



Head and Neckers

Newsletter of the Head and Neck Cancer Survivors' Support Network, NZ

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We meet in Domain Lodge on the first Thursday of the month. Our meetings start at 9.30 am and finish at 11 pm. There is time before and after for conversation with other head and neckers.

Very soon we will have an online presence so that everyone can participate in news and discussion.

Head and Neckers Move Ahead

We are aware our group is a small number of the people affected by head and neck cancer. There are many more people affected by head and neck cancer, whom we do not meet. To reach out, support, educate, and advocate for these people, we need to change.

Kevin has started this process by getting us to think about our name, logo and by-line. He and I are strong supporters of an online presence to bring people together across time and space.

To do this, we need to formalise our group by becoming an incorporated society. Incorporation will allow us to apply for charitable status. With charitable status, we can apply for funding. It is important that we, who advocate for head and neck cancer people, are credible and clear in our purpose.

Before our next meeting I would like you to think about our purpose. I have drafted a starting point for discussion.

Our purpose:

- Supporting head and neck cancer people, their families and carers.
- Educating people, their families, carers and the community about managing head and neck cancer.
- Advocating for better services and outcomes for head and neck cancer people.
- Raising awareness in the community of the head and neck cancer.

Our meetings will need to change to meet our new way of working. Each meeting will now begin with a brief formal meeting. When that is over we will move on to our speaker and general discussion.

A briefing paper outlining the details of our plan for the future will be available at the next meeting. You will have the opportunity to comment and make suggestions. Your planning committee is Noelle, Maureen, Alison, Kevin and Diana.

If you have any questions or queries I am most happy to speak with you. You can contact me, dianaayling@outlook.com or 021 2130178. *Diana*

This Month's Meeting

Our meeting was focused on new developments for our group as well as an excellent talk about health psychology by Amy Richardson.

Kevin addressed the meeting first and received feedback about the choice of a logo for the group. He reminded us that we need to forge an identity. *Head and Neck Cancer Survivors' Support Network* would be more descriptive he said because we have professionals at our meetings as well as patients. We can make the group even more of a network by creating a cloud (internet) based entity. We could even run an open forum on the website.

I informed the group that we needed a committee to run with Kevin's ideas and that committee meetings would take place after the main meetings. Anyone was welcome to stay behind and discuss this.

Alison has suggested two recipes for easy to eat foods. They are

Parsley-Passion-Smoothie from www.bite.co.nz and Super-Easy-Chicken-Rice-Soup from www.landolakes.com

She will also check out the food from The Pure Food Company who deliver good looking pureed foods.

A big welcome to the new people who joined us. It was good to see a full house and to feel the positive buzz that the group generates. Alan's name stickers have given us a focus at the beginning of the meetings and a way to get to know each other better.

We were very sorry to hear that Mac's son has passed away. All our love and condolences to you, Mac.
Maureen

Psychological Factors and Head and Neck Cancer (HNC)

Amy is a PhD candidate in the Department of Psychological Medicine at the University of Auckland. Her supervisors are Professor Randall Morton and Dr Elizabeth Broadbent. She explained the importance of psychological factors in head and neck cancer and then mentioned her own research. What follows is a summary of Amy's presentation.



Health Related Quality of Life (HRQL)

This refers to how well we function physically, mentally, emotionally and socially. Depression and anxiety vary amongst Head and Neck (HNC) Cancer patients depending on the effect the cancer has had on basic functions and appearance but about 50% of patients will experience these feelings and HNC is often regarded as the most traumatic cancer to experience. HNC caregivers also suffer from psychological distress, sometimes showing higher anxiety than patients. All these factors are important because our state of mind affects us a lot even to the point of long term outcomes.

Illness perceptions

Amy explained that how we perceive our cancer can affect how we deal with it. A smoker who believes that smoking was not a causal factor will go on smoking, for example.

Coping Strategies

Adaptive coping means actively dealing with the cancer. For example a patient might seek support. Avoidant coping means trying not to deal with the cancer e.g. denial and substance abuse. Studies have shown that patients who use avoidant or negative coping strategies suffer more distress and poorer health outcomes.

Adaptive Strategies

- Stay informed
- Continue to do the things you enjoy
- Develop and maintain a support network
- Ask for help
- Take it easy
- Distract yourself
- Use relaxation
- Exercise
- Keep a journal

Psychological Interventions

These are programmes to help patients deal with the emotional and social aspects of the disease. Strategies include cognitive behaviour therapy which deals with our beliefs about the disease, psychoeducation which gives information about an illness and relaxation training to keep us calm.

The Cancer Society can also provide a CD with relaxation exercises.

Amy's Research

Her aim was to examine the relationship between illness perceptions and coping strategies at diagnosis and outcomes in patients with head and neck cancer and their family caregivers six months later. The outcomes she examined were quality of life, general distress and anxiety from a sample of 98 patients and 80 caregivers. A few dropped out after the start of the research.

The first part of the research was to issue a questionnaire booklet at the multi-disciplinary meeting. She found that around a third of patients and caregivers experienced depression or anxiety at diagnosis and again six months later with patients tending to be more positive about the illness than caregivers.

She said that her findings were consistent with other research. Illness perceptions predicted quality of life. Avoidant coping strategies and self-blame at diagnosis predicted low quality of life and more distress.

The second part of Amy's research which is still ongoing is to investigate the use of a psychological intervention to help patients cope with the cancer. The intervention includes three 45 minute sessions with a health psychologist, prior to treatment, at the beginning of treatment and toward the end of treatment. These can be at the home or at the hospital and include caregivers as well as patients. Session one is about education, session two is about coping and session three is about the future.

The implication of this research is that depression, anxiety and quality of life are related to a wide range of health outcomes in patients with cancer. Interventions that are effective in improving psychological well-being might also benefit overall health.

Finally Amy acknowledged her supervisors, the medical professionals and organisations that have helped her, and our group meetings from which she has gained helpful insights.

Meditation for Beginners

In her talk Amy included meditation in her list of adaptive coping strategies. If you have not practiced meditation before it can seem daunting. Now there is an easier way into this relaxing and beneficial practice. All you need is a Smartphone and an app (application) called Headspace.

Headspace is a digital health platform, providing guided meditation sessions and mindfulness training. The content is accessible online, or via their mobile app. There are more than 2 million users, in 150 countries. The first 10 sessions are free, and even if you do nothing else these are valuable. You can buddy up with friends to keep motivated. <https://www.headspace.com/>

If you have an iPhone you will go to the App Store. If you have an Android phone you will go to the Play Store. Search for Headspace, and then download. Happy meditation! *Diana*

Cancer Connect

When I found out I cancer I wanted to learn more. I particularly wanted to hear from someone with first-hand experience. As my cancer is rare, there was not a person immediately available for me to talk to. My cancer liaison nurse suggested Cancer Connect. Cancer Connect NZ is a free support service. It puts you in touch with a peer supporter – someone who has had a similar cancer experience to you.

It doesn't matter where you live in New Zealand - all you need is access to a phone. Every Cancer Connect NZ peer supporter:

- Has had cancer, or cared for someone living with cancer
- Is trained and carefully selected to meet strict criteria
- Receives ongoing support

Find out more by calling 0800 CANCER (226 237).

The phone lines are open Monday to Friday, from 9am - 5pm. *Diana*

Patient Story: Maureen Jansen

Things were too busy this month to ask ahead for a patient story from someone else so here is mine, the condensed version.

I'm a 69 year old mother of three and grandmother of one and 8/9ths. During my working life I was an English teacher, something I am often reluctant to admit in case people think my English should be perfect. Or that I'm bossy. Heaven forbid.

I was born in Whakatane, grew up in Auckland and spent 35 years in Rotorua. We retired to Whangarei in 2009 but moved down here for family reasons in 2012.

On four separate occasions I've been given a cancer diagnosis, once for ovarian cancer in 1996 and three times for oral cancer (tongue and inside of cheek) in 2007, 2009 and 2014. The gods weren't smiling on us because in 2011 my husband was diagnosed with dementia and went into a dementia unit just before I was told that I had a new oral cancer primary. This was not a good time for any of us but somehow the family has made a sort of peace with it and I seem to be thriving in spite of the fact that my last surgery has disfigured me a bit and made eating difficult.

I've been a caregiver and a patient. Being a caregiver to a dementia patient was incredibly stressful but I received excellent support from the Waitemata DHB and the Alzheimer's Society. Being a cancer patient with no partner is also difficult. Other family rally around during times of crisis but there's nothing like a spouse on hand to help with daily tasks and transport.

I think I've been lucky, however. I seem to bounce back well from treatments, more by good luck than good management. I know that there is support out there if I need it and I'm no longer too scared to ask.

What can be taken from my little story is that cancer is not something that happens in a bubble to a patient and caregiver. It happens in the middle of a person's life, a life that might be full of all sorts of other challenges, griefs and responsibilities.

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

United Kingdom

- Macmillan Cancer Support website 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/
- Merseyside Head and Neck Cancer Centre UK <http://www.headandneckcancer.co.uk/>



The photo was taken last winter not long after radiotherapy finished. I was still thin then but glad to get my energy back.

If you want to be informed you can learn a lot from websites like the Oral Cancer Foundation and Cancer Compass. They inform as well as support.

Their forums are excellent and can provide support when you just don't know how you are going to cope.

Canada

- [Head And Neck Cancers - CancerCompass](http://www.cancercompass.com/message-board/cancers/head-and-neck-cancer/1,0,119,39.htm)
<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
- Support for People with Oral and Head and Neck Cancer
<https://www.spohnc.org/>

Upcoming Events

2015

Our next meeting is on 5 November 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.ifhnosauckland2016.org/>

Support Organisations

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

Dove House <http://dovehospice.org.nz/>

Contact us: specialist nurse, Noelle Farrell (noellef@adhb.govt.nz) and for newsletter matters, Maureen (mjansener@gmail.com)

Thank you to Amy for the presentation!

Maureen