

# Head and Neck Cancer Support Group Auckland City Hospital

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*Minutes of a meeting held on 2 September, 2014 at 10 am*

Room 2 Domain Lodge

Noelle from ORL chaired the meeting which started at 10 am. There is a list of people (18!) and their email addresses at the end of these minutes.

Staff members present were Ruth from the Cancer Society, Noelle from ORL and Elspeth from Oncology.

Vicky (ORL) sent her apologies. None of the surgeons were available to talk to the group today. They need to be booked a year or so ahead.

The support group needs a new focus now that Jeanette and Susan who kept the group going for years have retired. We need to get to know each other and work out what we want to achieve. Laughter essential (Val), crying an option (Noelle).

A new member told us about her two-year journey which involved four surgeries with part of her jaw removed and replaced with tissue from her leg. She's very pleased to have maintained her voice throughout because she "loves to talk". She is now a phone volunteer on Lifeline, finding it very rewarding. Talking is going well, apart from some consonants, but eating is not so easy. Project your voice from the chest she said, not from the lips.

Another member said that she found f's and p's hard to say and found her own name difficult to pronounce. In some social situations she has resorted to giving a false name, like "Helen"! Her eating is going well but stringy meats just won't go down.

One person said at the end of the meeting that she lives on Fortisip. People need to know that we can still make a good life for ourselves with limitations like that. You get used to the lack of food.

A spokesperson from the Cancer Society explained that there was a government mandate for different health professionals to work together for patients: ORL, Oncology and the Cancer Society. How can we make head and neck patients aware of this group? When should people be invited? Suggestions below:

- Invitation
- Newsletter
- Leaflet exists and could be scanned and sent out
- Friday Multi-Disciplinary Meetings? (Some thought this was too early)
- Website

**Noelle suggested that everyone write down what they would like and bring it to the next meeting.**

There was general agreement that mutual support is beneficial. Other Head and Neckers can share their information about the time frame for healing, how to deal with mucous and phlegm problems and how to learn to live with challenges like these. Mutual support is also like counselling with a small 'c'.

What about Counselling with a big "C"? Someone explained that people can ask to be referred to a Cancer Society psychologist at Domain Lodge with a waiting time of two weeks.

Cancer Connect is a sort of peer mentoring system offered by the Cancer Society.

<http://www.cancernz.org.nz/support-services/cancer-connect-nz/>

The Auckland Cancer Society also offers a five week Moving Forward programme for patients referred by or through a Domain Lodge psychologist.

Eastern Bay Hospice (Dove House) offers support to cancer patients but mainly for women dealing with breast cancer. <http://www.ebhospice.org.nz/>

Head and neck cancer is more conspicuous than other cancers, said another member. A video shown to the group two years ago shows the prejudice faced by people who have any sort of blemish. Two members said they are interested in supporting other patients. They thought that face-to-face encounters with survivors who have had obvious surgeries is empowering for others.

How many people are there out there with head and neck cancer? The Cancer Society spokesperson said that only a small proportion will use a support group. The consensus of the meeting seemed to be that if people are out there and could do with the support, it would be great to get them in the group and provide a real focus for Head and Neckers in Auckland. We could send newsletters to people in Northland too or even meet up with groups from other parts of New Zealand.

MJ