

# Cottage Capers

The Newsletter for Bear Cottage families



## March 2017

The New Year is well underway and we have started on a very positive note by holding our first Bear Cottage Family Consumer Advisory Group. The group comprises parents/carers of Bear Cottage children along with Bear Cottage staff members.



The purpose of the Advisory Group is to:

- 🐾 Provide advice to ensure that Bear Cottage is responsive to the children, parent/carer input, needs and experiences;
- 🐾 Provide a consultation forum to review documents, incidents or events and make recommendations for promoting and improving child and family centred care;
- 🐾 Ensure that children, parents and consumers are involved in strategic and operational planning, safety and quality improvement activities and the evaluation of feedback relating to Bear Cottage.

At present we have a small cohort involved who are both past and present Bear Cottage parents. We would love to expand this group and learn more from our knowledgeable Bear Cottage community.

There are just four meetings a year, held in the evening. If needed, a stay at Bear Cottage can be organised which will also provide a great opportunity to take a break, meet other families and provide input in a relaxed friendly environment.

If you would like to be involved we would love to hear from you. Just email Narelle at [narelle.martin@health.nsw.gov.au](mailto:narelle.martin@health.nsw.gov.au) or call **9976 8301** to have a chat.

This year we celebrate Bear Cottage's 16th Birthday. The Cottage was officially opened on the 17th March, 2001 with the first children arriving in May that year. Since then, over 1000 children have been referred to our service. Each year our support programs have grown and our team look forward to continuing this growth and to deliver the very best of care to the children and families who come through our doors. One such program is our **"Gramping Camp"** for Grandparents. If you or your partner is interested in attending this camp, please contact Social Worker **Liz** on **9976 8336**.

Congratulations to **Jo Ford**, one of our very valuable AINs who recently received the **Rotary Club of Balgowlah's Community, Pride of Workmanship Award**. This is wonderful news and very well deserved. Jo has always gone above and beyond in whatever role she has been in (Volunteer, Housekeeper and more recently AIN). Her calm and caring manner, creative skills and passion for Bear Cottage and the children in her care, are truly valued and it is great to see her being recognised in this way. ■



**Narelle Martin, Nursing Unit Manager**

## When words fail, music speaks

*Annabelle Keevers RMT (Bear Cottage Music Therapist)*

One of the things I most love about my work is the way in which music offers a way to communicate which is available to almost everyone, even those who are unable to speak. This morning, together with Jane, one of Bear Cottage's many dedicated volunteers, I sat down to make music with Mitchell, one of our young patients. His eyes almost closed, Mitchell sat curled up in his chair. I was unable to tell at first if he was asleep or awake nor even if he was aware that I was present.

At times like this, even after many years of practice, I can be aware of a sense of apprehension, wondering how best to begin, wondering, in fact, if it will be possible for me to find a way through to help Mitchell come out of himself for a while and join me in the music.

I begin our session by singing hello, letting Mitchell know my name and greeting both him and Jane. Mitchell has come to Bear Cottage while his family takes a short holiday and when Rachel, one of our nurses, comes to give Mitchell some medication, she mentions his brother by name. Mitchell smiles, so I ask Rachel about the other members of his family and improvise a short song about them, using the name of each one.

During this short interaction, I watch carefully and so begin to discover further clues about how to connect with Mitchell. I see that he begins to move his fingers, almost imperceptibly at first, then a little more quickly. Here, then, is my next opportunity! I sing another song, a tune known to everyone, Kumbayah, but rather than singing the usual lyrics, I substitute with words about Mitchell and what he is doing in that moment. "I see Mitchell move his fingers, I see Mitchell move his thumb, I see Mitchell wiggle his fingers, Mitchell's fingers are moving some..."

The tune is repetitive, but its very simplicity makes word substitution easy, in so doing, providing a gentle commentary on what Mitchell is doing. It allows me to let him know I am with him in the moment. I am not merely singing a song to him, I am singing about him.

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*Mitchell relaxing with music by the fish tank*



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Another music fan – the smile says it all . . .

Mitchell begins to move his fingers a little more quickly. He puts his hand to his mouth and begins to flick at his lower lip with his fingers. His beat is almost the same as that of my song.

Here's another way of connecting with Mitchell! I can now show that I am with him not only with my words, but also with my music. As his fingers move increasingly quickly, I sing faster to match his movement. When he stops, I stop with him. I try to allow Mitchell lead the music. Perhaps it is one of the few times in Mitchell's life when it is truly possible for him to be in control?

I quietly strum my guitar. If I simply sing at Mitchell without ceasing, then I am taking too much control over our interaction. When I leave some spaces in the music, I create opportunities for Mitchell to further communicate. Mitchell begins to vocalise, making a variety of different sounds. I listen to each one and then sing them back to him. Each of the sounds has a different timbre. I try to let him know I have heard each one by repeating them accurately. We continue in this way for several verses.

I try to allow for some different kinds of interaction in each session, so after a while, I ask Jane if she will watch Mitchell's feet as they are now beginning to move. She is to shake the tambourine to reflect each of those movements, slowly for slow movement, quicker for more expansive ones. I begin to improvise some music on the piano, also responding to Mitchell's movements, using flowing chords when his movements are large and high, quick notes when he begins to raise his hands above his shoulders. From being still and mute a few minutes before, Mitchell is now moving in his chair almost constantly. There is a sense of flow and energy.

Music therapists sometimes use the expression, "golden moments" to talk about those special times of connection which can suddenly occur during therapy. As Jane and I make music with Mitchell, following and responding to his movements, we experience together one of these treasured times. To a casual listener, our music would seem unremarkable, some flowing chords on the piano without any recognisable melody and the intermittent shaking of a tambourine.

**"I can now show that I am with him not only with my words, but also with my music."**

For Mitchell, however, it is my hope that there was for him a sense of coming out of himself, of being present, not merely by sitting mute in his chair, but by being able to hear who he is in the emerging sounds which filled the room, sounds which had been formed out of the attentiveness of two people beside him, watching and responding to his every movement. ■

**Timbre:** refers to the tone colour of a sound. If you think about the difference in the type of sound between a clashing cymbal and a gently strummed harp, then you are thinking about tone colour. When working with patients, it is important to become aware of the tone colour of their responses and also the tone colours to which they are most responsive.

**Matching:** music therapists use matching as a means of showing empathy in the music, a way of showing they have heard the patient. So I matched Mitchell's sounds, a way of saying, "I hear you." Sometimes after matching, it is possible to make different sounds and create a conversational exchange in the music.

**Improvisation:** is when the patient and I create spontaneous music which does not come from a written score. Music therapists are taught to improvise in ways which responds to the patient, but here, Mitchell was improvising, too. He verbalised spontaneously to the music.

## My story: Jamieson

Living in Dundedoo, it's not easy to do and get to a lot of things. Bear Cottage has helped me in so many ways.

I'm a 14 year old girl and I live with my Mum, Sister and Brother. We've been coming to Bear Cottage for around six years now. I remember when I first came to Bear Cottage it wasn't at all what I expected. I thought it would be more like a hospital but it isn't, it's very homely. I find everyone so kind and I feel so comfortable talking to everyone and making friends.

When I come to Bear Cottage I get to do things that I don't get to do at home. I know it sounds small but a bath is huge for me and having a long warm bath is something I love to do when I'm at the Cottage. I love getting pampered, which we don't get to do in Dunedoo. At Bear Cottage I have my nails done and get my long locks cut and styled. I also love to go



for coastal strolls along the beach with my Mum. It's pretty neat that she can stay with me and so can my sister and brother. I also love going on the wheelchair swing – you see, I'm a bit of an adrenaline junkie and I get to go pretty high.

This year has been a big year for us. My Mum had a pretty bad back injury and had to have surgery. I was able to stay at Bear Cottage so the nurses and team could care for me whilst Mum recovered. Speaking of back surgery, I too had back surgery a few years ago and it was so good being able to come to Bear Cottage as a step down from Hospital. The team kept an eye on me and supported me every day.

Without Bear Cottage I wouldn't be able to stay in the hometown of my favourite footy team. I am the Manly Sea Eagles' biggest fan. Staying at Bear Cottage helps me go to the local footy games. Some of the players visit me at the Cottage and



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## A welcome return

Bear Cottage is fortunate to have a number of passionate and dedicated Assistants in Nursing. The AIN program at Bear Cottage has been running since 2010 and is co-funded by the **McCullough Foundation** and the **Mill House Foundation**.

Some of our AINs are Undergraduate Nurses and the experience they develop over the 12 month program at Bear Cottage is unique and invaluable and enhance their nursing experience. These AIN positions are highly sought after and we have been fortunate to have such wonderful recruits. The AINs also relish the opportunity to learn so much from the patients, families, volunteers and staff.

It is always sad to see our Undergraduate AINs leave Bear Cottage when they have completed their nursing degrees. However, we are so proud to see them pursue their careers and extremely fortunate that many of them, having had their interest in Paediatric Palliative Care ignited, will return to Bear Cottage as fully qualified and experienced Registered Nurses. This also means they are able to bring back the experience they have gained further afield.



Past and present AINs – Sevi, Georgia and Lani

We are delighted that our former AINs, **Naomi, Georgie and Sevi** have all now returned to Bear Cottage as RNs. They bring with them invaluable experience gained from working as RNs at both SCH, CHW and further afield. **Emily** has also returned after a stint of nursing in outback WA. All are passionate about paediatric palliative care and continue to gain experience through their post graduate studies. We are very grateful to each of them for all the skills and passion they have brought back to Bear Cottage and consider ourselves very lucky to have them. ■



Naomi and Sevi on Graduation Day



Our multi-talented RN, Emily

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have helped make some of my birthday celebrations pretty special. I've also met heaps of great people through different events and fundraisers for Bear Cottage. I'm a creative chick. I love to draw, colour complex pictures and create keepsake objects that I can take home. When my Mum was in hospital, I made two dream catchers. I kept one and Mum had one, that way we were connected in some way and all our bad dreams caught and taken away. There's so much opportunity to make things and make memories at the Cottage. I'm always happy when I'm at 'Bear'. ■



## Parents' corner

### Big red button

Some of us may love a little sweet treat every now and again and for one of our recent visitors, afternoon tea is all about something sweet. With the help of a **Jelly Beam Switch** and a blender, **Asher** was able to create his favourite "BCCC" treat which is a combination of banana, chocolate cake and custard. The Jelly Beam switch is also known as an **Ability Switches**. These are designed for people with physical disabilities, offering them an alternative means to interact with computers, speech generating devices, appliance controllers and switch adapted, battery powered toys. A specialised adapter is required to be able to connect the switch to the appliance, we use a PowerLink 4 Control Unit. For more information, visit: [www.spectronics.com.au/product/jelly-beamer-twist-wireless-switch-2](http://www.spectronics.com.au/product/jelly-beamer-twist-wireless-switch-2) or [www.spectronics.com.au/product/powerlink-4-control-unit](http://www.spectronics.com.au/product/powerlink-4-control-unit) ■



### NDIS made simple

We know that many of you are currently working through your NDIS plans and may be experiencing difficulties. Our Social Worker **Liz** is very happy to help you navigate the system. She can connect you with the right people and would be happy to discuss any concerns or queries that you may have during your stay at Bear Cottage. Liz can be contacted on **9976 8336**. ■ **Parents, if you have any tips or advice regarding your own experience with the NDIS, we would love to share them.**

## Remembering our children

**Hannady Naboulsi**  
8.01.04 – 28.01.17

**Timothy Bottero**  
17.12.99 – 22.02.17

*The reality is that you will grieve forever. You will not 'get over' the loss of a loved one; you will learn to live with it. You will heal and you will rebuild yourself around the loss you have suffered. You will be whole again but, you will never be the same, nor should you be the same, nor would you want to.*

Elisabeth Kubler-Ross and John Kessler

## Staff news



Sadly, just after Christmas we said goodbye to two of our Registered Nurses.

**Sharon and Ann-Marie**

have both moved on to roles at SCH and RNSH respectfully. Both will be missed at Bear Cottage but we wish them well on their new journeys. **Philly** will now be in the role of Clinical Nurse Specialist in a full-time capacity. ■



## Fundraising news

Planning for our two major fundraisers for Bear Cottage is now well underway. From 23-29 July we will be holding our sixth **Superhero Week**.

We would love you to get your schools, workplaces and community groups onboard once again to make this even more successful than last year's event. For details go to [www.superheroweek.com](http://www.superheroweek.com)

We are also very much looking forward to our **A Bear Affair Gala Ball** which will be held on 26th August in the Grand Ballroom at the Hyatt Regency in Sydney. Tickets are on sale now and we would love you to join us at this special evening. For more information contact [des.poelingoer@health.nsw.gov.au](mailto:des.poelingoer@health.nsw.gov.au) ■



## Calendar

Apr 1-2: Senior Sibling Camp

Apr 7-9: Footprints in the Sand Camp

May 14-18: Mum's Camp

May 21: Remembering Day

Jun 16-17: Grandparent's Camp

**bear cottage**  
kids

an initiative of  
the children's hospital at Westmead

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[bearcottage.schn.health.nsw.gov.au](http://bearcottage.schn.health.nsw.gov.au)

## Colourful creations

Wheelchair art is a fun and creative activity that we love at Bear Cottage. It is enjoyed by our mobile and not so mobile children and allows each child to make their mark.

It takes a team of willing volunteers to transform the garage into a studio. With music blaring from the iPod, our group of excited parents and children are all prepared to get their hands (and feet) very dirty!

We cover the floor of the garage with a patchwork of paper and fill 50 ml syringes with brightly coloured paint in readiness to shoot it across the blank canvas. Of course all times being vigilant to make sure that it doesn't fire across the bonnet of a staff member's car!

Unknowingly, the use of syringes has an unexpected effect on one small boy helping to de-stigmatising the use and previous association with feeds and injections. After some initial hesitancy, he embraced the idea of having some control over this 'medical tool' by squirting his favourite colour green in the air.

The mixture of wheelchair tyre tracks, trolley trails, foot prints and even the shuffling of bottoms makes for a colourful, tactile, sensory experience for everyone involved and even after hands and feet were washed, the children were delighted with the abstract colours that adorned their wheelchair wheels long after we had packed up.

The wonderful end result is vibrant and colourful canvases that are too precious to throw out. Instead we preserve these special memories and use them for the production of our gift cards and our Butterfly Wishes given as thank you gifts for our donors and generous supporters.

Jackson Pollock eat your heart out! ■



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The Sydney  
children's  
Hospitals Network

care, advocacy, research, education