

2015-16
Summer
Dec - Feb



Breath of LIFE

Magazine of LIFE - Lung Information & Friendship for Everyone
The IRH self help group for people with chronic lung disease, family & carers

SUMMER TIME SURVIVAL TIPS

- Make sure you drink enough water. Dehydration can cause thicker mucus which is harder to cough up and can harbour bugs.
- Remember to keep taking your medication regularly, including rescue medication (Ventolin or Bricanyl) in the early stages of any flare-up. Plan ahead for public holidays when chemists are harder to find open.
- Call your GP or respiratory specialist's clinic if shortness of breath increases, and don't delay getting to urgent care or an emergency department if it worsens and doesn't respond to medication. Try the after hours GP services if needed.
- Plan essential outdoor activities during mornings or evenings
- Stay active, maintaining your exercise program, but schedule it in the cooler times of day or walk at an air-conditioned shopping centre
- Keep indoors if bushfire smoke is around and use air conditioning

Let's celebrate the festive season!

Join LIFE, community members of the Institute for Respiratory Health in celebrating the end of another year.

CHRISTMAS PARTY 2015

Monday 7 Dec 12 noon – meet ground floor lobby

Perkins Institute for Medical Research
Building, QEII Medical Campus.

More details inside.

We really must have your RSVP by Monday 30 Nov. So do it now!



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L I F E MEETINGS & EVENTS

LET'S CELEBRATE THE FESTIVE SEASON

Mon 7 Dec from 12 noon



Institute for Respiratory Health: Meet at ground floor lobby, 12 noon, Harry Perkins Institute of Medical Research Building, Queen Elizabeth II Medical Campus (where Charlie's is)

Cost \$15 per person, payable on the day

Bookings essential - let Mary or Raema know you're coming by 30 November.

Getting there: Map available from Jenni. The new Perkins Building is shown as building QQ on maps of Charlie's. It is a tall dark grey building next to new PathWest building (which is covered in red blood cell images).

Drop off: Enter from Aberdare Road, to Gairdner Drive to end of Verdun Street.

Park: Multi-deck car park (enter from Winthrop Ave) or on Gairdner Drive under the Cancer Centre (Building D).

Mobility assistance: To be picked up and taken to the Perkins Building from the QEII campus call Charlie's Chariot M 0481 438 721.

Gift Exchange: We expect an appearance by Santa if we're lucky. If you'd like to join in our Kris Kringle, please bring a gift valued at no more than \$10-\$15 - labelled if suitable only for one gender.

RSVP by Mon 30 Nov: Mary T 9337 1286 E mvfedele@bigpond.com

Raema T 9349 0617



Big thank you to all those L I F E members who have contributed to the running of the group during 2015. Even by just showing up. Particularly to Sal, Shirley, June, Sarah, Raema, Tom and Mary. Without you L I F E just would not be the same.

RECENT MEETINGS

On 2 September we heard about sudden deaths in nineteenth century Western Australia, by Dr Lenore Layman covered the interesting topic of accidental deaths, murders and suicides by poisons. The group enjoyed themselves at the Spring lunch at B shed Freo on Thurs 29 October which featured the sight of a visiting ocean liner in dock opposite ☺ and the odour of a sheep ship ☹. Perth people know what this means. At the October meeting Sara Coleman, respiratory nurse educator shared tips about using puffers and spacers and outlined the function of different types of respiratory medication. Our November meeting was a discussion about how we can actively manage our health and get the most out of our relationships with health professionals.

Thurs 5 November there was a Shine A Light on Lung Cancer event at Subiaco.

Thurs 19 November was World COPD Day.

NEWS

Welcome to new and renewing community members of the Institute for Respiratory Health. You are now also members of L I F E! Please drop in to one of our events.

Warm welcome to Maddison Meagan Straw, newborn daughter of Institute of Respiratory Health Clinical Trials Unit Manager Meagan Shorten, born 4 Aug 2015. Isn't she a cutie?



Get wells Long time member **Ann Fulton** has been very unwell again and missed several meetings – not like her at all. Hope you are on the mend soon Ann. **Denise Wright** has had interstate visitors and is enjoying having some extra help with household tasks at home.

Thanks to the L I F E Volunteers at the Clinical Trials Unit



Here's the result of the October working bee! Sal and her crew of L I F E volunteers ran another medical equipment sorting session in October, just before the L I F E meeting. Sal, Raema, Shirley, Rosemary and June took part. In November a crew of four assembled patient files. The Clinical Trials Unit appreciated their well-spent time. And everyone had had a jolly good

chat while they were working. If you'd like to join the crew in 2016 just speak to Sal at the next meeting or call her on T 9331 3651.

LUNG LAUGHS

My grandpa started walking five miles a day when he was 60. Now he's 97 years old, and we have no idea where the hell he is.

I like long walks, especially when they are taken by people who annoy me.

I like to walk early in the morning, before my brain figures out what I'm doing.

The advantage of exercising every day is so when you die, they'll say, 'Well, she looks good doesn't she?'

If you are going to try cross-country skiing, start with a small country.

I know I got a lot of exercise the last few years - just getting over the hill.

Every time I start thinking too much about how I look, I just find a pub with a Happy Hour, and by the time I leave, I look just fine.



RESPIRATORY RECIPES

(Jenni brought this dish to the October meeting. Recipe by request)

T = Tablespoon (20 ml)
t = teaspoon (5 ml)
c = cup (250 ml)

VEGETABLE SLICE (gluten free if required)

½ c (125ml) dairy free margarine – melted and cooled

1 onion, peeled and grated

¾ c grated cheese

1 ½ c (285g) sweet potato, peeled and grated

1 c (230g) carrots peeled and grated

1 c (230g) zucchini or other vegetable, peeled and grated

1 c (125g) chickpea flour or besan (health food shop or Asian grocery)

1 t gluten free baking soda

1 t cumin powder

2 eggs beaten



Pre-heat oven to 160°C. Lightly grease a small baking tin or 12-hole muffin tray.

In a medium bowl, thoroughly mix together all ingredients. Spoon mixture into a tin, cover with a layer of baking paper and then with foil.

Bake for 30 minutes. Remove the baking paper and foil, then continue baking for another 15 minutes or until firm and golden brown.

Based on a recipe at [UniMedLiving](#)

WATER TIPS

How many people do you know who say they don't want to drink anything before going to bed because they'll have to get up during the night?

I asked my doctor why do people need to pee so much at night time? A cardiologist says that gravity holds water in the lower part of your body when you are upright (legs swell). When you lie down and the lower body (legs, etc.) is level with the kidneys, it is then that the kidneys remove the water because it is easier.

When is the best time to drink water for maximal effectiveness?

2 glasses of water after waking up - helps activate internal organs

1 glass of water 30 minutes before a meal - helps digestion

1 glass of water before taking a bath - helps lower blood pressure (who knew?)

1 glass of water before going to bed - avoids stroke or heart attack (good to know!)

A GP said that drinking water at bed time will also help prevent night time leg cramps. Your leg muscles are seeking hydration when they cramp and wake you up with a "Charlie Horse".

Contributed by Janelle Griffiths, leader South West Lung Impaired Support Group

SHORTS

STAY ON YOUR FEET

Do you feel a bit wobbly on your pins sometimes? Even have a trip, slip or a fall?

There are ways of staying on your feet and avoiding falls, and getting on with enjoying life to the full.

During 2016 L I F E is hoping to have a speaker from the Stay on Your Feet WA people. In the meantime, find out more information yourself at the website or by ringing for a free booklet of tips (Move - Improve - Remove) and exercise



sheets (Move Your Body – Build Your Balance) with simple things you can do safely at home to strengthen your legs and build your balance. As we all know the less active we are, the more we are at risk of a fall.

More T 1300 30 35 40 W www.stayonyourfeet.com.au

Suggested by Jo Cockram

WHAT IS CONSUMER CENTRED CARE?

Consumer centred care is about you and your health care needs. It puts you at the centre. The main principles of consumer-centred care are: Access, Equity and Affordability. In considering whether your latest interaction with the health system was consumer-centred you could ask these questions.

Access

Did you experience any barriers to safe, timely, appropriate services that met your healthcare needs and/or managed your condition? If Yes, what barriers do you face?

Equity

Did health services, professionals and the healthcare system recognise and address any dimensions of health inequality that are relevant to your situation?

Affordability

Did you delay seeking treatment or care – or not seek them - because of cost? Did you experience anxiety or stress because of the cost of treatment or care?

Information and understanding

Were you given suitable information (orally or written) and could you understand it? Did you need more information?

Informed consent and informed financial consent

Were you provided with the information and support you needed to give your informed consent to treatment? Did you give your informed *financial* consent (i.e. consent to incurring that particular cost beforehand)?

Appropriate care

Did you get the right care, at the right place, right time, and from the right professional?

Respectful care

Did you receive care that showed respect for you, your culture, values, characteristics, preferences and expressed needs?



Whole of person care

Did care and treatment respond to the 'whole person'? Did you notice unmet mental, emotional or physical care needs?

Coordinated care and supported transitions

Did health professionals and services work together to ensure any transitions in your care were smooth? Did you experience good coordination between services and health professionals?

Safe and high quality care and treatment

Did you experience any actual harm caused by care or treatment? Were any harms or risks associated with your care or treatment explained to you in a way you understood?

If there was an adverse event, was this openly disclosed? If you made a complaint about your care, was there a clear process for making the complaint, and was there a response? Does your experience of a health care service show a culture of openness and transparency around issues of safety and quality in care or treatment?

Control and choice

Did the healthcare experience provide you with a sense of control and choice over your life and health?

Did you have opportunities to inform service delivery and health care policy?

Social, economic and community participation

Did health or healthcare impact on your ability to work, train or study; take part in social or community activities; or on your housing situation? Did you encounter any stigma or discrimination during this health care episode? Can you think of anything that could have improved your social, economic or community participation?

Carers and support

Did you encounter any issues related to the support of family and friends during your time with the health service? Were carers supported to care for you? Were family, friends or other carers involved in decision-making and care planning?

Source Based on a webpage at Consumers Health Forum www.ourhealth.org.au

Topic suggested by Pulmonary physiotherapist, Jo Cockram

PULMONARY REHABILITATION ON MEDICARE?

Lung Foundation Australia has been lobbying Medicare through the Australian Government's Medical and Scientific Advisory Committee to enable Pulmonary



Rehabilitation in primary care to be on the Medicare Benefits Schedule. Currently this is not the case, there is no item numbers for pulmonary physiotherapy. This means funding must come from hospital budgets and other State funding sources.

Physiotherapists cannot deliver pulmonary rehabilitation privately in the community with consumers claiming back from Medicare. But most pulmonary rehabilitation programs have no secure funding stream, and so are subject to the whims of State budgets.

We saw this in Western Australia a couple of years ago when the State Government wanted to close down pulmonary rehabilitation. After some public support for pulmonary rehabilitation from physiotherapists and participants the budget slash was cancelled – that time. Without some Medicare funding pulmonary rehabilitation is not sustainable for community based physiotherapists to run in private practice, due to small numbers and absence due to illness.

Some other States aren't nearly as lucky as WA because they do not even have regular pulmonary rehabilitation programs. Pulmonary rehabilitation has been shown through research to improve quality of life for people living with chronic lung conditions and to keep people out of hospital over the longer term. So it is cost-effective.

Written by Jenni Ibrahim after a suggestion from Jo Cockram

RISK OF COPD EVIDENT IN ADOLESCENTS?

A Danish study indicates that accelerated drop of lung function is not a prerequisite for chronic obstructive pulmonary disease (COPD). It has been generally assumed that everyone with COPD experiences a faster drop in lung function than others without COPD, which is why so many large studies have focused on reducing this rapid decline. However, this study reveals that this is true for only about half the people with COPD, whereas the remaining half develop the condition with virtually the normal rate of lung function decline.

“This long-term chronic disease can be developed in different ways, so achieving normal growth in lung function in early adulthood is an important factor in terms of future risk,” said Peter Lange, MD, Hvidovre Hospital and University of Copenhagen, Copenhagen, Denmark.

For decades, the development of COPD has been ascribed to accelerated decline of lung function from a normal level achieved in young adulthood. However, this study indicates that not all at risk patients show accelerated lung function decline. This may explain why, so far, the effect of various treatments of lung function decline has been difficult to establish.

For the first time, researchers could measure two major paths for lung function decline which led to COPD:

- **the fast decline path** (where lung function declined very fast from a normal level) and
- **the alternative path** where inadequate lung function development during childhood and adolescence was the major determinant of COPD in older age.

Data from three large groups of people who did repeated lung function tests over many years was studied. In two of the groups, the longest follow-up period was approximately 25 years.

This study may enable a better understanding of how COPD develops and play an important part in prevention. It shows that the best level of lung function achieved in childhood and early adulthood is an important determinant of future COPD risk.

“Thus, every effort should be undertaken to achieve normal growth of lung function - including non-smoking during teenage years, treatment of asthma in childhood and reducing exposure to agents such as passive smoking,” said Dr. Lange.

Source: Lange et al [Lung-Function Trajectories Leading to Chronic Obstructive Pulmonary Disease](#) NEJM 2015; 373:111-122 July 9, 2015 DOI: 10.1056/NEJMoa1411532 cited in [DG News](#)

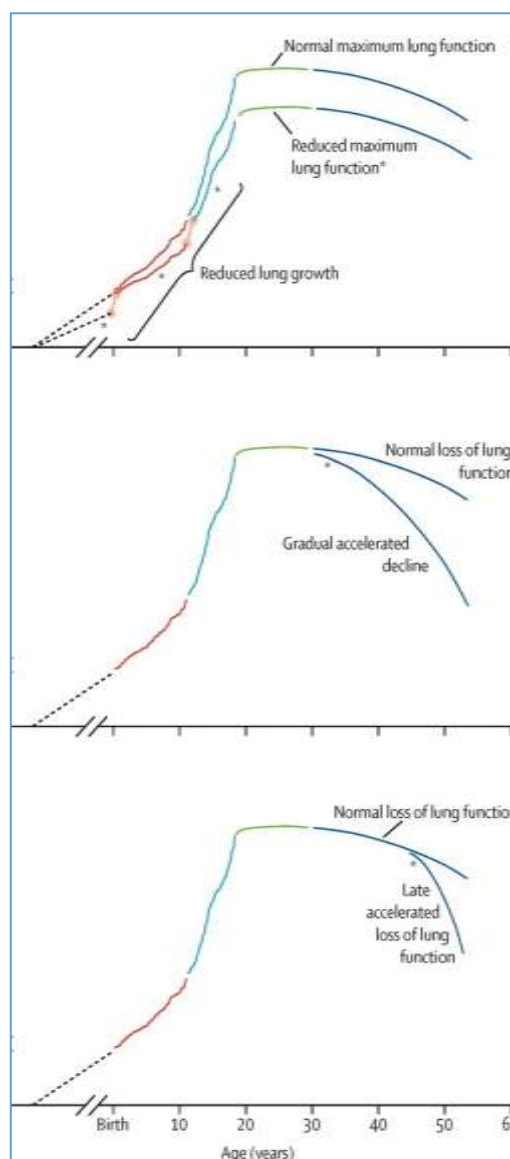


Figure 1 Accelerated and normal decline in lung function (not from this study)

FORGET ABOUT KALE!

The US Center for Disease Control and Prevention has named watercress as the biggest powerhouse food. Watercress has key nutrients that inhibit cancer development and regulate blood clotting.

Kale is often touted as the best of the best when it comes to superfood. But it



seems there are more than a dozen other vegetables that pack more nutritional punch than the favourite green of hipsters and health food bloggers.

Chinese cabbage, spinach, parsley and even some types of lettuce are just some of the vegetables that have been found to contain more of certain essential nutrients than kale.

But the veg that you should move to the very top of your next shopping list, is watercress. This delicate and deliciously peppery salad green is the only one to get a perfect nutrient density score of 100. A score assigned by a US research team that identified fruits and vegetables containing 10 per cent or more of the daily recommended intake of critical nutrients, including fibre, iron, protein and vitamins B,C and K. We want to eat foods rich in these nutrients as they have been linked with a reduced risk of developing chronic diseases, including some forms of cancer and cardiovascular disease.

Source www.abc.net.au/news/2015-09-16/powerhouse-foods-watercress/6659222

GO TO SLEEP AGAIN WITH 4-7-8

At the November meeting Jenni shared her 4-7-8 technique for getting back to sleep. For those who missed out (or were there and have forgotten) here it is:

Exhale fully with a “whoosh” (say it as you breathe out)

4 – Close your mouth and **inhale** through your nose to the count of 4

7 – **Hold your breath** for the count of 7 (or as long as you can)

8 – **Exhale** through your mouth to the count of 8

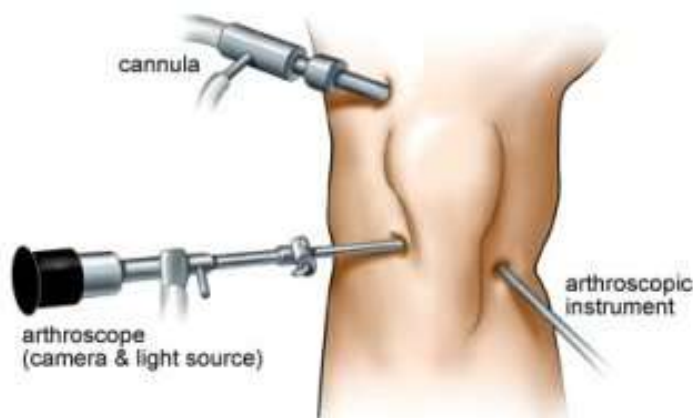
Don't worry if you can only do this by counting quite fast. That's OK. With practice you may be able to slow it down. Repeat this 3 more times. Soon you will be fast asleep.



KNEE ARTHROSCOPY – BENEFIT VS HARM

The small inconsequential benefit seen from interventions that include arthroscopy for degeneration of the knee joint doesn't last long and is absent one to two years later. Knee arthroscopy is associated with harm. Taken together, these findings do not support the practice of arthroscopic surgery for middle aged or older patients with knee pain - with or without signs of osteoarthritis.

This conclusion comes from a meta-analysis using the compiled results of nine studies published since 2000 and covering 1,270 patients. If your specialist is recommending it, consider the potential risks and benefits very carefully - both of having it done, and of not having it done.



Source Thorlund J B, et al. Arthroscopic surgery for degenerative knee: systematic review and meta-analysis of benefits and harms, *BMJ*. 2015; 350: h2747. Published [online](https://doi.org/10.1136/bmj.h2747) 2015 Jun 16. doi: [10.1136/bmj.h2747](https://doi.org/10.1136/bmj.h2747) PMID: PMC4469973

APREPITANT EFFECTIVE FOR RELIEF OF COUGH IN PATIENTS WITH LUNG CANCER

Many people with lung cancer have a bothersome cough which can be difficult to control. A study conducted in Manchester, England assessed the effectiveness of Aprepitant¹ in controlling cough in people with lung cancer.

In this study, researchers assessed Aprepitant's possible role as an antitussive (anti-cough agent) using objective daytime ambulatory cough monitoring as the primary endpoint. Ambulatory cough monitoring was carried out for 24 hours using a wearable device. The secondary outcome measure was the change in the patient's perception of cough as measured by a rating scale.

The study involved 20 people with lung cancer and a self-assessed "bothersome" cough. They were randomly placed into one of two groups: a 3-days of oral aprepitant (120 mg, 80 mg, and 80 mg on day 1, 2, and 3, respectively) or placebo.

On days 1 and 3, cough severity was self-assessed by the people using a visual analogue scale (see figure) and two questionnaires, and by the physician using the Common Terminology Criteria for Adverse Events (CTCAE) system.

After a 4 to 6 days of neither medication, people were then switched to the other group from days 7 - 9, i.e. the active drug if they'd had placebo before, and the placebo if they'd already had the active drug. The same assessments



¹ Aprepitant, (brand name: **Emend** used in English-speaking countries) is a compound that has been used against vomiting and nausea. It belongs to a class of drugs called substance P antagonists.

were done on days 9 and 13 or 14. Adverse events were also assessed at 2 weeks.

While the trial was small, the measures were powerful enough to detect a difference in cough frequency of 30%.

Daytime cough frequency at the beginning was 15.9 coughs per hour. Cough frequency after 3-day treatment with aprepitant was 12.8 coughs per hour versus 16.2 coughs per hour with placebo. The aprepitant-related decrease in cough frequency was significant ($P = .03$).

The visual analogue scale measured cough severity on 0-100 scale, with higher scores indicating greater severity. It showed 57.0 at baseline, 40.8 after the 3-day aprepitant treatment, and 49.8 after 3 days of placebo. The decreased severity related to aprepitant use was significant ($P = .008$).

The scores from one questionnaire (range 1-50, with a higher score indicating greater cough impact) was 25.2 at baseline, 19.5 after 3 days of aprepitant, and 21.7 after 3 days of placebo. Again, the effect of aprepitant in reducing cough severity was significant ($P < .001$).

There were no serious adverse events.

“This is the first trial to assess the efficacy of a novel antitussive using validated subjective and objective cough tools in lung cancer and the first to investigate a centrally acting NK-1 antagonist in humans,” said Dr. Harle. “Aprepitant treatment was associated with statistically significant improvements in objective and subjective scores.”

Source Based on an article by [Brian Hoyle October 13, 2015](#), about a paper presented at 2015 American Society of Clinical Oncology Palliative Care in Oncology Symposium titled A Placebo-Controlled Trial of Aprepitant for Cough in Lung Cancer. Abstract, Boston, USA

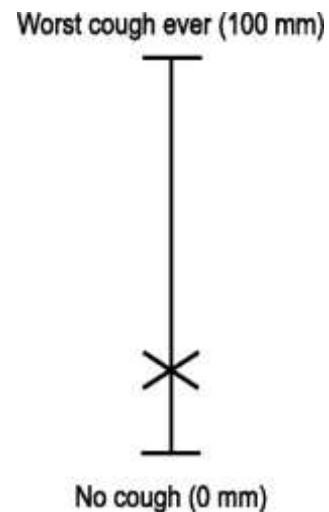


Figure 2 Visual Analogue Scale for cough, 0-100

DOUBLE LUNG TRANSPLANTATION USING DIABETIC DONORS IS SAFE

More and more people need transplants and so more and more donor organs are needed. But the prevalence of diabetes is rising too. In the past, diabetes was thought to increase survival risks for the recipient. A new US study has carefully examined whether there really are increased risks.

The findings suggest that when cautiously used, double lung transplantation from diabetic donors is safe.

“There was no increased mortality risk with diabetic donors,” said lead investigator Vishnu Ambur, MD, Temple University, Hospital, Philadelphia,

Pennsylvania, on 6 October. “Recipients from diabetic donors did have a longer length of hospital stay. The duration of diabetes was not associated with mortality.”

Dr. Ambur explained that lung transplantation is the gold standard for patients with end-stage lung disease, and there is a shortage of available donors despite expanded donor criteria. “While previous studies have reported increased mortality with diabetic donors, these studies did not differentiate between transplant type, and were performed prior to the advent of the Lung Allocation Score,” he added.

Dr. Ambur and colleagues analysed data from the United Network for Organ Sharing (UNOS) to examine the issue of double lung transplantation using diabetic donors. A search of the database for the period January 2006 to June 2014 revealed adult primary double-lung-transplant recipients (n = 8,881) with 6.7% from a diabetic donors (n = 592; 55.4% male) and 93.3% from non-diabetic donors (n = 8,289; 56.7% male). Of the diabetic donors, 316 (53.4%) had a history of diabetes of over 5 years, while 221 (37.3%) were diagnosed with diabetes only within 5 years of lung donation.

The study’s primary endpoint was death. Secondary endpoints were length of stay in hospital and post-operative complications. A further analysis examined how long the donor had had diabetes.

Post-operative complications between the diabetic and non-diabetic donor groups were similar in terms of number of deaths and causes of death, acute rejection episodes, airway dehiscence, and stroke (P = .79). Significant differences were evident in length of hospital stay and dialysis (P = .04).

Kaplan-Meier 8-year survival estimates revealed a comparable median survival of 5.92 years for recipients of lungs from diabetic and 6.45 years for non-diabetic donors, respectively (P = .09). The median survival for recipients from diabetic donors who had had diabetes for less than 5 years compared with over 5 years was also comparable (P = .23).

Those who received the lungs of diabetic donors were older than those whose lungs came from non-diabetic donors, and they had greater body mass index.

Source [DocGuide](#) online

WA PRIMARY HEALTH ALLIANCE

Just when you’ve almost got used to the name and role of Medicare Locals (previously known as Divisions of General Practice), they’ve **changed the name yet again!**

Since July 2015, following a review, the Federal Government has replaced 61

Medicare Locals with a smaller number of organisations which they hope will operate more efficiently. They are known as Primary Health Networks (PHNs).

PHNs are being established to **increase the efficiency and effectiveness** of medical services for patients, particularly those at risk of poor health outcomes; and **improve coordination of care** to ensure patients receive the right care in the right place at the right time. They relate to primary care, that is “first point of contact” care – by your GP, respiratory nurse, emergency department etc.

In WA, there are three Primary Health networks – Perth North, Perth South and Country WA.

The **WA Primary Health Alliance Limited (WAPHA)** is a collaboration of mainly non-government organisations and key stakeholders across WA who believe that Primary Health Networks (PHNs) can enable an effective, reformed and innovative primary care system in WA. It has been selected by the Australian Government to operate the three **Primary Health Networks** in WA. Yes, I know it’s confusing.



In coming months as consumers we expect to be invited to get involved with our local Primary Health Network and to hear what services they may provide for people with chronic lung conditions.

(Previous names of Primary Health Networks: Medicare Locals, Divisions of General Practice, WA GP Network.)

More

Chairman of the WA Primary Health Alliance is Dr Richard Choong.

Contact details for all PHNs at the moment is Learne Durrington, at WAPHA, Unit 2-5/ 7 Tanunda Drive, Rivervale, WA, 6103 T (08) 6272 4900

There is an [online locator](#) so you can find out which area you are in.

Sources [Australian Department of Health](#) and [WA Primary Health Alliance](#)

LIVING WITH CYSTIC FIBROSIS (part 2)

Concluding Gary Smallacombe’s story from the Spring issue. Gary was our May speaker. After becoming very unwell during a trip to Melbourne for the AFL Gary was back in hospital in Perth, this time for five weeks. His lung function had improved by the time he left but was still only 45% of normal.

About a year or two earlier, my lung function was approximately 65%. There was talk about next stages, like when my best would be only 35%, or other options such as lung transplants. These talks started to be quite overwhelming.

The 45% is still where I am at today, so thankfully changing my life, as I'll talk about soon, has meant in the last eight years I have kept the same health. However, before things became better, they became a whole lot darker for me for the next year or two.



After coming out of the hospital, I carried on, but something was different. What made matters even worse was that, one of my uncles had been diagnosed with cancer that could no longer be treated. I visited him in the hospice over a number of weeks. For the next month or so after his passing, I had nightmares about this environment, every time I closed my eyes. I don't know how much I actually slept during this time.

I started to think about my last time in hospital and could not get this thought away. It was the only thing I kept thinking about. I would drive to work (half an hour) but couldn't remember how I got there. I just felt emptiness all around me. I started to drink alcohol a lot more heavily than normal, but not for enjoyment anymore. Once I even walked to the shops at lunchtime and was almost run over as I didn't look crossing the road. I was so deep in thought about the same thing over and over again. I couldn't think about the future at all. About this time the stats came out that the average life expectancy for a CF person was 37. That was only a few years away for me.

I ended up seeking help, and was diagnosed with severe depression and insomnia. I was put onto antidepressants and had counselling. Both of these helped me back to being able to think properly again. While I still had the same thoughts occasionally, I could start to think past them. The basis of it all come back to when I was in hospital and done this damage to myself. Once I decided that I was to blame and I could fix this, my life started to change. I now call it my 'New Life'. My loving wife, and friends were invaluable during this time.

What come out from all of this, I realised, was that I could not continue what I was doing if I wanted to extend my life. My condition is a serious life threatening condition. I have learnt the importance of routine in doing my nebulised medicine, taking tablets every day, and slowly building up to doing more. Also regular clinic visits to keep track of slow declines, and hospitalisations when required, to keep a tab on things. My loving wife is also a constant reminder (or constantly reminding me, I should say!) where and when she can. I can still do more. I hope to get to a point of a life balance, while still striving to do more.

It has also taught me to be more open about my condition, and while I still do not tell people immediately that I have CF, I do open up, once I get to know

them a bit better. I mainly do this to start with, as unfortunately there are people in this world that will treat you differently. While on one hand I don't want to miss out on an opportunity, I also equally do not want to be given the easy road or have people feel sorry for me. My attitude now has taught me not to think I am hindered by this disease, because for the dozen things that I cannot do physically, there are twice as many things I excel in mentally because of it.

My 'New Life' has been really good to me, and I'm starting to see the benefits to my life changes. Over the last six to seven years I have taken a trip around Europe for a month where I proposed to my wife. I was able to walk around everywhere I went without a problem. A few years back I even climbed the Sydney Harbour Bridge, something I didn't think I would ever get to do. I married my wife Jo in our hometown of Albany.

More recently we have just purchased a house in the Perth Hills, and while I still struggle with things sometimes, I can overcome this with help from Jo, and am able to think about the future. I certainly have a more positive spin on life now.



I think this has helped me with my working life as well, as I have worked for the last three years at one place. Prior to this I worked at a job for five years. I'm still blown away at how understanding most of my work colleagues have been. Maybe I have been lucky.

For example about two years ago I got an infection, which required me to go into hospital for a period of time. I was lucky this time as I was able to be in hospital for just five days, then do the other 10 days from home. I was able to work from home, no questions asked. I had the option of using sick leave but I like to save that for a rainy day. When I am having antibiotics at home, I would rather be on the computer working and keeping busy than being on the couch!

So this is where I am today. Still continuing to do what I can to look after my health daily. A few years back I got involved in some CF drug trials. This year I've been on an extended study on a drug, and I think it's keeping me more stable than ever. It's not a cure, but starting in that realm of things. This one actually goes to the core issue of CF - the salt transfer between the cells. And all of this in

a tablet. It's the first time a drug is not just dealing with the symptoms, but fixing the issue. Hopefully this will turn into a cure one day. It gives me a good deal of satisfaction to know that others especially children just being born will have a much better quality of life. The technology and drugs that have changed over time, in just the time that I can remember is unbelievable.

While the distant future is still unknown for us, we have already started planning for after the current drug trial finishes at the end of this year, to start IVF and try to have a baby together. Due to CF I am infertile, yet still produce sperm, so this is our only option. We are both hopeful of starting a family one day, but we have alternate plans if it doesn't eventuate, and worst case scenario, we will still have each other.

Again, thank you to Gary for sharing your experiences and feelings so openly.

If you'd like to give back, like Gary has, and volunteer for a clinical trial at the Institute for Respiratory Health, go to the volunteering section, Opportunities to Make a Difference.

CARING FOR YOUR EQUIPMENT

In the autumn 2016 issue of Breath of L I F E we'll be covering how to care for your respiratory equipment, like inhalers/ puffers, spacers, nebulisers, CPAP, portable oxygen concentrators etc. If you have some special tips for others about caring for your equipment please share it by phoning Jenni T 9382 4678 or E life@resphealth.uwa.edu.au . **Deadline is 31 January.**

ROSE'S STORY

By Rosemary Hawkins, L I F E member

I've been a member of L I F E for three years but a member of the choir, The Spirit of the Streets, for about seven. It's a street choir inspired by and based loosely on The Choir of Hard Knocks of television fame.

The Spirit of the Streets started out in a small way with a few Big Issue vendors under the tutelage of Bernard Carney, a local musician and choir master. It has grown considerably in its nine years to become a working choir of about 35 with over 70 registered members and many casual attendees. We meet on a Tuesday afternoon in St Alban's Church Hall on



Beaufort Street in Highgate. The choir sings from 2-3.30 pm, but from 12.30-2 pm there are refreshments, giving us all time to interact.

It's a very welcoming choir, dedicated to helping people who might otherwise miss out, the opportunity of taking part in our many choir engagements. There's no auditioning and no pressure applied to sing or join. So for people wanting to 'try before they buy' it gives the wherewithal to do just that.

There are some rules, such as no alcohol, which includes not drinking at (performing) venues, even when the patrons are freely imbibing. This is because many of the choir members are vulnerable and it's easier to have this general rule than watch out for those people.

There is one warning I would like to give. As I've found myself, once you join, you can never leave!

More

W www.spiritofthestreetschoir.org.au E info@spiritofthestreetschoir.org.au

W www.thebigissue.org.au

Thanks to Rosemary for sharing her Spirits of the Streets choir experience.

SEVEN DOGMAS DOGGING PEOPLE WITH LUNG DISEASE

This is a slightly edited version of the paper presented by Jenni Ibrahim, Editor of Breath of L I F E and Coordinator of L I F E to the July 2015 conference of the WA branch of the Thoracic Society of Australia and New Zealand (TSANZ), the professional body for health professionals and researchers working in the respiratory field. The conference theme was Challenging Dogmas. Jenni is grateful to the TSANZ for the opportunity to speak to conference participants. In 2016 the national conference of the TSANZ will meet in Perth.

I wish to present a consumer perspective about living with a long term lung condition, not merely my own experiences, but those of the many others I am in contact with through involvement with respiratory self help groups.

My own lung condition arose quite suddenly in 1998 from severe community-acquired pneumonia, hospital-acquired pseudomonas and Acute Respiratory Distress Syndrome - when I was 48. I am eternally grateful to the health professionals at Charlie's - in ICU, on the respiratory ward and in pulmonary physiotherapy, whose professional care saved my life and later enabled me to lead a vastly improved quality of life than the one I left hospital with. My FEV₁² is currently 47%. I need oxygen when flying. Like COPD - but not quite.

² FEV₁ is exhalation Forced Expiratory Volume 1 sec, the amount of air you can forcefully breathe out in the first second of the out-breath. It is measured by spirometry, which is a breathing test carried out in a pulmonary physiology laboratory or at your specialist's or GP's clinic. FEV₁% compares the

Dogmas to challenge

I have seven dogmas to discuss. They reflect many widespread misperceptions in the community. So they include the views of some patients, particularly the newly diagnosed, and their family/ carers - even a few health professionals.

1. Lung disease is COPD. Everyone has COPD.

Members of our support group, L I F E , have COPD, chronic asthma, bronchiectasis, pulmonary fibrosis, sarcoidosis, lung cancer, asbestosis, cystic fibrosis, to mention just some. There is a self help group in WA which just focuses on people with pulmonary hypertension. The labels don't help us much. We cope with many similar symptoms and their consequences.

People dislike disease names which are acronyms, especially COPD. The acronyms confuse many.

On the other hand, people with the less common chronic lung conditions sometimes feel ignored by the lung community's major focus on COPD. They believe that too few researchers are looking into their lung condition - which they rarely hear of in the media. Some feel that when diagnosing, doctors sometimes overlook the possibility of these rarer conditions.

At the same time others are fed up that quite a few rarer health conditions are better known in the community than chronic lung conditions, which - in the public mind - are all caused by smoking. I'll talk about this issue in a moment.

2. Everyone with the same disease experiences life the same way

We meet others with chronic lung conditions in support groups and pulmonary rehabilitation classes and see the differences with our own eyes. People with differing levels of support in the family and community, differing personal circumstances, degrees of disability, rate of disease progression, different co-morbid conditions.

Yet even people with different lung conditions find a lot in common. The four big things we all manage, to a greater or lesser degree, no matter what condition we have, are:

- breathlessness on moving
- fatigue (lead weighted legs - as we experience it)
- chronic cough and mucus
- regular, sometimes frequent, infections and flare-ups

number of litres you can exhale this way with a person of the same size, age and gender, expressing this as a percentage.

Many people also are additionally challenged by

- fear and anxiety, even panic attacks, when breathlessness increases, especially if alone at night
- feeling self-conscious in public about having an oxygen cannula, a wheeled walker, or a PIC line
- depression (“I just want my old life back”)

Many are frustrated at how hard it is to find out what services are available, how to get to the services, especially if relying on public transport. This can be difficult for some with lung conditions, depending on where they live.

People are also frustrated trying to navigate the health system. Why do different programs have different criteria? Why programs do disappear or have funding threatened? We don’t understand why there are gaps in services. For example, how can we learn effective airway clearance techniques if we don’t have cystic fibrosis? How can we get access to pulmonary rehabilitation in the country or some parts of the metro area?

Most people feel that their lung condition is largely invisible. They are frustrated that their own family often doesn’t understand the impact of their condition. Many family conversations take place seated when we are not breathless. So we often don’t look ill or disabled – to some family members and to the wider community.

People are discouraged that the wider community doesn’t understand the disabling aspects of living with long term lung condition. For example, you can get insulted for leaving your car in a disabled parking bay despite displaying a valid ACROD sticker - because we’re mostly not in wheelchairs. We’ve printed and laminated this sticker to put near the ACROD sticker to help inform the public.



3. You have COPD. You smoked. Only got yourself to blame.

When you tell someone you have a lung condition, the first question you regularly get is, “Did you smoke?”

I’ve even heard of doctors who have reportedly told their COPD patients not to come back until they’ve quit smoking. Many people with COPD already feel very guilty about having smoked, or being unable to quit. Not everyone with a lung condition is a smoker or an ex-smoker, e.g. many people with idiopathic

pulmonary fibrosis, pulmonary hypertension, bronchiectasis, asthma have no history of smoking.

In any case many smokers were addicted to nicotine well before the science and the Quit campaigns were around. As you all know, nicotine is a highly addictive substance and people need lots of help and encouragement to quit. Not guilt trips. Luckily now there are lots of resources to help. Please direct people to these resources through the Quitline 13QUIT.

The QUIT campaign has so successfully established the link in the public mind between smoking and lung disease, that people with any kind of chronic lung condition endure an ongoing stigma, whether or not they smoked, whether or not their lung disease is even related to smoking. For example, mine wasn't; and I'm a never smoker.

In any case, by looking around our family and friends, we all see that not every smoker develops COPD. Of course you know, and I know, that smoking is the biggest single risk factor for COPD. But there are clearly many other factors at play too.

We would like to see more respiratory research to uncover what these other factors are, and the effective communication of the findings to the wider community. We want everyone to understand too.

4. Health consumers and their carers can't contribute much to decision-making about their own care

This view is held by a significant number of consumers and health professionals who believe self management is rubbish. In their minds only 'doctor directed care' is effective.

Well I'm a great advocate for self management. My view is that we - who live with a chronic condition - already spend 95 per cent of our waking hours self managing that condition. Only 5 per cent of our time is spent with health professionals. So those of us with chronic lung conditions already do self management, whether we know it or not. But we can all better self manage our condition with more effective support from our health professionals. A change of attitude is needed in some health professionals. Increasingly consumers are taking more control of managing their condition, with effective assistance and information from our health professionals.

I know that self management is not for everyone. That doesn't mean it should be for no one. Good support is vital for people who want to take an active role in their own health care.

Modern medical training recognises that health care decision making is a joint process involving the consumer, family members and a range of health care professionals. Only dinosaurs would believe otherwise.

My respiratory specialist once told me: “My job is to enable you to live the life that you want, to do what you want to, as far as possible”. You can see why he is my specialist. This kind of attitude is supportive of self management.

There are now lots of resources around to help people with chronic conditions and health professionals with self management. You could start by looking at the Lung Foundation Australia website, the new WA Health corporate website and the new Healthy WA consumer website. There are courses and resources for health professionals about how to develop better skills at supporting self management in consumers. And there are courses and resources for consumers in self management skills.

But the main thing that self management requires of many health professionals, consumers and carers - is a different attitude.

5. Support groups aren't worth mentioning to patients because there's no scientific evidence that they are effective

Effective at what? How would you conduct a randomised controlled trial of the effectiveness of support groups?

What support groups do well falls into the domains of the psychological, educational, cognitive and physical. They do not offer counselling or psychotherapy.

Not everyone will want to join a support group, but everyone needs to know they are there. One day they may want to meet others with a lung condition – people who understand the path they are travelling on.

Support groups may involve regular meetings, a speaker program (covering lung health, other health and general interest topics), social events, day trips, shared meals, displays at expos, and an online presence (social media, website and online forums), information sharing and newsletters.

Self help groups are not run by health professionals, but very much appreciate their support and encouragement.

In Western Australia there are currently 11 respiratory self help/ support groups, eight in metro Perth and three in country WA. Across Australia there are over 100 and four totally online groups. Based on population distribution, there should be one in Kalgoorlie and one south of the river in Perth.

6. Support groups are just negative whinge sessions

Like health professionals and respiratory patients, support groups are not all the same.

The best support groups leave people feeling glad they came to a gathering. Members realise they are not alone. They feel happier, more at peace with

themselves, more knowledgeable about their body, their condition, their treatment and the care available. Many are reassured that they don't have to "get their papers in order" - just yet. Yes, when first diagnosed with COPD, some believe they are about to die.

Members are frequently inspired by meeting others whom they see as worse off than themselves, even if a health professional might see it differently.

They see a new and positive role of contributing to the welfare of others like them, living with lung conditions. The members of self help groups derive great satisfaction from helping others, contributing to the whole group, despite illness and disability. They feel more worthwhile at a time when traditional roles have become challenging.

7. Pulmonary rehabilitation is a waste of time. People won't exercise. Their condition is progressive. They've just got to learn to live with the symptoms.

Without pulmonary rehabilitation I would not be where I am today -actively volunteering in many organisations, travelling to Europe and bush camping in remote WA.

Before I acquired lung disease I'd sooner have had my head in a book than gone for a walk. Pulmonary rehabilitation helped me understand the importance of physical activity and led me to take up regular exercise for the first time in my life. True story.

Walking is the most unnatural thing if your condition makes you breathless. Any normal person would stop and rest as soon as they felt breathless. We have to push through this to create a habit of regular walking and other exercise, despite the (at times) extreme discomfort. We really need pulmonary rehabilitation to do learn how to do this confidently.

Without regular physical activity the lives of those of us with chronic lung disease shrinks to an armchair. Yes, I know that may be where some of us may end up. But it's not where we should start. Left to our own devices we spend more time sitting than we should. Unless other medical conditions prevent it, make sure your patients know about pulmonary rehabilitation and encourage them to give it a go. I've been doing pulmonary rehabilitation maintenance classes since 1999 and like so many others I still get a vital benefit.

Benefits of consumers' experiences

Besides supporting strong self management in people with chronic conditions, health planners, researchers and professionals can gain valuable insight and perspectives in health service research, policy and planning from health consumers themselves.

Consumers are partnering with researchers and getting involved in their research. Helping researchers make decisions about research priorities, policies and practice. Not as subjects - but as valued partners. The National Health & Medical Research Council expects this. There are programs supporting consumer participation in research - at the School of Public Health at the University of Western Australia and at Telethon Kids Institute. Researchers discuss their research ideas with a panel of trained consumers and get real benefits from this. Western Australia is one of the world leaders in this field.

Consumers contribute to health service quality through accreditation processes, health policy and planning through the Health Consumers Council and WA Health's Health Networks. Here are a couple of examples.

Not long after L I F E began in 1992 some members formed the observation that it progressed more rapidly in men than women. L I F E founder, the late Edna Brown shared this opinion with me in the late 1990s. I thought that her observation could possibly be due to more women than men joining the group, and at an earlier stage of the (progressive) disease. One of our respiratory physician speakers stated at the time that there was no evidence in the literature. However, more recently, I understand that a gender difference is now being detected in the pattern of disease.

After being prescribed oxygen when flying in 2010 I found it hard to get detailed information about how to negotiate airline policies and oxygen supply arrangements. So many flights later, I wrote my own [consumer's guide to flying with oxygen](#), with Prof Philip J Thompson as co author.

Final words

Do dispel these myths in the community – especially if you spot them among your peers.

Do involve consumers more in research, policy and planning – they have lots of ideas and experiences to contribute.

Do tell patients about pulmonary rehabilitation, self help groups, and resources to quit smoking.

Do recognise that it's not all COPD, neither is it all about any other single lung condition.

Do help people to take control of managing their condition more effectively through supporting self management strategies.

See the individual and hear what they have to say.

OPPORTUNITIES FOR YOU TO MAKE A DIFFERENCE

You can help in medical research and presenting the views of consumers

Take part in a respiratory medication trial that might improve your respiratory health

The Institute of Respiratory Health Clinical Trials Unit specialises in the conduct of clinical trials for respiratory conditions. If you live with a respiratory illness, a clinical trial may give you access to new, innovative treatments as well as first class care from a range of specialists.



institute for
RESPIRATORY HEALTH

They conduct clinical trials for the following respiratory conditions

- Asthma
- Chronic Obstructive Pulmonary Disease (COPD – emphysema & chronic bronchitis)
- Bronchiectasis
- Alpha-1 Antitrypsin Deficiency
- Idiopathic Pulmonary Fibrosis (IPF)
- Cystic Fibrosis
- Mesothelioma
- Sarcoidosis
- Pulmonary Hypertension

If you live with **any** of these conditions register your interest in taking part in a Clinical Trial. Contact Leisa Wilson, Recruitment Officer, T 9346 4483, E admin@resphealth.uwa.edu.au or register your interest online at www.resphealth.org.au.

Someone you know could help bridge the gap between genes and respiratory disease

The Institute for Respiratory Health is also looking for **healthy volunteers**, WITHOUT a respiratory condition (i.e. don't have any of the conditions above) and would be willing to provide a sample of their breath and/or blood to assist with valuable research. This might be a partner, relative or friend or somebody else you know.



institute for
RESPIRATORY HEALTH

Investigation and research of patients WITH a respiratory condition is vitally important, but being able to compare the substances and genetics of these patients against healthy individuals who DO NOT suffer from a respiratory condition can provide valuable information. This helps increase understanding about respiratory conditions, assists in research into COPD and asthma, and aids ground-breaking discoveries in these fields.

Contact Leisa Wilson, Recruitment Officer, E admin@resphealth.uwa.edu.au or T 9346 4482

LUNGSCREEN WA

Lung cancer remains the number one cause of cancer death in Australia. Most lung cancer is found after it has already spread outside the lungs and so survival rates are not good. Although declining smoking rates will reduce the rate of lung cancer into the future, ex-smokers are still at an increased risk of lung cancer.

In the past, screening has not been recommended because the technique exposed people to too much radiation. A large US study in 2011 showed that lung cancer screening can save lives when a new **low radiation dose** CT chest scan is used instead. When compared with usual chest X rays, the new approach reduced lung cancer deaths by 20% in people at risk of lung cancer.

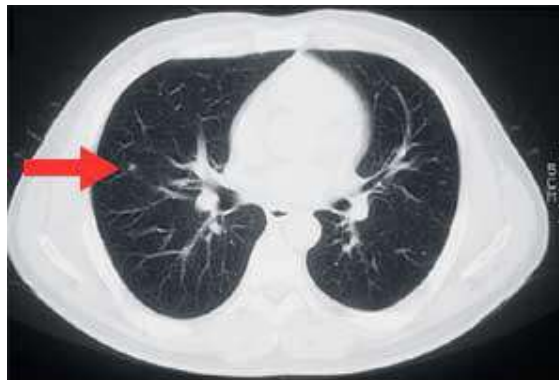


Fig1 : 5mm lung cancer detected by CT scan

Currently, CT scan screening for lung cancer in Australia is not recommended as there is neither the infrastructure nor enough information about the overall Australian costs.

The **LungScreen WA Project** is a pilot lung cancer screening trial being undertaken at Sir Charles Gairdner Hospital to investigate the role and cost of lung cancer screening in Perth.

The study, led by Dr Annette McWilliams and Dr Fraser Brims, is looking for people aged 55-74 years old, who are either current or former smokers. Subject to their individual lung cancer risk, participants will be offered a CT scan **at no cost**. Your involvement could help with the planning of a future lung cancer screening program in Australia.

More If you want to take part call LungScreen WA T 1800 768 655

HELP TRAIN THE DOCTORS OF THE FUTURE

Ever thought you could help the future doctors?

The University of Western Australia's Doctor of Medicine course is looking for community members for their simulated patient program.

Simulated patients work with medical students in small group teaching sessions. Students might take your history, perform a physical examination or make an assessment, just as they would with real patients.

They are looking for people who have medical conditions as well as those who are healthy. Medical conditions may include:

- Arthritis, Osteoporosis
- Heart conditions
- Parkinson's disease or past history of other neurological disorders
- Lung conditions
- Past surgeries
- All sessions are conducted under the supervision of a tutoring doctor and no invasive procedures are undertaken.



You **always** have an option of saying no whenever they contact you for a particular session - if you are not feeling well or not available. To register your interest or for further information please contact the Doctor of Medicine Admin Team on T 6488 7528 or E mdpatients-fmdhs@uwa.edu.au

We have a little space left here.

Maybe you could use it to jot down your Christmas shopping list?

DISCLAIMER

The information contained in Breath of LIFE is provided in good faith and believed to be reliable and accurate at the time of publication. However, the information is provided on the basis that a reader will be solely responsible for making their own assessment of the information and its accuracy and usefulness.

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LIFE

LIFE (Lung Information & Friendship for Everyone) is a self help support group for people with chronic lung disease, family and carers. It is the community support group of the Institute for Respiratory Health (IRH). It's run by and for people with chronic lung conditions. Started in 1992 as LISA, it changed its name to LIFE in July 2009.



LIFE is also a member of [Lung Foundation Australia](#)'s network of respiratory support groups T 1800 654 301. LIFE is grateful for the continuing support of the Department of Respiratory Medicine at Sir Charles Gairdner Hospital.

Breath of LIFE magazine

Our magazine is published 4 times a year - March, June, September & December. It is distributed to all LIFE members and other community members of the Institute. The editor is Jenni Ibrahim. Send contributions to E life@resphealth.uwa.edu.au or 7 Ruislip St, W. Leederville, WA 6007. [Read online.](#)

Institute for Respiratory Health

The Institute for Respiratory Health (formerly LIWA) is a collaborative respiratory research organisation. [Donations to the Institute](#) are tax deductible. Membership is open to interested community members, as well as researchers, health professionals and medical research students. Join LIFE through the Institute for Respiratory Health.

LIFE Membership

Contact Dorothy at the Institute for LIFE membership enquiries. E life@resphealth.uwa.edu.au or T 6151 0849. LIFE membership fees are due each 30 June - \$20 (incl. GST). Please advise us of any change of address. Members' help and ideas are always welcome - magazine, speakers, social events.

Contacts

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Postal: LIFE c/- IRH, Ground Floor E Block, Sir Charles Gairdner Hospital, Hospital Ave, Nedlands WA 6009
Email: life@resphealth.uwa.edu.au **Web:** [LIFE on the Institute website](#) [LIFE on Facebook](#)



Meetings

1st Wednesday of every month, 12 - 2.30pm, Feb-Nov. Speaker usually starts at 1.00pm. Respiratory Library, Department of Respiratory Medicine, 1st floor, B Block, Sir Charles Gairdner Hospital Nedlands. Wheelchair and gopher accessible. Light refreshments. If you can, please bring a plate to share.

COMING UP

Mon 7 Dec	Christmas Party	Perkins Building. Meet on G floor 12 noon. RSVP
Jan 2016	No meeting	
Wed 3 Feb	Social meeting	Come and catch up after the break.
Wed 2 Mar	Recipes and Remedies of Old	Dr Lesley Silvester
Mar or Apr	Autumn lunch	Further details next issue
Wed 6 Apr	TBA	TBA

Seeking information about your lung disease and how to cope with it?
Like to meet others in a similar situation?
Join LIFE!