

Cottage Capers

The Newsletter for Bear Cottage families



Summer 2017



As 2017 draws to a close, it is time to reflect on the past 12 months. It has been a busy year at Bear Cottage with many new referrals. The service is growing by the day and reaching out to many.

Sadly, we said goodbye to 21 children who have been cared for at Bear Cottage. Each child is unique and remembered with fondness by the staff and volunteers at Bear Cottage.

Our Family Support Programs continue to develop and grow in popularity. Mums, dads, siblings and grandparents are all enjoying the experiences of being with others travelling the same journey. These programs are now inclusive for both present and bereaved families. We have had wonderful feedback on our camps and I encourage you to look at our calendar for 2018 and contact me on **99768301**, or **Philly** on **99768311** if you or your child would like to be involved.

2017 has also seen the inception of our **Consumer Advisory Group** which is made up of Bear Cottage parents, both past and present. This has been a wonderful success, with parents and staff coming together to ensure we are getting things right for you, the consumer. We have recently produced a new Bear Cottage video which you can view on the website and the input from the group on this has been invaluable. I would like to thank them all for their time in 2017, their contribution to **'A Bear Affair'** and their ongoing commitment to this group, whilst juggling busy lives.

In 2018 we hope to develop a short questionnaire that will go out to all of our families to gain further valuable feedback from the greater Bear Cottage community.

On behalf of all the staff and volunteers at Bear Cottage, may the Christmas and New Year period bring much happiness and many memories to you all and we look forward to catching up with you in 2018. ■

Narelle Martin, Nursing Unit Manager

Dogs with jobs

We all know how special **Frankie** our Assistance Dog is to everyone at Bear Cottage and author **Laura Greaves** agrees. She has recently written a book called "Dogs with Jobs" which shares inspirational tales of the world's hardest working dogs.

As Laura says, "As dedicated employees go, they don't get more conscientious than Frankie."

Frankie has a whole chapter devoted to her and what her role at Bear Cottage encompasses. Nurse **Annie**, who is Frankie's main carer was interviewed for the book and was delighted to share some Frankie stories.

"Frankie is always happy to see people and loves interacting with everyone. We always ask the kids if they want to brush Frankie. We get them involved in her care and it gives them something to do to make them feel that they're valued. Frankie sleeps on the sofa at the front door so that she can see people coming and going. I think she feels responsible for everybody in the building. Every day she does her rounds of the rooms. She visits every room to see who's there and what they're doing. She's very inquisitive and just wants to be there. She wants the children to know that she understands".



Frankie is certainly a very important part of our Bear Cottage family and it is wonderful to know that with the book being released in Australia and overseas, the whole world will know too. ■



Male bonding

It is not often our Dads get the chance to totally relax but our recent **Dad's Camp** weekend held at Bear Cottage, gave them the opportunity to do just that.

It was an action-packed weekend which started on Friday afternoon with a 'behind-the-scenes' brewery tour at **4 Pines** in Manly and some welcome drinks.

Saturday morning began with a craft workshop led by our Art Therapist **Judy**, which was followed by a very successful fishing trip and BBQ lunch with the crew from **Sydney Harbour Escapes**.

Dads were also able to enjoy a lovely meal together at the Hotel Steyne and a visit to the **Sydney Tower Eye and Skywalk** donated by our friends at **Merlin**.

To finish off the camp the Dads were treated to a "pampering" experience with a full barber shop experience at **Flying Tiger**. This certainly meant that despite the huge weekend, the dads went home looking terrific!

While the focus of the weekend was to ensure that the Dads had fun, there was also plenty of time to allow dads these connect with each other and share their stories. As one dad said *"I really appreciated the time with a group of dads who simply get it, without having to try and explain stuff"*.

We have two Dad's Camps in 2018 so please get in touch if you would like to come along. ■



My Teddy

Bear Cottage has recently entered into a wonderful partnership with the team from **My Teddy** who will be donating a beautiful personalised 'Hero Bear' for each patient when they visit Bear Cottage. My Teddy founders, **Chris and Toni Nightingale** were inspired to support Bear Cottage in this way, as well as helping us promote our events and raise awareness through their large customer network. Thank you so much to the My Teddy team for this wonderful support! ■



Reminders

Please remember that the confidentiality and privacy of others is paramount when staying or visiting Bear Cottage. The taking of photos or posting on social media about children and families is inappropriate. ■

Flying high

Sami is one of our Bear Cottage AINs and whilst she is with us at Bear Cottage she still has the opportunity to do additional placements as part of her undergraduate studies.

Recently she was fortunate to secure a placement with the **Air Ambulance Service** and she shared her amazing experience.

I have been an undergraduate AIN at Bear Cottage since August 2016.

I absolutely love working here as it is a great opportunity to learn so much about paediatric palliative care and how to care for children with complex medical needs.

One of my favourite parts of the job is meeting the beautiful families and becoming part of their journey. It is so special to be able to care for children and their families in our Bear Cottage home. I particularly enjoy developing complex communication skills with our non-verbal children and being able to advocate for them.

A couple months ago we had a very special little girl staying with us at Bear Cottage and she was going to be transferred home using the Air Ambulance Service.

As I was preparing my patient for the flight I was talking to her about going on the Air Ambulance flight and reassuring her as she was understandably quite nervous about the experience, having never been on a flight before.

I was already quite familiar with the Air Ambulance Service, particularly because each Christmas we are fortunate to have them land one of their helicopters in the Bear Cottage grounds to deliver Christmas presents. This is an event that we all very much look forward to.



A few months later, the opportunity came for a student placement at the **NSW Air Ambulance** in Mascot and I was eager to apply for the position. I was thrilled to be selected for the placement because I knew this would be a fantastic opportunity to learn about the experiences of our

Bear Cottage kids throughout other health services. Working with the staff at Air Ambulance, I was able to talk about Bear Cottage and shed light on caring for children with complex needs.

I particularly enjoyed learning about how to care for a patient in flight and also gain a better understanding about situations that could potentially cause stress for our patients.

In a unique environment, the Air Ambulance Service enables equity of access to healthcare services for all people living in rural and remote areas. Many of our Bear Cottage families are from rural areas around NSW and it was wonderful to see first hand that the Air Ambulance Service is such a fantastic, professional and experienced team who are available to transfer our rural patients so they too can access Bear Cottage. ■



Connection and reflection



In November, Bear Cottage held its fourth **Footprints in the Sand Family Bereavement Camp**, a free, retreat-style camp for families with children coping with the death of a child. Four families, from as far as the border of NSW and ACT, spent the weekend at Lands Edge in Chowder Bay. Here they relaxed, reflected, connected and processed their healing journey. The camp is about supporting the grieving process of our bereaved families, whilst providing a safe and healing experience.

The camp included a performance by a show-stopping magician who amazed our kiddie campers with 'how-did-he-do-that' magic tricks and balloon making. Campers participated in a range of outdoors activities including barefoot bowling, a high tea, a 'parents only' dinner, movie night and a beach-style picnic.

"It's a place where feelings of togetherness are fostered . . ."

The camp also provided therapeutic activities. Families were invited to share photos and memories of their child by creating family trees. We know that many of our families find meaning in learning the stories of others while sharing their own stories and this helps to reduce their sense of isolation.

On Sunday, our campers gathered for a Remembering Service for their loved ones. We shared a poem and released leaves with messages and flowers into the ocean. We finished the camp with a relaxed beach picnic.

Expressing feelings, sharing memories, trying new activities and learning that one is never alone in their grief, is central to the camp. It's a place where feelings of togetherness are fostered and participants feel free to laugh, cry, play, create and

remember their child or sibling. Our families have expressed that they and/or their children feel 'normal' because everyone on the camp has passed through a similar experience and understands what it's like to lose a precious loved one.

"It's good to know that people around me have lost their child too. I felt like this year was my year to connect with others. It's been good for my girls to meet other children who are just like them. I've never seen them immediately connect like they have done on this camp" Bear Cottage bereaved mum. ■

Understanding your needs

At Bear Cottage, we are constantly looking for ways in which we are able to improve our care.

Two members of the Bear Cottage team, **Philly** our Clinical Nurse Specialist and **Liz** our Social Worker, in partnership with **The Children's Hospital Westmead**, are currently conducting a research study involving our bereaved families.

We understand that this is a sensitive and emotive subject. We are hoping that with your help, the results of this study will allow us to better understand the needs of families at this devastating time and the effect of after-death care on the long-term bereavement process. The primary aims of the study are to look at the needs of the family following the death of their child and to evaluate the services provided by Bear Cottage.

It is a study of bereaved families from January 2012-January 2016 whose child died at Bear Cottage and accessed our special room, Clifton Gardens. Families will be invited to express their interest in participating in the study. If you don't receive a letter and study information in the mail and would like to participate, please don't hesitate to call Philly or Liz on 9976 8300. ■



Parent's Corner

Support for mums

MumSpace is a new website launched to provide a one-stop shop for the prevention and treatment of perinatal depression and anxiety. This is designed to support the mental health and emotional well-being of pregnant women, new mums and their families.

MumSpace is designed to connect women quickly with the level of support they need, from advice and support in the transition

to parenthood, to effective online treatment programs for perinatal depression and anxiety. It is also a resource for healthcare professionals.

The online resources and apps available through MumSpace are evidence-based and have been evaluated by the Perinatal Depression e-Consortium partners in research studies conducted in Australia. ■

www.mumspace.com.au



Footprints in the Sand

Bear Cottage's Bereavement Service



Remembering our children

Kayla Roberts

27/09/2000 – 29/07/2007

Kristopher Vincent

22/05/17 – 20/08/17

Chase Kendall

20/09/17 – 20/09/17

Imogen Stone

17/11/06 – 8/10/17

Emersyn Tapp

11/04/17 – 8/11/17

Harry McLeish

15/11/17 – 19/11/17

Gabriel Gerry

4/03/17 – 18/11/17

Staff news

Meals are an important part of every family's day and it is important to us, that whilst at Bear Cottage, the food served is fresh and tasty. We have recently welcomed **Shannah** to the kitchen and into the chef role and we look forward to tasting her delights.



Shannah



Hayley

We have some changes in our nursing team with Registered Nurse (RN) **Hayley** recently joining us and **Emily, Ella** and **Fiona** taking up Assistant in Nursing roles whilst studying to become RNs. In the upcoming months we will farewell **Georgia, Tess** and **Sami** who have all been successful in gaining new graduate placements at SCH and CHW.

RN **Naomi** has recently enlarged her family with the arrival of **Finley** and we wait in anticipation for the announcement of RN **Hayley's** new arrival.

Congratulations to all for your new roles and new arrivals! ■

Valuable volunteers

Making a difference

Our volunteers bring a variety of skills to the Cottage to assist our children and their families. Hairdresser Natalie is one such volunteer who visits Bear Cottage every second Wednesday.

My name is Nat and I live nearby on the Northern Beaches so I have always known about Bear Cottage. I'm also a hairdresser with two beautiful and very busy children.



I've always been the type of person to help people in need or those less fortunate than me and when I heard that there wasn't a hairdresser offering their services at Bear Cottage, I decided to get involved and signed up for the volunteer training course. Hairdressing is more than just doing hairstyles. It's a chance for the parents and children alike to sit, breathe, relax and allows them to put themselves first for a short time. This is something that so many of us take for granted but for them, it is a really incredible experience.

I work alone with the families most of the time and it humbles me to share their stories and hear about the journey they are on. All the families have taught me so much about myself.

When I walk through the door at Bear Cottage, the first thing I see is colour followed by smiles. I hear laughter and the piano playing – everyone is having so much fun.

I love the time I spend at Bear Cottage and have met the most incredible people over the years. My shifts are very diverse and I have cut hair in some interesting places! Of course, a shift is never complete without a hello and a cuddle with Frankie the dog – another amazing Bear Cottage resident.

I will continue to give my time to Bear Cottage and I hope that I can make some kind of positive difference in the lives of the children and families I meet.

Thank you for having me at the Cottage!
Nat x

A warm welcome

Bear Cottage has recently welcomed an intake of new volunteers, an exciting development as it means we continue to expand the breadth of skills, knowledge and experience amongst our volunteer pool, something which we really value and appreciate. The volunteers at Bear Cottage offer an extension of the care and support we provide to the many families who come and stay at Bear Cottage. Their interactions with children and their siblings are particularly valued, offering much needed entertainment at the craft table, with music or in the garden. This allows parents the time and space for their child.

We place great importance on the training of new volunteers by providing two days of learning and reflection to ensure we are recruiting and supporting volunteers to the highest standard. We encourage volunteers to reflect on the role they can play within the house and find different ways to acknowledge the difference they make, however big or small. We support volunteers to think about the different ways they can connect with a child by being fully present and aware so that moments of connection are not lost.

We encourage volunteers to be guided by the family, the child and our Allied Health team, looking for those fleeting interactions and connections and building on this, whether it's a smile, a sound or a movement of the eyes or hands. Every child who stays with us is unique and we have a lot to learn from children and their families; a message we offer as guidance to our volunteers.



Naomi and Callum enjoying the swing

One volunteer, **Naomi** shared her experience of just that, a moment of connection with a child during story time:

"Every Friday afternoon I work as a volunteer at Bear Cottage. My primary role is to interact with children to give them company and support. Often I am unsure whether a child is aware that I am there beside them but recently I left Bear Cottage feeling that I had made a difference to a child. The child was on the floor, wriggling. He couldn't talk or walk – he just lay there and wriggled. I sat beside him on the floor and I asked him whether he wanted me to read him a story.

There wasn't a response but I decided to read all the same and again, there was no response. I noticed that he had shifted his head from the TV to me, but I didn't know whether he was aware that I was there. But then I wondered: how would he react to my singing? I started singing – some Hebrew melodies, something from 'The Sound of Music', the last chorale of the 'St John Passion' – a random selection of songs. To my surprise, our interaction changed immediately. He looked at me, engaged my gaze and smiled. He was obviously not only listening but also enjoying it. There was real pleasure in his face. He couldn't ask for more, but when I stopped I had a feeling that he would have wanted to. And the most amazing thing is that after a while of singing, I started reading again and he seemed more responsive to the story I was reading. He really seemed engaged. The power of music! ■

Dare to dream



Visitors to Bear Cottage often ask us who it was that had the idea to create such a special place for families who are caring for a child with a terminal or life-limiting illness. The answer is **Dr Michael Stevens**, Paediatric Oncologist at the Children's Hospital Westmead.

We were delighted to recently welcome Dr Michael Stevens and his wife **Margaret** back to Bear Cottage and to hear him share the story of how Bear Cottage came from being a dream to a reality. Michael and Margaret had spent time researching hospices in the UK and on their return they were able to

share their ideas which ensured that Bear Cottage would include all the very best elements of what they had seen.

Many of our families will be familiar with the name plates on the bedroom doors and it was wonderful to hear Dr Stevens share with us how his daughter designed these to reflect the home-like environment at Bear Cottage.

We thank Dr Michael Stevens for having the vision and passion to ensure Bear Cottage exists to provide paediatric palliative care at this very special place. ■