



Royal Visit edition

May 2014

Welcome



It was certainly a very 'Good Friday' when Bear Cottage hosted a visit from the **Duke and Duchess of Cambridge**.

This was a wonderful opportunity

to showcase to the world what a wonderful facility Bear Cottage is. The only thing we couldn't anticipate was the weather, but we were not let down as the sun shone brightly over Manly.

Eight children and their families were in house on the day to spend time with the Duchess, who is a very keen advocate and spokesperson for children's hospice services in the UK and beyond. An additional seven bereaved families spent time sharing their precious stories with the Duke of Cambridge who is Patron of the Child Bereavement Trust in the UK.

The couple were greeted on the pathway by staff and volunteers before proceeding inside to a very warm welcome by children, families, staff and volunteers. To say it was a magical afternoon is an understatement.

Princess 'Kate' met the families individually, was shown our baby possum and Easter chickens and joined in with music therapy in the back garden. Both the Duke and Duchess were visibly moved by the warmth of Bear Cottage and in seeing the amazing strength our families have, when faced with such difficult times.

The afternoon finished with a 'Royal' afternoon tea and the Duchess speaking of the need for children's hospice services and the incredible job they do.

I have been asked several times "what

were they like?" I am sure that everyone who met the Duke and Duchess would agree that they are incredibly warm, friendly people who are empathetic and interested in improving the lives of our very special children and their families.

A big thank you to everyone who assisted in ensuring Bear Cottage sparkled on the day and in the lead up. The awareness generated was phenomenal and will go a long way to ensuring Bear Cottage continues to provide the care so desperately needed.

The day also has provided many happy memories for those here and is recognition to the many children who have been part of our family during the past 13 years and the children and families that will do so in the future.

The 18th April 2014 will certainly go down in our history as the day 'The Royals' came to Bear Cottage, brought so much happiness and put smiles on so many faces. 🐾

Narelle Martin, Nursing Unit Manager



Royal Visit

A day to remember

It's not every day that royalty comes to visit, so for all the little 'princes and princesses' of the Bear Cottage family, the chance to meet the Duke and Duchess of Cambridge was a dream come true.

Patients, families, staff and volunteers were dressed in their finest as they welcomed the royal couple with open arms and open hearts, to their home-away-from-home.

"We feel quite honoured to have Prince William and Princess Kate come here while we are staying," one mother said. *"The Duchess was so lovely and graceful when she spoke to us. She was incredibly compassionate and knew exactly what to say. For us, the royal visit means we've got something so memorable that we can all share as a family."*

Bear Cottage was the only location where the Duchess made a formal speech and she praised the "incredible work" of Bear Cottage.

"The haven that you have created here is inspirational and there is so much you can share with each other as you continue to support and nurture those in your care," said the Duchess.

There was also the chance for Bear Cottage to thank the Duke and Duchess for their warmth and generosity by presenting them with a unique artwork. Under the guidance of Art Therapist, Trypheyne, patients, families, staff and volunteers all contributed to the colourful and abstract artwork, capturing their prints on large sheets of cardboard. *"One of the most important and powerful memory making tools we have at Bear Cottage is to copy a child's fingerprints,*



handprints and footprints. With that in mind, we created a unique artwork from as many Bear Cottage children, families, staff and volunteers as possible," Trypheyne said.

The artwork, which was presented to the Duchess of Cambridge by bereaved siblings Sophie and Killarney, acknowledges the history of Bear Cottage and celebrates the hospice's beautiful location on Manly Beach.

The wording inscribed on the back of the artwork explained the significance of the gift.

"We are as unique as our fingerprints – there is no foot too small, that it cannot leave an imprint on this world"

This artwork has been created using the fingerprints and footprints of our children, siblings, parents, staff, nurses, doctor and volunteers at Bear Cottage, specifically for this gift. The footprints of a nine month old little boy direct you to walk through the landscape with him. A three year old girl's handprints encourage you to fly like a bird. A doctor has a gentle three finger touch, while the nurse's hands touch all over. The landscape is full of the typical loving touch that makes Bear Cottage such an exquisite place. This gift is in honour of everyone who has travelled their journey at Bear Cottage.



Superhero Week

We have lots to look forward to in the next few months with **Superhero Week** taking place during **21-25th July**. We'd love you to get involved and hold your own event – at school or in the workplace.

Keep an eye out for our Superhero Week trucks driving on a road near you. Donated by **AHG**, these trucks will be busy helping to promote the event.

For more information, see the flyer enclosed or go to our website. 🐾



Website unveiled

Check out our new website when you have the chance and be sure to take a tour with Frankie! We are very grateful to **AnalogFolk** and **Hello Future** who kindly donated their services to this project. 🐾



Remembering our children

Jessica Tuivava – 26.07.93 – 24.01.14

Levi McCormack – 17.02.04 – 14.02.14

Rhea Lakhota – 13.12.12 – 13.02.14

Samuel Morris – 27.08.03 – 22.02.14

Jessica Diaz – 8.10.98 – 8.03.14

Kaylah Ramsay – 13.11.01 – 30.03.14

Arianna Beagle – 4.11.10 – 21.03.14

Nikki Hawthorne – 7.07.11 – 1.04.14

Luke Blazejko – 1.02.04 – 12.04.14

Samuel Barnard – 19.01.01 – 27.04.14

Hugo White – 29.04.09 – 1.05.14

Our thoughts are with these precious children's families and friends



Our story

Mia our beautiful, affectionate funny and determined daughter was diagnosed in May last year with a rare neurological degenerative disease. It feels like that day was in another life before we had heard the term 'life limiting' or knew of Bear Cottage or listened to the words of our doctor, *"Mia probably won't make it to high school, we are talking about years not decades."*

Mia was born in 2009 a healthy robust baby. She met all her development milestones with ease. She was crawling at nine months, walked at twelve months and was a great enthusiast for baby sing song. She babbled early and was generally fine and healthy. Mia was an inquisitive, joyful baby and toddler, full of love and a little bit of mischief too.

Toby, Mia's younger brother arrived on the scene in 2011, and we felt so lucky to have two beautiful boisterous kids. A baby boy and a two year old little girl with blonde curls commanding our household and keeping us on our toes and running circles around us.

Mia's behaviour and language at this time were becoming challenging and we had some mild concerns which were allayed by her GP, paediatrician, and nursery teacher.

She was quick on her feet, loved scooting and racing around on her balance bike and everyone reassured us she would start to focus on her talking soon. The behaviour changes and concerns were explained by the 'terrible twos', the arrival of her younger brother and the upheaval of moving to a new home and Dad travelling regularly for work. As time progressed the concerns became more acute but nothing we believed couldn't be overcome with dedication to speech, behaviour, occupational therapy, and a whole lot of love and patience.

In August 2012, aged 3, Mia had her first seizure. She had her second a month later and after various tests (EEGs and MRIs) Mia was diagnosed with epilepsy. Development delays persisted but we remained confident and hoped she would outgrow the condition.

Unfortunately Mia's health continued to deteriorate as her seizure frequency increased and her language and memory suffered. Mia began suffering frequent falls and lost the confidence to walk down steps or run.



In May 2013, nine months after Mia had her first seizure, she was diagnosed with the life limiting condition late infantile Neuronal Ceroid Lipofuscinosis or as it is more commonly known Batten Disease. Our hearts broke.

We immediately relocated to Sydney after seven years overseas to be closer to family. During those first few months settling back into home life was burdened with grief and was chaotic and confusing, trying to navigate a new medical system and disability and education systems. Early on many we met mentioned Bear Cottage.

We eventually made it to Manly, only a ten minute drive from our home, for a tour with Narelle. The place was lively and light and friendly. Toby was super impressed with the trains and other children and Mia was mesmerized by the fish tank and Frankie. We feel fortuitous that we live so close by and eagerly accepted the offer to join in some music therapy classes, as Mia wasn't yet enrolled in a preschool or day care.

Phoebe's music therapy is the best medicine. I love being in the garden watching Mia and Toby play instruments, engage with other children and enjoy the sunshine and enthusiastic singing.

Making memories for Mia has become a bit of a mantra in our household and it was in the garden at Bear Cottage that Mia met the Duke and Duchess of Cambridge. Kate sailed into the garden gracefully and joined in singing Twinkle Twinkle Little Star and we watched enraptured as she interacted with the children. She made her way around the group meeting each family and chatting. She listened so attentively to us and crouched down engaging with Mia which was very sweet and probably not very comfortable. Mia said the word "baby"

and Kate replied *"yes, I have a baby, baby George."* My husband

was tapped on the shoulder only to turn and be face to face with Prince William *"You must be Hamish, Mia's father?"* William was personable and engaging and complimented Mia on her beautiful princess dress.

It was a beautiful sunny day and we will cherish forever meeting the Duke and Duchess at Bear Cottage.

On the same day we met another family with a daughter affected by Batten Disease, which was moving and made the day even more significant for our family.

I read in the papers the following day that Kate said on leaving Bear Cottage, *"inspiring but we're also ready for a big sob."* I too felt emotional at the end of the day. For me it was inspiring being surrounded by so many beautiful loving families and feeling a part of a compassionate and caring community.

Bear Cottage offers us a place where we feel Mia is fully recognised and her days celebrated.

We want to make every day count. We want to make her life matter, her time with us special and her days as fun and fulfilling as humanly possible. We cannot comprehend the future so we are living with our little family in the present.

We feel blessed to have family, friends and Bear Cottage who offer us empathy, strength, understanding, patience, love and creativity to help support us as we care for Mia and try to give her all the joy, respect and love she deserves.

We also hope that if Mia cannot survive this horrible disease that she is at least the last generation to suffer from Batten. Bear Cottage and the Royals have helped to raise awareness that we hope leads to more research and eventually a cure. 🐾

Peta Murchison, Mia's mum

Valuable volunteers

Bear Cottage is lucky to have wonderful support from the corporate sector. We regularly hold working bees where these volunteers happily give up their time to do all manner of tasks – painting, cleaning, gardening. One such group is the KordaMentha and NAB team who have been regular visitors. Sophia Spiliotopoulos from KordaMentha and Ann Sherwood from NAB talk about what inspires them . . .

Corporate Responsibility has become a new way of thinking for **KordaMentha** and **NAB**. Together we have embraced the opportunity to do more of what matters to people and our communities.

KordaMentha and NAB first became involved with Bear Cottage in 2011 as the chosen recipient of our annual



fund raising event, now well known as the 'Stair Challenge'. This event provided a wonderful platform for competitive spirit to thrive and in doing so, engendered

generous support from family and friends to donate to a most worthy cause.

Bear Cottage touched the hearts and minds of all participants and donors alike, in a way that is not easily achieved and to date we have raised almost \$60,000.

As a 'once a year' fund raising event, the Stair Challenge was great, however we all agreed that we wanted to become more deeply and more regularly involved with other volunteer activities at Bear Cottage. There was a desire to make a difference to this organisation in a very tangible way. Our journey began in early 2012, when our volunteers spent an afternoon each month transforming the gardens for the children and their families under the guidance of



The hard working KordaMentha & NAB team with Sophia and Ann (front row)

Bear Cottage volunteer, Peter Lavery. We also participated in activities at Christmas time, making cards and helped prepare for various events. More recently we spent time at Bear Cottage repairing and planting new gardens and painting furniture in preparation for the visiting Royals.

As individuals, our work at Bear Cottage has been a very personal realisation that we truly can make a difference in a meaningful way and it has provided a sense of 'doing something good for a unique facility'. We are very fortunate and thank the wonderful team of people at Bear Cottage, who welcome us at each visit. 🐾

Dates for the diary

May 16-18	Senior Sibling Camp
May 25-31	Palliative Care Week
May 11-15	Mums' Camp
June 15	Back to BC BBQ
June 17-21	Intermediate Camp
June 23-27	Boot Camp
July 1-25	Superhero Week
July 25-27	Boot Camp
Aug 22-24	Boot Camp
Aug 28	Dads' Camp
Sept 12-14	Junior Sibling Camp
Sept 15-18	Mums' Camp

Staff news



Over the past few months we have welcomed to our team **Dr Greg Kelly** as Staff Specialist. **Liz Arnott** has taken on the Social Worker job share role with **Sue Hearn**. Liz and Sue

both work five day fortnights and offer much needed support to families and staff.

Anyone who has stayed at Bear Cottage knows how important food is. We have recently welcomed Kylie into the kitchen after saying goodbye to Ina. Kylie has already proved, that weight loss will

continue to be difficult during a stay at Bear Cottage. Sadly, **Penny Douglas**, the volunteer manager will also be leaving us at the end of May. 🐾



Reminders

Parking

With our ongoing increased occupancy we are also experiencing an increase in parking problems. As you are aware, Bear Cottage has very limited parking for staff and families so there is a limit of one car per family when a child is staying and we can't accommodate vehicles being left at Bear Cottage if a child is unaccompanied.

Meals

Please note that we can only provide meals for those staying at Bear Cottage. Unfortunately our budget does not extend to visitors. Visitors are welcome to bring their own food and share the facilities.

Occasionally exceptions are made in emergency situations and for our bereaved families if arranged in advance with the nurse in charge. 🐾



Contact details

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