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Cancer Connections

– Deborah Woodley, Manager, Cancer Programme

WELCOME TO THIS EDITION OF CANCER CONNECTIONS.

As the Ministry's National Programme Manager for Cancer I work alongside John Childs to lead the Ministry's cancer work programme and coordinate the work of the Cancer Control Programme.

The Cancer Control Programme is a national programme that covers Ministry of Health, District Health Board and regional cancer networks activity to implement the Cancer Control Strategy. Governance is provided by a joint Ministry and DHB Steering Group and informed by the advice provided by our three main advisory groups (and their sub-groups):

- the Cancer Treatment Advisory Group (formerly the Cancer Treatment Working Party) chaired by Garry Forgeson
- the Palliative Care Working Party chaired by Barry Keane
- the Cancer and Palliative Care Information Advisory Group chaired by Tony Blakely

A summary of all the work being undertaken as part of the Cancer Control Programme for 2008/09 is on the Ministry of Health's Cancer web page. Do visit.

Alongside DHBs and regional cancer networks, the Ministry is currently in the middle of planning the work

programme for the 09/10 year. As well as improving quality, reducing waiting times and, improving palliative care, extra focus will go on two key cancers: bowel cancer and lung cancer.

In order to advance work on bowel cancer, the Ministry has established a Bowel Cancer Team. This team is led by Mhairi Porteous (Programme Manager) and Dr Carol Atmore (Clinical Director). A key priority for this team is to undertake the development work associated with the implementation of a bowel cancer screening programme.

Our Cancer Networks provide a very important role in providing regional leadership within the Cancer Control Programme. They do this by working across organizational boundaries to promote a collaborative approach to service planning and delivery. This edition profiles the work of the Northern Cancer Network and highlights how this Network is involving the wider community in aspects of cancer control. This includes their consumer forum and the use of design students to design special mammography gowns to help women feel more comfortable when undergoing mammography.

Our next edition will profile the Ministry of Health's cancer work programme for 2009/10.

Consumer forum established in Northern Region

The Northern Cancer Network (NCN) has established a Consumer Reference group with the aim of providing consumer perspective and participation into Network projects.

At present the group consists of seven voluntary members covering many of the tumour groups. It includes cancer consumers and carers of cancer patients.

Auckland lawyer Rowena Mortimer is Chair of the Consumer Reference group and explains that “consumers can play an important role in the planning of how services and information are delivered to cancer patients, and their whanau and supporters. They have a unique insight into the cancer treatment pathway”.

Rowena has admiration for those who are prepared to lend their time voluntarily to improve cancer service delivery to others. Many people understandably, do not want to look back on their cancer journey however this group is prepared to give their time for the purpose of improving cancer care.

The group first met last November and from that meeting agreed a terms of reference and undertook a workshop exercise designed to assist the identification of important issues that confront cancer service consumers.

Key issues identified and discussed in the meeting included:

- the difficulty in accessing social support services,
- information and benefits,
- the need for greater communication,
- the need to provide a world class standard of care, and
- disparities in accessibility to services and treatments across the region.

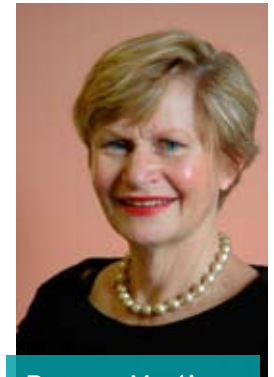
Following the second meeting on the 5th March the group agreed they would meet every two months, with the next meeting scheduled for the 7th May.

At present the group is liaising closely with the Network’s Maori Leadership group (MLG) via the Network Regional Cancer Collaborative (RCC) to ensure the views of as many cancer consumers as possible are heard. The Northland DHB Cancer Control Steering Group will continue to work with the Network to ensure consumers from Northland have a means of providing input in to Network planning and activities. The group is currently seeking representation from Pacific and Asian consumers.

One of the key items of interest for the group to focus on this year will be the current regional radiotherapy strategic review. Maree Pierce, the manager of the Network, is leading the review with an aim of reducing cancer waiting times.

Members of the consumer reference group aspire to encourage participation from consumers from a greater range of tumour groups. They are keen to make a difference and are looking forward to providing input into the Network projects and future.

For further information on this group please go to www.northerncancernetwork.org.nz or contact project manager Rachel Harley on 09 589 3905 or email rachel.harley@ndsa.co.nz



Rowena Mortimer

Reducing cancer waiting times is top priority for the Northern Cancer Network



Northern Cancer Network

Now that the Northern Cancer Network (NCN) is well established in the region they have a dedicated team ready to deliver tangible results and one of the key areas of work will be reducing cancer waiting times.

2008 was a successful year for the Network Manager, Maree Pierce and Clinical Director, Richard Sullivan having recruited four new team members between June and July and establishing a Maori Leadership group (MLG), a Consumer Reference forum, a Cancer Care Coordinator forum and Lung Cancer Workstream group.

The Network forums provide a mechanism for everyone involved in Cancer Control within the region to work collaboratively to improve patient outcomes and ensures wide representation and participation of all key stakeholders including Northern DHBs and cancer services.

There is an even busier year ahead for the team with some of the key workstreams already well in progress:

- Reducing inequalities
- Lung cancer workstream
- Radiotherapy (RT) strategic review

Reducing cancer waiting times especially for radiotherapy (RT) is a specific area of focus for the Network. Maree is leading a regional RT strategic review alongside Auckland DHB Business Development

Manager Margaret White in conjunction with the Auckland Regional Cancer Service.

The project group includes representatives from each Northern DHB provider division. The project is using international models to confirm demand projections in order to identify the capacity required over the next 10-15 years and will analyse a range of RT services for the region. The final strategy is due for completion early in 2009.

Gary Thompson the Network's Inequalities project manager is paving the way for better outcomes for Maori and Pacific. The establishment of the Maori Leadership group brings great pride to the Network. Their key objective is to provide culturally sound guidance and advice to all Northern Cancer Network initiatives grounded in tikanga (best practice) and kaupapa Maori (traditional methodologies). It is an open forum for portfolio holders committed to reducing inequalities for Maori with respect to cancer and inclusive of whanau, hapu and Iwi, Maori Health providers in community, primary and secondary and tertiary cancer services. The group also invites health promotion and prevention



Maree Pierce

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services, cancer care navigation services, carer support and palliative care providers, consumers, DHB Maori Health managers, funding and planning managers and regional MaPO representatives. The group is chaired by Miria Andrews, chief executive for Tainui MaPO.

Pieter ten Have recently recruited from the Netherlands is leading the way for the Network's tumour streams with a lung cancer tumour stream already underway and meetings currently taking place to set up the second tumour stream being 'bowel cancer'.

www.northerncancernetwork.org.nz

Community Pilots

The three community cancer pilots (West Coast PHO, Tamaki Healthcare, Te Kahui Hauora) that the Ministry is funding for three years met on 20 February in Auckland for a provider hui. This was the second time that the providers had all got together, with Te Kahui Hauora hosting the inaugural hui in Rotorua in May last year.

Dr Debbie Ryan facilitated the day. "It was an honour to listen to the people delivering these services on the ground and seeing their enthusiasm and dedication. I was also pleased to see that the services are being evaluated. Too often the richness, impact and value of these community health initiatives are lost."

The theme of the hui was reflecting back on the previous year, and looking at the services going forward. The hui timed nicely with the first evaluation report, which is due at the end of March, and was a good opportunity for the evaluation team to listen to the providers highlight their achievements and challenges. The evaluation team also presented initial findings from information gathered from providers and users of the service.



Members of the Tamaki Healthcare, Te Kahui Hauora, West Coast PHO, Ministry of Health and Health Outcomes International at the provider hui.

Mentoring programme accelerates new graduates

The Auckland Radiation Therapy team have implemented an innovative new programme that is not only retaining new graduates at the coalface, but keeping them in New Zealand.

Charge Radiation Therapist Linda Flay is delighted with early results, but cautious still about long-term retention.

“But the feedback is very, very positive.”

The transition from student radiation therapist to staff is huge. Although the three-year course has prepared graduates for the great wide world, they have not had a great exposure to some of the day to day operational decision making processes.

Originally Canterbury came up with the idea of providing a mentor for the graduates, providing one-on one peer review and also facilitating group work where things like conflict resolution/ dealing with difficult situations can be worked through. The innovative idea was trialled as part of the 23 implementation projects funded by the Ministry of Health in 2006. It seemed a good idea to try this in other cancer centres.

With funding support from the Ministry of Health, departments are able to retain graduates beyond their funded FTE. In 2008 eight graduates lined up for the programme in Auckland.

“One Auckland graduate went overseas and one went down to Wellington” Linda Flay noted.

The six worked through the half-year - there was an appraisal at three months - and as positions became available some were able to



Linda Flay

move into permanent positions, which helped retain these graduates.

“Without the mentoring programme, we may have lost many of them,” Linda says. “Now, they have developed the skills and abilities to allow them to be a valuable member of the team anywhere.”

“The difference was amazing, and all are still working with us, which is great.”

Being realistic, Linda knows the great OE still looms, but she knows too that after two or three years experience, these graduates will be highly skilled, and ready for the next step.

“If they leave, and work overseas, they will continue to build their skills and abilities, and learn the latest in techniques. Hopefully, they will come home.”

From the staff side, mentoring was also successful - six put up their hands to be the next mentor. Unfortunately, there were only four graduates for the next programme, from the national pool of 22. As the expansion of cancer services keeps up the demand, Linda sees little respite.

If you cannot keep qualified people, employers have to look overseas for staff.

Now, with an orientation programme that achieves key objectives new graduates become an integral part of the team at an earlier stage.

“Confidence is the biggest thing. The staff all noticed it. The new grads were capable of doing the job, but now they KNEW they could do it.”

High fashion option for functional gowns

Sitting waiting for a medical report following your mammography screening is difficult enough. Sitting in a gaping one-size-fits-all white hospital gown compounds the apprehension about what the news is going to be.

While they fight to retain their modesty, confidence sinks lower and lower, women told the Breast Cancer Service Patient Journey Improvement Project at Waitemata District Health Board. As well as a 25 percent reduction in waiting time for breast cancer surgery, the project is doing something about the gowns.

“After all,” says project manager Hilary Boyd, “we are here to support the patient; it’s their experiences, their journey.”

So, when the plans are complete, Waitemata mammography patients will be clothed in a more modest gown, a smarter gown to boost self-esteem designed by design students being mentored by top fashion designer Annah Stretton.

“It still has to be functional, but let’s make them look better, feel better.” It was one idea thrown up in the mine of information when patients and nursing staff sat down together to talk the journeys through.

“We first had to understand the patients’ journey, and try and help them understand what it is they will go through.

“They get a whole box of information, but on its own it can be overwhelming and contradictory.”

Now, they are also working with their consumers to improve the material patients receive on diagnosis.

Patients were keen to be involved through the whole planning of the project, and the Healthcare Improvement Team at Waitemata DHB wanted to be very inclusive. It was often very emotional as patients shared the whens and the wheres, the whys and how they felt.

Based around NHS methodology from Britain, the project has involved a discussion group of 21, 14 patients and five staff.

As an aside, patients have given excellent feedback about the compassion shown by staff, and been very complimentary over all.

With Richard Harman the clinical leader of the breast service, and Public Health physician Bernie Mullin – the former director of the Waitemata DHB Healthcare Improvement team – they looked for continuing incremental improvement. If analysis shows they are successful, there will be feedback to the overall DHB wide project, and they will roll the concept out into other areas.



Maori cancer providers set to show and tell

Reducing the access gaps that exist in our health care of Maori is one of the most urgent priorities facing health practitioners. Cancer is no different, but Maori health leaders like Edith McNeill out in West Auckland are intent on speeding up the process.

Maori providers have been working with their people around the country, and Edith and project manager Kimiora Raerino are set to provide a forum where the progress for Maori people can be shared amongst all providers.

Edith, general manager of Wai Health in Henderson, and Kimi are setting up a national Maori Cancer Care Conference from 12-14 August 2009. Many key note speakers have already confirmed, Dr Johnathan Koea, Dr Mihi Ratima, Dr Peter Jansen, Dr Donna Cormack, Dr Lis Ellison-Lochsmann, Dr Bridget Robson, Dr Felicia Hodge (Los Angeles), Dr Patricia Valery (Australia), Matthew Town (Canada) and Maui Hudson. This is a very impressive line up and promises to be very exciting.

The pair are planning a hui where the six Maori providers currently running cancer pilots around New Zealand can tell their stories.

Wai Health is a business unit of Te Whanau O Waipareira Trust, and they are working in partnership with the Waitemata DHB to deliver the Whanau Ora Navigator Cancer Care service.

They work with Maori - and non-Maori if they wish to join in - to support all cancer sufferers, helping them to understand the often difficult jargon. They help lead people through the system, "trying to enhance their journey, and helping them to get there a lot quicker," Edith says.

They have been working with patients, nurses and other staff to



Kimiora Raerino (left) and Edith McNeill aim to build more resilience in cancer patients

ensure they are getting to hear the stories of real people, which can be so heart-breaking."

Like the mother-of-six who presented to North Shore Hospital, and was quickly admitted; but Dad and the six kids didn't have the money to pay the \$5 parking charge. They waited until later that night when the parking attendant left.

Edith points out they are quicker than that now; with early support becoming part of the system.

But there are still areas where Tauranga nurses, for instance, are spending 70 percent of their time in non-clinical work.

Emily remembered the mother in April who, had eight kids and no transport. "They need advocates."

"They come to us fearful and isolated, full of frustration and anxiety, and they get to the clinics very irate and frustrated."

continued..

“They need support, in order to become more resilient, and they need to have the barriers to secondary care removed.”

Kimi’s conference organising committee have spent two days workshopping the possibilities.

“We’re getting good information already, and by the middle of the year the pilot programmes should have all been evaluated.”

They have also produced resources for patients, delivering support for patients in all tumour groups.

The books help demystify cancer, and attracting interest from the Northern network and from others who have heard of the resource.

“We may have upset some people by holding them back,” Edith says, “but we wanted to make sure the people who took part - and the western community - had the chance to work with them first.”

Once the patient resources have passed that first test - and been through the updating wringer, they will be only too happy to spread them further.

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