

Cancer Connections

A large, stylized yellow silhouette of a crowd of people is positioned at the bottom of the page, extending across the width of the content area. The figures are simplified, showing heads and shoulders, and are arranged in a dense group.

WELCOME to the Winter Edition of **CANCER CONNECTIONS**, put out by the cancer team at the Ministry of Health to ensure you stay up to date with some of the great work being done about the country.

WINTER 2008

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Adolescent and Young Adult Oncology Haematology Service (AYA OHS) Care Coordinator

For Ellyn Proffit, looking younger than her 33 years is a major asset.

Her role within the Midland Cancer Network is with Adolescents and Young Adults around the 14 to 24 year age range.

'I think I'm lucky enough to look younger than I am, so I think I get on pretty okay with them.'

She's been living "loud and proud" among Tainui, an East Coast girl from Ngati Porou who is also quick to keep open the lifeline to Gisborne throughout her 11 years nursing in paediatric surgery and oncology.

Ellyn took up the oncology role in the last five years of that stretch, and that has been very useful as she knows many of the young patients now coming into her service from paeds.

'Some of them want to know everything; some just want to go with the flow and just let it happen - faster. Sooner they get in the sooner they get out.'

Some are amazingly resilient.

Ellyn has a big territory, right across the Midland area of Waikato, Lakes and Bay of Plenty. Ellyn has been supported for the first year by Mariah Hudler, project officer (currently having a well deserved holiday) to help establish the service within the Midland region. The network has a work group formed of the key people that work with adolescents and young adults with cancer to assist and guide Ellyn and service development.

And she must maintain close links with Starship in Auckland.

The first eight months of her job was spent largely in marketing the role, not only to involved families, but also to the local health professionals who can provide the regional and local support necessary.

She recalled one young fellow in the eastern Bay of Plenty who was struggling, to the extent it was starting to take over his whole day as he worried about the cancer coming back.

'We were able to put support in for him locally, once we knew the problem existed.'

That however is one of the difficulties they face, where there is a need for a specialised service, with no immediate solution in the small towns.

'We know there are lots of counsellors out there, but the question is whether they have the specific skills required to deal with these adolescents and young adults.'

There is, she says, a huge gap for her people - 'Gi-normous.'

'But for adolescents and young adults - they are either put into the children's ward, or in with the adults, and they often have totally different issues going on with them.'

By maintaining her contact, she can now step in as her people transition from one area to the next and ensure the services and resources are appropriate.

'They've got their own health needs, they're not children. They are developing, they're special.'

It has been a learning environment too for Ellyn Proffit, where she can often sit in front of a computer, working out her next presentation, a little intimidated that she no longer speaks only for herself, but for the service.

She takes her own strength from her peers, and a fortnightly teleconference with her colleagues across the DHBs helps to keep her focused with her feet on the ground.



For Ellyn Proffit, looking younger than her 33 years is a major asset.

Support on the Journey

John Childs, National Clinical Director is enthusiastic about the progress being made around patient care coordination. In addition to the community based cancer support pilots in progress in West Coast, Tamaki and Rotorua, there are currently three major projects in progress to support the patient and family through their journey.

The **Guidance for Improving Supportive Care for Adults with Cancer and their Families and Whanau** is about to be released for wider sector consideration. The guidance includes reference to the broader social services sector, NGOs and allied disciplines which impact on the patient's quality of life from diagnosis to post treatment. (see page 11)

'We expect some robust debate and input,' says National Clinical Director, Cancer, Dr John Childs, 'but hope to inform people's understanding of where they are now, and where they need to be.'

The work of care co-ordinators is another component in the work to support the patient through what is often a confusing experience. As always in New Zealand, one size doesn't fit all.' Work also needs to be done about the role of the care co-ordinators, one of the key roles in supporting patients. 'We need to ensure patients get on the right pathway, that the right support is there for them, and that their care follows through.' 'Again,' he says, "one size does not fit all.'

In smaller DHBs one co-ordinator may be able to handle things, but in larger areas, the solution would lie very much around particular types

of cancer, ie breast cancer, prostate cancer. 'Some people can actually navigate themselves quite well through the pathway - so there is a real hierarchy of need. 'Some are high need, some intermediate, and some self-caring and capable. It's not have they don't have a need, it's that they have their own support systems.'

Co-ordinators have to be really careful in all this, he says, to ensure they are not detracting from people's ability to be self reliant.

John Childs talks about patients, such as in the Northland district, for whom the decision can be made that they should attend various clinics for assessment and procedures.

'What really is needed is that their clinicians and care coordinators sit down and work with an understanding of the patient need, how the appointments could best be managed.

'It comes down," he believes, "to two-way communication.' It is not just simply about putting resources into a problem, but about communicating and understanding, about sharing support information to improve decision making and ensuring the right framework is in place.

A major project about to get under way is work being led by the Regional Cancer Networks on developing a patient management framework for cancer patients in New Zealand.

A Wellington workshop being held in August will discuss proposals to develop clinical pathways for various tumour streams.

A vital aspect of all the work is to get the right up to date information. The flow of information is an essential part of the solution, continued..



John Childs
National Clinical Director

and work is being done on what our next generation patient management systems should be like.

The Ministry, networks, cancer centres and clinicians are working together to develop an information system that can track the patient's progress through the system, the referrals, waiting times, lab results, treatment modalities and hospital and out patient treatment episodes etc.

'It's about linking the information we have,' John Childs said, with:

1. The clinical information about patients and whether they are being properly cared for
2. Finding information about what is actually happening out there in real time
3. Accessing and linking the knowledge that flows around all these networks.

'It's about achieving equity of outcome, not so much as inequality of access'.

Good pathways improve access, at the same time exposing some of the other issues that need to be addressed.

Patient Management Framework

A one day workshop in Wellington in August could have a major influence on the delivery of cancer treatments and support services.

Midland and Central cancer network managers Jan Hewitt and Jo Anson visited Victoria (Australia) to see first-hand the structures being put in place.

'We need a common understanding of where we are, and whether models such as the Victorian framework could potentially give us the high-level framework and direction we need,' says Dr John Childs, National Clinical Director, Cancer, at the Ministry of Health.

Dr Childs said we would not achieve that just by transplanting another system, but needed to configure our own delivery and support services within it.

'In the meantime,' he said, 'there are a whole lot of pieces of work to be done.'

The workshop is open to surgeons, oncologists, and other related disciplines in the cancer sector.

The workshop, focused on the clinical pathway, will be held 21 August. Contact [Marjan van Waardenberg](#) for further information.



‘Exciting, stimulating and we’re making a difference’

Reviewing the work and successes of the Midland Cancer Network sets out a positive view of what may eventually be a national template.

Midlands’ Jan Hewitt was the first network manager appointed, and her early progress charted a path for the other three networks.

The geographical coverage of the NZ cancer networks is solely based on the medical oncology and radiotherapy patient flow. Therefore Midland covers three districts - Waikato, Lakes, Bay of Plenty, with an open invitation to Taranaki and Tairāwhiti as they may access other services such as cancer surgery from Waikato.

Regional planning and implementation for cancer started with a Midland plan for non-surgical cancer treatment - this is medical and radiation oncology and haematology.

With the support of funding from the Ministry back in 2005 Midland had two major projects working towards the requirements of the NZ Cancer Control Strategy Action Plan 2005-2010; creating the framework for the Midland cancer network, and continuing with the previous work on mapping the patient journey and the associated parallel processes for the major tumour groups.

As a result the MCN was formed late 2006 when Jan stepped aboard as the network manager, along with then Clinical Director Dr Jeremy Long.

To her nursing background, Jan had added an MBA as she headed into health management after working in all hospitals in the Midland region. She also added a postgraduate certificate in public health.

The network has a leadership, facilitation and coordination role, working across organisational / service boundaries to reduce the incidence and impact of cancer and to reduce inequalities with respect



Caleb Lewis (Inequalities portfolio), Loryn Scanlan (Service and patient mapping portfolio), Jan Hewitt (Manager), Dr Charles de Groot (Clinical Director), Margie Hamilton (Project officer), Absent: Mariah Hudler (Project officer)

to cancer. A key requirement is to support implementation of the NZ Cancer Control Strategy Action Plan. The network covers everything from primary prevention, screening, treatment, palliative care, support and research, workforce, capacity - it’s a huge scope and complex area of work.

To support this the network has two key work programmes, patient and service mapping, and reducing inequalities that cut across three work streams, service improvement, tumour specific and population based work groups.

And just two years later, in a presentation to the Cancer Control Council, Jan Hewitt was proud to point out, on the Midland Non Surgical Treatment Plan, that of the 27 recommendations:

- 12 of them achieved
- 14 ongoing

continued..

‘Exciting, stimulating and we’re making a difference’ continued..

- One not achieved; as a result of efficiency improvements as part of the whole process had eliminated the need at this point in time.

Work in progress includes patient and service mapping of early stage breast, lung, colorectal and prostate cancer, where all staff understand what happens and the patient views are considered when planning and improving services.

The network recently published a detailed findings and plan on improving services to breast cancer women within the region. “We all need to write things down on paper. So there is clarity of decision or direction, with no ambiguity. “

Jan commented a key achievement was creating a resident medical oncology and haematology service in Tauranga; and reinstating chemotherapy services in Taupo.

‘These are getting the benefits down into the community level; where patients now don’t have to travel so far, with reduced waiting lists, and reduced waiting times.’

‘The public don’t know what it all means, but they do understand when they see a doctor behind a desk.’

The network doesn’t deliver services, nor do they fund them.

‘We try and facilitate things, to improve the services offered to patients’ she says.

Sometimes, the need is to get both the health professionals and the very passionate volunteers “who do such a good job”, in one room, talking together.

Other key developments include enhancing continuity of care through nurse care co-ordinators. The network has promoted the employment of new generic cancer care nurse coordinators for hospitals that have smaller volumes for the different types of cancers; and dedicated nurses at Waikato where the patient numbers are higher, such as in breast screening, breast treatment, colorectal, gynae-oncology, adolescent / young adult. Waikato already has lung and haematology nurses in place.

The network has established a care coordinators forum to support the numerous nurse coordinators in the community, primary and hospitals – about 19 altogether.

‘It’s exciting, it’s stimulating – we know we are making a difference. We can prove we have brought improvement by bringing people together, with very little resource. Cancer touches everybody, and we all want the best of care you can get.’

That’s where the focus is.

Clinical Director

Charles de Groot describes himself as a communicator - he believes it a key requirement of his new role as Clinical Director of the Midland Cancer Network.

'People are beginning to notice things are happening, and the structures are now going into place to push the networks forward,' he says.

'Therefore, communication is vital.

'We have to tell the clinicians and health professionals what we are doing, then listen to them tell us we should be doing, letting them guide us.'

The path he looks for is to reduce duplication, although he admits one size doesn't always fit all.

Dr de Groot had been in his new job just a week when interviewed by Cancer Connections; he emigrated from South Africa five years ago, "recruited" by sister Cecile who is a GP in Edgcumbe further north-east from his Hamilton base.

Charles and wife Jennie brought Lucien, now 6 as a 15-month-old, while Julius, 3, is the real Kiwi.

They have no regrets at their choice - they found emigration here after a holiday look around surprisingly easy.

Waikato was taken with the South African graduate who had taken off for two years OE - "just like here" - in the United Kingdom. Several of his jobs in those two years were in medical oncology, and he found himself enjoying the work.



Dr Charles de Groot,
Clinical Director MCN

He qualified in both clinical chemotherapy and radiology, whereas the New Zealand system now tends to go either/or.

'I have found it useful having both insights,' the not-yet 40-year-old says.

When Cecile called he was ready for a new challenge, and now he walks in the shoes of the pioneering Dr Jeremy Long as the network work programme expands in the Midland

region to fulfil it's mission of improving access to services and reducing inequalities.

And for Charles and Jennie, 'the longer we are here, the happier we are that we took the big step of emigrating.'

His parents followed, with all their grandchildren in New Zealand. Sadly, Charles' mother has died, but granddad lives in Whakatane.

Reversing a trend

Richard North followed the money and the training opportunities after graduating from Auckland medical school, and specialising in oncology.

His postings in New Zealand's Anzac neighbour - ending at Newcastle, which he really enjoyed - were building a fine life for the North family, mum, dad and the two kids.

But they came back.

'It wasn't the money,' he is quick to reveal, with his current salary half of what he was receiving in Newcastle.



Dr Richard North,
Oncologist

And the lifestyle was fine, and the leisure. But he and wife didn't want their two young boys growing up as Aussies.

His family was in Auckland, hers in Hamilton, so the chance at running the cancer section at Tauranga Hospital was quite compelling.

When he arrived early in the new year, Whakatane opened their new cancer centre, where he visits fortnightly. And now nearly completed is the new Tauranga community funded cancer centre that will make life that much more comfortable for Bay of Plenty patients.

'It will be a nicer place to come,' he says of the new centre tucked away in the corner of the hospital campus.

'There will be more chairs there, so more patients can be treated.

'There will still be a bottleneck - me,' he concedes.

The additional facilities have definitely improved things already for Whakatane patients, with the new bonus of not having to grind across Bay of Plenty to visit Waikato Hospital.

Now Tauranga is the option.

'It's a big step up,' Dr North says.

His fulltime role - and a .5 position for a visiting Hamilton specialist will soon be boosted by advertising already underway for a further oncologist, and a haematologist.

Only then will the throughput of patients improve, 'because I'm already stretched. And we have a waiting list. You can really only work at the pace of your slowest component, at present that's me.'

Push too hard, and burnout becomes a factor, exacerbated by professional isolation.

He therefore visits Hamilton fortnightly, to maintain his collegial links for his required continuing medical education, and to take his cases to the new multidisciplinary sessions, where all the Midlands oncologists discuss the care and treatment of each case.

Dr North - just 36 - defends his peers who head overseas for the money and lifestyle.

'The student loan thing is a killer,' he says. Talking about the pull back to New Zealand, he said that if any one thing brought him back -

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The new Tauranga cancer centre on a corner of the hospital campus

apart from the family - it was the way Australia is developing into a two-tier system, with the private component of their system allowing the wealthy to get treated faster.

'They don't get better treatment,' he says, 'but they get it faster.'

Australian oncology also tends to be by the numbers, where the doctor gets paid \$50 for seeing each patient, a further \$100 if treatment is prescribed.

'Here, with the one-tier system, everything is fair.'

Dr North is also happy at the way the Western Bay of Plenty DHB has responded to his requests for resources, but points out he will have to keep asking for more with the Bay population heavily weighted over 65.

'It's the older people that get cancer,' he points out, and in Tauranga they often need more community support, having retired and then moved away from their family.

Breast cancer mapping

People often become closely involved in the fight against breast cancer because of the loss of a loved one. Loryn Scanlan's mother died from breast cancer.

A lot of her leisure time is spent supporting and competing in dragon boating with the Hamilton team of breast cancer survivors, and on into whaka ama.

Her day job is analysing the patient journey of those with breast cancer, painstakingly setting it down on long strips of paper that tell a fascinating story to experienced eyes.

Action areas show up, processes where the Midland Cancer Network can focus to improve the service patients get from their health professionals.

The data and the follow-up work - interviewing patients, holding focus groups - is based on a British NHS model, and it takes in depth mapping both in the patient processes and the information that is captured as well, to draw the very complex relationships together.

The two years of work has shown that no journey of different patients is ever the same, with the data gathered from the work of three DHBs always different.

For the breast mapping, Loryn interviewed 48 patients.

'It was a very humbling experience sitting in focus groups as women shared their stories.'

The waiting time to see an oncologist was similar for all three DHBs, but access to surgery was much quicker in Bay of Plenty.

'Equally there were areas of concern right across the DHBs, like support for patients when the news is unexpected.' These are highly stressful times.

The breast screening programme tended to provide one-stop clinics, where patients could be seen, then referred on the same day for multi-disciplinary care.'

Best practice would have available a team of pathologist, surgeon, radiologist and oncologist, continued..



Loryn Scanlan

but reality reported the ideal was not always achieved, purely because of workforce issues.

From the mapping, the network team was able to identify 10 key areas for improvement, and action plans have been written for those, included among them improving the outcomes for Māori and Pacific women, and lining up the waiting times for surgery right across the region.

And from the workshops the importance of co-ordinators emerged strongly, because patients often do not know what is out there for them, or how to access appropriate support.

Like the woman from Taupo who had to drive to Rotorua and back for the five or six weeks of radiation treatment, because she had a dog at home and no-one to look after it.

Or when WINZ denied a benefit to someone who had had to leave her job because of the tough treatment.

And the young mum with three kids at home and no support.

Often, Loryn Scanlan says, the problems come down to communication and education.

Breast Cancer Care Coordinators and Nurse Clinics established

Being able to coordinate care and support to cancer patients from diagnosis right through their journey is an important part of the new work being done by the Midland Cancer Network.

Waikato's two breast care coordination nurse specialists can be involved from the first moment, part of the screening programme or if referred by the GP, right through the patient journey.

About one-third of breast cancer patients come into the Waikato system through the screening programme, the others finding a lump and getting it checked out.

It used to be that one woman in 10 would have breast cancer, but now the statistic is one in eight.

Twenty hours of Rachael Collier's week is with the screening programme, the other 20 in a job-sharing role in the cancer care treatment pathway offering coordination and support with Lyn, and the other members of the vastly experienced breast team.

Lyn noted network team member Loryn Scanlan had done some excellent patient mapping of the breast-screening journey for women.

Among all the interviews and focus groups conducted, Loryn had found that women often have over 80 something steps from screening or clinic to the time she was diagnosed until completion of treatment and can have contact with 80 + services / departments along the treatment pathway.

Interviews with the women found for many, the waiting period for "women under investigation" or between services can be the most stressful, and support is vital. Rachael and Lyn in response to the women's need have established a clinic to offer advice and support.

Even though there may not have been a diagnosis, it is not uncommon for the pair to receive an early referral because of the stress and trauma facing some patients, particularly where there may be young family.

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'One of our roles is to be that consistent link, to try and reduce the duplication of appointments by keeping an eye on what is happening. To identify any gaps, and make certain no one is falling through them,' Rachael said. Lyn said, 'Its really a case of coordinating care as case managers for women with very complex needs between the various points along the journey.'

'We don't do home visits, but there is a lot of telephone contact, whatever they need,' Rachael added. The nurses run their own clinics, and sometimes they accompany patients who need support at a particular appointment, where their breadth of experience can be very helpful.

Rachael came into the network role with a background working with the Cancer Society over 15 years, while Lyn worked more within palliative care in the hospice and the hospital.

Rachael enjoys the screening role, but 'it works really well for me to be able to follow the ladies through, working with the screening programme then into my other role in the treatment phase.'

They also act as advocates for the service and for women, using the clinical expertise of the other nurses to providing input into the planning of case management.

They also interact with general practice and primary care through their clinics.

'Our backgrounds have given us good insight into the importance of good interaction with the community.'

Supportive Care Guidance for Adults with Cancer and their Families and Whānau

Improving the quality of life for those with cancer is a key strategy of the fight against the disease.

The Ministry of Health is working with a sector advisory group on the development of high-level supportive care guidance for adults with cancer and their families and whanau.

To improve access to high-quality supportive care throughout New Zealand, the guidance will provide:

- an evidence-based source of advice on planning and delivering supportive care
- best practice models, and
- a measure of strategic direction.

The principles behind the guidance are:

- high quality care and effective services are available from both government and non-government agencies, regardless of ethnicity, culture, or where they live
- services are coordinated and integrated across providers
- consumers are helped to access services, and make choices about those services
- consumers are involved in planning, delivering, and evaluating the services they receive
- services are configured to promote access for groups facing inequalities in cancer outcomes
- complementary, alternative, and traditional therapies are acknowledged.

The draft guidance document is expected to be available for wider sector consideration by the end of September 2008.

Ministry contact: [Emma Hindson](#)

Check out Friday, 14 November 2008 in your calendars

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