> rule in throughout all activities<sup>2</sup>.

Avoid any activities involving close contact including hugs and handshakes.

*Source: Lung Foundation Australia*

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## LUNG FOUNDATION PEER SUPPORT NETWORK ONLINE

Lung Foundation Australia (based in Brisbane) supports people who lead self help groups for people living with chronic lung conditions and advocates for those groups, currently numbering about 60 across Australia. L I F E has been there from the beginning, in fact, even before the beginning of the [Lung Foundation's Peer Support Network](#). People who contact the Lung Foundation are given the leader contact details for a lung support group near where they live.

Until Covid-19 hit almost all groups were face to face groups, and many, perhaps most, will remain that way. But Covid has forced us all to think about ways we could utilise technology to keep in touch, support each other and ensure that, at the end of the pandemic, we still have a group to meet.

Lung Foundation Australia has set up an [online Peer Support Network](#) for respiratory support groups so that

- Existing face to face groups can have an online presence –have online video and text chats, share documents, speaker presentations, articles, other useful resources and hold online meetings using the Lung Foundation's Zoom licence.

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<sup>2</sup> Western Australia has reached the 2 sq m per person stage, unlike many other Australian jurisdictions.

- Groups can operate purely online, such as a group for people with a very rare condition with members spread across Australia, or a group for people living in remote areas

This is free to use for all support groups and their members.

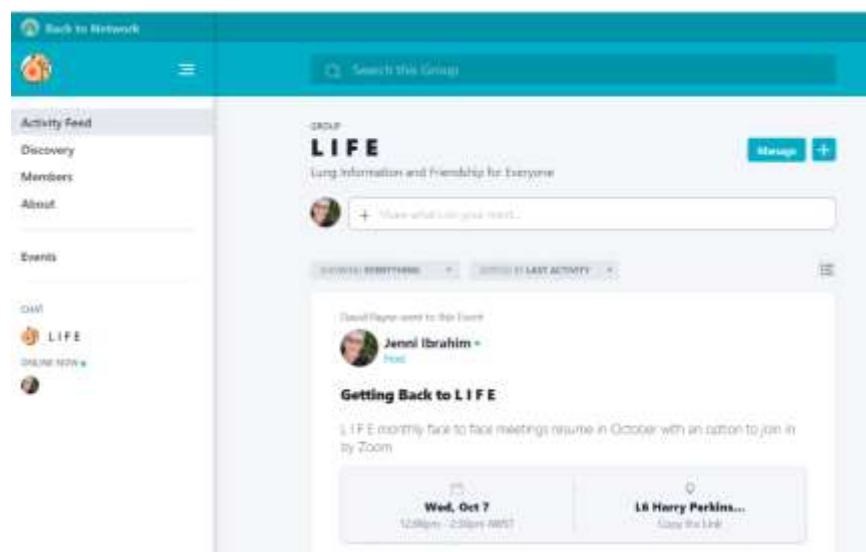
L I F E has no plans to go completely online but is interested in using the Zoom facility for L I F E Leadership Group meetings and to allow some members to join in to L I F E meetings from home via Zoom. This can help members who are ill, caring for someone at home, have transport or mobility problems or live too far away to attend. All groups are private and are expected to follow Lung Foundation Australia's Online Network Guidelines.

This Zoom facility is better than the free Zoom some members use to keep in touch with friends and family, because it is a subscription version, so there is no 40 minute time limit.

### **To use the Zoom facility you need to do two things**

#### *1. Join L I F E's online group at the Lung Foundation's Peer Support Network*

Register your interest in one of the Lung Foundation's affiliated groups by completing the [online form here](#) or join the Peer Support Network by responding to the email send to L I F E members



by Jenni Ibrahim on 4 November 2020. The message had the Lung Foundation logo and invited you to our L I F E online community, at Lung Foundation Australia Peer Support.

It takes just a few minutes to join and together we can share our stories, experiences, and ideas. Join in our monthly face to face meetings from home using the Network's Zoom video call feature. I know you'll love it. See you here!

The message asks you to click on a link to join L I F E at the Lung Foundation Peer Support Network. This is the [link](#) if you want to do it yourself.

#### *2. Let us know you want to join a L I F E meeting by Zoom*



Let Jenni know before the date of the meeting (T 9382 4678 or E [life@resphealth.uwa.edu.au](mailto:life@resphealth.uwa.edu.au)) and the morning of the meeting you will receive an emailed link to join the meeting by Zoom. It's best if you have already downloaded the Zoom app onto your laptop or computer. Click on the link in the email and wait until we let you into the meeting. You can also indicate in the online page that you wish to attend a particular Zoom event. Looking forward to seeing you face to face or online!

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## ELIZA-JANE'S BOOK RECOMMENDATION

Member Eliza Jane contacted Breath of L I F E about this book she discovered. Though she hasn't finished reading the book yet, perhaps it may interest you too.

### **Breath, The New Science of a Lost Art**

James Nestor

Riverhead/ Penguin Random House, May 2020

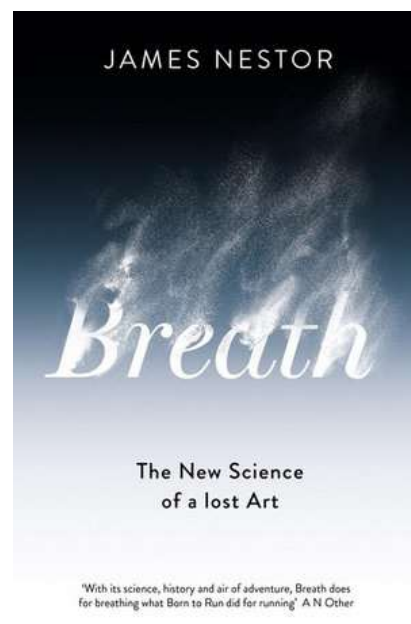
The [author writes](#):

The (book) explores the million-year-long history of how the human species has lost the ability to breathe properly and why we're suffering from a laundry list of maladies—snoring, sleep apnoea, asthma, autoimmune disease, allergies—because of it. I ended up traveling the world in an attempt to figure out what went wrong and how to fix it.

The answers, I discovered, weren't found in pulmonology labs but in the muddy digs of ancient burial sites, secret Soviet facilities, New Jersey choir schools, and the smoggy streets of Sao Paulo. Drawing on thousands of years of medical texts and recent cutting-edge studies in pulmonology, psychology, biochemistry, and human physiology, *Breath* turns the conventional wisdom of what we thought we knew about our most basic biological function on its head.

From a [bookseller's website](#):

There is nothing more essential to our health and wellbeing than breathing—take air in, let it out, repeat 25,000 times a day. Yet, as a species, humans have lost the ability to breathe correctly, with grave consequences.



Journalist James Nestor travels the world to figure out what went wrong and how to fix it. ... Nestor tracks down men and women exploring the hidden science behind ancient breathing practices like Pranayama, Sudarshan Kriya and Tummo and teams up with pulmonary tinkerers to scientifically test long held beliefs about how we breathe.

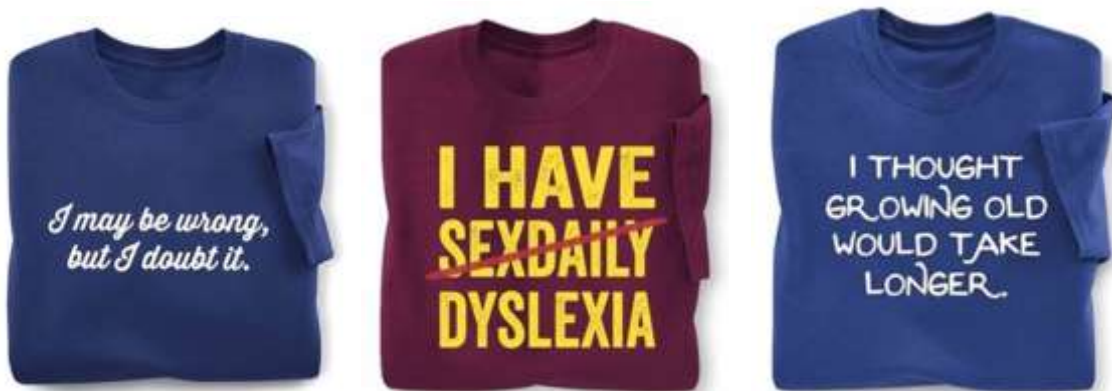
Modern research is showing us that making even slight adjustments to the way we inhale and exhale can jump-start athletic performance, rejuvenate internal organs, halt snoring, allergies, asthma and autoimmune disease, and even straighten scoliotic spines. None of this should be possible, and yet it is. ...You will never breathe the same again.

Also available as an e-book. More readings about breathing on the [author's website](#)

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## LUNG LAUGHS IN THESE STRANGE PANDEMIC TIMES

Three T shirts you might like for Christmas



*Twenty years from now, you will be more disappointed by the things you didn't do, than by the ones you did. -- Mark Twain*

*Warning, this is an American joke*

**An Aussie calls 000 because his mate has just been hit by a car**

Aussie: Quick, get an ambulance, he's bleeding from his nose and ears and I think both his legs are broken.

Operator: What is your location sir?

Aussie: Eucalyptus Street.

Operator: How do you spell that sir?

Silence....(heavy breathing) and after a minute or so...

Operator: Are you there sir?

More heavy breathing and another minute later...

Operator: Sir, can you hear me?

This goes on for another few minutes until...

Operator: Sir, please answer me. Can you still hear me?

Aussie: Yes, sorry 'bout that. I couldn't spell eucalyptus, so I just dragged him around to Oak Street.



### **How Embarrassing**

A very shy guy goes into a pub and sees a beautiful woman sitting at the other end.

After an hour of gathering up his courage he finally goes over to her and asks, tentatively, "Um, would you mind if I chatted with you for a while?" To which she responds by yelling, at the top of her lungs, "No, I won't sleep with you tonight!"

By now, the entire bar is staring at them. Naturally, the guy is hopelessly and completely embarrassed and he slinks back to his table.



After a few minutes, the woman walks over to him and apologises. She smiles at him and says, "I'm sorry if I embarrassed you. You see, I'm a graduate student in psychology and I'm studying how people respond to embarrassing situations."

To which he responds, at the top of his lungs, "What do you mean \$200!"

### **A man goes to the doctor...**

"Help me", he says, "I think I might have asthma because I have a really hard time breathing."

The doctor does a couple of tests and tells him: "From now on, I want you to sleep with your windows wide open."

A week later the man comes to the doctor again. The doctor asks him: "So, did you follow my recommendation?"

"Yes I did, doctor, I slept with my windows wide open every night"

"And what about your asthma? Did it disappear?"

"No, but my watch, my laptop and my TV did."



Source of some of these: <https://upjoke.com/breathing-jokes>

### **Some puns to grate (amuse?) the grandchildren**

The fattest knight at King Arthur's round table was Sir Cumference. He acquired his size from too much pi.

I thought I saw an eye doctor on an Alaskan island, but it turned out to be an optical Aleutian.

She was only a whiskey maker, but he loved her still.

A rubber-band pistol was confiscated from algebra class, because it was a weapon of maths disruption.

No matter how much you push the envelope, it'll still be stationery.

A dog gave birth to puppies near the road and was cited for littering.

A grenade thrown into a kitchen in France would result in Linoleum Blownapart.

*Thank you to David Payne for these. More coming next issue!*

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## **L I F E CARD CLUB**

Get well soon to long time members Ina Mitchell and Tom Murnane!

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 Jan know about yourself or other members. Contact Jan - T 9339 3617 or E [janjohn1968@bigpond.com](mailto:janjohn1968@bigpond.com)



## WHILE WE'RE TALKING CARDS

This beautiful hand made card was produced by **Veronica Kitt** of Kalamunda who has been a member for many years. She doesn't often get in to L I F E meetings because she lives in the hills and cares for her husband.

She wrote to thank L I F E for the Puff of L I F E, the short newsletter we introduced during the pandemic when we couldn't share news at meetings.

When Breath of L I F E editor complemented her on her beautiful thank-you card she offered to send some to L I F E for Jan Maiorana, our Card Coordinator, to use. L I F E sends a huge thank you to Veronica for this generous gift of her own talented handiwork. Members in our Card Club can look forward to receiving one of Veronica's creations in the coming year. When you next receive a birthday or get well card, look on the back and check if it has been "Hand Made By Veronica".



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## CHRISTMAS RECIPE

### Mini Christmas puddings

Easy to make. Keep in the fridge for guests who drop in.

700 g dark fruit cake (a supermarket brand is fine)

250 g milk chocolate buds melted in the microwave (or omit if preferred)

¼ cup brandy (or sherry or fruit juice)

½ cup white choc bits

1 packet snake lollies

Crumble the cake and mix in the melted chocolate and brandy/sherry/juice.

Roll the mixture into almond sized balls. Place on baking paper.

Melt a small amount of the white chocolate bits and drizzle over the mini puddings.

Cut up the snakes into small pieces to garnish the top of the pudding to look like holly leaves and red berries. Repeat the process until all the mini puddings have been decorated.





## SHORTS

### ME & MY MEDICINES

November speaker Jo Armstrong, a pharmacist at Sir Charles Gairdner Hospital, provided links to these websites with extra information.

Video on [Getting the most out of your pharmacist](#)

Video on [Learning about medication information](#)

### MY HEALTH RECORD

Whether you realise it or not, many of your clinical health records are already stored at My Health Record. Most GP practices, pathologists, hospitals and pharmacies already automatically upload your records there. If you are involved in an accident or urgently admitted to hospital health professional access to your My Health Record can potentially save your life.

My Health Record is linked to your secure MyGov account (containing your other Government records, including taxation and Centrelink). All you need to do is access your MyGov account online. If you haven't done this yet, it is easy to do. Centrelink staff can help.

The only people who can access your My Health Record are:

- You
- Doctors and other healthcare providers who are involved in your care
- People you have invited to access your record (also called *nominated representatives*, such as a close relative or trusted friend)
- People who have legal permission to access your record if you lack the capacity to manage it yourself (also called an *authorised representative* such as your enduring guardian or enduring attorney)

You can also control who can see your information by altering the settings.

My Health Record is a set of online documents containing clinical information about your health and care. There's a wide range of information that can be added."



“These can include:

[Your shared health summary](#) –an important summary of your health, usually added by your GP. It can include conditions you have been diagnosed with and medications you take. It can also contain allergies and adverse reactions that other healthcare providers need to know about.

[Hospital discharge summaries](#) –information about your stay during a visit to hospital.

[Event summaries](#) - these are created when you have an important health event. For example, starting or finishing a treatment, seeing an improvement in a health condition, or a procedure that is relevant to your future care.



[Specialist letters](#) – a letter that a specialist who is treating you writes to your GP. Specialist letters provide GPs with information and recommendations that are relevant to your ongoing care like diagnoses, medication changes, and treatment plans.

[Referrals](#) – these are usually created when a GP refers you to a specialist. Referrals include information the specialist needs to know, like why you were referred, your medications, test results, allergies/adverse reactions, and your medical history.

[Test results](#) – including pathology reports (e.g. from a blood test or a biopsy) or diagnostic imaging reports (e.g. from an x-ray or MRI).

More Video on [Where to find documents in your My Health Record](#)

Video on [How to manage information in your My Health Record](#)

Video about [Rose's My Health Record story](#)

## TELEHEALTH UPDATE

Medicare-funded telehealth consultations by phone with your specialist or GP became available to people in Australian cities during the Covid-19 pandemic and were scheduled to wind up at the end of September. Due to the ongoing pandemic situation they have now been extended till March 2021.

Good news for people with chronic conditions!



## INHALERS

(From Jo Armstrong's November presentation)

Videos on inhaler techniques by Debbie Rigby for Lung Foundation Australia. Look on your inhaler to see what type it is and select the most relevant videos:

- [Pressurised Metered Dose Inhaler](#)
- [Turbuhaler®](#)
- [Handihaler®](#)
- [Accuhaler®](#)
- [Respimat®](#)
- [Rapihaler®](#)
- [Breezhaler®](#)
- [Ellipta®](#)
- [Spiromax®](#)
- [Using a spacer](#)

Get your pharmacist or respiratory health nurse to check your inhaler technique regularly. We all slip into inhaler bad habits at times.

## MUSCLE FUNCTION AND BREATHLESSNESS AFTER LUNG TRANSPLANT

A study in Italy investigated why people who have undergone lung transplants still got breathless and had muscle pain and limitation. They wondered whether the lung condition which lead to the need for a transplant had somehow altered the muscle function in a longer term way.

The researchers concluded that symptoms experienced during exercise in lung transplant

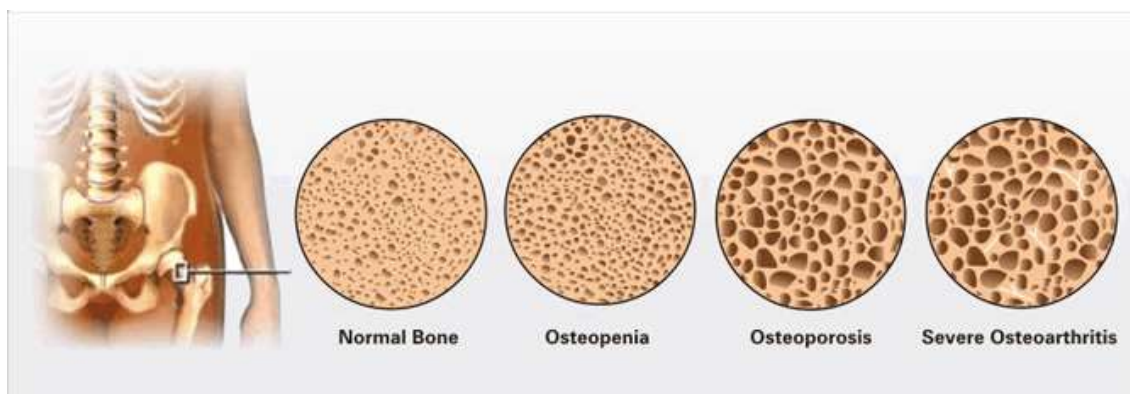


recipients represent the combination of several mechanisms involving a complex interaction between pre-transplant and post-transplant conditions. This small study included an analysis of heart and lung function measurements and symptom assessment with a tailored exercise prescription. However more research is needed to fully answer these questions.

Source <https://respiratory-research.biomedcentral.com/articles/10.1186/s12931-020-01535-5>

*Our medical reviewer comments: This study used a methodology that always finds a set of associated factors, even if they are meaningless. Studies like this using machine learning should not be interpreted like the classical type of A vs B comparisons we are used to. Multi centre studies are essential to study uncommon problems (like those related to lung transplant). The number of people in this study is too small to conclude anything robust. Anyone with a rare disease should be asking to be part of a cross-border study or observational registry (like is done for cystic fibrosis, mesothelioma, etc).*

## BONE DENSITY AND CORTICOSTEROID THERAPY



Many readers will have experienced long or shorter term treatment with systemic corticosteroids, such as prednisolone tablets. Long-term treatment with corticosteroids is known to cause loss of bone density, but it's not clear what the effects of using short-term high-dose systemic<sup>3</sup>-corticosteroid therapy to treat acute flare-ups of chronic obstructive pulmonary disease (AECOPD). This Danish study aimed to determine whether high-dose

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<sup>3</sup> Systemic means taking a drug within your whole body, such as through tablets or infusions into the blood stream. It does not include corticosteroid puffers which act locally rather than systemically.

corticosteroid therapy affected bone turnover markers (BTMs) to a greater extent compared to low-dose corticosteroid therapy.

Short-term, high-dose systemic corticosteroid treatment caused a rapid suppression of biomarkers of bone resorption. Corticosteroids did not suppress biomarkers of bone formation, regardless of whether people received low or high doses of corticosteroids. This therapy was, therefore, harmless in terms of bone safety, in our prospective series of people with COPD.

Source <https://respiratory-research.biomedcentral.com/articles/10.1186/s12931-020-01531-9>

*Our medical reviewer comments: It's an interesting study, but the findings are not consistent with other published papers (which they acknowledge). We should take this as an interesting set of findings but not something completely reassuring. Oral steroids are still very bad for bones.*

## THE HAPPY HYPOXEMIA CONTROVERSY

Hypoxemia is low oxygen saturation in the blood. This is directly measured by analysing a blood sample, usually from an artery in your wrist, and indirectly measured by a pulse oxygen oximeter (finger prong).

Many of us in the lung condition community have experienced increased breathlessness and low oxygen saturation (hypoxemia) during flare-ups and, in our minds, they are intertwined. Health professionals have tried to convince us that they are not. The global covid-19 pandemic has brought up this phenomenon again.

In July 2020 a Belgian research group discussed Happy Hypoxemia that had been reported in some Covid-19 patients who had very low oxygen saturation - but showed no signs of respiratory distress, no breathlessness, certainly not in proportion to the severity of their hypoxemia. The researchers pointed to the need to look beyond pulse oximetry and watch how the person appeared, and to check blood saturation too, in order to care adequately for these people.

The research group also considered how to manage people in this condition, and recommended lying them on their stomachs for periods of time and some other treatments used for people with Adult Respiratory Distress Syndrome, a





condition usually requiring being placed on a ventilator and looked after in intensive care.

The researchers tried to explain the disconnect between the severity of hypoxemia and the relatively mild respiratory discomfort reported by the patients.

And then more recently in September 2020 some US clinicians questioned the treatments recommended in the July report for people with Happy Hypoxemia, arguing the treatments were relatively untested and that simpler measures would be just as effective and safer.

It sounds like we need to wait and see what further developments emerge in this debate.

Sources [Pathophysiology of happy hypoxemia in Covid-19](#) and [Misconceptions of pathophysiology of happy hypoxemia and implications for management](#)

*Our medical reviewer comments: The fact that breathlessness and hypoxia are not closely related is something that is important for people with lung disease to understand e.g. because we don't treat breathlessness with oxygen, and normal oxygen levels don't mean one is well.*

*I agree with the team that wrote to the journal that the authors of the original articles have misunderstood some key issues. We are seeing that a lot (now) with articles rushed out because they relate to COVID-19.*

*Perhaps the key message is that a variety of mechanisms can cause low oxygen levels without great respiratory distress (eg middle stage pulmonary fibrosis), just as other mechanisms can cause very serious illness and breathlessness when oxygen levels are normal (eg asthma).*

## **ARE GLAUCOMA AND SLEEP APNOEA CONNECTED?**

Glaucoma and obstructive sleep apnoea (OSA) are both widespread conditions. OSA may presumably partly cause or worsen glaucoma, although the connection is unclear. This German study looks systematically at the possible association between different types of glaucoma and OSA.

Ophthalmologic parameters like intraocular pressure or mean defect depth were not strongly associated with the Apnoea Hypopnoea Index<sup>4</sup> (AHI), but

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<sup>4</sup> Apnoea Hypopnoea Index is a measure of the severity of sleep apnoea, obtained by assessing how frequently the person stops breathing or shows abnormally slow or shallow breathing.

there was a strong correlation between the clinical classification of the glaucoma types and the AHI.

In particular people with Low Tension Glaucoma differed significantly from those with Primary Open Angle Glaucoma (POAG) and healthy controls in terms of OSA-defining parameters, such as the AHI. They conclude that OSA leads to an increase of Intra Ocular Pressure (IOP) and to types of glaucoma associated with high IOP.

Moreover, there is no correlation between OSA and Low Tension Glaucoma (LTG), which might support a different origin of LTG.

They recommend further studies to investigate the need for routine screening for OSA by one-night home sleep apnoea testing specifically targeted to people with definite POAG and definite ocular hypertension.



Source <https://respiratory-research.biomedcentral.com/articles/10.1186/s12931-020-01533-7>

*Our medical reviewer comments: Two good take home messages for readers*

- 1. If a study of associations is small, like this one, any positive results are likely to be by chance. e.g. there were only 12 people with ocular glaucoma - by chance a higher proportion of them might have been wearing black socks or have come on the bus today. Therefore, people shouldn't spend much time reading small studies.*
- 2. If the primary analysis is negative, don't spend much, if any time, reading the secondary analyses. There are plenty of real examples of negative trials that have been positive for people in arbitrary groups, such as by star sign.*

*These messages are important when people see studies that apparently show benefits for fringe treatments like stem cells or show associations between something surprising and a disease. We don't want to get people's hopes up around quack treatments, or mislead them about spurious associations. We also want them to be reassured that the treatments they take have been tested on thousands of people, and the associations we advise on (such as obesity being the second major cause of cancer) (are) based on data from hundreds of thousands, if not millions, of people.*

Thank you again 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

## COVID-19 STATS AT A GLANCE

How many days since the last **community transmission** of Covid-19 in Western Australia and other parts of Australia?

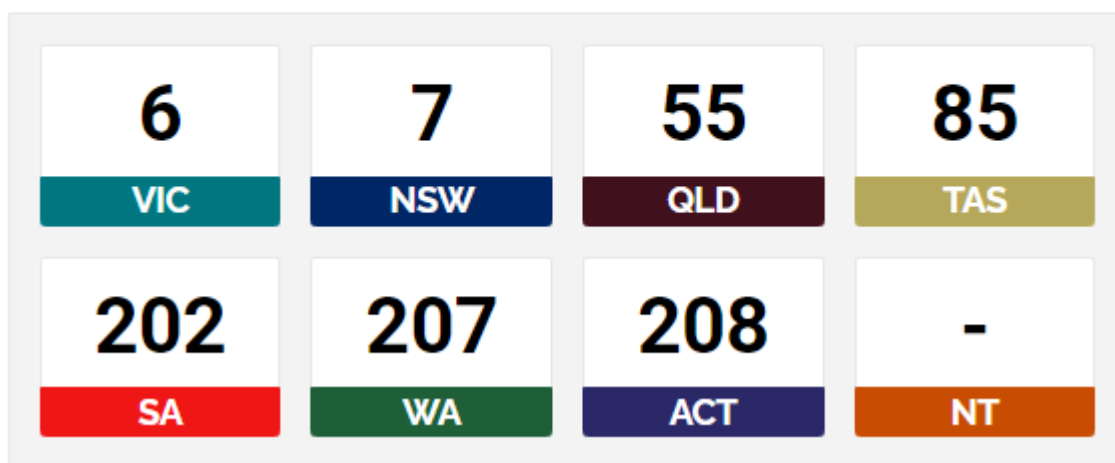
**Community transmission** is when, after thorough contact tracing, the source of someone's Covid-19 infection is unknown.

For WA this good news about community transmission gives us confidence to meet family members and come to meetings of L I F E, while still maintaining good hand and cough hygiene and social distancing – just in case. Our WA state borders are opening on 14 November and we hope that things continue safely.

Keep vigilant everyone!

## UNKNOWN

Days Since Last Community Transmission



Source Downloaded on 4 Nov 2020 from [CovidLive](#) which sources data taken from State & Australian Government sites

More at the [Australian Government's Health site](#)  
and [WA Health's site](#)

## INSPIRATIONS



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## A SHARED CHRISTMAS MEAL

At the heart of Christmas celebrations is the coming together of family and friends. Just because you have always been the host and the main chef, doesn't mean you must this year. If it's starting to feel too much tell your adult children or your dear friends that you need a bit more help this year. They may have been waiting for the opportunity to help more. Sit down together and work out a menu. Work out what you can do, perhaps with preparation the day before. It doesn't have to be at your place, just because it always has been. New family traditions are forged in the love you have for one another. Make it a peaceful and joyful day.



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## 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.

*Though face to face volunteering has been a problem early in the pandemic, things are less restricted now in Western Australia. You can always find something you can do from home, like telephoning.*



1. **Volunteer for L I F E** – by helping our L I F E group or another community organisation near you. Help in the Breath of L I F E mail out or the Phone Tree 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](mailto: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, seen promoted online 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.
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## 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. Phone numbers are included where available.



### 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 a referral from a respiratory specialist who has admitting rights to a WA public hospital (even if you see them privately).

[Chronically Inspired](#) – a sister support group to L I F E. Contact Melissa at E [chronicallyinspiredau@gmail.com](mailto:chronicallyinspiredau@gmail.com) or M 0418 930 291. Formerly Pulmonary Hypertension Network Australia



[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) a breathing technique that 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

[Inhaler Use](#) videos at Lung Foundation Australia

## 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](#)

## Exercise

[Mall Walking](#) groups COTA T 08 9472 0104

[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).

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

## **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](mailto: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

**UPDATED** [Indigo \(formerly Independent Living Centre\)](#) T (08) 9382 0600 Country callers 1300 885 886 choose and access equipment, technology and services for independence and wellbeing for people with disability and older people throughout WA. Centres at Nedlands and Westminster.

## **NEW Medicines**

Video on [Getting the most out of your pharmacist](#)

Video on [Learning about medication information](#)

## **NEW My Health Record**

My Health Record [Your shared health summary](#)

My Health Record Video on [Where to find documents in your My Health Record](#)

Video on [How to manage information in your My Health Record](#)

Help signing into and managing your [MyGov](#) account

## **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 and 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

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## 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.



### 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](mailto:life@resphealth.uwa.edu.au) 7 Ruislip St, W. Leederville, WA 6007. [Read it online](#).

### L I F E Membership

Join L I F E by becoming a community member of the Institute [online](#), pay at a meeting or by credit card by contacting T 6151 0815 (Sarah) 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.

**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!**

### Contacts

**Phone** Coordinator **Jenni Ibrahim** T 9382 4678 M 0413 499 701 [life@resphealth.uwa.edu.au](mailto:life@resphealth.uwa.edu.au)  
Deputy Coordinators **Sal Hyder** T 0409 336 639 [salhyder1@gmail.com](mailto:salhyder1@gmail.com)  
**David Payne** T 0439 048 897 [perthmillwall@yahoo.com.au](mailto:perthmillwall@yahoo.com.au)  
and **Gaye Cruickshank** M 0417 908 647 [gmcruick@bigpond.net.au](mailto:gmcruick@bigpond.net.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](mailto: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 (may be subject to change)

<b>Wed 2 Dec</b>	<b>Christmas lunch</b>	<b>Pre-payment essential by 20 Nov.</b> More info on page 3
<b>2021</b>	<b>Happy New Year!!</b>	<b>Let's hope it's a better one!</b>
<b>Jan</b>	No meeting at Perkins	Come to our planning meeting on 20 Jan! More inside.
<b>Wed 3 Feb</b>	Social meeting	Catch up with L I F E members over a cuppa
<b>Wed 3 Mar</b>	Living with Alpha-1 Antitrypsin Deficiency	Speaker is member David Payne who has this genetic lung condition