



# Head and Neckers

Auckland City Hospital Support Group held at Domain Lodge

AUGUST 11, 2015

VOLUME 1, NUMBER 1

## Minutes of August Meeting

### General

The minutes have been going for a year now and seem to have a good reach apart from some hiccups with email addresses which I will clear up next time. Meanwhile Diana has helped me make the jump from minutes-with-extra-bits to a proper newsletter. Please let us know what you would like to see because this is something that has evolved over the months and *you are all part of it*.

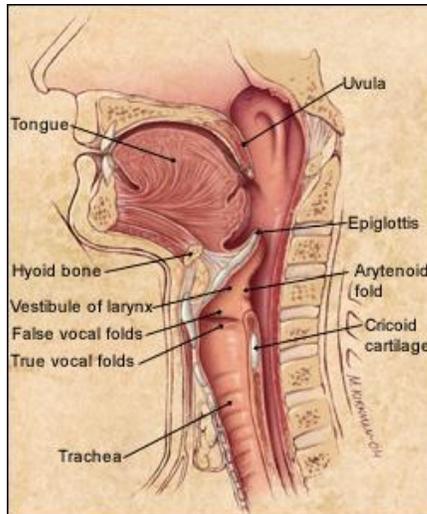
There were nineteen of us present with three staff: Noelle, Esther and her student SLT, Martin. We welcomed a new member, Alison. We were such a noisy bunch that Graham had to blow his referee's whistle. Unfortunately Lisa Guest, the dietician, had lost her speech to laryngitis so Esther Ong, the speech therapist had to speak for her. This meeting followed on from Dr. Dorman's lecture on swallowing.

*New newsletter format!*

*Much more than minutes.*

*People present at the meeting were as follows: Alison, Merle, Diana, Maureen, Peter Smith, the other Peter, Warren, Judy, Kevin, Jill, David, Mac, Marlene, Alan, Graham, Trevor, Ken ... as well as Esther, Noelle and Martin.*

### Nutrition, Eating and Drinking



I have just seen the animated movie *Inside Out* (recommended). In it a child's emotions are the main characters, Joy, Sadness and Fear etc. They pull levers and push buttons to help the child get through life. Esther's talk reminded me of that. When we swallow we use 50 different muscles. To prevent swallowing from going wrong, there are three important characters who push the right buttons. They are the uvula which stops food entering the nose, the hyoid bone which anchors muscles in place and moves up when we swallow and the epiglottis which acts like a toilet seat to close the wind pipe. The hyoid is unique because it isn't connected to any other bone as in "the thigh bone is connected

to the hip bone". It's just placed under our chin all by itself to support us. **Uvula**, **Hyoid** and **Epiglottis** deserve their names in lights, although they are only some of the factors in successful swallowing.

People who have had a laryngectomy don't have to worry about the epiglottis because food and drink go down a separate tunnel. But the muscles can get very tight, sometimes making balloon dilatation necessary.

Food is a very important part of life, said Esther. It has social and cultural implications too. For Asian people for example food plays an important role. Learning to swallow again after surgery and radiation is of utmost importance and it is unfortunate that a minority of head and neck cancer patients never get to do this

*Our meetings are held every first Thursday at 9.30 am. Speakers start at 10 am and the morning finished at about 11.30, sometimes a little later.*

but must be tube fed. Even those of us who can swallow might have limited food options. Steak becomes a long distant memory. This can be a problem as one member said if you have to cook for a big family and can't eat what you cook. Soup can be a good standby said another who looks out for supermarket specials on good quality soups.

Here are some useful points

- A chin tuck may be beneficial if there is food residue behind the tongue (in the vallecular which is the space between the epiglottis and the back of the tongue).
- Fifty-seven percent of head and neck cancer survivors suffer malnutrition four years after treatment. This could mean things like iron deficiency. To counteract any gaps in our diet, it would be good to have recipes and recommendations in the newsletter. Alison reminded me of the Pure Food Company that will deliver pureed foods: <http://thepurefoodco.co.nz/>
- The swallowing muscles become weaker with age and weaken when not used so it's important to give them a workout on a regular basis. Some older people with swallowing issues need thickened liquids to slow the progress of the drink through the system.
- Trismus (limited jaw opening) also affects our ability to eat and swallow. Esther demonstrated once more how to use an increasing number of tongue depressors to stretch the muscles.
- Cucumber is soothing for some people with dry mouth and she recommended putting essences into oil, for example mint or rosemary. Someone found miso soup helpful too.
- People with severe swallowing issues can aspirate saliva. Aspiration is less of a problem if the mouth is clean. David Hay (previous oral health specialist) used to say that if the mouth is dirty we could be sending sewage down into the lungs.
- Keep active. In fit people, the hairs in the lungs are useful for getting the gunk out.

There was a lot of information on Lisa's Nutrition PowerPoint which we did not discuss. I have written all this down in some previous minutes and can send the notes to anyone who needs them.

We tried to involve everyone in the discussion about eating and nutrition by handing out pieces of paper and felt tips so everyone could ask a question that could be answered by the speaker. It didn't really work this time because we handed them out too late. Next time we will try this earlier on so that *everyone* is involved.

Thank you Esther for providing us with information and demonstrations.

### **Niki's Message**

We know that the group works when we get a message from someone who came by on one occasion and was uplifted by our encouragement. Niki called into see us during her radiation therapy. She is now back in Kaikohe but emailed Noelle to say how much our words of comfort helped her during her treatment. We told her she would get through it and she did.

Noelle and her  
whanau

## Sustainable Transport

One of the greatest frustrations of Head and Neck patients at Auckland City Hospital is the lack of parking. It turns out staff are occupying 77% of the car parking and not leaving much for the rest of us. The Auckland District Health Board (ADHB) and AUT University are combining together to solve the problem with the Sustainable Transport project. They aim to move staff into other modes of transport including buses, trains, shuttles, bikes and two legs. The second phase of the project is to provide better transport information and options for patients. You can check out the progress of the project here.

[http://www.adhb.co.nz/news/mediareleases/Transport\\_Project\\_Update\\_MediaRelease\(2\).pdf](http://www.adhb.co.nz/news/mediareleases/Transport_Project_Update_MediaRelease(2).pdf)

## Profile of the Month: Noelle Farrell



Who am I?

I am the youngest of three children born into a military family in Shropshire, UK. I was a home birth and yes, with my name, you are right, I was born just before Christmas, and the midwife decided my name, as my mother's choice was 'Carol' so the midwife talked her out of it. My early life was spent in the Middle East and Germany and we eventually settled

back in England when dad retired from the army. Holidays were mostly camping or caravanning in Europe, a real treat.

Jump to my working life and finding my way. I always wanted to be a nurse - a missionary nurse - as I had a great aunt who spent most of her missionary life nursing and delivering babies in the Solomon Islands and I wanted to be just like her, because her life sounded exotic and full of purpose. I remember looking at a map of the world, trying to find this place called the Solomons. It seemed a very long way from Surrey.

But I did not go into nursing as a young woman, and instead joined the Foreign and Commonwealth Office in London with the lure of overseas placements and spies!! It was the 1970's after all, when there was such scandal with high profile political figures. There were airplane hijacks and bombs and lots of IRA activity. I felt so important, all secret squirrel in the department where I worked. But it was scary stuff, and we were forever vigilant, alert for unattended luggage on pavements and around parked cars. Explosions and smoke and the sound of sirens were not uncommon in London.

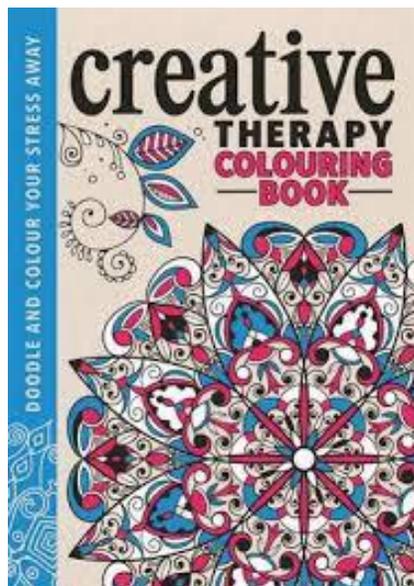
It was during this time that I met my future husband, a lovely New Zealander on his big OE. We married in 1976 and had two children while we lived in West Sussex, England and then had a third child in New Zealand a few years later when it was time for him to return home. We stayed for four and half years and then returned to West Sussex for a couple of years. But the children were homesick for beaches and bare feet. So back to New Zealand we came.

I went into nursing during this time and ended up working in Oncology at Auckland Hospital, first as a ward nurse, then eventually becoming the Nurse Educator for a

number of years. I joined the Head and Neck team at the start of 2011. Surgical nursing was quite a different type of work to what I was used to, but I have enjoyed the challenges and experiences of this field of nursing and have learned so much. My children are all grown up now, my oldest son and his wife and daughter residing in Chile, my daughter and her husband and their three children living more locally in Katikati and my 'baby' son and his girlfriend living in Melbourne. This year all the family were able to make it back for a family catch up which did us all the world of good.

Just over five years ago, my daughter was diagnosed with aggressive breast cancer and so as a family we were all on tenterhooks as she went down the road of surgery, chemotherapy, radiation therapy, follow-ups, and ongoing issues and side effects that a cancer diagnosis and treatment bring. Sandy Cavell's talk to us about uncertainty after a cancer diagnosis rang very loudly in my own ears. The thought of recurrence is never far away, and at the same time not allowing it to dominate day to day life and activities can be a challenge. There wouldn't be many people in this world who are untouched by cancer either personally and professionally. I mention this because I think some disclosure of the pain we feel and helplessness at times can be eased by sharing with others.

As regards the Head and Neckers, well what a great group of people to spend time with. The contribution made by members as well as our excellent speakers has been immeasurable as far as camaraderie, encouragement and direction are concerned. I certainly feel we have so much to contribute and our mantra 'having a voice' is gaining momentum. Bring it on!!



*The symbol on the top left of the newsletter is the burgundy and ivory head and neck cancer ribbon from the US. I'm not sure we want to use that but it is something to think about.*

### **Art Therapy**

I have just discovered that Dove Hospice in Glendowie helps people with life-threatening illnesses as well as people who are diagnosed with terminal disease. There's a link to Dove Hospice below. It is interesting that some of their practices are called Creative Therapies (Art, Music and Journaling). One of our group, Peter Smith, is into adult colouring books which are very popular all over the world right now for stress reduction. Colouring is a meditative process in which you focus on colours and designs. It means you are living in the moment, something the therapeutic concept of "mindfulness" is all about. The most popular are *Secret Garden*, *Animal Kingdom* and *The Mindfulness Colouring Book*.

### **World Head and Neck Cancer Day 27 July 2015**

The International Federation of Head and Neck Oncological Societies declared 27th July World Cancer Day. In New Zealand TV3 ran an article a few days later, which you can view here. This is an interesting piece because it focuses on a preventable cause of head and neck cancer, HPV. There is a vaccination for it but only girls are offered it. <http://www.3news.co.nz/nznews/calls-to-vaccinate-men-against-hpv-2015072918#axzz3hKmiai1a>

## Useful Web links

### New Zealand and Australia

- [Standards of Service Provision to Head and Neck Cancer Patients in New Zealand \(Provisional\)](#)
- Australia and New Zealand Head and Neck Cancer Society <http://www.anzhncs.org/>
- Cancer Council Victoria, Australia [http://www.cancervic.org.au/about-cancer/cancer\\_types/head-neck-cancers](http://www.cancervic.org.au/about-cancer/cancer_types/head-neck-cancers)

### United Kingdom

- Macmillan Cancer Support website [www.macmillan.org.uk](http://www.macmillan.org.uk)
- Mouth Cancer Foundation <http://www.mouthcancerfoundation.org/>
- Head and Neck Cancer Hub [http://www.ncin.org.uk/cancer\\_type\\_and\\_topic\\_specific\\_work/cancer\\_type\\_specific\\_work/head\\_and\\_neck\\_cancers/head\\_and\\_neck\\_cancer\\_hub/](http://www.ncin.org.uk/cancer_type_and_topic_specific_work/cancer_type_specific_work/head_and_neck_cancers/head_and_neck_cancer_hub/)
- Merseyside Head and Neck Cancer Centre UK <http://www.headandneckcancer.co.uk/>

### Canada

- Head And Neck Cancers - CancerCompass <http://www.cancercompass.com/message-board/cancers/head-and-neck-cancer/1,0,119,39.htm>

### USA

- The Oral Cancer Foundation <http://www.oralcancerfoundation.org/>
- The American Head and Neck Society at [www.headandneckcancer.org](http://www.headandneckcancer.org)
- Support for People with Oral and Head and Neck Cancer <https://www.spohnc.org/>

## Upcoming Events

### 2015

Friday, 28<sup>th</sup> August Daffodil Day [Click here to volunteer.](#)  
Our next meeting is on 3 September at 9.30 am, Doman Lodge

### 2016

*Australian and New Zealand Head & Neck Cancer Society, Annual Scientific Meeting and the International Federation of Head and Neck Oncologic Societies, 2016 World Tour.*

25 – 27 October 2016

The Langham Auckland

Auckland, New Zealand

Website: <http://www.ifhnosuckland2016.org/>

## Support Organisations

New Zealand Cancer Society <https://auckland-northland.cancernz.org.nz/>  
Dove House <http://dovehospice.org.nz/>

*Cheers*

*Maureen, default editor© Thanks to Diana for webpages and piece on sustainable transport.*

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*Noelle would like us to be involved in the Head and Neck conference next October.*

