

Head and Neck Support Group

Auckland City Hospital, 7 May, 2015

Amy Richardson' research into the psychological effects of head and neck cancer (at the end) is our extra story this month. Next time we'll need another patient or staff story

Minutes

Today we started with general mingling before Noelle and Pauline arrived to start the meeting. There was a big group today with four staff members and 15 patients. I think this will be the pattern from now on: 9.30 to 10.00, tea, coffee and chat, followed by the topic for the day at 10 am. This means that people who find it hard to get here at 9.30 don't miss out. If the talk or lecture is only one hour, we have 30 minutes afterwards for questions and discussion.

While it's good to catch up with individuals, it's also nice to hear from the whole group. I'd like to see the 9.30 to 10 am slot or the 11 to 11.30 part devoted to a sort of roundtable discussion where everyone tells their story or asks a question. How do others feel?

Noelle told us that DHBs have meetings of co-ordinators from all over the North Island. Other districts wanted to know about our group so our minutes are now sent out to other coordinators. Our voice is getting out there, a big deal for head and neck patients.

Hypatia from the Cancer Society has emailed us all to help her with her new dry mouth booklet. This is another way that we can be heard. Give us more.

Noelle welcomed Merle who speaks very effectively with a microphone-like device. There are many ways and means to talk.

After that things got physical when Pauline, our physiotherapist, demonstrated how we can maintain our posture and fitness with short "do anywhere" exercises. I wish I'd brought my camera because we were doing squats, lunges and star jumps while three people were hooked up to heart rate monitors. Pauline said that better oxygenation through exercise can help counter the side effects of treatment. Exercise can optimise our strength and cardio health. Shoulders are often affected so posture is important. Keep your head up, shoulders back and everything aligned, as in the figure on the next page from Pauline's handout.

More from Pauline's handout

Physiotherapy aims of exercise

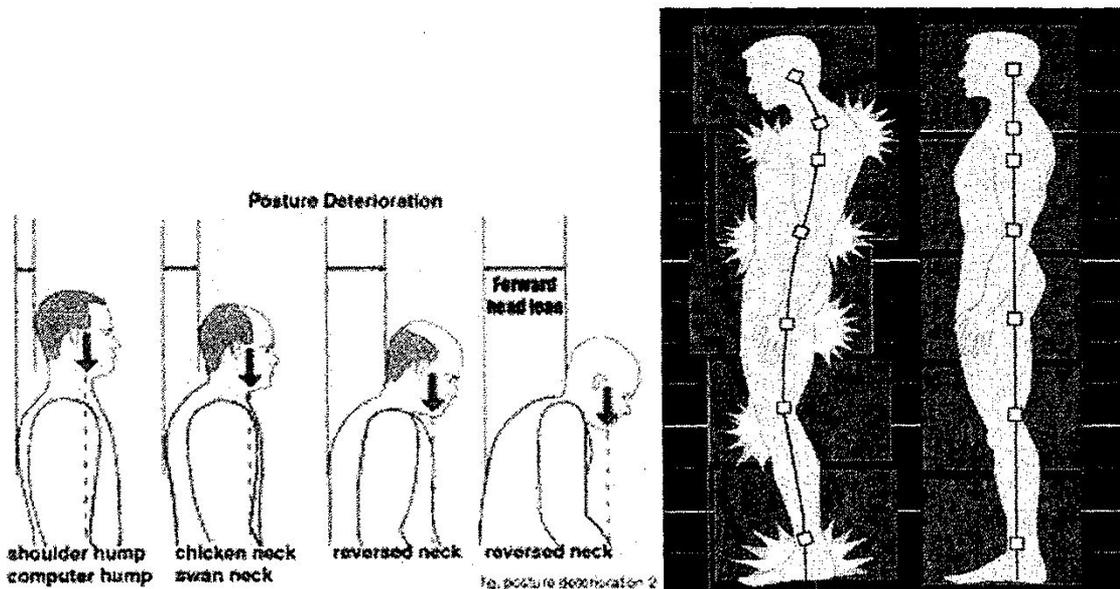
- Obtain optimal positioning of the shoulder
- Maintain range of motion of the shoulder/neck
- Reduce the chance of deterioration of function
- Attempt to reduce pain levels experienced by stiffness of the joint

Physiotherapy- if you first do not succeed try and try again

Shoulder pain disability

- "70% of patients following neck dissection have shoulder pain that has considerable impact on activities of daily living" (Dijkstra et al, 2001)
- "46% gave up work solely due to shoulder disability and 36% complained of moderately severe to severe shoulder pain" (Shone and Yardley, 1991)

This is a reality, so what are we/you doing to do about it?



POSTURE

- Prevent tightening of anterior chest muscles (stretch anterior chest muscles)
- Keep shoulders pulled back (Rhomboids)

One exercise for the shoulders is to put your arms up with thumbs up. Another one is to roll the shoulders.

Fatigue

Fatigue can be relieved by exercise but there has to be a balance between rest and activity. After three days of inactivity muscle strength can reduce by 50% so it's important to do some exercise.

From the handout

Exercise to try to manage levels of fatigue

Fatigue is a very common symptom for patients with cancer. Studies have shown that over 70% of the subjects express that with each radio or chemotherapy treatment cycle there is an increase in their level of fatigue.

The national comprehensive cancer network describe cancer related fatigue as

" a distressing and persistent subjective sense of physical, emotional and/or cognitive tiredness related to cancer and cancer treatment that is not proportional to the recent activity and that interferes with usual functioning" (Kuchinski et al, 2009)

Exercise is one method that is recommended to help reduce this symptom.

It has been shown that exercise is beneficial for:

- Increasing the efficiency of the heart, blood vessel, lung, and endocrine systems
- Enhancing muscular endurance
- Improving emotional stresses
- Reducing pain
- Increasing flexibility
- Improving functionality with daily tasks
- Improving quality of life

Thirty minutes of accumulated activity/exercise has been suggested as the ideal amount normally.

Studies with cancer patients have shown that even 10 minutes of activity can make a big difference in a person's well-being.

Suggestion on types of exercises:

- Walking
- Stationary-cycle
- Treadmill
- Gym program
- Community based exercise/walking groups, tai chi, bowling
- Swimming , aqua aerobics, water walking
- Chair/seated exercises (some suggestion on ACC website)

The main purpose is to try and take the activity as you are able and progress as you feel comfortable.

Start off slowly. You may need to try only **10 minutes 2x week** and **progress the duration to 30mins and frequency to 5x week**. Keeping an activity diary is a good way to keep track of your own progress.

Here is a link to the ACC booklet from Otago University. You have to download it as a PDF and there are diagrams at the end:

<http://www.acc.co.nz/publications/index.htm?ssBrowseSubCategory=Older%20adults>

This is a good link too:

<http://www.nhs.uk/Livewell/fitness/Pages/sitting-exercises-for-older-people.aspx>

Diana pointed out that **Domain Lodge holds a yoga session** for folk in cancer treatment or recovery each Wednesday, 11-12pm. The sessions are held in either the hall or support room. There is no charge for the class. The sessions are gentle with a focus on relaxation and meditation.

Heart rate

We need a little *overpressure* to get fit.

To figure out your maximum heart rate for exercising, subtract your age from 220. You want to work at a rate of 65% to 70% of that.

Pauline recruited three volunteers to wear heart rate monitors. One of the volunteers had a resting heart rate of 70. With easy exercise it went up to 78 but after star jumps and/or lunges it was up to 127.

We did squats which involved getting up from a chair, mostly with our arms crossed for one minute. That was too moderate for the volunteers so we did star jumps or lunges which lifted all of them to nearer their maximum.

Questions and Comments

How do we keep our neck and jaw working after surgery and radiation?

- Pauline gave out the Head and Neck Exercises booklet which most people are given in Ward 74. Need to hold the stretches for at least 30 seconds. The exercises cover all the different muscles used.
- Esther showed how we can use the spatula method to gradually stretch the jaw if mouth opening has been limited by surgery and/or radiation. You need to hold the stretch with the maximum number of sticks for 10 seconds. Twenty-four sticks is good. Gradually increase the number. You can buy ice block sticks in the supermarket or \$2 shop (or buy Magnums and save the sticks).

What are some other good exercise programmes?

- The Arthritis Foundation has a good exercise DVD for \$20:
<http://www.afstore.org/Hot-Items/TAKE-CONTROL-WITH-EXERCISE-DVD>
- Earl reported that Laura Ferguson (rehabilitation centre) in Great South Road Greenlane will offer an eight-week exercise course for head and neck patients if there are enough numbers. The programmes would be focused on individual needs. Pauline needs to ring them to check the safety issue. People were reluctant to commit because of the time-factor, the eight-week commitment and distance for people travelling from the Shore. Someone pointed out that there's a bus stop right outside it. If Pauline approves, maybe I could collect names by email.
- Your GP can refer you to various exercise classes run by local DHBs.

- Club Physical is very helpful.
- Tai Chi is very good. You have to be careful with yoga and Pilates.
- Back stiffness as you age can be alleviated with exercises like lying on your back and moving the knees sideways with shoulders stable.
- Sports like bowls, tennis, badminton and golf can be helpful
- Take the stairs and remember that exercise is always more fun with music.

Below is the Modified Borg Scale which is different for everyone because it is your “perceived” breathlessness or exertion. We should be working at about a three or four. Don’t make it too hard or it takes too long to recover. There is also the MET score chart which gives a list of activities and their metabolic effects.

Modified BORG Scale of Perceived Breathlessness/Exertion

(From the handout)

This scale measures your breathlessness/exertion/muscle effort from 0 (nothing at all) to 10 (the worst you have experienced). We should be working at about 3 to 4 on the scale.

0	Nothing at all
0.5	Very, very slight/light (just noticeable)
1	Very slight/light
2	Slight/light
3	Moderate
4	Somewhat severe/hard
5	Severe
6	
7	Very Severe/hard
8	
9	Very, very severe/hard (almost maximal)
10	Maximal

MET score/Activity Level Measure

MET is the Metabolic Equivalent of Task.

See next page for chart.

Physical activity	MET
Light intensity activities	
sleeping	0.9
watching television	1.0
writing, desk work, typing	1.8
walking, 1.7 mph (2.7 km/h), level ground, strolling, very slow	2.3
walking, 2.5 mph (4 km/h)	2.9
Moderate intensity activities	
bicycling, stationary, 50 watts, very light effort	3.0
walking 3.0 mph (4.8 km/h)	3.3
calisthenics, home exercise, light or moderate effort, general	3.5
walking 3.4 mph (5.5 km/h)	3.6
bicycling, <10 mph (16 km/h), leisure, to work or for pleasure	4.0
bicycling, stationary, 100 watts, light effort	5.5
Vigorous intensity activities	
jogging, general	7.0
calisthenics (e.g. pushups, situps, pullups, jumping jacks), heavy, vigorous effort	8.0
running jogging, in place	8.0
rope jumping	10.0

Finally, here is the article on Amy whose research sounds very promising

Psychological Wellbeing Study

What are the psychological factors for patients with head and neck cancer and their family members? Would a brief psychological intervention, involving three sessions with a health psychologist across treatment improve patient quality of life and psychological well being?

These are the issues being investigated by Amy Richardson a PhD student in the Department of Psychological Medicine at the University of Auckland.

She gave head and neck cancer patients and their families a questionnaire at diagnosis and then six months later. Thirty-four percent of the 98 patients reported significant distress at diagnosis. (This means that they had depression or anxiety that needed treatment.)



Six months later distress had decreased but quality of life had often worsened. Briefly summed up, these questionnaires showed that patients' and families' beliefs about the disease, as opposed to the facts of the disease, had an impact on their mood and quality of life at diagnosis and six months later.

The results of the questionnaire informed the second part of her study. Most patients and family members wanted psychological support, particularly early after diagnosis and during treatment. They suggested face to face sessions with individualised information about what to expect from head and neck cancer and its treatment together with coping strategies to manage the disease.

The resulting study is a randomised controlled trial, in which patients and their family members are randomly assigned to receive a psychological intervention in addition to standard care, or to standard care alone.

Recruitment for the study is currently underway. Those patients and family members assigned to the intervention group participated in three 45 minute sessions with a health psychologist over a three month period. Sessions are designed to address beliefs about head and neck cancer and provide education about the disease and its treatment. They also aim to help with the development of coping strategies, including relaxation skills and self-care.

Amy hopes that the results of her research may help to establish the importance of making psychological support easily accessible and available for all patients and families affected by head and neck cancer.

Have a good month, everyone, and thanks to Pauline for the taking the exercises and giving such good demonstrations.

Maureen

People Present

Staff: Pauline, Noelle, Esther, Amy. Patients and Partners: Earl, Diana, David, Jill, Judy, Warren, Shirley, Graham, Merle, Trevor, Ken, Alan, Marlene, Kevin, Maureen