



# Still Talking

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



Laryngectomee Association.N.S.W

All Correspondence to: The Secretary, Laryngectomee Association of N.S.W

No 195

March 09

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**SHOWER SHIELDS, STOMA COVER MATERIAL AND WELFARE MATTERS.**

Carol Gardner, P.O Box 380 Belrose 2085 NSW Fax & Phone 02 9451 7926

**ACCOMMODATION ASSISTANCE WHEN NEEDING OUT PATIENT TREATMENT AND AWAY FROM HOME:-**

Cancer Council of NSW 153 Dowling St WOOLLOOMOOLOO 2011 (PO BOX 572 KINGS CROSS 1340) Ph 02 9334-1900 Fax 02 9357-2676 Or contact social worker at the hospital you will be attending

**Association web page** [www.stilltalking.org](http://www.stilltalking.org)

**International Association of Laryngectomees..**

<http://www.larynxlink.com/>



## **NEXT MEETING**

**Wednesday 18th March 2009**

**Uniting Church Hall Carrington Avenue**

**Strathfield. 11am**

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## **MONTHLY MEETINGS**

**N.S.W Association** 3rd Wednesday of month Uniting Church Hall Carrington Avenue. Strathfield at

**NEW ENGLAND:** Meets at 2pm 1stWed. Feb. Apr. June. Aug. Oct. Dec. 2pm Conference Room. Rehab Unit Tamworth Base Hosp. 02 67678369

**NEWCASTLE:** 3<sup>rd</sup> Tues. Monthly Mayfield Bowling Club. Ingall St. Mayfield. Contact John Lovett 02 4954 8308

**NORTHERN RIVERS:** 4 times annually at rotating venues 67678377 Contact Speech Pathology Lismore Base Hospital

**ALBURY:** Contact Ph. 02 63232011 ext. 323

**CANBERRA:** 1<sup>st</sup> Thu. at 11am. Mar. June. Sep. Dec. Canberra Hospital

**SOUTHERN DISTRICTS:** Last Wed of month. 11am. Thomas Rachael Moore Education Centre. Liverpool Hospital. Contact Pres. Richard Patman 9607 6708 or John Peden 0422 543 036.

**MID NORTH COAST** Port Macquarie Community Health Centre. Feb. May. Aug. Nov Contact : David Mc.Clymont President 6559 8383

**CENTRAL COAST** Meet at Central Coast Leagues Club. Coordinator(s) Vicky Kelly (S.P.) and Ann Moloney (Gosford Hospital ) assisted by Bill Byfield 0402 045048

## Editor's Corner



Got a shock over the Xmas break and took a look at my passport— decided I was starting to look like both my passport and driving licence pictures so it must be time for another holiday. So we have booked another trip to Bali in April—we will be away for 3 weeks or longer if the mood takes

I recently trialed the HME system and voice (free) without much success. This was not the fault of the system but rather my anatomy. I had great difficulty maintaining a seal and the adhesive was a constant irritation, also as a result of my steroid medication I have tender skin, everyone say (ahhhh) and I constantly ripped away skin as I removed the plate.

However regardless of my results the cost was prohibitive at \$80—\$100 over a week add another \$240 per year if you use the hands free device.

We express concerns about the P.A.D.P at times but thus far all my dealings have been positive, however as we all know with this system funding is always a problem so it's disconcerting to see money wasted. I have recently had a prosthesis delivered and waiting for the courier on 4 separate days after arrangements had been made and keep being told they had been was annoying.

What was even more annoying was the fact that 2 should have been sent and there was only one the other to be sent later. The package from In-Health came in quite a large box with masses of bubble wrap in it . Cost of freight \$22! It could have been sent by Australia Post delivered the next day in a padded bag for about \$2.50. We now have to go through the same process for second one to be s delivered as InHealth only had one in stock! another \$22 wasted!

*Take care—go well!*

CB



*There are no strangers—only people you have not yet met !*

## Dead Funny



Charlie opened the paper one morning and was dumfounded to read in the obituary column that he had died. He quickly rang his best friend Willy "Have you read the paper" asked Charlie "They say said I've died" "Yes I saw it" Said Willy and after a long pause "Where are you ringing from?"

\*\*\*\*\*

We all have vivid memories of the dramatic landing of the plane on the Hudson River— sent the following to Comlumn 8 in the Sydney Morning Herald

You have previously included people with appropriate names for their jobs in your column," writes Kelyvn Steggles, of Mosman. "How about this one? Chesley Sullenberger is the pilot who recently landed a disabled passenger jet on the Hudson River in New York. According to a book of baby names I have, Chesley means 'a place to land on a river'. Spooky or what?"

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## Words of Wisdom



"An old Cherokee is teaching his grandson about life. "A fight is going on inside me," he said to the boy. "It is a terrible fight and it is between two wolves. One is evil - he is anger, envy, sorrow, regret, greed, arrogance, self-pity, guilt, resentment, inferiority, lies, false pride, superiority, and ego." He continued, "The other is good - he is joy, peace, love, hope, serenity, humility, kindness, benevolence, empathy, generosity, truth, compassion, and faith. The same fight is going on inside you - and inside every other person, too."

The grandson thought about it for a minute and then asked his grandfather, "Which wolf will win?"

The old Cherokee simply replied, "The one you feed."

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My name is Julie Deleemans. I have been a Web-Whispers member for the last year. In March of 2006, when I was eighteen, I was diagnosed with stage 4 larynx cancer and immediately had a laryngectomy, followed by chemotherapy and radiation. There is no

known cause for my type of cancer. I use a TEP to speak.

I will be competing for the title of Miss World Canada 2009 in Toronto in March! Out of thousands of girls across Canada who applied for a spot in this competition, only forty-five of us were chosen to compete for this prestigious title! The winner will go on to represent Canada in the International Miss World competition, which is to be held in Johannesburg, South Africa, in late 2009.

The Miss World Canada Beauty Pageant began in 1951 and has since developed into an internationally known label and success. The motto of the Miss World Canada organization is "Beauty with a Purpose" and this is demonstrated in their involvement with many children's charities around the world, in particular the SOS Children's Villages Charity. Please check out more about the Miss World Canada organization by visiting their website: <http://www.missworldcanada.com/index.htm> and check out my group on facebook: "Julie Deleemans for Miss World Canada 2009"

I was raised on a farm just outside of Aylmer (Ontario). I have ridden horses competitively since I was two years old up until I was about eighteen, however now I just ride for fun; I also love animals!

Obviously my laryngectomy has had a huge affect on me and the person I am today; it also allowed me to discover my passion for helping others in need and my desire to pursue a career in Health Sciences as a Medical Radiation Technologist.

I have volunteered with Animal Aide, SARI – Therapeutic Horseback Riding for Children and Adults with Special Needs and Robertshaw Moncrief and Associates Veterinary Clinic in Aylmer, to name a few. I soon plan to be volunteering for the Canadian Cancer Society also. Some of my interests include horseback

riding, baking, reading and writing, spending time with family and friends and of course my pets!

If I were to earn the title of Miss World Canada I would like to be able to inspire others who are having a tough time. I would hope to show them that even if life has dealt them a poor hand they can still make something out of it and achieve even their most unlikely of goals. I would strive to use the title to give hope to people who need it and to show them that if you work and try hard enough anything is possible.

Should anyone like to get more involved with supporting me you can do so by visiting the Miss World Canada website and voting for me for the People Choice Award; if I win this event I will automatically advance to the semi finals!



I would like to thank everyone who has supported me thus far and I hope to make you all proud!

Best Wishes,



**IMPORTANT NOTICE!**

As a result from discussion from the floor of the AGM it was resolved at the AGM that as a TRIAL the June meeting will be held in the City at The Sydney Mechanics Institute on Pitt Street (all details will be published later once enquiries have been made as regard dates, suitability etc.)

This venue is a 2 minute walk from Town Hall Station as well as more comfort (warmth in the winter months) it is central and should be more accessible to all members, it has comfortable air conditioned rooms and facilities for refreshments. If suitable and a decision made it is hoped that this location will encourage more members to attend . I am presuming a final decision on this will be made at at March meeting, so either attend or drop me a line with any thoughts you ay have

Like all changes this may produce one or two problems and this is why we ask that as many members as possible attend so that it can be discussed in a proper manner and a conclusion reached that suits the majority.

## FEELING SORRY FOR YOURSELF?

Then read on!



*Wyn and I often buy a copy of the magazine "The Big Issue" from the street vendors whom you have all probably seen around the town and suburbs. The cost is \$5 half of which goes to the vendor— my sentiments are that these unfortunates are at least trying to do something for themselves. There are some interesting articles usually and here is the story of one of the vendors. Also if you have a minute to talk to them you will find some very intelligent people amongst their ranks who have opinions on most things—Come to think of it they might do better than the current NSW government, anyway here is one story for us to reflect on if we are feeling hard done by or down!*

I WAS BORN IN 1946, AND MY FAMILY LIVED ON A FARM about five hours out of Perth. I boarded at a school, where I was gang raped by other students when I was nine years old. My father did not believe me, and when my mother spoke to the school they closed shop and denied it.

I was devastated and started drinking whisky secretly. I left Perth for Adelaide at 16, to get away from this memory, and joined the CMF (Army Reserve) while training to be a nurse.

In 1968, I joined the regular army and in 1969 was sent to Vietnam for the first of two tours of duty. While in the first-aid station a young soldier was brought in having stepped on a 'jumping jack' mine. That young man was my brother. He was just 19 years old. He died. This hit me like a ton of bricks and I broke protocol to phone Mum and Dad before the army could.

I came back from Vietnam and worked in Victoria Barracks, Sydney. In 1973, I met a young lady who was working in the army office and we married in 1974. We had a son, Wane, born in 1975 and a daughter, Beverley, in 1977. Life was good to my family, but in 1987, while I was working at the army base, a phone call to the base hospital came through for two nurses to go to the main gate, where there had been a bad crash. I grabbed my medical kit and rushed out. A car had been hit by a huge truck as it was turning to come into the base. I looked into the car and found that it was my wife, son and daughter in the car. They had been coming

to visit me for my son's birthday. My wife and kids were killed in the crash; the children died instantly My wife was six months pregnant.

I took three months off and was counseled through my grief by my second cousin, who was the chaplain. I sold the house, as it had too many memories, and lived on the base.

I stopped work and started drinking heavily. I got a medical discharge from the army in 1991 and returned to Perth. I started supporting the Geelong Cats (just to be different) after watching the 1992 Grand Final when the Cats played the Eagles. I have supported them ever since.

I came into contact with The Big Issue when attending a counseling session in the same building as The Big Issue office, and was told about selling magazines by the vendor coordinator. I started selling and found that it gave me a new view of life and a way to meet people and keep my mind off the past.

The drinking has continued, however, and a bad fall while drunk left me with a badly broken leg, which stopped me selling for several months.

Now I am back selling again, and am determined to get off the grog with the help of The Big Issue and friends."

by Jim Petrie



## Esophageal Speech: How hard is it to learn? By Elizabeth Finchem.

Elizabeth is a past director of the International Association of Laryngectomees and well know teacher. This is the first of three articles which she has given me permission to publish

Since we are beginning a New Year perhaps it is time to take a fresh look at what could be, for many, the answer to a prayer. Currently we are all looking for simple inexpensive solutions to practical problems. Esophageal speech is the stated goal for some of our newest members. I'd like to share some information to gain a basic understanding of how esophageal speech works.

First, let's deal with why some of us, without question, accept the statement that "esophageal speech is too hard and takes too long to learn". Compared to what? Assuming it isn't necessary to restate here that we are all as different now as we were prior to our laryngectomy surgery; the cancers and the necessary therapy were also very different. The one thing the majority of us have in common is a laryngectomy.

For speech options you probably met with a speech/language pathologist (SLP) prior to surgery or soon after. This is a very critical time for several reasons, because it can set the tone for your post-op rehabilitation and the rest of your life. Most SLPs, as graduate students, had limited classroom instruction and lab time to deal with a laryngeal voice in communicative disorders classes. Six hours is average. They are lucky if they have one of our outstanding mentors with PhDs, who are clinicians as well as teaching professors and who have worked first hand with laryngectomees during rehabilitation.


In some cases the doctor ends up in a position to make decisions for us, especially when it is an emergency surgery. The doctors may have been instructed on how to deal with laryngectomy surgery, and the quick solution of primary puncture for TEP as part of the laryngectomy. When there is a little time pre-op, some doctors include the patient (and family members) in the decision making with a pre-op visit to an SLP, and/or a local laryngectomee support group where they can observe the various methods of speaking without vocal cords used by well rehabilitated laryngectomees. This one hour visit can make a huge difference in how the whole family imagines the recovery and future.

Let's go back to the question of "how hard is it to learn esophageal speech? (ES) That's esophageal – "gee-al" as in gee whiz, not "geal" as in geese. Esophagus, as in "Gus" - two different "g" sounds due to the vowel that follows -E or U. Forgive me, but while we are diverted, I really have to cover the other mispronunciation that is common.

This is for the newest members who want to learn everything about their new experience. The word larynx is pronounced "lair-inks", not "lar-nicks". In my neck of the woods I was taught the wrong way of putting the y after the n (larynx instead of larynx). I had to get with the program when speaking about my situation. Don't take my word for it. Look it up in the dictionary. Yes, even professionals mispronounce these words. We teach everyone we talk to about our surgery and rehabilitation. We didn't know much about all of this before our surgery and we can help by teaching others as we adjust.

If you are lucky the first mention of ES is during the meeting with an SLP since this seems to be the most common scenario. Remember they are people too, and as different from one another as we all were pre & post-op. I understand where they are coming from, and why they arrive at these assumptions after trying to produce ES themselves. We also have to keep in mind they may have been told that ES is "hard to learn", and, by implication, hard to teach.

Their physical problem with ES is that they still have a larynx. Yes, they can close their vocal cords and achieve some esophageal voice for demonstration. It is possible. Some are really good at uttering a complete sentence in ES. Now, imagine the resistance your larynx presented when you recall speaking on a long burp after a meal or drinking carbonated beverages. Although this gaseous air is moving up the esophagus very powerfully this is not what we mean when we refer to esophageal speech. For those who use the electro-larynx (EL), you may hear a double phonation while you're speaking and a rush of air with a burp creates another voice at the same time. That air may be from a meal or air from the consonants you've been exaggerating while talking with the EL, or mouthing with the hope your listener will read your lips or hear your "almost whisper". A "K" from the back of the tongue is like shooting a cannon full of air straight down into your esophagus - powerful enough to go straight to your stomach non-stop.

There are so many physical changes for us when the larynx is removed and the resistance from cartilage and tissue are no longer there. It is much easier for us to get air into the esophagus and release it up and out if we know the next step to keep it moving dynamically north instead of south. 

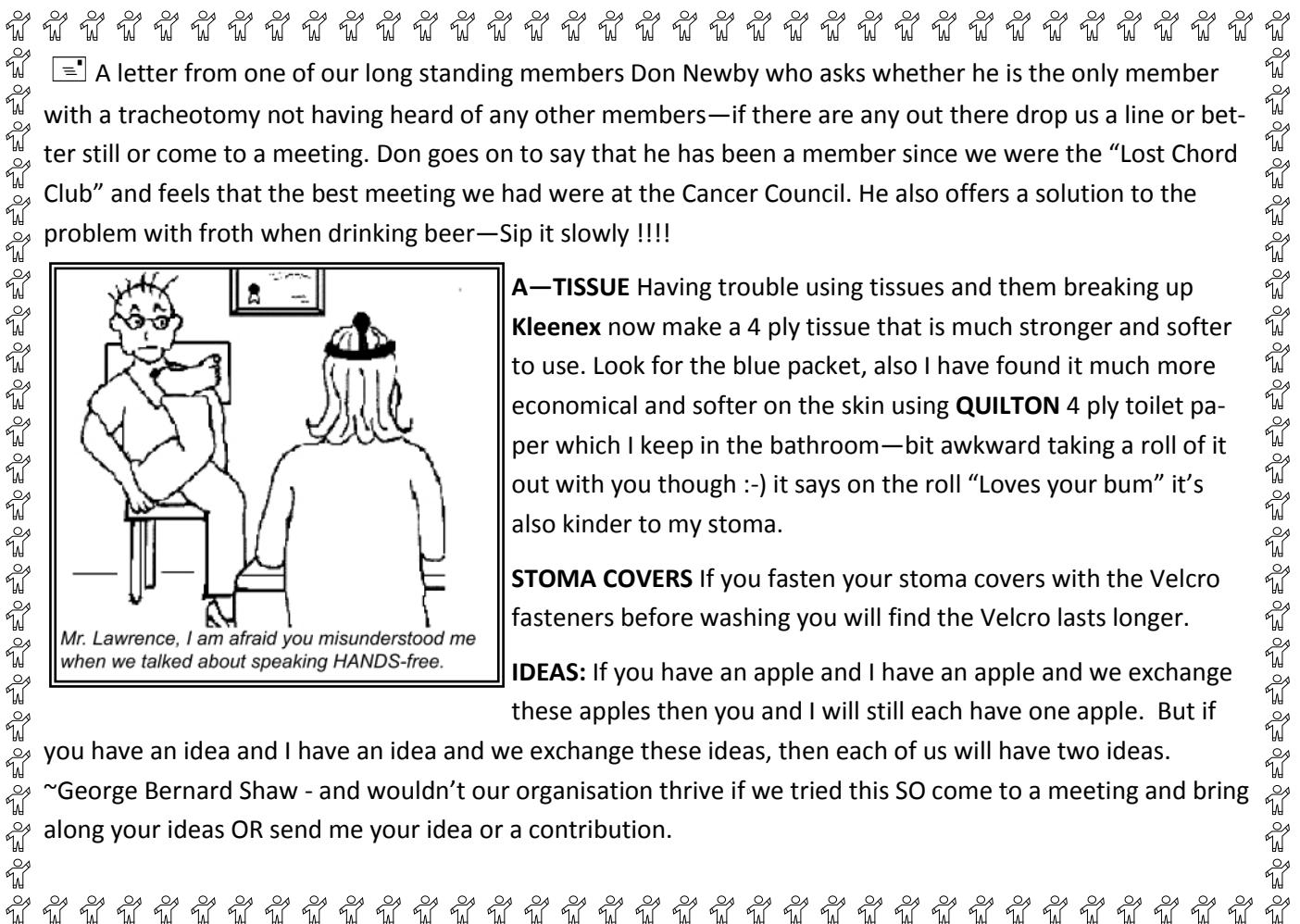
An example I use while teaching is the balloon. To begin, put your lips together and let the air in your mouth puff out your cheeks. No lung air is necessary for this step. If you have a small balloon to work with...fine. Or, you can imagine moving the air from your mouth into the neck of the balloon to inflate it one mouthful at a time. Do not remove the neck of the balloon from your mouth to re-inflate your cheeks. This air is coming into your mouth from your nose. Surprise! Your nose is still connected to your mouth. You may even have an increased sense of smell doing this exercise. An important part of this exercise is to observe the air in the balloon that was under pressure and how it escapes on its own.

Use this fundamental concept to allow the air to move up your esophagus, and out of your mouth as sound. Speak the names of things around you if this happens. For a simple ES exercise put your hand in front of your mouth and feel the air that come from making the letter "P" sound. Really press your lips together to pop the P sound. Understand that the same amount of air is also going back into your mouth and will under this pressure enter the top of your esophagus...no "swallowing" of air necessary here. If you do this in front of a mirror you will probably be able to see the air inflate your esophagus just like a balloon.

The next move is to learn to open the top of the esophagus to allow the air to pass upward and out into your mouth to be shaped into a sound like "P-ie" or "P-ah. The top of the esophagus is the sphincter called the cricopharyngeus, or swallowing sphincter. Now, remember...with the balloon we didn't have to swallow anything. Swallowing is when we move saliva, food or liquid down toward our stomach. Air can be moved into the top of the esophagus in small amounts under very little pressure that is more like tucking, pressing, or moving about a tablespoon of air - that amounts to a mouthful or less. The target is where the larynx used to sit. Imagine now a figure 8 of dynamic air that goes down into the esophagus and in less than an instant it returns up the esophagus, vibrating the walls of the esophagus (like the neck of the balloon) all the way up as a sound generator.

Once you master how this feels, and how it works for fluent, continuous ES, there is nothing more to charge, buy or have replaced by someone else. You can travel the world with hands free speech. A goal that I believe is worthwhile. It is entirely possible to use ES, TEP and ELs, and the Tokyo, each at a different time for demonstration or need.

In future articles I plan to offer a list of very practical hints that will make the concept of esophageal speech less "hard" for those who wish to master the technique. *Elizabeth Finchem*



☰ A letter from one of our long standing members Don Newby who asks whether he is the only member with a tracheotomy not having heard of any other members—if there are any out there drop us a line or better still or come to a meeting. Don goes on to say that he has been a member since we were the "Lost Chord Club" and feels that the best meeting we had were at the Cancer Council. He also offers a solution to the problem with froth when drinking beer—Sip it slowly !!!!



**A—TISSUE** Having trouble using tissues and them breaking up **Kleenex** now make a 4 ply tissue that is much stronger and softer to use. Look for the blue packet, also I have found it much more economical and softer on the skin using **QUILTON** 4 ply toilet paper which I keep in the bathroom—bit awkward taking a roll of it out with you though :-)) it says on the roll "Loves your bum" it's also kinder to my stoma.

**STOMA COVERS** If you fasten your stoma covers with the Velcro fasteners before washing you will find the Velcro lasts longer.

**IDEAS:** If you have an apple and I have an apple and we exchange these apples then you and I will still each have one apple. But if

you have an idea and I have an idea and we exchange these ideas, then each of us will have two ideas.

~George Bernard Shaw - and wouldn't our organisation thrive if we tried this SO come to a meeting and bring along your ideas OR send me your idea or a contribution.

## **MINUTES IF MEETING HELD 18TH February 09—Laryngectomtee Association of NSW**

**IN ATTENDANCE:** R Green. B Hodges. Ray Chapelow, J Peden. D Lovett. V Stumbles. P Grey. T Anderson. T Krasnodebski. N Gildea. D Newby. J Chaloner. C Bolton. B Gardner. L Walton. J & D Lovett. E Anderson. N Hamor. W Bolton. C Gardner. P Dawson.

**APOLOGIES:** P Lamont. P McGregor. J F Jefferson. P Ewan. B Brunter. M Haliburton.

**MINUTES OF 2008 AGM HELD 20TH FEB** Resolved J Chaloner/J Peden that the minutes be accepted as a correct record with no matters arising.

**PRESIDENT'S REPORT** Resolved C Bolton that the president's report be accepted.

Brian welcomed everyone to the 51st annual meeting of the association

**SECRETARY'S REPORT.** Resolved B Hodges The secretary's report be accepted.

Correspondence from Cancer Council re grants for district association. Annemarie Misnamer.

**TREASURER'S REPORT.** All accounts have been audited (copies available from Treasurer) and a summary will be included in next Newsletter. The value of our accounts has diminished by \$153,000 this includes expenditure of \$108,000 so the loss in investments is around \$50,000. The cost of hiring the hall has increased from \$60—\$75 and has been booked for a further 3 months

**WELFARE REPORT:** Return thanks from Walter Biggs widow and Ray Chapelow following the death of his mother. Marylyn Felanges is in hospital awaiting surgery. Dudley Hughes has been diagnosed with lung cancer. Mary Halliburton is unwell . Donations and sent along with renewals and compliments on the newsletter

**ELECTION OF OFFICERS:** Resolved on a motion by J Gifford that all current serving officer be re-elected to their respective positions. With the exception of the minute secretary Mary Haliburton who is unwell. Wyn Bolton as elected in this position on a motion by B Gardner.

**NOTICES OF MOTION: (a)** Resolved/Brian Gardner That the life membership of Dawn & John Lovett be ratified.

(b) Resolved/Colin Bolton That Carol Gardner be made a life member of the association.

**GENERAL BUSINESS:** Re affirmed that patient packs should be given to and distributed by Speech Pathologists. The booklet "You can say that again" is still in the hands of the Cancer Council awaiting editing/printing.

**Xmas party:** Resolved that the Xmas party be held on the 1st Sat in December at the usual venue (if available) Pat Dawson to be in charge of arrangements.

**Hospital visitors** to complete form after visiting (form to be sent to Secretary by Bruce Hodges and then distributed to authorized visitors)

**Decals (Transfer)** Julie Maclean advised that she had no more decals available (advising that a patient is a neck breather)

John Lovett thanked the meeting on behalf of Dawn and himself for being made life members of the association.

There being no further business the meeting closed at 12.15 for lunch and fellowship

### CAN YOU HELP?

I am informed by the District Cancer Council that the contact number for Albury on our front page directory is not correct— can anyone give me a new number for it. I am not sure if a group meets there or not !

### Speech Aids Co-ordinators' report – February 2009

Donning my theatre critic's hat! –

I went along to the Newtown Theatre to see the Short & Sweet plays during the week that "Haircuts" was on (the play that uses a Servox lent by us, which I mentioned in the last newsletter).

It was on the Thursday night of the very hot week we had, culminating in the disastrous weekend of the Victorian fires. It was stinking hot and the audience was just dripping!

The plays however were terrific, especially (I thought) Haircuts. There were 3 actors in it – the barber, his wife and the young man.

It was the story of the young man's relationship with Giuseppe [almost a substitute father] and how the barbers' life was changed by, but still continued after, his operation. There was a strong anti-smoking message too, and much humour as well as sadness. A lot to squeeze into 10 minutes! The use of the Servox achieved the required effect of highlighting how Giuseppe's voice had changed, although as I had suspected the result wasn't great because the extra flesh in a normal person's neck made it hard for the 'sound' to penetrate through to the mouth.

The voting procedures for Short & Sweet, and for the Movie Extra awards that are also within them, are complicated and Haircuts at each stage seemed to just miss out but then, through good fortune, to just continue to the next one.

During their week it just missed being voted best play by the judges but ran away with the people's choice for that week – so much so that they were odds on to make the finals as the overall people's choice. However they just missed out on that too, but then were asked to appear in the finals at the request of Movie Extra pay-TV channel (which meant they wouldn't be eligible for the Short & Sweet awards but were for the Movie Extra awards).

I again went along, to the Seymour Centre, for the Finals night last Friday. The 13 plays were very, very good and again I thought Haircuts was excellent – for the larger auditorium they'd pre-recorded Giuseppe's 'Servox' speech and that was much better.

I've just spoken to Con Nats, the playwright & director, and he and his crew are over the moon. At the awards announcements on Saturday night they just missed by half a point on being the best play in the Movie Extra awards but their lead actor Adam Hatz (Giuseppe) won Best Actor!! They are very grateful to our Association for our assistance (we were thanked in print in to program for both nights).

In June there will be a series of programs on the pay-TV Movie Extra channel about this years Short & Sweet and "Haircuts" will feature prominently – I'll keep you posted.

That's it for the culture this month! - John Chaloner

### EDITORS NIGHTMARE:



This is the bit where you have done all work and end up with 5 centimetres of space - A space that of course could be filled with even one readers contribution. So how about it????

Of concern to us should be I have just been told that the Speech Pathologist position at Port Macquarie has been removed. The popular speechie there Camilla Strain has secured a position elsewhere. Larry's are being directed to a private Speech Pathologist of course with no medicare rebate and no health insurance cover. David McClymont will be organising and running the meetings (details front page) .

I am also informed much to my surprise that PADP funding varies from area to area— I have had no problems with the Balmain Branch, if you have had difficulties let us know then at least we can get all the facts together.

*Colin Bolton* Editor