



Breath of L I F E

Lung Information & Friendship for Everyone

People with long term lung conditions, their family & carers

Winter 2017

Jun - Aug

ISSN 2207-0028 Digital

WINTER – THE TIME WE DREAD

6 more things to do to stay healthy

You've had your vaccinations, right? What else can you do to reduce the risk of those nasty chest infections hanging about in winter?

1. Keep walking. Winter isn't too severe in Perth, so it isn't hard to find a suitable time for a 15-30 minute walk 4-5 times a week. Walking maintains muscle tone and helps you clear mucus. Just take it a bit easier if you are fighting an active infection.
2. Keep drinking plenty of fluid. Thinner mucus is much easier to cough up. Bisolvon tablets can also help. Ask your pharmacist.
3. Eat a healthy diet.
4. Get some regular time outdoors in the sunshine. This boosts vitamin D which helps your immune system.
5. Refrain from smoking and being around smokers - give your lungs a chance.
6. Stay connected to friends and family - by phone when there are bugs around. Come to L I F E.



It'll be a while before we see kangaroos in the snow in Perth



E-COPY

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<http://tinyurl.com/kdtrqxc>

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Switch to an e-copy - get a full colour magazine, save trees, and let more of your membership fee support L I F E and the Institute for Respiratory Health.

life@resphealth.uwa.edu.au

Breath of L I F E Archives

A copy of every issue of Breath of L I F E is lodged with the State Library of WA and the National Library of Australia. Our digital record number (ISSN) now appears in the top right corner of the cover.

We started as LISA News and became Breath of L I F E in 2009.

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L I F E EVENTS

Recent

Mystery Autumn lunch was ...

After an inspection of the new Perth Busport (new for some) we took a short ride on the 960 alighting right opposite the Victoria Park Hotel. A great lunch and conversation. Thanks to June who kept us on time and did a recce of the route. Another mystery trip next year June?



Meetings

Two Perth Observatory volunteers, speaker, **Arthur Harvey** and chairperson, **Diana Rosman**, enthralled those at the May meeting. They told us about the Perth Observatory organisation and about our place in space.

Here are Sal Hyder's recollections:

Wow! We have just returned from a trip to outer space, leaving the 6th floor of the Perkins Building and passing the space station. Looking back to the earth 500km away. Next the Hubble telescope, then catching up with satellites:

Low earth orbit satellites (LEO) which orbit with 160-2,000km altitudes above earth. MEO (Medium Earth Orbit) satellites orbit at between 2,000-35,786km altitude. And are used by ships for navigation and for mobile phones. GEO (Geostationary Earth Orbit) satellites which travel round the earth at the same rate as the earth rotates daily, so stay in the same position relative to the earth. There are even some private satellites

up there too.

Had a good look at the moon and discussed its relationship with earth. The sun at present in a low energy era. Its flares which affect earth come from the equator line. It takes 26 days to rotate. Negotiating the Asteroid Belt we visit the planets. Discussed Saturn and the Cassini probe also the rings stabilised by Saturn's many moons within also its outer ones. Inner ones are called shepherd ones.

Venus and Uranus travel clockwise. We are at the edge of known space. Two previous exploring robots New Horizons and Pioneer 10 are still travelling in a straight line powered by thermos-generators.

A few other things we discussed were

- *Closest stars and nebulae (gas forming new ones)*
- *Jewell Box, a loose collection of stars and Tarantula, a close grouping. Both continue to rotate with all stars within it.*
- *Helio Pause is where it has reached the farthest point where the sun can have an effect and outer space.*
- *Closest other galaxies*
- *History of telescope development.*
- *Comets, e.g. Halley's which appears every 76 years.*

An amazing presentation. Rosemary's interesting questions contributed greatly and so we asked her to present a gift from us a L I F E pen.



Sal recommended a trip to Perth Observatory in Bickley, either by day (see the sun through special filters) or by night (see stars, satellites and planets, providing there's no cloud). She concluded by saying that if all the Observatory's speakers were all as good as Arthur they will do it very proud.

Arthur was impressed with L I F E's probing and intelligent questions -

especially Rosemary's.

Soon you will be able to make donations to Perth Observatory which has applied for charitable organisation status.

More

If you want to find out about visiting the Perth Observatory at Bickley by day or night, visit the website W www.perthobservatory.com.au

T 9293 8255 E infor@perthobservatory.com.au

P 337 Walnut Road, Bickley. Operated solely by volunteers, it's only open for scheduled tours, so don't drop in without prior arrangement.

The best nights are when the weather is fine and there is no moon (Dark Sky Nights). See more details on the website.

They offer winter night sky tours from June to mid September. In winter if clouds obscure viewing on your scheduled tour, they will show you all around their amazing observatory or transfer your ticket to another date.

If a tour is not for you, think about giving family members a voucher for a tour.



Your Wellbeing – Your Plan

Presenter **Dr Bob Ziegler**, now 87, is still actively involved with COTA, an organisation representing older people. His involvement has included being on the board as well as being a volunteer speaker. He has spoken to L I F E many times and came again in April, speaking about wellbeing when you get older. He thought he was far older than all of us, but he got a surprise.

Some of the important points from his talk are written up elsewhere in this issue.

Bob has a family connection to the respiratory community. His (step)son, Dr Peter Eastwood, is a professor of human sciences at UWA and a respiratory scientist at the sleep clinic at Sir Charles Gairdner Hospital.

Letter to My Lungs

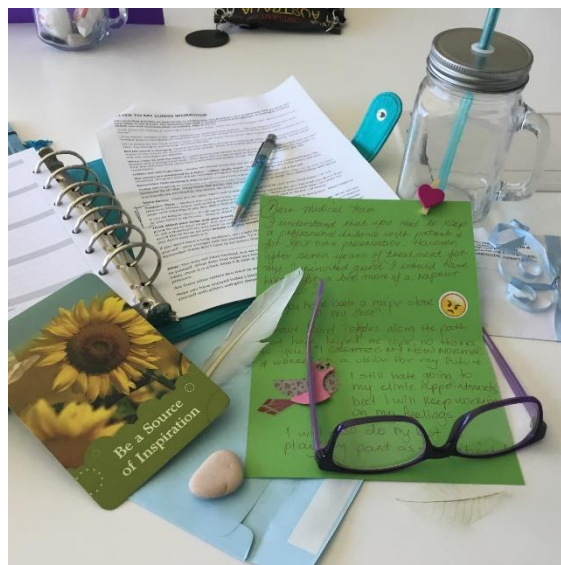
L I F E's Jenni Ibrahim and Melissa Dumitru from Pulmonary Hypertension Network Australia have been working on a workshop entitled Letter to my Lungs, based on the work of UK arts and communication consultant, Elspeth Penny. In March 2017 they facilitated the first with L I F E members and in April another was conducted with PHNA members.

People selected from a range of papers, pens, stickers, feathers, sayings, and letter containers and sat down to write their letters and decorate the pages. One thought she had nothing at all to say and went on writing page after page about her long term lung condition. Another wrote to her lungs but it turned out she was more concerned about her heart.

Though there was no pressure put on participants to share the letter they'd written, a number did. Some wrote to another part of the body that concerned them, another to a health professional who frustrates them. Some thanked their lungs, some apologised to them.

People were moved and better understood the journey others were taking. Letter writers experienced relief as they spelled out feelings and thoughts that had been spinning around inside their heads for ages. Grief, anger, thanks, fear.

If you are also involved with another group that might like to try this, contact Jenni life@resphealth.org.au 9382 4678 or Melissa meli@westnet.com.au



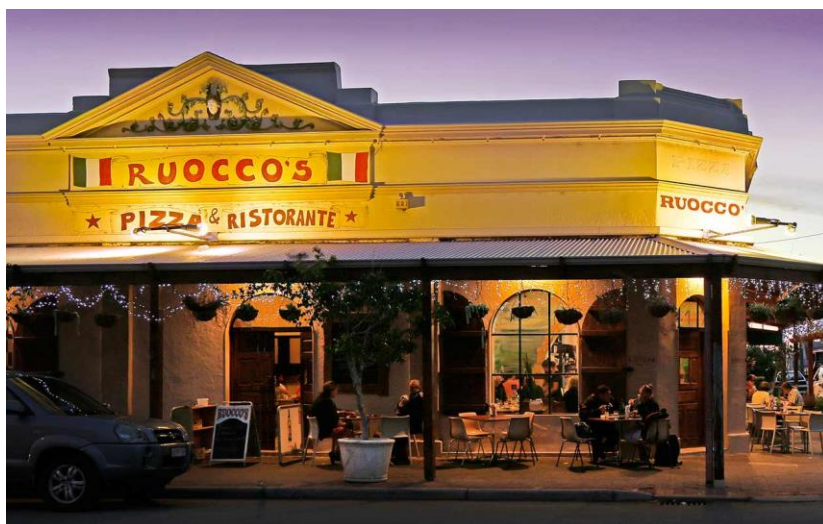
Coming Events

Winter lunch

Wednesday 19 July, 12 noon

Ruocco's (pronounced "Rocko's"), 217 South Terrace, South Fremantle

This famous Italian restaurant is a Fremo institution. It's been around for ever and is still going strong. Besides the wood-fired pizza Ruocco's is so famous for, there's salads, house-made pasta, seafood, meat and vegetarian dishes. A kids' menu is also available for older kids like us who don't feel too hungry at lunch. If you want something lighter, we could order a number of pizzas to share. It's licensed.



Public transport

Catch the Fremantle train at 11.15am from Perth. At Fremantle station hop on the Blue Cat bus over the road in Phillimore Street and this will drop you right over the road at 11.55 am (stop 10441). For

other options contact Transperth Infoline 13 62 13.

Access One step at front and side entrances. Parking can sometimes be hard around there, according to Jan. So if you can come by public transport it would be easier.

Please RSVP by **Monday 17 July** to Mary E mvfedele@bigpond.com
T 9337 1286

RESPIRATORY NEWS

Membership

Your membership of L I F E (= community membership of the Institute for Respiratory Health) falls due on **1 July**. You'll receive a membership renewal letter from the Institute about then. If you prefer, you can renew at a meeting (we have envelopes for your name and money), or by phone to Sarah Cermack at 6151 0815 or [online](#). Still only \$20 a year. Good value – don't you think?



Welcome new members of L I F E and the Institute for Respiratory Health. If you are looking for information about any aspect of your lung health or services that can help, contact Jenni on E life@resphealth.uwa.edu.au
T 9382 4678 or Sal on T 9331 3651 E salhyder1@gmail.com

Portable Oxygen Concentrator

Here's the kind Sandy Willsher who donated a portable oxygen concentrator (Respironics SimplyGo) to L I F E to benefit members. We need to get it serviced before members use it. If you would like to donate something towards helping us cover the service cost that would be wonderful.

We plan to enable people on oxygen to use it at meetings (instead of their bottles) and probably will later hire it to members for a few weeks for a holiday or trip.



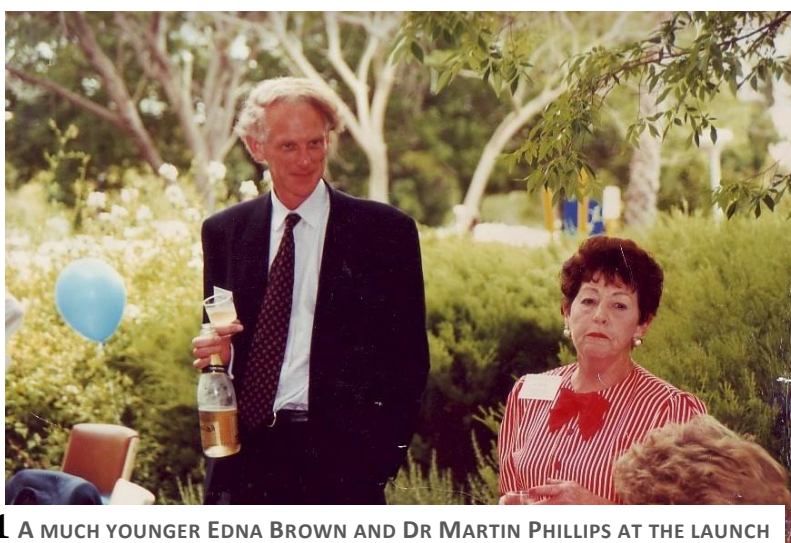
Happy Birthday To Us!



In August 2017 L I F E celebrates its 25th birthday. Yes, we have been going for 25 years. We are the oldest respiratory support group in Australia.

We started in 1992 after Edna Brown was diagnosed with idiopathic pulmonary fibrosis.

Recently widowed Edna thought, I need some support to deal with this and to find out information about it. So she reached out to others with fibrosis. Initially they met at people's homes until Sir Charles Gairdner Hospital's Respiratory Medicine Department kindly helped out by offering a meeting room in B block. The group also extended a welcome to people with other lung conditions.



1 A MUCH YOUNGER EDNA BROWN AND DR MARTIN PHILLIPS AT THE LAUNCH

After media coverage people with lung conditions started ringing Edna from around Australia to ask how to start a support group. She told Sir Charles



2 AT THE LAUNCH. SISTER SUE MOREY CENTRE IN WHITE

Gairdner Hospital's Respiratory Physician, Dr Martin Phillips, then chair of Lung Foundation Australia, asking him whether the Lung Foundation could help emerging support groups. So LungNet, the Lung Foundation's national network of respiratory support groups, was born and launched here in Western Australia.

Edna died in 2014 and Dr Martin Phillips is about to retire! And we are 25. A lot of tea and cake has gone "under the bridge" since then.

We'll mark the occasion later in the year.

Meanwhile thank you to all those who have contributed over the past 25 years, especially to Dr Martin Phillips and Sister Sue Morey CNS

and all those members past and present.

L I F E's Guide to Flying with Oxygen (revised)

L I F E's revised guide to help you plan and manage the process if you may need oxygen when flying (whether or not you need it on the ground).

Available under News and Events/ Publications tab on the Institute for Respiratory Health website [here](#) or <http://tinyurl.com/kb6rjko>

Lung Leaders Network

Since July 2015 L I F E has been convening a gathering of leaders of other WA respiratory support groups. Sort of like a support group for support group leaders. We've been sharing ideas, resources and issues regularly since then. The fifth gathering of the WA Lung Leaders Network will be held on 7 July 2017.

Lung Foundation Australia



By the time you read this the Lung Foundation consumer education seminars in WA will be over. They are scheduled for Monday 29 May in

Geraldton and Tuesday 30 May at Floreat. Topics to be covered in Perth are bronchiectasis and care of the throat and voice, while in Geraldton the topics are about supplementary oxygen and exercising when unwell. If you want to

receive a posted invitation for 2018 you will need to join the Lung Foundation's Love Your Lungs Club (LYLC, \$30 p.a.) In 2017 the invitations went to everyone on their list, whether a LYLC member or not.



The Lung Foundation is in the process of establishing an online forum for people with lung conditions to chat with each other.

Breathing Space Forum aims to support people with lung conditions and their carers, regardless of location, age, health or mobility.

The Foundation is seeking volunteers who might be interested to be an early user (starts off the forum with some early discussion), an administrator (reminds members of the forum rules when needed) or a patient champion (stimulates discussion going by asking the group an open question about living with their lung condition). L I F E has an expression of interest form we can send you if you are keen. Or if you are interested contact Karen enquiries@lungfoundation.com.au 1800 654 301. (Remember the time difference; they are in Brisbane)

LUNG LAUGHS

Greenie

Australia's 'Chief Woman Greenie Tree-Hugging Activist', who was responsible for getting horses banned from National Parks and State Forests, was climbing a tree to have a look out over the forest when a tawny frogmouth owl attacked her for invading its nesting site.

In a panic to escape, she slid down the tree, getting a great number of splinters lodged in her crotch area. In considerable pain she hurried to the nearest doctor, told him she was an environmentalist and how she got all the splinters.

The doctor listened with great patience and then told her to go into the examining room and he would see if he could help her. She waited for 3 hours before the doctor reappeared. Angry, the woman demanded, "What took you so long?"

"Well..." replied the doctor, "I had to get permits from the Environmental Protection Agency; the Forestry Service; the National Parks and Wildlife Service; the Wilderness Society and the Department of Conservation and Land Management before I could remove "old growth timber" from a "recreational area". I'm sorry but they all turned me down."



What is love? Young children's explain...

'When my grandmother got arthritis, she couldn't bend over and paint her toenails anymore. So my grandfather does it for her all the time, even when his hands got arthritis too. That's love.' Rebecca, aged 8



'When someone loves you, the way they say your name is different. You just know that your name is safe in their mouth.' Billy, aged 4

'Love is when a girl puts on perfume and a boy puts on shaving cologne and they go out and smell each other.' Karl, aged 5

'Love is what's in the room with you at Christmas if you stop opening presents and just listen.' Bobby, aged 7

A child's whose next door neighbour was an elderly gentleman who had recently lost his wife. On seeing the man cry, the little boy went into the old man's yard, climbed onto his lap, and just sat there. When his mother asked

what he had said to the neighbour, the little boy said, 'Nothing, I just helped him cry' Stevie, aged 4

Thanks to Janelle Griffiths, leader of the south west support group, SWILS

First Year Economics

Communism: You have 2 cows. The State takes them both and gives you some milk.

Socialism: You have 2 cows. You give one to your neighbour.

Fascism: You have 2 cows. The State takes them both and sells you some milk.



Traditional capitalism: You have 2 cows. You sell one and buy a bull. Your herd multiplies and the economy grows. You sell them and retire on the income.

Bureacratism: You have 2 cows. The State shoots one, milks the other and throws the milk away.

American corporation: You have two cows. You sell one and force the other to produce the milk of 4 cows. It dies and you hire a consultant to analyse why the cow died.

Irish corporation: You have 2 cows. One of them is a horse.

British corporation: You have 2 cows. Both are mad.

French corporation: You have 2 cows. You go on strike, organise a riot, and block the roads because you want 3 cows.

Italian corporation: You have 2 cows. You do not know where they are. You decide to have lunch.

Swiss corporation: You have 5,000 cows. None is yours. You charge the owners for storing them,

Indian corporation: You have 2 cows. You worship them.

Australian corporation: You have 2 cows. Business seems OK so you close the business and go have a couple of beers to celebrate.

Now you have almost passed 1st year economics. Contributed by the late Mike Watteau, foundation leader of sister support group Bentley Bronchiatrix

RESPIRATORY RECIPES

I know you want a winter warmer soup, but I found this recipe for a four ingredient fruit cake and thought you'd like it. Too easy. Just 4 ingredients: dried fruit, orange juice, SR flour and spice. I've tried some and it is absolutely scrumptious. Vary the spices or add nuts.

Abbreviations

T = Tablespoon

t = teaspoon

c = cup 250ml

L = litre 1,000ml/ 4 c

4 Ingredient Fruit Cake

1 kg dried fruit and 2 c orange juice - soak overnight

Next day, grease and line a large cake tin. Preheat oven to 150C

Mix into the soaked fruit:

2 c self raising flour and 2 t cinnamon

Spoon into cake tin and bake for 1 ½ hours.

Bump it up to 5 ingredients by adding a different spice or nuts.

Makes a large cake. Slice half up and freeze. Then you have cake on hand for visitors or bringing to L I F E.



Soup Tricks

Instead of a soup recipe are some tips for making great soups more easily this winter.

DIY Croutons



Left over bread from the ends of the loaf or the crusts you cut off for children can be frozen. When you have a bagful, cut into cubes, spread on an oven tray and slowly bake at 140C till crisp and dry. These in turn can be frozen and used straight from the freezer as garnish on a soup or to add crunch to a salad.

Stock on hand

When you peel prawns, reserve the heads and shells, boil them up and freeze. Always on hand to use in soup or risotto. Similarly for beef or chicken bones, vegie peels and trimmings.

Another stock tip is Massel vegetarian “beef” and “chicken” stock cubes and powder. Vegetable also available.

Chopping vegetables

Some people with weakness or arthritis in their hands, find chopping vegies for soup a challenge. Just put the vegies in a food processor (or blender with water) before tossing in the soup pot. Instead of pureeing the soup afterwards, basically do it first up. Either way it runs the risk of looking a bit like the colour of baby food (or baby poo).

And while we’re on chopping vegies, if you brown the onions and vegetables in a little vegetable oil before adding stock or water, you’ll find your soup has so much more flavour.

Increase the “umami” in your soup

The fifth human taste (after sweet, sour, salty and bitter) is *umami*. Known for eons, but only named with this invented Japanese word in the 1980s it is the flavour that makes things taste yummy. The following ingredients are high in umami, so include one or more into your soups (and other dishes for that matter):

Vegemite – yes, our favourite Australian spread is high in umami. Add a teaspoon to a soup for deeper flavour.

Parmesan rind (the thick bit from the outside of the wheel that won’t grate). Add it early on and let it simmer.

Tomato (paste, puree, fresh/skinned) - we all know it makes soups yummy

Soy sauce - don’t overdo or it will get too salty

Shiitake mushrooms (pictured) dried whole or sliced, can be found in the Asian section of most supermarkets. Soak in hot water and use the soaking water too. Sometimes also available fresh in the refrigerated section of the supermarket.



Miso – a brown paste made from soy beans and available in the refrigerator section of Asian grocers and most supermarkets. Main ingredient in Japanese miso soup. A spoonful adds a hearty, almost meaty flavour to any soup. Add it just before serving to keep the nutrients intact. Mix in a bowl with a little of your hot soup or water, then add near the end of cooking. Try just a teaspoon at first to see how you like it. A packet lasts well in your fridge.



Garnishes

Make your baby-food soup look more grown up by adding a garnish. Home-made croutons (see above), a dollop or yoghurt or sour cream, a sprinkle of paprika, chilli, cumin, some shopped herbs from your garden.

SHORTS

ASSESSING THE WORSENING OF COPD OVER A YEAR

The Global Initiative for Chronic Obstructive Lung Disease (GOLD) works with health care professionals and public health officials to raise awareness of Chronic Obstructive Pulmonary Disease (COPD) and improve prevention and treatment of this lung disease for patients around the world. GOLD divides people with COPD into 4 categories A-D, based on severity, as assessed by symptoms and risk of flare-up. The different categories can guide medication and other treatment. People in category A show the least airflow narrowing (as measured by breathing tests), the lowest risk of flare-ups, and the fewest symptoms as reported on a standard COPD questionnaire. Symptoms assessed by the



questionnaire include cough, phlegm, fatigue, breathlessness, impact on daily activities and work.

According to a group of British researchers, the features and pattern over time of people with COPD classified as GOLD B are not well understood. They set about assessing the clinical characteristics and natural history of GOLD B patients over 1 year in a multicentre cohort of COPD patients in the COPD MAP study.

They aimed to identify the subgroup of people whose condition “progressed” to GOLD D (unstable GOLD B) and identify characteristics associated with that change.

Three hundred seventy people with COPD were assessed at the start and 12 months later. Demographics, lung function, health status, 6 minute walk tests and levels of systemic inflammation were assessed, using statistical tests.

One hundred seven (29%) of patients were categorised as GOLD B at the start. These GOLD B patients had similar spirometry results/ breathing tests (FEV1) to GOLD A patients (66% predicted value). More GOLD B patients were current smokers ($p = 0.031$), had chronic bronchitis ($p = 0.0003$) and cardiovascular comorbidities ($p = 0.019$) compared to GOLD A. After 12 months, 25% of GOLD B patients progressed to GOLD D. These patients who were now classified as GOLD D (unstable) had worse health status and symptoms and lower FEV1 (60% v 69% $p = 0.014$) at the start, compared with stable patients who stayed at GOLD B.

The researchers concluded that people initially in the unstable GOLD B category who were a year later assessed as GOLD D, already had a higher level of symptoms at the start of the study.

Source Lawrence P J et al. Characteristics and longitudinal progression of chronic obstructive pulmonary disease in GOLD B patients, [BMC Pulm Med.](#) 2017; 17: 42 online 2017 Feb 20. doi: [10.1186/s12890-017-0384-8](#)

COPD SEVERITY: GOLD 2017 GUIDELINES

The article above refers to the GOLD guidelines which have been recently revised. What are the GOLD Guidelines anyway?

Global Initiative for Chronic Obstructive Lung Disease (GOLD) has revised its ABCD grading system, introduced in 2011, to categorise the severity of COPD. The 2017 ABCD grading system considers COPD symptoms along with exacerbation frequency and symptom severity (A is better, D is worse).

Airflow limitation (obstruction on spirometry breathing tests) is now *not* a component of the ABCD severity system. (Spirometry remains important

mainly for diagnosis, prognosis and consideration of therapies. It's no longer part of the severity grading system because airflow limitation correlates less well with functional limitation and quality of life than do the person's reported symptoms and history of flare-ups.)

COPD Treatment: GOLD 2017 Guidelines

Long-acting bronchodilators Almost all patients with COPD who experience more than occasional breathlessness should be prescribed long acting bronchodilator therapy. This could be a *long-acting beta agonist* (LABA), a *long acting muscarinic antagonist* (LAMA), or both. Patients with persistent COPD symptoms while taking one long-acting bronchodilator should be prescribed two (or a combination agent containing two long acting bronchodilators).



Inhaled corticosteroids are not recommended as monotherapy in COPD. Combination agents containing inhaled corticosteroids along with long-acting beta agonists are considered appropriate step-up therapy for patients experiencing COPD exacerbations while taking long-acting bronchodilators.

Oral PDE4 inhibitors, like cilomilast and roflumilast¹ are considered an add-on therapy only for patients with COPD with chronic bronchitis and severe airflow restriction who experience COPD exacerbations despite use of a combination bronchodilator with inhaled corticosteroid.

Drugs for secondary pulmonary hypertension due to COPD are not advised.

Oxygen Not Recommended for Most COPD Patients

The 2017 GOLD guidelines generally advise against the routine practice of prescribing supplemental oxygen to stable COPD patients without severe resting hypoxemia. In a randomised trial in >700 stable COPD patients with moderate hypoxemia, supplemental oxygen did not improve clinical outcomes or quality of life during the follow-up period. The guidelines do suggest that individual patient factors may be considered when evaluating a patient's need for supplemental oxygen.

¹ Both not currently available in Australia

COPD patients with severe resting hypoxemia (oxygen saturation $\leq 88\%$ and certain other patients with COPD) should all receive supplemental oxygen to be worn continuously.

The ABCDs of COPD Treatment in 2017 GOLD Guidelines

The 2017 GOLD guidelines go further in advising physicians exactly what class of medication to use, in which COPD patients according to where they fall in the ABCD grading scheme.

COPD GOLD Grade A Any bronchodilator (short or long acting), titrating² or switching to another as appropriate.

COPD GOLD Grade B A long acting bronchodilator (LAMA or LABA), and both if symptoms persist on one drug.

COPD GOLD Grade C A long acting muscarinic antagonist (LAMA), switching to LAMA+LABA or to LABA+ICS if further exacerbations occur.

COPD GOLD Grade D More complicated, requires individual management, often multiple drugs, consideration of roflumilast³ and azithromycin⁴ in selected patients.

Inhaler technique should be demonstrated for all patients and technique confirmed before concluding a medication is not working.

Non-Drug Treatment of COPD: GOLD 2017

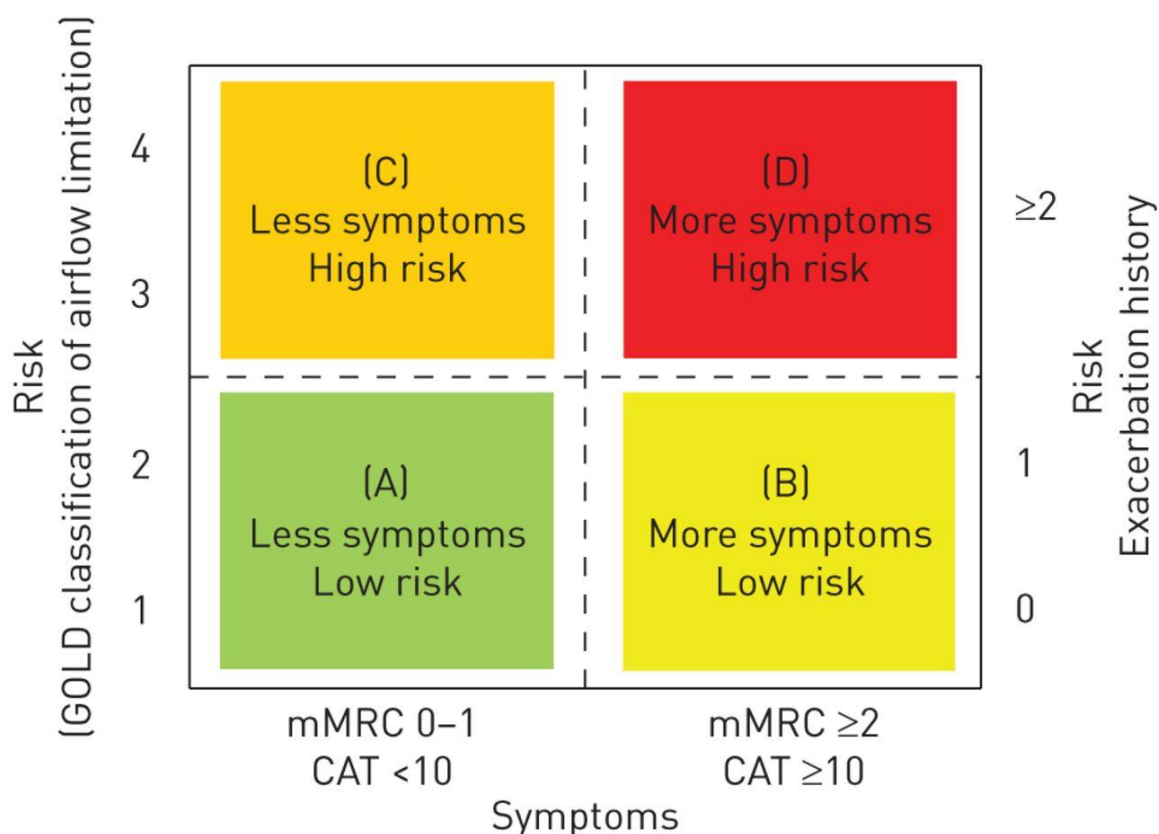
The 2017 GOLD guidelines also cover other aspects of the management of COPD:

- Pulmonary rehabilitation recommended for patients with severe symptoms or frequent exacerbations
- Exercise for all patients
- Vaccination against influenza (all COPD patients) and pneumococcus (all COPD patients older than 65 or with other cardiopulmonary disease)
- Daily oral opioids for severe COPD symptoms refractory to medical therapy
- Palliative care

² **Titration** means measuring and adjusting the balance of (a physiological function or drug dosage).

³ **Roflumilast** is not available in Australia

⁴ **Azithromycin** is available in Australia



The 2017 GOLD guidelines reflect improvements in COPD therapies and the latest evidence from multiple large randomised trials, and all this should help patients. The choice of inhaler device has to be individually tailored and will depend on access, cost, prescriber, and most importantly [the] patient's ability and preference.

In other words, the best inhaler for COPD is the one a patient can afford, understands, agrees with and will use regularly.

More [Global Initiative for Chronic Obstructive Lung Disease \(GOLD Guidelines\)](#)

Source [PulmCCM review of new GOLD guidelines](#)

SHARE THE WORD

Share the word with people you meet - family, neighbours, friends, random strangers in the supermarket queue. Tell them about L I F E, the Institute for Respiratory Health and about respiratory conditions.

We have smart business cards you can use, with L I F E contact details and a space for your name and phone number - if you think the person might like to contact us or come along to an event. There's nothing like personal contact.

It's a great way to give back to the respiratory community, improve awareness of lung health and win new members for L I F E. We'd love some new members. And there are people out there who don't know about us, seeking to meet others living with lung conditions like them.

Support groups like us rely a lot on word-of-mouth to spread the word about the benefits of belonging to a respiratory self help group.

Contact L I F E if you'd like some cards to keep at hand, in your wallet or handbag. Or pick some up at one of our monthly meetings. Even if you don't attend many functions, but love reading *Breath of L I F E*, tell others about this!

More life@resphealth.org.au Jenni 9382 4678 Sal 9331 3651|



PLACEBO EFFECT & RECOVERY FROM HEART SURGERY

We've all heard of the *placebo* effect. Testing a new medication usually involves one group of people taking an inert "medication" to compare it against the new one. Does the new medication work significantly better than if the person just thought they had taken a medication? Why not make use of the placebo effect to make other treatment more effective?



Making use of the placebo effect significantly improved the recovery of people undergoing heart surgery, according to recent research at the University of Marburg, Germany.

People who were given psychological support to raise their expectations

about post-surgery recovery scored lower on tests of disability, had a better mental quality-of-life, reported more hours of physical activity and better fitness for work six months after surgery, compared with people who received no additional support.

This is the first time the placebo effect has been studied in heart surgery outcomes from a pre-operative perspective and is the first to study the effects in a controlled trial.

The researchers split 124 patients into three groups, an 'expect' group receiving psychological support from a therapist who specifically aimed to raise expectations, a 'support' group who received the same amount of time with the therapist but did not discuss expectations and a control group who received no additional psychological support. Data on the patient's mental quality-of-life, disability, fitness for work and physical activity levels were collected before the study and six months after surgery.

Placebo effects are known to contribute substantially to the efficacy of clinical treatment, improving pain, measured clinical factors, such as cardiovascular measures and biological markers of the immune system. Labelling an activity a "treatment", how it is presented to people and who presents it, have all been shown to influence the placebo effect.

Source [*Rief et al. Preoperative optimization of patient expectations improves long-term outcome in heart surgery patients: results of the randomized controlled PSY-HEART trial, BMC Medicine 2017;15:4*](#)

ANTIBIOTICS FOR CF CAN CAUSE PERMANENT HEARING LOSS

A powerful group of antibiotics provides life-saving relief from chest infections for people with cystic fibrosis (CF). However, a recent study reveals the significantly increased risk of permanent hearing loss with high cumulative dosages over time.

When treating the symptoms of respiratory infections associated with CF doctors may be able to consider alternative drug strategies that do not increase the risk of hearing loss, particularly when people are not responding to that antibiotic class.



Newer medications have shown a reduced toxic effect on both the kidneys and ears of these people, while still treating infections effectively.

“Preventing or ameliorating the effects of permanent [hearing loss] is crucial for patients with CF who already have a significantly compromised quality of life due to the disease,” wrote Angela Garinis, PhD, Oregon Hearing Research Center, Oregon Health & Science University, Portland, Oregon, and colleagues.

The study examined the medical records of 81 patients with CF aged 15 to 63 years, dividing them into 4 groups based on the cumulative intravenous dosage of vancomycin, an aminoglycoside antibiotic.

The researchers found that the 2 highest dosage groups were almost 5 times more likely to experience permanent hearing loss than the other two groups with the lower cumulative dosage, after taking account of age and gender.

“This is an early step toward developing a model for predicting hearing loss in these patients,” said Dr. Garinis.

Aminoglycosides inhibit bacterial protein synthesis, and they are often necessary to clear life-threatening respiratory infections. However, these medications can degrade auditory function in the inner ear (as well as impairing kidney function).

Previous research had shown a greater risk of hearing loss from aminoglycoside antibiotics. However, this study is the first to take account of cumulative exposure over a person’s lifetime, while also weighting the daily dosing schedule used. The findings suggest it is important for doctors to routinely monitor hearing in anyone receiving intravenous *aminoglycosides*.

“This information will allow both the patient and the physician to discuss possible modifications to the treatment regimen, particularly if an alternative approach is or becomes available,” the authors wrote.

Patients with cystic fibrosis are living longer, raising the importance of maintaining their quality of life over a longer period of time.

Cystic fibrosis (CF) is an inherited life-threatening disorder that damages the lungs and digestive system.

Source [DG News](#) and Garinis A C et Al. *The cumulative effects of intravenous antibiotic treatments on hearing in patients with cystic fibrosis*, *Journal of Cystic Fibrosis*, 24 Feb 2017, [DOI](#)



YOUR WELLBEING - YOUR PLAN

Notes from Bob Ziegler's discussion with L I F E in April.

Last year Bob updated us on developments in aged care under the new consumer directed care (CDC) model being implemented across Australia, and more recently in WA. Under CDC it is consumers who say what kinds of services will help them in their senior years, not care providers telling them what they offer, as a take-it-or-leave-it model.

This time Bob wanted to raise the issue of how we work out what kinds of services we need.

He suggested we each develop a **Wellbeing Action Plan**, using the following headings:

Where am I now? How well am I?

Body

Mind

Social

Where do I want to be?

Body

Mind

Social

Dreams

Goals

Lifestyle

Emotional wellness

How am I going to get there?

My choices

My controls

Step Forward

What *could* I do?

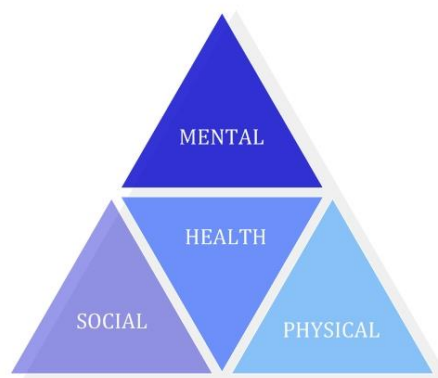
What *can* I do?

What *will* I do?

So, once you work out the gaps in your well-being, and imagine how they could be filled, then you think about how particular assistance that could enable you to meet that need. These gaps could be temporary, while you recover from surgery or an infection, or might be part of a managing longer term deterioration in health and capacity.

For example, you think you are getting on pretty well physically and mentally but miss the spiritual and social side of going to church. Your eyesight is deteriorating and you cannot drive any more. It's too far to walk with your lung condition. You decide you need help to get to church at least once a fortnight. You decide to swallow your pride and ring a friend from church to see if anyone could pick you up and drop you home.

Bob showed us a chart divided into three equal pieces – social, mental and physical. To keep well as we age, we need to address each sector of our lives. While living with a chronic health condition, we can sometimes neglect the other sectors of our lives.



The more mentally stimulating activities we take part in, the longer our telomeres at the end of our chromosomes. The longer the telomeres, the better our mental function. So far so good.

Many of us feel we keep our brain stimulated doing cross word puzzles or Sudoku. But did you realise you still need to learn new things to maintain optimal mental function? It's not just about doing things we already know how to do. It's also about learning new things. For example, a language, a type of puzzle you never do, a skill like painting or drawing, a craft skill you used to be good at. Try doing something with the opposite hand from the one you usually do.

What new skill are you going to learn this year?

By attending L I F E activities we certainly address the social part of our wellbeing. Other groups do too. Did you know that Men's Sheds is now the largest men's club in Australia?

We all know that when we don't use muscles over a period, they don't just sit there waiting for the next time we might need them. The muscle will actually

reduce in size, making a physical task so much harder next time. This point will be taken up by Nola Cecins in her presentation about pulmonary rehabilitation at the L I F E meeting on 2 August. Find out what exercises are not only **suitable** for people with lung conditions, they are **vitaly important**.

Regular exercise helps your heart, increases muscle mass, increases your immunity and reduces recovery time. If you have arthritis, exercise stimulates the body's natural anti-inflammatories, reducing pain. You don't have to go to a gym or buy equipment. Use what you have at home.

Try lifting a 400g can of tomatoes or beans or 1kg pack of sugar. Do ten repetitions of each of the two exercises shown in the pictures, shoulder raises, and curls. A third exercise, punches, involves holding your weights at shoulder height and stretching your arms forward in front of you. If 10 is easy, try 15 or 20 each day.

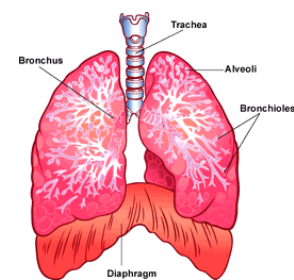


What will you write down for your Wellbeing Action Plan?

Even if you do not need outside help right now it can be helpful to make a plan to help guide your future decision-making

RESPIRATORY A TO Z

In the last two issues we've been exploring the A to Z of respiratory terms. Next up, L. Unsurprisingly, there are a lot of respiratory L words.



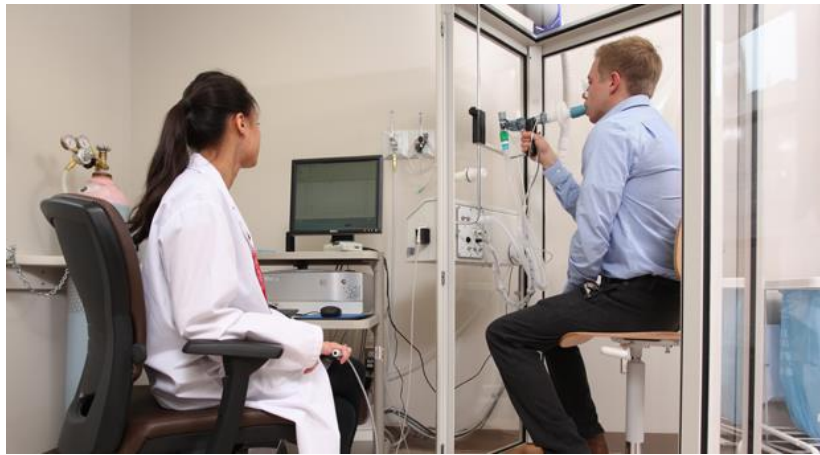
Lung cancer - a malignant tumour that grows in an uncontrolled way in one or both of the lungs. Cancer that starts in the lungs is known as **primary lung cancer**. It can spread to other parts of the body such as the lymph nodes, brain, adrenal glands, liver and bones. Primary cancer types include: small cell, non-small cell, and mesothelioma. Sometimes a cancer starts in another part of the body and spreads to the lungs. This is known as **secondary or metastatic cancer** in the lung.

Each year, about 11,000 Australians are diagnosed with lung cancer. The average age at diagnosis is 71. It is the fifth most common cancer in Australia and accounts for close to 9% of all cancers diagnosed. More men than women

develop lung cancer. The risk of being diagnosed before the age of 85 is 1 in 13 for men and 1 in 22 for women. Nine out of ten primary cancers are caused by tobacco smoking.

Lung's function is mainly to help oxygen from the air we breathe enter the red cells in our blood. Red blood cells then carry oxygen around the body to be used in the cells found in our body. The lungs also help the body get rid of carbon dioxide (CO₂) gas when we breathe out.

Lung function tests provide an easy way of measuring the function of the lungs without the need to physically examine the lungs themselves. Lung function or breathing tests are important investigations which help to diagnose suspected lung



disease, to plan treatments and decide whether treatments should be continued, changed, or are no longer needed. There are various types of lung function tests, including the spirometry and flow volume curve test, which measures airway narrowing, the carbon monoxide transfer test, which assess how effectively your lung absorb oxygen from the air and remove carbon dioxide from the body, exercise tests, skin prick tests (to assess the impact of allergy), measuring arterial blood gases.

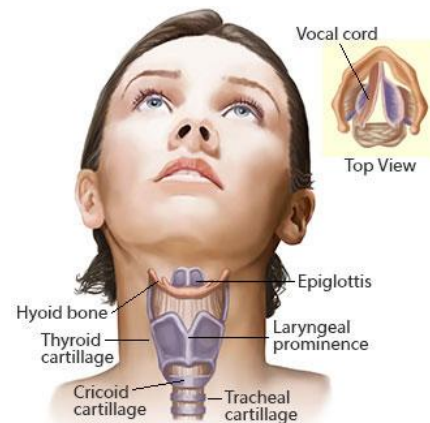
Lung volume reduction surgery – an experimental procedure for emphysema (part of COPD) in which over-inflated alveoli (air sacs) have lost their elasticity. It involves surgically cutting and removing the most severely affected areas of lung. This can improve the function of the diaphragm and provide more space in the chest cavity for the lungs to expand and contract more effectively. Alternatives to surgical removal is to insert a device like a valve in some airways, enabling the section of lung beyond the valve to deflate.

Lung transplant - a patient's diseased [lungs](#) are partially or totally replaced by lungs which come from a donor. Donor lungs can be retrieved from a living donor or a deceased donor. A living donor can only donate one lung lobe. With some lung diseases a recipient may only need to receive a single lung. With other lung diseases such as [cystic fibrosis](#) it is imperative that a recipient receive two lungs. While lung transplants carry certain associated

risks, they can also extend life expectancy and enhance the quality of life for [end-stage respiratory](#) patients.

Larynx - your voice box, located at the top of your trachea or wind-pipe. See diagram.

Laryngitis - when your voice box or larynx becomes inflamed, and your vocal cords become swollen and can't vibrate properly. This causes you to sound hoarse or to lose your voice. Normally you will recover from laryngitis without treatment. Other symptoms of laryngitis sometimes include sore throat, fever and cough.

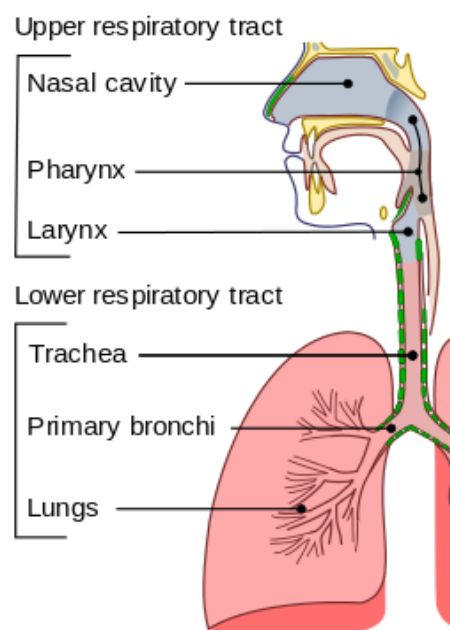


Hoarseness and loss of voice last for up to a week after other symptoms are gone. Commonly caused by a viral infection, such as a cold or flu, or from overuse of the voice, yes, talking or singing too much or too loudly. Bacterial infection rarely causes it. Laryngitis is said to be chronic or long term when it lasts for more than three weeks.

Chronic laryngitis is usually caused by smoking or excessive alcohol use, irritants such as fumes, dust and chemicals, reflux, repeated overuse of your voice.

Lower limbs – a term beloved of physiotherapists and medical practitioners. Oh why can they not just say 'legs'?

Lower respiratory tract - the windpipe (trachea) and within the lungs, the bronchi, bronchioles, and alveoli.



Deep in the lungs, each bronchus divides into secondary and tertiary bronchi, which continue to branch to smaller airways called the bronchioles, which have the tiny air sacs, alveoli, on the end. In contrast with the **upper** respiratory tract.

If there's a particular medical term you'd like to have clearly explained, let us know! Contact Jenni at E life@resphealth.uwa.edu.au or T 9382 4678 or M 0413 499 701.

HOW CAN I GIVE BACK?

Doing something that helps make the world a better place, feels good too. Here are five things 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.
2. **Share the word** with people you meet. Tell them about L I F E, the Institute for Respiratory Health and respiratory conditions. Our business cards have L I F E contact details and a space for your name and phone number. Contact us for a bundle.
3. **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 9331 3651 E salhyder1@gmail.com
4. **Register with the Clinical Trials Unit** of the Institute for Respiratory Health to take part in the trial of a new respiratory medication. Call Sandy T 6457 3198 E sandy.burnett@uwa.edu.au
5. **Become a simulated patient** at the University of Western Australia's School of Medicine and help train doctors of the future. Call the Doctor of Medicine Team T 6488 7528 E mdpatients-fmdhs@uwa.edu.au
6. **Volunteer to be a research subject** in a project advertised here or in your local paper.
7. **Donate** to the work of the Institute for Respiratory Health. Call 6457 3198.
8. **Mention the Institute's important research** into lung disease to friends and relatives who also might be interested to make a donation.



INSTITUTE FOR RESPIRATORY HEALTH

The [Institute for Respiratory Health](#) (formerly LIWA) 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 is 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 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 7 Ruislip St, W. Leederville, WA 6007. [Read it online](#). ISSN 2207-0028 (Digital version)

L I F E Membership

Join L I F E by becoming a community member of the Institute. Come to a meeting or contact the Institute T **6457 3198** or E life@resphealth.uwa.edu.au. Membership fee of \$20 a year (incl. GST) is due each 1 July. Members' help and ideas are always welcome - magazine, speakers, social events. Please tell us if you change address.

Contacts

Phone Coordinator **Jenni Ibrahim** T 9382 4678 M 0413 499 701

Postal L I F E c/- Institute for Respiratory Health, Ground Floor E Block, S C G H
Hospital Ave, Nedlands WA 6009

Email life@resphealth.uwa.edu.au **Web** [L I F E on the Institute website](#) [L I F E also on Facebook](#)

Meetings

1st Wednesday of every month, February to November from 12 - 2.30pm. Speaker starts at 1.00pm.

Level 6 Meeting Room 612A, Perkins Institute Building, Queen Elizabeth II Medical Campus, Nedlands. Wheelchair and gopher accessible. Light refreshments. If you can, please bring a plate to share. (We no longer meet at the Respiratory Library, Department of Respiratory Medicine, 1st floor, B Block.)

COMING UP

Wed 7 Jun	Medication reviews	Stephani Johnston, Pharmaceutical Society
Wed 5 Jul	Social meeting – no speaker	Come and have a chat over a cuppa
Wed 2 Aug	What is pulmonary rehabilitation?	Nola Cecins, Senior physiotherapist, SCGH
Wed 19 Jul	Winter lunch at Ruocco's	South Freo. More details inside. RSVP please
Wed 6 Sep	Gut bacteria and infection with cystic fibrosis	Dr Anna Tai, SCGH and Institute for Respiratory Health
Wed 4 Oct	Indoor air pollution	Dr Peter Franklin



institute for
RESPIRATORY HEALTH

**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!

