



Cottage Capers.

The newsletter for Bear Cottage families.



February 2015



Welcome to 2015, a year we hope will offer support and care to the children and families who visit Bear Cottage.

2014 was a particularly busy year and the number of families Bear Cottage supports continues to climb. With this comes the challenge of ensuring the exceptional care we provide continues.

Whilst it is always extremely difficult when much needed respite is cancelled, we strive to ensure it doesn't happen too often. To those families who have been disappointed of late, thank you for your understanding and we look forward to seeing you soon.

Due to our increased occupancy levels there is a need to make a few changes. Only immediate family members can be accommodated for booked respite. Children can only be cared for unaccompanied if you are going on holiday for a maximum of two weeks and only one of these weeks can fall in school holiday periods.

Our **Family Support Team** has been busily planning a number of valuable programs across the service and you will find a copy of the 2015 calendar of events enclosed in this issue of the newsletter. Please take the time to see if there is anything that you would like to be involved with. We have also included a fridge magnet with some handy contact numbers for Bear Cottage.

Finally, it is always difficult to say goodbye to staff who have dedicated parts of their lives to Bear Cottage. **Matthew Seidl** has been our Business/Facility Manager at



Bear Cottage for the past six years.

Over these years, Matt has been involved in many changes and led Bear Cottage through an enormous

growth period. He has been a leader and a friend; he's donned working gear, fancy dress and always been on hand wherever needed. His role has been varied but always performed with a smile and a true belief in what Bear Cottage is about.

Bear Cottage will miss him, I will miss him, and we wish him well in his new career move. 🐾

Narelle Martin,
Nursing Unit Manager

House news

Bear Cottage has been full of fun and action over the last few months with a huge variety of activities for kids of all ages to take part in. Take a look at what we've been up to . . .



Our family story

Hunter and Ljae

I had a very good pregnancy, I ate only organically, I did daily yoga, stopped all coffee and alcohol and worked right up to the day I went into labour, at 41 weeks. I even did hypno birthing, as I didn't want any sort of "poison" in my son. I did everything right. Pfffft, if only I had known!

Hunter was born after 24 and a half hours of labour. He entered the world with the help of vacuum when it became clear he was stuck. Little did we know that he was unable to help himself, as he already had significant physical disabilities.

Hunter started having seizures as soon as we got home from hospital and we now suspect he was having seizures in utero. And we thought he had the hiccups!

For the first eight weeks of his life Hunter was having up to 20 seizures every day. The problem was that no one believed me. I went to several GPs asking for referrals to paediatricians. I took him to the Emergency Department many times but they thought I was just a panicky new mum and told me he just had colic or wind or some other "normal" baby ailment.

Finally, at eight weeks of age I was referred to a paediatrician and what a godsend he was (and still is). Within minutes of meeting him, he sent us home to pack and to meet him at the local hospital.

This was the start of hundreds of hospital admissions and many fights for life.

Hunter was diagnosed with epilepsy at nine weeks of age with warnings that there was something else not quite right. At nine months he was diagnosed with



'Cerebral Palsy with seizures', and referred to a neurologist at CHW.

This was to become our 'home away from home' for the next eight years. We spent more nights in hospital than we did at home, and there were more emergency paramedic runs and NETS helicopter flights than can be counted.

Hunter's seizures were out of control and no medication helped. He would spend days in PICU having seizures, at age two he deteriorated significantly. He lost all the skills he had worked hard to acquire, he lost his ability to swallow liquids and was given a peg for fluids. At age four he deteriorated even more and lost his ability to commando crawl, hold his head up, eat solids and communicate. Despite countless tests it wasn't until Hunter was six and having seizures every 30 seconds that we discovered he had the rare, drug resistant, catastrophic seizure disorder, Dravet Syndrome.

It was around this time that we were introduced to Bear Cottage. What a lifesaver! For six years (as a single parent), I had barely slept. I was working part time and studying full time and pretty much living out of a suitcase as we bounced from hospital to hospital. My social circle consisted of mums I met in hospital and the school that Hunter attended. I was missing classes at Uni and missing many days at work. I was exhausted, my family lived interstate and I was refused all respite as I was considered 'too functional'. Weight was falling off me and I was surviving on adrenalin and went through the days on automatic pilot.

On our very first day at Bear Cottage, I walked in and Hunter was taken from me. I was sat down and offered a cup of coffee and was told 'you look exhausted, let us take care of Hunter and you relax'. I could have cried with relief.

We have had many stays at Bear Cottage over the years, some for simple respite, some for recovery after surgeries and two stays were after horrific times in PICU when we almost lost Hunter. We have also had family from interstate come and stay with us at Bear Cottage so that Hunter can spend some quality time with his much loved cousins, aunts and uncles.

I grew up on the Northern Beaches so Bear Cottage visits are not only a time when Hunter is cared for, but when I can catch up with my closest friends from my 'before' years. It's the only time I feel like a 'normal'



parent, where I'm Ljae and not 'Hunter's mum'. I can momentarily forget the difficulties, heartache and challenges involved with having an ill child. A chance to go 'home' for a week.

Our stays have not been without sad times, Hunter has lost some close friends at Bear Cottage, including two of his classmates and it took a while for us to go back. I am so glad we did though as it is our favourite place to be. The staff are beautiful and supportive, the food is delicious and Frankie the dog brings the joy that only a dog can.

The time spent there exploring Manly and visiting the local cafés with friends, are the best weeks of our year. Hunter instantly relaxes there and when he is unwell, he recovers so much more quickly than when in hospital. After one surgery Hunter failed to recover and went downhill rapidly. When he finally started to show signs of improving, the surgeon released us into the care of Bear Cottage saying, 'please go to Bear Cottage before we kill him'. He looked like his old self within two days at Bear Cottage.

They say it's the sea air that brings such recovery but I think there is some 'magic' in the halls of Bear Cottage. 🐾

Remembering our children

James Stellakis – 13/09/07 – 31/10/14

Natesha Gill – 11/05/2000- 7/11/14

Annalise Holmes – 19/01/01-28/11/14

Caden Chapman – 9/08/09 – 16/12/14

Eli Jarvis – 11/06/14- 27/12/14

Luke Koh – 20/06/14 – 2/01/15

Joanne Lee – 18/11/06 – 6/01/15

Eloise Luke – 2/04/13 – 14/01/15

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

Back to school . . .

Whilst starting a new school year is a happy milestone for many families, for bereaved parents it is a reminder of milestones that have been taken away or never met.

No sooner has the stress of Christmas started to fade, the adverts for school clothes, shoes and supplies appear everywhere. Just a few days after Australia Day, the streets and public transport are full of children going back to school and social media is alive with photos of first days.

This reminder becomes another phase of your grief. Sometimes these reminders will slip past you without too much sadness. Sometimes they don't. There is no rhyme or reason as to which one may be the hardest. Taking the time to care for yourself may help in making the pain easier to bear (see our article **Looking after YOU** for practical strategies).

If you have other children at school, make sure that the school is aware of the situation every year and ensure

that their classroom teachers or year advisors are updated.

There are also some practical suggestions for parents or caregivers for grieving children to help create that good support system at the school such as:

- 🐾 Inform the school staff of the child's loss. Include at least the principal, teacher or school counsellor on the list of people you inform.
- 🐾 Schedule a private session with your child's teacher to discuss any concerns that you have about his or her return to school and the classroom.
- 🐾 Encourage your child to talk with his or her teacher (and the school counsellor if possible) to share the loss and their experience in their own words.
- 🐾 Assure your child that they don't have to answer every question if they feel uncomfortable doing so. Tell her or him that they have a right to privacy when questioned by anyone at the school.
- 🐾 Set up a plan for when your child may be overwhelmed by his or her grief at school. You could arrange for special

permission for the child to leave the classroom and go to a designated safe place to receive support and comfort. However, the child should understand that this permission is not an excuse to get out of everyday school work or responsibilities.

- 🐾 Keeping lines of communication open between home and school and working together can ensure that your other child(ren) feel supported. Make sure the school has your phone numbers and contact information in case of emergencies.

All milestones that are missed are hard but the ones that others may overlook are even more difficult for bereaved parents – going back to school is one of these. You will heal, learn to cope and find greater happiness in the simple things that others may never know. We are thinking of all our bereaved families at this time of year.



Looking after YOU

As well as the joy, caring for your child can be monumental and all consuming.

Beginning to take time out to care for yourself will remind you that caring for your own needs is important.

Having a well-cared-for mind and body can make you feel good about yourself and your life, and conveys to others that you value yourself. This can contribute to long-term feelings of wellbeing and allow you to be a better parent.

- 🐾 Make regular time available for social contact.
- 🐾 Take time for you, even it's just 20 minutes. You will feel refreshed and have a stronger state of mind.
- 🐾 Eat wholesome, nutritious foods.
- 🐾 Many people find that exercise helps clear the mind, boosts energy levels, and improves sleep. Twenty minutes can do the job – a walk, a bike ride, yoga or a swim. Walking as a family near your home will benefit everyone.

- 🐾 Practise mindfulness and breathing exercises.
- 🐾 Try to do something for yourself everyday. It can help to make a plan the day before.
- 🐾 Acknowledge your feelings and take time to work through them with support.
- 🐾 Don't be afraid to ask for help. You'll be amazed the difference a friend running an errand for you or doing a load of washing, can make.
- 🐾 Over time it is easy to get into a pattern of putting everyone else's needs before your own. Bear Cottage has a number of programs to help you change these patterns.

Nourishing yourself in a way that helps you blossom in the direction you want to go is attainable, and you are worth the effort.

~ Deborah Day ~

Consider booking in to our **Mum's Camp** or **Dad's Camp** which both provide a great program of self-care and wonderful activities that you otherwise may not get a chance to try. **BootCamp** is a program of wellness that offers exercise, good food, rest, yoga, meditation, loads of information about nutrition and wellness. Our next program starts in March.

- 🐾 Finally, remember that you are not superhuman. You're a loving parent doing your best, giving your child your time, your support, your attention, and your unconditional love. Just be sure to save a little bit for yourself and look after YOU.



Fundraising news

Kid stuff

We are so lucky to have many kids in our local community wanting to help our own Bear Cottage kids. This was the case when we were invited to hold a stall at the **St Joseph's Primary School Spring Fair**.

This was a great family day with fun and activities for all age groups. The sense of community spirit and real interest in Bear Cottage was evident. The stall sold items including craft and cards and went on to raise over \$680.

Huge thanks to **Josh** and **Jessica (Kylie the chef's children)** and **Maeve (CNC Ann-Marie's daughter)** who very happily gave up their day to assist on the stall. 🐾



Christmas cheer

We broke our fundraising record this year on our Wrapping Station raising over \$18,000. This would not have been possible without the incredible work of more than 200 individual volunteers, over a total 164 hours! Thank you to **Westfield Warringah Mall** for providing us with this amazing opportunity. Huge thanks to our wonderful Bear Cottage and community volunteers. Thank you to volunteers from **Allianz, Clarke Equipment, Diageo, Turner & Townsend, Howards Storage World, Boehringer Ingelheim, Merck, Dell, GE Capital, Warner Bros, Pfizer** and **Stella Maris**. Finally, thank you to the generous local community for their incredible generosity and Christmas cheer. 🐾



Valuable volunteers

Scott FitzGerald

I work for Fire and Rescue NSW. A 'normal' day at work for me can involve anything from house/building fires, to chemical spills, car fires, motor vehicle accidents, industrial accidents, flooding, and much more!

We are also responsible for checking the truck and testing our equipment at the beginning of each shift to make sure it is all working correctly. We also have community engagement duties, such as the SABRE program (Smoke Alarm Battery Replacement for the Elderly), Fire Safety talks at schools, kindergartens, nursing homes, and evacuation talks at residential buildings, office blocks and any other places where people request them.

I'm also dad to an amazing three and a half year old boy, Bowie.

I decided to volunteer at Bear Cottage after Bowie was born. When Bowie was a baby, he had clicky hips so I spent a little bit of time at The Children's Hospital at Westmead where I saw a lot of really unwell children. I realised how lucky I was that I was only there for Bowie's clicky hips and knew it could have been so much worse. I thought to myself, "What can I do to help make a difference?"

Growing up on the Northern Beaches, I was well aware of the wonderful work that Bear Cottage does, so I decided



to enrol in their volunteer training classes.

The reason I volunteer at Bear Cottage is to try to make a positive difference in these children's lives. I also wanted to volunteer specifically at Bear Cottage because of the amazing place it is!

I am loving the time I spend at Bear Cottage and it is such a phenomenal place. Volunteering there is very diverse and no two days are the same. I help out by playing with the kids, drawing, painting, reading, playing instruments. I also help out in housekeeping, in the kitchen and outside in the gardens.

I love it, and I'll be doing it for years to come! 🐾



Staff news

After leaving in December on maternity leave, RN **Emma** has recently given birth to baby **Edison (Eddie)**. Other staff who have recently ventured off on different pathways are our vivacious and much loved housekeeper **Lisa**. Lisa was also our 'behind the scenes' Facebook administrator.

Bear Cottage consultant **Greg Kelly** is off to further his career in Brisbane and AIN **Tara** will be commencing employment as a Community RN. Late in 2014 we also said goodbye to chef **Tim**.



With these departures comes new and not so new staff. **Liz** has come into the housekeeping role and **Owen** has returned to a chef position. Some of you may remember Owen as the full time chef at Bear Cottage a number of years ago. 🐾



Contact details

2 Fairy Bower Road Manly NSW 2095. PO BOX 2500 Manly NSW 1655.
Tel: 02 9976 8300 Bookings: 02 9976 8301 Fax: 02 9976 8303
www.bearcottage.chw.edu.au

