

Auckland Regional Head and Neck Cancer Newsletter

June 2019

Update on Northern Region Head & Neck Cancer Project



The Northern Cancer Network which supports the four DHBs in the north of New Zealand (Northland DHB, Waitemata DHB, Auckland DHB and Counties Manukau DHB) is in the process of implementing recommendations from its 2017 Head and Neck Cancer Service Review. This sees the establishment of an integrated, truly regional head and neck cancer service for the northern region, based on an internationally accepted “Role Delineation Model.” Based on this model, there will be one “Level 6”

facility at Auckland City Hospital (ACH), where highly complex patients will receive their initial surgery, radiotherapy and/or chemo-radiation. The model ensures that patients are treated at a facility (ACH or their local DHB) where they have access to the appropriate level of support for them, including inpatient nursing and allied health practitioners experienced in managing head and neck cancer patients.

Implementation is progressing well and is starting to transition from “project mode” to “business-as-usual.” This will see the changes implemented by the DHBs and overseen by a regional oversight group, which has two patient representatives (Diana Ayling and Maureen Jansen). Patient and whanau input into the 2017 Review, 2018 Framework and subsequent implementation planning, based on the principles of co-design, has been critical. Many of the recommendations for change are based on your feedback.

For example you told us that access to and payment for supplies and equipment was different depending on which DHB was responsible for your care. This issue has been resolved for Heat Moisture Exchanges (HMEs) and their consumables. We are in the process of finalising an agreed regional list of other supplies, including some dental supplies. Once approved, these items will be available to eligible patients at the 4 DHBs, according to regionally consistent guidelines.

We also received a lot of feedback about how overwhelming the multidisciplinary meeting (MDM) process was for new patients. Most people did however comment that they appreciated having access to all the experts in one place. We will soon be implementing changes to MDM processes to make the experience more patient-friendly. Changes include launching a new information booklet providing better detail about what to expect at the MDM, which will be provided to patients ahead of the meeting. We plan to pilot this new booklet in the very near future. We will soon be introducing a private room for the endoscopy procedure, with video and voice connections both ways to the large clinician group in an adjoining room. Management of the MDM has already been strengthened with the appointment of a Chair and Terms of Reference which are consistent with Ministry of Health's national MDM best-practice guidelines.

One of the major concerns you raised in the 2017 Review was patients not knowing who to contact if they had concerns/questions at each stage of their treatment and after treatment is completed. The Head and Neck Cancer Clinical Nurse Specialist (CNS) is now the patient's key contact person. Patients are provided with their CNS's contact details at the MDM.

Access to Oral Health support, especially after the completion of active treatment, was raised by many of you as a priority issue to address. There has recently been a change to the management structure of the regional Oral Health Service which is managed by ADHB. The new management team is currently developing a plan with implementation timelines, to enhance oral health support.

Work has commenced on documenting a multidisciplinary clinical pathway which will detail service provision by each clinical specialty within the multidisciplinary team along the care

continuum, from initial referral, through treatment and follow-up and into survivorship. This will assist in providing patients and whanau with a clear picture of their care plan and what to expect.

A new regional recruitment model, especially for surgeons involved in head and neck cancer patient management has been agreed and implemented. This ensures that whenever a new or replacement position is recruited for, the process will look at needs across the 4 DHBs instead of just the local DHB. This means that we recruit complimentary skills, ensuring that patients have access to the best possible range of head and neck cancer surgical expertise which includes ORL (otorhinolaryngology), microvascular, plastic surgery and maxillofacial skills.

As part of implementing these changes we are mindful that we need to measure their impact and continually look for other areas that require improvement. In addition to surveys via the HNC Support Network, we are also working closely with the Ministry of Health's project to review the Head and Neck Cancer National Standards. This includes revisiting current Quality Performance Indicators (QPIs) and development of new Patient Related Outcome Measures (PROMs). This is a work in progress which may take several years to complete.

The Implementation Oversight Group, with Diana and Maureen's input will continue to oversee and monitor implementation planning.

Fiona Ritsma
Project Support to the Regional Head and Neck Cancer Project



Head & Neck Cancer Support Aotearoa



Auckland/Northland members of our group will know Bernard Sanders of Nelson. Bernard has been a mainstay of HNC Support Aotearoa, always open about his own struggles and incredibly kind to others. Unfortunately, Bernard lost his wife Pat last month and we all mourned with him.



Bernard paying it forward. Cutting hair to raise money for the Cancer Society.

An informal poll in our Facebook group showed that the most common long-term side effect is dry mouth, closely followed by swallowing issues. We have members from New Zealand, Australia, the UK and the US but as you know, these issues cross national boundaries. I was surprised that some of

our members have suffered from radiation related cataracts.

It was timely that Auckland held a hygienists' conference last week where I went to see one of our members. Robert Pietersen, who owns the Oral 7 company. He has been generous in supplying us with free samples and cost price products over the years and it was good to meet up with him and his Auckland distributor. We're always looking for ways of dealing with dry mouth and dental decay.

Facebook has had a bad rap lately, but our community is doing well. It is a chatty, friendly group but we deal with the big issues too.

We are always there to vent to and encourage in-person meetings on a regular basis in the city or the North Shore.



Toni, Lucky and Adam at a meeting in Avondale

HNC Support Aotearoa members will have a strong showing on WHNCD at Auckland Hospital on 24 July at North Shore Hospital, on 27 July. Coffee afterwards at approx. 2 pm.

Updates on dates/times of coffee groups can be found on the Facebook page under events.

www.facebook.com/groups/HNCsupport.Aotearoa

Email: hncsupport@gmail.com

Blog: <https://hncsupport.blogspot.com>

Maureen Jansen

Head & Neck Cancer Support Network



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The Network has a new Board for the 2019/20 year. Diana Ayling (Chair), Heather Anderson (Secretary), and Board Members, Monica Koia, Brian Sheppard, and Gaynor Anderson. We elected to change the name of the “Committee” to “Board” and to allow online voting for any meeting of members. You can access the Minutes of the AGM on our website.

<http://headandneck.org.nz>

The Board is committed to two projects in the year ahead. We will be focusing on bringing the head and neck cancer community in New Zealand to have “One Voice” and to “Build our Community” by connecting people to the Network and with each other.

There are new developments with our website, the creation of a new form of Facebook group, and the continuing development of face to face support through support groups. We will keep you up to date through our Network News on our website.

We are pleased to be working with the Auckland Health Foundation to refurbish the whanau room in Ward 74 of Auckland City Hospital. The hospital is a hub for patients from the greater Auckland and Northland area. We want carers, family/whanau and friends to feel comfortable while supporting those affected by head and neck cancer. If you can donate please do...make sure you follow the link to Ward 74. <http://bit.ly/2HrWUSj>

Diana Ayling

A Big Thank you



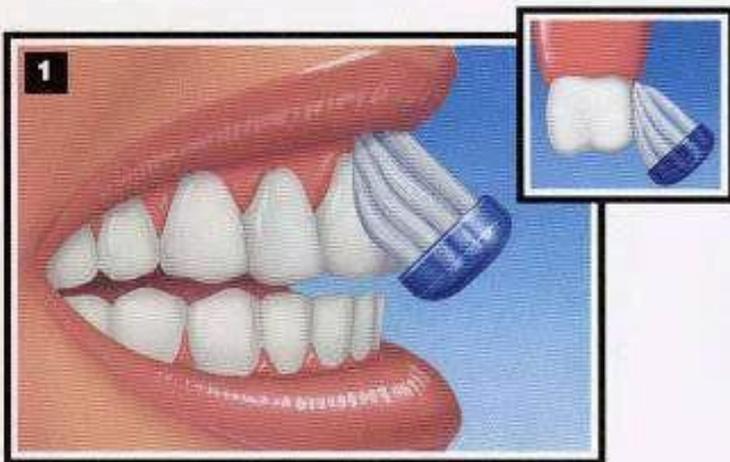
A big thank you to Shane and Narelle Hoarton, from the Head & Neck Cancer Facebook Support Group, for the generous donation of 5 boogie boards.

These are light weight LCD writing boards that will be more convenient for patients to use especially when coming in and out of hospital for treatment.

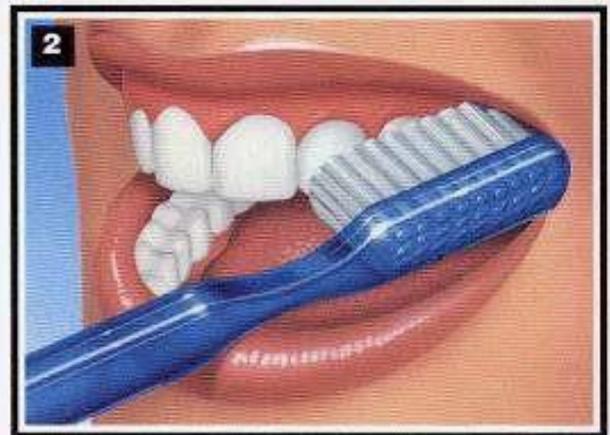
We will be celebrating World Head and Neck Cancer Day a few days early this year, at Auckland City Hospital, on the 24th July 9am - 12. There will be a stall on level 5 main where we will be focusing on signs and symptoms and risk factors. There will also be a stall at North Shore Hospital main foyer 10:00 – 2pm. This was a great morning last year with lots of support from the Head and Neck community. I look forward to seeing some of you there again this year.

Karen Shaw

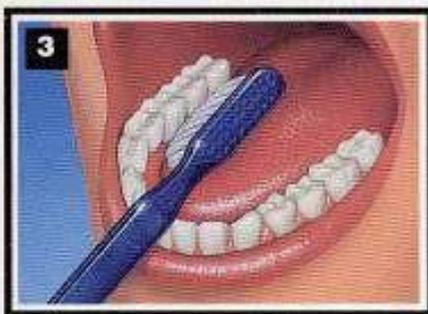
correct brushing technique



1 Place bristles along the gumline at a 45° angle. Bristles should contact both the tooth surface and the gumline.



2 Gently brush the outer tooth surfaces of 2-3 teeth using a vibrating back, forth & rolling motion. Move brush to the next group of 2-3 teeth and repeat.



3 Maintain a 45° angle with bristles contacting the tooth surface and gumline. Gently brush using back, forth & rolling motion along all of the inner tooth surfaces.



4 Tilt brush vertically behind the front teeth. Make several up & down strokes using the front half of the brush.



5 Place the brush against the biting surface of the teeth & use a gentle back & forth scrubbing motion. Brush the tongue from back to front to remove odor-producing bacteria.



DENTURES

If you wear dentures (false teeth) please take these out when using mouth rinses.

ROUTINE DENTURE CLEANING

Use a denture toothbrush to clean your dentures after every meal. Soak dentures in a denture cleanser (dissolvable tablets) regularly as per packet instructions, e.g. Polident.

LEAVE YOUR DENTURES OUT AT NIGHT

Keep dentures moist in a container with a drop of water or a wet tissue - do not let them dry out.

Charlotte Kenny Dental House Officer

Upcoming Events 2019

Wednesday 5th June 10:00 – 11:30

Cancer Society Outreach Programme. Botanical Gardens, 102 Hill Rd, The Gardens, Manurewa

Emotions and support

Wednesday 12th June 10:00 – 11:30

Cancer Society Outreach Programme. Sturges West Community house. 58 Summerland Dr, Henderson

Emotions and support

Wednesday 19th June 10:00 – 11:30

Cancer Society Outreach Programme. Franklin, The Centre. 12 Massey Road, Pukekohe

Emotions and support

Wednesday 26th June 10:00 – 11:30

Cancer Society Outreach Programme. Glenfield Community Centre. 411 Glenfield Road, Glenfield

Emotions and support

Wednesday 3rd July 10:00 – 11:30

Cancer Society Outreach Programme. Botanical Gardens, 102 Hill Rd, The Gardens, Manurewa

Managing stress and sleep

Wednesday 10th July 10:00 – 11:30

Cancer Society Outreach Programme. Sturges West Community house. 58 Summerland Dr, Henderson

Managing stress and sleep

Wednesday 17th July 10:00 – 11:30

Cancer Society Outreach Programme. Franklin, The Centre. 12 Massey Road, Pukekohe

Wednesday 24th July 09:00 – 12:00 World Head and Neck Cancer Day Auckland City Hospital

Wednesday 27th July 10:00 – 14:00 World Head and Neck Cancer Day North Shore Hospital

Managing stress and sleep

Wednesday 31st July 10:00 – 11:30

Cancer Society Outreach Programme. Glenfield Community Centre. 411 Glenfield Road, Glenfield

Managing stress and sleep