

G R A C E

Parents & Carers Newsletter

Edition 4, Autumn 2011



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Staff Profile: Kathryn (Kathy) Meredith

Name and title/role

Kathryn (Kathy) Meredith

Clinical Nurse Specialist
and Acting Discharge
Liaison/
Family Support Nurse

I facilitate the process of children leaving hospital and returning home, although for many young babies this may be the first time they have been home since their birth. I support families through this process, sometimes visiting the higher-risk infants at home, working in conjunction with the early childhood nurses and assisting parents over the phone too when they have questions or concerns. I liaise between the medical and allied health teams and the families to also help in the discharge process.



Work Experience/History

I studied Applied Science (Nursing) at the University of Western Sydney (a few years ago now!) and came out into the work force with thousands of other newly registered nurses that were not able to be employed in local Sydney hospitals due to government funding etc. I remember going for a job interview at Gosford Hospital with 700 other applicants for a small number of positions. They were desperate times for new nurses and I thought I'd be joining the many who were going back to Uni to become a teacher or choosing another profession.

I got into agency nursing and worked in various hospitals before I found a semi-permanent position in Occupational Health and Safety at a Woolworths warehouse doing night shifts!

My next job was at Westmead Neonatal Intensive Care Unit- what a learning curve! I studied Critical Care Nursing, majoring in Neonates at the University of Sydney and then, after five years or so, I wanted a change and began to do casual shifts at The Children's Hospital at Westmead. A year and a half later I decided to try the surgical side of neonatal care and asked to come and work in Grace Centre for Newborn Care and I've been here ever since. I have been in the current role of Acting Discharge Liaison since October 2009.

Favourite part of the role and least favourite part?

My favourite part of the role is watching the parents become empowered - it's nice to see when you begin with parents who are apprehensive about caring for their infant at home, with or without equipment, medication and a thousand medical appointments, and once you've taught or reassured them they realise that they are fine and they have the ability to cope with the circumstances they find themselves in. Of course, the least favourite part of the job is when nothing works and you feel like you haven't helped.

Why did you become a Nurse and choose to specialise in NICU?

I became a nurse because I felt an affinity to it and I felt a compassion that was easily channelled through the job. I think that is just the way my brain is wired. I'm certainly not akin to accounting or politics. When I was at University the first time I did a clinical placement at Westmead Hospital in paediatrics and surgical units and the preceptors took us on a tour of the NICU there. I was fascinated by this and the NUM at Westmead saw how eager I was and they eventually trained me.

Your aspirations/goals

My work goal for the coming year is to try to learn more about my role and child and family health and to advance my skills in this area.

How do you relax after work?

I have eight nephews and two nieces that I love to visit and baby-sit – they often come to my place for sleep overs. Although it may not be completely relaxing, it's entertaining - and I can give them back afterwards! I relax by watching DVDs, reading books, playing my guitar, listening to an eclectic collection of music and planning my next holiday.

What advice do you have for parents in Grace?

Take a deep breath and let it all wash over you! What else can I say? Every one of the parents in the unit will cope in different ways. Take time to cry and laugh. Talk to your children - we won't think you're crazy. Don't be afraid to touch them and ask to be involved in their care. They are yours and in my 15 years experience, even tiny babies definitely know who their parents are.

Patient profile: Samuel

Lisa is a member of the Grace Parent Advisory Council. In 2001. Lisa and Mark's baby was born prematurely with feeding and breathing difficulties.

My story is about my extraordinary little man, Samuel.

Let me give you a snapshot of Samuel:

- He's 9 years old and loves school
- He's clever and kind
- He loves to play cricket on weekends
- His favourite food is sushi and chocolate croissants
- He won't eat fruit, but he will eat some vegetables (but only on his terms)
- He is a fantastic brother to Benjamin and Madeleine
- He loves going to his friends' birthday parties

“When I first saw my little boy in Grace Ward, he had a tiny beanie on to keep him warm and was surrounded by alarms, monitors, wires, tubes and cords. ...”

Samuel is now leading a very normal, healthy, happy life. He's a unique character. We first noticed that Samuel looks at challenges in a lateral and innovative way when we were trying to help him learn to crawl as a baby. Samuel was about seven or eight months old and we had put a chocolate about a metre in front of him – hoping to encourage him to crawl towards it. But not Samuel. He grabbed a plastic golf club that was lying next to him and tapped the chocolate back to him rather than him having to move!!



Samuel as a newborn in Grace Ward

More recently, we were playing a game with the kids at the dinner table and they had to answer the question, “If you were stranded on a deserted island what three things would you take with you?”

Without missing a beat, or rather some of his pasta, Samuel chimed in with “A boat!!” – and that was the end of the game for everyone...

Samuel in Grace Ward

Now if we skip back to December 2001 when Samuel was born, it wasn't all fun and laughs like we have with him now.

Actually, through some parts of the pregnancy and during his stay in Grace Ward we weren't sure if he would ever make it out of the hospital, never mind get to where he is now.

Samuel was born prematurely and was impacted by a condition that affects children in many different ways. Samuel was affected in three significant ways.

He had a condition called **Exomphalos**, where some of his internal organs were still in the umbilical cord. He was born with an **adult size tongue** that meant when he slept or lay on his back it would fall back and block his airway. He was also unable to regulate his **blood sugar levels** which, if left uncontrolled, could lead to permanent impact on his cognitive processes.

Samuel arrived six weeks early in Westmead Hospital, just next to The Children's Hospital at Westmead. He was stabilised and transferred within the hour to Grace Ward through the interconnecting corridor.

We had visited Grace Ward just the day before to see what the ward looked like – it is potentially a frightening place for new mums and dads – especially when seeing their baby in that environment.

When I first saw my little boy in Grace Ward, he had a tiny beanie on to keep him warm and was surrounded by alarms, monitors, wires, tubes and cords.

He had a tube down his throat, was connected to a ventilator that was helping him breathe, had a drip in each tiny little hand, wires attached to his chest to monitor heart and pulse and his umbilical cord that contained part of his bowel was attached to him and wrapped in Glad Wrap (seriously) for protection. He was attached to monitors on his feet to read the oxygen level in his blood and he had a tube from his nose to his stomach for feeding.

Our first cuddle was amazing and the nurse looking after him was simply fantastic. We started bonding with him regardless of all the equipment he was connected to.

This was the first of our 61 days in Grace Ward.

On day two, he headed to the operating theatre for his first operation to repair his tummy. While the prospect of surgery on our little baby was frightening, we knew he was in good hands.

Living in Grace Ward

After some time, Samuel had progressed to the Extended Care section – still connected to the monitors but able to breathe on his own.

A wonderful and vital aspect of Grace Ward is the encouragement of family-centred care. From the start, we were encouraged to have his brother beside Samuel's bed. When Sam got better, he could help bath him and hold him. This helps normalise things in an extraordinary environment. It also helped to give us the confidence that we could care for Samuel at home.

A set back

One Friday, Sam started to experience some difficulty in keeping his oxygen saturation levels high enough. He had been struggling all day. At one stage, he started to go blue in my husband's arms.

That night there was a doctor on duty, an Englishman called Neil, who was on rotation through Grace as part of his neonatal intensive care training.

Neil was magnificent – watching, monitoring, caring, treating and ultimately having to intubate Samuel again and have a machine help him breathe. The dedication and commitment to our children's wellbeing from the staff in Grace is part of their job every day.

Lots to learn

The weeks spent with Samuel in Grace were a massive learning curve for us. The staff taught us about feeding a baby who had difficulty swallowing - he was fed through a tube until he was about eight months old.

They taught us what all the monitors measured, as when he came home he was still connected to two of the monitors – his bedroom was like a mini-ward for a while there.

They taught us how to use a C-Pap machine that would aid his breathing. They also introduced us to a range of specialists that would support Samuel as he developed through each stage – many of whom we still use and refer other parents to.

The staff in Grace Ward are remarkable people who helped us care for our little boy and gave us the confidence that we could care for him at home. To all Samuel's medical team who were always there to answer our never-ending questions and to quietly reassure us – thank you.

SIDS Guidelines



1. Sleep baby on the back from birth NOT on the tummy or side
2. Sleep baby with face uncovered (no doonas, pillows, lambs wool, bumpers or soft toys)
3. Avoid exposing babies to tobacco smoke before birth and after
4. Provide a safe sleeping environment (safe cot, safe mattress, safe bedding)
5. Sleep baby in their own safe sleeping environment next to the parent's bed for the first six to twelve months of life

www.sidsandkids.org/safe_sleeping.html

Staff in GCNC may not always follow the SIDS Guidelines owing to medical needs of babies. You will be advised if SIDS guidelines are not appropriate for your baby or speak to a staff member if you're not sure.

Support Group



The Day of Difference Foundation is dedicated to working for critically injured children and their families. Throughout Australia over 60,000 children are seriously injured each year.

They work together with sponsors and donors to build a community of support for all children and their families who are struggling with life changing critical injuries.

Their mission is to make a difference to the lives of critically injured children and their families by supporting them on their journey from emergency to recovery.

Website: www.dayofdifference.org.au

Phone: (02) 8920 9000 or 1800 DOD KIDS

Email: enquiry@dayofdifference.org.au

About Grace Centre for Newborn Care

Grace Centre for Newborn Care takes its name from Grace Bros Staff Aid to Charities, an organisation which promotes fundraising for many hospitals. The Children's Hospital has been a major beneficiary since 1924.

Grace is a Neonatal Intensive Care Unit which specialises in caring for babies with surgical, cardiac and complex medical conditions. The neonatal period is defined as the first 28 days of life, but we do care for babies older than that, depending on the condition they have and if they have been born prematurely. We work closely with the PICU and many babies are admitted there if they are outside our criteria.

Over 80 staff are employed on shifts to care for 23 babies at any one time. We are currently funded to have eight ventilator beds and 16 High Dependency beds. Behind the front office there are many back office staff – lactation specialists, occupational therapists and a research team.

Interesting facts about Grace:

- Over 130 babies were admitted in the past three months - over 620 babies in the past year
- Average length of stay is approximately eight days
- There are three shifts for nurses per day - 13 nurses in the morning, 12 nurses in the afternoon and 11 nurses at night
- The support staff consist of a Nurse Educator and two Clinical Nurse Educators who work rotating shifts to cover the nurses' needs, three Clinical Nursing Unit Managers, two Lactation Specialists, a Discharge Nurse and Clinical Nurse Consultant and various Allied Health Staff, such as Occupational Therapists, Speech Therapists and Social Workers.
- Over 850 nappies are used on average per week

Tips for parents

- **There are a number of food outlets available a short walk from the Hospital, either on Hawkesbury Road (out the front entrance of the hospital on level two and turn right) or on Redbank Road (behind Ronald McDonald House past the children's playground, accessed from level one).**
- **You may be able to get reduced parking rates. Speak to the Grace Social Worker to find out if you qualify.**
- **The courtyard is available for use at all times. If the door is locked, speak to the receptionist or your nurse. You may even be able to take your baby outside with you – please discuss this with your nurse.**
- **Use the baby journal provided by Grace Ward to record memories of your baby's stay – the nurses will update it, but you are free to as well. It will provide you with memories to look back on in the future.**
- **Do you know there is a walking track at the back of the Hospital? It is past the playground at the back of the Hospital.**

Grace Guidelines/Rules

- **Always wash your hands every time you re-enter the Centre – this is the most important way to prevent infection.**
- **Remove watches, coats and jumpers before entering the nursery.**
- **Store valuables in the lockers provided - ask the ward clerk for a key.**
- **No more than two visitors are allowed at the bedside at a time.**
- **No hot drinks in the Centre at any time.**

Baby advice – Settling

While this information has been taken from the Huggies website, The Children’s Hospital at Westmead does not endorse this brand of nappies over other brands.

Refer to the Huggies website, www.huggies.com.au, for further information on many topics from feeding, sleeping, care and development. Discuss your baby’s specific circumstances with your nurse to determine the best options for you.

Some babies settle to sleep easily and don’t need much help from their parents. Others are a little more resistant and need soothing and persuasion to calm down and drop off to sleep. For lots of babies, actually staying asleep for longer than a few minutes is something they need to learn.

There is no “one size fits all” approach when it comes to settling management. Every baby has their own little personality and temperament which influences a range of behaviours, including sleep. Similarly, every family will have their own ideas on what is normal and acceptable. If your baby is happy and thriving and their sleeping patterns are working for you both, there is no need to change what you are doing. If not, here are some options and tips on how to improve your baby’s sleep habits.

First things first

Tired babies are generally cranky. Although they can’t say they’re tired and want to go to sleep, they do try to communicate this in a number of ways.

Young babies will often show tired signs by:

- Becoming tired after feeding or within ½ – 1 hour after finishing a feed. The best time to settle them is when they have been fed, aren’t hungry or due for a feed.
- Being irritable and hard to please. They might have trouble focusing on your face, start yawning and even look a little pale. They can’t be as easily distracted with talking and playing and may keep crying even when you are cuddling them.
- Clenching their fists, grimacing up their face, looking away and having jerky movements.

Encouraging your baby to fall asleep on their own

- Try looking for and being sensitive to their tired signs. Babies get overtired, making it harder for them to settle to sleep.
- Think about how important sound sleep is to your baby. Good sleeping habits support your baby’s growth and immune function. When they are well rested, being around them is generally more pleasant. Looking after a tired and cranky baby is hard work.

- Aim to place your baby into their cot when they are sleepy but not quite asleep. Babies who are rocked, cuddled or fed until they go to sleep learn to associate these factors with settling.
- Young babies love to be wrapped securely. Swaddling them in a light cotton or muslin wrap helps to keep young babies on their backs, which is the safest sleeping position.
- Aim to be consistent and predictable with how you settle your baby. Placing them into their cot for all sleeps gives them the message this is where they go to sleep and where they will wake up. Regular routines before settling help babies to feel secure and safe.
- Good feeding habits directly influence sleeping habits. Babies who are thriving and getting enough nutrition generally have better sleeping habits than those who don’t.
- Babies whose routine has changed, who are sick, who have reached a new developmental stage or who are feeling insecure will not sleep as well as they would normally. Aim to be patient, sensitive and kind when you are settling them. Your emotions will have an effect on how safe your baby feels.

Different options for settling

Settling in parent’s arms:

- Small babies often go to sleep when they are being fed or cuddled. For lots of parents, their baby settling in this way isn’t a problem as long as they stay asleep when they are put into their cot. If this happens, try to interpret their cry as either a genuine need for cuddling or one which is telling you they are just tired and grizzling. This is a learned skill and one which may take some weeks.
- Gentle patting, shshshing, rocking the cot, playing music or singing a lullaby often helps to calm a crying baby. Loving human contact is important for young babies and helps with their brain development.
- There will be times when it just works to cuddle your baby until they go to sleep. Small babies need their parents to comfort them when they are unsettled because they do not have the skills to soothe themselves.



Hands on settling:

- This is a good mid-way point for babies who are used to being cuddled to sleep but parents are keen for them to learn how to settle in their cot.
- Place your baby into their cot, clean, dry, and comfortable, fed though awake and rest your hands gently on them. Rocking, patting, stroking or just leaving your hands gently on their body will be reassuring.
- You can stay until they are calm and then leave before they are asleep or alternately, stay until you know your baby is sleeping.

Comfort Settling:

- This is a good way for older babies to go to sleep in their cots more independently. Try leaving the room before your baby is actually asleep and give them a chance to settle on their own.
- If your baby cries go back in to them and offer reassurance. Again, listen for their cry and try to interpret if they really need you to go back in to them.
- Leaving your tired, older baby to settle on their own is fair and reasonable as long as all of their needs have been met.
- There are other options for older babies who are used to having a parent with them to go to sleep.

These techniques require consistency and time to work effectively. There are other options available to parents who may find them too difficult to try on their own without support.

Parent Council

The Grace Centre for Newborn Care Parent Advisory Council (GCNC PAC) was established in 2004 in response to the team at GCNC believing that families are the cornerstone of all activities and processes that occur in the unit.

The PAC is a group of volunteers who have had babies in GCNC. Through our own personal experiences, we understand that having a baby in GCNC is a very traumatic time.

Our aim is to make sure there is a place for families to provide their ideas or raise any needs or concerns. We also act as a resource for the GCNC when input is required or changes are being developed for improving family and newborn care.

We get involved in a range of activities, including communication and information for parents, arranging facilities (such as the parents' library), seeking donations for products for the Parent Care Packs, fundraising for the Unit and being available to speak with parents whose babies are in GCNC.

If you would like to be involved, we would love to hear from you!

How can you contact us?

You can either complete a contact sheet and return it in the secure Suggestions Box (located in the Parents Tea Room) or you can email GCNC@chw.edu.au.

Parent Care Packs

Parent Care Packs are organised by the Parent Advisory Council to provide some essential items to parents who often arrive at Grace with little or no advance warning and no time to prepare and pack. The Parent Care Packs rely almost entirely on donations for the products provided.

We'd like to gratefully acknowledge the support of the following organisations who have supported us: St George Bank, Colgate Palmolive, Nestle, Oral B and Kimberley Clark.

If you have any suggestions of items which would be useful, or you know of any companies who may wish to support us by donating products, please contact us at GCNC@chw.edu.au. Any donation of goods (large or small) is greatly appreciated.

Games to play with your baby

Facial expressions

There are many activities you can do with your baby that are not vigorous, or even active. Quiet time is equally important. Babies, especially newborns, are easily overstimulated. Intimacy between parent and child depends as much on touch and eye contact as it does on giggles, tickles and toys. In other words, time spent simply gazing into your baby's eyes is time well spent as it allows the two of you a chance to relax and bond.

- Choose a time when your baby is alert and receptive. Cradle him in your arms, on your lap or leave him lying in the bed.
- When he is looking at you, gaze into his eyes. Speak or sing his name softly. Introduce him to some facial expressions - a smile, an opened mouth, raised eyebrows or a stuck-out tongue. Then go back to simply looking at him and saying his name softly.
- Your baby may surprise you by imitating your expressions, even the littlest babies will sometimes mirror the face of a caregiver. But if he grows restless or turns away repeatedly, stop the activity. Babies need to withdraw from intense interaction to process all they've experienced.

From Baby Play – 101 fun-filled activities to maximize your baby's potential. Edited by Dr Wendy S Masi and Dr Roni Cohen Leiderman. Gymboree Play and Music Programs 2001.

We want to hear from you!

We would like to be able to share your stories, experiences and knowledge.

If you have something to say, we are listening. There is a feedback form and secure Suggestion Box located in the Parents Tea room.



You can obtain more information about Grace Ward and the Parent Advisory Council on our website www.chw.edu.au/parents/fac/grace

Roles and Responsibilities Overview

We know how confusing it can be to understand who is responsible for what within Grace. To help explain, you will find a 'Roles and Responsibilities Overview' on our website at: www.chw.edu.au/parents/fac/grace.

NETS – Newborn and Paediatric Emergency Transport Service.

NETS is a statewide service of NSW Health. It is the only service of its kind in Australia, providing expert clinical advice, clinical co-ordination, emergency treatment, stabilisation and inter-hospital transport for very sick babies and children up to the age of 16 years.

It operates 24 hours a day, 7 days a week.

The service offers peace of mind to a parent during a time of despair and disbelief that there could possibly be something wrong with their precious child.

Many hospitals do not have the resources for the sickest of babies, infants and children. In fact, in NSW and the ACT, only ten hospitals have intensive care for babies and just three have paediatric intensive care. Therefore, most hospitals need to send their sickest babies and children to the specialist centres for expert care.

During the journey from a country hospital, or even a suburban hospital, sick children can deteriorate during the journey. It is known the sooner babies receive intensive care

the better their chance to survive. NETS takes the intensive care to the patients and transports them to the appropriate hospital.

In February 2009, A Current Affair aired a story on NETS. Reporter Belinda Russell was granted unprecedented access to the NETS service to prepare the report. She described NETS as a highly specialised baby ER service - a mobile intensive care unit on wheels and in the air.

Some interesting facts on NETS:

- One in 50 families will use its services in their lifetime.
- In 2009, they responded to 3000 emergency calls.
- An average NETS mission takes over six hours and costs the equivalent of one to four days of intensive care, depending on the time and distance involved.

If you would like to see the Current Affair report, learn more about NETS or make a donation to support their crucial service, visit their website at www.nets.org.au.



the children's hospital at Westmead

Grace Centre for Newborn Care

Corner Hawkesbury Road & Hainsworth Street

Locked Bag 4001 Westmead NSW 2145

Telephone +61 2 9845 1178 Fax +61 2 9845 0559