

# G R A C E

## Parents & Carers Newsletter

Edition 1, Spring 2009



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## Staff Profile: Nadia Badawi



### Name and title/role

Nadia Badawi - Medical Director Neonatology -  
Co-Head Grace Centre for Newborn Care.

### Experience

I have over 20 years experience and have been working in Grace for 12 years. My father is from Egypt and I completed my undergraduate degree at Cairo University where I worked for a couple of years in Paediatrics. Most of the children suffered from malnutrition, gastroenteritis, polio, tuberculosis and rheumatic heart disease.

I soon realised that I needed to gain experience in the developed world and having an Irish mother, I ended up in Dublin, Ireland where I specialised in Neonatology and met an Australian Obstetrician who is now my husband.

We decided to return to Australia and I was lucky enough to be able to study for a PhD in Medicine at the University of Western Australia with Professor Fiona Stanley (Former Australian of the year), Dr Paddy Pemberton (an extremely skilled and compassionate Neonatologist in Perth) as well as Dr Jennifer Kurinczuk from Oxford University. I also completed my Australian specialist qualifications and then my dream job came up at the Grace Centre in 1998.

### Favourite part of the role, least favourite part.

My favourite part of the job is to watch a very sick baby recover and be back in their parents' arms; a baby having a cuddle with his or her parents even if they are on a ventilator and seeing the babies in our follow-up clinic thriving and well. I still find such moments overwhelming.

Having a baby die or suffer disability fills me with great pain.

### Why you became a doctor and why you choose to specialise in newborns.

I only realised I wanted to do medicine one week before university started. It was a great shock to me and my family as I had always said I was going to study English Literature.

Over the years I have come to the realisation that I was probably motivated to become a doctor following the death of a young family friend of childhood cancer and the birth of a close family member with cerebral palsy. I find newborn intensive care very rewarding as most babies recover so well. It is also a rapidly developing area of medicine and we are doing things better all the time. The work fills me with hope for the future.

### Aspirations/goals

To build a follow-up clinic so we can provide proper long term care for the babies who graduate from Grace. This way we can spot any problems early on and provide early intervention, thereby helping them fulfil their potential and improve their quality of life. I am always looking for newer and better equipment and more staff.

### How do you relax after work?

I love spending time with my family and friends as well as reading. My secret vices are watching British detective stories and shopping.

### What advice do you have for parents in Grace?

I hope that parents in Grace will give us feedback to help us provide better care for the babies and their families.

## Patient profile: Stephanie by Louise Gage

“I remember feeling my life was spiralling out of control.”



**On 19 May 2007 our lives felt complete – our third child Stephanie was born at North Shore Private Hospital seemingly completely healthy. A little sister to brothers Jack (4) and Cameron (2).**

Unfortunately the joy didn't last very long. Overnight she became increasingly unsettled and after a string of tests and X-rays they suspected a twisted bowel, but her results were inconclusive. She seemed too tiny, too perfect to possibly have anything wrong with her.

At midday the surgeon advised he wanted to transfer her to The Children's Hospital at Westmead.

NETS arrived to take her. At the time, I thought walking out of the Hospital without our baby was the hardest thing I'd ever done. Little did I realise it was only the beginning of the roller coaster ride.

The next few days were a blur – further tests, talk of exploratory surgery, nights spent in the maternity ward surrounded by other peoples baby's but not my own. On the Tuesday she went to surgery, our feelings were mixed, pure fear combined with a sense of relief that we would get some answers.

The operation went for longer than expected, but finally we were called and I will never forget the words 'Unfortunately it didn't go as well as we'd hoped.....' Again I can't recall much else of the conversation, but a few things stuck – “duplication cyst, gangrenous small intestine, two thirds had to be removed, babies needing at least 30cm of small bowel to survive.”

The cyst was 29cm long.....had it not been for the skill and dedication of the surgical team being able to remove the cyst, while retaining the intestine and ultimately giving her 49cm, we would not have our daughter today.

Rather than rejoining straight away she was given an Ileostomy (where the intestine is brought outside the body and a bag used to catch poo) and she was fed TPN (Total Parenteral Nutrition) via a central line. We were told her intestine would be re-joined at some stage – be it six weeks or six months away...the waiting game began.

I remember feeling my life was spiralling out of control. Only a few days before everything had been perfect but now we were facing things I'd never even imagined having to deal with. The level of uncertainty was unbearable....but step-by-step, day-by-day you just keep going.

Seeing your baby in pain and not being able to help them is a heart-wrenching experience. A number of nurses told us ICU was very much two steps forward and one step backwards. We learnt the trick was to celebrate the forward ones and try to not dwell on the backward (advice given to us by a wonderful family we met during our stay).

We slowly settled into a routine. The morning walk along the corridor to Grace would alter between a feeling of increasing dread as to what news would meet us when we arrived, to other days each step bringing a feeling of happiness – knowing we would soon see our gorgeous baby girl again. The 'real world' seemed to vanish and we lived the next few months in the surreal world of “Grace”, on the one hand terrifying and overwhelming, and on the other a safe and supportive refuge where we could be with our baby and other people who understood what we were going through.

“...the trick was to celebrate the forward ones and try to not dwell on the backward”

Over time, on the suggestion of the nurses, we brought Stephanie in some sheets and wraps from home, to try and introduce some 'normality' to our life. The boys would come and visit on the weekend, and even two years on they still ask if they can go play at the 'pirate ship' park at Stephanie's hospital – they at least thought Westmead was an awesome place to visit!

Without a doubt the hardest part of every day was saying goodbye. With two young boys we couldn't stay late, but leaving her alone of an evening became harder and harder to bear. We also had to try and leave the stress, pain and fear behind, as the boys expected 'mum and dad' to be ready to play,



## Patient profile continued

“Stephanie is now nearly two and a half years old and an incredibly happy and cheerful little girl.”

rumble and just be normal. As hard as that was some days, having the boys at home was a tremendous help – they were so positive and accepting of what was going on and so supportive and excited about their new little sister.

After nine and a half weeks we got to take Stephanie home. She was failing to gain weight and still had her central line, so we had twice weekly visits from the Discharge Nurse. The constant threat that she may have to go back to Hospital if she did not improve made this a very stressful time, however the support we'd felt while patients of Grace continued once we'd left. When we finally got the 'all clear' and the central line was removed we threw a “Pink Party” in October to celebrate the arrival home of our baby.

Stephanie is now nearly two and a half years old and an incredibly happy and cheerful little girl. To look at her you'd never know what a rough start she had. At her recent two-year check-up I was over the moon to be told she is actually slightly overweight for her age – we have the wonderful team at Grace to thank!!



*Credits: Photo of Stephanie in hospital on page 3 by Jackie Dean, Dean Photographic*

## Grace vital statistics

**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. The Grace family also has close links with the Hospital. Mrs BA Grace was appointed to the Board of Management in 1951, becoming Vice President in 1971.**

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 the Centre does care for babies older than that depending on the condition they have and if they have been born prematurely. Grace works closely with the Paediatric Intensive Care Unit (PICU) and many babies are admitted there if they are outside the criteria.

More than 80 staff are employed on shifts to care for 23 babies at any one time. There is currently funding 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 studying the development of babies who have been operated on in the first crucial 90 days of life (see the article on The Daisy Study in this issue).

### Interesting facts about Grace:

- Over 130 babies were admitted in the past three months, and over 620 babies in the past 12 months
- 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, two Lactation Specialists six out of seven days per week, a Discharge Nurse and Clinical Nurse Consultant who work Monday to Friday.

## Tips for parents

- **Are you aware you may qualify for reduced parking rates? Speak to the ward Social Worker.**
- **If friends or family offer you any help say 'yes'. Most helpful things include cooking dinners, doing some washing, caring for siblings, sitting with your baby for an hour or so to give you some time out or just having a cup of coffee with you.**
- **Do you know there is a walking track at the back of the Hospital if you would like to get out for a bit of fresh air? It is past the playground out the back.**
- **Tummy Time mats are available in the ward. Speak to your nurse to see if your baby may be able to use these.**
- **Bring in some books and read stories to your baby. Make the most of the time you have to bond with your new baby.**

## Baby advice – breastfeeding

**Disclaimer: This information is for education purposes only. Please consult with your doctor or other health professional to make sure this information is right for your child.**

Breast milk has the perfect ingredients for your baby. Remember that sometimes problems occur, however they are generally (or usually) only temporary. There are fantastic support groups in the community to help you with any problems you may encounter. Ask a staff member or a lactation consultant for more information. The following Hospital fact sheet is also helpful.

[www.chw.edu.au/parents/factsheets/breastfeeding.htm](http://www.chw.edu.au/parents/factsheets/breastfeeding.htm)

## 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](http://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.

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

## Support Group – HeartKids

HeartKids empowers those affected by childhood heart disease through support, awareness, research and advocacy.

For more information on how HeartKids can help you and your family, visit the website

[www.heartkidsnsw.org.au](http://www.heartkidsnsw.org.au);  
phone the HeartKids Line on **02 9294 0800**;  
or email  
[mail@heartkidsnsw.org.au](mailto:mail@heartkidsnsw.org.au)



## 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.



## Grace Guidelines/Rules

- **Always wash 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 allowed at the bedside at a time.**
- **No hot drinks in the Centre at any time.**

## Parent Advisory 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 whose babies were in GCNC and therefore 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. The Council also provides a family perspective to GCNC on decisions that need to be made or changes being developed for improving family and newborn care.

We are 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 Centre including Grace's Gala 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! You may want to join the Parent Advisory Council or become involved in the Grace Gala.

### How can you contact us?

You can either complete a contact sheet and return it in the secure Suggestion Box located in the Parents Tea Room, or you can email us at [GCNC@CHW.edu.au](mailto:GCNC@CHW.edu.au).

## Feature story: Research studies being undertaken at Grace – Development After Infant Surgery (DAISy)



**About 1500 infants with congenital heart disease are born each year in Australia and about one third of these children will require surgery in infancy. Most of the cardiac surgeries performed by surgeons at The Children’s Hospital at Westmead are done on infants less than 90 days old.**

As survival rates have climbed significantly over the past 10 years in NSW, attention is turning to the quality of outcomes following surgery and in particular, developmental outcomes. Research shows that major surgery in infants, although necessary and life-saving, may be linked with neuro-developmental impairment. Yet despite the research, these high-risk infants in NSW are not part of any developmental follow-up programs. Because of this, the opportunity for early intervention may be missed.

“Most of the cardiac surgeries performed by surgeons at The Children’s Hospital at Westmead are done on infants less than 90 days old.”

The DAISy (Development After Infant Surgery) study is a unique population-based study which aims to determine the long-term neuro-developmental outcomes of infants undergoing major cardiac and non-cardiac surgery in the first three months of life and compare their outcomes with a group of healthy infants. Enrolment began in 2006 at The Children’s Hospital at Westmead and involved all the paediatric surgical units in NSW and their co-located maternity units. Enrolment stopped in December 2008, with 785 infants enrolled in total.

At one year of age, babies were assessed using the Bayley Scale of Infant and Toddler Development (Version-III). The one-year old assessments will be completed in December 2009 and the first three-year-old children have started returning for their three-year assessments.

## 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](http://www.chw.edu.au/parents/fac/grace)

the children’s hospital at Westmead

### Grace Centre for Newborn Care

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