

# Cottage Capers

The Newsletter for Bear Cottage families



## Armed and not so dangerous

We recently held our first Bear Cottage **'Sibling Day'**, for children aged 5-10 years. The action packed day allows for siblings (bereaved and non-bereaved) to connect with one another, make friends and most of all have FUN!

We held the day out at **Newington Armoury**, Newington, with the assistance of the wonderfully energetic and creative **Mark Boyle** from Drumbuzz. It was a fabulous day filled with lots of laughter. The kids started off the day with parachute games, they launched water rockets, played water drums, made their very own bagpipe horns (of course they played these with GREAT enthusiasm), they formed the Newington marching band and searched for clues and hidden treasure.

It was a beautiful warm day, so for those of us who managed to get wet, we dried off very quickly. The feedback from the kids was that it was an awesome day, so we look forward to holding our next Sibling Day later in the year. The one day camp meant that kids had plenty of time to connect and feel exhaustedly happy at the end of the day. ■



## May 2015

It is with much pleasure that we recently welcomed **Roy Anlezark** into the Business Manager role at Bear Cottage. Roy comes from a corporate background and has also been a volunteer at Bear Cottage. Roy is looking forward to meeting many of you on your next visit and working with our team to ensure Bear Cottage continues to make a difference to so many lives.

Last year, Bear Cottage was given \$2 million by the Federal Government to undertake some long overdue capital works which will commence in the next few months. It will involve replacement of the roof and air conditioning systems, painting and building of a new meeting space. Unfortunately there will be some disruption to our service and increased noise, but we will endeavour to minimise this to our families. There will be a reduced number of beds for booked respite available as we juggle the internal work but priority will be given to families in emergency situations. It is hoped that the work will be completed within three months of commencing.

Nursing Unit Manager **Narelle Martin** recently attended the 'Sod Turning' for a new children's hospice being built in Brisbane. Hummingbird House will be modelled largely on Bear Cottage and will provide much needed care to the families in Queensland. Prime Minister Tony Abbott spoke of the increased need for children's hospice services and acknowledged the wonderful work being done at Bear Cottage.

It is hoped that Bear Cottage families were not affected by the recent storms and bad weather and we look forward to seeing many of you, either in house, at one of our programs or at our **'Super Hero'** launch over the next few months. ■





## Eli's story

I found myself sitting on the grass at Freshwater Beach with my partner Dean, one sunny afternoon in July last year. We were contemplating the enormously stressful journey, started just four weeks earlier with the birth of our precious little boy Eli.

Our journey very quickly moved to the Children's Hospital at Westmead, the day after Eli's birth. He had been born with heart issues, but after many tests and a few weeks later, they discovered he had a rare genetic disorder; Trisomy 9 Mosaic. This news was a complete shock to us! It was dreadful, horrendous and heartbreaking. We were told our newborn baby boy would have a limited lifespan and we simply had no idea what to expect. It was so rare and no one had really seen it before. I had a lot of trouble dealing with this shock diagnosis. I fainted. What just happened to us?

A few days later, Dean met with the social worker at Westmead, who put forward the idea of transferring Eli into palliative care at Bear Cottage. I had heard of Bear Cottage before. I knew it was a children's hospice in nearby Manly. Eli was transported there when he was just four weeks old.

I was unable to see my son Eli for several days after his arrival. It was just too painful and I didn't want to believe this was happening to us, so Dean stayed with him. But whilst sitting at Freshie beach that day, Dean showed me a video on his phone of Eli's arrival at Bear Cottage that morning and so the following day I worked up the courage and strength to go there too. That day was the start of a very important relationship with Bear Cottage staff, nurses and social workers. They were so incredibly welcoming, caring, thoughtful and understanding. Eli was placed in his own beautiful, special bedroom. He was so adored and fought over for many cuddles! Over the following weeks they helped

and supported us in so many ways. From bottle feeding and bathing Eli, to administering his medical needs, to looking after our emotional welfare, providing us with meals at times when eating was the last thing we felt like doing, to the many hours of listening to us as we continued to absorb and come to terms with a very small baby born with a life-shortening genetic disorder. It was a difficult and dark time.

As we live so close by in Freshwater, we chose in the first few weeks to leave our first born baby in the care of the nurses at Bear Cottage and return home each night to rest. We spent many hours there each day, caring for our new baby. We were able to come and go as we pleased and call them at any time to check on our son. Life was very uncertain. We didn't know how long he would live for, but our little boy was tough and he seemed to be progressing well. After a few weeks, we finally gained the strength to take him home.

Over the ensuing months, Eli progressed at home with some ups and downs. During this period, we were visited and called regularly by the wonderful palliative care nurses and social workers. The support was always there, even though our environment had changed. After a while, I decided to bring Eli into Bear Cottage every Friday for visits. It was convenient and nice to share a cup of tea and a chat with everyone. Again, our son was always fought over for cuddles once we got there! He was a beautiful little soul and undoubtedly brought absolute joy to everyone he met. He just loved his bath time, his lamby toy and his daddy's cuddles.

Sadly, Eli's journey ended just two days after Christmas. We dearly loved our little boy and we are so very grateful for the all encompassing support that we received from Bear Cottage in a time that was incredibly tough – and then some. ■

**Mandy, Eli's mum**



## Remembering our children

**Shriya Fotedar**  
24/01/11 – 19/01/15

**Sandra Badr**  
16/04/07 – 1/02/15

**Joseph Goodwin**  
14/07/12 – 8/02/15

**Dezarae Jones**  
18/03/06 – 1/03/15

**Noah Ryczak**  
17/12/02 – 3/03/15

**Tate Burley**  
9/01/15 – 6/03/15

**Ayaan Sharma**  
16/09/14 – 10/03/15

**William Lipscombe**  
4/03/04 – 19/03/15

**Gabriella Por**  
18/03/13 – 22/03/15

**Miles Murdoch**  
25/05/09 – 26/03/15

**Olivia Mattes**  
23/03/15 – 29/03/15

**Aidan Brown**  
20/04/05 – 12/04/15

## The Ring Theory

Most families have a wide support network, including immediate and extended family, close friends, colleagues and acquaintances. For bereaved families these people are even more important and the support they provide is vital, but doing the supporting can be difficult too. Friends and family may not know the right thing to say or do.

The 'Ring Theory' concept of "comfort in – dump out" can be helpful. This theory involves having concentric circles, with the bereaved family in the centre. Each circle outside of that will have a member of their support system – starting with those closest to the family and moving outwards.

The concept is that those in the middle of the circle, such as the bereaved family, can say whatever they want to whomever they want. Those in the other circles can also do this but only to people in the circles outside of them – comfort in, dumping out. For

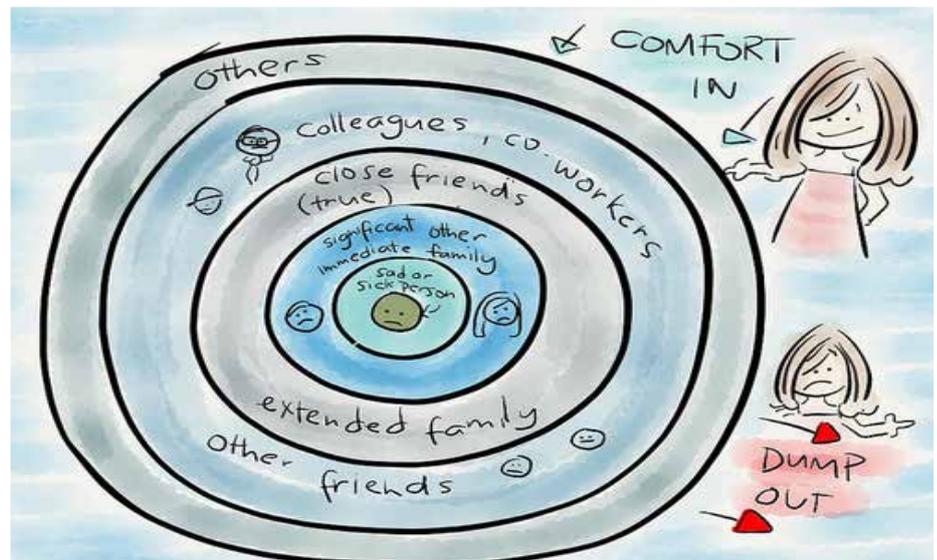
example, the bereaved family in the middle can say whatever they want about how sad they are, how angry they are or how unfair life is. Grandparents who might be in the second circle may also experience all these feelings but it may not be helpful for them to share this with their children, that is the bereaved family. They can, however share these feelings with other friends, family or professionals who sit in the larger rings. This will continue moving outwards.

Trying to help your friends and family in understanding what is OK to say can be difficult. Having this visual diagram on the fridge may be helpful in assisting them to understand the more supportive things to say. ■



**Footprints in the Sand**

Bear Cottage's Bereavement Service



## Staff news

Our former fundraising manager **Rebecca** has welcomed a new baby daughter, Sophia. **Emily** from fundraising has finished her time here to go travelling and AIN **Natalie** has finished her training and will begin a New Graduate placement at SCH. Thank you to all of you for being a wonderful part of the Bear Cottage team and we wish you all the best.

Emily



Natalie



Our CNS **Ann-Marie** and Social Worker **Liz** have recently been spreading the word about Bear Cottage when they presented at the Asia Pacific Hospice Conference in Taipei. Their talk was entitled 'Walking with Families . . . the road less travelled' and was very well received. It is wonderful to have the opportunity to raise awareness of Bear Cottage at an international level. ■

Ann-Marie and Liz



## A Bear Affair

Bear Cottage's annual fundraising ball, **A Bear Affair** will be held on **Saturday 29 August**. Tickets are now available by contacting **Des Poeling-Oer** on [des.poelingoer@health.nsw.gov.au](mailto:des.poelingoer@health.nsw.gov.au) or by calling 9845 3131. The ABA committee are also sourcing auction prizes so if you are able to assist in this area we would be very grateful. ■





# Our volunteers are unpaid but to us they are priceless

**What do a fireman, an award winning actress, a bank trader, a professional fairy, a yoga teacher and a lawyer all have in common?**

These are just some of the day jobs of the Bear Cottage volunteers. We now have 141 active volunteers that put in over 10,000 hours a year. These wonderful people juggle family and day jobs to be able to volunteer at Bear Cottage.



Our volunteers do so many different roles at Bear Cottage, from assisting with play, art and music therapy, housekeeping, kitchen help, gardening, reception / admin, reflexology and even walking our dog, Frankie. Recently we have also introduced an in-house volunteer hairdresser and yoga teacher. Our volunteers come from all walks of life and each brings their own skills, love and compassion. Between them they speak 15 different languages. The only thing they all have in common is a big heart and a collective goal to help the families and children of Bear Cottage.



Tuesday March 17th was Bear Cottage's 14th Birthday and also the day we recognised our wonderful team of volunteers in a Volunteer Thankyou function themed **'Let Love Grow'**. All volunteers were given a small gift of thyme seeds to thank them for their 'thyme'. Those celebrating anniversaries for volunteering for five years in 2015 were given lemon trees. We also recognised our wonderful **Lynda Harris** who has reached the remarkable 10 year anniversary volunteering at Bear Cottage as one of our receptionists. We are so grateful to this entire group of dedicated people who give so willingly and selflessly of their time.

Bear Cottage would not be able to do what it does without our amazing volunteers. Our volunteers provide the most fundamental act of philanthropy – they give of themselves. They may not necessarily have the time but they just have the heart and somehow make it happen and we thank them from the bottom of our hearts. ■

## Calling all superheroes!

Superhero Week will take place during 20-24 July 2015. Now in its fourth year, Superhero Week is our chance to celebrate our very own superheroes – our courageous children and their inspiring families.

Enclosed in this newsletter is a flyer about the event and how you can get involved. Please spread the word amongst your family and friends, schools and workplaces. You will find more information on by clicking [www.superheroweek.com](http://www.superheroweek.com)

Start preparing your costumes and look out for our television commercial appearing on Foxtel channels soon. ■

*Our heroes, the Parratt family*



## Cabaret for a cause

John Clements and his wife Sue recently held their Cabaret night. This is the seventh year of this event which has seen them raise over \$30,000 for Bear Cottage. It was a wonderful evening and we are incredibly grateful for this support. ■

## Time to get running

Registrations are now open for the annual City2Surf and you can support Bear Cottage by joining **Team Bandaged Bear**. Details on how to join are available on [www.city2surf.com.au](http://www.city2surf.com.au) ■

*Sue and John Clement presenting their cheque*



## Calendar

June 13  
**Back to Bear Cottage BBQ**

July 19  
**Superhero Week Launch**

August 20-24  
**Dads' Camp**

August 28-30  
**Junior Siblings' Camp**

August 29  
**A Bear Affair ball**



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[www.bearcottage.chw.edu.au](http://www.bearcottage.chw.edu.au)



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