

Cottage Capers

The Newsletter for Bear Cottage families



June 2016



2016 is flying by! Work is continuing on our renovations at Bear Cottage and we are now just over half finished. At present the downstairs areas are closed with installation of new air conditioning and lighting and upgrading of the spa. Meanwhile, a new meeting room and office space is about to be completed. In a few weeks, the work will move back upstairs affecting all rooms in the Eastern wing. Once again, we apologise for any disruption caused to your family during this process. We look forward to being fully operational by mid-July.

Bear Cottage values family feedback which enables us to continually strive to improve our service and ensure that we are providing the best possible care to your child and family. This year we would like to ask parents to be a part of a new *Family Advisory Committee*. It is envisaged that meetings will take place every three months at Bear Cottage, with facilities for families who cannot make the journey to be able to teleconference. If you would like to be a representative on this committee please contact me on narelle.martin@health.nsw.gov.au or 02 99768301. We would love to hear from either non-bereaved or bereaved parents.

Our *Remembering Day* service was held recently on a beautiful sunny Sunday in May. This is now an annual event for our many bereaved families, staff and volunteers. It is always an honour to share this occasion with families and remember and celebrate the lives of the many children who are no longer with us.

Finally, we'd like to thank Bear Cottage mum, **Peta Murchison**, who generously shares her family's story in this issue.

We look forward to catching up with you in the upcoming months and hope that you will be able to attend our Superhero Week party coming up in July.

Narelle Martin,
Nursing Unit Manager.

The powerful lessons my six-year-old has taught me

Our beautiful, affectionate, funny and determined daughter **Mia** was diagnosed when she was three years old with Batten, a cruel, rare neurological degenerative disease.

Just over three years later she can no longer run, jump or sing, and we're used to hearing things from doctors like "Mia probably won't make it to high school, we are talking about years not decades."

Batten disease is rare so most doctors, let alone parents have not heard of it.

Mia was born a healthy baby and grew into a cheeky inquisitive toddler. At three years old she could sing, scoot and swim and sadly at six years old Mia now relies on us for all her needs. She can no longer walk, sit up, talk or eat. She is also now blind.

Our sweet six-year-old has taught us some powerful lessons and shows us every day what really matters. Here are a few things we have learnt:

1. The goalposts don't just move, they vanish

It was so hard watching our child regress, going through her milestones in reverse and losing all her acquired skills. Everything we'd celebrated and photographed: holding her head up, crawling, sitting, first words, using a spoon, first steps – it all faded away over three years.

But letting go of all markers and comparisons to other kids brings a sense of freedom. I now see Mia and Toby more for who they are and relish their quirks and achievements whenever they happen and not in relation to how they match up.

2. Sorrow and joy can exist simultaneously

I can be heartbreakingly sad, but still have a joyful life. Our sad journey (that I would do anything to change) is also a great privilege in so many ways. It's not all doom and gloom because we do have to get on and live every day. Though it definitely has a



continued overleaf . . .



profound effect on us, our experience gives so much clarity to what is important and the incredible people and love in our lives.

In many ways I feel so blessed and at the same time sad beyond any words.

3. Just let it go

I can't change our situation. There is no karma. Mia's crap illness is simply extremely unlucky and can happen to anyone. I've eventually let go of the what-ifs and why's and the self-blame and focused on what I can control, which is making every day for Mia as engaging, fun and comfortable as possible.

The joy on Mia's face when she rides a horse each week, or the little smile when her wheelchair bounces over rocks on a walk or just turning up the music really loud and singing out of tune.

4. Death is not taboo. It's part of life.

At our kitchen bench while cooking dinner my four-year-old son asked "when will my teeth fall out?" I responded "Probably when you're about five or six like Mia", to which Toby asked "Will I still be able to walk when I'm five?"

We chatted about him being healthy and not being sick. He asked: "Why can't Mia be a grown up with Batten (disease)?" Our lives have been so dramatically changed by Mia's illness it has forced me to stare down my deepest fears and then just keep breathing.

My husband and I are very open about Mia's illness and are even talking about Mia's death and where we want it to happen. It is very hard but hopefully it helps us prepare for what will be the most painful moment in our lives and we want to ensure it is as peaceful and painless as possible for Mia.

We talk about death and dying with Toby in the hope that he understands (as best he can). We don't want it to be a taboo topic. Children sometimes ask us if Mia will die and we try to answer with a simple yes, and that it's OK to talk about it if they want. Everyone dies. We don't know when it will happen but it is inevitable and sadly we say goodbye to some people far too young.

I want friends to visit us and be with us as Mia's disease progresses. I don't want them to wait until the funeral to say goodbye or send flowers! I know I'd much prefer to enjoy those flowers while I am still alive and kicking.

5. Life is a bittersweet journey

Birthdays and New Year's Eve celebrations are bittersweet reminders of time slipping away and markers in the sand of how much stronger and healthier Mia was 12 months prior.

Mia has shown me these special occasions aren't just about champagne, fireworks and cake. I no longer banish a year behind me and embrace the next with crazy resolutions on diet and exercise. I reflect and cherish each year, even the horrible parts, I see how these tough moments and days help me grow.

6. Don't beat yourself up

I've learnt to really lower my expectations. Some days the house will be chaos and a mess and I don't care. We'll eat scrambled eggs or Weetabix for dinner occasionally if it has been a really long day and I don't beat myself up if the kids aren't eating organic ethically sourced home cooked meals three times a day



(although Mia's diet is better than anyone's in our house because she cannot say no to her vegetables!)

7. Don't forget to sing

I've learnt to really like my kids as well as love them. Mia's condition has made us more focused on the present and spending time together. That engagement with the kids has been so rewarding and I feel very close to them. This is not a stage of life to get through, this IS our life and embracing their challenges has made me very close to them.

I'm no saint but I've learnt that getting angry or frustrated in the middle of the night when Mia won't sleep just makes me more cranky. I find the quickest way to settle Mia at 3am is to give her a big hug. Feeling our chests rise and fall together and her breath on my neck is when I am most content.

I have more fun with Toby and Mia now ... I get on their level and do stuff they enjoy and it's not always hard work. We rumble, ride bikes, have baths together, sing, go for swims at sunset and hug every morning and tell each other we love each other every day.

8. You can learn a lot from kids

Kids have an incredible instinct for kindness and acceptance. I have honestly met the kindest, funniest and most loving people who are six-year-olds. Kids hold Mia's hand at her local primary school, prop her head back up on her headrest when it falls off, read to her and stand by her side watching out for her. Mia's sweet friends write cards "you make me smile" "you are better than rainbows" "I love you". I see that people truly care.

Mia has taught us so much. Mia has shown me the most tender and giving elements of the human spirit. Kids that hug and smile even though they are in pain, families that don't get any sleep but still function, women who lift wheelchairs and care for their children all day every day.

I have seen families facing hardship and loss that are full of boundless love and warmth.

Mia is resilient, patient and calm. To me she has a serene beauty and grace that I admire with everything she endures.

I am proud our daughter teaches kindness, empathy and acceptance. They are beautiful qualities to foster in our children. ■

Peta Murchison, Mia's mum

**Photos by James Brickwood*

Footprints in the Sand Camp



In modern society men have been conditioned to hide their emotions and be "the strong ones". The feelings experienced at the loss of a child must be similar for both parents and although it is acknowledged that grief is an individual experience rather than based on gender, it would appear that a dad's grief may be

hidden. A bereaved dad's role may include protecting the rest of the family, taking on the practical aspects of family life, and having the role of being the provider.

Having the opportunity to spend time with other dads and talking about their experiences can be very supportive. Dads who do have the opportunity to share their feelings with other bereaved dads can find this very helpful. One such example of peer support is experienced by the dads attending the Footprints in the Sand Bereaved Family Camp, which is held annually. Pete Edenborough, a Bear Cottage father and dad to Chaise and Eli has been able to put this experience down on paper.

Hi my name is Peter and I'm a Bear Cottage dad.

A year ago we received an invitation to attend the Bear Cottage Bereavement Family camp, and at first I was unsure about attending the camp because I didn't know what it was about.

After giving it some thought we decided to attend the camp despite not knowing what to expect.

In 2016 we attended our second camp and I am so glad I did. There was so much to do, not just for the kids but also for the mums and dads.



We met many other families who have travelled a similar journey to ours and were able to share our stories with each other. The staff and volunteers from Bear Cottage organised so many activities there was always something to do.

Some of the activities were arts and crafts for the children, a visit from the clown doctors, kayaking for the whole family, ten pin bowling for the dads and pampering for the mums.

Some of the dads I had already met and some were new, but it was great talking to the other dads and being able to share our stories with each other. We laughed and shared memories, but we also had a few tears remembering our children.

On the last day of camp we all went to the local park and enjoyed the day together with a lovely bbq lunch. The kids played in the park and had a swim. After lunch, we headed down to the beach and we had our remembrance time, a time where we remember our children who are now angels. We listened to a poem and placed flowers and a message to our children into the water while we had a few moments of silence remembering our children. When I leave camp I leave with a smile.

Thank you Bear Cottage for your support you have shown our family for the last two years. ■

Written by
Pete "Luigi" Edenborough



Footprints in the Sand
Bear Cottage's Bereavement Service

Parent's corner

Understanding the NDIS

The National Disability Insurance Scheme (NDIS) is rolling out over the coming years across Australia. To see when it is likely to roll out in your area, check the NDIS rollout map <http://www.ndis.gov.au/about-us/our-sites>

The first step is to check eligibility and this step doesn't take long online - <http://www.ndis.gov.au/ndis-access-checklist>

Prepare, prepare, prepare

Once you have confirmed eligibility for the NDIS by the National Disability Insurance Association (NDIA) you will be sent a workbook to help you with the planning process. The 'Participant Workbook' will help you to prepare prior to meeting with your NDIS planner who will meet with you to create your individual NDIS Plan.

It is suggested that you think about what goals for your child's life before you meet



your planner. The workbook will help you. It will take you through your child's current activities and supports, what's working, and what you'd like to achieve for your child or change. The workbook comes in a range of different languages and is found using this link http://www.ndis.gov.au/sites/default/files/documents/planning_guide.pdf

We suggest signing up to the eNewsletter on the NDIS website (<http://www.ndis.gov.au/news/subscribe>) to keep up to date with new information, events and progress. Keep your eye out for local free workshops – these are often run by non-government organisations and focus on getting carers up to speed with the latest happenings with the NDIS, assist you in getting ready for the scheme's introduction and find out how non-government organisations can help you. ■

Remembering our children

Flynn Marks
3.02.16 – 03.02.16

Hartaj Othi
25.05.05-4.02.16

Isobel Tarlington
30.09.11- 22.03.16

Isaac Farache
24.01.03 – 29.03.16

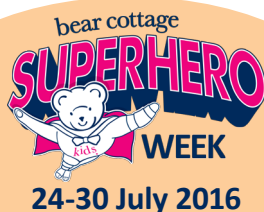
Ethan Krause
17.09.09 – 3.04.16

Grace Horne
27.07.12 – 6.04.16

Harley McEnally
20.12.14 – 30.04.16

Mason Armstrong
13.05.16 – 13.05.16

Superhero Week

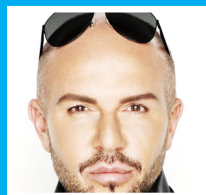


We will be celebrating **Superhero Week** from **24-30th July** this year. We are hoping that this year will be bigger than ever and we are asking you to get involved.

We'd love your schools, workplaces, sporting groups to take part and you can register now by going to our website www.superheroweek.com ■

Television stars

Make sure you look out for our new Superhero Week television commercial which will go to air in July across Foxtel Channels and Channel 10. This year our ad features many of our children and long-time ambassador **Ed Halmagyi**, as well as designer **Alex Perry**, NRL star **Ben Ross**, model, singer **Cheyenne Tozzi** and Bondi Rescue star **Anthony "Harries" Carroll** making an appearance. We are incredibly grateful for them supporting our event and helping us raise awareness. ■



Superhero Launch Party

Our **Superhero Week launch party** will be held at Bear Cottage on **Sunday 24th July** and we hope to see all of our children and families at this event. You will receive an invitation with all the details shortly. ■



City2Surf

Registrations are open now for this year's City2Surf. For more information go please visit <https://city2surf2016.everydayhero.com.au/bear-cottage> ■

Fundraising news

Digging deep

CPB John Holland Dragados, are responsible for developing Australia's biggest public transport project, the \$8.3 billion North West Rail Link and have been long term supporters of Bear Cottage.

Their partnership has driven a range of fundraising initiatives including raffles, proceeds from vending machine sales, family fun days and other fundraising events, as well as the sale of Bear Cottage merchandise. They recently held an extraordinary fundraising event deep underground within the North West Rail Link tunnel itself. This gala charity ball 'A Sparkling Night' raised over \$180,000 for Bear Cottage. A truly remarkable night. ■



A fond farewell



In the past few weeks we have said goodbye to two very valuable staff members. Our wonderful Social Worker **Sue** and AIN **Hannah** have both

moved in different directions.

Sue onto retirement and new adventures, Hannah to pursue her career as a Registered Nurse. Bear Cottage has been very fortunate to have had these two in their ranks and they will be greatly missed. Social worker **Liz** will now be at Bear Cottage full time. Some of you may remember past AIN **Emily**. After gaining broader paediatric experience, we are delighted to have Emily back on the casual nursing pool at Bear Cottage. ■

Cottage news

Award winner!

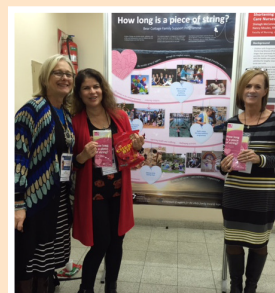


Congratulations to our CNS **Philly Smith** for winning a "2016 Nursing & Midwifery Excellence Award".

We all agree that

Philly goes above and beyond the call of duty to ensure our children and their families have the best experience possible. Her passion and dedication is amazing and this is very well deserved recognition. ■

Argentinian adventure



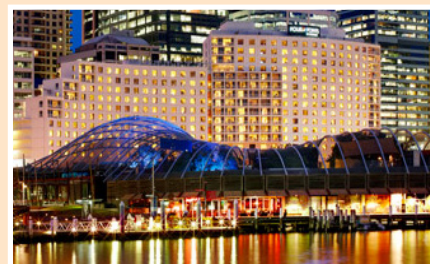
Three of our Bear Cottage staff recently had the opportunity to attend and present at the **International Children's Palliative Care**

Network's conference in Buenos Aires. With the theme of this year's conference being "**Children's Palliative Care – NOW!**" the conference brought together over 400 people from around the world and from all professions working with children with life-threatening and life-limiting conditions to encourage the exchange of knowledge, new and innovative ideas, research and experiences between them.

Nurses **Sue Bartolini** and **Sarah Clark** and Community Relations Manager **Bronwen Simmons** shared information about our Wellness "Boot Camp" program, Family Support program and Superhero Week. This was an incredible opportunity to showcase Bear Cottage and learn from other experts from around the world. ■

A Bear Affair

Our annual fundraising ball, **A Bear Affair** will be held on Saturday 27th of August at the Four Points Hotel, Darling Harbour. If you are interested in attending or assisting with the donation of prizes, please contact **Des** on des.poelingoer@health.nsw.gov.au We would love to see you there! ■



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The Sydney children's Hospitals Network
care, advocacy, research, education