CANBERRA LUNG LIFE SUPPORT GROUP

May 2013 Newsletter

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

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Next Meeting
Thursday 9 May 2013
10.15 am – 12 noon

Burns Club
8 Kett Street
Kambah

Guest Speaker: The topic of Rusty Woodford's presentation is
Steady Meds – Managing Medicines to Minimise Falls.

Dates for your diary

Thursday13 June	Lung Life Support Group Meeting
Wednesday 20 November	World COPD Day

News Break

Chris Moyle

Thanks to Pam for organising another successful visit to the physiotherapy students at Canberra University. Eight people attended – Pam, Anne, Judy, Chris and Val plus Brian from the gym and two others from the Lungs in Action exercise class. Wendy and Nicole supervised the students and gave us many helpful tips. Wendy thanked us for our attendance, saying it's so much better than practising on each other or calling in an actor. Thanks to Pam for providing transport for Chris and Anne who both said they were looking forward to the next visit.

For Sale

- InogenOne portable oxygen concentrator with trolley and accoutrements. Serviced last January by Independent Living Specialists
- A smaller portable concentrator - EGET brand - bought last August from The Wheelchair Factory. Will sit in trolley basket or on table etc
- Electric mobility scooter in very good condition - PRIDE - has recently been serviced by The Wheelchair Factory.

If you are interested, please contact Sue Rosly on 6297 3708.

April Meeting Report
Chris Moyle

Mark Copley's presentation generated a lot of interest. Mark is a Director at Toscan Dinn Funerals, a locally owned company located in Liardet Street, Weston. Although, as the old saying goes – "Nothing is more certain than death and taxes", death and funerals are topics we shy away from. However, as Mark says, the worst time to talk about a funeral for the first time is after the death has occurred. It is far better to discuss funeral matters prior to death. With a little forethought a great deal of benefit can be achieved.

Pre-paid funerals
The wishes of the client are recorded during the negotiations and the cost of the funeral is set, providing a long term financial investment. One funeral plan contract can be set up to cover two individuals (an either/or contract). The plan can be paid as a lump sum or over 12, 24 or 36 months with no interest or administration fees. A travel insurance component may be included which allows for the transportation of the body from place of death to place of funeral service.

Funeral insurance plans
Some companies offer these plans but be aware you can pay **a lot more** in funeral insurance over the many years prior to the activation than paying off a pre-paid plan.

Enviroboard coffins (cardboard)
Enviroboard is the ideal material for digital printing allowing any image, style or colour of design to be achieved thus providing completely personalised and customised designs. Using recycled material and environmental inks and glues gives the benefits of 60% less emission and reduction of the carbon footprint.

Costs
An adult burial package costs about $9,500 while an adult cremation package costs about $5,500. The cost is dependent on the cost of the features chosen eg the coffin, flowers, etc.

A Complete Care Package (Cremation or Burial)
This package includes a comprehensive range of services, from an initial Arrangement Conference through to collection and delivery of ashes upon request.

2013 Lung Health Education Day
Introduction

Juliet Brown from Lung Foundation Australia, located in Brisbane, welcomed us to the third Lung Health Education Day to be held in Canberra. She was 'delighted to see a very good contingent' (24 in all) of our Canberra Lung Life Support Group members in attendance. *The Australian Lung Foundation*, a not for profit organisation established in 1990, changed its name to *Lung Foundation Australia* on 1st January 2013, in order to make it more accessible and easier to locate on websites etc. Juliet and Jenny Hose (also present) make up two of the twenty staff members. The Foundation receives no on-going Government funding for core business activities. Lung Foundation Australia is involved in public awareness campaigns, information and education for patients and health professionals, educational brochures, on-line training, lung cancer support groups, putting people in touch with support groups, research and advocacy.

The LungNet News is mailed to 12,900 individuals and this number is continually increasing. A hard copy and an electronic version are available.

New resources

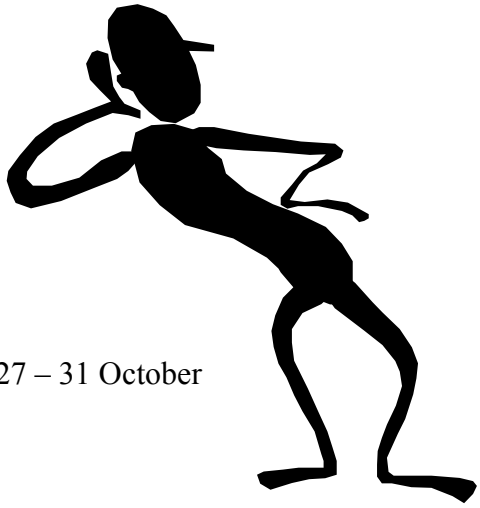
- Updated 2nd edition of "Better Living with COPD" $15
- "Better Living with Lung Cancer" $15
- Mesothelioma DVD (free)

World COPD Day

Wednesday 20 November 2013. The aim is to improve awareness and care of COPD around the world. Group events are encouraged.

COPD Task Force

The objective is to raise awareness of COPD. Monthly teleconferences are held to discuss COPD issues.



Lungs in Action

After attending the Pulmonary Rehabilitation Course Lungs in Action helps you retain the benefits of Pulmonary Rehab. One of these exercise classes is held at University of Canberra. A new program is commencing in June at a centre in Wiseman Street, Macquarie, ACT.

Lung cancer events 2013

The 15th world lung cancer conference will be held in Sydney 27 – 31 October 2013. Local Shine a Light vigils are encouraged.

Idiopathic Fibrosis Registry

A national registry to determine the incidence of IPF in Australia was launched in April 2012. There are 189 registry participants on average 70.4 years of age with 65.6% being male.

Lung Foundation Australia can be contacted on free call 1800 654 301 or by email at enquiries@lungfoundation.com.au.

The Winner!

Margaret Geaghan, one of our newest members, won two prizes, a raffle and the "Lucky Door Prize" while John Kovac took home a collection of chocolates. Not too shabby a representation.

Breathlessness – Its Causes and Management Strategies

Presenter: Dr Willson, Senior Lecturer in Physiotherapy at the University of Canberra and Director of the Sleep and Lifestyle Clinic

Why and how do we breathe?

We breathe to fill cells with oxygen (O2), to burn food we are taking on board. The waste product of that metabolism is carbon dioxide (CO2). The purpose is to move fresh gas into the body so we get O2 for fuel and to remove CO2, which is toxic to the body. The lungs are fantastic gas exchangers. The alveoli (or air sacs),2mm in diameter, are small cells where gas exchange takes place. Lung tissue is made up of airways bringing air down to these air sacs. We breathe approximately 8,000 litres of air daily and some air is always trapped in the lungs.

A normal adult lung capacity is 5 litres of air. The main work of respiration is done by the diaphragm (the muscle of breathing), which works like a piston and is shaped like a parachute. The diaphragm changes the volume in the lungs so we can draw in fresh gas. When we breathe in the diaphragm is lower in the chest. It sits high in the chest when we breathe out. In disease processes other muscles

are used as well i.e. chest muscles such as pectorals, abdominal, scalene and trapezius muscles. They lift the chest up and augment the action of the diaphragm. Chest muscles in addition to the diaphragm also assist the performance of athletes.

What controls breathing?

The respiratory controller is in the primitive part of the brain stem (automatic control) and the cortex (behaviour control). The cortex allows you to hold your breath. Sensors send information to the brain stem about changes in the amount of gas i.e. high levels of CO2 from exercising working muscles. The muscles will then be prompted to increase their workload to allow more O2 to be taken in, and the brain sends messages to motor neurons in the lungs. Breathlessness is the result of a missing match between the central respiratory motor output and incoming information from receptors in the airways, lungs and chest wall structures. That is because of a disease process which has altered the level of blood gases. The primitive level of the brain can't match up with what is required A healthy diaphragm is a domed shape and signals are easily matched, but an obstructed, flattened diaphragm means lungs remain hyper-inflated and there is a mismatch. The diaphragm is not going to work so well in the piston manner and other muscles will therefore need to be used. A mismatch leads to breathlessness (dyspnea) in the person.

How do we describe breathlessness?

According to The American Thoracic Society it is "a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity". If there is a sensation of "unsatisfied expiration" then distress can occur. Breathing feels "unsatisfied" and has an "emotional" aspect. People describe breathlessness as:

- a sense of effort
- air hunger
- chest tightness
- suffocation
- a lot of work
- tight, heavy, crushing feeling in chest

Descriptions vary depending on what is causing the breathing problem. Patients tend to experience anxiety, frustration, anger and fear, but they don't feel depressed. The insula and amygdala are the areas of the brain firing off when you have these sensations. The insula is far less active in asthmatics, which shows they become accustomed to the breathlessness over time.

Management

Emotional and cognitive management comprises:

- counselling and support
- open environment
- relaxation
- distraction e.g., music
- psychotherapy
- pharmacological e.g., bronchodilators and oxygen therapy
- physiological factors
- Counselling and support is a worthwhile endeavour which is provided by Lung Foundation Australia.

Music can take us out of ourself and into another head space.

Physiological

Factors include:

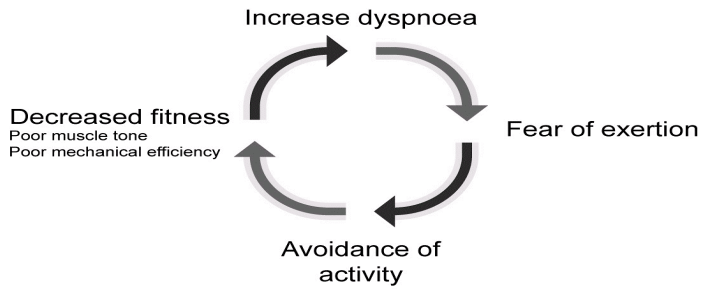
- exercise
- pulmonary rehabilitation
- inspiratory muscle training

- supported posture
- non-invasive ventilation
- supportive devices to use at night.

Effect of exercise on breathlessness

Exercise reduces breathlessness by altering a number of different factors. It affects the action of the heart to make the heart more efficient, which means more oxygen can be taken in. Our muscles also become more efficient which decreases the demand for a given amount of ventilation. We therefore don't have to breathe as much for a given level of work. It is easier to move the thoracic skeleton after we train our muscles, and the body develops a tolerance for exercise. Exercise also improves muscles and prevents deterioration. It breaks the cycle of deconditioning.

Cycle of Inactivity and Deconditioning



Studies were conducted on a pulmonary rehabilitation group who exercised and a control group who didn't exercise at all. There was a marked reduction of breathlessness in the pulmonary rehabilitation group.

Inspiratory muscle trainer

This devise may improve the muscle mass and the efficiency of the respiratory muscles. A group of COPD patients used this device for 12 months, 6 days a week with two 15 minute sessions daily. A significant difference was only realised after 9-12 months of continuous use.

Managing breathlessness

Most people benefit from using a walking frame. Support positions, such as leaning forward on a fixed object, can be used.

Conclusion

Breathlessness is a subjective sensation which can impact dramatically on the sufferer. Most of the effective management strategies involve the participation of the sufferer.

Understanding Personal Plumbing – Diagnosis, Management, Treatment

Presenter: Fran Morson, Continence Clinical Nurse Consultant from the Community Care Program, Rehabilitation, Aged and Community Care, ACT Health Directorate.

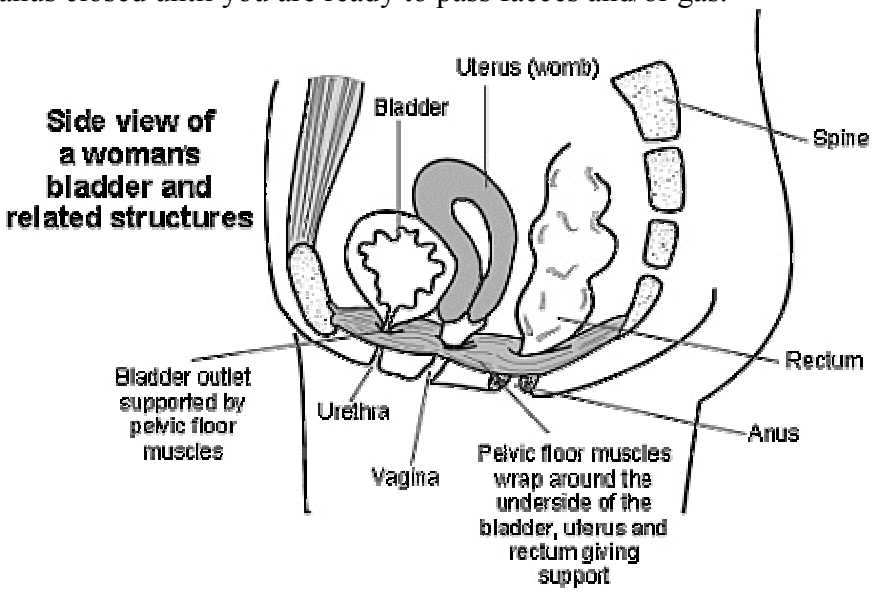
How the urinary system works

The bladder stretches as it fills and stores urine. It has a capacity of 350-550 mls. Nerves communicate with the brain to signal the bladder is full. During the voiding process the bladder contracts, the internal sphincter muscle relaxes, the urethra opens and the external sphincter (which is under conscious control) relaxes, allowing urine to pass out of the body. Too many fluids can over-

expand the bladder and there will be leakage, while too little fluid aggravates the bladder wall and causes more frequent urination.

The pelvic floor muscles

The floor of the pelvis is made up of layers of muscle and other tissues which support the bladder and bowels, and the uterus in women. It also keeps the urethra closed until you are ready to pass water; and keeps the anus closed until you are ready to pass faeces and/or gas.



Symptoms of a weak pelvic floor

Urgency

Urgency, a sudden and urgent need to go to the toilet and an inability to 'hold on' can develop from:

- going to the toilet "just in case"
- infections
- smoking
- medical conditions such as alzheimers, stroke, dementia, diabetes or multiple sclerosis.

Incontinence:

A leakage of urine or faeces from the bladder or bowel is known as incontinence.

Stress incontinence

A small leakage of urine when the pelvic floor is stressed by activity such as:

- coughing
- laughing
- sneezing
- straining
- lifting
- jumping
- running
- exercising
- playing sport

Be prepared! Don't let a minor annoyance spoil the enjoyment of participating in something you enjoy!

Constipation or straining

The inability to defecate without great effort is evidence of constipation. Eating breakfast followed by a hot drink can activates the gastro-colic reflex, which triggers a bowel motion.

Frequency
A need to go to the toilet frequently, which indicates an inability to 'hold on'. It is normal to urinate between 6-8 times a day.

A prolapse
In women a prolapse is the protrusion of a pelvic organ ie uterus, bladder or bowel into the vagina. A pessary can be inserted into the vagina every couple of months to keep the organs in place, or pelvic surgery may be necessary.

How common is incontinence?
Urinary and faecal incontinence are very common, affecting 1 in 3 women and 1 in 8 men.

Pelvic floor muscles can be made weaker by:

- not keeping them active
- constipation
- being pregnant and having babies
- being overweight
- heavy lifting
- coughing that goes on for a long time, bronchitis, asthma or smoker's cough
- growing older

What can you do to strengthen your pelvic floor?
A weak pelvic floor cannot do its job properly. Research has shown that the pelvic floor responds to regular exercise. In fact, the sooner you start pelvic floor exercises, the better your chance of preventing or overcoming many of the problems associated with a weak pelvic floor. If you experience stress incontinence, using 'the knack' technique can help to protect you against leakage. 'The knack' technique is when you simply contract the pelvic floor muscles before any activity such as coughing, sneezing, lifting or jumping. This will decrease pressure to the pelvic floor and the likelihood of leakage. Practise this technique regularly to ensure that it becomes a lifelong habit.

How to do pelvic floor exercises
The preferred position is sitting or lying comfortably with the muscles of your thighs, buttocks and abdomen relaxed.

For men:

- Tighten and draw in strongly the muscles around your anus and urethra all at once, trying to hold them up inside.
- Hold this contraction as you count to five and then relax.
- You should have a feeling of letting go as you relax.
- Rest for at least 10 seconds and repeat.
- Aim to do 10 contractions.

For women:

- Tighten and draw in gently the muscles around your anus, vagina and urethra all at once, trying to hold them up inside.
- Hold this contraction as you count to five and then relax.
- You should have a feeling of letting go as you relax.
- Rest for at least 10 seconds and repeat.
- Aim to do 10 contractions.

When doing these exercises:

- do not hold your breath
- do not push down
- squeeze and lift up
- do not tighten your buttocks or thighs

Strengthening the pelvic floor muscles takes time. If you have very weak muscles initially, they will fatigue easily. **Don't give up.** These exercises do work if done regularly. **Be patient.**

Nocturia

Nocturia is having to get up more than twice a night to pass urine. Causes are age related changes, having a small bladder and/or medical conditions. Wearing compression stockings, lying down with legs elevated and restricting caffeine and alcohol can help to manage the condition.

Functional urinary incontinence can be caused by:

- decreased mobility
- cognitive factors (i.e dementia)
- dehydration
- medications
- arthritis (affects manual dexterity)
- toilet availability
- poor eyesight
- new environment

Solutions for functional incontinence are:

- pelvic floor muscle exercises
- cessation of smoking,
- weight loss (if overweight)
- good bladder and bowel habits
- avoiding caffeine and alcohol
- reviewing medications
- preventing and treating constipation
- it may be necessary to consider mobility aids, clothing modification, pain management and home assessment.

Overflow incontinence

Overflow incontinence is common in prostate problems. It requires specialist medical review, medications and either a temporary catheterisation which can be taken in and out, or a permanent catheter inserted into the tummy.

Faecal incontinence

To remain continent, two intact sphincters are required. When the two sphincter muscles, the internal which is not consciously controlled and the external which is under voluntary control, are not functioning correctly this form of incontinence can result and is caused by:

- long time straining
- medications
- food intolerances (e.g. alcohol or lactose)
- severe diarrhoea or constipation
- weak back passage muscles
- surgery or radiation therapy
- medical conditions
- nerve disorders (e.g. spinal cord injury)

Constipation

Severe constipation needs to first be treated with an enema to clear the bowel, then managed with high fibre foods, including psyllium husks and a high water intake. Also exercise as able and go when you need to go. The longer the bowel motion is left in the colon the drier it becomes and damage can be done. Need to keep the stool soft and avoid straining, which can cause haemorrhoids. The best position to use on the toilet is to sit with feet on a stool and lean forward with elbows resting on thighs.

Diarrhoea

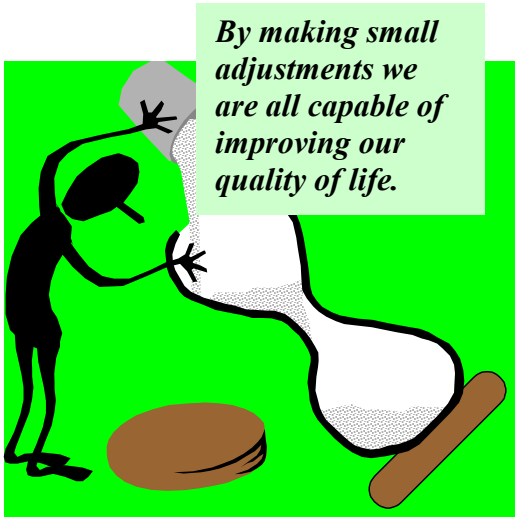
Causes

- an overuse of laxatives
- infection
- bowel disease such as irritable bowel and diverticulitis
- food intolerance
- radiotherapy
- weak pelvic floor muscles

Treatment

Treatment includes:

- treating impaction
- learning to defecate effectively
- incontinence aids (pads)
- surgery



Some simple steps to keep your bladder and bowel healthy

- Try to drink at least six to eight cups (one and a half litres) of fluid a day unless advised otherwise by your doctor.
- Limit the amount of caffeine - coffee, cola, tea and alcohol as these drinks irritate the bladder.
- Try to go to the toilet only when your bladder is full and you need to go. Emptying your bladder before going to bed is fine.
- Take your time when urinating so your bladder can empty completely, but avoid straining. Don't force out the last drop.
- When thirsty you are partially dehydrated. If urine is dark yellow you are highly dehydrated. Light yellow colour is good and clear urine is perfect.
- Keep your bowels regular and avoid constipation.
- Keep your pelvic floor muscles in good condition.

Speak to your doctor or continence advisor, or contact the National Continence Helpline (Free call 1800 330 066) if you are having difficulty or have concerns about your bladder and bowel function.

Energy conservation

Presenter: Melinda Roe, Occupational Therapist at The Canberra Hospital.

The occupational therapist's role in respiratory care is to assist chronic respiratory patients with matters such as equipment provision, home assessment, education and information on energy conservation. Melinda spoke in regard to alternative ways of carrying out everyday tasks to ease the restrictions, for example shortness of breath and fatigue, imposed by COPD.

The six Ps in energy conservation:

Prioritise
Plan
Pace
Positioning
Pursed lip breathing
Positive attitude

Keys to a better quality of life.

Prioritise

Ask yourself "What is it that I ***absolutely need*** to do, and what do I ***want*** to do?" Some tasks are not necessary. Perhaps someone else can do the task e.g. cleaning.

Plan

- Use a diary or calendar to plan your activities.
- Complete activities when you have the most energy.
- Break up tasks into smaller segments.
- Arrange all the items you need within easy reach.
- Allow time to do tasks.

Pace yourself

- Don't rush.
- Take your time and breathe.
- Take regular breaks.
- Maybe clean one room of your house each day.
- If you do too much in one day you will be more fatigued and less likely to cope well the following day.

Positioning

- Complete tasks at waist or chest height.
- Ensure good posture.
- Take care of your back.
- Sit down to complete tasks where possible.
- Avoid overhead reaching or bending down.

Celebrate your achievements no matter how large or small.

Pursed lip breathing

- Inhale through the nose and exhale through pursed lips (purse your lips as though whistling).
- Inhale for 2-3 seconds and exhale for 4-6 seconds.
- Breathe out when you complete any effort to help you finish the task and provide a rhythm.

Positive attitude

- Focus on the things you can do.
- Don't give in!
- Find ways to adapt tasks you enjoy.
- If you achieve your goals you will gain more confidence.

Practical ideas

Eating

- Support elbows on table.
- Use light serrated cutlery.
- Use lightweight or plastic plates and non-stick pans.

Showering

- Be well prepared.
- Sit down on a shower seat or shower stool.
- Lean the stool against shower wall to support your back.
- Shower when you have the most stamina.
- Use a mitt bag tied to your wrist to prevent dropping the soap.
- Use a long handled brush/sponge to wash back and lower legs.
- Use a terry towelling dressing gown to dry your back.
- Use a long handled reacher with a towel to dry between your toes.
- Avoid using the bath as transfers in and out of the bath can be difficult.

Grooming

- Sit in front of the basin for cleaning face, brushing teeth and combing hair.
- Use an electric toothbrush.

Shopping

- Shop with a friend or relative who can help with heavy lifting.
- Some stores have a home delivery service.
- Use a trolley.
- Make a list and shop less frequently.

Preparing food

- Use frozen and canned foods.
- Plan ahead and cook larger quantities of food.
- Freeze single meal portions ready for the occasions when you're too tired to prepare a meal.
- Use electric appliances where possible e.g can opener.
- Use lightweight cooking items.
- Use a perforated spoon to drain items from
- saucepan.
- Use pot mitts.
- Slide saucepan rather than lift it.

Laundry

- Sort clothes on work bench or table.
- Hang small items on clothes horse or airer.
- Do small loads regularly.
- Purchase clothes requiring little or no ironing.
- Sit down to iron.

Cleaning

- Use long handled brushes, mops, brooms etc.
- Use spray-on detergents that can be wiped off later.
- Limit cleaning to one room daily.

Work

- Adjust hours to suit your capabilities.
- Ensure a good posture when completing tasks.
- Avoid unnecessary trips to and from your desk.

Environment

- Home modifications may help e.g., installing handrails, ramps etc.
- Items should be placed within easy reach.
- Heavy items need to be stored in lower cupboards and lighter items stored higher.
- Use a 4-wheel walker with a basket and seat and a kitchen trolley to assist you.

Equipment around the house

Bathroom

- over-toilet frame
- throne rails (can have extension on it to raise the toilet as well)
- toilet surround (arm rails to help you get up)
- bath board
- bath transfer bench
- shower chair; shower stool
- leg lifter
- soap bag
- long handled sponge
- long handled reacher to grab towel to dry toes

Communicate! There are so many ways in this day and age to do just that!

General:

Make use of equipment that reduces the stress and strain on you such as:

- the long handled reacher with magnet to pick up keys
- the long shoe horn
- a jar opener
- an electric food slicer
- a long handled dust pan and brush
- an electric lift recliner (helps to boost you up out
- of chair)
- elephant's feet (lifters under bed-head or chair)

Talk to other people to exchange ideas. It's good to know we are not alone.

Visit the Independent Living Centre, 24 Parkinson Street, Weston to see their range of equipment. Phone 6205 1900 to make an appointment.

Note:

Dr Mark Hurwitz was overseas in Barcelona and unable to deliver his talk on the latest developments in lung disease. Thanks to Melinda Roe for stepping in with her very interesting and informative presentation.