



Still Talking

Dedicated to the welfare of Laryngectomees and those with similar vocal disorders.

ALL CORRESPONDENCE : The Secretary, The Laryngectomee Association of NSW

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Issue No. 304

The Laryngectomee Association of NSW©

August 2019

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ACCOMMODATION ASSISTANCE WHEN NEEDED

OUT-PATIENT TREATMENT AWAY FROM HOME:

Cancer Council NSW, 153 Dowling St, WOOLLOOMOOLOO, 2011 (PO Box 572, Kings Cross, 1340), Phone: 13 11 20. (Information & Support) Or contact Social Worker at hospital you will be attending.

www.cancercouncil.com.au

ASSOCIATION WEBPAGE:

www.stilltalking.org.

INTERNATIONAL ASSOCIATION OF

LARYNGECTOMEES: www.theial.com/ial

WEB WHISPERS: www.webwhispers.org

MEETINGS

February – November, 3rd Wednesday Of the month. Sydney Mechanics School of Art, 280 Pitt St, SYDNEY at 10.45 am. (EXCLUDING JULY, DETAILS TO BE ADVISED) Regional meetings Pg. 2 Meetings will be followed by light refreshments. Laryngectomees, friends, families, professionals all welcome.

Regional Meetings

NSW ASSOCIATION:

3rd Wednesday of month (Feb - Nov) Next meeting 21st August

NEWCASTLE: 3rd Tuesday. Monthly Mayfield Bowling Club Ingall Street Mayfield Start 12.30 -2.00 Contact John Lovett (02) 4954 8308

[johndawnlovett@optusnet.com.au](mailto: johndawnlovett@optusnet.com.au)

NORTHERN RIVERS: 4 times annually in Lismore. Contact Speech Pathologist Allison Grady (02) 6629 4523 or (02) 6620 21 57

ALBURY: Meets alternate months from February. Contact Tanya Dawe- Speech Pathology Manager Phone 02 60584565, Mobile 0409543653

Email tanya.dawe@awh.org.au

MID NORTH COAST: The Colonial rooms Behind Saint Thomas's Anglican Church Hay St Port Macquarie Last Wed of March. June. September. & 1st Wednesday

December. Contact (02) 65801828

CENTRAL COAST:3rd Thursday of the month, Cancer Council Community Hub, The Hive, Erina Fair 10am –12 noon. Head and neck cancer nurse (02) 4320 9823

Cancer Council 4336 4500

Facillitator Gary Marr 0412 262 145

gsm18@live.com.au

COFFS / CLARENCE: Shearwater Lodge, Coffs Health Campus. 2pm every 3rd Thursday, Bi-monthly

Contact Melissa Parish 02 6656 7606

melissa.parish@ncahs.health.nsw.gov.au

Minutes

Laryngectomee Association of NSW Inc.

Minutes of the Meeting of 17th July 2019.

The July meeting of the LANSW was held at St. George Hospital on July 17th in Seminar Rooms 1&2 of the Research & Education Building. The event was hosted by Dr. Julia Maclean, Speech Pathologist at St. George Hospital.

The President opened the meeting at 11.00am, welcoming all those present and thanking Julia for the hospitality and venue.

Attendance Laryngectomees:

Peter Dixon, Nigel Balm, Vicki Pedras, Peter Kelly, Gail Barnett, Peter Tierney, Frank Campbell, Isaac De Klerk, Keith Anderson & Les Byrnes.

Attendance Non Laryngectomees:

Cathy Edwards, Glenn Williams, Christine Dixon, Judy Kelly & Jim Barnett.

Apologies:

Glenda Tierney & Yvonne Byrnes.

Guest Speaker:- Dr. Julia Maclean.

Les Byrnes addressed the meeting with the sad news of the demise of our Secretary/ Treasurer, Raymond Chappelow. Raymond passed away at his residence on July 2nd after a long period of poor health. His funeral was held on July 12th at the Leura Memorial Gardens

Crematorium, which was attended by myself and wife Yvonne, George Southgate & John Pyle representing the LANSW. It was a small gathering of his friends from the Peugeot Car Club and neighbours, with eulogies from Les, long time friend Peter McCabe, cousins Jill Peach & Geoff Peach.

The financial correspondence, renewals etc reports were not available, and until they could be retrieved from Raymond's residence couldn't be tabled.

Welfare Report:- 10 patient packs to Wally Bak. 5 patient packs to John Hunter Hospital. Balance b/f of float \$484.10 less postage and copy paper \$31.35. Current balance \$ 452.75.

At this point of the meeting Nigel Balm, a Lary since December 2016, volunteered to take on the position of Secretary/Treasurer. As there was no other nominee, Nigel was elected unopposed with unanimous thanks. Gail Barnett's husband Jim then volunteered to drive President Les to Lithgow to retrieve 3 boxes of documents etc. Raymond's next door neighbour, Ed Brennan has already packed the boxes and previously sent a USB containing valuable information of the LANSW , which will be forwarded to Nigel.

Dr. Julia Maclean then addressed the meeting with a presentation regarding the research taking place and procedures performed at St. George Hospital associated with swallowing problems and the pressures imposed on the oesophagus experienced by Laryngectomees. A summary of the material presented will be included in a future ST newsletter.

The meeting was then closed for refreshments and nibbles, jointly provided by the hospital and Peter Tierney. Our next meeting will be held at the Sydney Mechanics School of Arts, commencing at 10.45 August 21st.



RAYMOND LESLIE CHAPPELOW.

1st April 1949- 2nd July 2019

Raymond joined the Association following his operation in October/ November 2006. At that time he was the designated carer for his mother, with whom he lived at Seven Hills. He attended the Lary meetings regularly, rarely missing a meeting unless it involved him attending “ job training programs”.

Following the death of his mother, Raymond moved to South Bowenfels (a suburb of Lithgow city) , but still travelled to the city by train to attend meetings. In early 2015, Raymond stepped up and volunteered to take on the Secretary/Treasurer positions, which was greatly appreciated by Brian & Carol Gardner. The transition from the Gardner residence to Raymond’s residence back then of all the Lary business stuff required Raymond making two trips by car from South Bowenfels to Belrose.

Up until his demise, Raymond carried out the Association business extremely well despite the numerous times, over the past year or so, of poor health involving several times as a hospital inpatient. But Raymond never complained and still churned out the emails and papers for each our meetings, even though he was unable to attend. There was a time when he said to me that “perhaps we should get someone else “ because he felt guilty for not attending meetings. I assured him that as long as he can work his computer he stays on the job. He managed to do that until the very end.

May he Rest In Peace. All of us will miss you. Carol offered this anonymous quote which is so true of Raymond.

A MAN WHO HAS DONE HIS BEST, HAS DONE ENOUGH.

Before us great Death stands Our fate held close within his quiet hands. When with proud joy we lift Life’s red wine To drink deep of the mystic shining cup And ecstasy through all our being leaps— Death bows his head and weeps.

“**Rainer Maria Rilke**



July, outside Caerphilly Castle in Wales.

New Secretary Treasurer Officer

Following the sudden passing of our dear Secretary Treasurer, Raymond Chappelow, it was important that the association quickly found someone to fill Raymond's highly competent shoes. Fortunately we did not have to wait long, as Nigel Balm, who resides on the Central Coast in Woy Woy, volunteered his services and was duly nominated, and elected, to the role of Secretary Treasurer at the July 17 meeting held at St George's Hospital.

Nigel became a Laryngectomee in February 2016, under the skilled hands of Dr. Richard Gallagher at St Vincent's Hospital in Sydney. After around eight weeks recovery he returned to work, where he remained for the next two years, until deciding to take early retirement.

During his early working life he was a Medical Laboratory Scientific Officer at St James Hospital, Balham (part of the St George's Teaching Hospital in Tooting UK, featured in the TV programme 24 Hours in Emergency) and later The Great Ormond Street Hospital for Sick Children, where he specialised in paediatric Histopathology. But, as often happens in life, he took a major career turn and moved away from the medical world to the world of tourism, where he spent over 30 years working for various global and domestic tour operators in the UK and Australia.

Nowadays he keeps himself busy with home renovations, photography, travel and cycling. He enjoys all things digital and is a self-confessed technophile. "Hearing of the death of Raymond both shocked and saddened me. It was then that I realised that his passing would leave a gap. I was now settled into retirement and felt I had the time, and the motivation, to offer my services to the association. I hope that my marketing, budgeting and finance experience will be of benefit to the association and its members" said Nigel.

For all correspondence, membership applications and renewals, financial or secretarial questions, Nigel may be contacted by email at lansw@stilltalking.org or by post to PO Box 443, Woy Woy, NSW 2256.

Tonsil Cancer but No Tonsils!

This article was published by Lucy Elkins for the Daily Mail on 19 March 2019

Janice Atkinson initially thought the pea-sized swelling that developed on the left side of her neck last summer was no more than a swollen gland... a sign of an impending cold or sore throat. But, unusually for a swollen gland, it wasn't sore and, two weeks after it appeared, it was getting bigger. 'That's what made me think, "Hmmm, perhaps I should get this checked out,"' says Janice, an independent MEP for South East England. She saw a doctor at the European Parliament who urged her to have tests quickly. Back in the UK she saw a private ear, nose and throat specialist, who performed a needle biopsy of the lump, when a needle is used to withdraw some cells. A few days later, on a sunny Friday afternoon in June last year, he called a horrified Janice and told her the initial results pointed to tonsil cancer.

Always So Healthy! 'For the next two hours I was stunned. I had always been so healthy... and, yes, I did cry,' says Janice, 56, a mother of two sons, aged 23 and 27, who is married to Simon, 51, a banker. It might seem a surprising diagnosis given that, in 2012, following a bout of tonsil stones... where debris collects in the crevices in the tonsils and calcifies... she'd had her tonsils removed. But while having your tonsils out reduces the risk of cancer... by about 85%... tumours can develop in the remaining tonsil roots. The following week, after further tests, including a biopsy, there was more bad news: the cancer had spread. The swelling in her neck was where the cancer had spread to a lymph gland, and a dot-sized sore on her tongue, which Janice put down to a chipped tooth for months, was a cancerous lesion. There was another patch of cancer in her throat as well as the original tumour in the left tonsil root. 'Finding out I had cancer was one thing, but discovering it had spread was scary,' says Janice, from Chislehurst in Kent. 'All sorts of things run through your mind, but you have to shut them off. Initially, I only told my husband and my father-in-law... I didn't want to worry my sons.' A painless lump in the neck is a textbook symptom of this type of cancer. Others include a persistent sore throat, one tonsil becoming bigger than the other and difficulty swallowing. 'This kind of cancer starts to spread quite early on, but we don't know why,' says Christopher Nutting, a professor of oncology at the Royal Marsden Hospital in London. 'The lump in the neck occurs when the cancer has spread to a lymph gland in the area.'

Subtle Symptoms Tonsil cancer is easy to miss, as symptoms can be quite subtle. 'There is not good awareness of this cancer,' says Professor Nutting. 'The actor Michael Douglas is probably the most famous person to have it, and even he had to go to four or five doctors before he finally got a diagnosis. 'The problem is the symptoms are similar to many things. There are many instances where patients have been given several courses of antibiotics for a sore throat, when, in fact, they had cancer.'

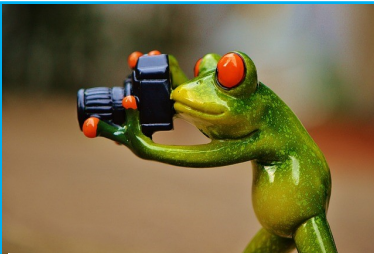
Alwyn d'Souza, an ear, nose and throat surgeon at University Hospital Lewisham, who treated Janice privately, says, 'I do see cases where I think, "How did this not get picked up until now? That's not necessarily due to a GP not spotting it,' he adds. 'It might be patients not getting their symptoms checked.' 'I saw a dreadful case recently where a man had a huge swelling in his neck... it was so big it was making him breathless... but he didn't seek medical advice before because he was scared.' In rare cases, left untreated, the cancer can spread to the liver or lungs, when it is harder to treat. Tonsil cancer typically occurs in those in their 40s and 50s, and cases have doubled over the past ten years, according to Cancer Research

UK figures. Every year, 1,600 new cases are identified. Some are linked to smoking and drinking, but tonsil cancer cases are rising sharply because of an increase in the prevalence of HPV, or human papillomavirus, a sexually transmitted virus that's so common, says Professor Nutting, 'virtually all of us will have been infected at some point. HPV is a highly infectious agent and typically causes a transient illness when people are infected in their teens or 20s,' he adds. 'This might be a sore throat but may be so mild that people are unaware that they have the virus. However, in one or two per cent of cases, the infection seems to be able to persist in the tissue of the tonsils and then, in some cases, 20 to 30 years later, it can cause tonsil cancer,' says Professor Nutting. Why is unclear. Many develop the infection as teenagers, so it may be related to some unhealthy element of their lifestyle at the time... perhaps a bad diet... which has a knock-on effect on the immune system. HPV is now thought to cause around half of all tonsil cancer cases. The virus is also linked to cervical cancer, which is why teenage girls have been offered a vaccination against HPV since 2008... and the vaccination of boys will start later this year. 'But there are still many people who were infected before the introduction of the vaccine and who may go on to develop tonsil cancer, so I would expect cases to continue to grow for the time being,' adds Professor Nutting. Janice had been infected with HPV as a young woman. This came to light after an abnormal smear test in her twenties led to followup checks. The fact that it had led to cancer so many years later was hard to bear. 'I didn't know it, but HPV was a ticking time bomb,' she says.

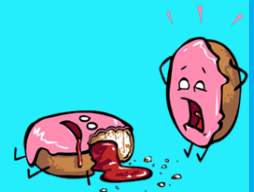
HPV virus

Only Good News The only good news was that, in around 90% of cases, the cancer is highly treatable... with radiotherapy, and usually chemotherapy, too... but as Professor Nutting concedes 'the treatment is pretty hideous'. After an initial single dose of chemotherapy, Janice then had six weeks of targeted radiotherapy... with treatment five days a week. This began last August and involved having her head locked in place with a cage to ensure she didn't move during each five-minute radiotherapy session. 'Because it's targeted, your cage is made to fit you, so you must not lose weight from the neck area during treatment. If you lose more than 1cm, the treatment would be stopped... which was the most frightening thing,' she says. But after two weeks of treatment her mouth was so sore from the radiotherapy that eating became very difficult. 'Trying to eat solid food was like eating glass,' she says. 'After four weeks, I was on supplements such as meal drinks, or yoghurt and porridge. I stuck to a milkbased dairy diet. Even with pain medication, any seasoning on my food caused agony. After three weeks, the radiotherapy had damaged my taste buds and my saliva glands, so it felt like I was eating cotton wool. However, my taste buds are now about 80% of what they were and my saliva is starting to come back... but not as before... it's frothy. If I eat chocolate, it just congeals in my mouth.' Yet Janice knows in many ways, she is lucky. A scan in January found her to be cancer-free and she has recently returned to work. But the experience has changed her. 'I'm more accepting and calmer. I don't have too much to prove. I'm still driven, but I'm more laid back, and I don't worry about work or the future like I used to.' But she is passionate that teens should have their HPV vaccine. 'Now we know the virus stays in your body, it is so important that girls and boys get this vaccine... it is also important that people become more aware of the symptoms of this cancer,' she says. 'If you have a lump in your neck or a sore throat that won't go away, just ask yourself, "Could it be something else?" If I hadn't asked that question, I could be in a very different situation now.

' (from Plymouth RHNC Voice Newsletter)



Funnies



"I went to my doctor and asked for something for persistent wind. He gave me a kite."

"Why did the chicken commit suicide? To get to the other side."

"What do you call an alsatian in a grey jumper? A plain-clothes police dog."

"A bit of advice: never read a pop-up book about giraffes."

"I said, 'It's serious doctor, I've broken my arm in 20 places.' He said: 'Well stop going to those places.'"

"My wedding was like a fairy tale. It wasn't magical; it's just that I've got an ugly sister."

"I got a package in the post last week, and on it it said, 'Please don't bend.' So how was I supposed to pick it up?"

"A cement mixer has -collided with a prison van. Motorists are asked to look out for 16 hardened criminals."

"I needed a password eight characters long so I picked Snow White and the Seven Dwarfs."

Unexpected sex - is the best thing to wake up, unless you're in prison..

To make it stand u wet it. To make it wet, u suck it. To make it stiff, u lick it.

To get it in, u push it!

Damn! Treading a needle at any age is no joke!

I feel sorry for the hypnotist I saw last night. He hypnotized 7 guys, then dropped the mic on his foot and yelled 'Fxxk ME' What happened next will haunt me for the rest of my life.

And God said to John, come forth and you shall be granted eternal life.

But John came fifth and won a toaster

What's orange and sounds like a parrot? A carrot.

Me: "Hello."

Scamer "Hello. This is Bob Bobson from Microsoft Support. We are seeing a lot of virus activity from your device."

Me: "Oh no. My device? Are you sure?"

Scamer "Oh yes, we have many reports."

Me: "Oh jeez. How can I fix it?"

Scamer"It's OK sir. We can help you right

now. Are you in front of your device sir?"

Me: "Yes. I was just about to use it. I'm glad you called."

Scamer "Yes sir, we are going to help you. Can you please push the Start button?"

Me: "I think it's already on."

Scamer "Okay, sir. Now you want to click on Control Panel."

Me: "I don't see that."

Scamer "Do you see a bunch of information above the Start button?"

Me: "Yes."

Scamer "That is your Control Panel."

Me: "Wow, I didn't realize it had a name."

Scamer "Yes sir, now press on Interne Options."

Me: "Yeah, I definitely don't see any Internet options. I don't think I purchased that feature. This is just a cheap one."

Scamer "They all have the Internet sir. Press the Start button again."

Me: "OK, it's the same as before."

Scamer "That's OK sir. We are going to restart your device. Can you please turn it off?"

Me: "Ummm...I don't know how. I've never turned it off. Since I bought it it just kind of stays on all the time."

Scamer NOT-Microsoft support: "There must be an off button on your device. How do you stop it when it's running?"

Me: "In those cases I usually press the big button beneath Stop/Cancel."

Scamer "OK sir. Please press that button."
Me: "Ok."

Scamer "Is your device off?"

Me: "No. The door popped open."

Scamer "Door? Is there a disc inside the door?"

Me: "No, there's a burrito."

Scamer "Why is there a burrito in your computer?"

Me: "Computer? I thought you said this was microwave support."