

POLIO NSW

formerly Post-Polio Network (NSW)

NETWORK NEWS

Incorporating – Polio Oz News

Editors: Nola Buck and Susan Ellis
Email: editor@polionsw.org.au
Website: www.polionsw.org.au

PO Box 2799, North Parramatta
NSW AUSTRALIA 1750
Phone No: 02 9890 0946

Patrons: **Michael Lynch AO CBE** **Professor Emeritus Sir Gustav Nossal AC CBE FAA FRS**

President's Corner

Gillian Thomas

At our 30th Annual General Meeting (AGM) held on 21st November 2018 the following members were elected to the Management Committee:

Gillian Thomas	<i>President</i>	Ella Gaffney
Susan Ellis	<i>Vice-President</i>	Chris Keun
Merle Thompson	<i>Secretary</i>	Bill McKee
Alan Cameron	<i>Treasurer</i>	Janette McKenzie
Anne Buchanan		Diana O'Reilly
Nola Buck		Shirley White

At the AGM we were sorry to farewell Charles Anderson. Charles had loyally served on the Committee for seven years, and was a great supporter of our events. Unfortunately, this year ill health caught up with Charles and he could not continue. We will miss his input at meetings. On a brighter note, we were pleased to welcome Bill McKee back onto the Committee after a seven year sabbatical. Bill was previously our Webmaster but this time around is looking for a new challenge.

The Committee will hold its annual Planning Meeting in January 2019, where we develop our activities for the year. As usual, to assist us in this process, we are asking for your input. For example, what information services do you need and in what format (e.g. printed, web based etc), what topics would you like to see covered in our Seminars, what types of information would you like on our website, and/or any other questions/ideas/feedback you have. 2019 is also the 30th year of operation of Polio NSW – how do you think we should celebrate this milestone? We would love to hear from you by 21 January.

Save the dates! The *Polio Health and Wellness Retreat* returns to NSW in 2019, from 17th to 20th October at St Josephs, Baulkham Hills (same venue as 2010 and 2014 Retreats). See past Retreats here <www.polioaustralia.org.au/retreats/> and check updates in upcoming issues of *Network News*.

The major article in this issue is Sue Ellis' report on our 2018 Mid-Year Seminar (pages 2-15). I believe this was the first Seminar I had missed in 30 years (a heavy cold kept me away) so, like other members who were unable to attend, I am very grateful to Sue for the wonderful job she has done in bringing us the content of the three excellent presentations.

Polio NSW once again participated in Polio Australia's annual *Walk With Me* fundraiser in October. So far I have raised \$4,235 and, as usual, my eventual total will be split equally between Polio Australia and Polio NSW to assist both organisations to provide their services to polio survivors. It is not too late to donate in support of the NSW campaign, just visit: <www.polioaustralia.org.au/wwm2018-nsw/>.

Finally, on behalf of the Management Committee I wish each and every one a joyous Christmas and a peaceful and healthy New Year, and hope you enjoy the holiday reading in this newsletter.

Unless otherwise stated, the articles in Network News may be reprinted provided that they are reproduced in full (including any references) and the author, the source and Polio NSW are acknowledged in full. Articles may not be edited or summarised without the prior written approval of Polio NSW. The views expressed in this publication are not necessarily those of Polio NSW, and any products, services or treatments described are not necessarily endorsed or recommended by Polio NSW.

Mid-Year Seminar Report - 27 June 2018

By Susan Ellis

Dr David Lamond, PhD – Chair of The Michael Hughes Foundation <www.mhf.life>. MHF aims to raise awareness of cardiac arrest by promoting the distribution of public access defibrillators, providing training in first aid, CPR and the use of defibrillators. David's presentation was "*Enabling Bystanders to Become First Responders*".

About the Michael Hughes Foundation: Michael Hughes was a migrant from the UK, he was a locksmith who lived in Dundas, was 2 years away from his 40th birthday, he and his wife Julie had a 9 week old baby girl Georgia, and he fell down in the shower after a sudden cardiac arrest. Despite his wife Julie's best efforts and the ambulance arriving, he passed away. The foundation was set up in his name, he was somebody who loved his family, loved his work and generally loved life.

Julie set up a fundraising evening to celebrate what would have been his 40th birthday and raised \$35,000 which enabled the foundation to buy 15 automated external defibrillators (AEDs). They then set out to work with local governments in Ryde, Parramatta and the Northern Beaches and they found that they couldn't give the AEDs away! Each of the Councils were concerned about the legal implications and they didn't want to take on the responsibility. Julie became perplexed with this and through a mutual friend who said "*I know a bloke*" who could help (David Lamond). Three years later the foundation began and 5 defibrillators went to Parramatta, 5 to the Ryde area, and 5 to the Northern Beaches.

They were able to work with the local governments after explaining the Good Samaritan section of the *Civil Liability Act 2002* – that as long as you are trying to do good there is no problem at all. Many people are concerned about stepping in when someone is having a cardiac arrest or someone has been skittled by a car; they worry that they could get blamed if anything went wrong. If you use common sense, there is no legal comeback. There is also no legal comeback if you choose to do nothing either. If you look to do your best to assist, then it is better than doing nothing at all.

Personal Liability

In NSW all Good Samaritans are protected by the *Civil Liability Act 2002 - Sect 57*

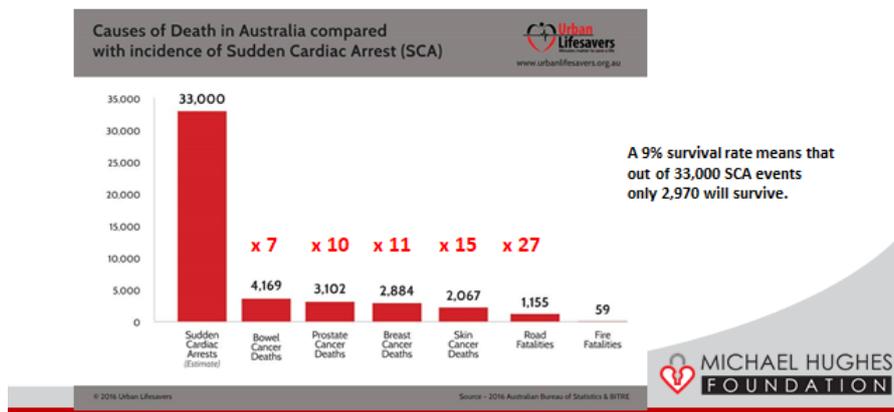
- ◆ A good Samaritan does not incur any personal civil liability in respect of any act or omission done or made by the good Samaritan in an emergency when assisting a person who is apparently injured or at risk of being injured.
- ◆ This section does not effect the vicarious liability of any other person for the acts or the omissions of the good Samaritan



33,000 people suffer sudden cardiac arrest in Australia per year – 30,000 don't survive. Every week 4 Australians aged under 35 die from sudden cardiac arrest. We have an Ambulance system here in NSW, and generally all around Australia, which is among the best in the world, the average response time for an ambulance to get to an emergency, is 10 minutes. The problem though is that by the time the ambulance arrives, if nobody has done anything, if no one has performed any intervention, they simply arrive very quickly to become a transport service to take the dead away. After 4 minutes brain injury begins to occur, and by 10 minutes the most likely outcome is that the person will have catastrophic brain injury and then death. So we need to find a way to overcome this problem in

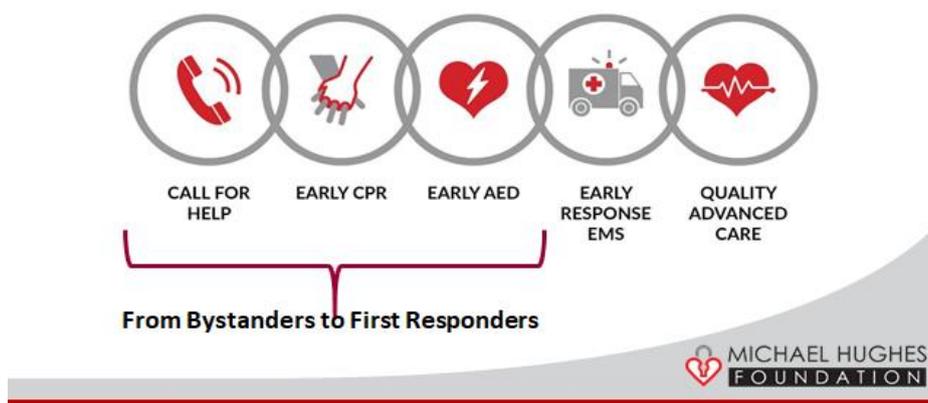
response time, the way we can do that through the Foundation is to encourage people to become first responders.

SCA in Context – the Australian Statistics



To put the 33,000 into perspective, sudden cardiac arrest has 7 times the incidence of bowel cancer and 27 times the rate of road fatalities. Then you think about the amount of money, attention and support that cancer and especially road safety get and that investment still gives 1,155 road fatalities, but remember that is 27 times fewer than the number of people who die each year from sudden cardiac arrests.

Cardiac Chain of Survival



Professor Robert Denniss, head of Cardiology at Westmead Hospital, is one of the Michael Hughes Foundation’s patrons and a very strong supporter of the Foundation. This is because he is sick of being called out in the middle of the night to perform lifesaving surgery for somebody who will be fundamentally neurologically impaired for the rest of their lives and trying to find that balance between the quantity of life and quality of life. He wants to see that when he comes to do that surgery to intervene, he finds not only a person that has been saved but who will go ahead and live a long productive life. One of the most important things about the Cardiac Chain of Survival is it involves us as bystanders who can recognise that someone is having a cardiac arrest – you can call for help, begin CPR, apply the automated external defibrillator (AED) and keep those things going until the ambulance arrives and the patient is transported to a quality advanced care unit.

What our Foundation wants is for people to think about how they could become a First Responder rather than an innocent bystanders.

Most people have the misunderstanding that a cardiac arrest is a heart attack. The difference between a cardiac arrest and a heart attack is like deciding whether to call a plumber or an electrician – a reasonably significant difference!

What is Sudden Cardiac Arrest?

Heart attack = circulation problem.

- Blood flow to the heart is blocked.
- Patient will show symptoms eg nausea, pain in neck, jaw, arm, etc.
- The patient requires immediate medical assistance
- The longer a person goes without treatment, the greater the damage.

Sudden cardiac arrest = electrical problem.

- Heart quivers or fibrillates – rather than pumping blood
- Blood is not being pumped to vital organs
- Patient will be unresponsive, have no pulse and not breathing
- Death occurs within minutes if the victim does not receive treatment.



Heart attack is a circulation problem, a plumbing problem. If David was looking at himself on balance as to whether he would have a cardiac arrest or a heart attack then he is a pretty good candidate for a heart attack. He has diabetes type 2, is overweight, he enjoys the benefits of medicinal quantities of red wine; he is the one who is going to have the plaque building up in the arteries around his heart and that is why this is called a plumbing problem. It is the blockages of those arteries that feed the life giving oxygen to the muscles in the heart that get clogged up. That is when you hear about people having stents put in to expand the artery, or bypass surgery when the blood isn't getting through these 'pipes' anymore, so they put in a new artery to bypass the blocked one.

If the blood flow to the heart is blocked you get a pain in the chest, it might radiate down the chest or the left arm, and you may also get pain in your neck or in your jaw – you are having a heart attack. Certainly the person requires immediate assistance but in terms of urgency and emergency, the urgency is not as much as it is with a cardiac arrest.

A cardiac arrest is an electrical problem. You may have seen a TV show where they call a Code Blue, when they get a crash trolley, they get a defibrillator and pulse signals on the screen; that is when we are looking at the problem which is in the electrics. The heart defibrillates (quivers) rather than pumping the blood. The sound of atrial and ventricle pumping is two sounds close together (lub dub, lub dub) – the sound of pumping in time. They can only hear that if the heart muscle is sound and getting the blood, also when the septum in the middle of the heart is sending the electrical charge to make those muscles contract, simulating pumping. During a cardiac arrest the person will not be conscious or responsive, there is no blood getting to the organs or to the brain, they won't be breathing and there won't be any pulse. Death will occur within minutes if no treatment is received, rather than hours as in the case of a heart attack.

Someone who is having a circulation problem, a heart attack, will have all the pain from the heart contracting and damage will certainly be done to the heart; they will be sweaty, complaining of chest pain, but you will still be able to feel a pulse. This is the difference between cardiac arrest and a heart attack, one is an electrical problem and one is a plumbing problem.

Early CPR is the key to Sudden Cardiac Arrest (SCA) survival – it is so important. A person needs to have a shockable rhythm before a defibrillator can be applied. And this is why is so important to get some kind of rhythm going using CPR.

The new AED machines (Automated External Defibrillators) – defibrillation for dummies – will tell you what to do and how to do it. It will also tell you whether the person needs to be defibrillated or not because once you attach the pads to the chest it will do its own diagnostics. It will say '*I have a shockable rhythm, stand clear, don't touch*', shock is employed and hopefully we get a normal rhythm – lub dub, lub dub. However, if that

rhythm is already there then there is no need to shock. OR you'll get the instruction, 'no pulse, continue with CPR'. Continue with CPR for a further 2 minutes, come back for a diagnostic test again, 'you have a shockable rhythm now, stand clear', shock. The AED will tell you how to attach the pads to the chest. If there is already a pulse then no shock is needed. If there is no pulse then a shock is needed.

DRS (doctors) ABCD – is the acronym used for how to respond to a cardiac arrest:

D **Danger**
Check for danger (e.g. electrical wires, water or other hazards).

R **Response**
Check for Response by talk and touch.

S **Send**
If unconscious, need for help by calling Triple Zero (000).

A **Airway**
Open Airway and ensure it is clear.
Tilt head, lift patient's chin and clear the airway.

B **Breathing**
Check Breathing.
If patient is not breathing or breathing is not normal, commence CPR.

C **CPR (30:2)**
Start CPR.
Use 30 Chest Compressions followed by 2 rescue breaths.
If unable or unable to perform rescue breaths continue chest compressions.
The Breathing: give 2 initial rescue breaths before starting compressions.
Ensure adequate forehead tilt (tilt when giving rescue breaths).
Compressions should be at a rate of 100-120 per minute in the centre of the chest and be 1/3 of the patient's chest depth.
The hands do not lift off the chest when administering breaths. Use 2 fingers to compress chest.

D **Defibrillation**
Attach an Automated External Defibrillator (AED) as soon as it is available and follow its prompts.

Continue CPR until:

- The patient responds or begins breathing normally.
- It is impossible to continue (e.g. exhaustion).
- A health care professional arrives and takes over CPR.
- A health care professional directs that CPR be ceased.

To get involved and learn to save a life, enrol at sls.com.au or call 1300 766 257

The information on this card is a summary for first aid training. For full details, refer to the manual that accompanies this card.

Australian for life

CPR Chart	
Cardio Pulmonary Resuscitation	
IN AN EMERGENCY REMEMBER YOUR DRSABCD	
Dangers?	Check for danger (e.g. electrical wires, water or other hazards)
Responsive?	Is the patient responsive and not breathing normally?
SEND FOR HELP!	<ul style="list-style-type: none"> Ring for assistance Use someone to call Triple Zero (000) immediately Use an AED/AED2
Open Airway	<ul style="list-style-type: none"> Tilting the head back and lifting the chin for the airway Remove any object from the mouth Use a jaw-thrust
Normal Breathing?	<ul style="list-style-type: none"> Look, listen and feel for breathing Normal breathing is present (rate or depth correct or both) Normal breathing is absent, commence CPR (30 compressions to 2 breaths at 100-120 compressions/minute)
Start CPR	<p>DRSABCD:</p> <ul style="list-style-type: none"> Place hand in the centre of the chest Compress hard and fast (100-120 compressions per minute) Continue until the AED is ready to be used Compress to a depth of 1/3 of the chest Use 2 fingers to compress chest <p>REMEMBER:</p> <ul style="list-style-type: none"> Hands do not lift off the patient Continue normal breathing when the AED is ready to be used Continue with the compressions by 2 breaths
Attach Defibrillator	Attach Automated External Defibrillator (AED) as soon as available and follow prompts

MICHAEL HUGHES FOUNDATION

CPR Steps

1. Make sure there is no **danger** to you or the patient i.e. no live wires, water etc.
2. Is the person responsive (i.e. cardiac arrest), no **response** to stimulation, no breathing, no pulse.
3. RING 000 or tell someone to ring 000.
4. Check **airway**.
5. Check **breathing**.
6. Tilt head back. Start **CPR**.
7. Defibrillation if indicated.

CPR

- ◆ Cardio Pulmonary Resuscitation (CPR) is proven to make a difference, **a real difference!**
- ◆ Compressions on the lower half of the sternum
- ◆ CPR recommended **30 compressions to 2 breaths**
- ◆ **At a rate of 100-120 per minute**
- ◆ Compress **1/3** of the depth of the chest (Approx. 4-5 cm)
- ◆ CPR is very tiring if possible rotate rescuer every **2 minutes**

MICHAEL HUGHES FOUNDATION



After calling 000, you will find the operators will be very efficient and helpful but one issue for them is locating where you are calling from. If you have a Smartphone, they can pick up your signal. There are free apps for your phone e.g. Emergency+ that will locate exactly where you are within seconds and relay this to the operator. The app can be used to call any emergency service e.g. police, SES, ambulance service.

CPR early is vital in surviving a sudden cardiac arrest, the first 4 minutes are critical; CPR makes a huge difference to the outcome. The survival rate for SCA is about 10% in

Australia. In Seattle the survival rate is 63%, there they promote completing a CPR course for all driver's licence holders.

The Adams Family beat is the rate that you should use for compressions or "Staying Alive" by the Bee Gees or "Another One Bites the Dust"; 4x4 time, 100-120 beats per minute. A normal pulse rate is 70-80, for some athletes 60 or even 40. The aim is to get that blood pumping around and also up to the brain.

Defibrillation

- ◆ Dry patient's body and/or move patient if any water is present
- ◆ Remove clothing on patient's torso including bra and any jewellery from chest area
- ◆ If male patient has chest hair, quickly shave section where pads are to be placed (for best contact of defibrillation pad)
- ◆ Correctly position defibrillation pads
- ◆ Follow AED voice prompts
- ◆ Do NOT touch the patient whilst delivering shock to patient

The use of an AED should NOT be restricted to trained personnel!



The AED will give visual prompts and audio prompts, it will tell you to push harder, and when ready to shock it will tell you to stand clear. It will tell you when normal rhythm has been restored. It won't let you shock the person unless they need to be shocked.

Maintenance: The batteries last 3 years, some 2-5 and some 7 years so check use by dates, battery levels etc. Most defibrillators self-check, displaying a green light if operable and ready to use or a RED light - not able to use.

Maintaining your AED

- ◆ Develop a maintenance program specific for your organisation.
- ◆ The AED automatically completes a regular self test
- ◆ The AED alerts you to ANY faults
- ◆ The Michael Hughes Foundation periodically audits the performance and condition of your AED and its components with each club
- ◆ Notify the MHF if you have any operational concerns with your AED



Cost of a defibrillator— standard community defibrillator would be \$2,500. Someone needs to be responsible for the maintenance of them. There is regulation for fire extinguishers but there is no regulation of defibrillators.

- Do an accredited first aid course!
- Don't be afraid to have a go!
- Call the Ambulance – ambulance personnel will support you
- Take a deep breath.....
- Any effort is better than no effort!
- You won't save everybody but you will dramatically increase their chance of surviving!

Associate Professor John Dearin – Rural doctor and VMO Lithgow Hospital as well as Senior Lecturer at University of Notre Dame Australia School of Medicine. Specialty Interests: General Internal Medicine and Geriatrics.

Our second presentation was “*Healthy Ageing: how to make the most of your senior years*”.

Professor Dearin spoke of his previous experience of post-polio syndrome when he ran a rehabilitation and geriatrics unit at Tamworth Base Hospital in the 1980’s. He also remembers as a child in the 1950s that his parents were terrified of their children contracting polio as some of Professor Dearin’s school friends had done.

According to the Bureau of Statistics around the world, once you turn 65 you are classified as ‘old’ and this includes him! He presented statistics relating to the ageing of the Australian population e.g. 15% of all Australians (3.7 million) were aged 65 and over in 2016 (in 1956 it was only 5% of the population); this is expected to grow to 22% (8.7 million) by 2056 and basically the reason is that we are all living longer.

Only about 5% of ‘old’ Australians end up in a nursing home and 76% own their own home. The ageing of the population creates both pressures and opportunities for Australia’s health and welfare sectors. Life expectancy has increased over the last 110 years which could be put down to the advent of refrigeration, vaccination, public health and probably better control of blood pressure.

Today in Australia the life expectancy of a male is now 84.5 years, and a female 87.3 years. There are only six other countries worldwide where both men and women have a life expectancy of over 80 years: Japan, Italy, Switzerland, Iceland, Israel and Sweden. So how are you going to spend those extra years?

Healthy Ageing:

- The health of the increasing number of older Australians is an important economic challenge facing Australia. It is also an opportunity, as extending a lifetime of good health enables older Australians to continue to contribute socially, culturally and economically to the wider community.
- A range of factors influence older people's ability to remain healthy as they age; these include a number of behavioural and biomedical risk factors as well as ongoing social and mental wellbeing.

Health and Functioning:

As the number of older people in Australia continues to grow, optimising their health and wellbeing is an increasingly important economic and medical challenge.

To best respond to the increased demands of this larger aged population, the health system needs to understand the most common health conditions that older Australians might experience. **7 in 10** older Australians considered they had good, very good or excellent health. **2 in 10** Australians aged 65 and over experienced a disability in the form of a severe or profound core activity limitation. This of course increases as we get older and this taps into the post-polio syndrome. **15%** of all deaths of Australians aged 65 and over were caused by coronary heart disease. The most common causes of death are coronary disease, cancer, dementia and being hit by a bus (accidents)!!

Many serious health issues, including some chronic diseases e.g. cardiovascular disease, chronic kidney disease, certain types of cancer, type 2 diabetes, influenza and high blood pressure, all relate to lifestyle factors which are **modifiable**. These factors include the lack of physical exercise, poor nutrition, obesity, smoking, excessive alcohol consumption, non-vaccination and psychological distress. All of these issues are important to how we age.

The Five Risk Factors: *Tobacco use* doubles your risk factors (responsible for 22% of all cancer deaths per year), *high body mass* (70% of older Australians are overweight i.e. BMI >25), *alcohol use*, *physical inactivity*, *high blood pressure*.

BMI = $\frac{\text{weight kg}}{\text{height m}^2}$ OR as Professor Dearnin prefers: the $\frac{\text{haunch}}{\text{paunch}}$ Ratio

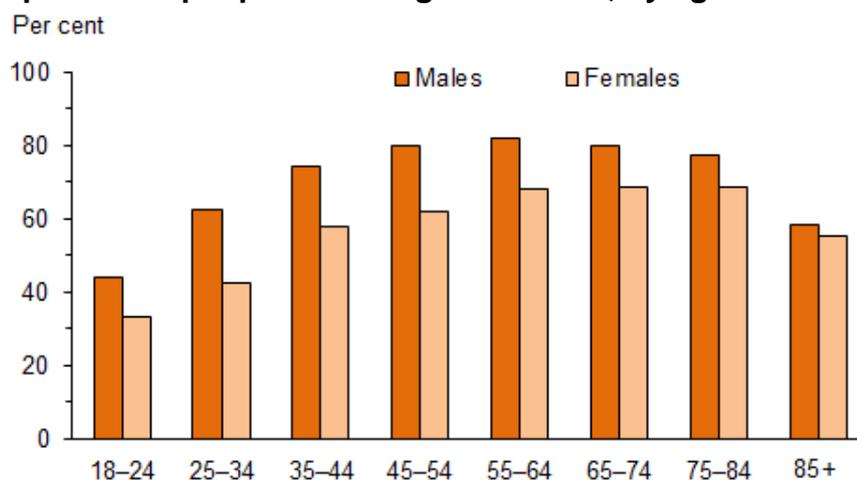
Recommendations:

National guidelines suggest that older Australians should aim for 30 minutes of moderate **exercise** on most days of the week (e.g. brisk walking, sports, gardening or swimming). Being active helps maintain a healthy body mass, improves both physical and mental wellbeing by reducing the risk factors for cardiovascular disease, diabetes, anxiety, depression and musculoskeletal problems, whilst enhancing social and community connectedness by providing opportunities for social engagement. Living the life of a hermit is not good for anybody; you need to mix with others. When you exercise, the body produces ‘happy’ hormones, called endorphins, which make you happy.

Nutrition: A rounded diet which includes 2 servings of fruit and 5 of vegetables every day protects against conditions such as heart disease, type 2 diabetes, and eye diseases such as cataracts and macular degeneration. Green leafy vegetables are good for your heart and good for your brain.

Obesity: Obesity is a key health issue for older Australians and can increase the risk of developing heart disease, type 2 diabetes and certain cancers, among other things. 80% of men and 69% of women are overweight or obese, this trend declines once 85 and over.

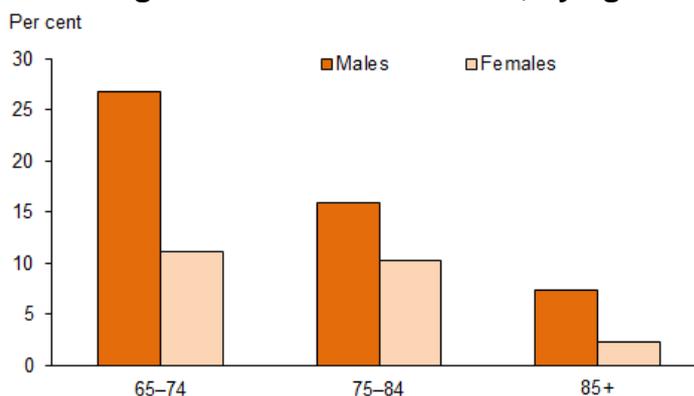
Proportion of people overweight or obese, by age and sex, 2014-15



Smoking: Rates of smoking have drastically decreased in Australia since the late 1980s; we are leading the world in this and may be due to an improved awareness of the negative health effects of tobacco, and a range of control measures aimed at reducing smoking rates. Smoking is the leading risk factor for a number of diseases and conditions, including coronary heart disease and lung disease. As well, smoking is estimated to be responsible for 22% of all cancer deaths per year; this includes not only lung cancer but kidney, bladder and probably pancreatic cancer. Older Australians tend to have much lower rates of smoking than younger cohorts – only 7% of people aged 65 and over are current smokers, compared with 18% aged 18-64. As well, 44% of people aged 65 and over reported being previous smokers. The main reason that people aged 70 and over reported for quitting was health (56%).

Alcohol Consumption: Alcohol plays a prominent role in society; most Australians drink at light to moderate levels. However, drinking excessive amounts of alcohol is a health risk, and can contribute to long-term health issues such as liver disease, some cancers, and brain damage and dementia. The NHMRC recommends no more than 2 standard drinks daily to reduce one’s lifetime risk, and no more than 4 drinks in one event to reduce single-occasion risk. Of the 70% of older Australians who did consume alcohol in the last 12 months, more than three-quarters (80%) did not exceed the recommended guidelines, while 16% drank above the recommended guidelines for lifetime risk i.e. the accumulated risk from drinking too much and too often over a lifetime. Men were more likely than women to drink excessively.

Proportion of people aged 65 and over who drank above The 2009 NHMRC guidelines of lifetime risk, by age and sex, 2014-15



Vaccinations: One of the most effective health interventions against preventable health issues is vaccination. Influenza and pneumonia can seriously affect the health of old Australians, vaccinations are free for people aged 65 and over to ensure a high coverage. The influenza vaccine is available annually; the pneumonia vaccine is administered once. In 2009, approximately half (51%) of older people were vaccinated against influenza and pneumonia – this needs improving.

Psychological Distress: Chronic stress can potentially lead to anxiety and depression and to physical health issues such as high blood pressure. So it is important to try and maintain equilibrium. 52% of 65+ age group said they were stressed in 2014-15. Stress management strategies such as relaxation, physical activity, time management and social connections can help lower stress levels and reduce the negative impact experienced as a result of chronic stress.

Staying Mentally Active: Staying mentally active throughout life can help maintain cognitive functioning, mental wellbeing, and promote independence into older age. In 2011, more than 14,000 people aged 65 and over were enrolled in a full-time or part-time educational course. Around 5% of people aged 65 and over had participated in an education or training group to help gain new skills for further engagement. In 2012, around 43% of men and 61% of women aged 65 and over reported reading books 3 or more times a week. Intellectual (cognitive) activities such as reading, writing and doing puzzles help participants to keep mentally stimulated. A group of 450 in a study in Queensland learnt a new language or a musical instrument and this proved to enhance their mental health. It is good for you, enjoyable and might stave off the dementia that we all fear.

Mental and Social Wellbeing: Healthy ageing involves more than just promoting good physical health. Social and mental wellbeing are also important determinants for a high-quality life into older age. According to the National Health Survey, older Australians typically have low levels of psychological distress (73%), which involves both measures of anxiety and depression in individuals.

Social Connectedness: Social connectedness can affect mental and physical health. A recent meta-analytic review found that the influence of social relationships on mortality is comparable with well-established risk factors, such as smoking and excessive alcohol consumption. The review included 148 studies, with data from more than 300,000 participants with an average age of 63.9. The analysis found that people with strong social relationships demonstrated a 50% increase in survival compared with those with weaker social relationships. Older Australians tend to have regular social engagement. In 2014, 19% of people aged 65 and over had daily contact with people outside their household, and 63% had contact at least once a week. When looking for support, 92% of Australians aged 65 and over believe they have someone outside the household in whom they can confide. Social engagement through community groups, sports, societies and volunteering can also help to strengthen and expand these social networks. So social connectivity is important and how to achieve social engagement could be through community groups, sports, societies, and volunteering; all of these help to strengthen and expand social networks.

Biomedical Risk Factors: Biomedical risk factors are bodily states that contribute to the development of chronic disease such as cardiovascular disease, type 2 diabetes, and chronic kidney disease. These states can be caused by a range of factors including:

- genetic
- socio-economic
- psychological
- behavioural
- or a combination of these

Biomedical risk factors may also be influenced by behavioural risk factors – for example, physical inactivity and poor diet can adversely affect blood pressure and blood cholesterol. Behavioural and biomedical risk factors tend to increase each other's effects when they occur together in an individual. Overall, older Australians experience a higher prevalence of biomedical risk factors than younger Australians, and these generally increase with age.

This snapshot focuses on 3 biomedical risk factors that have direct and specific risks for health. These risk factors may be able to be modified by undertaking sufficient physical activity and eating a healthy diet.

- 1. High blood pressure:** >140/90mmHg. When high blood pressure is controlled by medication, the risk of disease is reduced, although not to the level seen in unaffected people. Get you blood pressure checked at least yearly and have your doctor also take it whilst you are standing as we can feel a bit wobbly when we get up in the mornings and if your blood pressure is too low is can cause you to fall and break bones!
- 2. Abnormal blood lipids (dyslipidaemia):** Dyslipidaemia – abnormal level of blood lipids (e.g. cholesterol, triglycerides) is a risk factor for chronic disease such as coronary heart disease and for some types of stroke and has been linked to atherosclerotic damage to arteries and heart disease.
- 3. Impaired glucose regulation:** Impaired glucose regulation is a characteristic of pre-diabetes, a condition in which blood glucose levels are higher than normal, although not high enough to be diagnosed with type 2 diabetes. There are two measures of impaired glucose regulation – impaired glucose tolerance (IGT) and impaired fasting glucose (IFG). Both IGT and IFG are pre-diabetic states associated with insulin resistance – where cells fail to respond normally to insulin – which leads to high levels of blood sugar. Both IGT and IFG are risk factors for type 2 diabetes, and are associated with a greater risk of heart disease.

Advice: Get your Blood Pressure, cholesterol and blood glucose levels checked annually. Maybe not once you are 85 or over, after all **“85 year olds and older are biomechanically elite!”**

Professor Dearn also suggested that we get our Vitamin D levels checked – not only is Vitamin D good for your bones but it also good for muscle strength.

7 Habits of People Who Age Well:

Exercise and diet as well as attitude can be as important as genetics when it comes to growing old gracefully.

**“Old age,” as Bette Davis once said, “is no place for sissies”
Or as my wife says “She’s not taking it lying down”**

But that doesn’t mean you need to chicken out. Sure, growing older affects nearly every part of your body – including your hair, skin, heart, muscles, and more – but ageing may well be as simple as adopting these (mostly) easy everyday habits:-

- Maintain a positive attitude (set goals to be achieved)
- Watch what you eat
- And how much you eat
- Exercise regularly
- Stay social
- Protect your skin from the sun.
- Get plenty of sleep

Professor Dearn suggested a book by Mr Ian Litchfield OAM called *“Secret to Longevity”*. He then played a video of a 92-year-old friend of his who had been a sheep grazer all his working life; he is an intellectual and very articulate. Dr Dearn posed a question to him: *“So what about this ageing thing?”* Here are the points he made in his reply:-

- Firstly, it is essential that you rise early in the morning.
- Try and be active as much as possible, don’t sit on your backside.
- Diet is very important, eat wholesome food, don’t eat junk food.
- Eat a handful of a variety of nuts every day.
- Have a lot of interests in things and keep your mind active.
- Seek friends, you have to communicate with people, don’t isolate yourself.
- Drink a glass of red wine every day, it is very good for you.
- Companionship, you need to have someone that you can go out with and enjoy life with otherwise you don’t go out – go to a concert, the opera.
- Finally, you’ve got to listen to beautiful music which is very good for your overall well-being, it’s good for your mind.

He also gave Dr Dearn two quotes that he has carried with him throughout his life. The first is from a French poet and dramatist, Victor Hugo – *“The supreme happiness in life is the conviction that we are loved”* and for the second (on the value of music) he quoted Martin Luther, the great reformation instigator – *“Next to the word of God the noble art of music is the greatest treasure in the world”*.



Paul Cavendish, is an Exercise Physiologist who has worked with neurological conditions and is the Clinical Educator for Polio Australia. His presentation – *“Summary of the Late Effects of Polio Clinical Practice Workshops”* – included a review of the polio virus and the capacity of the human body to recover, the role of assistive technology, management of fatigue and pain, the role of exercise and activity, respiratory and sleep function, speech and swallowing and orthopaedic management.

Polio Australia's aim for the LEOp Clinical Practice Workshops is to deliver training to as many health professionals across all states of Australia as possible. At each workshop we have a polio survivor who gives an account of their experience and is also there to answer any questions from the health professionals.

Polio Australia also plans to develop online learning modules for health and medical professions as well as for survivors. We are also working at universities providing information and resources as well as with the Aged Care industry, including those who work within the industry such as case managers of home care. We also want to develop partnerships with health organisations and other neurological organisations and to increase awareness, support and advocacy for polio survivors.

The current workshops have been running since the end of October 2017 and we have trained 420 health professionals across Australia. We now have a Health Professionals Register on the Polio Australia and Polio Health websites where you can log in to find, by location, various health professionals.

Polio is nearly gone but not forgotten. With the efforts of Rotary and the Gates Foundation we now see very few new polio cases. There is still no cure for the polio virus or its after-effects. The inflammatory response from the virus (acute and chronic) may still mean that the polio virus will remain relevant for many years to come. Research is being done by the Swedish and Italians on inflammation and PPS. There have recently been clinical trials with Stage II Brain Cancer using the polio virus.

The stages of the polio virus: the early infectious stage when denervation of muscles occurs and then the recovery stage of mobilisation and activity with reinnervation of muscles. Hydrotherapy is something that really took off during the recovery period as a way of restoring function and it is still a way of maintaining your joints and muscles focusing on mobility rather than strength. Recovery plateaus for a period of 20+ years before there can be a sudden decline with the Late Effects of Polio (LEoP).

From a muscle point of view we often refer to our polio limb or non-polio limb but we should recognise that polio generally spread throughout the whole body and we can't be sure what is affected and what isn't.

The determination of a polio survivor and their attention to detail comes through professionally as in many well-known people from all walks of life such as Mia Farrow, Kerry Packer, Kim Beasley, Neil Young, President Franklin Roosevelt, John Laws and Joni Mitchell.

Psychosocial factors affecting polio survivors include:

- incredibly resourceful and independent,
- pain and fatigue a constant challenge,
- capacity to find new methods or strategies can become difficult,
- seeking assistance is challenging (finding knowledgeable professionals),
- facing rehabilitation again

Dealing with all of these issues influenced us in becoming determined and independent; some call "determination" in polio survivors "stubbornness".

From a health perspective this determination along with being extremely resourceful and independent makes us prone to pushing ourselves which can lead to more pain and

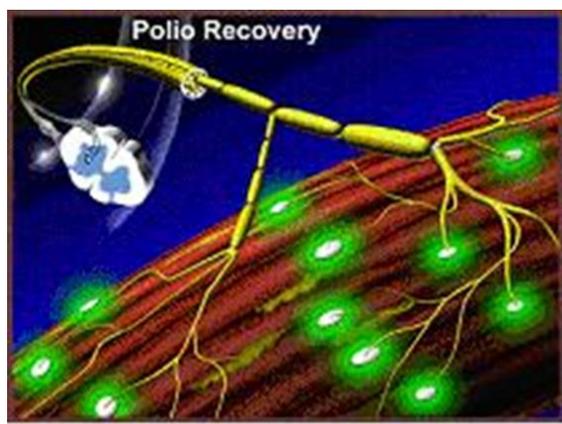
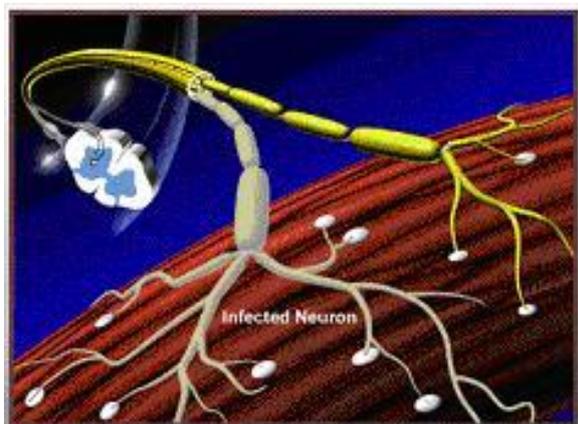
fatigue. The capacity to find new methods or strategies can lead to a frustration and difficulty when seeking assistance. Then there is the challenge of finding professionals who have the knowledge and skill to deal with PPS. The psychological effect when we are faced with dealing with deterioration of function may bring up all sorts of past issues. This might require you to seek some assistance and help (counselling) to assist you to work through these issues, working through acceptance and understanding of what is happening.

Aids and Equipment: It is important to plan ahead to future-proof your needs so you can maintain your independence both at home and in the car. Advice from an occupational therapist should be sought on the right fit for mobility aids such as wheelchairs, scooters, walkers, including the height and weight of the aids. Assessments are available through My Aged Care.

Orthotics: Discuss your current situation and history with your orthotist and include your activity levels, environment (hills, paths, challenges), how you use your orthotics or how you previously used them, what was successful and what failed. A comprehensive assessment is essential including a gait analysis, range of motion testing, muscle strength, and endurance testing for both limbs. Appropriate bracing and the stabilising of joints will help improve energy levels, reduce joint and muscular pain, preserve existing muscle strength and joint health of less affected limbs, and maintain current activity levels. Orthotics also reduce the risk of falls.

Fatigue Management: Various strategies such as pacing, planning, prioritising and positioning can help manage fatigue. Keeping an activity diary to identify those activities that cause you the most fatigue and pain is recommended as the best way of managing fatigue as well as pain. This will help you decide what changes you need to make to continue a particular activity more easily. Occupational Therapists can advise on strategies to help with fatigue, as well as offer solutions to any difficult tasks you may have in your activities of daily living, to make life easier. Pacing is looking at what you do and making adjustments to how you do an activity. Rather than pushing yourself, spread an activity out (pace yourself) rather than doing the activity all in one go, causing fatigue and pain. Make sure you get the appropriate amount of sleep.

Exercise and LEOp: Paul quoted studies from “*The Polio Paradox*” by Richard L Bruno regarding exercise and muscle strength. Any muscle activity is exercise, hydrotherapy, walking, or even household chores. We need to be careful with the amount of effort we put on our remaining muscles. Muscles decrease in strength by 1-2% per year after 25-50 years post-infection i.e. after the period of stability.



The first stage of the polio infection is when denervation occurs; this is followed by reinnervation of motor units during the recovery period. With age there is a reduced capacity to maintain reinnervation of large motor units. It is important that we need to *conserve to preserve*.

If we keep pushing we could lose even more muscle strength. A generalised exercise example does not exist for polio survivors i.e. 30 minutes daily for the generally healthy population. For polio survivors we must have **individualised** exercises which relate to our level of fitness and strength.

It has been found that exercise intensity at levels that normally result in fitness adaptation did not improve muscle strength or fitness for polio survivors. Individualised exercise must be performed without monitoring the heart rate, exercise with moderate intensity. “*B-Fit! Guidelines*” are being developed by a research group at AMC (Netherlands).

Take Home Message: An appropriate exercise prescription can maintain or improve strength. Work at a comfortable intensity i.e. 2-4/10 (fatigue levels are your best guide) with low repetitions (8), and short bursts of activity with frequent rest stops is recommended. Activity (any) should complement your day.

Manual muscle testing to measure muscle strength is an essential tool when developing a suitable exercise program as to whether exercise can successfully strengthen a muscle or whether a ‘drop out’ of strength will occur. Muscle strength is rated out of 5, any muscles



rated 3 or less must be treated cautiously and not given strengthening exercises, this in fact can cause more damage and decrease strength further. The aim here would be just to maintain muscle strength at the current level. The muscle strength chart can be used as a benchmark of strength for future assessments. It must be noted that, when performing the manual muscle strength assessment, it is necessary to do the movements 3 times to get a true reading, a single movement can be done easily whereas 3 times will replicate the muscle fatigue that occurs in polio muscles.

Bulbar features of LEOp:

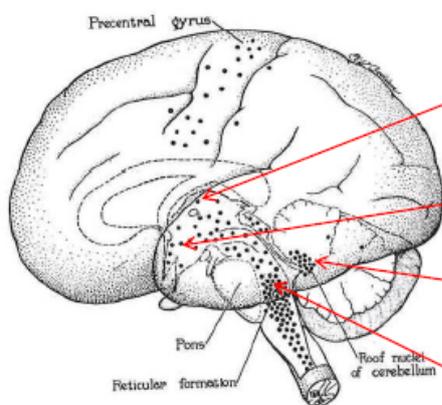


FIG. 1. Bodian's schematic view of the human brain which includes the upper portion of the spinal cord. The solid dots show the general distribution of lesions of poliomyelitis (from Bodian, n. 17). Reproduced by permission of the National Foundation for Infantile Paralysis.

Thalamus and basal ganglia:
adjustments in muscles tone and body position

Hypothalamus: temperature, thirst, heartbeat, blood pressure

Cerebellum: balance

Brainstem and reticular formation:
Breathing, sleep/awake, heartbeat, blood pressure, muscles of neck and face

Respiratory Assessment and Referral: It is important to note that respiratory issues should be considered as neuromuscular insufficiency (weak muscles) not lung disease. Is it bulbar innervated issues or is it breathing muscle issues e.g. abdominals? Breathing capacity tests should be done in a seated position but also lying down to get a true reading of breathing muscle strength. Again testing should be done 3 times to gauge fatigue and strength.

Sleep Studies: Symptoms of sleep apnoea – morning headaches, fatigue, constant tired feeling, decreased appetite, depression, impaired concentration. Current machines and masks have greatly improved and are well worth revisiting, it can make a huge difference to our general health and wellbeing.

Speech Pathology and Therapy: More polio people are experiencing difficulties with speech production, vocal fatigue, swallowing and constricting/full sensation in the throat. A speech therapist can recommend techniques for swallowing and advise on types of food to make swallowing easier to avoid choking.

Orthopaedic Management: This is a growing area with wear and tear occurring on our joints over a long period of time. Functional outcomes for knee replacements are similar to non-polio survivors – the strength of quads is an important factor. The revision rates are higher for polio survivors. Functional outcomes and long-term follow-up for hip replacements in both unaffected and affected hips is similar to the osteoarthritic population. Carpal tunnel release is common (22% of polio survivors). **IMPORTANT: Anaesthetic considerations are vital for all surgical interventions.**

Where To From Here?

Health Professionals Register (to find experienced professionals in your area)
<www.poliohealth.org.au/post-polio-health-professionals/>

Polio Health website (for information on topics relating to post-polio)
<www.poliohealth.org.au/>

Development of networks



Reprinted from Amigo Mobility International "*Friendly Wheels*" – Polio History www.myamigo.com

Early version of iron lung on display at Australian museum



Both Iron Lung

A museum in Glen Innes, Australia, has an early version of an iron lung on display. In the late 1930s, Australian engineers Edward and James Both designed a "breathing machine" for use in the Glen Innes Hospital. An earlier "American Drinker iron lung" had been very heavy and enormously expensive, so the Both brothers developed one that was made mainly of plywood. Their iron lung was transportable. It was in service at the hospital until 1956. It is now on display at the Land of the Beardies History House Museum and Research Centre.



The surgeon who runs India's last polio ward

Working on an 18-hour shift daily, Dr Mathew Varghese has devoted his entire career to restoring mobility and dignity to those left crippled by the disease.



Dr Mathew Varghese (right) talks to a patient in the Artificial Limb Centre at St Stephen's Hospital in Delhi

Polio victims are a common sight on the streets of Indian cities. There was a time, less than a decade ago, when eradicating polio from India — home to nearly half of the world's polio cases — seemed impossible. However, after years of relentless work by dedicated community health workers and vaccinators who went from door to door, village to village, giving every child those precious two drops of the vaccine, the tide turned and the country saw its last case of polio in 2011.

Still continuing the good fight, Dr Mathew Varghese is a true legend of the war against polio. An orthopaedic surgeon, he runs India's only polio hospital ward that offers free corrective surgery for people with deformities associated with the disease.

Pillar of community: In the 1990s, when the viral epidemic crippled more than 50,000 children each year in India, Dr Varghese rolled up his sleeves and waded into uncharted waters at St Stephen's Hospital in Delhi, and has been there since. *"I stayed on because it is easy for patients to track me. They keep coming back for braces, and other minor issues,"* he says. *"In fact, a few of the patients who got married and have college-going children still come to me for health advice like a family physician."*

"I wish there's no need for my ward. But I know there are so many out there, with paralysis, who will keep coming to me as long as I am alive."

Getting all the way to zero cases, to track down more than 170 million children behind every door of every dwelling in this vast nation has been a long, hard and arduous journey. Widespread poverty, dense population, poor sanitation, high levels of migration and a weak public health system made the task that much more difficult.

Reminiscing on his early years in hospital, the surgeon who has transformed thousands of lives, says, *"in the beginning, the ward was busy with rapid turnover of patients and the combination of paralysis varied from patient to patient"*.

"I was stimulated to study more, think more and understand the nuances of managing paralytic patients," adds Dr Varghese. *"But I never understood the social dimension of the disease. I began to understand that aspect — of what it means to be paralysed and poor — only when I started going to an urban slum to do voluntary work."*

Link between poverty and polio: To Dr Varghese, poverty and polio are inextricably linked. Those living in extreme poverty are far more likely to contract polio, and being paralysed by polio can prevent a child from rising out of poverty.

Seen as a pioneer by the polio community, Dr Varghese works on an 18-hour schedule daily. At work, he doesn't wear a watch, studiously avoids almost all phone calls, and never accepts an incoming call from someone unknown. *"I don't like the concept of working to a clock time, and avoid distraction,"* he says. *"I work to complete a task and see or operate all the cases I need to."*

Many patients, including some of the poorest in the country, who are paralysed in their lower limbs hear about the ward and travel to Delhi in the hope of correcting bent legs and feet. No one is turned away.

"We never postpone cases for want of time. We never say 'no' to a patient," Dr Varghese says. *"I'm not sure how many patients I have operated on but easily several thousands,"* he adds.

The polio ward at St Stephen's Hospital was started by surgeon Dr Balu Sankaran in 1987, who "convinced" then hospital director Dr Lucy Oommen to start a free ward for poor patients. *"In the 50s, Dr Sankaran was trained in the US with the best surgeons in the world when polio was common there. I was lucky to work with him, and picked up several surgical tips and tricks from him,"* Dr Varghese says.

Lower numbers: Over the years, the number of surgeries has dwindled. *"Earlier, the numbers were higher — at about 600 patients a year. But now a lesser number of patients occupy the beds for a longer time."*

These days, he mostly treats people in their early 20s, who contracted polio in their infancy. *"Treating deformities of older patients is difficult and takes a longer time. The surgery is not technically demanding but the decision-making can be tricky."*

Most are equipped with a pair of calipers and have to undergo at least three operations to straighten each hip and knee to be able to walk.

"Restoring the dignity of human existence, of seeing a non-walking patient stand, and walk, is immensely satisfying." That work and the joy it brings, he says, *"no amount of money can ever buy."*

To Dr Varghese, who has devoted his entire career to restoring mobility and dignity to those left crippled by one of the world's oldest diseases, reconstructive surgery is "life changing". *"It removes the social stigma of being disabled. In fact, many young women have found their life partners after surgery."*

Simply put, he assists with therapy, surgery and more. Since it takes patients a couple of months of multiple surgeries and rehabilitation at the hospital to be able to walk, Dr Varghese says he interacts "very closely" with patients. *"I listen to their non-medical problems such as education, jobs and marriage!"*

Lack of funds: *"Often times, I request some Rotary International members and some of my wealthy patients to financially help patients who are poor and not well-educated in setting up small shops. Some ask for help buying a house but I haven't been able to find any sponsor for that."*

In fact, lack of funds is a "huge barrier" for polio treatment in government-run hospitals, but one of his most steadfast collaborators on the frontline of India's polio eradication efforts is Rotary International. *"Since 2001, Rotary has been very supportive, funding 50 per cent of the expenses for reconstructive surgeries at St Stephen's."*

While Rotary Clubs organise health camps where the needs of polio patients are assessed, and non-profits such as the Jaipur Foot provide free prosthetics, no other hospital in India has a ward devoted to polio patients, says Dr Varghese. *"There's only a handful of senior*

surgeons who have the skills and the wisdom to assess and do corrective surgeries. Corporate hospitals are not interested as polio is a poor man's problem."

For Dr Varghese, there's little time to rest. Although there are no accurate figures as to the total number of polio-affected people in India, health experts put the number at over four million. Most of the patients are from the northern Indian states of Uttar Pradesh and Bihar, which recorded the country's worst affected polio cases.

"There are so many out there who need help. I am only doing a small bit," he says.

He wants to heal more, and frequently travels around the country, training young surgeons and medical students on how to address conditions such as club foot and polio. *"It's just another way to help more patients,"* he says. *"I train doctors at government-run medical colleges because that is where the poor go."*

"But when students come up to me and thank me for my classes, I feel all that I am doing is worth the effort," he adds. Recently, Microsoft founder Bill Gates on his Facebook page described Dr Varghese as his "inspiration" and his "real-life hero" for *"fighting and [having] dedicated his life for polio eradication in India"*.

"I feel more humbled than elated. While it feels good to be recognised, I am uncomfortable with the publicity," says Dr Varghese. *"However, my work continues as before ..."*

Working day: In the last three decades, Dr Varghese's work routine, a testament to his persistence, has remained the same. *"My working day starts at 5:45. I have tea with my mother and watch BBC news. It's my way of keeping in touch with the world. When I leave home at around 7:15am, most people are sending their children to school or having their morning walks. When I get back it is usually close to midnight."*

Despite his hectic schedule, Dr Varghese says he manages to find time to do things unrelated to work. *"I love photography and making portraits. My friends often joke about it saying, 'Mathew is never without a camera, for one never knows when God will appear'."* He chuckles. *"I read obsessively as well."*

It's been seven years since polio was detected anywhere in India, and worldwide victory over polio is in sight too. It's a significant milestone that the surgeon quietly celebrates. When asked what his dream now is, his answer is simple. *"I wish there's no need for my ward. But I know there are so many out there, with paralysis, who will keep coming to me as long as I am alive."*



Consumer Health Forum of Australia, Thursday, 2 October 2018 – Media Release. Consumers Health Forum of Australia receives funding from the Australian Government as the peak national healthcare consumer organisation under the Health Peak and Advisory Bodies Programme

Who do we trust on health apps?

Health apps available on smart phones should be subject to an authoritative regulatory system that rates them for efficacy, according to an overwhelming majority of respondents to a survey conducted by the Consumers Health Forum through *Australia's Health Panel*.

The survey found that almost 90 percent of respondents said that there is a role for the government in regulating health and wellness apps. Almost 60 percent of respondents said that the government should review and rate health apps, while 31 percent said that the government should fund a separate organisation to perform the role.

The survey is the first to be undertaken through *Australia's Health Panel* which has been established by the Consumers Health Forum to harness community sentiment on contemporary consumer health issues.

It also found that consumers were most likely to trust recommendations by general practitioners and pharmacists on health and wellbeing apps. The results indicate that consumers trust their peers to give good recommendations on apps, but not completely. 'Big tech' avenues such as search engines like Google and Apple are much less likely to be trusted sources of health apps advice.

The CEO of the Consumers Health Forum, Leanne Wells, said the survey results highlighted the growing public demand for credible and effective oversight of health apps given their accelerating reach into every aspect of health care.

"As consumers increasingly turn to health apps to aid and monitor their health and treatment, there's clearly a need for people to know whether they can trust the apps, and whether they offer the best health option available and are worth the investment in time and money.

"To ensure the health system makes the most of the rapid developments in digital technology now gripping health care, the Federal Government should be moving now to assess how best to support and regulate the safety and quality of health apps.

"Given the rapid entry of health and wellbeing apps into health care, it is time now for the Government, consumers, health providers and app companies to come together to determine the fundamental principles that should govern this activity.

"The CSIRO's recent Future of Health report states that there were approximately 318,000 mobile health apps as at last year. While that presents increasing opportunities for consumers to manage their own health, many remain unregulated despite making health claims, and they have no accountability for health outcomes. As the CSIRO report suggests, highly engaged consumers are demanding faster, cheaper, more personalised and preventative health solutions. There is enormous benefit to be gained by more widespread use of health and wellbeing apps to monitor and self-manage health conditions, but also to 'nudge' good lifestyle behaviours and choices," said Ms Wells. "However, the digital divide in the community is real: enhancing digital health literacy for people to benefit from this technology is becoming more important. As the CSIRO report says, we need to develop robust consumer rating tools, symptom checker apps, and publicly available information sources for such health services.

"The value of the findings of Australia's Health Panel is that while they reflect the responses of a modest sample of 260 respondents, they nonetheless give an insight into how people are viewing this relatively new and still largely unregulated development in health care.

"Importantly, the sentiments expressed by Panel participants flag areas where we need to do more research and policy development. When health and wellness apps are such that they start interacting with the more formal health system, further questions emerge such as whether they should form part of a treatment plan or even be prescribed and whether they should attract government funding in some form.

"The survey highlights the important role Australia's Health Panel can play in bringing to policy-makers' attention the thinking of the community on vital issues," Ms Wells said.

Australia's Health Panel is a recent CHF initiative designed to complement the advice and insights we draw from our extensive membership. Interested members of the community can register to be on the Panel by going to <chf.engageable.net>.

A copy of the report: *Results of Australia's Health Panel Survey on Recommendations and Regulation of Smartphone Apps for Health and Wellness* can be found at <chf.org.au>.

Vale - Dr Margaret Cooper OAM

By Nola Buck

It is with sadness that we report the passing of life-long advocate for people with disabilities, Dr Margaret Cooper OAM, on Saturday, 27th October 2018. Although Margaret was a member of Polio NSW, she lived in Victoria and had been the Vice-President of Post-Polio Victoria for several years.

Margaret contracted polio in 1947 at the age of 4. She lived a full, independent life, attended university, became a social worker, and worked full-time for 27 years.

In 2017 Margaret was nominated by Frances Henke for the Australian Human Rights Commissioner's *Best Achievement in Human Rights* award, and I believe the following quotation from that submission sums up Margaret's contribution to the disability rights movement both nationally and internationally.

"For over fifty years, Margaret Maxine Cooper has played a leading role in advocating on behalf of people with disability. Recently, she set up Post-Polio in Victoria, providing research to and communication with the government to get the needs of polo survivors recognised."

"Margaret began moving in activist circles in the 1970s participating in planning the International Year of the Disabled Person (IYDP), an event that made a huge difference to the lives of people with disabilities. Throughout the 1970s and 1980s Margaret was identified as someone who could lead and be a strong role model. Margaret took on the role of Vice-President (Policy) with Disabled People's International (DPI Australia)."

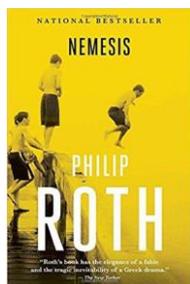
"Margaret attended the DPI Asia Pacific Regional Assembly in 1984 and DPI World Assembly in 1985. She was one of a large group of women who refused to participate in the conference unless their issues were discussed at length. Her leadership placed women's issues firmly on DPI Australia's agenda."

People who have had polio and all people with a disability have lost a strong advocate in Margaret and we will miss her.



Below are two articles reprinted from Pa. Polio Survivors Network June 2018 <www.papolionetwork.org>

NEMESIS: by Philip Roth - A book review by Kathy Galletly



This story takes place during the polio epidemic of the summer of 1944. It is centered on the character Bucky Cantor, a playgrounds director in a park in Newark, NJ. Bucky witnesses the devastation as this terrifying disease cripples and takes the lives of the young boys on his playground.

The author describes the absolute helplessness and grief of parents who watch their young healthy children being struck down, one by one, by this awful illness. Terror takes over the city as the disease escalates. Where is this polio coming from? Who or what is causing this awful petulance? Is it the summer sun, the drinking water, the hot dogs at the local eatery, or the dirty Italian boys who spit on the ground? The terror, the anger, the frustration and the prejudice escalates. Would escaping to the Pocono Mountains in Pennsylvania be the cure?

Philip Roth is a master at capturing the horror of these terrible epidemics; you feel the escalating fear and sadness with every page. For many of us who were old enough to realize the survivors that we are. On a personal note – if you are aware of anyone who has a problem with fascinating their children, suggest they read this book.

AFib Medications and Fatigue by Dr William DeMayo Q&A Clinic



Question: I had polio at 3 months old – my right leg was affected. Now I'm 65 and have PPS. I have AFib (Atrial Fibrillation) and was put on Eliquis and Metoprolol. Can either one of these medications cause pain and make you tired all the time? I've always had fatigue issues. It seemed to get worse after taking these medications. It's very difficult, as you know, to find someone who knows about PPS.

Answer: In short, Yes!

Your medications and medical condition can certainly be causing your fatigue. In fact if functional loss is primarily from fatigue, and there is not clear focal weakness and atrophy that has worsened in recent years, the issues could be entirely medical and not PPS at all. Since I don't have a full history, I am simply saying that to emphasize the functional impact of the medical issues at hand rather than to say PPS is not the cause (that is a specific diagnosis that needs to be between you and your treating physician).

Atrial fibrillation is an uncontrolled rapid and irregular beat of the atrium (top chamber) of the heart. Contractions can be so quick that the actual pumping of blood is affected leading to the risk of developing a clot in the atrium that could later be pumped out into the circulation and cause a stroke. This risk is addressed by the Eliquis (an oral blood thinner). Eliquis itself has a few side effects but the big concern is uncontrolled bleeding – it is an important drug to be aware of but not pertinent to your current complaints. Metoprolol on the other hand has common side effects of fatigue, sleep disturbance, and even depression. It is meant to slow the heart and counteract the potential rapid heart rate of the AFib. If mild, these are sometimes symptoms that need to be tolerated since the rapid heart rate can be a bigger issue. This risk/benefit ratio is very patient specific and well beyond the scope of this reply. Nevertheless, it is certainly possible that the fatigue is entirely due to Metoprolol and this should be discussed with a cardiologist. Sometimes other medications are available OR a simple dose adjustment is needed.

Lastly, Atrial Fibrillation can occur in isolation but also can occur in the setting of heart valve issues or coronary heart disease. You have not mentioned those diagnoses but, if present, they can also clearly contribute to fatigue and loss of function due to ineffective cardiac output (the amount of blood pumped out with each beat).

In summary: Yes, medications can certainly be playing a role and risks/benefits of medications in this setting is very individualized and best addressed between the patient and their PCP (primary care physician) or cardiologist.

On a separate but related note, it struck me that you were not aware that Metoprolol causes this side effect. There are easily accessible resources online and it is certainly something your pharmacist could tell you about. It is surprising that your prescribing physician did not mention it or you did not recall that he did. (Additionally, I am making a presumption that you did not bring up the fatigue as a clear issue and ask about the medication.) This might be a situation where you have a doc who is just not taking the time OR that you are not clearly organizing your concerns and questions in advance, often it's a combination of both. Either way, I am certain that your PCP or cardiologist will engage this once you bring it to their attention. If you are not satisfied with the response after a couple of attempts, then it might be a good idea to seek care elsewhere.

I hope this helps. Warm Regards from my temporary home in the UAE.

Summary of Anesthesia Issues for the Post-Polio Patient

Polio results in widespread neural changes, not just destruction of the spinal cord anterior horn (motor nerve) cells, and these changes get worse as patients age. These anatomic changes affect many aspects of anesthesia care. No study of polio patients having anesthesia has been done. These recommendations are based on extensive review of the current literature and clinical experience with these patients. They may need to be adjusted for a particular patient.

1. Post-polio patients are nearly always very sensitive to sedative meds, and emergence can be prolonged. This is probably due to central neuronal changes, especially in the Reticular Activating System, from the original disease.
2. Non-depolarizing muscle relaxants cause a greater degree of block for a longer period of time in post-polio patients. The current recommendation is to start with half the usual dose of whatever you're using, adding more as needed. This is because the poliovirus actually lived at the neuromuscular junctions during the original disease, and there are extensive anatomic changes there, even in seemingly normal muscles, which make for greater sensitivity to relaxants. Also, many patients have a significant decrease in total muscle mass. Neuromuscular monitoring intra-op helps prevent overdose of muscle relaxants. Overdose has been a frequent problem.
3. Succinylcholine often causes severe, generalized muscle pain post-op. It's useful if this can be avoided, if possible.
4. Postop pain is often a significant issue. The anatomic changes from the original disease can affect pain pathways due to "spill-over" of the inflammatory response. Spinal cord "wind-up" of pain signals seems to occur. Proactive, multi-modal post-op pain control (local anesthesia at the incision plus PCA, etc) helps.
5. The autonomic nervous system is often dysfunctional, again due to anatomic changes from the original disease (the inflammation and scarring in the anterior horn "spills over" to the intermediolateral column, where sympathetic nerves travel). This can cause gastro-esophageal reflux, tachyarrhythmias and, sometimes, difficulty maintaining BP when anesthetics are given.
6. Patients who use ventilators often have worsening of ventilatory function post-op, and some patients who did not need ventilation have had to go onto a ventilator (including long-term use) post-op. It's useful to get at least a VC pre-op, and full pulmonary function studies may be helpful. One group that should all have pre-op PFTs is those who were in iron lungs. The marker for real difficulty is thought to be a VC < 1.0 liter. Such a patient needs good pulmonary preparation pre-op and a plan for post-op ventilatory support. Another ventilation risk is obstructive sleep apnea in the post-op period. Many post-polios are turning out to have significant sleep apnea due to new weakness in their upper airway muscles as they age.
7. Laryngeal and swallowing problems due to muscle weakness are being recognized more often. Many patients have at least one paralyzed cord, and several cases of bilateral cord paralysis have occurred post-op, after intubation or upper extremity blocks. ENT evaluation of the upper airway in suspicious patients would be useful.
8. Positioning can be difficult due to body asymmetry. Affected limbs are osteopenic and can be easily fractured during positioning for surgery. There seems to be greater risk for peripheral nerve damage (includes brachial plexus) during long cases, probably because nerves are not normal and also because peripheral nerves may be unprotected by the usual muscle mass or tendons.

For more information:

Review "*Post-polio Syndrome and Anesthesia*" by David A Lambert, MD; Elenis Giannouli, MD; and Brian J Schmidt, MD; The University of Manitoba, Winnipeg, Canada, in the September 2005 issue of *Anesthesiology* (Vol. 103, No. 3, pp 638-644). This article reviews polio, post-polio syndrome and anesthetic considerations for this patient population.