



November 2014

Welcome



It seems incredible that we are now drawing towards the end of 2014. What a year it has been for Bear Cottage and our families.

The commitment of much needed funding, a Royal visit, the introduction of further support camps, Super Hero week . . . the list goes on. But most importantly, an occupancy of 99%, means the walls of Bear Cottage are filled with laughter, tears, support and living every day of the year.

As Christmas approaches we look forward to celebrating the past year and the future with you at our **Family Christmas Party** on the **14th of December**. We also take the time to remember the many babies, children and young people who are no longer with us. Some were known to Bear Cottage for many years, whilst for others it may have been for just a few days. Each one, very special to the Bear Cottage family.

Every child is like a flower. Each one unique, some with small imperfections, some will live longer than others, but put together, they make a beautiful garden. Bear Cottage is that garden and what a beautiful one it is.

In 2015 we hope to work closely with families in ensuring that the best possible care is provided. We now have an Admission Check List form that will be sent out with the admission paperwork prior to each child's admission. It is a reminder of things that need to be brought with your child on admission.

We are also updating our Parent Feedback form. Your feedback is very important to us and assists us in ensuring the needs of the child and family are met.

On behalf of the team at Bear Cottage I would like to wish you all a safe and happy festive season and we look forward to seeing and supporting you in 2015. 🐾

Siblings in Surfers!

The September school holidays have been an exciting time for our siblings. Our Social Worker Liz, reflects on our very first **"Siblings Surfers Camp"**.

As I write this article and remember our trip, I think, WOW! What an incredible experience I was lucky enough to share with some very special Bear Cottage siblings. Thanks to a very generous donation, we were able to hold a camp at Surfers Paradise for six of our current and bereaved siblings.

The adventure kicked off with a short but exciting flight from Sydney to the Gold Coast – many of our siblings being first time flyers.

The siblings had their priorities right so when we arrived at the hotel, it was straight to the pool! After a fun filled afternoon, it was time to head to the **Australian Outback Spectacular's 'Spirit of the Horse'** – a unique and exciting dinner show filled with music, drama and action.

The next morning, the kids woke bursting with energy and excitement for a day at **Movie World**. Little did we know we had some thrill seekers amongst us. The staff weren't getting away with sitting on the



sideline – the siblings had us on all the rides with them!

After a night at **Hurricanes Restaurant** and plenty of rib-sauced faces and hands, the siblings were ready for the next day at **Sea World**. The visit was filled with lots of surprises – meeting, feeding and playing with Moki (a beautiful and very friendly dolphin), to going behind the scenes and coming face to face with polar bears Liya and Nelson and then meeting "baby" Henry who weighed a mere 180kg – the newest addition to the Sea World polar bear family.

That evening we tested the siblings' ability to catch their dinner with teppanyaki! A very entertaining evening filled with lots of laughter, especially at the staff who just couldn't get their dinner catching skills together.

Our final morning was spent in the pool followed by an indulgent beach side brunch of Canadian pancakes and milk shakes. Sadly the adventure had to come to an end and after a return flight they were met by their eagerly awaiting parents.



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Who would've thought the Social Work role at Bear Cottage would include riding roller coasters, coming face to face with polar bears and competing in handstand competitions in the pool!!

Every day, parents supporting a terminally ill child are faced with obstacles and hardship. They get through it with help and love of their family and friends, but what about the siblings? Being the brother or sister of someone with a terminal illness is different for each child, yet they are linked by the common thought that they love their sibling, no matter what.

There are the daily challenges and rewards that come with being in a family with someone who has different needs. Our Sibling Camps provide them with an opportunity to enhance their self-esteem, encourage peer support, share unique experiences together, make new friends and reduce any sense of isolation. 🐾



Remembering our children

Baha Qarizada
25/02/14 – 11/08/14

Rebecca Askew
6/12/06 – 14/08/14

Rhys Hubble
22/08/04 – 23/08/14

Danna Valle-Boghossian
31/03/07 – 9/09/14

Andrew Northover
18/11/99 – 16/09/14

Eva Wen
22/05/14 – 16/10/14

Neve Brady
6/01/10 – 21/10/14

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

10 reasons why we chose Bear Cottage over home

From our first visit to Bear Cottage, my husband, Anthony, and I knew this was where we wanted to say our final goodbyes to our darling son, Aidan. Thankfully, when he died in July, our wish was granted.

With the help of Bear Cottage staff, we were able to bring Aidan from PICU at the Children's Hospital at Westmead to Manly for his final hours and stay with him in the days following his death.

Below is an extract from my blog, **Parenting in Limbo** – the ups and downs of parenting a terminally ill child, written prior to Aidan's passing. It explains why we wanted Aidan to die at Bear Cottage and not at home or in hospital:

- 🐾 Anthony and I get to be parents and spend quality time with Aidan without having to worry about making and administering medications.
- 🐾 Unlike our dark house, Bear Cottage is light, bright and airy - it's as close to heaven as we can get on earth.



- 🐾 There is no housework to worry about or meals to prepare, freeing us up to focus on Aidan, our other son, Ollie, and ourselves.
- 🐾 We have three well rounded meals available to us to ensure we maintain our strength and health.
- 🐾 Nursing and medical staff are available around the clock should we need assistance and advice.
- 🐾 A social worker is available to help us navigate this unfamiliar territory.



- 🐾 Visitors can be limited to short periods during set times and, since it's not our house, we don't need to worry about providing refreshments, making sure the bathroom is clean and all the other little things that come with entertaining guests.
- 🐾 There are lots of things to do to distract our niece, nephews and friends' children who will likely find the experience overwhelming.
- 🐾 We don't have to worry about finding a GP to write a death certificate.
- 🐾 We can stay with Aidan as long as we need after his death, days if we like, until we are ready to say goodbye.

While we only had hours at Bear Cottage before Aidan died, it was without a doubt the best decision we ever made. Not only did we receive the benefits listed above, but a whole lot more. The staff held our hands through every step of the process, ensuring our final time with him was a treasured experience. 🐾

Kylie Sammut, Bear Cottage mum



Creativity takes courage

The ability to express oneself creatively is one of the most important things for holistic health but is often one of the first things to be thrown out the door when a child is ill and in need of intense care.



Mums' Camp is a special opportunity for mothers to spend time doing things, which they often have not allowed themselves to do for many years, but which their soul craves.

At Bear Cottage, many wonderful experiences are offered during Mum's Camp that supports this creativity. One of these experiences was made possible with the generous support of a local lady, Sarah from **Sarah Spear Pottery**.

Sarah comes to Bear Cottage to run pottery painting classes. She supplies all the required materials, and then takes the pieces home to fire them and returns them to Bear Cottage.

"My experience at Bear Cottage is a mixture of so many emotions. I've known a number of families who have had children at Bear Cottage. I always thought it is an amazing place that offers a service for families who sadly find they need that kind of support.

I was touched by the enthusiasm of the mums. Even though many of them said they could not paint, they all had a go and said the experience was very therapeutic.

During my visit in May I had left some plates to be used in whatever way might be useful and was touched and saddened



to return in September to pick up three beautiful plates done by the siblings of a 14 year old boy who had sadly passed away the day before.

They had painted and written the most lovely memories of their brother. I was aware they wanted these glazed, fired and back in time for the funeral and was happy that I was able to return them to the family for that special day.

I have come away from Bear Cottage with such admiration for the staff and their dedication to making such a difference to families in their time of need. I hope to be able to continue to be a very small part of that in the future."

Sarah's story is touching in its simplicity and shows how the ripples that occur from supporting families to have time, and the means by which to express their creativity, can have powerful and long lasting memories for so many. 🐾



Footprints in the sand

On a sunny Sunday afternoon a group of families are sitting out on a verandah enjoying a snag and a cold one . . . This is a scene that you might see any weekend all over Australia, but this is at Bear Cottage, the children's hospice.

Providing bereavement support is an essential component of what we do at Bear Cottage, and every three months we give our bereaved families the opportunity to visit by coming to our **Back to Bear Cottage BBQ**.

The transition from non bereaved to bereaved is obviously very difficult, but we hope that these informal get-togethers can be therapeutic and useful. *"The BBQs are a good excuse to come back"* one mum said. She loves catching up with the staff – the people who knew her little girl. For dad, the best thing is meeting new families or re-connecting with old friends whose journeys are, in his words, *"different but the same"*. For the siblings . . . they just love coming back. *"Before our little girl died, whenever we left Bear Cottage after an admission, the first thing her siblings would ask is when we were coming back? This was no different after she had died – they loved being here and couldn't understand why just because their sister was no longer with us they couldn't keep coming. The BBQs give them the opportunity to do this and on a fairly regular basis."*

As staff, we are in a very privileged position caring for these amazing families and it is a wonderful opportunity to see them again.

Some families come back again and again, other families may come back only once after the death of their child, and some families may never feel the need to return to Bear Cottage. There is no right or wrong and our job at Bear Cottage is to offer families support in a variety of ways. Everyone lives their lives differently and everyone will live their bereavement differently. Bear Cottage is here to offer support however it may be needed. 🐾



Parents' Corner

Parents' Corner a beautiful part of the connections made between parents at Bear Cottage and the sharing of information about helpful services and tips. This is your corner. Please let us know about services that have been useful and we will include them in future *Cottage Capers*.

Association for Children with a Disability NSW

ACD provides information, support, membership and advocacy to families of children or young adults with any type of disability. The association is parent run, and therefore understands the issues parents and families come across day-to-day.

Membership is free to families and a quarterly newsletter is sent out. The parent written ACD publication



Through the Maze can be purchased by members for \$10-\$14. This is a comprehensive guide to disability services in NSW

and a key to understanding the way the service system works. It covers the stages from diagnosis of a disability or developmental delay in childhood through to adulthood.

Bear Cottage Parent Tip

Be persistent when making enquiries to different service organisations. Follow-up regularly by ringing back and keep written details of names and numbers, phone conversations and agreed actions. 🐾

Dates for the diary

November

7-9: Boot Camp

December

14: Family Christmas Party

**please note this has changed from the 7th*

8: Voyage to the Deep (see flyer insert)

24: Closed for respite

29: Open for respite

Valuable volunteers

Wendy Blacklock

We know them as "vollies", the wonderful people that you see at Bear Cottage, always ready to lend a hand and mostly wearing pink. But what did they do before come to Bear Cottage . . .



I spent 30 years as a performer and a further 30 years as a producer of Australian artists (dance, circus, puppetry, performance,

Aboriginal plays and /or a mixture of all) where I not only produced but toured their work nationally and internationally. So for many years I trundled around the world (admittedly in my stilettos) to make sure we fulfilled our invitations and performed at some of the world's most prestigious festivals.

What would I do when I retired? (Which I had to do as the Opera House gave me a farewell!) The powers that be obviously decided that it had to be formal or they wouldn't get rid of me. I saw an article in the Sunday Telegraph which said Bear Cottage looks after desperately sick and

dying children, but is still a place of love and laughter.

Why would this attract me? I had never previously heard of Bear Cottage – didn't know where it was or anyone who had been there. I had no understanding of medicine, and had always been wary of 'volunteers', but I respond to the "twitch" on the end of the nose. For the uninitiated, this refers to making all decisions in life by intuition as opposed to logic (whatever that is!)

I am now a volunteer and learning more and more each time I come to the Cottage. When I was asked what was I getting out of it, I came back to being a mother and a grandmother and think how worried I am about the next generations. We have been so spoiled and in some ways so politically naïve in Australia, but Bear Cottage makes me feel less selfish, makes me acknowledge how lucky I am, and most importantly gives me back my faith in human nature.

As the article said "It is a place of love and laughter" but it is so much more. 🐾

Wendy Blacklock was a JC Williamson Award recipient for lifetime achievement in 2003. Wendy was awarded the Order Of Australia for her services to the arts in 1992. A pioneer and facilitator of young people wanting to enter the arts, she is also an Helpmann Award recipient. Wendy started Volunteering at Bear Cottage in May 2014.

Staff news



Over the past few months we have welcomed to our team a number of bright new and not so new faces. **Rebecca** has returned from maternity leave into her fundraising

role. A few years ago we were lucky to have **Georgie** (above) as an AIN. After graduating as an RN and gaining valuable experience at SCH, she has returned as a casual RN. With first hand experience as a volunteer, **Annabel** (right) has now moved into the Volunteer Manager role.

Following Keta's move to the UK, we welcomed **Kirsty** into housekeeping and finally, two new undergraduate nursing students have begun as AIN's – **Hannah B** and **Hannah N** are gaining valuable experience with us at Bear Cottage.



Sadly, we said goodbye briefly to bubbly fundraising manager **Claire** whilst she has a much needed break in Ireland. 🐾

A Bear Affair



Our annual **A Bear Affair** fundraising ball was held in August and over 450 guests were

treated to a magical night that exceeded all expectations. The sold out event left guests mesmerised by the awe-inspiring show of **Brad Blaze** and were kept on their toes by MC and long term supporter of Bear Cottage "**Fast Ed**" from Better Homes and Gardens. Over \$420,000 was raised on the night making this our most successful year ever. 🐾



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