Head and Neck Support Group

Auckland City Hospital, 2 April, 2015

More than Minutes

*This month we have a **patient story**. Next month we'll have a piece by Amy Richardson from Auckland University about her research into the emotional effects of head and neck cancer.*

It would be good to see other snippets turn up here: maybe a recipe for that delicious spinach smoothie someone mentioned or tips on how to eat without choking or making a mess. Patient stories are probably best of all though. You could write your own or send me some notes and I'll write them up.

We need pictures.

Minutes

Today Esther from SLT convened the meeting. The talk was by radiation oncologist Dr Hedley Krawitz but there was time for informal discussion before and after. There were seventeen people present, four staff members and 13 patients/partners. We were introduced to Karlene, the new SLT.

Difficulties with meeting times and transport

- Is the 9.30 start time inflexible? Some people have traffic and transport difficulties at this time. The Gold Card doesn't operate until 9 am for example.
- One member wondered if we should have ACH meetings every two months with local meetings in between.
- He said the first two years were miserable and the Support Group has been invaluable. He'd hate to think of people who need the group not being able to come.
- Could we introduce car-pooling?
- Someone suggested name tags to make the meetings friendlier.

The Role of Radiation Therapy in Cancer of the Head and Neck (Dr H Krewitz)

- The aim is to increase tumour control while minimising complications.
- Fractionation is important. Small doses each day builds up to a big dose overall which leads to better tumour control.
- Between treatments, there is some recovery of normal cells but tumour cells don't recover as well.
- The best total dose is between 60 to 70 grays.

Three ways of using radiotherapy

1. Definitive = radiation alone
2. Post-op
3. With chemo

This depends on site, cosmetic aspect and function. Surgery is often used for oral and larynx cancers for example, while radiation is used for oropharyngeal and nasopharyngeal cancers. Post-op is recommended if features indicate a risk of recurrence: close margins, more than one deposit, bone

or nerve involvement, more than one lymph node involved, or extra nodal spread. Decisions are made by the multi-disciplinary panel. Chemoradiation is for advanced cases. It controls the tumour more but is not for everyone because there are worse side effects.

(Two studies show improvement in tumour control with post-op chemoradiation.)

What is the evidence for the use of radiotherapy?

- Definitive radiotherapy for stage one cancers leads to a 90% tumour control rate. Post-op, it reduces risk of recurrence at primary site and in neck.
- The gold standard is a randomised study. If margins are clear there is only an 11% recurrence rate with radiotherapy. With surgery alone there is a 17 to 31 % rate of recurrence.
- There are other percentages for close margins and “involved” margins but overall radiotherapy reduces the rate of recurrence by 50 %.

How is RT administered?

- The mask is used to immobilise the head and neck - and for accuracy. People who suffer from claustrophobia find this unpleasant.
- A tongue depressor is used to protect some of the tissues in the mouth. This can be uncomfortable.
- Radiation used to cover a wide area but now with Intensity Modulated Radiation Therapy (IMRT), the dose conforms more to the tumour, while reducing the effect on the parotid glands for example (major salivary glands).
- They try to shield food pipe and voice box if possible.

Side effects

- It is an intense treatment. Side effects can be described as "acute" or "late". (We covered these side effects last year so I won't repeat all of them in these minutes.)
- One of the notable late side effects is the risk of bone damage if teeth are removed from irradiated bone.
- There are two treatments to prevent damage: hyperbaric oxygen treatment and PENTACLO which consists of Trental, Vitamin E and an antibiotic.
- Some other long term effects are chronic otitis media (fluid on the ear), hearing loss, swelling problems and hypothyroidism. The latter can be fixed with thyroid tablets.

Conclusion

RT has an important role to play by itself, with chemo, or after surgery. Post-op it reduces the risk of the cancer coming back. For select groups, chemo is needed as well. Early tumours can have radiation alone.

Questions

Is radiation carcinogenic? Very small risk. Kills cancer cells better than it hurts normal cells. (Tumours escape the normal control of the body.)

Does Auckland use brachytherapy? Brachytherapy is a method where the radiation is very close to the tumour as in inserting wires into it. Not used in Auckland for head and neck cancer because complications are worse than the benefits.

How can we deal with fluid in the ear? Many people get this. It may clear by itself. Antibiotics can help. Can't use grommets because adult ears leak continuously when grommets are inserted.

How to cope with dry mouth? Products you can buy work temporarily. Spray mouth with cooking oil. Butter in the cheek lasts longer than water. (Esther)

Why does scar tissue or fibrosis keep growing in some people? Radiation affects the small blood vessels. The reaction of tissue without blood circulation is to scar.

The meeting ended with a cup of tea and caramel slice for those who can eat. Thank you to Findlay's wife. Niki called in to say hello and get some encouraging words from the old-timers. She is from the Bay of Islands and is staying at Domain Lodge while she has treatment. We wish her all the best.

Thank you to Dr Krewitz. The charts and statistics showing the effectiveness of radiation therapy were interesting and encouraging. This sort of information helps us put up with the side effects.

Patient Story: Mac Redmond

In 2007 Mac's voice had been getting croakier by the month so he went to his GP who sent him to North Shore Hospital. He was diagnosed with a growth on his voice box. He was in a daze but was "half happy" when he met with a panel of doctors at Auckland Hospital who said they could fix him with radiation. This was unsuccessful so in 2008 he had surgery. The surgery was daunting because he had his throat cut from ear to ear. Fortunately he had a lot of support from family and friends.

Mac and a kingie. This photo was taken last year.

He felt that the journey of recovery described to him by hospital staff was too much too soon. He thought his days were numbered and they were talking about ways to talk after his voice box was removed.

For the first few months after surgery he couldn't make a sound but he gradually learned to talk again with the help of the "speech ladies", some Botox, neck exercises and reading aloud to himself. His family gave him a t-shirt with "Pick him. He can't talk" on it. Humour and feeling wanted played a big part in his recovery.

In time, Mac was contacted by Massey University to chat to speech therapy students. He has had two types of talk valves so could explain how they worked and how he cleaned them. He spoke about how a laryngectomy affects him in his daily life. The students examined his stoma and looked at the first aid kit he carries with him.

Before his surgery, Mac, at 68, was semi-retired but an active person racing yachts 12 months of the year and fishing on a regular basis. He has two grandchildren and they took up a lot of his time too. Some people would say he lived the life of Reilly.

What advice would he give other head and neck cancer patients? Mac treated it like a job and tried to get on with the plan. It's easier said than done. Coping with cancer is frightening. If people feel they are not coping they should see their GP or hospital staff quickly. Don't procrastinate because time is important. He also suggests joining a support group.

"There may be people better or worse off than you. Hang around with positive people or frequent positive places."

Mac says the meetings of the Support Group have been a great help with ideas that you can try out to see if your quality of life improves. The talks from surgeons and the like keep you up with progress. As hospital staff say, we are all different, but any progress towards better life quality gives satisfaction. The advice is to keep participating in life in general. Don't change the past completely when adapting to the new situation.

He is also a Meals on Wheels driver, saying it makes you get out and meet other people that need a hand up for one reason or another.

"It helps you. It's a wonderful feeling when they say thanks and you can reply, 'Have a nice day. See you next time.' I am not sure I have always believed that 'one volunteer is worth 10 pressed men' but I am sure that getting out into the community is a great help to your rehabilitation."

Quote from a cancer site

"Scars may heal, blood counts may normalize, years may pass. But never again will the simple act of waking up to a normal, boring day as a healthy individual be taken for granted, nor go unappreciated." - Allison A., Cairo, Egypt

Note from Maureen

From offering to take minutes to making something like a newsletter I'm getting to be a sort of unelected editor. Doing this is good for me and is a productive use of my time. But if anyone else wants to contribute or do something different, sing out☺

Cheers

Maureen