



Editors' note

Welcome to the first edition of Cancernet for 2016. The main focus of this edition is on palliative care, cancer survivorship and pastoral care for people with cancer.

Palliative care is discussed from a national perspective by Jane Rollings who provides a palliative care update for 2016, surveying work underway in the review of palliative care services in NZ. Palliative nursing as a specialty is looked at by Wendie Ayley and offers an insight into her role as a clinical nurse specialist providing palliative care in the community.

Inga O'Brien examines cancer survivorship and how the categorisation of cancer as a chronic illness may downplay important cancer experiences and explores the delivery of cancer survivorship care within existing models of care in NZ. Living with cancer is further looked at from a personal perspective by Mia Carroll who explores the need to shift from chronic management to working with people living with cancer to strengthen self management. Offering pastoral care to people with cancer is explored by Kath Maclean in her role as a Healthcare Chaplin.

Cross-Tasman cancer nursing collaboration to strengthen chemotherapy delivery standards is reported on, highlighting the successful two day workshop sponsored and hosted by Central Cancer Network at the end of last year.

We hope you enjoy this edition and invite you to suggest topics and share your clinical practice for up and coming editions of Cancernet. Please check out the guidelines for contributing on page 11.

Melissa Warren and Kirsten Unahi



In 2001 the New Zealand Palliative Care Strategy was published which set in place a systematic approach to the provision and funding of palliative care services, to ensure equitable access and culturally appropriate services to all those who needed it affected by life limiting illness. Five years on and a lot has happened in palliative care and a lot is still to happen. At times it can feel like an uphill journey and the wheels move slowly and at other times we can get swept along by the pack, working in an integrated and collaborative way. However fast we are pedaling, the journey is always exciting and challenging.

Dame Cicely Saunders founded the first Hospice in the UK in 1967. She revolutionized the way that society cares for the ill, the dying and the bereaved. The Hospice movement spread internationally and in NZ it started as a nurse led service and was mainly cancer focused. We are now seeing a much higher proportion of non-malignant disease in palliative care services – approx. 30 – 40% may be non-malignant. The demographics of those affected with life limiting illness is changing also as our population ages. The projected deaths for NZ to 2068 is truly an uncomfortable figure. From a projection of 30,500 deaths in 2016 to 45,000

deaths in 2068. What we know about these projections is that there will be many more of the very older person who will have more co morbidities and complexity of care needs.

The challenges that palliative care in NZ will encounter are no different than what any other area of health care faces. Not only do we have a growing need with the ageing and increasing population with more complex health care needs, we are also faced with differing expectations from consumers and referrers and an ageing workforce to try to meet

on the next page...

In this issue:

Palliative nursing as a specialty	3
Report from the Chair	4
Cancer survivorship	5
Pastoral care	8
Cross-Tasman collaboration	10

PEDAL POWER

KEEPING UP WITH PALLIATIVE CARE 2016 (CONTINUED)

those needs! In order to address these challenges the palliative care sector has been working closely with the MoH to prepare a national response.

This year the Ministry is leading a Review of Adult Palliative Care Services, asking the questions to understand how best to ensure equitable and high quality care whilst also considering projected needs for palliative care.

The sector welcomes this review as a timely look at and reflection on what has been achieved since the publication of the Palliative Care Strategy in 2001 and what is still to be achieved. This review will focus on palliative care provision not only across the specialist service (a team or organisation whose core work focuses on delivering palliative care, for example a hospice or hospital palliative care team - 2) but also that provided by providers of primary palliative care (care provided by all individuals and organisations who deliver palliative care as a component of their service, and who are not part of a specialist palliative care team 2).

Recognizing our ageing population and the impact it will have on palliative care, the Government last year announced additional funding for hospice services. The funding was divided into two components using a population-based funding formula;

- \$13 million per annum for sustainable funding of hospices and current services
- \$7 million per annum (from 2016/17) funding for new services and innovations
- starting with an initial \$3.1 million in 2015/16

The key message for the new service funding was that hospice would get the money but the value had to be shared with patients and families in Aged Residential Care, primary care and community settings. The purpose of it being to provide new roles and services that would improve the quality of palliative care in these areas.

Proposals are currently with Hospice New Zealand undergoing a national review before being presented to the MoH for approval. This is certainly an exciting time for Hospice services as they look forward to being able to support and empower colleagues to provide quality palliative care.

Another major piece of work which was published in December 2015 is Te Ara Whakipiri: Principles and guidance for the last days of life. Due to an UK independent review of the Liverpool Care Pathway (LCP) in 2013 which recommended replacing the LCP, the then Palliative Care Council of New Zealand (PCCNZ), undertook a review of the pathway and end of life care.

Te Ara Whakipiri is the culmination of an extensive literature review and evaluation and is a guidance document applicable to our NZ unique context. It provides outline and recommendations for best practice at the end of life for adults in NZ and is endorsed by key professional organisations.

Whilst a robust and credible document there is some acknowledgement that what the LCP offered us in New Zealand as a tool for those working in Aged Residential Care, is missing from Te Ara Whakipiri. To that end, the newly formed Palliative

Care Advisory Panel (PCAP) has agreed to reestablish a Last Days of Life Working Group to look at the provision of such a tool and also to develop an implementation plan.

Whilst the PCCNZ, the role of which was to provide advice to the Minister of Health and to support and encourage the continued development of palliative care leadership, started off this piece of work, it is the PCAP that now keeps the momentum going so how did that come about?

The PCCNZ was established as a subcommittee in 2005 by Cancer Control New Zealand (CCNZ). The Minister of Health announced the disestablishment of CCNZ under section 11 of the New Zealand Public Health and Disability Act 2000 effective from 7 August 2015. Consequently the PCC NZ was also disestablished with effect from 7 August 2015.

The Minister asked Ministry officials to transition the PCCNZ to a Ministry advisory group. Hence the establishment of PCAP, which is to provide advice to the Ministry of Health on palliative care services for adults.

Within their work plan also, PCAP will provide a report to the Minister of the Review of Adult Palliative Care Services by April this year. This review will no doubt look at how the Resource and Capability Framework, published in 2013, is being integrated into the work of specialist palliative care and how it is interpreted.

This framework is a key document for palliative care. It defines the model of care that all specialist services should be

working towards to achieve accessible and equitable care for all and it also is designed to provide guidance to funders and policy makers. There is variability to the response to that document nationally and understandably due to differing funding models.

How specialist services work collaboratively with primary providers of palliative care is essential – the model should be supportive and empowering. Specialist palliative care cannot do it all and neither should they. The providers of primary palliative care are critical in ensuring equitable care for all.

There are still many challenges in palliative care. There are multiple interfaces, differing understanding of what palliative care is and what the model of care means. Probably the biggest challenge of all that we face on a daily basis is being able to honour a person's journey by acknowledging their life, their value, hopes, fears and dreams. However, this is not just a challenge. More so it is a privilege and I am grateful to be part of this sector.

I look forward to the continued growth of palliative care and the recognition of the value it can bring to the health care sector and the patients and families who receive it. Working with others in a collaborative way to achieve the best for the patient is our central focus.

Working together and pedaling in the same direction on a bicycle built for... many!

**Jane Rollings, RN, MA(Nursing), Chair,
Palliative Care Nurses New Zealand**

Palliative nursing as a specialty

Many of us when we complete our nurse training assume that we will spend our careers supporting people to wellness. It is a strange thing then to end up in a specialty where end of life is the expected outcome. Some nurses know from the beginning that they belong in Palliative Care and many of the staff at Mary Potter have been in Palliative Nursing for many years. So what is it about palliative nursing that pulls people in and keeps them there?

The hospice movement really began its current life in the early 20th century as a place for “incurables”. Care was around providing nursing and spiritual care at the end of life and much of this work was done by holy sisters. However the modern hospice movement began in the 1960’s and can be attributed greatly to Dame Cicely Saunders, who studied nursing, social work and ultimately went on to study medicine and become a Palliative Physician. She introduced concepts such as constant pain needs constant control. In 1967 she opened St Christopher’s hospice in London and hospice as we know it began. St Christopher’s offered holistic care for both patients and their families. The term

palliative care appeared in 1975 from Dr Balfour Mount a urological-cancer surgeon.

Today hospice services offer support in both in-patient facilities and the wider community. Most of the work of hospice takes place in people’s own homes allowing them to continue living life as long as possible and admission to an inpatient unit is usually for review of complex symptom management or end of life. Many of our patients are never admitted to the inpatient unit and all their care and their death takes place in their own home.

As our population ages and people live increasingly longer lives without the traditional family unit support we are seeing a significant growth in Aged Residential Care and these facilities now offer much of the palliative care for the elderly. Mary Potter supports these facilities with specialist education for staff and consultative support with patient symptom management.

So what is it like to be a palliative nurse? I came into palliative nursing from a background of community nursing indeed I have spent the majority of the last 34 years working in the community. I moved to

Mary Potter from a role as community cancer nurse where I was increasingly supporting patients undergoing palliative chemotherapy. I was struggling with an increasing sense of having “failed” patients who I supported through “curative” treatment only to have them referred back to me some time later receiving palliative treatment. I decided the time was right for me to shift the focus of my care to the last part of the journey where death would be an inevitable outcome.

As a community palliative nurse I had the joy of working with people in their homes who were indeed still getting the most out of life. I had to schedule my visits around tramping trips, bridge club, fishing expeditions. Sometimes I had to wander around the garden to find a patient who was bottom up in the rose bed. I always told people “If you get a better offer don’t feel bad about canceling my visit. Life is for living”.

But there were some very difficult times, talking with families whose child was dying, offering support to young mothers having to face leaving their children with no Mum as they grew up. There were the patients whose pain we

“How people die remains in the memory of those who live on.”

DAME CICELY SAUNDERS

struggled to control and the families who phoned an hour after I had left to say “Mum just vomited again”. Clearly the magical syringe driver and prn antiemetic weren’t so magical!

Often when I made first contact patients denied all knowledge of the referral to Mary Potter. They had been told they were being referred to palliative services, not Mary Potter, that’s a hospice for people who are dying! I would then have to become the hospice salesman and talk my way “In the door”. One lovely gentleman, after I had explained our service told me I was very welcome to come again but “I don’t want them hospice people coming here”! Needless to say I continued my visits, gave advice on all sorts of symptoms and supportive therapies, talked about his deteriorating health and eventually talked about dying. I was never sure if he realised I was one of those hospice people or not.

The job was about being able to meet people in their place of comfort and safety, help them to journey through the hardest time of their life, empower families and whanau to see that they are the ones doing all the important work, the loving, caring, supporting, listening. My visits were just part of their support team and someone to get them back on track or give them new options, or very occasionally bring them in to the inpatient unit to provide some respite and complex management

Report from the chair



It is with pleasure and trepidation that I now take over the role of the chair of the CNC NZNO. Pleasure because I, as all of you, care. We care about the health of New Zealand people and we care about improving cancer nursing, service delivery and outcomes.

Trepidation because I have big shoes to fill! Our previous chair Angela Knox has performed an outstanding role, steering the committee and working groups admirably to achieve completion of projects including the knowledge and skills framework and the development of the draft national standards for administration of antineoplastic drugs. Angela is thankfully still contributing to the CNC in completing the national review of the KSF document and its implementation.

I know Angela has put countless hours over the last two years as chair, leading committee core business and representing cancer nurses at numerous meetings. Thank you Angela, you are an absolute treasure.

We have a great new committee and had our first meeting in February. We welcome Kirsten Unahi, Joseph Mundava, Felicity Drumm and Fiona Sayer.

We also sadly farewell Wendy Jar, vice chair and Cancernet editor. Wendy has continued to take the Cancernet to a new level. She has also put hours into the website development project. Wendy will still be supporting CNC as she continues this project.

Please enjoy this edition of Cancernet and share with your colleagues.

Kind regards,

Judith Warren, Chair
NZNO Cancer Nurses College

Palliative nursing as a specialty (CONTINUED)

then get them home again.

Working with patients and whanau in the community is about giving them the confidence to watch you walk out the door knowing they have the tools, the strength and the knowledge to see their way ahead for the next few days whilst also knowing help is at hand if they need it.

It is also about recognising that dogs, cats and even cockatoos are very loved and adored so if by chance they should decide to sit on you, no matter how large they are, take it as a compliment, and if the cockatoo feels your ear needs some remodelling, take it in good stead. You really are very privileged that they are sitting on your shoulder! Some visits were extended due to a cat falling asleep on my lap which led to the patient finally trusting me and telling me her real fears and worries.

I was very grateful to that particular cat. Sometimes patients would be testing me through their animals, would I show fear? Would I be judgemental? Pass the animal test and you are halfway there!

And what about the family photos? Being a palliative community nurse is about recognising the personhood of this person. They may be dying now but they have lived and their legacy is their family. Rather than ask about pain or bowels, I often began a visit with enquiries about the children, grandchildren, great grandchildren.

As the stories were told I took the opportunity to “notice” guarding, restlessness, discomfort, sadness. Expressions of symptoms which revealed

themselves as the patient relaxed and told me their stories.

There is more than one way to skin a cat! A lovely gentleman refused to discuss his symptoms with me at all but loved having a tea party with me. We would have tea from bone china cups and he would always make a cake in preparation of my visit and as we drank and ate then he would tell me his “troubles” but I was never allowed to walk in and ask without the “Tea party”.

So being a palliative community nurse is about understanding that the person comes first. Each encounter will be unique. Each person will respond slightly differently and much of your time will be spent answering questions they have asked of others to see if you will give a different answer. “No of course you are not dying you have years left” is what they would love me to say but if I did they would know I was lying and I would lose all integrity.

But this journey, this relationship, is a strange one. I play a very significant role, yet I am not significant. I must remain “*Just a nurse*”. Not someone they need to depend on, not someone they feel fearful of leaving them. Not someone who loves them or becomes whanau. Just a nurse, with a basket of knowledge, good ideas, great backup from the multidisciplinary team back at base, the District Nurses and the GPs who I regularly liaised with and a lap that cats can fall asleep on.

Wendie Ayley
Clinical Nurse Specialist Palliative Care
Mary Potter Hospice, Wellington

CANCER SURVIVORSHIP

Survivorship care pathways are needed in Aotearoa New Zealand

Cancer and survivorship were once words with opposite meanings. In this day and age, more people live with cancer, than die from it. The increasing cancer survival rates are a great success story.

But, novel care pathways for this substantial population group have not evolved as quickly. Progress by survivor advocates, scientists, nurses and research participants have made advances in cancer diagnosis, treatment and survivorship possible.

Care pathway redesign to incorporate cancer survivorship is now a priority. The USA, UK, Canada and Australia have demonstration project or other survivorship initiatives in place. Although no demonstration project has worked seamlessly, each project adds to the rapidly evolving knowledge base on survivorship care. It is time for NZ to put in place survivorship care pathways and suggest quality-of-care indicators to enable evidence of pathway value to be explored.

History

Dr Fitzhugh Mullan coined the term 'cancer survivor' in his groundbreaking 1985 *New England Journal of Medicine* article, entitled **The Seasons of Survival**. He pointed out the need for advocacy by people living with and beyond cancer to address unmet needs over three time periods which he coined as seasons. He called these seasons of survival: acute survivorship, extended survivorship and permanent survivorship.

He described the category of acute

survival as beginning at diagnosis and extending through primary treatment when fear and anxiety were constant and heightened.

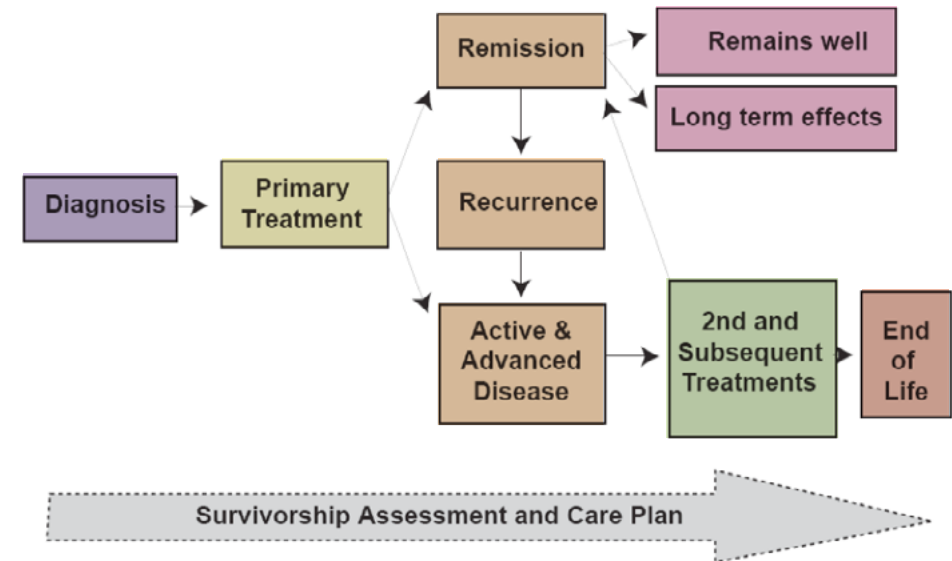
Extended survival began at the end of primary treatment when fear of recurrence and recovery from treatment-related physical limitations took place amidst periodic follow-up appointments.

Mullan's permanent survival season encompassed the five-year survival mark indicating "cure" but often with ever-present secondary impacts on mental and physical health.

As survivor advocacy and survivorship research progresses, so does the understanding of survivor seasons. Mullan's (1985) original stages of survivorship have been variously re-framed. This makes sense considering that cancer-related impacts, survival rates and unmet needs vary by cancer site and by population group. So, do these survivorship seasons work for NZ population groups?

In many countries, survivors have established formidable advocacy forces to get recognition for their ongoing needs. The needs of cancer survivors internationally are unique and not well understood. Most of the time, the impacts and needs are invisible but very real. Diverse groups of advocates have fought for resources and delivery of appropriate survivorship care to get unmet needs recognised and addressed.

Lance Armstrong made a phenomenal impact on cancer survivorship by using his celebrity status to raise awareness about the challenges of cancer survivorship.



Armstrong described feeling powerless after completion of treatment and unsure of what he was supposed to do to help himself. The foundation he began, now called LIVESTRONG, continues to be a great resource for cancer survivor information, support and advocacy.

Cancer survivors' experiences were described in the 2006 book on cancer survivorship, **From Cancer Patient to Cancer Survivor: Lost in Transition**. This book aimed to raise awareness of cancer survivorship, define quality health care for survivors, and identify strategies to improve the quality of life for survivors. It clearly showed that many people complete primary treatment relieved and overwhelmed but unaware of ongoing challenges, for example, fear of recurrence.

MacMillan Cancer Support in the United

Kingdom is another leader in the survivorship space. Their vision of working in this space is illustrated by the survivorship pathway that has evolved into a lateral or cyclical pathway beyond primary treatment.

Source: Department of Health, Macmillan Cancer Support and NHS Improvement, NCSI Vision, 2010, p. 23

It must be stated, that the tireless efforts of surgical, oncology, community and care coordinator nurses to provide quality cancer care amidst organisational and system challenges is phenomenal. But, it is not enough. The efforts of nurses alone to address cancer survivorship will fall short, no matter how hard you are trying, if systemic issues such as human resourcing, financing, IT capability and accountability for quality care are not addressed.



Survivorship care pathways are needed in Aotearoa New Zealand (CONTINUED)

NZ experience

NZ cancer survivorship is associated with health loss. Survivors face post-treatment challenges to physical health, finances, relationships, emotions, identity and future prospects. High-levels of uncertainty are present. NZ survivors show great strength in their efforts to keep calm and carry on.

Rising above the terminology debate on the applicability of the words 'cancer survivor' in NZ, NZ survivors need new care pathways to support them. Most cancer survivors are grateful for second chances and practice positive thinking but still need support to address ongoing or intermittent cancer-related morbidity or disability. Cancer survivorship 'ain't' easy, even with the documented associated possibilities for post-traumatic growth and new outlooks. Cancer care delivery in NZ has not systematically adapted to integrate support for people living with long-term cancer impacts.

Survivorship initiatives are underway. Some oncologists are using survivorship care plans as a way to provide a treatment summary and build awareness of potential survivorship issues for patients at the end of treatment. In addition, The Cancer Society's Otago/Southland division delivers a group programme developed by Otago University researcher Dr Sue Walthert called Bridge to Health. Further, The Nelson Regional Breast & Gynaecological Trust makes available online A Survivorship Passport developed by NZ cancer survivor advocate, Andrea Fairbairn.

Although cancer has been traditionally treated as an acute condition in NZ, the trajectory of this group of diseases now consists of what can be described as a chronic phase. Life for cancer survivors is characterised by significant lingering

impacts on well-being, finances, social identity and family/workplace communication. Improved care pathways are needed.

Is cancer survivorship best served by classification as a chronic condition?

A recent PhD study by the author involved adaption and testing of a chronic care intervention in cancer care settings. The World Health Organisation classification of cancer as a chronic condition guided the choice of intervention. But, is cancer survivorship really a chronic condition?

To answer that question on whether cancer is best served by classification as a chronic condition, the value and applicability of using the Chronic Care Model to guide cancer survivorship care was explored. It is easy to draw a parallel between the illness experiences of people living with chronic conditions and cancer survivors. A diagnosis of a chronic condition and cancer both alter a person's physical and psychosocial health. They each impact on perceptions of identity and how people feel about themselves and how they feel perceived by others. Further, they each must be managed to prevent re-occurrence of acute symptoms and minimise adverse consequences. They impact on quality of life. Under the Chronic Care Model, survivorship care pathways would include supported self-management intervention, action plans, and partnership processes between general practitioners and survivors.

However, there are some important differences between cancer and other long-term chronic conditions that make the question of appropriate care pathway not so easy to answer. From the diagnosis of a chronic condition, the person diagnosed is treated as a co-partner in care

management and considered an expert in their illness. For cancer survivors, this is not the case because it is not realistically possible for survivors to take equal responsibility for managing their illness from diagnosis when a speedy response is needed. In addition, the complexity of cancer treatment pathways are very different from most chronic illness care pathways. Further, the impact on identity is more severe due to cancer survivors' normal contemplation of death as a possible outcome and the common condemnation or advice received from others over lifestyle choices.

The conclusion proposed is that despite cancer having aspects in common with other chronic illnesses, cancer survivor experiences are distinctive. The categorization of cancer as a chronic illness may downplay important acute experiences and impacts from the cancer experience. This complicates the view on which approach to survivorship care pathways best serve survivors' needs and desires to move forward.

Models of survivorship care

The delivery of any cancer survivorship pathway needs to fit with the predominant existing models of care in NZ. The main models of health care and delivery, as influenced by the predominant publicly-funded health care system, can be described as disease-centred care, person-centred care and Māori-whānau centred care. In general, within each of these models, the workforce, infrastructure and culture impact on interventional approaches and care delivery.

The majority of published survivorship research centres around the themes of shared care, survivorship care plans and

supported self-management intervention. Shared care involves a planned and formalised process of transition for the cancer survivor from oncologist care to general practitioner care. Survivorship care plans include a treatment summary and a patient-driven care plan. Supported self-management intervention in cancer care incorporates self/whānau-assessment surveys, guided interviews/sessions, and care plans to empower people to better manage survivorship transitions. The survivors' and families' values, priorities and goals guide negotiated actions documented in a person-centred care plan.

So, in answer to the question: Should cancer survivorship care in NZ follow an oncology pathway, a chronic condition pathway or a shared care pathway? The answer is not clear. What is needed is further research and the development of a cancer survivor risk stratification tool that takes into account diversity in culture, priorities, health complexity and life complexity. It is difficult to conceptualise a 'one-size fits all' care pathway considering the diversity and complexity of survivors' experiences and priorities.

Cancer survivorship may be delivered in an acute rehabilitation model, guided by a chronic care model or as a shared care model. There is no right approach. It is worth considering weekend survivorship clinics based in cancer centres and Cancer Societies. The focus of moving forward survivorship clinics could include a combination of illness-related work, biographical work and practical support. Survivorship care is needed in NZ and this would be a start.

Inga O'Brien, Supportive Care Manager and Deputy CEO, Cancer Society, Wellington

Do you practice in or have a special interest in an area of cancer nursing?

Do you want a forum where you can share ideas, information and expertise with others in the same cancer care subspecialty?

Do you want this forum to contribute to the objectives of NZNO Cancer Nurses College, New Zealand's recognised professional organisation for cancer nurses?

- Network with colleagues in your subspecialty within New Zealand
- Develop a newsletter for your SIG and contribute to it!
- Participate in discussions with other SIG members
- Share your expertise
- Support/mentor a colleague
- Distribute information and communications to your colleagues, eg educational opportunities, calls to action, recent advances in care, articles and research, newsletters, meeting minutes
- Contribute to the mission and objectives of NZNO and NZNO CNC
- Utilise NZNO support and resources

APPLICATIONS OPEN NOW!

Please contact the SIG coordinator for further information about how to establish a SIG and an application form at cancernursesnz@gmail.com

NZNOCNC provides members the means to form Special Interest Groups (SIGs). All members of NZNOCNC are eligible to belong to a Special Interest Group.

Here are just a few potential SIG examples

Haematology

Solid tumours

Clinical trials

Clinical nurse specialists

Prevention/early detection

Surgical oncology

Survivorship

Quality of life

Cancer genetics

Chemotherapy

Radiation oncology

Ethics

Complementary therapies

Palliative care

Lymphoedema management

The 2016 Cancer Nurses College COMMITTEE



L-R Back row: Anne Brinkman, Judith Warren, Melissa Warren, Sharron Ellis, Moira Gillespie.

L-R Front row: Felicity Drumm, Joseph Mundava, Kirstin Unahi.

A warm welcome to our new Cancer Nurses Committee members Felicity Drumm, Joseph Mundava and Kirstin Unahi who represent both the North and South Islands of New Zealand in cancer care. Profiles on our newest committee members to come in the next edition of Cancernet.

Nursing is great for so many reasons, but there is one reason that means more than any poll results, amount of money, or job security: Nurses make a difference.

BRITTNEY WILSON, RN, BSN

Strengthening self-management for people living with cancer.

A PERSONAL PERSPECTIVE FROM MIA CARROLL

My goal in life is, as the French say, “Je ne regret rien” ...to get to the end of my having lived mindfully and with no regrets. That means I want to “be in charge” of me, as much as is possible, right to the end. Autonomy is such a precious thing. In this sense, I am using autonomy to mean my capacity to choose; to choose what I want, what I decide and what I will do to self-manage.

What this requires when faced with long-term illness are health professionals who are emancipatory in their self-management support. Yeah right! Big word like gumboot but what does emancipatory mean? Well, for me it means lots of things.

Firstly, it means health professional being willing to “see me”, not just my illness or cancer.

It's them being willing to dance with me, collaboratively, compassionately, and with a totally transparent and negotiated agenda. It means sharing the choice of which dance, where we will dance, and to what music. We have to negotiate who will leads, for how long, and will that always be the case? It means being mindfully present with me, to listen to “what matters most for me”, not just “what is the matter”?

Our relationship is key and this is by no means simple. It requires personal insight into the values and ethics, which underpin and drive our decision-making and our practice. We have to know our motivations and intentions; especially if

they are in conflict with those we serve. Every interaction we have with people and their whanau has the potential to ‘heal’ or ‘harm’... to empower or disempower. They need us to be on their team and this may require we drop or adapt our agenda.

Secondly, language and approaches matters!

We need to shift from Chronic Care Management to working with people living with long-term conditions. These are people ‘living with’ cancer not ‘lung cancer patients’ or ‘breast cancer patients’. The word patient implies a dependent somewhat subservient role and we need to be particularly careful not to fuel learned helplessness or passive recipient responses. They are more than their illness.

Our relationship to strengthen self-management in an emancipatory way requires a solution-focused, strengths-based approach as opposed to a deficit or problem-oriented approach.

Our people may not always have had “great experiences” with us; they may feel blamed for their illness if their lifestyle has not been ‘healthy’. They can feel fatalistic and powerless. Our work is to remove obstacles and barriers to their “staying in charge” so we have to recognise, praise and maximise their current strengths, abilities, resources and supports, be they physical, emotional, cultural, intellectual, social and or biomedical.

We have to believe in them and their

*Ko koe ki tēnā,
Ko āhau ki tēnei
Kīwai o te kete*

*You hold that handle
And I'll lift this handle
And together we can
carry the kete*



whanau that they “can handle whatever needs to be handled” and accept whatever cannot be changed. This may involve grief work and certainly requires skills in the assessment of their level of anxiety, fears and possible depression. We need to be hope-generating not spirit-breaking.

Thirdly, to be emancipatory means being willing to share power.

That means offering me access to information in a way that is accessible, supports shared decision-making and allows me to understand the risks, benefits and harms of all treatments and interventions.

This requires me to understand the numbers of people needing to undergo these treatments before there is a benefit or harm (NNT, NNH). We know that this is currently not done well and we also know that if people are given this information they often make different choices, which may include fewer interventions.

Finally, we need to be servant leaders who act with humility, cultivate cultures of trust, facilitate, coach and partner our people.

We need to respond to their changing needs along the journey as part of a

collaborative team. Again, this can be challenging given we have been educated in silos and tribes to cure, solution and ‘fix’ things. We may need to expand our capabilities of assessing self-management of our people, their whanau and their community. We may need to grow our strengths of coalition building and community organising. We may need to learn and offer acceptance commitment therapy and of course we need advance care planning.

The bottom line is we need to fully understand “What valued directions our clients want to go in after making informed choices and what's getting in their way?” and as that African Proverb says: If you want to walk fast, walk alone, if you want to walk far, walk together.

Nga Mihi nui

Mia Carroll, RN, BA, DPH, MHSc, FCNA (NZ)
Professional Teaching Fellow,
School of Nursing,
Faculty of Medical and Health Sciences,
The University of Auckland.
Advance Care Planning Facilitator,
National Advance Care Planning (ACP)
Training Programme.

Offering pastoral care to people with cancer

In my ministry journey of offering pastoral care to people with cancer, I have walked with many people; some have a faith and belief in God, agnostic or atheist, and others have other e.g. belief in a higher being, meditation, goodness. One thing several of the people have in common is a feeling of isolation and loneliness that enabled them to recognize they had a need for spiritual/pastoral care and they approached me. Getting alongside and listening to how people describe their condition is where I begin.

Do they talk about cancer with a small c or in capital letters CANCER. I recently had a phone call from a person who I had had contact with when her husband died and I facilitated the funeral, she rang me up and we had a chat then she said in a matter-of-fact way that she was dying, she named the cancer and gave me the medical names and that it would happen sooner rather than later. She asked me to take care of her funeral and keep company on the journey.

This began a journey that concluded at

the funeral. I visited regularly and we chatted about whatever was on her mind at that particular time. She shared her childhood faith and church-going experiences. She still believed in God. She talked through her diagnosis and she was talking about cancer with a small 'c'.

What part does fear play?

For some people especially those who have a family history of death from cancer. There is a constant fear that they live with that almost overshadows their life. The expectation is not if I get CANCER but when. I have had this voiced several times to me.

From a pastoral perspective my role is listening to how people describe their journey with cancer, being fully present and facilitating an exploration of the fear or fears. This involves naming and talking about the impact and hopefully deflating and normalising thoughts and feelings.

Fear is real not something to be dismissed rather it needs to be understood and integrated. With the person who

contacted me fear was at a low level, the focus was on staying warm, having her hair fall out and "What can I eat? I am so hungry". In talking of her death she shrugged her shoulders she was very aware that each day she lived was a celebration and she appreciated her family who were constantly with her.

Do they describe their response as flight, fight or acceptance?

People respond in different ways and some don't want to acknowledge what is happening so they try to carry on as usual, which is not always possible.

Others go into fighting mode and I will fight this to the end, I will beat it could be their motto. The person who called me was in a place of acceptance, all treatment was finished and she was waiting. It was a planned waiting, with time in the hospice included.

How do they view their body? What are their thoughts about their body that has grown this cancer? Do they see the cancer as an invader? What labels do people use in describing their cancer?

- This is 'evil'
- This is a 'test'
- This is 'punishment'
- This is a 'mission'
- This is it, just is

They are talking about their body, so how are they experiencing their physical body and how is that impacting on their thinking. The way people think or respond can generate energy and this energy can deplete them physically, mentally and spiritually.

Listening to their stories?

It is essential to listen to how they view self, e.g. being a victim or loss of identity, as well as understanding and hearing their creed about faith/life and cancer. Hearing from them, what do they need? Discovering rituals or practices that are meaningful for them (e.g. mindfulness, sacraments, prayer, journaling).

Together we unpack the confusion. We find small things to celebrate, one lady loved hedgehogs so whenever she had an appointment a fluffy hedgehog would keep her company. She had a hedgehog key ring and we made cards, the message being we are never alone and that we have someone keeping watch.

Other ideas maybe planning small celebrations, anniversaries of surgery, some people give names to their stomach after bowel removal, so in one family they sent birthday cards to this new person and joke, as it has a man's name about keeping a man close by.

It is important to normalise change, enjoy laughter and quality time together. Others want to work on their relationships or spend time quietly on their funeral service. The person who called me said she wanted the same service as her husband. She liked to watch the roses in her garden that were blooming. She enjoyed her grandchildren's visits.

Pastoral care to people with cancer reminds us all that yesterday is history, tomorrow is mystery and today is a gift.

**Rev Canon Kath Maclean, M.HSc.
Accredited NZ Healthcare Chaplain,
Chaplain Te Korowai Whariki. CCDHB**

Cross-Tasman cancer nursing collaboration aims to strengthen chemotherapy delivery standards

Sarah Tomkins, the eviQ Education Manager at the Cancer Institute of NSW was the invited guest to a two-day series of workshops hosted by the Central Cancer Network (CCN) in Wellington at the end of last year. Sponsored by the Capital and Coast and Mid Central DHB Directors of Nursing, the event was aimed to build on the progress made with the regional pilot to introduce the Antineoplastic drug (Chemotherapy) Administration Course in the central region. The course was developed by the Cancer Institute of NSW and is now recognised as the best practice standard programme for chemotherapy administration services across all states in Australia.

For a number of years the cancer nurses sector in NZ has identified the need for a nationally-consistent best-practice-based chemotherapy assessment and training programme. The eviQ ADAC programme with its strong evidence base and online learning methodology was identified as providing the solution to a number of issues regarding the sustainability of the current range of different programmes available in NZ.

Presently, each chemotherapy treatment service has developed their own bespoke and largely paper-based programmes which require regular updating with no ability to develop national consistency. Under this model it has been difficult to develop an agreed national standard for chemotherapy administration and safe handling in NZ.

ADAC was developed by the Cancer Institute NSW and follows a strict governance process that includes the involvement of a wide range of clinical experts to ensure the content reflects current best practice. Because it used online learning methodology it can be continually updated at source.

It supports health professionals develop the necessary knowledge and clinical skills to administer antineoplastic drugs via different routes and handle related waste safely. The course itself is linked directly to 'eviQ Treatments on line' which is a point of care clinical information resource already widely used in NZ.

In March of 2015 the two cancer centres in Wellington and Palmerston North, under the Central Cancer Network, embarked on a pilot project to implement ADAC in their region. The pilot also includes Taranaki and Hawkes Bay DHBs as they provide chemotherapy services under the MidCentral DHB Regional Cancer Treatment service. After much preparation, including sending two nurse educators to be trained as ADAC facilitators in Australia the implementation went live in July of this year. Key collaborators in the project have been the online learning providers for the central region DHB's, Ko Awatea for MCH and 'Connect Me' for C&CDHB.

Though the pilot is not due to finish till April 2016 there has been much interest nationally from other cancer centres and DHBs in implementing the ADAC programme. For this reason it was decided to invite

Sarah Tomkins out in support of the CCN pilot and to respond to the growing interest nationally. Co-sponsorship by the Directors Nursing at Capital and Coast and Mid Central DHBs was provided to enable Sarah to travel to New Zealand.

The two-day workshop was a great success with over 30 nurse educators and senior nurses from around the country attending the facilitator training workshops. This included three from paediatric oncology for which there is an associated ADAC course. Feedback from the participants was overall very positive.

About 40 people attended the second day which covered the wider resources available through eviQ treatments online and an evaluation of the CCN pilot so far later in the day. Stakeholder attendees included service managers, colleagues from other disciplines and consumer representation.

Regarding the future direction of ADAC in NZ it was agreed to build on the existing relationship between the CCN pilot study team and eviQ Education. Those present endorsed the suitability of the ADAC programme for wider role out nationally. They also supported the move to a closer partnership with eviQ in terms of NZ membership of their Advisory Committee and NZ involvement in the expert clinical advisory groups through which eviQ maintains its best practice standards.

Part of the purpose of the pilot was to consider what aspects of the course require greater contextualising to the NZ setting including alignment of the Treaty of Waitangi and our own legislative requirements for managing cytotoxic materials. The cultural aspects was an area the Australians have a keen interest in given



In the photo are right to left: **Andrea McCance**, Director of Nursing and Midwifery, Capital & Coast DHB. **Sarah Tomkins**, eviQ Education Content Author and Project Manager, Cancer Institute, NSW. **Barry Keane**, Nurse Director, Central Cancer Network and MidCentral DHB. **Michele Coghlan**, Director of Nursing, MidCentral DHB. **Karyn Sangster**, Director of Nursing Primary Care, Counties Manukau DHB and currently holds the national portfolio for Cancer Nursing. **Paul Smith**, CNM Wellington Blood and Cancer Centre and Nurse Director, Central Cancer Network.

the different context for the programme other countries such as NZ represent.

The event proved to be of great value in cementing a partnership with our Australian 'cousins' in supporting our need to strengthen standards of chemotherapy care in NZ in the interests of patient care and staff safety. It also aligns strongly with government priorities to strengthen our, in this case, nursing workforce to meet the future cancer care need in our community. The pilot itself also demonstrated the value of collaboration between cancer centres and nursing leadership in developing standardised best practice approach to care provision for the population we serve.

For enquiries regarding ADAC implementation project in New Zealand please contact Barry Keane or Paul Smith.

Professional Development in Oncology/Palliative Care for Registered Nurses

January – December 2016

CPIT Aoraki offers a wide range of courses for Registered Nurses so we can be your institute of choice for lifelong learning. These courses are available at CPIT Aoraki during the academic year. You can choose from:

Course Dates	Course Title	Course Code	2016 Fees
Semester One:			
22 Feb-18 April	Care of the Dying Person: Managing Nausea/Vomiting [online]	GCNV700-16-T1	\$285
2 May-27 June	Care of the Dying Person: Cultural Perspectives [online]	GCCU700-16-T2	\$285
9-11 May	Communication, Bereavement and Ethics	GCBF700-16-T2	\$285
30 May-1 June	Understanding Cancer	GCUC700-16-T2	\$285
13-15 June	Nursing People with Leukaemias	GCNL700-16-T2	\$285
Semester Two:			
11 July-12 Sept	Care of the Dying Person: Chronic Illness [online]	GCCI700-16-T3	\$285
15-17 August	The Nursing Management of Breast and Gynaecological Cancers	GCBG700-16-T3	\$285
5-7 September	Management of Cancer Related Problems	GCCP700-16-T3	\$285
19 Sept-21 Nov	Care of the Dying Person: Managing Pain [online]	GCEP700-16-T3	\$285
31 October-2 November	The Nursing Management of: Lung & Central Nervous System Cancers	GCLC700-16-T4	\$285

Dates and fees may change – contact us for the most up-to-date details.

To secure your place in class, you need to either pay, or indicate your employer will be paying your course fees.

Contact us for further details and enrolment enquiries:

0800 24 24 76

www.cpit.ac.nz

info@cpit.ac.nz

GUIDELINES FOR CONTRIBUTING TO CANCERNET...

Why contribute? Why publish?

- To share knowledge
- To advance your field of practice
- To disseminate key findings or opinions
- To contribute to policy debates

Introduction

Cancernet is a newsletter that is published three times a year by the New Zealand Nurses Organisation Cancer Nurses College. Cancernet aims to inform and encourage nurses managing people with cancer to share opinion, resources, clinical practice and continuing professional development.

Types of articles

All types of articles are welcomed and can include;

- Opinion
- Clinical practice
- Case studies
- Continuing practice development
- Literature review
- Advanced study (e.g. BSc or MSc) write-ups

Submitting your work

- Articles should be submitted in Microsoft Word via email to cancernursesnz@gmail.com
- Acknowledgement of receipt of your submission will then
- Acknowledgement of receipt of your submission will be sent by email.

Word count

Opinion articles should be between 700–1000 words long. However, clinical-based articles and literature reviews and advanced study articles, these can range from between 1,500 and 3,500 words, including references.

Illustrative and images

Authors must obtain permission for the use of illustrative material or images and ensure that this material is labeled and captioned.

Referencing

A recognised referencing system to be used. If the reference list is long, the reference list is available on request from the author.



Funding options to attend conferences or courses

Funding to attend conferences or courses is becoming increasingly hard to source.

Apart from your local DHB, here are some funding options that you may not have thought of.

To apply for funding you need to be organised with many groups having funding rounds and deadlines throughout the year.

- For members, the NZNO offers several funding streams. These include NERF, Florence Nightingale, Thomas Tippet award, just to name a few. For further information including criteria and closing dates:

 Visit the Scholarships section on the NZNO website

- The NZNO CNC also has a grant available for those that have been members for longer than two years. Additionally a grant, generously sponsored by Roche, is open to NZNO members (CNC membership not a prerequisite). For further information including criteria and closing dates:

 Visit the Grants & Awards section on the NZNO website

- The Genesis Oncology Trust has various award rounds throughout the year to support health professionals working within cancer care to attend courses or conferences. For further information on criteria and closing dates go to:

 Visit the Grant Application section on Genesis Oncology website

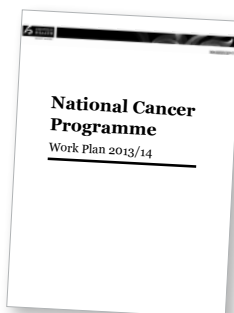
- The Blood Cancer NZ and the Cancer Society offer grants for health professionals to attend conferences or courses. They usually have funding rounds. For further information contact the Cancer Society or Leukaemia and Blood Cancer NZ.

If you are aware of other funding streams that are available and you want to publicise them, please contact us on  cancernursesnz@gmail.com

National Cancer Programme update


The Ministry leads a national work programme which provides a strategic focus for cancer control and for system-wide improvements across the spectrum of cancer services.

 Keep up to date on the National Cancer Programme



Online cancer learning

 www.cancernursing.org

 www.cancerlearning.gov.au/build/edcan_learning_resources.php

 www.ons.org

 www.isncc.org

 www.eviq.org.au

 www.nccn.org

 www.cancercontrolnz.govt.nz



HSANZ
Haematology Society of
Australia and New Zealand

Haematology Society of Australia and New Zealand

New Zealand Annual Branch Meeting

4 – 6 April 2016

**Diary these dates to attend
HSANZ in 2016
Further information to follow**

Rydges Latimer, Christchurch
4 – 6 April 2016
www.spconferences.co.nz/hsanz-2016

Important diary dates

4-6th April, 2016, Christchurch
HSANZ 2016 Annual Scientific Meeting

 [Find out more information](#)

12-14th April, Brisbane
The Inaugural World Indigenous Cancer Conference 2016

 [Find out more information](#)

20-22nd May, 2016, Queensland
Australasian Skin Cancer Conference

 [Find out more information](#)

23-25th May, 2016, Barcelona
The 16th International Conference on Integrated Care

 [Find out more information](#)

26-27th May, 2016, Auckland
The 5th NZ Lung Cancer Conference

 [Find out more information](#)

4-7th September, 2016, Hong Kong
ICCN 2016: International Conference on Cancer Nursing

 [Find out more information](#)



Cancer Nurses College badges

are now available for purchase for \$8 each.

They can be purchased from CNC committee members or by emailing the committee on cancernursesnz@gmail.com and using internet banking.

Cancer nurses committee

cancernursesnz@gmail.com

CHAIRPERSON
Judith Warren
021 475 876

COMMITTEE
Felicity Drumm
021 983 829

SECRETARY
Moira Gillespie
027 447 3775

COMMITTEE
Joseph Mundava
021 145 6106

TREASURER
Sharron Ellis
027 525 4865

COMMITTEE
Kirstin Unahi
027 403 1814

CO-EDITOR
Melissa Warren
04 806 2615 or
027 839 1902

PROF NURSING
ADVISOR
Anne Brinkman
04 494 8232










Roche +

What you need to know and more



Register now

Roche-plus is a resource website for New Zealand healthcare professionals. It features useful online tools and information on Roche's products, access programmes and services.

-  **Patient Resources:** Latest patient support materials
-  **Access Programmes:** Information on current Roche Access Programmes
-  **Journal Access:** Full access to over 1800 journals
-  **Medical Image Base:** Full access to over 20,000 high quality scientific images, illustrations and animations
-  **Events:** Details of events and Roche support available
-  **Grants:** Information on financial support available from Roche
-  **Products:** Information on Roche oncology, haematology and rheumatology medicines, as well as the Roche oncology pipeline

Go to roche-plus.co.nz and register now

We welcome contributions to Cancernet. Interesting stories, notices and photos relevant to our nursing community are always appreciated. Email us at

 cancernursesnz@gmail.com