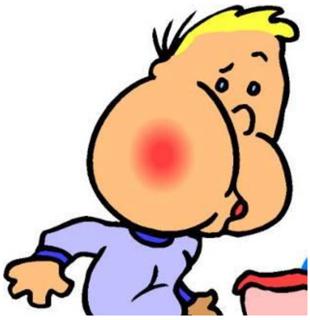
2015
Autumn
Mar - May



# Breath of LIFE

liwa Lung Institute of Western Australia Inc

**Magazine of LIFE - Lung Information & Friendship for Everyone**

***LIWA's self help group for people with chronic lung disease, family & carers***

## *AUTUMN ARRIVES*

In Australia autumn arrives officially on 1 March. Writing this on a 40C day in late February it is hard to imagine the days getting cooler. Perhaps autumn should be changed to start at the autumn equinox on 22 March, as it does in the northern hemisphere.

Our main tasks for autumn - while it remains hot - are to keep hydrated by drinking plenty of water, and try to fit in a daily walk - even on hot days - by walking early or late, or using a shopping centre or other large air-conditioned space.

By May we should all have had our 2015 flu vaccinations. Some older people are advised to have the flu vaccine twice a year, because the older immune system responds less effectively to the vaccine.

Look out for an article about flu vaccination in the Shorts section of this issue.

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**SAVE THE DATE!**

*Mon 20 April*

**Café lunch** at Sully's, Rockingham with Rockingham Respiratory Support Group (more inside)

*Thur 14 May*

**LungNet Education Day** at Boulevarde Centre, Floreat (more inside)

## WHAT'S INSIDE

## LIFE MEETINGS & EVENTS

### L I F E GOES TO LUNCH IN AUTUMN

**Café Lunch** overlooking the sea at Rockingham
With members of the Rockingham Respiratory Support Group

Monday 20 April from 12 noon

**Sully's Café**

7a Rockingham Beach Road, Rockingham

T 9527 4883

**Please let Mary or Raema know you're coming**

**Getting there**

Drive and park nearby. Or take the 11.01am train from Perth Underground (platform 2) to Rockingham, hop on the **BLUE** Transperth Rockingham City Centre Shuttle bus (#555) from Rockingham Station carpark to the foreshore at stop 23893 Kent Street/ Railway Terrace, a 12 minute journey, leaving every 15 minutes.

**Future lunches in 2015 (subject to confirmation)**

**Winter**: Christmas in July- Hot Christmas lunch with all the trimmings

**Spring**: Somewhere floral? Where will it be? Please give your suggestions to Mary or Raema.

**Contact**: Mary T 9337 1286 E mvfedele@bigpond.com Raema T 9349 0617

## RECENT MEETINGS

Our **December** meeting, our annual Christmas party, was perversely held in November. The LIFE Party was held at LIWA's staff lunch area in the new Perkins Building. Twenty members attended and some LIWA staff popped in (Geoff Laurent, Meagan, Emily, Michelle, Sarah, Janet, Sian and Dorothy). The room and decorations were magnificent. Greg Browning was our special Santa. We welcomed leaders from two other self help groups in Perth, Melissa and

Brian from Pulmonary Hypertension WA, and Bernice and Greg from Heavy Breathers Midland.

A huge thank you LIWA staff who helped us organise the event, especially Dorothy Koh. And thank you to Mary, June, Sal, Shirley, Raema and Sarah who rang members to check if they were coming. Thank you to LIWA for subsidising our lunch and providing such a lovely venue.

There was no meeting in **January**.

**February** was a lively meeting, ably chaired by Ann. **Jan Maiorama** came to our gathering for the first time after meeting us at the LIWA members' lunch at the Nedlands Bowling Club in December. Without a speaker we were free to roam around a range of topics from this year's calendar, to setting up advanced health directives and appointing an enduring guardian. A number of members have done this already. Others are interested to discuss more fully, so one of our meetings this year will be a facilitated discussion about these topics, with handouts provided. Watch page 28 for the date. Mary brought in some Herman the German Friendship cake to share, along with some sour dough starter and the cake recipe (below).

## NEWS

**Warm welcome** to **Ellen Ayling, Ernie Bindel, Danielle Blakey, Lyndell Gore, Chris Grey, Robert Gill, Robert Herbert, Janice Maiorana, John Neale, Brigitta Rawson, Pavan Prabhala, Sally Reed, Dino Bee Aik Tan** and **Dr Kimberly Wang**. Some of you may have been L I F E members for a while, so this welcome may be a little belated. We synchronised our mailing lists and found you. Welcome!

### Get wells

Welcome back who've been away with illness or surgery in recent months, especially Jack Fulton who had surgery in November and again in February, initially sending Ann into a bit of a spin. But she has survived sufficiently to chair the February meeting with great gusto. Glad to see Jack in between "theatre appointments".

### In remembrance

In January we fondly remembered, Edna Brown, our dear friend and the founder of L I F E - and its precursor, LISA. Edna died on 28 January last year after living with pulmonary fibrosis for 22 years. She spent almost all that time running the first Australian self help group, supporting people living with chronic lung disease, their family and carers. Remembered with gratitude.

## NEW GROUP STARTING IN GERALDTON

There's a new respiratory support group starting up in Geraldton. If you're interested, contact Respiratory Nurse Educator, Liz Whitehurst, WA Country Health Service Midwest, Geraldton Hospital, 51-85 Shenton St, Geraldton, WA 6530. T 99561989 E: liz.whitehurst@health.wa.gov.au L I F E's Jenni is going to speak to the new group in March.

## LAUNCH OF LIWA'S NEW NAME

On 28 April the Lung the Institute of Western Australia will hold its Annual General Meeting and then officially launch its new name, the Institute for Respiratory Health. You'll see the new logo in the next issue of Breath of L I F E.

## MOBILITY SCOOTER AVAILABLE

A mobility scooter ("gopher") is available for loan. Use it while you need it. When no longer required, to be returned to Department of Respiratory Medicine, Sir Charles Gairdner Hospital, so others can benefit too.

Contact Jenni Ibrahim, L I F E coordinator T 9382 4678 E life@liwa.uwa.edu.au .

## LUNG EDUCATION DAY

**Lung Foundation Australia's** annual education day for Western Australians with lung disease and their families, is on again this May. Displays and speakers to interest everyone. Catch up with friends from L I F E and other groups. Book early to make sure of your place. Family and friends welcome too.

LUNG FOUNDATION
AUSTRALIA
*"When you can't breathe... nothing else matters"™*

If you are already on the LungNet mailing list an invitation will be posted to you in February with the LungNet newsletter. If you're not, just ring the free-call number below and register for the event.

**Thursday 14 May 2014, 9.45am — 2:00pm,**
**Boulevard Centre (below Cambridge Library)**
**99 The Boulevard, Floreat, WA**

Speakers this year will include

- A pharmacist on medication interactions and medication reviews
- Motivational speaker Peter Dhu, on unlocking your potential under challenging conditions
- Chronic cough and lung disease (to be confirmed)

The seminar room is air conditioned and can get cool. Accessible by lift from the upper parking level to the centre below. You can get to the Boulevarde Centre by bus. Call Transperth T 13 62 13.

If you're driving, make sure you park in the allocated area, or you may get booked for overstaying in the shoppers' area. Free parking vouchers to display will be available at the registration desk on the day or, before the event, either posted with your LungNet newsletter late February, at L I F E meetings in April and May, or by contacting L I F E T 9382 4678 or E life@liwa.uwa.edu.au.

**Cost:** $15 (includes lunch and refreshments). **Booking is essential:** 1800 654 301 (free call) or E enquiries@lungfoundation.com.au RSVP **before 7 May.** Advise of any dietary requirements when you book.

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## LUNG LAUGHS

### SHARP ONELINERS FROM SOME FUNNY PEOPLE

Billy Connolly (1942-): My definition of an intellectual is someone who can listen to the William Tell Overture without thinking of the Lone Ranger.

Dorothy Parker (1893-1967): 'If you want to know what God thinks of money, just look at the people he gave it to.'

Bob Newhart (1929- ): 'I don't like country music, but I don't mean to denigrate those who do. And for the people who like country music, denigrate means 'put down'

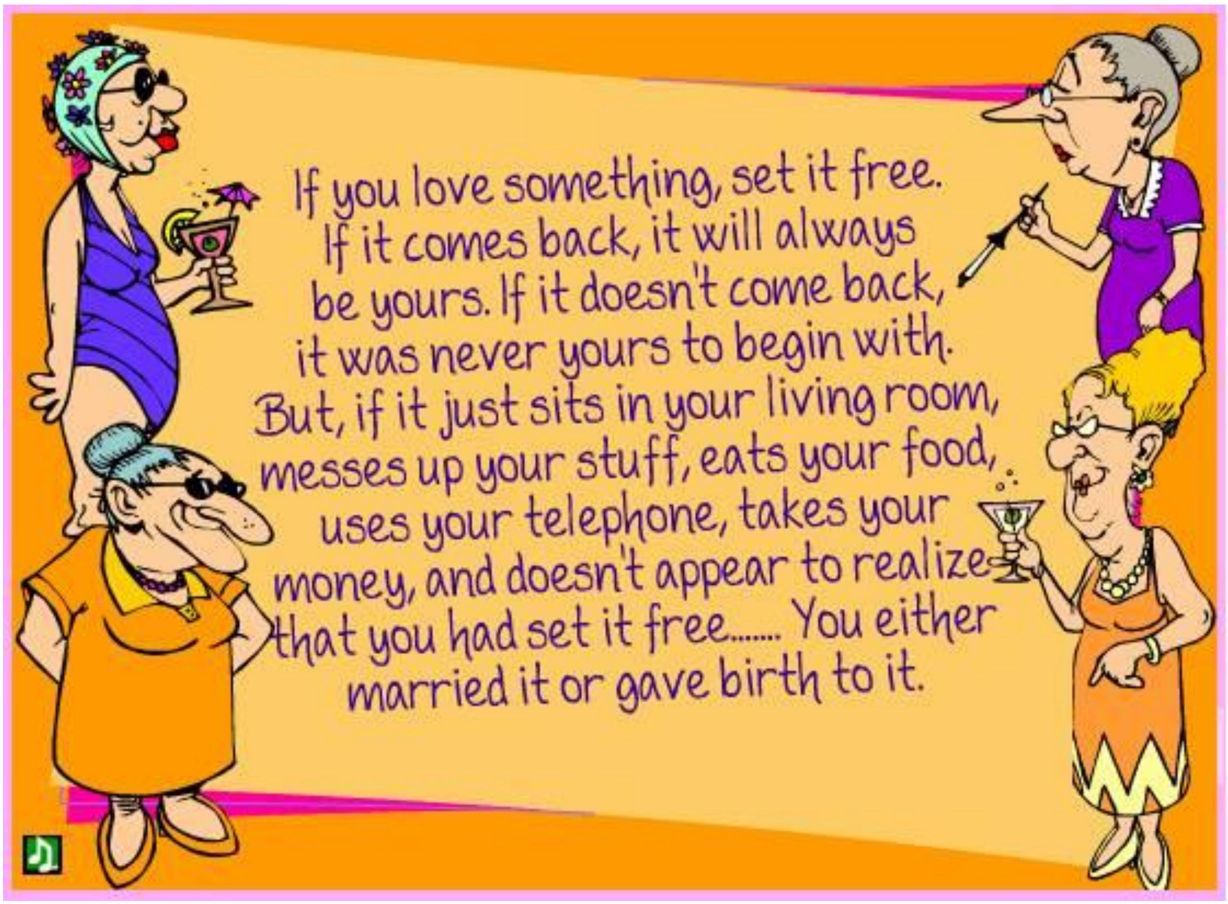
Noel Coward (1899-1973): 'Never trust a man with short legs… his brain's too near his bottom'

Mark Twain (1835-1910): 'Age is an issue of mind over matter. If you don't mind, it doesn't matter.'

Jay Leno (1950-): 'Politics is just show business for ugly people.'

Ambrose Bierce, author of The Devil's Dictionary (1842-1913): 'War is God's way of teaching Americans geography.’

Homer Simpson (1987-): 'Trying is the first step towards failure.'



**OLDER BRAINS**

Brains of older people are slow because they know so much.

People don’t decline mentally with age, it just takes them longer to recall facts because they have more information in their brains, scientists believe.  Much like a computer struggles as the hard drive gets full, so, too, do humans take longer to access information when their brains are **full**.

Researchers say this slowing down process is not the same as cognitive decline. The human brain works slower in old age, said Dr. Michael Ramscar, but only because we have stored more information over time. The brains of older people do not get weak. On the contrary, they simply know more.

Also, older people often go to another room to get something and when they get there, they stand there wondering what they came for. It is NOT a memory problem, it is nature's way of making older people do more exercise.

So there!

## PICK-UP LINE

Having already downed a few power drinks, she turned around, faced him, looked him straight in the eye and said, “Listen here, Good Looking. I screw anybody, anytime, anywhere, your place, my place, in the car, front door, back door, on the ground, standing up, sitting down, naked or with clothes on, dirty, clean - it doesn't matter to me. I've been doing it ever since I got out of uni and I just love it.”

Eyes now wide with interest, he responded, “No kidding. I'm a lawyer, too. What firm are you with?”

## KNOCK, KNOCK

There was a knock on the door one morning. I opened it to find a young man standing there. Hello sir, I'm a Jehovah's Witness, he said. Come in and sit down, I replied. I offered him coffee and asked, "What do you want to talk about?”

“Buggered if I know,” he said, “I've never got this far before.”

# RESPIRATORY RECIPES

## HERMAN THE GERMAN FRIENDSHIP CAKE

Hello, my name is Herman. I am a sourdough cake. I'm supposed to sit on your worktop for 10 days without a lid on. You CANNOT put me in the fridge or I will die. If I stop bubbling, I am dead.

Day1: Put me in a large mixing bowl and cover loosely with a tea towel.

Day 2: Stir well

Day 3: Stir well

Day 4: Herman is hungry. Add 1 cup each of plain flour, sugar and milk. Stir well.

Day 5: Stir well

Day 6: Stir well

Day 7: Stir well

Day 8: Stir well

Day 9: Add the same as day 4 and stir well. Divide into 4 equal portions and give away to friends with a copy of these instructions. Keep the fourth portion.

Day 10: Now you are ready to make the cake. Stir well and add the following:

1 cup of sugar (225g)
2 cups plain flour (300g)
1/2 t (teaspoon) salt
2/3 cup of cooking oil (160ml)
2 eggs
2 t vanilla essence
2 cooking apples cut into chunks
1 cup raisins (200g)
2 heaped t cinnamon
2 heaped t baking powder

Optional topping: ¼ cup brown sugar and ¼ cup melted butter

Mix everything together and put into a large greased baking tin. Sprinkle with topping, if used. Bake for 45 minutes at 170- 180C. Test the middle with a clean knife; you may need to cover in tin foil and bake for a further 20 minutes to make sure your Herman is cooked properly in the middle. When baked, Herman can be frozen.

*Many thanks to Mary Fedele for sharing this recipe and her starter culture. The cake she brought to our February meeting was delicious. The whole process is a lovely way to share a cake and some starter with some friends over afternoon tea.*

*More http://www.hermanthegermanfriendshipcake.com/ with recipes for other things you can make with the starter. If you don't know anyone with some starter you can make your own from directions on the website.*

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## INSPIRATIONS

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| **I Believe...that either you control your attitude or it controls you.** |
| **I Believe...that heroes are the people who do what has to be done when it needs to be done,** |
| **I Believe...that my best friend and I can do anything or nothing and have the best time.** |
| **I Believe...That sometimes the people you expect to kick you when you're down will be the ones to help you get back up.** |
| **I Believe...that sometimes when I'm angry I have the right to be angry, but that doesn't give me the right to be cruel.** |
| **I Believe...That maturity has more to do with the experiences you've had And what you've learned from them and less to do with how many birthdays you've celebrated.** |
| **I Believe...that it isn't always enough to be forgiven by others, sometimes you have to learn to forgive yourself.** |
| **I Believe...that no matter how badly your heart is broken, the world doesn't stop for your grief.** |

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| **I Believe...that our background and circumstances may have influenced who we are, but we are responsible for who we have become.** |
| **I Believe...that you shouldn't be so eager to find out a secret. It could change your life forever.** |
| **I Believe...two people can look at the same thing and see something totally different.** |
| **I Believe...that your life can be changed in a matter of hours by people who don't even know you.** |
| **I Believe...that even when you think you have no more to give, when a friend cries out to you, you will find the strength to help.** |
| **I Believe...that credentials on the wall do not make you a decent human being.** |
| **I Believe...that the people you care about most in life are taken from you too soon.** |

*Contributed by member Eliza Jane Sharpe*

## POSITIVE+

Positive+ is a new column in Breath of L I F E. You will find tips that can help you stay positive - an important part of keeping mentally healthy and living with chronic lung disease.

Positive is a new column in Breath of L I F E. It covers inspiring words, tips and activities to help you stay positive, a vital part of keeping mentally healthy while living with chronic lung disease.

You will need two or three different newspapers, scissors and some sheets of plain paper. Cut out the articles that seem positive. Put them together by sticking them onto the plain paper. You can also do this using a computer and news websites, choosing the stories that please you and printing them out.

Professional journalists work just like you. They select the stories that from hundreds that arrive in the newsroom. They might like to choose the ones that appear interesting to them. However, their employer insists that they publish only the ones which will increase newspaper sales.

Now read a regular newspaper and write down how you felt afterwards.

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Next, read your own newspaper and write down how you felt afterwards.

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Is there a difference?

*The world is neither grey nor rose-coloured. It's multi-coloured. It's our eye that lingers on the beautiful or the ugly, the positive or the negative.*

What do you do that helps lift your mood? If you have tips or words you'd like to share with readers, please send them in to share with others.

**Contact** E life@liwa.uwa.edu.au Jenni 9382 4678

*Based on Exercises for Being Positive: brain games for personal wellbeing, Yves-Alexandre Thalmann, Little Exercise Books series, Five* Mile Press, 2010. Trans. P. Abott-Charles.

## SHORTS

### NEW GUIDE TO FLYING WITH OXYGEN

L I F E has published a detailed guide to flying with oxygen. The 10 page guide covers these easy steps.

Talk to your respiratory specialist in case you may need an altitude test. Plan your trip around airline policies, flight schedules and oxygen supply. Only then make your booking and get travel insurance. Send the completed Medical Clearance Form to the airline. Organise oxygen by portable concentrator or bottle - unless the airline is to supply a bottle. Plan for your departure day. Have a safe and enjoyable flight!

You can download the guide from the L I F E webpage: Go to LIWA webpage, Quick Links on the front page, then jump to L I F E Publications. Or pick up a copy at a L I F E meeting.

*More Flying with Oxygen*

### CREATE POSITIVE CHANGE IN HEALTH CARE

Join the next Health Consumers' Representative Skills Development Workshop. The workshop covers: consumer participation in the health sector, sitting on committees and boards, understanding and applying systemic advocacy and report writing. On completion you will have a better understanding of your rights and responsibilities as a health consumer and how to contribute a health consumer opinion effectively. Interested? Contact Health Consumers Council T 9221 3422 E info@hconc.org.au

## ACROD PARKING

If you are a registered user of an ACROD permit for parking in bays for people with disabilities, you may have noticed that since 1 Dec 2013 the State Government was paying the costs previously recovered by the fee you paid. Thank you State Government!

Some local authorities provide discounts or exemptions to paid parking for people with ACROD permits. Contact the local authority concerned to find out what each offers.

City of Perth Parking offers two hours free in its own post-paid carparks (ie you pay as you leave). Using pre-pay car parks you are eligible for 50% discount, so insert enough coins to cover half of the time you expect to need. More information contact City of Perth.

## COPD and ASTHMA ACTION PLANS

L I F E has copies of these handy wallet sized cards you can use to record your usual lung health management strategies (medication, puffers etc) as well as how to keep an eye out for a flare-up and what to do then. Contact L I F E for a copy.

## TAKING A SUPPORT PERSON TO A DIFFICULT MEETING OR MEDICAL APPOINTMENT

If you sometimes take a support person to a meeting or appointment, here are some important steps to consider:

- Talk to your friend beforehand about what it is that you want to leave the meeting having achieved.
- Tell your friend that you do not expect them to speak for you UNLESS you ask them to.
- Give your friend permission to speak if they think it is critical to achieving the goal of the meeting.
- Introduce your friend at the beginning of the meeting but don’t say. 'This is **just** my friend' as that weakens their standing as your support person.
- Say that you give consent for the discussion to be open in front of your support person.

This simple preparation is a good basis for taking someone with you into a meeting and also helps them to know what you expect of them. For more information, please contact Health Consumers Council T 9221 3422 or E info@hconc.org.au

## CAPSICUM COMPOUND AND CHRONIC COUGH

Chronic unexplained cough triggered by environmental irritants is characterized by increased cough reflex sensitivity, which can be demonstrated by means of inhaled capsaicin, a compound naturally occurring in chillies and other plants in the capsicum family.

Topical capsaicin (applied on the skin or inhaled) can be used to improve non-allergic rhinitis and intestinal hypersensitivity and reduce neuropathic pain. Researchers in Sweden investigated whether an **oral** intake of natural capsaicin (chilli) could desensitize the cough reflex and improve unexplained coughing.

Twenty-four patients with irritant-induced, unexplained chronic cough and 15 controls were included in the study. For 4 weeks, the participants took capsules with pure capsaicin, and for 4 weeks, they took placebo capsules. Under the study design neither the researchers who met with participants, nor participants themselves, knew which group a participant was in (placebo or active ingredient). People were randomly allocated to group A or group B. Group A had the placebo for the first 4 weeks, and the capsaicin for the next 4 weeks. Group B had it the other way round.

Cough sensitivity during the study was evaluated by a standardized capsaicin inhalation cough test that assessed the capsaicin concentration required to reach two coughs and five coughs. Participants were also given questionnaires on cough and cough-related symptoms. Three patients withdrew before the study end, one during the active treatment period and two during the placebo period.

After the capsaicin treatment phase, it took more inhaled capsaicin to make a person in either group produce two coughs compared with after the placebo phase. Among people taking capsaicin capsules, the amount of inhaled capsaicin needed to trigger two coughs or five coughs increased after taking capsaicin capsules, compared to cough thresholds at the start of the study. The cough symptom scores improved after 4 weeks of active treatment compared to the baseline scores. Capsaicin powder taken orally decreased capsaicin cough sensitivity and cough symptoms. The findings suggest the improvement was due to desensitization of the cough-sensitive transient receptor potential vanilloid-1 (TRPV1).

*Source* *Ternesten-Hasséus, Ewa, Johansson, Ewa-Lena, Millqvist, Eva University of Gothenburg, Sweden Respiratory Medicine, November 2014*

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## FIBROSIS, ASBESTOSIS AND SMOKING

The diagnosis of pulmonary asbestosis is most often based on clinical criteria and has both clinical and legal implications. Unfortunately, one of the confounding features in the diagnosis may be a history of heavy cigarette smoking, which can produce interstitial opacities (areas which are not clear) on chest imaging as well as diffusion defects on pulmonary function testing, criteria that are also used in the diagnosis of pulmonary asbestosis. That is, both smoking and asbestosis can produce similar results on X-ray (radiographically) and lung function testing.

The aim of this study was to examine the relationship between pulmonary fibrosis detected by X-ray or CT scan with fibrosis attributable to asbestos by microscopic examination of tissue samples from the lungs. The study participants were people referred for diagnosis of an asbestos-related malignancy in the context of litigation. Researchers examined the slides of 186 cases with reported asbestos exposure, referred in consultation for asbestos-related malignancy and the presence of pulmonary fibrosis.

Sixty-five people had what was judged to be adequate tissue sampling for microscopic examination, as well as having an adequate X-ray or CT scan assessment of pulmonary fibrosis. Of 24 people judged to have asbestosis radiographically, who also had sufficient tissue for pathologic examination, six showed asbestosis by microscopic examination. The remaining 18 people (mean smoking history of 53 pack-years) showed interstitial fibrosis that was judged to be most consistent with smoking-associated pulmonary fibrosis, rather than asbestosis.

Researchers concluded that the clinical diagnosis of mild asbestosis cannot be reliably distinguished from interstitial fibrosis in heavy smokers.

*Source* *Bledsoe JR, Christiani DC, Kradin RL, Smoking-associated fibrosis and pulmonary asbestosis, Massachusetts General Hospital, Boston, MA, USA* *and* *Review*

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## HIGH-DOSE FLU VACCINE FOR FRAIL ADULTS IN LONG-TERM CARE

For frail older adults living in long-term aged care facilities, the high-dose influenza vaccine appears to be a better option than the regular shot, producing a stronger immune response than the standard vaccine, according to a study published online in the Journal of Infectious Diseases.

The high-dose vaccine may play a key role, along with improving vaccination rates among healthcare workers and other strategies, in preventing flu in this vulnerable and growing population. About 90% of the deaths associated with influenza in the United States annually are among adults aged 65 years and older, according to estimates from the Centers for Disease Control and Prevention (CDC).

Those aged 85 years and older who live in long-term care facilities are particularly at risk, as they are more likely to be exposed to influenza, their immune systems are not as responsive to vaccines, and other medications or medical conditions may impair their immunity.

In the first study of its kind in this population, researchers compared the immune response generated by the high-dose vaccine with that of the standard dose. Conducted during the 2011-2012 and 2012-2013 flu seasons, the randomised controlled trial included 187 frail older adults from 15 long-term care facilities in western Pennsylvania, USA. The participants' average age was 86.7 years. The high-dose vaccine produced a stronger immune response to all but one of the influenza vaccine strains, according to antibody titres from blood samples collected just prior to vaccination and 30 and 180 days after.

“For frail older adults, the high-dose vaccine appears to be a better option to protect against flu than the standard dose,” said Dr. Nace. “Even in the frail, long-term care population, the high-dose flu vaccine looks like it produces a greater antibody response than the standard dose vaccine.”

Even so, the stronger immune response prompted by the high-dose vaccine was still modest, Dr. Nace said, highlighting the need for continued work to develop better influenza vaccines for this at-risk population. The findings, he noted, also underscore the need for a multi-pronged approach to flu prevention in this setting that also includes boosting vaccination rates among healthcare workers and other steps.

*Source David A. Nace, , University of Pittsburgh, Pittsburgh, Pennsylvania, USA and colleagues High-Dose Flu Vaccine Superior to Standard Dose for Frail Older Adults in Long-Term Care, December 18, 2014, Infectious Diseases Society of America, Arlington, VA, DG News Pulmonary/ Respiratory Medicine*

## VITAMIN D AND COPD

*Another study suggesting the association between vitamin D and COPD flare-ups. However whether vitamin D deficiency is a* ***cause*** *of flare-ups is not yet clear. It could be just a sign of the person's vulnerability to infection. If you get frequent flare-ups and/or chest infections, ask your doctor about your vitamin D levels.*

BOOST VITAMIN LEVELS BY EXPOSING AT LEAST YOUR FACE, ARMS AND HANDS, OR EQUIVALENT AREA OF SKIN IN THE SUN. YOUR SKIN MUST NOT BE COVERED WITH CLOTHING TO PRODUCE VITAMIN D. EXERCISE ALSO HELPS PRODUCE VITAMIN D. THERE ARE SMALL AMOUNTS IN SOME FOODS.

Acute exacerbations of COPD (AECOPD) are common and strongly influence disease severity and relative healthcare costs. Vitamin D deficiency is frequent among people with COPD and its contributory role in disease exacerbations is widely debated. The aim of this study was to assess the relationship of blood serum vitamin D levels with COPD severity and AECOPD. Serum vitamin D (25-hydroxyvitamin D) levels were measured in 97 COPD patients and related to lung function, other conditions, FEV1 decline, AECOPD and hospital admission during the previous year. Most patients (96%) had vitamin D deficiency, which was severe in 35 (36%).

No significant relationship was found between vitamin D and FEV1 or annual FEV1 decline. No difference between patients with, and without, severe vitamin D deficiency was found in age, gender, BMI, smoking history, lung function, and comorbidities, apart from osteoporosis (61% in severe deficiency vs 23%). In multiple logistic regression models, severe deficiency was independently associated with AECOPD and hospitalization. The odds ratio of being a person with frequent flare-ups if you had severe vitamin D deficiency was 18.1. This is statistically significant, while the odds ratio of hospitalisation of 4.57 was also significant.

In people with COPD, severe vitamin D deficiency was related to more frequent disease exacerbations and hospitalisation during the year before the measurement of vitamin D. This association was not related to other patient characteristics and conditions.

*Source Malinovschi, A, Masoero, M, and 8 others, Severe vitamin D deficiency is associated with frequent exacerbations and hospitalisation in COPD patients, Respiratory Research 2014, 15:131*

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## ARE WE TOO NAÏVELY OPTIMISTIC ABOUT HEALTH CARE?

*"It might do me some good and it won't hurt to give it a go."*

How often have you heard a phrase like this?

Most people have a naïve optimism about medical care. That's the finding of a review of available research on common medical treatments published in December 2014 by Tammy Hoffman and Chris Del Mar from the University of Queensland in the journal JAMA Internal Medicine.

The authors set out to put together all the research to date that asked people to quantify the benefits, and/or harms, of common medical treatments, tests and screens (where people are tested for a disease without any symptoms or signs, e.g. mammograms or PSA blood tests). Where possible they also aimed to compare people's expectations with the actual benefits and harms, based on the research.

Most screening studies were about cancer screening and conclusions were similar regardless of the cancer of focus (breast, cervical, prostate, bowel).

Expectations for various treatments had been studied and included surgery (such as hip and knee replacement, back surgery, cataract surgery), medications (such as those for inflammatory bowel disease, osteoporosis, statins for cardiovascular disease), and other things like cardiopulmonary resuscitation (CPR).

This was a big search: they screened over 15,000 papers to find the 35 studies which met their inclusion criteria. Together these studies had covered over 27,000 people.

In most studies, most people overestimated benefits and underestimated the harms. There was only one study where the majority of participants underestimated the benefit and one where the majority overestimated the harm. Across most studies, the proportion of people who correctly estimated intervention benefits and harms was generally low.

In other words, people appear to have set a halo around medical care, expecting it to deliver better outcomes than is reality. In marketing terms, clinicians have a dream sell: their “product” is thought to be far better than it really is.

For the most part, this finding was echoed across various interventions, settings (primary care and hospitals), and countries.

The first question, of course, is why do people have such great expectations about medical management? The answers can only be speculative.

Why are we so optimistic about medical care? The answers may be patient-related, or clinician-related.

There may be patient-related factors, such as: assumptions that the more health care you get, the better; optimistic bias (when individuals perceive that they are at less risk than their peers); and unrealistic expectations may allow psychological needs such as hope and reassurance to be met.

Over-selling is something we come to expect in everyday marketing transactions and we are used to wearing a protective shield of scepticism, if not downright cynicism. But we seem to be generally less sceptical of medical care.

There are also probably clinician-related reasons, such as: clinicians wanting to convey hope and encouragement; the strong drive to do something rather than nothing, and the related fear of litigation; and clinicians themselves sometimes being unaware of the true effectiveness or benefit-harm trade-offs of interventions.

But there may also be more subtle factors such as the regression-to-the-mean-effect. This means that as even when an intervention is ineffective, clinicians often see patients improve anyway and this can lead to the false belief that the intervention provided was responsible for the improvement.

Greed on the part of some clinicians who are less scrupulous is probably involved too, especially in largely fee-for-service environments.

But clinicians’ enthusiasm for their speciality is also likely to be a larger contributor. To the man with a hammer in his hand, the world looks like nails. Surgeons are more likely to recommend surgery, radiotherapists radiation oncology, physiotherapists to suggest physiotherapy, and so on.

The next question is does this matter?

Very much so. Overly optimistic expectations undoubtedly contribute to the ever increasing use of health services and the growing problem of over-diagnosis, where disease labels are given even though the latent disease might not have ever caused symptoms, and over-treatment, where unnecessary treatments given.

Every intervention has benefits and harms and both should be acknowledged and communicated.

There seems to be a vicious cycle in which people have overly optimistic expectations about interventions and request them from their clinicians, who then provide them because it was requested, even if doing so causes the clinician discomfort. Receiving the intervention subsequently reinforces people's belief that the intervention is beneficial and necessary and so the cycle continues.

Many payment systems favour providing an intervention rather than "just" talking with patients and there is the efficiency appeal of ordering a test or writing a prescription rather than taking the time and effort to explain to a patient why it may not be needed.

A third question is what can be done to counteract these unrealistic expectations?

Many groups have a role to play. Every intervention has benefits and harms and both should be acknowledged and communicated. This applies to:

- **Researchers** – harms are notoriously under-reported, and even in this review, many more studies assessed expectations of benefit than harm, or benefit and harm
- **Journalists** – media stories often portray interventions in a misleading way
- **Health services and the pharmaceutical industry** – for example, screening invitations and drug advertisements often present information tilted towards or only about the benefits
- **Clinicians** – conversations between patients and clinicians tend to focus on the benefits of interventions and may not address, or downplay, the harms.

Patients, and indeed anyone considering a screen, test, or treatment, can also be involved in the solution. Beyond being aware of this tendency to assume that interventions help a lot and harm little, asking their clinician three questions before consenting to any intervention is a good habit to acquire. They are:

- what are my options?
- what are the possible benefits and harms of each option?

- how likely is it that each of those benefits and harms will happen to me?

Asking these questions can trigger a conversation between clinician and patient that hopefully enables an informed decision to be made.

Similarly, the Choosing Wisely campaign[1] underway in many countries (and on its way to Australia) provides evidence-based information for the public about interventions that are commonly used, yet may be unnecessary, and encourages a conversation between clinicians and patients.

Modern medicine is slowly moving towards a commitment to true partnerships between clinicians and their patients. Realising that people often come to consultations with preconceptions and expectations is a step closer to achieving this.

In the process of negotiating the best clinical option, clinicians should elicit the patient's expectations and preconceptions about what they are expecting from the intervention, discuss any misperceptions, and provide accurate information about the benefits and harms of each management option.

Only then can any genuine "shared decision making" start to occur and perhaps the impact of these great expectations lessened.

*Based on Hoffman T and Del Mar C Great expectations: our naive optimism about medical care The Conversation 23 Dec 2014*

## MORE LUNG LAUGHS

*Mike Watteau sent in some beauties. You can't have too many jokes.*

### CHURCH LADIES WITH TYPEWRITERS

*They're back! Those wonderful Church Bulletins! Thank God for the church ladies with typewriters. Maybe this should now be ladies with computers. These sentences actually appeared in church bulletins or were announced at church services:*

The Fasting & Prayer Conference includes meals.

Scouts are saving aluminium cans, bottles and other items to be recycled. Proceeds will be used to cripple children.

Ladies, don't forget the rummage sale. It's a chance to get rid of those things not worth keeping around the house. Bring your husbands.

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[1] Choosing Wisely is a campaign of the ABIM Foundation an American organisation promoting medical professionalism to improve health care. The campaign aims at encouraging more conversations between health care providers and patients to reduce the need for unnecessary tests and investigations to make better health care choices.

Miss Charlene Mason sang 'I will not pass this way again,' giving obvious pleasure to the congregation.

For those of you who have children and don't know it, we have a nursery downstairs.

Next Thursday there will be try-outs for the choir. They need all the help they can get.

Irving Benson and Jessie Carter were married on October 24 in the church. So ends a friendship that began in their school days.

*And this one just about sums them all up*:

> The Associate Minister unveiled the church's new campaign slogan last Sunday: 'I Upped My Pledge - Up Yours.'

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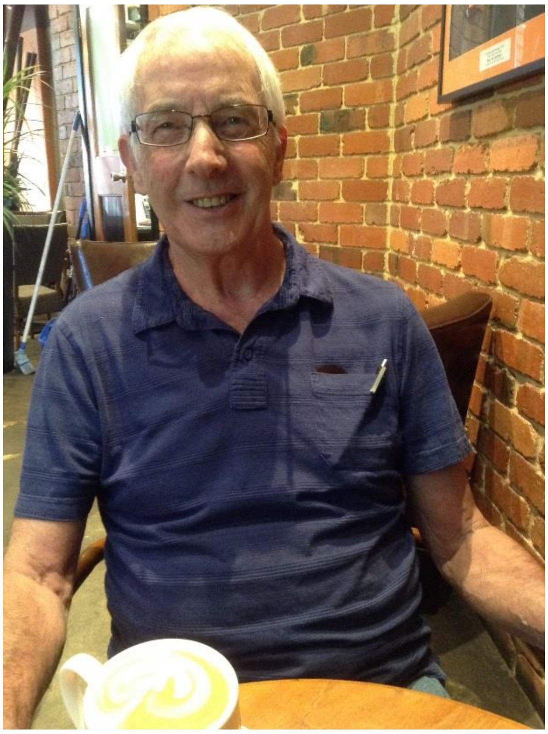
## BEING A CLINICAL TRIALS PARTICIPANT

*By Peter Thomson, as told to Jenni Ibrahim*



I'm 78 and I have been diagnosed with COPD for about eight years, after feeling short of breath, having a smoking history and doing a number of tests. In mid 2013 I rang the Lung Institute of Western Australia after I saw an advertisement in the paper. I wondered if I might be suitable to be a clinical trials volunteer. They took some details and straight away I started the process to take part in a new drug trial. I've been in two trials so far, the first lasting just 3 months, the second for 12 months.

I had my first of many appointments at the Clinical Trials Unit of the Lung Institute of Western Australia on the ground floor of E block, right near Charlie's pharmacy. To start with there is a lot of paperwork to read, understand and then agree to. You cannot be paid for taking part in clinical trials but the Lung Institute covered my travel and parking costs and a meal if I've had to stay over that time. During the second longer trial there were three or four occasions when I had to stay the whole day for various tests and so on.

At the start of the process you are examined by the Institute's doctor and then you see a nurse who explains everything to do and not to do, does some tests (like breathing, ECG and blood tests, depending on the trial), and provides you with the drug you are to take. You don't know whether you are having the real drug they are testing - or a placebo (an inactive compound), and the staff don't know either. You are scheduled to come back at certain times for more tests and to pick up more medicine.

In one trial I also had to fill out an electronic diary twice a day, reporting on the medication I'd taken and how I felt. I was given an electronic device to this and it reminded me twice a day. I stuck rigidly to the instructions given by the Lung Institute Clinical Trials Unit staff, though there were occasions where they were able to fit things around my plans, including a trip I'd booked. At the end of the process I received a letter telling me whether I'd had the active drug or the placebo. In the first trial I'd had the placebo.

On one of the trials I had to stop my usual respiratory medication, but not on the other. Each trial has different requirements, so saying no to one trial doesn't mean you wouldn't be considered for, or be interested in, another. I was recently contacted for a third trial and was very keen to take part. After the preliminary tests though I was found to be not "bad enough" for that particular trial. Though disappointed I realise there will be another one before too long.

I would really encourage anyone interested in taking part in a clinical trial to do it, if they can fit it into their daily life. I keep on being interested in doing clinical trials because the staff are so lovely, they really look after you well. And of course you feel like you are doing good, helping drug companies produce new and improved medications for COPD and other lung diseases.

I have a final message for people who still smoke: If you want to have letters after your name like me, Peter Thomson, C.O.P.D., carry on smoking. If you'd rather not, get help to quit. It's worth it. I gave up in 1980 after 25 years smoking. Without realising it then, my lungs were deteriorating. Some activities had become more and more difficult, others I just had to give up, even things I really enjoyed. Just do it!

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## VOLUNTEERING OPPORTUNITIES

*You can help in medical research*

**Take part in a clinical trial that might improve your respiratory health**

LIWA's Clinical Trials Unit is the largest respiratory trials centre in Australia and is respected internationally for the high quality of its work. Participants say that not only do they appreciate having the opportunity to get access to new treatments, they also feel like they're getting great care and assistance in managing their condition from friendly LIWA staff.

If you are living with any of the following conditions and would like to know more about taking part in a trial please visit the LIWA website or contact LIWA on 9346 4964 for a confidential discussion.

LIWA Clinical Trials Unit is now targeting:

Asthma | Bronchiectasis | Cystic Fibrosis | COPD | Pulmonary Fibrosis

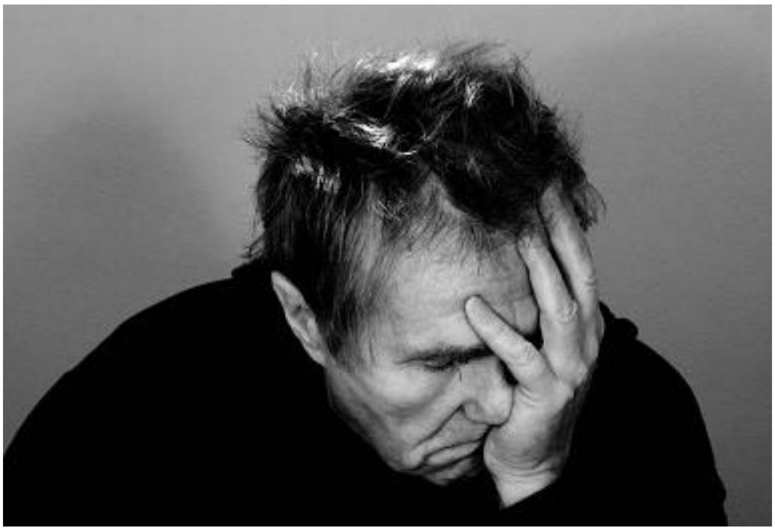
If you need help to get to Sir Charles Gairdner Hospital for the trials, mention this when you ring up.

## FATIGUE

*Each issue of Breath of L I F E features one long article and some snippets about relevant health news (Shorts). Until 2014 the long articles have covered a wide range of chronic lung diseases, both the more common ones and the rarer ones. During 2014 Breath of LIFE began a series of longer articles about the major signs of chronic lung disease, covering breathlessness, cough and mucus. In 2015 we will continue with three more common signs: fatigue, repeated chest infections and cyanosis.*

Fatigue is an overwhelming feeling; normal activity becomes an effort of the mind as well as the body. The fatigue you experience in advanced illness is not the same as fatigue when you are well. It is often hard to describe to others what fatigue feels like. Some words used are drowsiness, tiredness, lethargy, exhaustion, inertia, and weakness.

Fatigue also includes feelings of being unable to be interested in anything, lack of motivation, irritability, frustration, and loss of concentration. Unlike normal tiredness or drowsiness fatigue in advanced illness is not necessarily brought on by activity, and is not relieved by sleep.



You can wake up feeling tired no matter how much sleep you have. You may experience fatigue as a general tiredness or it can be an overwhelming exhaustion. Even the littlest thing can feel as though it takes too much effort. Many people say fatigue is more distressing and disabling than any other symptom. It is often associated with a lack of appetite and interest in food, and involuntary weight loss. Changes in the way you look can be as upsetting as the way you feel.

Other people can find it difficult to understand your experience of fatigue. Your family and carers might feel that you have given up, when in reality it is something you can’t control.

What causes fatigue? Fatigue is often caused by a combination of factors. Advanced disease is the most common cause of fatigue. Severe heart and lung disease, kidney and liver disease, as well as cancer and its treatments are also associated with fatigue.

Recent research shows that your internal repair system – the immune system – produces chemicals called cytokines as it tries to heal the body. An excess or over production of cytokines can affect your body’s internal balance, resulting in loss of appetite, loss of muscle bulk, reduced energy levels and stamina, reduced muscle strength and irreversible weight loss. The body uses a lot of energy fighting disease and coping with the effects of disease and disease treatments.

**What can be done about fatigue?**
Talk with your doctor about your fatigue. Everyone is different and there are some conditions where specific treatments may be useful. These include:

- Disturbed sleep;
- Poorly controlled pain or nausea;
- Anxiety or depression;
- The side effects of medicines, painkillers, antidepressants and sedatives;
- Anaemia or a mineral imbalance; or
- Persistent infection.

IT IS IMPORTANT TO REALISE THAT TOO MUCH REST CAN LEAD TO MUSCLE WEAKNESS AND CAN IN FACT MAKE FATIGUE WORSE

Generally, a detailed history and examination will uncover these causes, but occasionally some blood tests may be necessary.

**What can I do to manage fatigue?**
Once your doctor has ruled out any reversible causes, there are changes you can make to your day to day life which will help you conserve energy and maintain independence.

Practical strategies include:

- Plan your important activities for the times of day when your energy is highest;

- Rest before and after activities;
- Focus on priorities – these may be things you really enjoy doing, 'must be done' jobs, or long held goals;
- Delegate tasks to preserve energy for what is important;
- Break large tasks into smaller goals;
- Look for different and less taxing ways to do familiar things; and
- Arrange assistance for the tasks you can no longer do.

Regular gentle repetitive activity will help you to reduce feelings of fatigue, give a feeling of well-being, and help to keep muscles and bones strong. Walking, swimming, water aerobics, resistance (weight) training done regularly are often of benefit. The greatest hurdle to overcome is the mental fatigue that comes in just considering exercise.

**Are there medications to help?**

In certain circumstances there are medications which may give a short term boost to energy levels, however results are variable, and there are side effects which need to be considered. The medications can be useful to give you energy for a special occasion - you will need to discuss this with your doctor or palliative care nurse.

**Carer fatigue**

Families and carers of people with serious illness often become fatigued through the physical, mental and emotional load of caring. This constant load can lead to the carer experiencing tiredness or exhaustion leading to irritability, frustration, and lack of concentration. Often not understanding what is happening to the person they are caring for is a big stress as well.

It is important that family member and carers make sure that they themselves eat well and get regular exercise; and that they have adequate support, rest and respite so that they can continue to care. Attention to these things can make a big difference to the experience of caring.

**Working with your health care team**

- Don't suffer in silence - your health care team can help you.
- Your doctor can identify, treat or manage reversible causes.

- Your nurse can help you with practical strategies and decision making, and link you with support services.
- Occupational therapists in particular have expertise in different approaches to everyday tasks, showing you how to do things more easily and safely, and providing equipment to reduce effort.
- Physiotherapists can help with appropriate gentle exercises.
- Social workers can support you and your family and carers with the emotional impact of fatigue.
- Volunteers may be able to help with tasks you don't want to waste energy on, and provide respite and support for your family and carers.

There has been quite a lot of research into COPD and fatigue, a common feature of this common of chronic lung diseases. Pulmonary rehabilitation is a major plank of treatment for COPD and many other chronic lung diseases.

One of the major benefits of pulmonary rehabilitation is a drop in fatigue levels. Who would have thought that a specialised exercise training program could actually help you feel more energetic? So if you have not heard of pulmonary rehabilitation or not done a program yourself, ask your respiratory specialist whether it would be suitable for you.

Breathlessness and fatigue, the two most common symptoms experienced by people with chronic obstructive pulmonary disease, result in people being less active and having a poorer quality of life.

The main measurable benefits of pulmonary rehabilitation have been a drop in symptoms (mainly breathlessness and fatigue) and an increase in exercise endurance. However, exactly how pulmonary rehabilitation improves these symptoms is not really understood.

**What is fatigue like for people with COPD or asthma?**

In 1999 a Canadian group studied the actual fatigue experiences of 36 people with COPD or asthma by interviewing them about their fatigue, causes and trigger factors, associated sensations and feelings, the effect on relationships and everyday activities, and coping strategies and resources.

THERE HAS BEEN A LOT OF RESEARCH INTO COPD AND FATIGUE

Participants with COPD or asthma shared similar experiences of fatigue. It was described as a feeling of general tiredness and “sapped energy” that occurred daily, sometimes persistently, or with a flare up.  Sound familiar?

Fatigue was associated with laboured breathing and a feeling like you cannot get enough air. Participants identified 3 types of fatigue triggers:

- those that caused a **flare up** of the condition (e.g., common cold or flu),
- those that caused **laboured breathing** (e.g., physical exertion, environmental tobacco smoke, strong odours, or the weather), and
- those that affected their **level of fatigue** directly (e.g., interrupted sleep).

Fatigue contributed to a gradual decline in people's ability to perform activities of daily living, like bathing, eating, shopping. Most people felt that their fatigue did not interfere with their relationships with family and friends though.

Although fatigue caused irritability, frustration, and depression, participants felt that they coped well with it. Coping strategies were both

- **problem focused**, including energy conservation, use, and restoration, and
- **emotion focused**, including being positive, accepting physical limitations, distracting from limitations, and behaving normally (i.e. not focusing on the illness but trying to maintain a normal life within the limitations).

### Pulmonary Rehabilitation, COPD and Fatigue

Another Canadian study looked at how fatigue affects people in pulmonary rehabilitation programs. It examined the emotional, behavioural, cognitive, and physical dimensions of fatigue and their relationships to breathlessness, mental health, sleep, and physiological factors. Forty-two pulmonary rehabilitation participants with COPD completed questionnaires measuring fatigue, anxiety and depression and sleep quality. Information on other clinical variables (like oxygen saturation, breathlessness ratings, distance walked etc.) were taken from pulmonary rehabilitation program health records.

Almost all (95.3%) participants experienced high levels of physical fatigue. High levels of fatigue were also reported for the dimensions of reduced activity (88.1%), reduced motivation (83.3%), mental fatigue (69.9%), and general fatigue (54.5%).

Close to half (42.9%) of participants reported symptoms of anxiety, while almost one quarter (21.4%) reported depressive symptoms. Age was related to the fatigue dimensions of reduced activity and reduced motivation. Anxiety was related to reduced motivation.

Fatigue was not associated with symptoms of depression, sleep quality, gender, supplemental oxygen use, smoking status, or breathlessness scores.

Fatigue (particularly the physical and reduced motivation dimensions of it) was experienced by almost all participants with

PULMONARY REHABILITATION IS A VITAL PART OF GETTING MORE ENERGY

COPD attending this pulmonary rehabilitation program.

Fatigue affected greater proportions of participants than either anxiety or depression. The high prevalence of fatigue may affect enrolment, participation, and drop-out rates in pulmonary rehabilitation programs, warranting further investigation.

**Conclusions**

**When you have chronic lung disease, feeling so fatigued that you can't do much is totally understandable, especially in advanced disease. Your health professionals can help you, especially pulmonary physiotherapists, occupational therapists, your GP and your respiratory specialist. Pulmonary rehabilitation is a vital part of feeling more invigorated. Respiratory specialist referral is needed for pulmonary rehabilitation. Occupational therapists are available at public hospitals and in private practice.**

*The first part of this article was based on a brochure for people receiving palliative care. But many others experience fatigue too, including those of us with chronic lung disease.*

*Sources Fatigue, Tasmanian Department of Health & Human Services, Palliative Care Service.*
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## 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.

LIWA shall in no way be liable, in negligence whatsoever, for any loss sustained or incurred by anyone relying on the information, even if such information is, or turns out to be, wrong, incomplete, out of date or misleading.

LIWA is the Lung Institute of Western Australia and includes each employee or agent. Information includes information, data, representations, advice, statements and opinions, expressly or implied set out in this publication. Loss includes loss, damage, liability, cost, expense, illness and injury (including death).

## *L I F E*

**L I F E** (Lung Information & Friendship for Everyone, formerly LISA) is a self help support group for people with chronic lung disease, family and carers. It is the community support group of the Lung Institute of Western Australia (LIWA). It's run by, and for, people with chronic lung conditions. Started in 1992 as LISA, it changed its name to **L I F E** in July 2009.

**L I F E** is a member of Lung Foundation Australia's network of respiratory support groups T 1800 654 301. **L I F E** is grateful for the continuing 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. The editor is Jenni Ibrahim. Send contributions to E life@liwa.uwa.edu.au or 7 Ruislip St, W. Leederville, WA 6007. Read online. Join L I F E to receive a posted or emailed copy.

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

**Like to meet others in a similar situation?**

**Join L I F E!**

## *LIWA*

The Lung Institute of Western Australia is a charitable organisation dedicated to the investigation and treatment of lung disease. Donations to LIWA are tax deductible. Membership is open to interested community members, as well as researchers, health professionals and medical research students. LIWA membership entitles you to join L I F E at the same time at no extra cost.

## *L I F E MEMBERSHIP*

Contact LIWA for membership enquiries or application forms. T 9346 3198 or E life@liwa.uwa.edu.au or W online. Membership fees are due each 30 June - $22 or $16.50 concession (incl. GST). Please advise us of your change of address. Members' help and ideas are welcome - magazine, speakers, social events.

## *CONTACTS*

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Hospital Ave, Nedlands WA 6009
**Email:** life@liwa.uwa.edu.au **Web:** L I F E on LIWA website L I F E 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*

| | | |
|---|---|---|
| **Wed 4 Mar** | Portable Oxygen Concentrators | Bernie Somers, Respiratory Supplies |
| **Wed 1 Apr** | Red Cross Community Support Services | Bev Wilkin, Manager Community Care, Red Cross |
| **Mon 20 Apr** | Autumn lunch | Sully's café, Rockingham - RSVP please |
| **Wed 6 May** | Living with Cystic Fibrosis | Gary Smallacombe |
| **Wed 3 Jun** | Wombats and why I write about them | Frances Maber, writer and carer |
| **Tues 30 Jun** | Membership subscriptions due | Pay online, at a meeting, by phone or by post |
| **Wed 1 Jul** | Advanced care planning workshop | Lead by Jenni Ibrahim. Handouts available |