

# Head and Neck Cancer Support Group Auckland City Hospital

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

Room 2 Domain Lodge.

Today's meeting was about nutrition and swallowing with presenters Lisa Guest (ORL dietician) and Esther Ong (ORL speech language therapist) filling the hour with a massive amount of information. We had a 14 patients and partners here today as well as four health professionals: Lisa, Esther, Vicki and Noelle.

There's a list of people present at the end of the minutes.

## **Nutrition and Swallowing**

Food, said Lisa, is needed for nourishment and fuel; for enjoyment, socialising and to meet cultural needs. Big adjustments need to be made so head and neck patients can enjoy food. It can be a struggle.

Esther was there to talk about the "technical stuff" and Lisa was going to speak about the "fluffy stuff".

## **Swallowing**

Esther projected a huge diagram of the inside of the mouth and neck onto the screen. It was so high she could barely reach the epiglottis so (don't tell the Domain Lodge people) someone had to unscrew a Venetian blind pole for her to use as a pointer. It worked. She could reach the uvula way up at the top of the back of the mouth.

## **Swallowing**

It's hard to understand the complicated dynamics of swallowing but here are some of the important points that I gleaned. These are the bits you need to swallow

- Lip seal
- Manipulation of food in mouth
- Tongue tip to alveolar ridge
- Grooved tongue for guidance and cohesion
- Saliva
- The uvula and epiglottis<sup>1</sup> move simultaneously
- The wall of the pharynx squeezes food and the larynx rises
- The hyoid bone or muscle closes

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<sup>1</sup> epiglottis - a flap of tissue that closes over the trachea when you swallow so that food does not enter your airway

- The food pipe only opens up when food is there
- We stop breathing for a moment as the food goes down

Crumbly stuff can get stuck in this process. Coughing is useful. Vital structures like the epiglottis can get stiff after RT and this will obviously affect swallowing. Sometimes the epiglottis doesn't come down properly. Other structures affected by surgery and RT will affect this swallowing process which is normally subconscious and automatic.

## Nutrition

Nutrition is the second most important sign of how well a patient does, in other words an important "prognostic indicator". Anyone who loses a lot of weight quickly is going to suffer from malnourishment.

Malnourishment is caused by lifestyle issues (tobacco, alcohol, diet), by tumour location and burden and the side effects of multi-modal treatment regimes.

This is a website Lisa referred to

[http://wiki.cancer.org.au/australia/COSA:Head\\_and\\_neck\\_cancer\\_nutrition\\_guidelines/Executive summary](http://wiki.cancer.org.au/australia/COSA:Head_and_neck_cancer_nutrition_guidelines/Executive_summary)

*A quotation from the Executive Summary: Malnutrition is common in patients with head and neck cancer, with the causes of malnutrition being multifactorial. Specialist dietitians from Australia, who were working with patients with head and neck cancer, had identified inconsistencies in dietetic practice and the need for a uniform model of nutritional care for this complex patient group.*

## Effects of malnourishment

- Impaired immune system
- Delayed wound healing
- Muscle wasting which can also affect respiratory function, cardiac function and mobility
- Altered gastro-intestinal function
- Apathy and depression
- General weakness and illness

## Consequences

- Risk of complications
- Hospital stays
- More requirements post-discharge
- Risk of readmission and doctors' visits

## Nutritional needs post-surgery

Metabolism increases and energy requirements are higher. It can take 12 months to recover well. Patients need supplements and/or high calorie, high protein foods post-op.<sup>2</sup>

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<sup>2</sup> A dietician in oncology told me during RT, "ice cream is your friend".

## Vitamins

(This is a note of caution rather than a recommendation to take lots of extra vitamins.)

**Vitamin E:** more than 400 IU/d leads to reduced survival (IU means International Unit)

**Antioxidants:** not during chemo and RT, can cause tumour growth

**Beta Carotene:** can reduce side effects but big doses have caused reduced survival in other cancers

**Vitamin A:** more than 200 000 IU/d has no benefit and can have an adverse effect on survival

Lisa said it was better to get your vitamins from food and if you're worried just take one multivitamin a day. Don't go in for the big doses.

## Minerals

**Zinc:** 25 mg/d linked to benefits but take care. There are unknown interactions. It can reduce side effects.

**Selenium:** this mineral is low in NZ and a certain amount MAY improve function but best to take it as part of a multi-vitamin.

## Effects of Radiotherapy and Chemo

I haven't noted down the side effects Esther mentioned (the usual suspects) but the consequences of these side effects for swallowing and related functions

- Altered chewing function
- Trismus. You should be able to stack three fingers up in your open mouth (four for a Big Mac). If you can't fit the three fingers in you've got trismus or limited mouth opening
- Oedema
- Ropy secretions
- Cervical oesophageal stricture
- Altered hearing
- Greater nutritional requirements for up to a year
- Emotional effects

## SLT recommendations

- Diet modification
- Strategies to manage dry mouth
- Techniques to control bolus like delay prior to swallowing; alternating fluids and solids; placement of bolus; slurp and swallow; adjust bolus size; lingual sweep. (Some people can learn to slurp without doing it too noisily.)
- Water is useful and a spray of a nice tasting vegetable oil into mouth can help.

- Massaging the salivary glands won't work if they're too damaged. As ex-Head of Green Lane Dentistry, David Hay, said, "You can't milk a dry cow"
- Postural techniques like chin tuck, head rotation, neck extension, and head tilt to divert food to strong side - even side or back lying on rare occasions.

## Airway protection techniques

- Safe swallow (supraglottic swallow) = half a hiccup to help swallow
- Suprasupraglottic swallow = holding breath effortfully

## Recovery

- Manage dry mouth
- Manage mastication and trismus
- Adjust to changes in structure (use or lose): stretch tongue and swallow as hard as you can. The epiglottis (or trapdoor) can get stiff
- Maximise mobility
- When you move on from the feeding tube the aim is to enjoy food but you may need to adjust to new normal

## Manage Dry Mouth

- Suck sugar free lollies or chew sugar free gum
- Brush after each meal and at bedtime
- Soft toothbrush, can soak it in warm water
- Use fluoride
- Gentle floss once a day
- Rinse mouth 4 to 6 times a day
- After meals rinse with salt and baking soda (half a teaspoon salt and half a teaspoon of baking soda in one cup of warm water)
- Sip water through day
- Avoid mouthwash with alcohol. Avoid Listerine. Savacol and Biotene make alcohol free mouthwashes. Salt and baking soda is the best and cheapest
- Humidifiers can be a great help to people with severe cases of dry/sore mouth. Even steam inhalation (hot water in a bowl) can help first thing in morning

## Eating with dry mouth

- Eight cups of fluid a day
- Avoid too much caffeine and acidic drinks, no tobacco
- Eat soft moist foods at cool or room temperature
- Use broth, sauces, butter, milk
- Full fat milk at mealtimes
- Use oil (flaxseed or light olive oil) or butter
- Avoid dry, coarse or harsh food

- Avoid acidic and spicy food. Some people from cultures where spicy food is the norm can tolerate this better

## Taste changes

- Make food look and smell good, lemon and orange flavours might help
- Use gum or sugar-free candies to mask bad taste
- Use other protein sources apart from red meat
- Marinate

## Long term impact

For the last five years a more specific and focussed type of RT has been used: Intensity-Modulated Radiation Therapy or IMRT. This is an improved technology but the research on its effects is not complete. In areas such as dysphagia the improvement in long term side effects is not as good as expected.

## Therapeutic Regimens

- Strengthen muscles
- Increase the precision of movements
- Increase the range of motion

## Post Recovery

This is to decrease the likelihood of cancer in general

- Keep as lean as possible
- Do plenty of physical activity
- Get nutrition mainly from plants
- Limit red meat
- No processed meat
- Limit alcohol
- Limit salt and mouldy cereals and pulses
- Get nutritional needs through diet alone (not pills)

## Questions and comments

- Tea and coffee? Don't have too much (like 15 cups of coffee a day). Green tea is good but not magic.
- Michael and Dulcie's green smoothie: packet of spinach, a carrot, a pear and a little water in a juicer (or blender?) every day
- Beetroot juice is good too with fruit
- Xerostomia is an antisocial thing. Food is important in our culture. Train family and friends to cope with your food needs. People will go out of their way to help

- Dave had RT 10 years ago. How can he find info on long term effects? Oral Cancer Foundation in the US has some 15 year survivors on its forum
- Vicki and Esther: RT issues can worsen through time with fibrosis etc. Can't predict how someone will be affected. Ten years ago the RT was "worse" than now
- Sun exposure. We've already had radiation. Exposure to UV is cumulative so sun makes radiated skin worse. Cover up and use sun screen.
- Lisa: for Vitamin D we need only 10 minutes of sun exposure a day to arms or legs
- How do we get enough iron when meat is hard to eat? Green veges contain some iron. Two red meat meals a week are ample: lamb, beef, pork. There's little iron in chicken. Easy to get iron levels checked by GP.
- Dulcie: on a plant-based diet, even with lots of spinach, she developed iron deficiency and felt awful
- At 11.10 am, before meeting closed, Noelle said that the discussion showed the importance of this group. In two years' time one of our surgeons is convening an international head and neck cancer conference. As this group grows more cohesive there could be an opportunity to present something at it. We can show rest of NZ an example of a supportive group of patients and hospital staff.
- Vicki: survivorship issues. An Auckland doctor, Randall Morton, is researching quality of life ... Perhaps we could get him to speak to us next year.
- Earl followed up with Club Physical for an exercise regime but while they were initially inviting they didn't follow through. Vicki said that maybe we need to look at small private local gyms to see what help they can give us.
- Noelle: Cancer Society will let us know soon about meeting times for next year. Susan Camber, the previous social worker, sends her Xmas best wishes to the group

Thank you to Esther and Lisa. The information was supragood and 100% sugar-free!

Happy Xmas everyone

Maureen