

Cottage Capers

The Newsletter for Bear Cottage families



Autumn 2020

Welcome

Welcome to 2020 and Bear Cottage's 19th year of operation. This year we are looking forward to continuing to work with each family in our care and providing the best care that we possibly can.

As you would be aware, there is currently much uncertainty with the outbreak of the COVID-19 virus. In accordance with the SCHN guidelines, we have had to cancel all of our Camp programs for at least the next two months. Whilst this is unfortunate, we are sure that you understand that the safety of our children and families is paramount. Please visit www.schn.health.nsw.gov.au for more information.

Your feedback is very important and we endeavour to get things right. Did you know we have a Family Feedback box? This locked box is located in the parent library and a feedback form is available on admission. We encourage you to complete the form and your comments will be treated confidentially.

Although Bear Cottage is not a hotel, we do our best to ensure our rooms are clean and ready for the children and families on admission. To enable this to happen, we do ask you to adhere to specific times for admissions and discharges. They are:

Admissions: 2pm-4pm

Discharges: Before 11am

If these times do not suit, please let us know when making the booking. Please note that unfortunately it is not possible to stay for lunch on the day of your discharge.

On behalf of the team at Bear Cottage, we look forward to seeing you all in 2020. 🐾

Narelle Martin, Acting Nurse Manager



Our Family Advisory Group

Our Bear Cottage **Family Advisory Group** is a small group of bereaved and non-bereaved parents, up to four Bear Cottage staff and a representative from the SCHN. The main purpose of the group is to provide advice to ensure that Bear Cottage is responsive to patients, family input, needs and experiences. Some of the contributions that the Group has made to date include:

- the establishment of the **Garden of Remembrance** including the bronze sculpture and plaque as tribute to all the children who have been cared for at Bear Cottage;
- securing a part-time physiotherapist to attend to the children's needs whilst staying in-house;
- input into the family support activities provided by Bear Cottage;
- suggestions on how to engage with families early on in diagnosis.

We are pleased to advise that **Malinda** (a parent in this group) would be happy to hear from you if you would like anything tabled at the meetings. Malinda can be contacted on: malindamartin@bigpond.com

Meet the team

Jennifer visits Bear Cottage regularly with her son **Alexander**. She shares a story of her travels with Alexander in this issue.

Vita and her husband **Peter** also visit regularly with their son **Ben** and his two little sisters and enjoy the opportunity to engage with other families in similar circumstances.



L to R back: Jennifer, Julie, Leo, Kaliph, Bronwyn and Karla
L to R front: Malinda, Bronwen, Philly and Narelle
Not pictured: Vita and Shelly

Kaliph and his family have been associated with Bear Cottage since 2010. His daughter **Keana** died a number of years ago and his family does what it can to support *"an essential place"*. Kaliph and another father have formed a 'Dad's Support Group' which currently includes 20 bereaved and non-bereaved fathers of Bear Cottage children.

Julie & Leo's involvement started in 2004 when their son **Michael** was diagnosed with Batten's Disease. They utilised the Cottage on many occasions until Michael's passing in May 2018. As members of the Group since its inception they *"have loved our time spent at Bear Cottage even in trying circumstances and hope we can continue to support and guide Bear Cottage through our involvement with the Group."*

Karla's daughter **Autumn** also spent her last days at Bear Cottage in 2010. Autumn's siblings enjoy coming back to the Christmas parties at Bear Cottage and have attended Sibling Camp.

Malinda and David's son **Joshua** was one of the first children to come to Bear Cottage in 2001 and Malinda reconnected with Bear Cottage as an active member of the family advisory group three years ago. She is enjoying providing her valuable feedback to this group.

Shelly and her family became involved with Bear Cottage in 2006 with their little girl **Aria**. Shelly remains connected to Bear Cottage, not only by being a member of the Family Advisory Group, but also as one of our valuable volunteers.

Bronwyn is our most recent member of the group. Bronwyn and her family spent time at Bear Cottage in 2017 with their little boy **Gabriel** and have enjoyed attending our Sibling and FITs Camp.

Our Family Advisory Group parents are all eager to ensure Bear Cottage provides a service that meets the needs of all families through the most difficult of times and would love to hear from you if you have anything that you would like addressed.

If you are interested in becoming a member of the Family Advisory Group, please contact Narelle.Martin@health.nsw.gov.au 🐾



Driving to Tasmania

For those of you who don't know our family, I'm **Jennifer**, I work as a professional photographer and I have 100% care of my 4 year old boy **Alexander** who lives with me. We are a Bear Cottage family.

Since August 2019, Alexander had four significant hospital admissions, with varying degrees of severity. By the end of 2019, we were faced with being trapped indoors because of the smoke from the fires. Alexander already suffers from respiratory issues and it seemed this was exacerbating things. I needed a plan to get out and take a break – a little reprieve in nature – to find some fresh air and carve out some time to decompress from the endless months of hospital appointments, admissions, therapy and home routine of being his personal uber driver, scheduler, planner, chief financial officer, grant writer . . . etc.



I had to go to Tasmania to drop off 44 mounted photographs to a gallery for an upcoming exhibition, so I took the opportunity to build on this and add on a quick little 'getaway'. Because of the amount of items I needed to transport, plus all the extra accoutrements that come

with having a high-needs kid, I decided the easiest and cost effective way to make this possible was to drive to Tasmania from Sydney, where we live. I negotiated with a carer to come with us for the two week trip because I knew I would need the help to manage all of his gastrostomy feeds, blending food, the endless packing and unpacking of the car, bathing him in unfamiliar locations that only had showers and just to have a second set of hands with me for things like hiking, ducking into a store to grab some groceries and in the event of an emergency to have someone there to help share the load.

Packing an entire bag full of hospital supplies, breathing filters, spare tubes, an extra G-tube peg, his bi-pap machine, a portable oxygen concentrator (for possible emergency situations), a pulse-oximeter, thermometer, feeding pump, all the possible pain medications, daily pharmaceuticals and regular vitamins that he takes. I packed a portable camping bed for him to sleep on, his wheelchair, nappies and personal care supplies, a really heavy Vitamix blender and the Deuter child carrier pack.



We packed the car, I set up the feeding pump with hydration and settled Alexander in his car seat in preparation for the 11 hour drive to Melbourne. We set a timer and stopped every four hours to feed him half of his feeds, then gave the rest of the feed an hour or so later while driving in the hopes his stomach would not feel overloaded and avoid a possible car-spewing situation.

We got to Melbourne, exhausted from the long day of driving and were very grateful that we spotted an abandoned shopping trolley on the sidewalk to unpack the car and push it all up in the elevator to our friends' apartment for the night. Because it was hard to keep his blended food cold, we used organic pumpkin soup that comes in a UHT packet in the grocery aisle of the supermarket and would use that for the journey as we could batch blend smaller amounts and use ice packs to keep the food cold for the few hours until Alexander's next feed. Keeping his food cold on the trip was one of the trickier things to manage. We added additional fats and ingredients to his blends to help keep up his calories. Things like avocados, extra virgin olive oil and coconut oil were also on hand in the car as "essential supplies".

We packed the car early the next morning and headed to the port to catch the Spirit of Tasmania ferry. We pre-booked a disabled parking bay and had to be there extra early to have time to park and unload



for the 10 hour boat ride. We drove the car and unpacked some essentials for the day once we were on board. Once you go up to the main area of the boat, the car gets locked away until you arrive and dock in Devonport. It's a pretty easy way to travel with a wheelchair as we were right next to the elevator. Taking the ferry made it a fun part of our journey to Tasmania.

Once in Tasmania, after the "official business" of dropping the artwork off at the gallery in Bernie, we were then free to explore the Island. We spent a night in a cabin in Cradle Mountain, exploring the outdoors and the erratic weather that comes with being up near the mountain. We had to be prepared for all conditions – one moment it was windy and blowing sprinkles of rain and ten minutes later, the sun was out.



Alexander was put in the carry pack and we walked, taking turns sharing the load with his carer. We took the shuttle bus to the lake and were walking around the lake when we realised that in all the rush to get to the shuttle on time, we must have forgotten his food bag in the car in the lower parking lot. The carer quickly left to get back on the shuttle bus and go retrieve the bag. I was alone with Alexander, cradled in my lap, sitting up on a rock and watching the incredible view of the mountain range. The sun was shining down on him. It was silent. The air was clear. We were snuggling – something I felt we hadn't really done in a while. With all the rushing him around, to and from appointments and therapy in autopilot mode for the last few months, it felt like a real rarity to have space to just sit, watch and cuddle. It felt so indulgent, yet so nourishing too. I missed "my little boy" and I felt like I finally had him again in my arms for an ordinary moment between a mum and her child.

We sat there for almost an hour watching the clouds come through and form and blow through again. No place to rush off to, no-one to share his time and energy with – just Alexander and I. It was delightful. I looked down to take a photograph of this moment and I could see this cheeky grin of contentment on his face. Alexander is non-verbal, but I could tell from the look on his face, he approved.





The rest of the trip was spent in southern Tasmania in the Huon Valley, surrounded by lush green farmland and nature. We paid a visit to Chef Matthew Evans at Fat Pig Farm. We toured around his organic farm in the fields, looking at the pigs, orchard and veggie patch, taking cuttings of herbs, tasting the raspberries freshly plucked from

the bush and letting Alexander taste and smell all these elements so he could experience this trip with all of his senses. Alexander was once again carried around on our backs in the pack for the farm tour and spent the rest of the time indoors seated in his wheelchair as we shared lunch with other families. I would swipe food off my plate with my finger and place it in Alexander's mouth so he could experience some of the flavours too. The following day we went on a boat ride down the Huon River with Matthew Evans' crew. We carried him again in the carrier and he felt the air breezing through his hair and tasted more delicious food and basked in the sunshine. I picked him up and took him to the front of the boat to see the river ahead of us, the air was crisp and clean to breathe – what luxury after months of ash-filled skies on the mainland.

We then headed up to MONA – the famous Art Museum near Hobart, spending the day looking at the incredible collection of art. We would push him up toward an artwork and let him carefully look at it – pointing out the shapes and colours. Museums are great because the artwork is big and it's usually well lit. I carefully curated a selection of high contrast, colourful or brightly lit pieces and wheeled him over to go explore them together – perfect for a little guy with vision impairment!

The less packing and unpacking at accommodation, the more enjoyable a trip will be. It is for this reason I decided to break the two week trip up into four places of accommodation as our "base". In hindsight that was still too many locations and next time I'd find one place that is central and just do "day trips" to explore the surrounding areas. Otherwise you spend all your time packing and unpacking the car. Each time we stopped it took between 2-3 hours to fully unpack and about the same to pack it all back up again. Between this and enteral feeding, it feels like the day just slips by on these transition days.

We drove to the upper North East part of Tasmania and stayed in Pioneer. We spent the last four nights here. The carer encouraged me to do something for myself and that was the "permission" that I needed to be okay to leave. The carer spent the morning with Alexander and I rented a mountain bike and hit the dirt trails at nearby Derby bike track for half a day. I fell over the handle bars – twice – but it was nice to know that there was someone with Alexander and that I could have time and space to possibly break my own arm or dislocate a shoulder – if I so wanted to.

A trip to a white sand beach and a lavender farm to smell the flowers concluded our final days in Tasmania. Our final night was spent back at Cradle Mountain. Under a clear open sky, in awe of the starry, starry night there was time to think about all the loved ones we had lost this past year and reflect on life outside of this galaxy.

One of the things about this fragile life that we lead, is that we don't prioritise time away. It can feel overwhelming or scary for some families to get away. Costly, prohibitive and mentally impossible to imagine how you'd manage it. It was actually a family of an older child at Bear Cottage who reflected on life with their son, and had told me to GO and DO the trips NOW while he's little, 'while it's easier to move him around', 'while you can still pick him up', 'while you can still change him in public bathrooms or the back of the car without too much difficulty'. This was exactly the encouragement that I needed to hear. I mean, what's the worst possible thing that could happen?

Our trip brought about a renewed sense of self. A grounded-return to nature that I desperately needed. I was so happy to be able to experience this memory with Alexander. I don't want all our memories to be in the back of a resus bay. I'd rather we weave some of these fun memories into the fabric of our patchwork quilt of a life together, than be burdened by the constant fear of, what if . . . 🐾

New to the Cottage

Bring Back the Book



2020 marks the start of two exciting initiatives at Bear Cottage. Books and reading are now high on our agenda and our new project **Bring Back the Book to Bear Cottage** aims for every child at Bear Cottage to experience reading as a daily occurrence.

Our Child Life Therapists **Gy** and **Wendy**, assisted by volunteer **Sarah**, are working on re-organising the bookshelf into categories. Volunteers and staff alike will be encouraged to spend increased face to face time with Bear Cottage children, reading age-appropriate books aloud.

Reading has so many benefits for children, providing cognitive stimulation and the opportunity for development of receptive and expressive language. Hearing stories read aloud has demonstrable developmental benefits. Scientific imaging has recently documented increased activity in the brains of children whose parents frequently read to them. (1)

The experience for a child having a story read aloud is very different from watching a movie or even listening to an audio book. This is because there is engagement with the parent or carer reading and talking about the contents of the book in ways which are meaningful for the child.

Not least of all, reading is a wonderful thing to do with children because it is something which is enjoyable for both child and adult, a simple yet wonderful way in which to enhance our relationships.

Play on

Annabelle, our Registered Music Therapist, is also working on her new project which is called '**Play On**'. Annabelle is preparing a series of recordings of the music she sings and plays to the children during group sessions. These



recordings will be made available for staff, volunteers and families, along with a clearly written guide on how to use the music in interactive ways. There will be a small kit for each song, comprising simple instruments such as shakers as well as puppet prompts.

Listening to music together can be a time for enjoyment and relaxation. However, music can also be used actively, providing a means to communicate and, like reading, may provide cognitive stimulation, assist with language development and encourage physical movement. Even the simplicity of a regular beat has been shown to assist with emotional regulation.

With the generous support of the **Ottomin Foundation** and **Sydney Hi Fi Mona Vale**, there will soon be some new and user-friendly sound equipment available in the lounge room.

Together with our Volunteer Manager **Rachel**, Annabelle will shortly be running some training sessions with volunteers to demonstrate how to use the music recordings and to train others to use the new sound equipment. Annabelle is also happy to provide her recordings and printed guides to any interested parents. 🐾

(1) www.melbournechildpsychology.com.au/blog/the-many-benefits-of-reading-aloud-to-your-kids/

Meet our staff

Amy our Bear Cottage Physiotherapist



In April 2020, I will have been part of the Bear Cottage family providing Physiotherapy services on a Tuesday and Thursday afternoon for 12 months. I'm not sure about you, but the time has flown!

I'd like to start by saying a big thank you to all the families who have welcomed me and allowed me to be a member of their child's care team. I hope my advice, support and treatments have been a welcome addition to your child's care.

If you're wondering who I am and what I do at Bear Cottage, I'm hoping the next few sentences will provide the answer to those questions. I've been a physio for a few years now and I also work at the Sydney Children's Hospital, Randwick. I am happy to see anyone who passes through the doors at Bear Cottage and to help ensure your child continues with their regular physiotherapy program whilst they're staying at Bear Cottage. I'm also happy to offer advice around equipment/AFOs, chest physiotherapy, positioning and the NDIS. I'm also happy to speak with your local therapist or team if there are any issues that need resolving.

To get in contact with me during your child's stay, just ask one of the Nurses when you're being admitted and they'll pass the message onto me. I'm also happy for you to come and find me on a Tuesday and Thursday afternoon.

As it is coming up to the 12 month mark, I am looking at evaluating the Physiotherapy service that has been provided at Bear Cottage to see what is/isn't working. As a part of this evaluation, you might receive an email with a survey attached over the coming months – this survey is completely voluntary and anonymous. If you do choose to participate, I encourage your answers and feedback to be as honest as possible as it will help me to tailor the service to suit Bear Cottage's needs.

I look forward to working with you all over the next 12 months! 🐾

Other staff news

Welcome back to our Staff Specialist **Dr Nicole Armitage** following the birth of her new baby boy **Harry**. Nicole will be with us at Bear Cottage on Mondays and Thursdays.

We have welcomed to our Nursing team **Wendy** who has many years' experience with babies and is excited to take up the challenge of working at Bear Cottage and meeting the lovely children and families who will come into her care. She is joined by **Roanna** and **Emily**, two new Undergraduate AINs who are also excited about the learning experience offered.

Sadly we have farewelled AIN **Sharnie** who had recently graduated as an Enrolled Nurse and is leaving to take up a position in this new role.

Finally, after many years at Bear Cottage, first as a Housekeeper and then as an AIN, **Bine** has decided to take the plunge and retire. Bine's smiling face and enthusiasm to provide the best care to children and their families will be greatly missed. 🐾



Dr Nicole Armitage



Nurse Wendy



AIN Roanna



AIN Emily



AIN Sharnie



Farewell lunch for Bina

Remembering our children

Madison Chessum
20.04.08–22.01.20

Charlotte Rathmanner
27.04.17–9.02.20

Recipe

Chef Shanna's Roast Pork is a favourite at Bear Cottage. For those wanting to try this at home, here's the recipe:

Pork Belly

Method

Dry pork belly out overnight
Score skin really well
Season flesh of meat with olive oil, fennel seeds, salt & pepper
Cook on high at 210°C for 30 mins
Turn oven down to 160°C for 1.5hrs
Let rest for 30 mins
Serve pork in apple sauce and gravy



Couscous Salad

Ingredients

Couscous
Fresh coriander
Sugar snap peas
Snow peas
Green beans
Cherry tomatoes (chopped in half)
2 tsp smoked paprika
1 tsp ground cumin
1 tsp ground cinnamon
Olive oil
Red wine vinegar
Salt & Pepper

Method

Steam couscous together with dry seasoning for 10 mins. Add the beans, sugar snap peas and snow peas and steam for a further 5 mins.

Mix all ingredients together and serve.



Camp Calendar

Dad's Camp No. 1

Friday 12–Monday 15 June

Grandparent's Camp

Friday 26–Sunday 28 June

Junior Sibling Camp

Saturday 8–Sunday 9 August

Mum's Camp No.2

Friday 11–Sunday 13 September

Junior Sibling Camp

Saturday 31 October–Sunday 1 November

Footprints in the Sand Camp

Friday 6–Sunday 8 November

Important events

Superhero Launch Party

Sunday 26 July

Bear Cottage Family Christmas Party

Sunday 13 December