

Head and Neck Support Group

5 March 2015

Today there was some confusion about the change to Thursdays and whether we start at 9.30 or 10. See the next email from Vicki and Noelle about next month's start time. In the end we had a great turnout although Val could make only a flying visit. Her camper van wouldn't fit in the underground car park, she had her cat in the van and she was off to Rotorua for a holiday.

Vicki welcomed us back: Noelle had an appointment somewhere else.

There is a photo of four of this select group at the end plus a list of people who attended.

What is the role of the specialist nurses?

- Vicki has been there from the start. Her job is meeting people on arrival. Originally she was the only nurse specialist.
- Then Noelle joined the team to act as a patient navigator. She receives referrals from all over the country and arranges information to be here for the Multi-Disciplinary Team.
- Counties Manukau now has a specialist nurse and so does Whangarei.
- Regional hospitals can lack knowledge about aspects of oral cancer, especially for issues like valves for people who have had laryngectomies. GPs can be flummoxed by flaps.
- Noelle and Vicki are very contactable. They can triage the problem. It's better to overcall than undercall. As someone said, jump on a lump.
- Getting appointment times out to patients is tricky. Mail service is getting more unreliable but schedulers are wary of changing to email. They are afraid of being flooded by patient queries. Vicki and Noelle do not find that to be so.
- There used to be a booklet for the Multi-Disciplinary Panel. Doctors were meant to give it out but it seems to have got lost in the process.
- Vicki is interested in what we can do better in the future and how do we deal with survivorship issues.

Improving the reach of the Support Group

- Support group is immensely valuable but only about 18 out of the 1000 people who get head and neck cancer in the region attend it.

- Just as important to speak to other patients as to listen to specialists. We receive support from others and camaraderie. Other patients out there might think we are moaners and groaners but we're not!
- Patients' statements and stories on the flyer might help attract people to the group.
- Some people are too scared to attend even if you offer to bring them in.
- What about a photo to give the minutes a human touch?
- A helpful angle might be, come along and see what you can do for us.
- The vast majority of laryngectomy patients who are asked to come and speak to people undergoing treatment are very willing to help out.
- More flyers need to be sent out, not just to patients on this list but to other head and neck patients.
- Previous conveners Jeanette and Susan were more active at catching people going into treatment but Vicki and Noelle are a bit hesitant because of privacy issues.
- Oral Health could also push the barrow.
- Maybe there could be a list of survivors for new patients to contact.
- People in the group could make a patient flyer with Noelle and Vicki acting as the conduit. People who are interested could email each other. We can set this up ourselves.
- There are a lot of patients in Northland which is one of the main contributors to Auckland ORL. How can they be helped?
- As for privacy laws, if someone consents it is okay to publish.

Layman's Terms

- Material should be expressed in plain language not jargon.
- Vicki stresses it with younger doctors.
- Sometimes doctors also try to sugar-coat when it would be kinder to come out and say that it is cancer.

Dental Issues

- People with their own teeth get only one free check-up at Greenlane while people with major issues are seen free.
- Greenlane (Oral Health) doesn't follow people who can be seen by their own dentist.
- People need to see dentists who know the guidelines for treating people who have had radiation.
- We need a proactive approach for seeking more funding.

- Some patients have seen Anna Dawson at Greenlane. She can be persuasive. It would be good to get her along later in the year to help advocate funding for the dental care of head and neck cancer patients.

Laryngectomy issues

- A discussion on care of laryngectomy stoma. A nebuliser at \$280 is a good investment.
- When you are breathing through a hole in your throat, the air breathed in is not being moisturised.
- Each human being makes up to 2 litres of phlegm a day. It gets thicker if it dries out.
- As age creeps up there can be issues with the stoma, patients can get tracheitis or find it hard to clear phlegm.
- Don't leave hole exposed to open air. Trevor's friend makes bibs for \$10. Mac uses see-through foam which he attaches with a plaster and washes each day. The bib or flap can be moistened to help the issue. Or people can spray saline solution from a spray bottle into the stoma.

Anxiety

- Fear of recurrence and anxiety about results will be dealt with later in the year when Sandy Kevell comes in.
- Someone said, "Don't borrow sorrow from tomorrow". It's important to learn not to worry about results until they come in. We need tactics to cope with "scanxiety".

Radiation

- The radiation booklet needs updating because there is still some confusion about Aqueous Cream for radiation burns. The research keeps changing.
- Good advice to radiation patients is to make changes to oral and skin care before having the treatment. Diet is very important.

Survivorship Issues

- The Ministry of Health has a Cancer Control Strategy which Vicki and Noelle are involved in:
<http://www.health.govt.nz/publication/new-zealand-cancer-control-strategy>
- There is a provisional Tumour Standards paper with a section on Head and Neck cancer :
<http://www.health.govt.nz/our-work/diseases-and-conditions/cancer-programme/faster-cancer-treatment-programme/national-tumour-standards>
- MD Anderson Hospital in the US is conducting a plan for future survivorship issues. Here's a link to their Head and Neck survivorship clinic:
<http://www.mdanderson.org/patient-and-cancer-information/cancer-information/cancer-topics/survivorship/follow-up-care/head-and-neck.html>



MJ

