

Cottage Capers

The Newsletter for Bear Cottage families



Autumn 2018



Now that the year is well under way, it may be time to think about booking in for some much needed respite and you may be wondering how bookings are managed:

- Each family is entitled to up to four weeks booked respite per year dependant on bed availability. With Bear Cottage getting busier, this may not always be possible and unfortunately, on rare occasions, we may need to cancel your respite at short notice. This decision is not made lightly and we will try to accommodate your needs as best we can.
- Only two respite bookings can be made in advance and only one week's respite can be booked during a school holiday period. This can only occur every second school holiday period.
- For January bookings, please put your name down in advance and a decision will be made in September and requests will be considered. January is a particularly busy time and we endeavour to be equitable to all.
- In emergency situations please contact us and we will see if we can accommodate your child at short notice.
- If your child has a carer and you would like them to accompany your child to Bear Cottage, contact me prior to your visit. Whilst at Bear Cottage, your child is under the care of the Bear Cottage staff and any medical decisions will be made by them in consultation with the parents.

As you would be aware, we have an amazing group of Volunteers that assist us with much of the operation of Bear Cottage. Although Volunteers spend a lot of time with siblings as part of our Play Therapy Program, siblings remain the responsibility of their parents at all times.

Time out

If you would like to arrange some time out from your children, perhaps to enjoy a dinner out, please speak with the nursing staff who in turn can check with our Volunteer Manager as to whether a Volunteer would be available. There is a four hour maximum for this service, between the hours of 9am and 10.30pm.

In 2017 we established our **Family Consumer Advisory Group** consisting of parents (both past and present) and staff.

We have a great group of parents that come along four times a year to give their input on what Bear Cottage does well and where we can improve. If you would like to be involved, we would love to hear from you.

Our next meeting will be **Thursday 10th May at 6pm**. Respite can be arranged for you and your child, enabling you to attend. Please contact **Narelle** on **02 99768301** or at narelle.martin@health.nsw.gov.au.

Family support



Bear Cottage is here to support the entire family and you are able to find out more about all the events and activities that we have coming up by checking our "Family Support" noticeboard located outside the Nurse's Hub.

One important part of this support is our Camp Program and Bear Cottage runs

several throughout the year. We have a full list of our up-coming camps listed below so please contact me on **9976 8301** for more information or to book.

We look forward to seeing you and caring for your family in 2018.

Narelle Martin, Nursing Unit Manager

2018 Camp Calendar

FITS* Camp No. 1: 13-15 April

Mum's Camp No.1: 13-17 May

Grandparent's Camp: 15-17 June

Dad's Camp No.1: 21-25 May

Junior Sibling Camp: 11-12 June

Mum's Camp No.2: 9-13 September

Junior Sibling Camp: 27-28 October

FITS Family Camp No.2: 9-11 November

Dad's Camp No 2: 15-19 November

*Footprints in the Sand Camp for Bereaved Families

From the heart

When families come to stay at Bear Cottage, much thought is given to the ways in which special memories of their children may be created and preserved for them in enduring ways. This year, a new form of memory making is now being offered at Bear Cottage. It is called "**Heartmusic**".

In ancient times, it was believed that the heart was the seat of our emotions and even though we now have a different understanding about emotional expression, the word heart remains an enduring one when we wish to convey intense and powerful emotions. This is the reason we continue to use expressions such as heartfelt, heartbroken and heartland to name a few.

A beating heart is necessary for sustained life, so it is very much part of the essence of our being. For some, merely the sound of our unborn baby's heart in itself seems like music. When the singer Beyonce heard the first ultrasound of her unborn baby, she declared, *"I heard the heartbeat which was the most beautiful music I ever heard in my life..."*

Music is so evocative and it can instantly transport us to other times, helping us to relive them.

With Heartmusic, we go one step further by combining a child's heartbeat with a special song or tune. Think of a song which you listened to when you first fell in love or perhaps the song that was played at your wedding. Remember the lullabies you may have sung when you first became a parent. Music is so evocative and it can instantly transport us to other times, helping us to relive them.

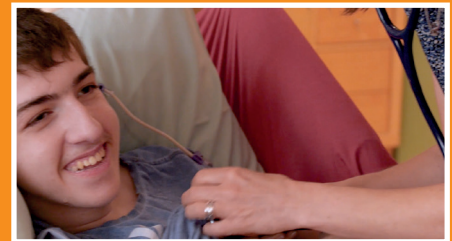
The concept of Heartmusic was developed by **Brian Schreck**, an American music therapist, who first came up with the idea of recording a child's heartbeat and using the pulse as the basis of a completely unique recording. He began by taking recordings of children's heartbeats and using these as the basis for beautiful, bespoke music.

Now, this same form of memory making is being offered here at Bear Cottage. With the aid of a special digital stethoscope which was donated by the **Ottomin Foundation** who fund the Music Therapy Program at Bear Cottage, it is possible to make a recording of the heartbeats of our young patients. These can be saved onto a computer and then, by using a multi-track recording program called Audacity, the heartbeat is used to provide an underlying beat. Musicians sometimes



talk of the pulse of music when they refer to its beat, and quite literally, the child's pulse gives the underlying beat to a special piece of music, one which has been specially chosen by the family.

We recently had a patient named Alex staying with us. Having turned 19 during his last visit, Alex was 'graduating' from Bear Cottage. Alex loves the movies from The Fast And Furious series. In particular, he loves a song from Furious 7 called "See You Again" and so this was the one he chose to be recorded with his heartbeat.



It was wonderful to feel the excitement in the Cottage at the beginning of this new venture as we began making this piece of Heartmusic, which would be used for Alex's graduation gift.

With the help of **Shootsta**, a video production company, we were able to produce a short video which documented the process of Alex's heartbeat being recorded and it was lovely to see Alex's smile when Nurse Philly helped him to hear the recording of his own heart on the digital stethoscope.

The tune he chose is also featured on the video as a backing track. Please visit our Facebook page to see the finished video and to hear the completed track.

If you would like to have a piece of music created by using the heartbeat of your child, do please talk to **Belle**, our Music Therapist. She will obtain the musical score for you and make a multi-track recording of your special song or melody to accompany the heartbeat of your child. This recording will be given to you as a permanent keepsake which can then be stored on your phone, computer or iPad for safekeeping. It will mean that you will be able to listen at any time to a truly unique piece of music which has come from within the heart of your own child. ■



Family connections

all to be together during what ended up being Patto's last Christmas. *"It's difficult to explain to people, but when we stayed at Bear Cottage we had such a beautiful time as a family, even though we were there because of something so terrible. I'm sure people think I'm crazy when I explain it like this!"*

This pays testament to what Bear Cottage is trying to achieve – a peaceful, supportive, compassionate environment that provides the highest quality physical, psychological and emotional support and understanding the differing needs of all family members along their journey.

"The support that we have received after Patto died has helped us to adjust to our life without him. I especially remember on what should have been his first day of school, when other parents were sad about their children starting school – we were sad about him not being able to start school at all. We had a lovely phone call from Nurse Sue to see how we were going that day. It is those thoughtful moments that are why we feel indebted to everyone at Bear Cottage."

The **Footprints in the Sand Program (FITS)** that supports families after their child's death, offers regular opportunities for parents to meet other families who understand what it is like to have lost a child. Emma and Richard have made lovely friends and they look forward to catching up with each other when they can.

This is very much the case for the siblings as well and Olivia has attended a number



of Sibling Camps and loves Bear Cottage because it is *"so understanding and such a happy place"*. She says *"I love that at Sibling Camp I have met lots of new friends and we have had heaps of fun together"* – something that some people may think may not be possible after the loss of a brother.

Olivia feels so strongly about Bear Cottage being such a happy place that she has raised money by having a lemon sale. *"I want to help them like they helped us when Patto was sick."*

Patto now has two more siblings, a little sister called **Alice** and a cute baby brother called **Max**. Olivia loves being able to show them off to their Bear Cottage family and she likes that they can come and get to know Patto through Bear Cottage. ■



Footprints in the Sand

Bear Cottage's Bereavement Service



Patto had just turned five when he and his family were referred to Bear Cottage for end of life care. His parents, **Emma** and **Richard** and his gorgeous older sister **Olivia** were obviously anxious about coming to Bear Cottage but as Emma explains *"I was so glad that we were encouraged to stay at Bear Cottage as we wouldn't have been able to manage at home"*.

The family were at Bear Cottage for six weeks with Christmas falling during the middle of that admission. One of the most



important things for the family was that Olivia and Patto's grandparents were able to stay at Bear Cottage too, allowing them

Parent's Corner

Feel The Magic

"A Place for Grieving Kids to Grow"

Siblings are a very important part of a child's family and they are also a very important part of the Bear Cottage family.

As all our families are aware, we have an extensive support program for our Bear Cottage siblings including our **Junior Sibling Day** for our 5-8 year olds, our **Junior Sibling Camp** for primary aged children and our **Senior Sibling Camp** for our high school children, destination camps for our 14-17 year old siblings and young adult sibling support dinners for our siblings that are over 18.

We have always combined our bereaved and non-bereaved siblings, which results in a dynamic mix of young people. They are given the opportunity to have fun, connect with others, build their confidence, resilience and inner strength in a safe and supportive environment supported by Bear Cottage staff that they are comfortable and familiar with.

Another organisation that offers sibling support is **Feel the Magic (FTM)**,



an Australian not for profit organisation that supports bereaved children. Feel the Magic provides children with support to develop strategies to allow them to move forward with their lives following a significant loss. FTM run **'Camp Magic'**, a free three-day camp for 7-17 year olds who have experienced the death of a parent/s, sibling or legal guardian. The camp follows a structured program of therapeutic sessions in addition to fun physical activities and resilience building challenges. Each child that attends a camp is paired with a trained volunteer mentor who is next to them every step of the way at the camp.

As with our Bear Cottage camps, the intention of FTM is to encourage children to meet those who are in a similar situation, realise that they are not alone in their grief and assist them to develop skills and strategies to make their everyday life a little easier. For further information about any of our camps or Feel the Magic, please call us on **9976 8336**. ■

Remembering our children

Hamza Alameddine
6/12/01- 12/12/17

Evie Weir
31/07/11- 19/12/17

Rio Fowler
21/07/16 – 15/01/18

Dean Brown
12/07/16 – 26/01/18

Edward Sharp
6/07/10 – 26/01/18

Sebastian Lamos-Montero
5/11/01- 31/01/18

Liam Ajaka
17/04/03-19/02/18

Felix Pellegrini-Landeira
2/01/17 – 24/02/18

Sonia Tadros
19/08/1999 – 25/02/18



Valuable volunteers

Time to put your feet up

Many of our families may have experienced reflexology during a stay at Bear Cottage. We are fortunate to have two fully trained reflexologists as volunteers. Reflexologist Ann Jooste-Jacobs talks about its benefits:



In May 2009, I began running a volunteer reflexology program at Bear Cottage.

Reflexology is offered to the parents, staff members and other volunteers. At the end of 2013, we were given permission to also provide reflexology for the children. We have also offered reflexology at the **Mum's Camp, Dad's Camp** and **Grandparent's Camp**.

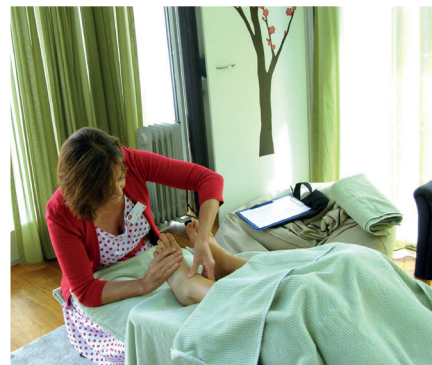
Reflexology therapy is offered in the lovely "quiet room" at Bear Cottage. We have had several volunteers over the years but currently there are two volunteers – myself and **Michelle Lloyd** – who offer the therapy every Tuesday.

Reflexology is based on the principle that all parts of the body are reflected in microsystems throughout the body – feet, hands, ears, eyes and face. A qualified

reflexologist will use a combination of pressure techniques on the feet reflexes in order to address imbalances in the mind and body. People of all ages and health states receive reflexology to relax, heal and prevent illness.

I feel very privileged to be part of the team offering this therapy. It enables the recipients to have an hour of total 'me' time – to relax and enjoy the benefits of the therapy. We as therapists receive very positive comments from both the recipients and from the staff. Recently one child who received reflexology from Michelle had a pain free night with no medication and had a really good sleep. My greatest compliment after a session was from a dad who said to me that he was so relaxed that he would have given me the pin details to his bank account! This was incredible given the stress he was experiencing at the time.

Due to the success of the program at Bear Cottage, I was able to set up a similar program at the Children's Hospital at Westmead in 2013, where a few therapists offer their services on a voluntary basis. The feedback has also been very positive and due to the



numbers, there is always a waiting list!

We encourage you to speak to a staff member and put your name down for a session. We would love to see you and your feet!! ■ **Ann Jooste-Jacobs, Reflexologist**

Fundraising news



Community support has been the backbone of Bear Cottage since before we opened our doors in 2001. We are delighted that this tradition remains strong through the **Rotary** network and the energetic support they provide to the residents of **Borgnis Street** with their Christmas lights for Bear Cottage.

The funds raised from this event have grown over the years and we were overwhelmed to receive \$34,100 as proceeds from the 2017 event. This is a wonderful example of many community organisations combining their skills to support the patients and families in our care.

We were thrilled to learn that the students from **The Forest High School** were

involved in supporting the Borgnis Street residents by collecting donations through the **Rotary Interact** program. The Interact program brings together young people aged 12-18 to help develop leadership skills while discovering the power of Service Above Self.

This inspiring initiative will provide us with the opportunity to access a growing number of young leaders to support paediatric palliative care into the future and for them to experience first-hand the value of philanthropy in the community.

We extend our heartfelt thanks to **Amelia** from The Forest High School who joined us at our recent Community Open Day to present their cheque. ■



Staff news

At the end of 2017 farewells were said to two wonderful members of our nursing team. After a number of dedicated years caring for our children, **Jo** and **Julia** have moved over the mountains to set up homes in Central NSW. Their care and compassion will be sadly missed but we look forward to hearing of their new adventures.

Fresh faces to our strong team of nurses are **Vikki**, **Susie** and **Emma** who all bring with them much expertise and enthusiasm.

Finally, **Heather** who many of you know through her dedication to play and the children at Bear Cottage has decided to branch out to another field and departed Bear Cottage in February. She also, will be greatly missed by all that had the pleasure of knowing her. ■



Jo



Julia



Emma



Susie



Vikki