

# Cottage Capers

The Newsletter for Bear Cottage families



Spring 2017



## What is a Super hero?

The Cambridge Dictionary describes a super hero as “someone who has a special strength and uses that strength to help others”, so it is not surprising that Bear Cottage holds **Superhero Week** each July.

Every child that enters the doors of Bear Cottage is a superhero.

They each show

incredible strength and resilience no matter where they are at in life's journey. That strength helps the staff and volunteers do what they do on a daily basis. Working together with the children and families is what makes Bear Cottage such a special place.

A huge thank you goes to our Community Relations Manager **Bronwen**, who each year co-ordinates our Superhero Week. It continues to grow and gets bigger and better, raising much needed funds and awareness for all the superheroes that come through our doors.

Social media can be a wonderful form of communication and Bear Cottage has its own Facebook page to let you know what is happening. Unfortunately, it is NSW Health Policy that staff cannot be friends with those they care for. We do ask for your understanding of this situation.

There is still some respite available from the 11th – 24th September and from the 8th October. If you are in need of a break, please either call **Narelle** on 02 99768301 or email [narelle.martin@health.nsw.gov.au](mailto:narelle.martin@health.nsw.gov.au) ■

**Narelle Martin, Nursing Unit Manager**

A hero is an ordinary individual who finds the strength to persevere and endure in spite of overwhelming obstacles.

**Christopher Reeve**

## Acting out

by Judy King, Art Therapist

In April Bear Cottage partnered with **ATYP** (Australian Theatre for Young People) for our annual **Senior Sibling Camp** for the first time. This was a space for them to use their joint creativity to tell '**A Bear Cottage Story**' using art, drama and music.

The ten siblings soon bonded over fun ice-breaking drama activities and by the first afternoon, a loose story started to appear from the collective drawings and ideas that bubbled and bounced between them. Simple props that included two doorways and, of course, a bandaged bear (borrowed from the Bear Wall just by the tea room), soon helped them create a 'journey through the forest' (both metaphorically and physically) towards Bear Cottage.

The ferry ride to and from the city, with a gentle walk through The Rocks to the wharf where ATYP are based, also became a part of the adventure. On the Sunday morning, as we walked down the hill to catch the ferry across to the city, I overheard two siblings talking about why sibling camp was so special to them. *"At school people don't really understand, or when you say you have a disabled sister or brother there's this awkward silence... but at sibling camp everyone understands and it's nice to be around those that do".*

With much excitement, they returned for the second day where the drama tutor really helped build a coherent story line that managed to incorporate most of the ideas and thoughts that the group had put forward. They negotiated and supported each other, gently encouraging those that might have been a little shy and applauding those that weren't.

As the Sunday afternoon approached, with the knowledge that their family and friends were arriving for a short performance in the theatre

*Performance preparation*

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*Caius making his stage debut*



Bear Cottage mum Jennifer Brankin is part of our Family Advisory Committee and has kindly shared her Bear Cottage story.

## A mum's story

I was 35 weeks pregnant. Then my world came crashing down. Following a meeting with the Royal Prince Alfred Hospital's Fetal Medicine team, I received news that my unborn baby had significant complications. Three days later my son Alexander was born via emergency C-section. Just 1.6kg with brain, heart and respiratory issues, he was rushed to the N.I.C.U. and eventually patient transported to the Grace Centre for Newborn Care at The Children's Hospital Westmead.

After five-and-a-half agonising months with my son under round-the-clock care, I was finally able to take my tiny baby boy home. With the guidance and support of his teams of doctors (at the Children's Hospital), along with dedicated and loving friends and family, I was able to help him improve while caring for him inside the comfort of my own home. I was managing his many needs – N.G. tube feeds, reliance on oxygen, bi-pap for sleeping at night – and I had adjusted to the stresses of his special care. The informal support network around me was helpful, however, as his only caregiver I had no one around to confidently take Alexander overnight so the weight of all parental responsibilities were placed on my shoulders.

Being a single parent is never easy but in October 2016 I was pushed to a new limit. Diagnosed with cancer, I knew my pending surgery would leave Alexander without his primary caregiver. Concerned with how he would be cared for during my treatment and extensive recovery, I turned to the social worker at The Children's Hospital for help who then connected me with the respite services of Bear Cottage. I graciously accepted.

I knew from reputation that we would be greeted with a warm smile, a hug and accepted unconditionally but what I wasn't prepared for was the instantly calming atmosphere, the homely feel, the plush toys and bookshelves, the hand-made quilt covers on each bed, the gracious volunteer who was playing the Cottage's grand piano and inviting children to gather around and enjoy the music.

**"Bear Cottage . . . allows me to maintain equilibrium in my life."**

As a mother I am overjoyed and inspired when I see my son able and encouraged to interact with all the fabulous programs here, like art therapy or music classes, where he is assisted to paint his own hand print or listen and explore a range of musical instruments. The gentle and supportive staff and volunteers, both inside and out of the sensory space, as well as on the facility's sunny balcony, brightens both our lives.

Access to Bear Cottage and its many services also allows me to maintain equilibrium in my life and that in turn helps me remain the best mum I can possibly be. I am grateful for the support and can't recommend this much-needed service enough. I'm unable to change my palliative child's chronic and complex condition. That much I know and accept. As Alexander's mother I now just focus all my time and energy on making his fraught and unpredictable life as comfortable as it can possibly be and I feel very fortunate that Bear Cottage is able to provide so much care for my son and I.

It's peace of mind to know Alexander will always be cared for by a dedicated team that understands his many needs. I am forever grateful that I can leave my 18-month-old son in safe, capable and caring hands. To the attentive staff who have continuously treated Alexander like someone's only child and not some patient, thank you. ■



## The gift of music

Bear Cottage has a collection of beautiful musical instruments and among these is one which is particularly special. It is called a Reverie Harp. You may perhaps have seen Bear Cottage Music Therapist **Belle** playing it for the children in the afternoons – a time when they may need music for rest – different from the morning sessions when music may be used more for stimulation and social enjoyment.

Whenever people pick up the Reverie Harp, they seem at once unable to resist running their fingers across its strings. It is a very inviting, tactile instrument made of mahogany, silky to the touch. Even children who have little physical movement are often drawn to it, moving their fingers to create music.

The Reverie Harp is in fact a type of lyre, an instrument which may be traced as far back as the ancient times of Mesopotamia. It is said that the earliest documentation of music being used for therapy is in the Biblical account of David playing a lyre for a troubled King Saul who was subsequently relieved and soothed by its sounds.

Even if you have never played an instrument, you can easily learn to play a Reverie Harp because it is impossible to



make a mistake. This is due to its pentatonic tuning which means that every single string on the Reverie Harp always harmonises with all others. People often remark that its distinctive tonality reminds them of music on holidays taken in Bali or other parts of Asia.

Next time you are at Bear Cottage, if you would like to try the Reverie Harp, please let Belle know and she can show you just how easily you may create simple musical patterns which will not only be soothing for your child, but also restful for you.

The Reverie Harp is not only for parents, however. Siblings are often very good at it and discover how much they enjoy sitting with their brother or sister and making beautiful sounds.

Music may be used as a gift from one person to another. When we play a Reverie Harp for another person, it is possible to convey that we are there for them, allowing its gentle sounds to express to them the depth of all our unspoken emotions and longings. ■



# Being a bereaved parent . . .

is like being a member of a club that you would give anything not to belong to. Parents report that the grief experienced after the loss of their beloved child never leaves them – they have to learn to live alongside it, entwining it into their everyday life. These are some things that might be helpful to consider if you are travelling this road.

🐾 We all have the right to our feelings. No one knows exactly what it is like to lose your child. No one has walked the exact same path as you. You have a right to feel how you feel about your loss. Some days will be better than others. There might be good days or good parts of days and there might be not such good days - today might be a good day, moments of laughter might even occur, but that doesn't mean two years from now a deep sadness might not wash over you and you will be teary when back to school time rolls around.

🐾 Everyone has the right to grieve how they grieve. It is important to remember that there is no right or wrong way to grieve. We are all unique and therefore, the way we grieve will be unique.

🐾 There is no time limit on grief. You will think of and remember your child for the rest of your life. The grief may shift and morph and move. Some days may be better than others, whilst some days may be very difficult to bear. You have the

right to grieve for as long or as little as you need.

🐾 You have the right to find peace when and if you are ready. Grief hurts. There are no words to describe the pain, it is disorientating, out of life's order of events and soul crushing. You may feel that you will never find a sense of peace again, however, over time, it may come although, it may not be the same sense of peace experienced before. It may be a case of getting to a place of knowing the pain and being accepting of it perhaps, with a realisation that peace and pain can exist on the same plane, in the same space and at the same time. You may find this place and embrace it when you are ready.

🐾 You have the right to remember and speak your child's name. You can say their name as much and as often as you wish to. It is okay to remember and talk about your child whenever you wish to, to remember their love and the joy they brought to your life. It is your right, as a bereaved parent to carry your child's memory and speak their name as much as you wish to. ■

## Parent's corner

Ever suffered from the feeling of brain fuzz or mental clutter? There are many ways to relax and different relaxation techniques to use to overcome this feeling and reduce your levels of stress. We all have the capacity to be more mindful. Simply cultivating our ability to pay attention in the present moment allows us to disengage from mental "clutter" and work towards having a clearer mind. We are better able to respond rather than react to situations, thus improving our decision making and potential for physical and mental relaxation.

### Techniques to practise

#### One Minute Exercise

Sit in front of a clock or watch that you can use to time the passing of one minute. Your task is to focus your entire attention on your breathing, and nothing else, for the minute. Have a go - do it now.

Progressive muscle relaxation involves tensing and relaxing specific groups of muscles from your feet all the way to your head, while focussing on your feelings of tension and relaxation.

You could also try breathing techniques, such as deep breathing or focussed breathing (breathing in through the nose and as you breathe out say a positive statement to yourself like 'relax' or 'calm down'). Place a hand over your diaphragm to make sure you're breathing slowly – you

should feel your hand move if you're doing it right. Focus on breathing in slowly for four seconds, holding your breath for two seconds and breathing out slowly for six seconds.

#### Mindful Eating

This involves sitting down at a table and eating a meal without engaging in any other activities – no newspaper, book, TV, radio, music, or talking. Now eat your meal paying full attention to which piece of food you select to eat, how it looks, how it smells, how you cut the food, the muscles you use to raise it to your mouth, the texture and taste of the food as you chew it slowly. You may be amazed at how different food tastes when eaten in this way and how filling a meal can be.

#### Mindful Walking

Here the same principle applies, while walking concentrate on the feel of the ground under your feet, your breathing while walking. Just observe what is around you as you walk, staying in the present. Let your other thoughts go, just look at the sky, the view, the other walkers; feel the wind, the temperature on your skin; enjoy the moment.

Try purchasing or downloading guided meditation or Apps such as Smiling Mind (Modern Meditation App for children also) or ReachOut Breathe (iPhone only). Start small and find a way that works for you. ■



## Footprints in the Sand

Bear Cottage's Bereavement Service

### Remembering our children

**Kristopher Vincent**

22.05.17 – 20.08.17

**Michael Melhuish**

7.11.89 – 5.06.17

**Laura Li**

24.06.14 – June 17

**Tammy Kang**

21.08.14 - 13.06.16

**Aaravi Dwakaranath**

5.04.14 – 13.06.17

**Finn Marker**

28.07.07 – 20.07.17

**Caleb Heddle**

22.03.05 – 25.07.17

**Ella Wilkins**

21.11.98 – 03.08.17

## Staff news

Over the past few months we have been very fortunate to welcome to our team of Registered Nurses **Tamara, Grace, Liz and Michelle**. They bring with them many years' combined experience in paediatrics and a great enthusiasm to work at Bear Cottage.

Congratulations to RN **Georgie** who recently welcomed into the world baby **Evie**. We are looking forward to a visit soon at Bear Cottage.

Our housekeeping team has also grown with **Julie** coming on board and the return of **Lisa** on a casual basis and we also welcome **Brendon** who has taken on the role of Maintenance Manager. ■



Tamara



Grace



Liz



Michelle



Julie



# Fundraising news

## Party with a difference



It has been a very busy few months for the Fundraising Department with **Superhero Week** in July which was quickly followed by our annual Gala Ball "**A Bear Affair**".

**Superhero Week** 2017 was one of our best yet with over \$200,000 being raised and funds are still coming in. This event has grown year on year and we are constantly amazed with the great efforts made across the country in so many schools and workplaces.

This year we held our first ever **Corporate Superhero Party** at the **Hotel Steyne** in Manly on 26 July which raised over \$26,000! The initiative came about thanks to the generous support of **Denis Muddle** and the team at the **Steyne Hotel**, who provided the venue and food and drink at no cost.

We were delighted to have **Fast Ed** on hand as MC and "arm wrestling judge" – thank you Ed for being such a true friend to Bear Cottage. A huge thanks to everyone who dressed as their favourite Superheroes and a special mention to former **Mayor of Manly, Jean Hay** who won a prize for the best costume – she channelled her inner Lady Gaga!

We would like to say a very special thanks to the schools that participated in Superhero Week as a tribute to their fellow students past and present for whom we have cared at Bear Cottage. Thank you for being part of the invisible string that continues to connect us through Bear Cottage.

Superhero fundraising continues into October when **Tas Cassim** will fundraise for Bear Cottage by walking 100km!! His mission is to raise \$10,000 so watch out for a Superhero walking on the road from Lake Macquarie to Bear Cottage!

We wish to extend our heartfelt thanks to all who supported Superhero events and made it such a success. Here's to Superhero Week 2018! ■

*Jean Hay AKA Lady Gaga*



## Going to the ball



**A Bear Affair** is our major fundraising event for Bear Cottage and this year was the biggest and most successful on record. We had 485 guests in attendance including Bear Cottage families and many generous donors. It meant a great deal to us to also have members of our Bear Cottage Family Advisory with us on the night.

We were thrilled that **Jenny Brockie** from **SBS Insight** was available to MC the event for us this year as regular MC, **Fast Ed** was unavailable. Jenny is a strong advocate for paediatric palliative care and we thank her for the kindness and empathy when interviewing our Bear Cottage parents **Karla** and **Leo** on stage at the event. We are grateful to them for sharing their stories which highlighted the ongoing need for paediatric palliative care.

We are overwhelmed with the success of **A Bear Affair 2017**, raising almost \$600,000. There was plenty of laughter in the room when ventriloquist **Darren Carr** appeared on stage. Huge thanks to **Paul** from **Device Technologies** who was a very gracious participant in Darren's show, not many of us would have been so brave to go on stage with a ventriloquist!

**A Bear Affair** takes months of planning and sourcing prizes. A huge thank you to **Fundraising Manager, Claire McCarthy** and the team of **Bear Cottage volunteers** who worked tirelessly in the lead up to the event – it was a joy to see so many pink tee shirts on the night!

Our Bear Cottage nursing staff wish to extend their heartfelt thanks to the kind donor who paid for ten of our nurses to attend the event . . . the photo shows how very happy our nurses were to be part of the **A Bear Affair** attendees!

Our thanks to everyone who attended the event and to all those generous donors who donated auction prizes . . . we cannot do what we do without you. ■



## Acting out

>> Continued from page 1



space, their focus and engagement went to another level, especially when lighting and dramatic sound effects were introduced. It also was apparent that this was a very special thing to be able to do – to explore, sing, act, write and draw and just share their stories in this way.

As well as their family members attending, **Frankie** (probably the most popular member of staff) was a surprise guest at the performance. She was perfectly behaved, she didn't even startle when one of the characters, 'A Cranky Nurse' banged a doorway or when thunder clapped and musical instruments were played loudly.

The final performance was powerful and it was wonderful to see the reaction of the parents as their children expressed their emotions with such creativity. It was evident that these siblings see and hear more than we sometimes allow for.

The feedback from the siblings was how much they valued this experience and we certainly look forward to partnering once again with ATYP to allow more of our siblings to take part in this inspiring camp. ■

The following link gives a short overview of the sibling's weekend: <https://vimeo.com/user13652328/review/216265534/3c155b140c>



## Calendar

Sat 14th October  
**World Hospice Day**

Tue 17th October  
**Bereavement Morning Tea**  
Sat 28-Sun 29 – 11am-12.30pm

**Junior Sibling Camp**

10-11 November

**Dad's Camp 2**

10 December

**Family Christmas Party**