

September 2016 Newsletter

Providing a supportive and informative environment for people with a variety of lung conditions and their carers.

Editor: Helen Reynolds 02 6259 7737
helenrev@creationcorporation.com.au
Acting Coordinator: Helen Cotter 02 6281 2988
lung.life1@hotmail.com
Meeting Coordinator: Chris Moyle 02 6288 8463

Next Meeting: Thursday 8 September 2016
10:15 am - 12 noon
Weston Creek Labor Club, Teesdale Close, Stirling ACT 2611

Guest Speaker: Richard Gray AM from COTA to talk to us about the Consumer Directed Care (CDC) Home Care Package. Since July 2015 all home care packages are delivered under a consumer directed care framework which gives consumers more choice and control in the management of their Home Care Package.

Dates for your diary

Thursday 13 October 2016 Canberra Lung Life Support Group Meeting
Wednesday 16 November 2016 World COPD Day

August meeting Helen Cotter

Margaret and Chris welcomed us all but then Margaret let us know that due to increased demands on her personal time she is stepping down as meeting coordinator. Chris, who has taken on the responsibilities of the meeting coordinator, would welcome a replacement for Margaret to assist with meeting coordination.

Business discussed:

- Our mid-winter lunch held at the Burns Club was very well attended.
- A morning tea/lunch was organised for Thursday 18 August 2016 at the Jamison Southern Cross Club.
- The trial regarding replacing oxygen cylinders with POCs is now being organised and should be up and running by the end of the year. It will look at both cost and benefit of the POCs.



- Pam Gaston borrowed our POC which made it possible for her to have her POC serviced while she maintained her personal social life. This is just one way the POC can be used.

- Helen Cotter reported on a SHOUT meeting she attended during the month. SHOUT is an organisation providing support services for self-help groups such as: a Heart Support Group, People with Disability, Bosom Buddies, ADHD, Pain Support and Asthma. SHOUT

provides office facilities and support for these groups eg as a mailbox, meeting rooms, disseminating information, some printing etc. We are an affiliated member - not a full member - and mainly use it as a source of information about the other groups which we disseminate to our members.

- It was suggested that we might investigate having a paid manager who is computer literate to overcome the difficulty of finding a person well enough and with enough computer knowledge to run our group. Then on to our speaker.



Guest Speaker

**Mary Pekin, CEO of Relationships Australia assisted by
Juleen Schiefelbein, ACT Manager.
Chris Moyle**

Relationships Australia was originally known as The Marriage Guidance Council, but changed its name about fifteen years ago. It provides a relationship support service, working with individuals, couples and families.

Ingredients of a healthy relationship:

1. communication
2. trust
3. tolerance.

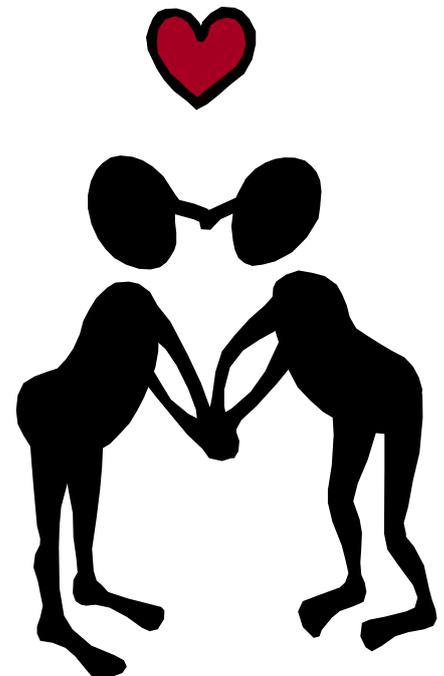
Three ways to get intimacy:

1. physical (from holding hands to sexual intimacy)
2. sharing feelings
3. sharing activities.

Everybody has a different style and we need to negotiate with each other. We need to be prepared as time goes by to recognise and adjust to changes in the relationship. It is a skill. There is no normal and no one size fits all. Every person is working out their own blueprint.

Three important ingredients for a healthy relationship are:

1. We need to know what we stand for ie: the values we fall back on when the going gets tough. They may be respect, compassion, honesty and fairness. The other person in your relationship could have different values.
2. We need to be ethical and realise we influence and affect each other. We are responsible to each other. Everything we do either brings us closer to our partner or pushes us further away. We need to care about that if we want to protect the relationship.



3. We need to feel safe (physically and emotionally), with each person feeling safe to speak up and able to act to express their needs.

There are times when a relationship needs repairing and one person doesn't want to repair it. The partner needs to prepare for a difficult conversation. A platform of strength needs to be built before starting difficult conversations, and we need to build that good foundation with at least five good experiences for every one bad experience.

Five good experiences:

1. Good will towards your partner.
2. Start softly. Find a really easy thing to talk about.
3. Speak up (it is worse if you don't) stating what you want and what you don't like.
4. Listen carefully and don't dominate or interrupt. Acknowledge what the other person says.
5. Know when the heat is too high. Take a break and come back to continue the talk.

General advice

- Be strong in your beliefs about yourself ... that you are separate to the labels 'disabled', 'old', 'poor' or 'divorced'.
- Focus on what you CAN do.
- People in valued long term relationships never give up. They just chip away one step at a time. Some relationships need to finish.
- Tough love may work if you have a platform of strength. If you want to maintain a relationship know how to look after it and seek help before it is too late.
- Some relationships with problems are left too long and can't be saved. Seek help rather than struggling alone.

Contacts for Juleen Schiefelbein, Relationships Australia

Phone: 02 6122 7145

Email: Juleen.Schiefelbein@racr.relationships.org.au

Address: 15 Napier Close, Deakin ACT 2600

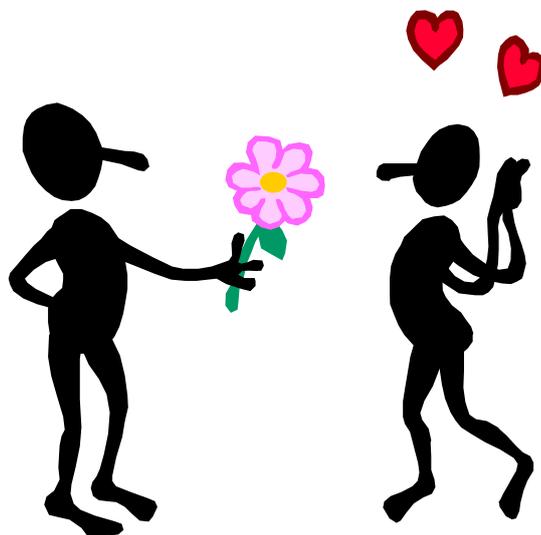
Sex and Intimacy

Chris Moyle

Couples who live with a chronic health problem, with either one partner or both having a problem, face a challenge in keeping this important part of their relationship alive and well. Fear of injury or of bringing about a health emergency can dampen desire in one or both partners. Sex, after all, is supposed to be joyful and pleasurable, not scary or uncomfortable!

For many people with chronic conditions, it is intercourse itself that is most difficult to sustain, because of the physical demands it places on our bodies. Intercourse brings about increased heart rate and breathing and can tax someone with limited energy or breathing or circulatory problems. Therefore, it is helpful to spend more time on sensuality or foreplay and less on actual intercourse. By concentrating on ways to arouse your partner and give pleasure while in a comfortable position, your intimate time together can last longer and be very satisfying.

One of the most subtle and devastating barriers to fulfilling sexuality is the damage that has been caused to a person's self-image and self-esteem. Many report that they believe they are physically unattractive as a result of their disease - their paralysis, their shortness of breath, their weight gain from medications, or the changing shape of their joints - a sense of not being a whole, functioning



being. This causes them to avoid sexual situations and they “try not to think about it”. This often leads to depression and depression leads to lack of interest in sex, and that leads to depression...a vicious cycle. Depression can be treated and you can feel better.

The most effective way to address the fears of both partners is to confront them and find ways to alleviate them through effective communication and problem solving. Without effective communication, learning new positions and ways to increase sensuality are not going to be enough. This is particularly important for people who may worry about how their health problem may make them look physically to others. Often, they find that their partner is far less concerned than they are.

If you decide that you wish to abstain from sexual activity because of your chronic health problem, or if it is not an important part of your life, that's OK - but it is important to your relationship with your partner that he or she be in agreement with your decision. Good communication skills are essential in this situation, and you may even benefit from both of you discussing the situation with a professional therapist present. Someone trained to deal with important interpersonal situations can help facilitate the discussion.

No matter what your chronic health problem, your doctor should be your first consultant about solutions to sexual problems caused by your condition. Sometimes something as simple as changing medication or its timing can make a difference. It's unlikely that your problem is unique - your doctor has probably heard about it before and may have some solutions to offer. Remember, this is just another problem associated with your chronic condition, just like fatigue, pain, and physical limitations. It is a problem that can be addressed.

Chronic health problems need not end sex. Through good communication and planning, satisfying sex can prevail. By being creative and willing to experiment, both the sex and the relationship involved can actually be better.

Source: *“Living a Health Life with Chronic Conditions”*

Thanks to you both Helen Reynolds

A small group of members from both the north side and the south side met at The Southern Cross Club in Cook for morning tea/lunch with Carolyn and Margaret. Two beautiful cyclamen pot plants, one white and one pink, and a large box of yummy chocolates said "thank you" to the two ladies for their work as coordinators over the past months.

POC for Loan

We now have an InogenOne G2 POC for loan to members. If you are on oxygen cylinders and thinking of buying a POC, you may like to borrow this one for trial. If you are on oxygen cylinders and need, for instance, to travel to another city for a break or to visit a doctor, this may help. The Inogen is only 6 months old and has all its attachments. We ask for a donation to Lung Life for its use.

Contact Helen Cotter on cotterhe@hotmail.com or phone 02 6281 2988.

Remembering long time members, Maddie and Pat Chris Moyle

Madeline Fleming suffered with COPD but recently passed away after a short battle with advanced pancreatic cancer.

Madeline, the youngest of 11 children, hailed from Cootamundra and came to work temporarily in Canberra. She stayed on and associated with many people in the community. This was evidenced by the huge number of people attending her funeral.

Our sincerest condolences to the Fleming Family and friends.



Madeline with husband Percy. Photo taken at our December 2012 Xmas lunch.



Pat's photo taken at our July 2012 Xmas lunch. Looks like she's had a big win.

Patricia Stewart also suffered from COPD and had not been well enough to attend meetings for a few years. Pat was a cheerful presence at meetings, not afraid to contribute with her opinions.

Recently Pat moved into Clare Holland House and died suddenly the next day.

Our sincerest condolences to the Stewart Family and friends.

“Don't be scared of grief - it is part of life ... and feels unbearable ... and it comes and goes.”
Relationships Australia

The A-Z of Preventative Medicine Chris Moyle

Probiotics can be enormously beneficial. These bacteria digest plant fibre, manufacture B vitamins, kill off the bacteria responsible for cholera, typhoid, dysentery, Clostridium, golden staph and salmonella, they prevent the growth of *Candida albicans*, and they help detoxify cancer-causing chemicals. In a healthy intestine there can be up to one hundred billion per ml. The best known are *Lactobacillus acidophilus* and the *Bifidobacterium* species. The enemies of the friendly bacteria are antibiotics and chemotherapy. Any course of oral antibiotics should be followed by supplements of at least acidophilus and *Bifidobacteria*. Supplements need to be live bacteria from the shop refrigerator and the concentrations should be at least one billion per ml. They should not be taken indefinitely - maybe for three to six months and then take a break.

Source: Roger French, “*True Natural Health*” magazine - Autumn 2013.

Request for unused medical equipment

Helen Cotter

NHEDF is a Nepalese organisation set up to help with the medical and rehabilitation needs of earthquake survivors. It collects and redistributes donated health care equipment throughout the country, facilitates the provision of medical care, provides nursing care, physio, rehabilitation and much more. You can find NHEDF (Nepal Healthcare Equipment Development Fund) on Facebook to see the work they are doing.

This organisation is looking for an oxygen concentrator - which they can repair and maintain if necessary. If you have unused oxygen concentrator of your own - or some other medical equipment you are no longer using - let me know and I'll pass the information on.

Helen Cotter lung.life1@hotmail.com

Nebuliser available

Anyone need a nebuliser? Needs mask and tubing. Please contact Helen Cotter on cotterhe@hotmail.com or 02 6281 2988.

Allergies and lung disease

Ainsley Ringma, Lung Care Nurse, Lung Foundation Australia

You may notice as the days get longer and warmer that you begin to have a runny nose, sneeze more and even your eyes may be itchy or watery. Welcome to spring, which, for some people, means allergy time. Allergies like allergic rhinitis (hayfever) can occur at any time of the year, but are more likely in the spring due to the increase in flower or grass pollen, tree moulds and more.

Allergic rhinitis affects around 15 per cent of the Australian population, or about 3.1 million people which equals about 1 in 6 people. Common symptoms include:

- sneezing
- runny and itchy nose
- itchy or watery eyes
- blocked nose and
- snoring at night.



Allergy occurs when a person's immune system reacts to substances in the environment that are harmless for most people. These substances are known as allergens and are found in house dust mites, pets, pollen, insects, moulds, foods and some medicines. Spring is a common time when these allergens are all around, especially with the changing of winds, and windy days. This is a perfect example of when we may encounter many of these triggers.

In a study by the Johns Hopkins University, published online in the American Journal of Respiratory and Critical Care Medicine, researchers looked at more than 1,400 patients with Chronic Obstructive Pulmonary Disease (COPD) and found that those with allergies were much more likely than those without allergies to wheeze, to have chronic cough and chronic phlegm, to awaken during the night

because of cough, and to have a worsening of COPD symptoms that required antibiotics or a visit to the doctor.⁴ According to Dr Nadia Hansel, an associate professor of medicine at the Johns Hopkins Asthma and Allergy Center in Baltimore, the findings suggested that treating allergies or avoiding allergy triggers may help reduce the number and severity of respiratory problems in people with COPD.⁴

If you experience hayfever or allergies, below are some tips for coping with or controlling symptoms and triggers:¹

- Be aware of what triggers your allergy and when it's likely to be a problem.
- Find out the remedies which help you best (such as antihistamines and nasal sprays) and keep them with you.
- Check whether you can take these remedies if you are on any other medication. You can talk about this with your pharmacist, nurse or GP.
- Check when you should start taking your remedy.
- Sometimes a little petroleum jelly inside your nostrils can stop some of the allergens reaching the lining inside your nose. If you're on oxygen, use a non-petroleum based lubricant such as Nozoil. Try using some as soon as your symptoms start.
- Wear wraparound sunglasses when outdoors to keep pollen allergens out of your eyes.
- Wash your clothes and hair more regularly, as this will help to get rid of the pollens.
- Keep your home clean and use a damp duster to stop pollens moving about your home.
- Avoid open, grassy spaces if possible and keep windows shut - at home and in the car.

Hopefully, these tips will help you reduce the symptoms and impact of hayfever so this spring you can be prepared and enjoy the warmer weather. Please discuss any concerns you have with your health professional who may be able to suggest some medicines to help.

References

1. <https://www.blf.org.uk/your-stories/controlling-summer-allergies>
2. <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=10737420519>
3. <https://www.allergyfacts.org.au/allergy-anaphylaxis/what-is-allergy>
4. <http://www.webmd.com/lung/news/20130510/allergies-may-boost-severity-of-lung-disease>

Source: <http://lungfoundation.com.au/allergies-and-lung-disease/>.

RECEIVING THIS NEWSLETTER: *If you would prefer to receive the Newsletter by email instead of snailmail you may send your request to us at lung.life1@hotmail.com.*

If you no longer want or need this newsletter, please send an email with the word "Unsubscribe" in the Subject.

All the Canberra Lung Life Support Group newsletters since December 2009 are available at:

<http://www.creationcorporation.com.au/Canberra-Lung-Life-Support-Group-Newsletters.htm>.

Available support for those with chronic lung conditions

- **Life Support Electricity Rebate for oxygen and CPAP users** provided by electricity providers such as ACTEW, Origin and TRUenergy need a letter from your doctor. For more details, check their websites or phone ACTEW 13 14 93; Origin 13 23 56; TRUenergy 13 34 66.
- **Essential Medical Equipment Rebate** for concession card holders using oxygen or CPAP see www.humanservices.gov.au or contact Centrelink.
- **Companion card** for those who need a companion with them in order to access theatre, sports and other events. You get two seats for the price of one. See www.companioncard.gov.au.
- **Australian Disability Parking Permit** must be assessed by a doctor. See www.rego.act.gov.au.
- **Pulmonary Rehabilitation** an exercise and life improvement course at Canberra Hospital. Need a referral from a specialist. For more details phone: 02 6244 2154.
- **Lungs in Action** an exercise program for people who have completed pulmonary rehab. Needs a referral from a doctor. For more details phone: 02 6201 5843 or go to www.canberra.edu.au.
- **Air Liquide** offers a 10% discount to Lung Life members. See <http://www.airliquide.com.au/>. Their EMERGENCY NUMBER for Healthcare/Medical Oxygen is 1300 360 202.
- **NSW National Parks** offer a free annual park entry to concession card holders (not for Tidbinbilla which is an ACT park). See www.nationalparks.nsw.gov.au.
- **ACT IPTAS** provides reimbursement for medical or oral surgical treatment in another city. Full details of the scheme and its guidelines are available on the internet at www.health.act.gov.au/iptas or you can telephone 02 6244 2234, fax 02 6244 3453 or email IPTAS@act.gov.au.