

Cottage Capers

The Newsletter for Bear Cottage families



June 2017

We are very fortunate at Bear Cottage to have a dedicated team of people that contribute every day to making Bear Cottage what it is. Many have been here for a number of years, some since the doors first opened in May 2001 and others for just a short time.

Every position is valued and without the individual contributions of our staff, we couldn't do what we do. What brings everyone to work each day is the knowledge that we are making a difference to a child and their family at a very difficult time in their life.

We were very excited recently to see one of our nurses recognised for all that she does. **Jo Ford** was named the **Barnados NSW Mother of the Year**, not only for the wonderful family person Jo is, but for all the love and care she brings with her to Bear Cottage. I am sure that if you have been lucky enough to cross paths with Jo, you would understand why she received such recognition. Congratulations Jo!

Many of you have, or are presently, getting your heads around the NDIS and what that means for your family. Please be assured that Bear Cottage remains a free service and should not affect your NDIS planning.

As part of the Sydney Children's Hospital Network, Bear Cottage recently took part in the accreditation process. Two specific areas were looked at – consumer engagement and medication safety. To comply with NSW Health standards, we now need to destroy partial unused tablets when administering medications. We are aware that this is not what many of you do at home and may cause inconvenience. To assist us in meeting policy, please ensure your child has a sufficient supply of medications during their stay at Bear Cottage.

The accreditation surveyors were very impressed with the programs available for families at Bear Cottage. One such program is our **Dad's Support Camp**. This will be held from Thursday September 7 until Monday September 11 and is open to non-bereaved and bereaved dads. Places are limited but if you would like to make a booking please contact me on **02 9976 8301**. ■

Narelle Martin, Nursing Unit Manager

A labour of love



Whenever you visit Bear Cottage, you can't help but notice our beautiful photo wall featuring photos of all of our Bear Cottage children. Maintaining this wall has been a labour of love for one of our former nurses (and now volunteer), Helen Carroll, and she shares her inspiration . . .

For the last 12 years, it was my privilege to be one of the Registered Nurses at Bear Cottage. I retired last year but my commitment to Bear Cottage did not retire and I am now one of the volunteers. One of my particular interests is the photo wall.

A house is built from bricks and mortar; a home is something more. It is where a family lives, where relationships grow and where memories reside. We talk about the Bear Cottage family and we hope that Bear Cottage is considered a home away from home by the families who need us.

Often when you walk into someone's home, you will be greeted by photographs of the family members who live there. I wanted to create a wall of photographs that would represent the children of Bear Cottage - and for their images to welcome our families and visitors, upon arrival. I would like to tell you about some of the reasons I had for creating the wall.

First and foremost I wanted to memorialise your beautiful children. The dictionary defines memorialise as "to preserve the memory of". I wanted to reassure you that your children are always remembered. We, as staff, think about them and talk about them more often than you think. We tell stories about them. We remember their preferences in so many things; who liked to wake up early and start the day, who growled at you to come back later. Who preferred Peppa Pig pyjamas to fairy dresses. Who had a dry sense of humour and who laughed until the tears ran down his face, watching a Clown Doctor blow bubbles. Who was only happy when he had his musical toys on his tray table, and who loved to cook. Whose staple diet was peanut butter sandwiches and whose face lit up when they made the water tube, in the multi-sensory room, change colour.

The wall is for you. Some families we have known for just a short time, some for many years. Some families come back regularly, some do not return. Either way, I wanted you to know your child's, your sister's or brother's, your grandchild's photo remains, as a special member of our family.

Early last year, Narelle was visited by a man, whom she had not seen in 15 years. His daughter was one of our first patients. Narelle and I were

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In May we held our annual Remembering Day service and we were honoured to have Bear Cottage dad, Matt Thompson share his family's story.

Remembering Jamie

Remembrance plays such an important part in all of our lives, but no more so when you are a bereaved parent.

It was late 2002 when I met my now wife, Jodie – an inspirational single mother of two young children. Tiarne was three and Jamie was five and they were two of the cutest kids that I'd ever met. It was easy for Tiarne to say "Hi" and tell me all about herself, but Jamie on the other hand was unable to say anything or tell me about himself. Tiarne gave it her best shot at communicating for him though! With the chatter of his sister, Jamie soon showed me that he really didn't need to speak to let the world know what he wanted. He really didn't even need to say hello, his expressions could replace a thousand words.

The four of us formed a strong bond quickly. In early 2004 we went on our first family holiday to the Gold Coast, with my parents too. This was a big decision for Jodie and I, stepping out of the comfort zone of an everyday life that some days felt far from normal. We made a conscious commitment to not let a wheelchair, Jamie's medication and his life-limiting condition deter us. Jamie had the time of his life on that holiday. Despite Jodie's protests, I even took him out into the surf, going over and under waves. We had never seen him laugh so hard or smile so much - he was having so much fun, like a normal 6 year old kid. Jamie may not have been able to tell you, but he knew everything that was going on around him and knew he too could have fun like his little sister.

Over the years, we had many happy holidays with Jamie; his 'Make a Wish' holiday to the Sunshine Coast and Gold Coast is a stand out, as it was then that he got to meet his beloved Shrek. We also took him on many family trips to Dubbo, Taree and back to the Gold Coast, and even on a road trip to Noosa to visit his cousins for Christmas. Quite often he ended up introducing himself at the different hospitals around the place, but that still couldn't stop us from wanting to see him experience new things and places, and to fill his life with fun. Jamie's favorite holidays of all were his Bear Cottage trips, as you all know the staff fuss over the kids so much and Jamie loved that.

Being a parent of a child with a life-limiting illness is hard, there's no disputing that. I think that it is even harder because you are meant to see your child grow older and venture into the world to discover who they are and what they love, but deep down you know that this is never going to happen. You do get to hold onto memories and moments though. I am very happy and proud to say, that on this day in 2005, Jamie had the honour alongside Jodie's Dad to walk his Mum down the aisle and give me her hand in marriage; this is something that I will remember and cherish the rest of my life.

In March 2006 we welcomed Jamie's newest little sister, Emma, into the world. I am sure that Jamie was thinking "great, another little sister to share my attention with" but it did not take him long to realise that both his sisters gave him all the love and attention that a big brother could ask for, sometimes love and attention that could have waited till after he was awake, or after his Shrek DVD was finished!

It actually wasn't until 2007 that we had our first Bear Cottage holiday. We regret not going earlier, but we always felt that there was someone who needed it more than us. From the minute we



walked in we felt right at home and it made us realise that we did need this amazing place, the help and support that they give is second to none. Meeting other families at Bear Cottage and learning how they manage day to day life made me realise that, no matter how hard and tough life may be getting, there is someone else out there doing it tougher. We have made many lifelong friends through Bear Cottage, all who are travelling or have traveled the same path in life as we all have, and it does make life a little easier knowing that we are not alone.

As Jamie got older his health started to deteriorate and hospital stays became more frequent, this generates a large amount of stress on the whole family. The worst part was to try to explain and convince Jamie's sisters that everything is going to be ok, that the doctors are doing their best. Convincing yourselves of the same thing and putting on a brave face for your kids is one of the hardest things you have to do.

“ . . . being at Bear Cottage made such a hard time so much easier . . . ”

Jamie became very ill leading up to Easter 2014 putting him in hospital once again, he ended up in ICU on Easter Sunday and after a few weeks and not without trying everything possible, we had to make a decision, one that a parent should never have to make. We made the decision to come to Bear Cottage for end of life. We were told by the doctors that Jamie may not make the trip, but thankfully due to good planning between Bear Cottage and the palliative care team at John Hunter (and some good luck), Jamie made the trip. Once at Bear Cottage we were told that we may only have few hours or if we are lucky a day or two. Once Jamie arrived at Bear Cottage though, it was like he knew where he was, he was in his happy place - once again Jamie proved the doctors wrong and he gave us as a family a full 7 days to let us make some lasting memories and embrace some much needed family time away from the hospital and ICU.

At 6am on the 7th May, Jamie passed peacefully in his sleep with both Jodie and I in his room. Being at Bear Cottage made such a hard time so much easier - for both the support and care that we received and the ongoing support extended to us, we are truly grateful.

Being Jamie's Dad has been an honour; I feel that it has made me a much stronger person. Jamie and his journey has helped shape his sisters into the amazing, thoughtful young ladies that they are and has helped make Jodie into the remarkable wife and mother that she is today. We do not always get a choice in the lives that we each lead, but I would absolutely do it all over again. The good times certainly make the hard times worthwhile. ■

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A labour of love

able to show him his daughter's photo on the wall. I had not met his little girl but her face was so familiar to me, and I knew that she loved Chicken Crimpy biscuits and that she always had a stash of them down the side of her water chair. He then asked about one of her friends, and was able to see her photo as well. I hope he left knowing his daughter's memory remained.

The wall is for the children. The photos are of the children who have died and of the children who still attend Bear Cottage. They like to see their image up on the wall and we often see them looking for theirs and their friends' pictures.

The wall is for the staff. They tell me it is important to them and sometimes they will stand, looking at it, quietly reflecting.

One staff member described it as a place she thinks, remembers, and is grateful. Your children have been wonderful teachers and each of them have taught us individually and as a group. They have taught us patience, they have taught us to enjoy the simple things, that our frustrations can be trivial and that seemingly small achievements can be immeasurably satisfying. They have taught us to find humour in unlikely situations and to be open to change. They have taught us to accept life's challenges and that time is important. To take time to ensure a little one is as comfortable as possible is time well spent. They have taught us you can fit a lifetime into a short time.

The wall is for the visitors to Bear Cottage. People visit for all sorts of reasons - they may be parents considering bringing their child to us, they may be politicians, interested community members, donors or health care professionals. We want whomever visits Bear



Cottage to see our precious charges.

Lastly the wall is for me. I love doing it. One thing has stood out for me since I laid the first photos on a table to position them. Despite all that life has dealt them, in almost every photo, the children are smiling. Each photo is a story and each story is important. I hope I have created a storybook on a wall. ■

If your child's photo is not on our wall, please email a copy to Jane.Molchanoff@health.nsw.gov.au



Parent's corner

Men often find it tough to ask for help and can find face-to-face discussions about difficult issues confronting. We encourage all our Dads to connect with support if they are having difficulties and this may be a fit for you.

Launched in 2001, **MensLine Australia** is the national telephone and online support, information and referral service for men.

It is available anywhere in Australia and is staffed by professional counsellors, experienced in men's issues.

When faced with a problem, men are often focussed on outcomes and practical solutions rather than their emotions and internal world.

MensLine counsellors offer a down-to-earth, practical approach to counselling, whilst also encouraging men to deal with important emotional issues in an effective way.

MensLine provides:

- A safe and private place to talk about concerns;
- Confidential, anonymous and non-judgmental support;
- Coaching and practical strategies for managing relationship concerns;
- A range of online resources, relevant information and linkage to other appropriate services and programs as required.

Available 24/7 you can call **1300 78 99 78** or www.mensline.org.au/ ■



Family support for whole family

Bear Cottage has a comprehensive Family Support Team that work tirelessly to support our families, from referral, throughout their journey and into their bereavement. Although every family's path is different, there are many similarities and there has been much research on the benefits of peer support and what like to call "the invisible string of connection".

Sibling support camps have run at Bear Cottage for the past 14 years. They started small and have grown into an extensive program that supports siblings from the age of five to adulthood, in separate age groups. We have always mixed bereaved and non-bereaved siblings together to illustrate there are others that are travelling the same journey. This concept worked so well with the siblings, that it was suggested that it might be beneficial for other members of the family.

Approximately eight years ago, we held our first **Mum's Support Camp**. A small group of Bear Cottage mum's were invited to spend time at Bear Cottage, with only their sick child. Staff cared for the children allowing mums time

to participate in organised activities to pamper and spoil them whilst making connections with the other mums. This was a great success and with careful evaluations from participants, the activities have been refined so mums gain the most out of their experience.

Dad's Camp was quick to follow, although the emphasis was less on pampering and more on competition and "blokey things" Last year, for the first time, bereaved and non-bereaved dads were invited together with very positive feedback. **Dad's Camps** have become so popular that we now run two each year.

The Camp ball was now rolling and over the last couple of years we have added **Gramping** for our very important grandparents and our **Footprints in the Sand Camp** to give our bereaved families the opportunity to spend time together as a family and to meet with other families.

It is often said, that once you belong to the Bear Cottage family, you are part of it, for as long as you need us and it is hoped that our **Family Support Program** illustrates this. ■

Remembering our children

Kara Crawley 3.03.99 – 27.03.17

Sophie Norman 2.03.14 – 7.04.17

Bowen Williams 22.01.11 – 11.04.17

Mason Windeyer 16.02.08 – 25.04.17

Nikolas Murdoch 2.11.00 – 15.05.17

Lucy McCallum 17.04.09 – 16.05.17

Zane Arja 18.07.05 – 21.05.17

Fundraising news

Stuart Fletcher Charity Cycle



At Bear Cottage we maintain a strong connection with our families for many years. A wonderful example of this connection is the recent Charity Cycle which was organised by **Stuart Fletcher** whose son Lincoln was a regular visitor to Bear Cottage before he died in 2012.

Stuart made a commitment to Lincoln that he would organise a Charity Cycle from his home in Albion Park to Manly and with thanks to his family and friends at the Lions Club of Cootamundra, he fulfilled this commitment.

In May, Bear Cottage staff were on hand to welcome Stuart and his cycling team mates Jeff Gold and Charlie Sheahan as they reached their destination! Despite two wrong turns, Stuart managed to find his way back into the peloton and home!

Thanks to Stuart and his team, Bear Cottage received a donation of \$5,500 to support our paediatric palliative care programs.

We were delighted to welcome the extended Fletcher family and their friends back to Bear Cottage as they celebrated this monumental achievement. ■

Charity Cabaret Night



Since 2011 **John and Sue Clement** have organised an annual Charity Cabaret Night for Bear Cottage at the Seaforth Bowling Club.

Their latest event on Saturday 13 May was a sell out and their biggest event yet. Thanks to ticket sales, a raffle and auction on the night, the event raised \$15,100 for Bear Cottage. This is an incredible result and the funds raised over the years have increased from \$6,000 in 2011 to \$15,100 in 2017! The success of this event is a direct result of the energy and enthusiasm that John and Sue put into its organising and planning and is a true reflection of their passion to support our Bear Cottage families. Bear Cottage was built with incredible support from the community and it is wonderful to see John and Sue Clement keeping this tradition alive.

John was nominated for an Australia Day Award for his community support, of which we are very proud. ■



Superhero Week

We will be celebrating **Superhero Week from 23-29 July**. Enclosed in this newsletter you will find your invitation to our **Superhero Family Party** being held on **Sunday 23rd** of July. You will also notice that we have included a flyer promoting this event. We would love you to share this with your school, workplace, friends and family and get them involved. More information about this can be found at www.superheroweek.com or by contacting bronwen.simmons@health.nsw.gov.au ■

Volunteer story



We have had the pleasure of welcoming new volunteers to Bear Cottage over the last couple of months, volunteers who are eager to give their time, energy and skills to the children and families we support. Bear Cottage is a unique place in many ways, not least in that it relies on so many volunteers to complement the support provided by staff here. From assisting the chef in the kitchen, to preparing rooms, to engaging in music, art and play activities – our volunteers have so many talents and skills. Where else would you find a pool of people that come from such a variety of backgrounds in nursing, project management, nutrition, accounting and counselling? Volunteers often apologise that they can't give more time to Bear Cottage but our reply is always the same – whatever you give is always needed and appreciated.



We are all excited to have them on board!

John Tokarczyk is one of these long standing Volunteer at Bear Cottage who many of you will recognise.

Joining Bear

Cottage was down to "serendipity" according to John. His children had just finished their HSC and he had more time on his hands after retiring from his job in Customs when he bumped into one of our other long-standing volunteers, Joe. Joe convinced him to sign up as a volunteer driver and he hasn't looked back since. That was in 2007.

Since then John has progressed to the prestigious role of Santa Claus at our Christmas in July celebration and the invaluable, and often overlooked, role of supporting the chef in the kitchen. John quietly gets on ensuring our families are well looked after when it comes to meal times and we can always depend on John to be on hand during various fundraising events such as our Bunnings BBQs.

In John's own words, working at Bear Cottage is "inspirational". ■



Calendar

- June 16-18
Grandparent's Camp
- July 23
Superhero Week Family Party
- July 23-29
Superhero Week
- August 12-13
Junior Sibling's Camp
- September 7-11
Dad's Camp



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