

CYN_et



Newsletter of the Advisory Group for National Child and Youth Networks

November 2012

From the chair..



In this issue of CYN_et we bring you what you have all been waiting for – information from the Clinical Networks that we have been developing. You may ask – why these networks? What is more important about these than the service that I work in?

In May 2011, Mollie Wilson and I, together with Mark Woodard who was contracted as a facilitator travelled around the country asking you, Child Health Professionals for your opinions.

We reminded you of Sir Ernest Rutherford's famous quote "We don't have the money, so we have to think". We noted that the goal for Clinical Networks is to improve quality and safety of health care for children and young people in New Zealand and that the elements of the quality improvement cycle are well understood. The tough question is "what shall we do first?"

You told us that you understood that we needed to start small and that improving the way services are delivered would take time. You also identified some key issues that needed to be addressed. These were:

- Information sharing at both the population and individual level.
- Information about best practice to be readily accessible to Child Health Professionals across the country e.g. guidelines, pathways, and protocols
- To be able to link with and talk with colleagues within the health sector and across other sectors relevant to child and youth health
- Access to training and continuing professional development to help you be effective and provide high quality services.

And in the last centre a very important point was raised about "professional respect". We need to respect the part that we all play in the complex system of health care and truly understand that without working in concert with our colleagues from the wide range of disciplines in health we cannot provide quality care. Each cog in the health machine is important. I think if this had come up at our first meeting then it would have been endorsed for in every centre.

When the Advisory Group met to select the initial Clinical Networks we were guided by what you had told us about what you thought was important. We discussed whether Clinical Networks should be developed around services or around programmes of care for specific problems

and concluded that there was a place for both approaches. We also wanted to avoid duplicating work that was already happening and to take advantage of areas that offered the opportunity to explore how we could best address the key issues that you had told us were important.

We chose a Clinical Network for type 1 diabetes to find ways of sharing information across the country that would help clinicians to ensure that every child and young person with diabetes has the best control possible.

We chose a Clinical Network for eczema to look at how clinical care can be improved across the continuum of health care from self care and primary care through to the tiny group of children with severe eczema who need tertiary care input. By providing good information we hope to see a reduction in hospital admissions where eczema is a contributing factor.

We chose a Clinical Network for Palliative Care to look at how services can be linked across services, disciplines and the care continuum.

And lastly, we chose a Clinical Network for Child Protection to support work across sectors that was already developing but needed a leadership focus.

The learning from these networks will help us to develop future networks.

Our aspirational goal is that every child and young person in New Zealand will receive the right care at the right time in the right place and by the right person. This fits with the Minister's imperative of Better, Sooner, More Convenient (BSMC)

In conclusion I would like to share with you a story about professional respect. This was told to me recently by a good friend. At lunch, another friend asked if she had met "Joe" at the hospital. Joe is in his first year as a newly qualified doctor. My friend's various achievements over her working life had been described to Joe. But Joe was unimpressed and his comment was "but she's only a nurse".

Our junior colleagues learn in many ways. They especially learn by the example set by more senior colleagues. Let's all make a resolution right now to extend professional respect to all our colleagues, junior, senior, professional and paraprofessional and non-professional – do you know the name of the person who keeps your work space clean?

Rosemary Marks

National Child and Youth Clinical Network Advisory Group

Palliative care for children

As the only current paediatric palliative care specialist in the country, Ross Drake, is hoping to have a colleague join the service in the near future. The rest of Starship team comprises 2 nurses, a social worker and part time psychotherapist and child psychiatrist. The only other DHB in the country with paediatric palliative care expertise is Canterbury which has recently employed a nurse in this demanding area.

Ross chairs the Ministry of Health Palliative Care Advisory Group which has just completed and had signed off by Hon Tony Ryall a document titled "Guidance for Integration of Paediatric Palliative Care Services in New Zealand". The document outlines a consistent and integrated approach to palliative care for New Zealand's children and young people, and through a strong implementation focus aims to provide some equity of care regardless of where the child lives. While specialist services cannot be replicated across New Zealand the Starship service provides support to the many health providers caring for these children and has been duly recognised as a national service in the document. With the focus on a team approach the document is about developing an extra layer of expertise between the paediatric services in the regions and Starship. It recommends establishing, supporting and educating nurses to provide a specialist level of palliative care for children in the regions. This is seen as the most cost effective way to provide the majority of care in the child's home, the setting of preference for most children and their families/whanau.

Wide Scope of Care

Contrary to popular beliefs, palliative care is not just about child cancers, in fact around 70% of the team's work is of children with non malignant conditions such as metabolic conditions, heart abnormalities, congenital and birth issues, chromosomal syndromes and neurological conditions like Duchenne's muscular dystrophy. Children with disorders of the nervous system makes up the majority of this work. Even more interesting is the work being undertaken when a fatal condition is diagnosed during the antenatal period. This gives the family the option of continuing their pregnancy with a birth plan developed with them and extended to embrace their babies death whenever that may be during the pregnancy, delivery and following birth. Again, the focus is on team work and the holistic approach to caring for the family/whanau.

The Importance of Listening

Ross describes the support his team provides as covering four key elements; the physical (te taha tinana), psychological and emotional (te taha hinengaro), social (te taha whanau) and spiritual (te taha wairua) that is the existential question of why and what does this all



Palliative Care Specialist Ross Drake.

mean! It also involves making sure attention is paid to good cultural care.

The team is always learning new things from the children and their families and can still be taken by surprise by the candid honesty of the kids. He says even more revealing can be what the families don't say when they are coping with a long-term and maybe life-threatening condition. "It is important for us to remain open to the families and to be able to listen to their needs", he says. "The children and young people do see things in their own particular ways, which I think is special." Ross recounts the story of a young man who went boating with his family while in the last stage of his illness. The young man was so unwell he slept for the outgoing boat trip. When he woke a pod of dolphins joined the boat and played around the boat for around 20 minutes. All of the

dolphins left, except for one dolphin which stayed with the boy all the way back to berth. For the family and especially for the young man this was special and spiritual and will stay with his family forever and will be with them long after his death."

The Wisdom of Children

Ross and the team at Starship describe palliative care as being far from depressing. "Of course, it has its difficult moments when we lose people we have become close to, but we are also treated to many very special moments," says Jess Jamieson, Social Worker with the Starship team.

Jess talks about how those "special moments" become very precious memories of the many wonderful children, young people and their families that members of the team have had the privilege to become involved with. Jess recalls one young person who had been sick since birth. This young man opened up the conversation about death and dying by saying that he had just been told that he was getting weaker and that his heart was working very hard so it was time to go home to "live the rest of my life on the couch." He talked about how he regarded his life as having been a "ministry" in that his illness had allowed him to meet so many people that he never would have if he had not been sick. He faced the last weeks of his life with great openness and humour, continuing his "ministry" via his computer and through the amazing generosity of his family in allowing his supportive community to remain closely involved through the most intimate time of their family life. Like many other young people who transition to palliative care, this young man really did focus on living as fully as possible throughout what remained of his life.

Jess recalls another young adult who knew that she was dying but who had two goals she needed to achieve. The first was to go to university and the second to go flatting. This young woman would be the first from her family to go on to tertiary education

and desire to go flatting was seen as an important part of the transition to adulthood. Surrounded by a good group of friends, she set about achieving these goals. Her friends found a home close to her chosen university which she saw and excitedly talked about and she bubbled with joy and enthusiasm when she talked about enrolling and then having her first day at university. It was with pride and a real sense of completion in her voice that she asked Jess to “tell them I got to university” just a few days before her death.

Children often have amazing insight into what lies ahead. One young child, from many years ago, when told that he was not going to have any further tests and that he and his mum were going to go and have breakfast at McDonalds (on a morning when he had been nil by mouth as he was expecting to go the theatre) asked “what are we going to do now mum”? Her response was that they were going to go home and they were going to treat him with love – “let’s see what love can do”. He accepted that explanation and went home, going out mushrooming with his favourite nurse the day prior to his death.

It’s a Privilege

Members of the Starship team talk about what a privilege it is to be involved with these children, young people and their families. We are often in awe of the ability of families who do their best through the very worst of times. While we are aware that we cannot change the outcome, interventions that can address the four elements that Ross discussed earlier can make the journey a little easier for the child and the family, as well as a very special experience for all the health professionals that may be involved in paediatric palliative and end-of-life network of care. ■

The white paper on vulnerable children

The long-awaited White Paper on Vulnerable Children has been generally welcomed by the paediatric community. Dr Rosemary Marks, President of the PSNZ said “the emphasis on collaboration across sectors and agencies at local and national level is most welcome. Only by working together can we make a difference to the lives of our most vulnerable children”. Alignment of boundaries for the different agencies and organisations working with children would support the development of strong collaborative processes and improve our ability to network effectively. The strong emphasis on training and developing appropriate skills for all professionals who come into contact with children is also welcomed. Professionals from all disciplines and across sectors need to know how to recognise vulnerable children and what action to take when they do identify a child at risk. They need to know who to contact and how to ensure that interventions to support the child and their family are put in place. ■

Paediatric diabetes group

Having just started formally networking at the beginning of this year, the Paediatric Diabetes Group is well down the track towards achieving some significant goals. Chair, practicing Paediatric Endocrinologist and Associate Professor Esko Wiltshire says the initial six work streams are working hard and making gains in several important areas. The twelve member executive committee comes from different DHBs.

The first work stream is working on establishing a national database of children and adolescents who have type one diabetes and their outcomes. Esko says that national consistency with resources and good data on the incidence is needed. “We know that nationally Type One diabetes is increasing and we are not sure why. We also want to ensure that all children and adolescents get the best and consistent treatment regardless of which DHB they are treated in”, he said. “We need good networks in every DHB”.

Another work stream is updating the ketoacidosis protocols for children. Esko says that children do need to be managed differently to adults, with a higher risk of cerebral

oedema and other complications, and nationally consistent protocols will improve the management of these children, especially where there is no paediatric endocrinologist.

A brief workforce survey has attempted to establish what differing resources DHBs have and what they need in a benchmarking exercise. The results of this will be fed back to members. Another work stream is looking at resources for families affected by Type One diabetes, including a website. “It is a very scary thing to have a child diagnosed with Type one diabetes – even the best management cannot totally remove the risks of premature death,” he says. “Any support we can give the family in ensuring the information they get is accurate and consistent will be empowering for them.”

Esko says that despite the current national inconsistency in treatments, type one diabetes is managed pretty well in New Zealand and on the whole our outcomes are as good as anywhere in the world, despite having fewer resources. “Even though it is not our primary role, we are prepared to lobby for new technologies to be available for New Zealand children and in every DHB,” he said. ■

Paediatric dermatology

For Starship Paediatric Dermatologist Diana Purvis, treating children with eczema and treating them well is a passion. "Eczema is a common condition, yet the impact it has on kids and families can be extreme. Eczema causes itch, pain, infections, loss of sleep and stops them from enjoying everyday activities such as swimming. So although it may not be life threatening, on a day to day basis eczema's effect on families is huge. Around 15% of New Zealand children have eczema, and it is a major risk factor for hospitalisation with skin infection" Eczema is now recognised as primarily being due to ineffective skin barrier function. This results in a 'leaky' skin which allows irritants, infections and allergens to penetrate and cause inflammation. Treatment is focussed on restoring skin barrier function through settling inflammation with medications (eg topical steroids), supporting the skin barrier with use of moisturisers, and minimising exposure to triggers. Sub-optimal use of topical medications in treating eczema is one of the commonest causes of treatment failure. This can usually be prevented through good education of the patient and caregivers. "Just as doctors don't prescribe an asthma inhaler without providing education on how to use it, I would like to see all prescriptions for eczema accompanied by education for caregivers on how topical products should be used" says Diana. Improving the treatment of eczema is one of the reasons the Paediatric Society opted to use networks to link primary care into managing and educating patients better. The aim of the Network for the Treatment of Childhood eczema is to upskill primary care providers, develop specialist eczema nurse roles to educate and act as a liaison between primary and secondary care, and improve access to specialist secondary and tertiary services. "Most cases of eczema are mild to moderate and able to be managed in primary care. For a small minority, around 10% of children with eczema, it is more severe and complex, and benefits from specialist care," says Diana. "It is frustrating to see families who have had to struggle with difficult eczema for years, when seeing a knowledgeable professional can turn their lives around within weeks. The aim of the network is to change this by encouraging healthcare providers to recognise when treatment isn't working and refer on," says Diana. Interventions utilising specialised nurses to deliver eczema education and care have been implemented in a number of DHBs with success. In Wellington Debbie Rickard, a nurse practitioner and nursing lead of the Eczema Network, has established nurse-led clinics and been inspirational to the development of nursing roles in the care of eczema in New Zealand. In Northland, eczema nurse specialist Pauline Brown is piloting delivery of an eczema education package to primary



Diana and her daughter Charlotte

care nurses, with evidence of improved knowledge about eczema by primary care nurses, and improved outcomes for patients.

Testimonials from patients and parents utterly support the network approach to their care.

"Her skin was shocking - I'm getting tearful now thinking about it...We had followed all suggestions, but nothing worked. The turning point came when the nurse educated me on the importance of getting Rose's bath routine right in order to optimise her skin hydration, and moisturising frequently throughout the day, not just at nappy changes. She also busted some eczema myths for me; e.g. bathing

every day is crucial. Within just a couple of days her skin had almost totally cleared up. I saw for the first time in months that baby had creamy skin - I could only remember it being red and angry looking. She sleeps for four hour stretches now, too".

"Since focusing on her baths the change in her skin has been dramatic. I think if more parents with eczema kids knew about the importance of baths, we'd spare more kids (and their parents) a lot of misery"

"Your help, guidance & support has been life-changing for our child & us. Thank you is not enough!"

"Overall we really did not think we would get results like this so quickly, it brings tears to our eyes just thinking of where we have come from.

We really have been bringing up eczema rather than a son, now it seems like we are bringing up a son and in the background he has eczema. We were so focussed on the eczema, it certainly is a blessing for what we are enjoying as a family now."

"There are Angels out there and they are called nurses!"

"I do think Wellington has been the exception (possibly throughout the world) with their involvement of nurses (in co-operation with doctors) and the difference that has made ...and hopefully the hospital realises they've been successful leaders in this approach...you can tell from the online blogs/questions about eczema that others don't have access to the same level of information on care of eczema."

In addition improved understanding of management of severe eczema including the use of immunosuppressants means that specialists can offer effective therapy even for those with the most severe disease. "There is a lot of good work happening in pockets around the country, the challenge to this network is to utilise these existing resources to lift the quality of care and improve access for all children with eczema no matter where they live", says Diana. ■

Supporting families to cope with stress

Training the trainers to support families to recognise when they need time out is the mission of Kati Knuuttila. Kati is the National Coordinator for the Prevention of Shaken Baby Syndrome (SBS) at Starship. On average, 20 babies are admitted to hospital around New Zealand every year with such injuries. Their average age is five months. Some are injured in the first month of life. Many have been injured more than once by the time of diagnosis. One in five of the babies that are diagnosed will die and 30-60% will suffer moderate to severe injuries often causing a life-long disability. There is evidence that many more babies in the community may be shaken, than are admitted with a recognised head injury. It is likely that diagnosed head injury is only the tip of the iceberg of inflicted head injury.

The Shaken Baby Prevention Programme gives a unique opportunity to provide effective, simple and consistent education about infant crying and the harm caused by shaking a baby. The Shaken Baby Prevention programme includes information about infant crying, and the dangers of shaking a baby. It also provides helpful tips to support parents on what they can do if they are feeling stressed, and where they can go for help. This is delivered through a one-on-one or group discussion. The participants are also given a brochure to take home and they are offered an opportunity to watch a DVD (Never, ever shake a baby. You have the power to protect).

Fundamental to the programme is the message that all of us can be pushed over the edge by a crying baby. It is how we respond to this stress that Kati is trying to change. Kati is currently working with 7 DHBs to implement the programme and has another 3 lined up. She also works with organisations outside the DHBs such as Plunket and CYFs. Plunket has been trained to deliver the programme to its staff. A good example of networking in practice is South Canterbury DHB who invited CYFs, NGOs, independent midwives and Police to the programme launch. All got the necessary information at the same time plus made the connections to work together. Kati believes, because of the nature of SBS and its indiscriminate appearance in all socio-economic groups that everyone working with families in any capacity, needs to be able to talk knowledgeably about this. Kati shares a story about a friend of hers – a high-flyer

in the corporate world who admitted to feeling out-of-control for the first time when she had a baby. "Everybody needs a 'frustration plan'. It is normal to feel frustration with a crying baby", says Kati. "Caregivers need to be able to take time out, check the baby every 5 minutes, but do not pick up baby until you are calm again. The message is simple. Everyone owns this. Everyone can lose it. We all love our kids but a momentary loss of control can have disastrous consequences", Kati says.

The DVD features kiwi families whose lives have been affected by shaken baby syndrome, and gives tips on how to cope with a crying baby. It also includes expert comment about shaken baby syndrome and the consequences of shaking a baby. This programme is based on a model developed by Professor Mark Dias in the United States, which significantly reduced the incidence of shaken baby syndrome. There are risk factors for this type of abuse such as age (infants are at highest risk), lower socioeconomic status, young mothers, a male living in the house who is not the biological father but is acting in the role of father and a history of partner violence. However, this type of injury can occur in any family and of any ethnicity, and is more likely to be missed in higher socio-economic groups.

The programme includes six key messages:

- Crying is how babies communicate, and it is normal for caregivers to get frustrated when the crying doesn't stop. Make a plan for what you will do when you are feeling frustrated.
- It's okay to walk away. First you should check if your baby is sick or needs feeding, changing etc. If you can't find a reason for the crying and you're getting upset, it's okay to walk away. Put baby in a safe place, close the door and take a break. Do not pick up the baby until you have calmed down.
- Never, ever shake a baby. A single moment when you lose control may damage your baby forever.
- Never leave your baby alone with anyone you think may lose control
- Share this information with anyone who looks after your baby.
- If you ever think your baby has been hurt, call 111. Don't let fear or pride stand in your way. It could save your baby's life. ■

Useful Links

1. HIIRC public site <http://paednetwork.hiirc.org.nz/>
 - Home page with introductory text <http://paednetwork.hiirc.org.nz/section/16370/child-and-youth-networks/?tab=3949>
 - Clinical Network Development in NZ <http://paednetwork.hiirc.org.nz/section/17102/clinical-network-development-in-nz/> - includes CYNets April 2012
 - International literature (11 documents) <http://paednetwork.hiirc.org.nz/section/17105/international-literature/?contentType=1311&tab=3953§ion=17105>
2. Paediatric Society Site <http://paediatrics.org.nz/>
3. New Zealand Child and Youth Epidemiology Service www.otago.ac.nz/nzcyes

4. Kidshealth www.kidshealth.org.nz a joint initiative between the Paediatric Society of N.Z. and Starship Foundation.

Together, our mission is to provide accurate and reliable information about children's health for New Zealand parents and caregivers, as well as the wider family and whanau who are involved in caring for our children.

Kidshealth is also a website for the range of professionals who work with parents every day, including doctors, nurses, early childhood staff, teachers, mental health professionals and others. We hope these professionals will refer parents to the site, or download and print its information for the parents they are working with.

Kidshealth will also increasingly include information written specifically for the range of health professionals who are working together in national child and youth health clinical networks.