

Cottage Capers

The Newsletter for Bear Cottage families



Summer 2018



After another busy school holiday period, Bear Cottage closed for five days to undergo the renovations of our bathrooms and flooring. It is important that we continue to maintain our facility in a manner fit for the wonderful children and families who visit. To those who may have been staying over this period, thank you for your patience and understanding.



In September we were deeply saddened to say goodbye to a very much loved Bear Cottage staff member. Registered Nurse **Wendy** died after a long battle with cancer. Wendy spent many years caring

not only for her own two children, but the many she came into contact with while nursing at both Bear Cottage and the old Children's Hospital at Camperdown. She came to work each shift with passion, dedication and a great sense of humour. It was a privilege to work alongside Wendy and she will be greatly missed.

There has been exciting news recently with the Premier of NSW, Gladys Berejiklian announcing that a hospice for Adolescents and Young Adults will be built on the grounds of the old Manly Hospital site (just over the hill). This will be built with Bear Cottage in mind and specifically for this important group of people. It will ensure that after the age of 18 years there will be somewhere suitable they can receive appropriate care and 'live life to the fullest'. Of course, such a place will not be built overnight, but we look forward to seeing and hearing about the development of what we hope will be a magnificent facility.



Artist's impression only

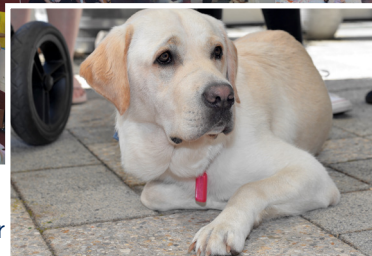
You will find our 2019 calendar included with this newsletter. If you are interested in making a booking for one of our camps or would like to find out more about how they work, please call on **02 9976 8301** or email **narelle.martin@health.nsw.gov.au** ■

Narelle Martin, Nursing Unit Manager

Goodbye Frankie, welcome Beau

We recently said goodbye to a very special member of our Bear Cottage family – **Frankie**, the Assistance Dog.

After eight years of devoted service, Frankie has retired from her duties at Bear Cottage and is now living a peaceful and relaxing life with our Nurse, **Annie**. Annie was Frankie's primary carer whilst she was at Bear Cottage, so it is only fitting that she spends the rest of her days in Annie's care.



During her time at Bear Cottage, Frankie has been able to provide comfort and support in her own very special way. The benefits have been immeasurable – she would often seek out someone who needed a little bit of extra attention – whether that was a child or a parent. She would hop up on a child's bed and allay night time fears or keep vigil outside a bedroom door. She also loved to have fun and was extremely tolerant. We have many photos of Frankie dressed in all sorts of hats and costumes – testament to her patience.

Whilst Frankie can never be replaced, our new dog **Beau** has settled in beautifully. He is two years old and has been trained by **Guide Dogs Australia**. He is big and gentle, loves other dogs and making friends with our Bear Cottage guests. We have discovered that he has a liking for raisin toast so we are making sure that all loaves are kept out of his reach! Beau will be looking forward to meeting you when you next visit Bear Cottage. ■

Frankie and Beau enjoying their farewell cake of mince and mashed potato icing



We are fortunate to have a dedicated group of volunteers who have loved (and walked) Frankie and who are looking forward to caring for Beau. Volunteer Irene Penches wrote and recited this beautiful poem at Frankie's farewell.

Goodbye Frankie

We've gathered here this afternoon,

*The reason sad to say
Is that Frankie is retiring
So she is going away.*

*After many years of service
At Bear Cottage on the hill
Giving love and spreading cheer
Amongst children who are ill.*

*The Mums and Dads just love her
And all the Siblings too
She always brightened up their day
When they were feeling blue.*

*We walkers sure will miss her
Always waiting at the door
Keen to have a walk,
Listen to us talk
It never was a chore!*

*So she's going home with Annie
To a lovely life ahead
Cuddles, walks and tummy rubs
At night a comfy bed.*

*Dear Frankie, we will miss you
You really are the best
Have lots of fun, laze in the sun
And enjoy a well earned rest.*



Bear Cottage Mum Fiona who recently shared her story to help promote World Hospice Day. Here is an edited extract . . .

Making memories with Max

Being the parent of a child with a life-limiting illness isn't easy. It's tough, it's stressful and it's tiring.

Fiona, mother of nine-year-old Abi and 11-year-old Max, who lives with Batten Disease, explains why Bear Cottage is a lifeline and the only place her family feels normal.

Max started having seizures when he was three. By four he started to lose his speech and mobility. At five he was diagnosed with Batten Disease – an inherited disorder of the nervous system. We had no idea what the future held for Max, but we knew our little boy was going to die.

At first I was apprehensive about going to Bear Cottage. It was fear of the unknown but Bear Cottage far surpassed my expectations – it has everything we needed and more.

As a parent it takes time to feel comfortable surrendering care of your child to someone else – especially when they have special needs. At first, I didn't want to hand over Max's medication; I didn't trust that anyone could look after Max as well as me, particularly not a stranger. It didn't take long before strangers became friends.

Now, when I walk through the doors I literally hand everything over, I give Max a kiss and know he's in great hands. But more than that, it allows me to be Max's Mum rather than his carer. I can sit in the sun and enjoy just being with him. I can also take time out for my own respite and spend time with Abi.

Words can't describe the luxury of being able to let go. Bear Cottage makes that possible. Thanks to full time housekeeping there's no housework to do and a chef to prepare nutritious lunch and dinner every day.

Max has fun at Bear Cottage. He loves being out in the garden, on the Liberty Swing or visiting the sensory room. During our last stay, Max celebrated his 11th birthday. His nurses, volunteers and some of the families we've met over the years came together to celebrate with us. I was overjoyed.

That same day Max had power wheels fitted to his wheelchair. I've never taken Max for a walk because I couldn't get him up and down the hills. Now with power wheels for the very first time, I pushed



Max out the front door and straight to the beach. It was so liberating.

The chance to be pampered recently at a Bear Cottage Mum's Camp was an absolute luxury. Hanging out with the other mums, sharing experiences and chatting about life over dinner and a show was fabulous. For a couple of hours, we felt normal. From a mental and emotional perspective seeing other children and meeting their parents was really beneficial and helped me accept Max's condition.

Spending one-on-one time with Abi at Bear Cottage is enormously helpful. Having a brother with special needs is all she has ever known. Interacting with the other siblings at Bear Cottage helps her realise she's not alone – there are other families like ours. She is more understood at Bear Cottage than out in the real world and I think she senses that.

I don't like taking Abi out of school but because Max is in the end stage of his illness, I've relaxed that rule. Realistically, something could happen to Max at any time and I want Abi to be with us. Thankfully Emma, the Child Life Therapist, helps Abi maintain her routine to ensure she doesn't fall behind with her school work.

We've recently been working on a beautiful project with Music Therapist, Belle, to record and set Max's heartbeat to music. When I listen to it I just burst into tears. It is a priceless memory that I will have forever!

Bear Cottage holds a very special place in our hearts. We will cherish memories created there forever. ■

Thank you to Fiona for sharing her story. We are always keen to hear from families who would be willing to share their Bear Cottage story. Please contact bronwen.simmons@health.nsw.gov.au if you are interested. Thank you!

This is the life!

For some of our patients a visit to Bear Cottage provides a chance to catch up with old friends. Child Life Therapist, Emma recently spent a delightful afternoon with three best mates.

Whilst the upstairs halls of Bear Cottage were busy with the happenings of a regular Monday morning, Enya's hypnotic tunes of 'Sail Away' beckoned the three musketeers – **Scott, Patrick and Jack** – to the Spa.

With their usual 'up for anything' attitudes and a taste for the finer, more sentimental things in life, the boys were met with a tray of delicious, fresh fruit mocktails.

As we all settled in and soaked up the warm bubbles – most from the jets :) – the boys raised their 'glasses' and gave Scott a beautiful final 'cheers' to Bear Cottage for his impending graduation. What followed



were hours of sharing memories of previous times at the house, fits of outrageous laughter and giggles and some jokes that I won't share here. Beautiful staff members, Claire and Sue even treated us all to the finest Lindt chocolates, just to sweeten our time – how could we say no?

It was however the karaoke that took the cake. With musical choices from 'The Greatest Hits of the 60's and 70's', it was no surprise that

numerous nurses came hastily to check the 'screaming coming from the spa' (we apologise to all and can confirm no one was physically hurt during our rendition of 'Footloose').

Also, Patrick, I would like to take this opportunity to publicly declare that I also think that Miles Davis is amazing; the other boys will come to their senses one day!

After losing complete track of time, we were brought back to the shores of Bear Cottage just in time for lunch. Wrinkled from head to toe yet reluctant to leave, we all slowly ventured out with our hibiscus umbrellas still tucked behind our ears, back upstairs with silly grins and more stories for another time.

It was such a privilege, as always, to spend this time with Scott, Patrick and Jack – what an outstanding bunch of gentlemen. I look forward to the next outing boys! ■

Emma – Child Life Therapist

Time together

Footprints in the Sand (FITS) is Bear Cottage's Bereavement Program. One of the activities in the program is the FITS Camp. FITS Camp is a two-night camp held at **Lands Edge** in Chowder Bay. The weekend is an opportunity for families to spend time together and meet and connect

with other families in similar situations. There is a therapeutic element to the time spent together and a few tears are shed, but there is mainly fun and laughter, the opportunity to experience new and exciting activities, making new friends and re-connecting with old ones.

We encourage Mums to chat with other Mums, Dads to be with other Dads and siblings to realise that there are other children who have lost a brother or sister.

This was the first year that **Scarlett Marker** attended camp with her sister **Scout** and their mum **Bridget**. Scarlett's drawing sums up her feelings about her first camp experience in the most beautiful way.

If you are interested in attending FITS Camp next year, please watch out for the expression of interest that will come out early 2019 or call Bear Cottage on **9976 8300**. ■



Parent's corner

Photo Wall

When people arrive at Bear Cottage and come up in the lift, one of the first things they encounter is the photo wall. It may be their first visit or they may have been coming for many years and the photos are as familiar as the children they represent. These faces are incredibly important - they are the faces of the Bear Cottage children.

Helen Carroll (former Bear Cottage Nurse and now one of our volunteers) is responsible for this labour of love and would dearly love to be able to include a photo of every child who visits Bear Cottage.

If you wish to have your child's photo displayed, there are two easy ways to do it. If you are coming to visit soon, please print off your favourite photo of your child and give it to one of the nurses to put in the "photo box" in the nurses' hub.

Or you may like to email a high resolution photo to philippalouise.smith@health.nsw.gov.au. If possible, we would prefer a photo of your child only. Thank you for taking the time out of your busy lives to do this. ■



Time for a break

From time to time we are contacted by generous organisations wanting to donate to Bear Cottage. Recently we have had some family accommodation in both Byron Bay and the surrounding hinterland, offered to Bear Cottage families for short stays. Visits would only be possible when there are vacancies and during times deemed suitable by the owners of the property. All arrangements would need to be made directly with the owners and all travel expenses would need to be incurred by the family. If you are interested in finding out more, please contact bronwen.simmons@health.nsw.gov.au ■

Booking information

Bear Cottage is about to go onto an Electronic Medical Management system in line with the Sydney Childrens Hospitals Network. There will be a few changes when you make your next booking and you will receive a different set of forms in the mail.

The medical management forms need to be completed by your child's doctor and returned to us at Bear Cottage two weeks prior to your child's admission. This will allow us to enter medication details into our system.

Unfortunately, if we do not receive the forms in time, nursing staff will be unable to administer your child's medication.

We will initially be giving you a reminder phone call and hopefully before long, the system will be streamlined and easier for you and us to navigate. ■

Did you know?

We currently have 135 Bear Cottage volunteers, with nine volunteers making themselves available for shifts each day. In total this amounts to:

- 27 volunteering hours per day
- 189 volunteering hours per week
- 9639 volunteering hours per year (51 wks)

In dollar values (e.g. \$30/hour) this equates to \$289,170 per annum. Our volunteers bring a wealth of knowledge and experience – we have GPs, Nutritionists, Board Directors, Actuaries, IT experts and Childcare Workers to name but a few!

In short, the community that is Bear Cottage would be incomplete without the passion, energy time and skills that our volunteers bring daily. The impact of our volunteers is immeasurable. ■



Riding for a cause

We are privileged to have many organisations in the local community enthusiastically supporting Bear Cottage in a number of different ways. One such group is the **Northern Beaches Harley Davidson Club** which recently held a fundraiser for Bear Cottage raising \$1781.20. This event was quite a spectacle with over 130 enthusiasts riding their Harleys from Brookvale to Wisemans Ferry and back. It was a novel way to raise money and awareness at the same time.

The Club was also keen to support Bear Cottage in other ways and generously gave up some time to allow our Dads to have an amazing experience at our recent Dad's Camp. Eight Dads paired up with Club riders for a scenic ride to Palm Beach and back – stopping on the way for morning tea. For many of our Dads, this was the first time on the back of a bike and from what we hear, it may not be the last! ■



Brooke from Northern Beaches Harley Davidson



Bear Cottage Dads getting ready for their ride to Palm Beach

The gift of education

Thanks to one of our generous corporate donors, **Device Technologies**, two of our nurses, **Grace** and **Vikki** recently had the opportunity to attend a conference in Malaysia.

The theme of the conference was **"Equipping Palliative Care Professionals with skills and resources to share their knowledge."** The focus was to teach different learning methods in order for the participants to educate their colleagues about Palliative Care.

Given Bear Cottage's geographical isolation and the fact that we are one of only three children's hospices in Australia, this opportunity was invaluable. It provided Grace and Vikki an opportunity

to network with their peers, learn from their experiences and exchange ideas that could then be brought back and shared with the Bear Cottage team. It was also a platform to showcase Bear Cottage's services to an international audience.

Following the conference, we were delighted to welcome a nursing delegate from the Philippines to Bear Cottage to continue the relationship which Vikki and Grace established at the conference.

Bear Cottage extends our sincere thanks to Device Technologies for funding our important Education Program. ■



Santa's flying visit – you're invited

Many of you will know that each Christmas we are visited by the **NSW Ambulance Rescue Helicopter**, accompanied by a very special guest with a white beard and red hat. This will be happening on **Tuesday 18th of December** and if you and your family would like to attend, you would be more than welcome. We would ask that families are here at 9am for the 9.30am helicopter arrival. If you would like to attend, please get in contact with **bronwen.simmons@health.nsw.gov.au** ■



Staff news

Whilst our new AINs (**Bryarna and Aaron**) are finding their feet at Bear Cottage, our 'old' AINs **Emily, Isabella** and **Fiona** have been busy finishing up at University and eagerly awaiting news on their new graduate placements for next year. All three have been successful in gaining placements within the Sydney Childrens Hospitals Network: Emily and Fiona at The Children's Hospital Westmead and Isabella at Sydney Children's Hospital, Randwick. Although it will be sad to see them leave Bear Cottage, it is wonderful news for the girls in advancing their nursing careers.

Bianka has now started in her role as Social Worker. She brings a wealth of experience from her previous roles working across all areas within an acute care hospital. She has specialist experience and training in grief and loss, trauma and oncology.

Congratulations also to our Registered Nurse **Michelle** who recently welcomed baby **Arlo** into her family. ■



Bryarna



Aaron



Emily



Fiona



Bianka