

# Cottage Capers

The Newsletter for Bear Cottage families



Autumn 2019



At Bear Cottage

It has been 18 years since Bear Cottage opened its doors and I feel very privileged to have been here every step of the way.

Many changes have occurred and Bear Cottage is bigger, busier and greater than we ever imagined it could be in 2001.

I have met so many amazing individuals over the years who have enriched my life in so many ways. On behalf of the Bear Cottage team, I would like to thank all the families for allowing us to be a part of your journey and to care for your precious children.

Since opening our doors, 1263 children have been referred to our service, with 937 of those admitted. Sadly, 554 babies, children and young people have since died. This is far too many but we hope that having Bear Cottage in their lives has made life and death a little easier for all of these families.

To commemorate the lives of these children we are excited to announce that a **'Garden of Remembrance'** will be built in the grounds of Bear Cottage - a special place for families, staff and volunteers to remember and to reflect. A beautiful bronze sculpture is currently being commissioned and we look forward to the official unveiling in a few months.

Many of you may be aware that our Business Manager **Roy** recently retired and I would also like to take this opportunity to thank him for his dedication to the Cottage over the past four years. Roy has been a wonderful colleague and a great person to work alongside.

He has always been happy to go that little bit extra and to fill in wherever needed, whether it be cooking lunch, driving the bus, shopping for that much needed item or attending functions. No-one makes a coffee or cooks a steak quite like Roy and these skills, along with many others, will be very much missed - particularly at our Dads' Camps. We all wish Roy and his wife Fiona (a Bear Cottage volunteer), a wonderful and happy life in the Adelaide Hills. 🐾

**Narelle Martin,**  
Nursing Unit Manager

## Coming of age

On March 17, we celebrated the 18th birthday of Bear Cottage. We are fortunate to have a large number of staff who have been here for many years and who share wonderful memories of the early days.

Four of our nurses, **Narelle Martin, Sarah Clark, Kerry Derz** and **Rachel Lobban** have been here from 'Day One' and they have shared their recollections of the early years.

*"In the early days, it was so quiet with only one or two patients," said Narelle, who began at Bear Cottage as a Registered Nurse and is now our Nursing Unit Manager. "We were working in unknown territory, away from an acute care setting and fighting to raise awareness of what a children's hospice could offer. It was a beautiful purpose-built building but we struggled to keep the doors open."*

Sarah vividly recalls the excitement of orientation week. *"There we were, a group of fresh-faced young nurses, excited about this new venture, which had been talked about in the media and was finally opening. I remember our first tour of the house; everything was new and there was a claw-foot bathtub in what is now the formula room. Although we were offering a great service to the community, referrals came in very slowly."*

*"I can still recall how excited the first patients and families were on arrival," said Kerry. "There were challenges with procedures in those early days and we all battled with paperwork and admission policies but we got the job done."*

The financial challenges Bear Cottage faces today were even more prominent in the early days. *"With no government funding and a very tight budget, we really had to be creative to deliver a first class service to our visiting families," said Narelle.*

Compared to what is now achieved with **A Bear Affair, Superhero Week** and the hundreds of other fundraising events we oversee, the initial efforts to raise much-needed funds to support the daily operations of Bear Cottage were far more humble. *"Nobody knew about us, doctors weren't referring eligible patients to us, so we had to work hard to raise our profile," said Kerry. "The wonderful volunteers who worked tirelessly on the first ball raised \$20,000. We didn't even know if we would be able to continue."*

There were many other challenges, notably the practical resources to ease the physical burden on the nurses. *"That claw-foot bath set on the floor was not practical for bathing," said Sarah, "and most of the rooms didn't have hoists so moving our patients around was much more physical and labour-intensive."*

Significant medical advancements have been witnessed by all the nurses over the last 18 years. *"These days the*

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Sarah



Kerry



Narelle



Rachel



## Coming of age *continued from previous page*



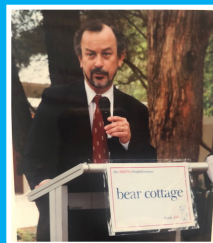
Digging the foundations



The first slab gets poured



Site inspection



Dr Michael Stevens



Opening day - 17 March 2001

children have far more complex medical conditions," said Narelle. "Many of those we looked after in the early days now have an increased life expectancy due to the medications and respiratory support devices on offer. Some no longer meet our criteria of a life-limiting illness as they are living into adulthood."

"It's great to see that new medications and regimes are helping kids with SMA and Duchennes Muscular Dystrophy," said Sarah. "We have far greater knowledge of palliative care now," said Kerry, "and we can treat symptoms much better. We are now a centre of excellence, with far greater occupancy and lots more staff. It's a real team effort with a social worker on site, a professional chef, plus art and music therapists."

The scope of services offered has also expanded dramatically. Bear Cottage now offers camps for siblings, mothers, fathers and grandparents, as well as a phone service, memory making and Footprints in the Sand. "We are also doing far more in Family Support," said Narelle.

As for the claw-foot bath, that was removed many years ago and replaced with modern water baths and even a spa, and hoists galore to ease the heavy lifting of patients.

All the nurses have special memories they will treasure forever. For Narelle, "my favourite memory is taking kids for a swim in the ocean. The nurses used to get out more when it wasn't as busy and we would load kids into the van and go to the rock pool or Manly Beach. For some it was their first experience of the ocean!"

Rachel has found it hard to name a favourite memory as there have been so many but said she feels so grateful to have "worked with many amazing people and having had the honour of looking after even more wonderful children, some for the briefest of times, some whom I watched grow up. I have shared cuddles, laughs, tears and occasional tantrums."

Kerry remembers the excitement of **Tim Bailey** filming his Channel 10 weather reports from Bear Cottage, as well as the thrill of having first therapy dog, Kara at the front door to greet and calm nervous new arrivals.

A highlight for Sarah was the visit about six years ago of an American men's choir. "I had organised the NSW tour and included a visit to Bear Cottage. In the room of a very sick boy, the choir gathered around his bed and sang a most beautiful song. It was a very special moment! It's times like this that keep me here. I've received many heartfelt expressions of deep gratitude towards our nursing staff from parents and grandparents over the years. These experiences are worth millions – I believe being part of Bear Cottage is a real privilege! All the staff are special and it's great to be surrounded by people like this in a work environment, which I think is rare – many of my colleagues have also become my friends. And throughout the years, the volunteers have kept us afloat. There is no way we could survive without them!"



Sarah, with the American Men's Choir visiting Bear Cottage

"We have always had volunteers but not on the scale we do now," said Narelle. "There was a handful to begin with and little training for them. Bear Cottage couldn't offer the high standard we maintain, within our budget, if it wasn't for the volunteers. They have made a tremendous contribution over the years."

"I am also very grateful to the families who have allowed me to care for their children. The staff are incredible and this is why we have such a low turn over," said Kerry.

Narelle said it's been amazing to witness the enormous changes over the last 18 years and to watch Bear Cottage grow into what it is today, because of the determination of staff, volunteers, donors and families who have been supportive in so many ways.

"This is a special work environment and it's rewarding to leave every day knowing we have made a difference. We are now a much bigger organisation but I think we have maintained the home-like atmosphere that was always intended - it's just a busier and more chaotic home." 🐾



Tim Bailey doing a Weather Cross helping to raise much-needed awareness



Narelle and Sarah with patient Brenton at Shelley Beach

## Remembering our children

John Khoury: 19/10/04-16/11/18

James McCorkindale: 15/06/15-20/11/18

Isaac McInnes: 20/02/05-26/11/18

Alaura Devril: 3/07/01-29/11/18

Kalani Ebbs: 9/08/16-12/12/18

Presley Wilson: 8/07/16-20/12/18

Levi Wheeler: 15/11/10-31/12/18

Hayley Gangemi: 7/9/16-6/1/19

Jasper Qiu: 12/12/18-12/01/19

Jesse Sierra-Toro: 13/06/18-3/01/19

Annabelle Potts: 10/06/13-16/01/19

Dunstan Mazeika: 6/9/11-31/1/19

Lara Kishor: 21/9/18-11/2/19

Saabiq Sheikh: 2/6/16-18/2/19

Alyssa (Dolly) Hermes: 21/12/13-25/02/19

Ethan Zhu: 10/12/18-26/02/19

Tyler Benko: 6/9/13-9/3/19

Amy La: 9/7/10-7/3/19

Winnie Lawrun: 22/10/19-10/3/19

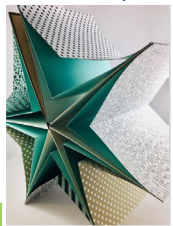


# Care and connection – Camps for Mums and Dads

Our Bear Cottage Camps are designed to allow those attending the opportunity to make connections, overcome feelings of isolation and loneliness but also to have fun and enjoy the rare opportunity to be pampered. These camps are held in the safe and supportive environment of Bear Cottage with the reassurance that their child is receiving the best of medical care.

Attending a camp for the first time can be daunting for some, but we hope the benefits received from participating outweigh any lingering doubts. For one of our mums, **Ann**, who recently attended a Mum's Camp, this was absolutely the case.

*"I was asked to write this testimonial a couple of weeks ago, but I have struggled. Put simply how do I describe a week that I will never forget? A week on a Bear Cottage Mum's Camp is such a wonderful thing.*



*It was a week in which I made real friends, friends who have supported me for six months, and friends who will be*

**Star Memories made during a Mum's Camp craft activity**

*there forever. Women who know my path, because they have been on the same path, felt the same pain, and knew so well not only my absolute heartache but also the blissful highs that can be felt on a journey which is uniquely that of an extra special needs parent. It helps, of course, that these women are phenomenal. I suppose we could have been staying anywhere, and if we just didn't get along, that would be that. However, when you mix a group of six women who just click, and give them a situation where their pain can be acknowledged, their heartaches soothed, and their hair let down, you just know that things are going to get fabulous!*

***"I believe a better week could not be found anywhere else!"***

*The activities were perfect - we were able to focus on therapies such as music, macramé and art, plus some retail, beautician and movie therapy, and the wonders of a night out where the driving, food and some fantastic entertainment was well and truly organised for us. The sore feet from wearing silly shoes was my own fault . . .*



**Ann (left) heading out for a night at the theatre**

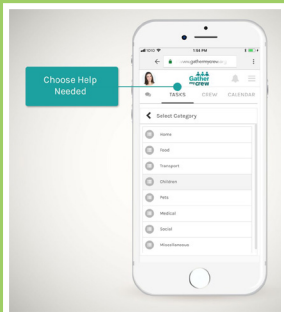
*I cannot tell you how good for the soul cups of tea and good old chats can be, but they were only ever surpassed by those same conversations with something alcoholic.*

*I can say I hope these friendships will last forever, but I know they will. My only regret was I hadn't met these wonder-women sooner. I put out a challenge to any of you who may be contemplating attending one of the camps in the future - I believe a better week could not be found anywhere else!"*

If you would like to join us for one of our camps or would like to find out more about them, please call or email **Narelle** on [narelle.martin@health.nsw.gov.au](mailto:narelle.martin@health.nsw.gov.au) or **0299768301**. 🐾

## Parent's corner

### Gather your crew



We often hear from our families that they have loving support networks, but lack meaningful practical help at home.

The trouble

is that in times of crisis, it can be really overwhelming to identify what help you need and then co-ordinate it amongst all the well-meaning offers of help. Without specific advice your friends and family can be left feeling helpless and unsure about what they can do for you, or they might end up supporting you in ways that aren't all that helpful.

**Gather-My-Crew** is a registered charity that helps people get the right kind of support from their friends, family and neighbours. Once you download the app, all you need to do is create a task list, invite your friends and family, and they can accept any task they'd like to help with. The best part is that it is a 'tick and select' list, so you don't even need to spend time figuring out what you need – just pick a few from their comprehensive list e.g. help with meal prep, walking the dog, mowing the lawn, or providing lifts to school/medical appointments. **Gather-My-Crew** is completely free and can be set up on a computer, smart phone or tablet. 🐾

### Handy hint

Our Bear Cottage nurses are extremely knowledgeable, but they always love the opportunity to learn from our patients and their families about any nursing care or tips and tricks that may make their lives a little easier.

We recently had one patient who was wearing a G-tube protective belt. Our nurses were extremely impressed with this device and the patient's parents felt it provided great protection for the gastrostomy button and also helped prevent the gastrostomy from being pulled out. It comes with two removable covers for the button - a soft one to wear any time and a hard 'Turtle Shell' cover that allows the feeding tube to be attached for a continuous feed.

These covers can be purchased online at: [www.benik.com/peds/wrap/g-tube](http://www.benik.com/peds/wrap/g-tube)

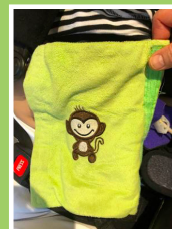
*G-tube protective belt with removable hard button covers*



The parents had also added a soft protective cloth with a Velcro edge from Baby Bunting to enclose the sharp edges of the extension tubing. 🐾



*The belt is secured by Velcro and the protective cloth protects against the sharp edges of tube*



### Did you know?

**There are 14 different languages spoken by 18 different Volunteers. Languages spoken are:**

Mandarin	Afrikaans
French	Japanese
Dutch	Italian
Portuguese	Vietnamese
German	Tagalog
Cantonese	Spanish
Arabic	Croatian



## Local support

We are fortunate to have many local businesses, hotels and restaurants supporting us in so many valuable ways. At a recent meeting of the **Consumer Advisory Group** (a consultative group of Bear Cottage parents who meet quarterly), it was suggested that it would be helpful for families to know which organisations do assist us, so that they in turn could support these businesses as a token of their appreciation.

In this issue, we would like to highlight the following local businesses:

- Sahsin Massage
- Ebony Hair
- MBarber Barbershop
- Pilu
- Novotel
- Hotel Steyne
- Ben & Jerry's
- Wholly Schnit Food Van
- The Boathouse
- Q Station
- Quest Apartments
- Novotel
- Hotel Steyne
- Manly Cobbler
- Budgy Smugglers

Donor support is vital and we recognise our donors in a number of ways such as providing them with a Thank You certificate or one of our beautiful hand made "Grateful Heart" frames that they can then display. Businesses are also provided with our "Proudly Supporting Bear Cottage" logo for their use and attend an annual "Donor Thank You" evening to acknowledge them in a more public setting.

This recognition is extremely important and always very much appreciated, although many of our donors prefer anonymity and do not want any recognition at all. A list of local businesses is displayed on the "Family Information" desk outside the Nurses Hub. 🐾



## Travel adventures



Scott with Mike Baird at Bear Cottage

We were delighted to hear some very exciting news from **Scott Green**, one of our former patients who is about to

embark on an exciting and educational trip of a lifetime.

Scott has been accepted into a new International Student Exchange program for people with disabilities. He will travel to Denmark in July and stay until mid December.

He will be studying and living at **Egmont Højskolen** (an adult age 18+ special University for students wanting to build life skills), as well as researching how Denmark has resolved independent housing for people living with disabilities. Egmont Højskolen accepts students from all over the world and up to one third of its students have disabilities.

Scott said, "Currently in Australia people **Egmont Højskolen in Denmark**

*with disabilities unfortunately don't have many places to go where they can live independently. The only option is usually to live with your parents your whole life or move into a nursing home which is not what a young person like me wants".*

Denmark is one of the world leaders in looking after people with a disability and this is why it is of such great interest.

There will be three students (all in wheelchairs) travelling to Denmark, accompanied by five carers. Once there, Scott will be able to choose four subjects from a range of options, from psychology through to international politics and outdoor adventures.

Scott is very excited about this trip and hopes to return with much useful insight into the practical and life-changing initiatives that Denmark is providing to support people living with disabilities.

Well done Scott - we are so proud of you and look forward to hearing about your research. Save travels! 🐾

For more information visit: [www.egmont-hs.dk/en/](http://www.egmont-hs.dk/en/)



## Staff news

Our latest recruitment of Undergraduate AINs have now commenced and are finding their feet at Bear Cottage. **Jess** and **Rosie** will be with us this year while they complete their final year of university studies. Also new to our nursing team is **Erin** who will be working half her week at **The Children's Hospital Westmead** and the other half with us at Bear Cottage. Look out for and please give a warm welcome to these lovely ladies on your next visit.



Jess



Rosie



Erin

Sadly this month we are saying goodbye to **Roy** our Business Manager who is moving into 'semi retirement' in the Adelaide Hills. Roy has been with us for the past four years and been instrumental in initiating many changes at the Cottage. He has also introduced a hip coffee culture with his great barista skills which will definitely be missed by all.



Roy

**Claire** our Irish leprechaun and Fundraising Manager is also moving on to bigger things. Claire has been involved at Bear Cottage for many years and her passion and dedication for what we do has been abundantly evident and her fundraising achievements have been very much appreciated.



Claire

We wish both Roy and Claire well in their new ventures and know that they will always remain a big part of the Bear Cottage Family, linked forevermore by a long strand of 'invisible string'. 🐾