

# GRACE

## Parents & Carers Newsletter

Edition 3, Winter 2010



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## Staff Profile: Susan Clarke



### Name and title/role

Susan Clarke

Social Worker – Grace Centre for Newborn Care

Providing practical assistance, emotional support and counselling to all the families who have a baby in Grace.

### Work Experience/History

I started my career as a Youth Worker after I completed a Bachelor of Arts at the University of New England in Armidale. It was while I was working as a Youth Worker that I was encouraged by my employer to undertake further education and in 1997 I completed a Bachelor of Social Work at Charles Sturt University. I have worked in a variety of areas such as mental health, children with special needs, foster care and child protection. I worked in the United Kingdom for eight years - it started as a working holiday for a year but I just never found my way home. It gave me the opportunity to work in a variety of different geographical areas. It also helped me focus the area in which I wanted to work in the long term. I eventually returned home in 2006, desperate for the Australian lifestyle that was familiar to me.

### Favourite part of the role and least favourite part?

I feel very fortunate to be working in Grace as I have the opportunity on a daily basis to meet families and work with experienced professionals who all share a passion for caring for babies in GCNC and their families.

The least favourite part is that I am mindful of the sadness that confronts families on a daily basis and as they celebrate

the hope of something good happening for their baby they can feel that it is bittersweet, given what can be happening around them. I would like to be able to protect families from this experience, but I can't. All I can do is support and be mindful of what is happening for families and allow them the opportunity to express themselves.

### Why did you become a Social Worker and choose to specialise in NICU?

I was fortunate to be able to observe the importance of social work in supporting families in crisis and the benefits this had to their ability to cope with what was happening to them. This helped me in the long-term to decide why I wanted to become a Social Worker and my experience overseas helped guide me to decide to apply for the position in Grace. I feel that my past experience has helped me develop the skills needed to support families.

### Your aspirations/goals

I have recently started a Graduate Diploma in Perinatal and Infant Mental Health at the NSW Institute of Psychiatry which I hope to finish at the end of 2011. I would like to complete a Masters of Social Work in the future.

### How do you relax after work?

I love spending time with family and friends, especially doing outdoor activities that involve the beach. I enjoy baking and reading, especially in the sun.

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

Parents have known their baby since the moment they discovered they were pregnant. Your baby knows your voice and responds when they hear you - this is very reassuring to them. This is important as all the things that are instinctive to you to comfort your baby, such as cuddling, may be restricted due to your baby's condition. Working with the nursing staff to find alternative ways to comfort your child that may not be familiar to you is important in helping parents feel empowered and that they are connecting with their baby under really challenging and stressful situations.

## Patient profile: Dominic Azzopardi

Jenny is a member of the Grace Parent Advisory Council. In 2003, Jenny and Tony's baby boy was born with congenital heart disease.

Our journey through Grace Centre for Newborn Care (GCNC) was a little while ago now. However, when I walk through Grace's doors in my current role as a member of the Parent Advisory Council, the sounds, smells and familiar faces transport me back to the day when our infant son Dominic was admitted to GCNC.

On 4 September 2003, our fifth child, Dominic, was admitted to GCNC with Congenital Heart Disease. Dominic was born on August 22, 2003 weighing a hefty 4.2kg. His four older brothers and sisters were very eager to dote on their new baby brother. Dominic's first week of life was uneventful, he fed and slept well.

**“Dominic was immediately admitted to Grace and placed on life support as his condition deteriorated. That afternoon he was baptised...”**

At about nine days old I had begun to notice Dominic would have episodes of fast breathing. At first I thought I was just imagining it as at other times his breathing seemed OK. However, by day 13 these episodes were more frequent and he was developing other symptoms.

With these concerns I took him to our GP. He examined him and had a few concerns of his own. He then scheduled an appointment for the next day with a Cardiologist at the Adolf Bassler Cardiac Institute here at the Hospital.

Dominic was examined and underwent a cardiac echo. It was there the diagnosis was made. Dominic had three defects to his tiny heart.



*Dominic in Grace*

He had transposition of the great arteries, which means the pulmonary artery and the aorta are in the reverse order. This was further complicated by a coarctation of the aorta, which is a narrowing of the aorta. The aorta is one of the main vessels that come

out of the heart to supply the body with oxygenated blood. Lastly, he had a ventricular septal defect, which is a hole in the ventricles of the heart.

Dominic was immediately admitted to Grace and placed on life support as his condition deteriorated. That afternoon he was baptised and underwent a procedure called a balloon atrial septostomy. This is done to keep open a hole in the heart's atrium. All babies are born with this small hole and it closes naturally up to 14 days after birth. By keeping Dominic's open it would allow mixing of oxygenated and deoxygenated blood to help his heart until he had surgery to correct his defects.

Unfortunately for Dominic the procedure was complicated by causing his heart to beat too fast. Medication was given to him to slow it down but it was ineffective. So then he needed cardio verting which, thankfully, was successful. It was a very anxious time for us, but Dominic was putting up a good fight and the excellent care and medical attention he was receiving helped him through it.

Two days after admission, Dominic had successful surgery to repair the coarctation of the aorta. Three days after that he had surgery again, this time open heart, to correct the transposition of the great arteries and the ventricular septal defect. This operation took six hours, so we were very relieved to hear from his surgeon that all went well once again. After this operation Dominic went to Paediatric Intensive Care, which is the practice for all babies who have open-heart surgery.

Dominic remained in intensive care for five days. He had a few ups and downs but made steady progress. He then came back to Grace breathing on his own after ten days on a ventilator. Now he began his road to recovery.

Dominic spent a total of 16 days in hospital, quite remarkable for a little boy who endured so much. We know this all has to do with the outstanding care, both medical and nursing he received in those 16 days.

Six and half years on and Dominic is a happy healthy little boy who has had an excellent outcome. He is now in year one at school, he plays football and swims and loves to ride his bike with no restrictions at all.

We owe his life to the team at Grace. We thank them every day for the precious gift that they have given Dominic and to the many hundreds of children that have gone before him and that will come after him. We will never forget them for the wonderful work that they do.



*Dominic today*

## Grace vital statistics

Grace Ward takes its name from Grace Bros Staff Aid to Charities, an organisation which promotes fundraising for many hospitals. The Children's Hospital at Westmead 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 eighty 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 and over 600 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 three Clinical Nurse Educators who work rotating shifts to cover the nurses' needs, two Lactation Specialists that cover six days per week and a Discharge Nurse and Clinical Nurse Consultant who work Monday to Friday.
- Over 3500 nappies are used each month!

## Tips for parents

- **There is a fridge and tea and coffee making facilities in the Grace Parent Room if you would like to bring your own lunch or snacks. There is a microwave in the Parent and Carer Resource Centre on level two which is open to all parents to use.**
- **The Hospital offers sibling care on level one. If you have other children, speak to your nurse to find out more or pop in to the sibling care on level one.**
- **Volunteers operate a stall every Monday and Thursday on the level one. They sell a variety of goods, including toys, books and clothes.**
- **Bring in some books, photos or pictures drawn by your family to show to your baby and to leave near their bedside.**
- **You can always ask your nurse if you would like to bath your baby – they will provide you with help and support and it's a great opportunity to bond with your baby.**

## 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.

## Baby advice – Swaddling

There are many different ways to swaddle or wrap your baby for sleep. Speak to your nurse for some help, but below are two different techniques you can try:

### Technique 1

**Step 1:** Fold down one corner of the wrap so it is partly a triangle.



**Step 2:** Place the baby with their head on the folded edge and feet towards the point. Make sure their shoulders are 5cm below the folded edge.



**Step 3:** Put their left arm straight down by their side and take the corner over the baby and tuck it in firmly under their bottom.



**Step 4:** Then put their right arm down by his side and bring the corner over and tuck firmly under their bottom again.



### Technique 2

**Step 1:** Lay baby down on a large muslin wrap so they are in the middle of the longest side with the edge of the wrap at about level with the bottom of their ears.



**Step 2:** Then bring the right side of the wrap over and put it over their right arm only and then under their back.



**Step 3:** Do the same with the left side. They should now have a wrap over each arm and behind their back but their chest is bare.



**Step 4:** Then you bring up what is left at the bottom and bring it up to their chin - and wrap it over their chest and arms (whole body) and the around their back - leaving the material at the back.



## Support Group – Cystic Fibrosis New South Wales

In 1967, a group of parents of children with cystic fibrosis (CF) and their doctors founded the Cystic Fibrosis Association of NSW. Originally a parent self-help group, the organisation has gradually employed a growing staff of professionals to provide a range of support services, an information and education service and an advocacy service. Today they employ 12 full-time, part-time and casual staff who are assisted by dedicated volunteers.

Their mission is to improve the quality of life for people with CF and their carers.

The group provides home visiting support services, which include a range of counselling services, practical support and home treatment to lighten the load of families caring for a child with CF.

You can contact Cystic Fibrosis NSW on **(02) 9878 2075** or free call **1800 650 614** (country NSW only) or email [general@cysticfibrosisnsw.corg.au](mailto:general@cysticfibrosisnsw.corg.au).  
[www.cysticfibrosis.org.au](http://www.cysticfibrosis.org.au)

## 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.**

## Feature Story: Child Restraint Rules

**From 1 March 2010, new child restraint laws for children up to seven years of age came into effect.**

**From 1 March 2010:**

- Children younger than six months must be secured in a rearward facing restraint.
- Children aged six months to under four years must be secured in either a rear or forward facing restraint.
- Children aged four years to under seven years must be secured in forward facing child restraint or booster seat.
- Children younger than four years cannot travel in the front seat of a vehicle with two or more rows.
- Children aged four years to under seven years cannot travel in the front seat of a vehicle with two or more rows, unless all other back seats are occupied by children younger than seven years in a child restraint or booster seat.
- In the interests of improved child road safety it is recommended parents and carers of young children make every effort to comply with the new requirements as soon as possible.

**If you would like some help fitting your restraint you can contact:**

- The RTA's Customer Service Enquiry on 13 22 13.
- NRMA Technical Advice on 13 11 22.

**For more information, you can try the following websites:**

[www.rta.nsw.gov.au](http://www.rta.nsw.gov.au)  
[www.kidsandtraffic.mq.edu.au](http://www.kidsandtraffic.mq.edu.au)  
[www.mynrma.com.au/childrestraints](http://www.mynrma.com.au/childrestraints)  
[www.kidsafensw.org](http://www.kidsafensw.org)

## 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).

## Games to play with your baby

### Hankie Wave

One of the best kept secrets about playing with young babies is that you don't always need fancy toys with electronic bells and whistles. In fact, sometimes just a cloth handkerchief or colourful scarf will do.

Place your baby on their back in the cot and hold a scarf, handkerchief or lightweight cloth about 30cm over their head. Bring it close to them, lift it farther away and bring it down again. Sing to them softly or call their name gently as you wave the cloth.

The scarf creates a tickling breeze and an intriguing visual object for your little one to follow. It will also boost your baby's ability to visually track and focus on object. By three months or so they won't be able to resist reaching out and trying to grab the cloth.

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.



## 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 Grace.**

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 to improve 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 Ball, 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).

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)

## Feature Story: Grace Gala



### Oh what a night!

On Friday 5 March 2010, Grace Centre for Newborn Care held its third Gala Ball. The annual Gala Ball is held to raise much-needed funds for a purpose-built Follow-Up Clinic, so babies who have 'graduated' from Grace can return to be assessed on a regular basis.

The evening was dedicated to the memory of Michael Grace. Grace Centre for Newborn Care bears its name from the Grace Family.

This year the Gala was held at The Art Gallery of New South Wales. On a rainy Friday night in Sydney, guests were transported to a magnificent French-inspired Grand Court. They were then welcomed by Masterchef's Matt Preston, who graciously volunteered his time as Master of Ceremonies.

Whilst guests enjoyed a meal that could have come from a French restaurant, they were entertained by Madeleine Peyroux. Then they fell silent as they listened to guest speaker Paul Dempsey's experiences of his son's journey through Grace.

Throughout the evening, guests enjoyed games of heads and tails hosted by Angela Bishop. Angela is a Grace Gala regular and herself a Grace parent.

Guests were also tempted by an exquisite set of Pandora Jewellery. Purchasing a glass of champagne gave them a ticket for this fabulous prize. The Grace Gala Raffle also gave guests an opportunity to win some great prizes.

Then, of course, there was the silent and live auctions. The live auction was headed by Christies' Ronan Sulich, who did his utmost to entice guests to bid and purchase what can only be described as grand prizes. What followed was overwhelming generosity as guests made their pledges to Grace.

The night was capped off as guests danced the night away to the beat of The Martini Club.

The Grace Gala Ball on that wet March evening raised a staggering \$225,000.

Special and sincere thanks go to all who make the Grace Gala possible each year.

2010  
*Grace Gala*

the children's hospital at Westmead

#### Grace Centre for Newborn Care

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