

End of life care location – home and hospital – two different experiences

Written by a mother who wishes to remain anonymous

What influenced your decision on choosing the end-of-life location for your children?



My son had complex needs, and many mistakes were made in the hospital. There were nurses there who did not seem willing to understand or even listen to me. We didn't have a care plan.

My son's doctor suggested that I we should end my son's treatment and take a palliative approach, so his care was peaceful. He seemed completely unaware of how I was feeling, which was traumatized and guilty. I didn't feel like my religious beliefs were respected.

When I questioned this care, I was told "you can't keep him in the hospital," so I thought "I'll do my best for him at home, and I'll do it alone."

We spent 3 months at home, and it was a huge challenge. I had other children, and work was busy, and my husband didn't speak English. Eventually we returned to the hospital.

*I didn't feel like I could trust the staff, so I stayed in the hospital with my son. I believe trust could have been established if the doctors just listened to me. **A mother knows her child better than anyone else.***

The palliative care team supported me with advocacy when I needed to be listened to, but it always felt like a fight, to get the best care for my son.

In hospital, you can't choose your doctor, and every day there is a different one. Some were difficult, but other doctors and nurses were beautiful, and became friends that I am still connected to.

I think it is more about the people around you, than the location, that makes the difference.

When my daughter entered end-of-life care, the experience was much better. We had a good plan, and everyone made sure I felt comfortable to bring her in to the hospital.

Our plan was shared with the emergency staff, the doctors and the nurses, and everyone had a willingness to learn. I felt heard and understood. The "Very Special Kids" team was wonderful – we still meet every month, and it has helped me to not feel alone.

I'm thinking about life better now. My thinking has changed.

I believe the best care comes when the mother is listened to, when the lived experience of the parent is respected, and then a plan is made together.

End of Life care location – hospice – a family experience

Written by Ryan Fowler – father of Rio



It was the place we said goodbye, but it gave us so much more.

Losing a child is one of the toughest things anyone can go through. It is crippling to say the least. With so many questions left unanswered, Doctors unsure, except for one thing, *"Mr and Mrs Fowler, what we do know is that your son Rio has a life limiting condition, and it seems that he does not have long to live..."*.

It was then a hospice called Bear Cottage in Manly, Sydney that without knowing much about it, would soon become our refuge when we needed it the most.

Initially as a father, I was against going to Bear Cottage, because of what it meant. For me, it initially symbolised us giving up on my son...the end. As a father that is hard to grasp. For us, we weren't the family that was born with a child that had a life – limiting condition, so we didn't know at the beginning that this would be on the cards.

Rio was a cheeky and carefree little boy, who was adored by his big sister, eternally loved by his mother and forever my son. Like all children, this is how parents and families see their children no matter what. Then when Rio became unwell, never did I think we would need palliative care and a hospice to help keep my family together. It is because of this, I share our experience to those parents who need a voice in understanding why Bear Cottage and hospices like it, are so important; special for families when they need it the most.

Once at Bear Cottage my perspective changed. In his final few weeks Rio, snuggled up with his big sister Remi, mum (Karen) and I, was able to have the moments with us as a family that every parent cherishes. If at home, this probably would not have happened, due to not having the support Rio and we needed to get through his failing health as a family.

Rio spent his last three weeks at Bear Cottage in Manly. We were one of the fortunate families that got the opportunity to be nurtured, guided, and supported through the toughest goodbye we would ever say. The staff at Bear Cottage are now extended family to us and the service they provided to our whole family unit was priceless. Rio passed away with *"mummy"* and *"dad dad"* on either side of him after spending days in the garden, feeling fresh air, being alongside the ocean and watching tv with his adoring big sister. We are so thankful for our end-of-life care. Even though it was not easy, and times were definitely tense and tough with Rio's ever-changing condition, the staff and doctors were always nurturing, and we could not think of a better place and now looking back, would not have wanted to be anywhere else during that time.

As the Director of Bear Cottage once told us, *"Children come here to live, not to die..."*. This resonated with me and illustrated how important Bear Cottage is, a home away from home, for families who have a child living with a life – limiting condition.

To be meshed back together as a family when Rio was unwell, is something that I will forever cherish as a father. We cannot thank Bear Cottage enough, in helping us to guide and shape our little boy Rio's final weeks, and with this provide a sanctuary for my family.

"Fearfully and Wonderfully Made..."

From Ryan, Karen, Remi and (Rio) Fowler

Because of our experience, the charity Rio's Legacy was created to support children with a life-limiting condition and their families, with the focus of building more facilities like Bear Cottage.