



Breath of L I F E

Lung Information & Friendship for Everyone

People with long term lung conditions, their family & carers

Autumn 2021
March, April, May



institute for
RESPIRATORY HEALTH

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[Read it online here](#)

AUTUMN

Welcome to Breathe of Life for Autumn, a little late and reduced Newsletter at this time due to the sad demise of our Group Leader Jenni Ibrahim, and so this issue is dedicated to her tireless support of the LIFE Group, we will miss her greatly.



Jenni Ibrahim

E-COPY

Please consider...

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

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

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

Contact us

life@resphealth.uwa.edu.au



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RESPIRATORY HEALTH

Breath of L I F E Archives

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

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

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VALE JENNI IBRAHIM

Jenni Ibrahim was an unfailing supporter of individuals living with a chronic lung condition for more than 20 years. She had been living with a chronic lung condition for this period as well, after suffering from a life-threatening bout of pneumonia, which left her with permanent lung damage. Immediately after this, Jenni became involved with the 'Lung Impaired Support Association' (LISA) which was the first support group in Australia specifically established to help people with chronic lung disease. This group then morphed into the Lung Information and Friendship for Everyone (L I F E) group in 2009. She became the group's Deputy Coordinator in 2004, and then Coordinator in 2012. Despite her own health problems, Jenni tirelessly lead with enthusiasm, concern and friendship. As L I F E's Co-ordinator, Jenni's role was diverse and required her to spend a significant amount of time on ensuring its relevance and value to its membership. For example, she produced the informative quarterly L I F E newsletter for members, which is also distributed to various respiratory health clinics throughout Perth. She organised volunteers to assist in promoting the general awareness of lung disease via expositions at shopping centres as well as helped organise 'working bees' to assist the Institute for Respiratory Health.



Jenni also delivered many presentations over the years, including addressing attendees on the patients' perspectives of living with a chronic lung condition at an annual TSANZ Conference. She contributed to a number of respiratory research projects by providing researchers with consumer advice and held a number of health consumer and community member positions. Together with Professor Philip Thompson, Jenni also put together a guide for people with respiratory conditions travelling by air.

In recent years, Jenni was diagnosed with liver cancer, and towards the end of 2020, she exhausted all the remaining treatment options.

Jenni will always be remembered as being strong, smart, caring, giving and humble. She will be greatly missed by all.



Jenni Ibrahim awarded a Medal of the Order of Australia (OAM)

Jenni Ibrahim was awarded a Medal of the Order Of Australia (OAM) in the General Division. Here is her official announcement:

The late Dr Jenni IBRAHIM

Formerly of West Leederville WA 6007

For service to community health.

Lung Information and Friendship for Everyone (LIFE - a respiratory self-help group within the Lung Foundation Australia's network), Institute for Respiratory Health, University of Western Australia

- *Coordinator, 2012-2021.*
- *Deputy Coordinator, 2004-2012.*
- *Member, 1999-2021.*

Health Consumer's Council of Western Australia

- *Consumer Representative, 1999-2021.*
- *Former HCC Representative, WA Data Linkage Advisory Board.*
- *Former HCC Representative, WA Data Linkage System Cross Jurisdictional Steering Committee.*

WA Health

- *Consumer Representative, Department of Health Networks, 2004-2017.*
- *Former Member, Western Australian Chronic Conditions Self-Management Reference Group.*
- *Consumer Representative, WA Primary Health Alliance, 2015-2016.*

L I F E EVENTS

Recently

Meetings and Social Events

L I F E had a get together meeting with the leadership team of Sal, David, Gaye and Jenni to review the situation. We have also been joining in virtual (online) meetings with other support group leaders from around Australia, hosted by Lung Foundation Australia.

Christmas Get Together

On December 2nd 2020, we had our Christmas Party at the Hyde Park Hotel to wrap up the year and give ourselves a huge pat on the back for keeping away from the Covid-19 virus. We have attached some photos to show that we had a great time.



Planning Meeting January 29th

We had a planning meeting at Harry Perkins on January 29th with a view of looking at where we stand now that Jenni is no longer with us. Many thanks for inputs and offers of help from our members that attended. We look forward to continuing the conversation on February 3rd.

Coming up!!

We were pleased to announce we will continue to meet face-to-face meetings on

Wed March 3rd at 12 noon

Unfortunately, we had to cancel February 3rd meeting due to lock down in Perth.

New conditions to make it safe for everyone

- All meetings are subject to change if the Covid-19 situation changes in WA. Confirm with Sal, Gaye, David contacts below.
- If you are feeling unwell, please stay home and get well soon.
- Please bring your own mug and your own food. No shared food.
- Please bring your own hand sanitiser. Use it every time you leave a bus or train and in the meeting room.
- If your mobile phone has the capacity please download, and turn on the Covid-Safe app.
- You can have a contactless temperature scan at the Perkins building entry and can sanitise your hands before entering the lift and room the meeting room 612A.
- While in 612A, please observe 1.5 metre physical distancing at all times.
- Wearing a mask is optional but encouraged, especially when on public transport where distancing is often difficult. L I F E member Tom says sitting up the front of the train often allows better distancing. Avoid public transport if you can. If you cannot, take all precautions.



Sal Hyder 0409 336 639 salhyder1@gmail.com

Gaye Cruickshank 0417 908 647 gmcruck@bigpond.net.au

David Payne 0439 048 897 perthmillwall@yahoo.com.au

On 4 November we had a hospital pharmacist Jo Armstrong speaking about medicines and on 2 December had our traditional (Covid-19-safe) Christmas party, see previous page.

Join our [L I F E Telephone Tree](#) - get the latest news and keep in touch. See page 5 for details.

L I F E NEWS

L I F E'S RESPONSE TO THE PANDEMIC

In March 2020, we established the L I F E Telephone Tree to keep members in touch and to help combat the aloneness of enforced isolation, especially for those who live alone. Everyone who wanted to join gets a phone call from another member, currently about once a fortnight or so. Many who receive calls also call one or two others. Currently there are almost 30 people on our phone tree. Although we are now meeting face to face we will still keep the telephone tree active for the future requirements should they arise.



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

If you are not part of our phone tree and would like to have an occasional or regular chat with a phone buddy, contact us on life@resphealth.uwa.edu.au.

We have also produced a [short video about managing during isolation](#) and [some home exercise suggestions](#). Both are also available from our [L I F E Facebook page](#).

There will changes to the way our group functions in the longer term, especially if there remain protective restrictions for people with chronic conditions like us, and no vaccine available. The new meeting conditions are on page 4.

PULMONARY POETRY

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



A Poem for some old Gits and others:

I remember the blocks of cheese of my childhood
and the bread that we cut with a sharp bread knife.
When all the children helped with the housework,
and the men went to work, not the wife.

The cheese never needed a fridge
and the bread was so crusty and hot.
The children were seldom unhappy
and the wife was content with her lot.

I remember the milk from the bottle,
with the yummy cream on the top.
Our dinner came hot from the oven,
and not from the fridge in the shop.

The kids were a lot more contented,
they didn't need money for kicks.
Just a game with their mates outside on the road
and sometimes the Saturday flicks.

I remember the shop on the corner,
where a pen'orth of sweets was sold.
Do you think I'm a bit too nostalgic?
Or is it . . . I'm just getting old?

I remember the 'loo' in the back yard was the 'dunny'
and the dunny man came in the night.
It wasn't the least bit funny
having to go "out the back" with no light.

Hung on a peg in that loo,
were interesting items to view,
from newspapers and the yellow pages cut into squares.
It took little to keep us amused.

Dirty clothes were boiled in the copper,
with plenty of rich foamy suds.
But the ironing seemed never ending
as Mum pressed everyone's 'duds'.

I remember the slap on my backside
and the taste of soap if I swore.
Anorexia and diets weren't heard of
and we hadn't much choice what we wore.

Do you think that bruised our ego?
or our initiative was destroyed?
We ate all that was put on the table
and I think our life was better enjoyed.

But a huge fact not hereto mentioned
in this mushy tale of nostalgic rejoice,
is the reason we all "enjoyed" our lot
Was that we had NO BLOODY CHOICE!!

L I F E CARD CLUB

If you are celebrating a birthday, you will welcome a card from L I F E to help make it special.

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

WHAT IS THE CURRENT COVID ADVICE?

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

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

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

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

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

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

- **Severity risk:** What is the risk that you as, an older person or someone with a chronic condition, gets the more severe form of Covid-19, requiring hospitalisation and perhaps, intensive care, with a much higher risk of death? If you do get infected, the risk of getting the severe form of Covid-19 is higher for people of any age with a range of chronic conditions or a compromised immune system. The risk of severe Covid-19 increases with age over 60.

Remember the Basics

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

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

Sources [Australian Government Department of Health](#)
[US Centres for Disease Control](#)

HealthDirect has a [symptom checker tool](#) you can use
National Coronavirus Health Information Line open 24/7 T 1800 020 080
Call your GP clinic if you think you may have symptoms of COVID-19
HealthDirect Helpline 1800 022 222 if you become unwell and cannot reach your doctor

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

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

Source [Australian Government](#)

HOW CAN I GIVE BACK?

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



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

USEFUL CONTACTS

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



COVID-19

HealthDirect Helpline T 1800 022 222.

Coronavirus Health Information Line T 1800 020 080

[WA Department of Health](#)

[WA Health - Frequently Asked Questions](#)

[Australian Government](#)

[Australian Government - Frequently Asked Questions](#)

[HealthDirect COVID-19 symptom checker tool](#)

Respiratory

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

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

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

[Pulmonary Hypertension Network Australia](#) – a sister support group to L I F E

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

[HealthyWA](#) - lung condition information from the WA Health Department

[BetterHealth](#) – lung condition information from the Victorian Health Department

[Asthma Foundation](#) WA T 1800 278 462

[Bronchiectasis Toolbox](#) for health professionals

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

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

[National Quit line](#) – help to quit smoking T 13 78 48

Exercise

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

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

[Strength for Life](#) programs in many areas, endorsed by COTA. Need GP referral. T 08 9472 0104

[Stay On Your Feet](#) information and resources to prevent falls and keep Western Australians active, because falls are preventable no matter what age

T 6166 7688 or Country callers 1300 30 35 40. Level 2, 297 Vincent Street, Leederville, WA

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

Mental Health

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

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

[Beyond Blue](#) mental health support service T 1300 22 4636

[Australian Men's Shed Association](#) – find a men's shed near you T 1300 550 009

[Lifeline](#) 24 hour personal crisis support and suicide prevention association T 13 11 14

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

[Mental Health Care Plan](#) for those with a diagnosed mental health problem. Referral by GP, Medicare rebates, gap payment needed, by allied mental health care providers. Covers up to 10 individual and 10 group sessions per year.

General Health

[Health Direct](#) look up reliable health information or speak to a registered nurse T 1800 022 222

[Better Health Channel](#) Victorian Government's health information website

[Cancer Council WA](#) T 13 11 20

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

[ABC Health Online](#) find reliable health news and information

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

Seniors

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

[MyAgedCare](#) aged care services you may be eligible for. Speak to your GP

[National Seniors](#) voice of older Australians T 1300 76 50 50

[Seniors Services](#) guide database of services and activities for older Australians

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

[The Move Into Aged Care](#) tools and resources supporting you and your family. Advocare is the WA contact.

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

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

[CentreLink](#) 13 24 68

[HaveAGoNews](#) read seniors' news online

[Computer basics guide](#) for seniors (free)

[Aged Care Navigator](#) trials across Australia, incl. WA T 1300 025 298

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

Health Consumer and Carer Rights

[Carers WA](#) supporting friends and family who care for others T 1300 227 377

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

[Patient Opinion Australia](#) share your experience as a patient and ensure the message gets passed on to the right people T 1300 662 996

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

Other

[TED Talks](#) watch videos of great speakers on a topic that interests you. Free

[Recycling](#) in WA - tips from South Metro Regional Council T 9329 2700

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

[The Australian Bereavement Register](#) stop unwanted mail to a family member who has passed away T 1300 887 914

INSTITUTE FOR RESPIRATORY HEALTH

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



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

The Institute includes a [Clinical Trials Unit](#) and the community support group – [LIFE](#) for people living with chronic respiratory conditions.

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

[Your tax deductible donation to the Institute](#) or bequest supports respiratory research.

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

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

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



Breath of L I F E magazine

Our magazine is published 4 times a year - March, June, September & December. It is distributed to all community members of the Institute, including L I F E members. Send your contributions to the editor, David Payne perthmillwall@yahoo.com.au

L I F E Membership

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

Contacts

Phone Coordinator TBA life@resphealth.uwa.edu.au

Deputy Coordinators **Sal Hyder** T 0409 336 639 salhyder1@gmail.com
and **David Payne** T 0439 048 897 perthmillwall@yahoo.com.au

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

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



Meetings

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

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

Please see page 4 for the COVID safe conditions we have been put in place to ensure everyone's safety:

COMING UP (subject to change)

Wed 3 Mar	Alpha 1 Antitrypsin Deficiency presentation	Speaker: David Payne
Wed 7 Apr	TBA	
Wed 5 May	TBA	
Wed 9 June	TBA	