



I grew up by the sea and like so many other South Australian kids, some of my favourite memories are at the beach and near the ocean. Before we received Seb's diagnosis of Tay-Sachs disease, we pictured raising our darling son in the sunshine, playing at the beach with his cousins and 'normal' family activities filled with carefree fun and happiness.

Now we take nothing for granted.

Our 'normal' daily reality is specialist appointments, procedures, medicines and clinical assessments.

Our 'normal' emotional reality is grief. Our 'normal' logistics are restrictions.

We can't leave Sebby for one minute. Bedtime isn't just putting him to bed. There's no turning on a baby monitor and having an hour to ourselves. When he goes to bed, one of us goes too. We have moments where we catch a glimpse of Sebby's personality and we share laughs together, our days used to be full of those.

Our lives are now consumed and revolve around his care, which is why we're so appreciative of any respite care. Last weekend we were lucky enough to hire a holiday home in Middleton – it was a chance for the whole family to have some precious moments with Sebby.

We had four generations under one roof. Seb needed the break – we all did. My parents help us so much around the house and it was just as important for them. This weekend was especially precious to us, as we know that as Sebby's disease progresses, the logistics of going away just won't be possible anymore, without the practical solutions the Beach House will offer to families.

Our weekend in Middleton meant we could give Seb the tranquillity that comes from being by the sea and the joy that comes from being with family. There is something so special about breathing in the sea air. It's about being in the moment and not having to think of anything else. The Women's & Children's Foundation Beach House will allow families to have a break from their reality and leave the restrictions behind.

The Beach House will be well-equipped with all the things we need to have a holiday by the sea, considering all of Seb's complex care needs and therefore not compromising his safety. With the Beach House being situated in a holiday destination, it creates a physical and psychological distance from our normally heavy routine and allows us to share in full, the moments that are unique to each part of the day.

On behalf of our family and all of the other families who will be gifted this experience because of the Women's & Children's Hospital Foundation, the Palliative care team and all of the generous and thoughtful people who support this cause – thank you!

We love our son so much. Our commitment is to make him feel loved, happy and comfortable.

Everyday.

That is our promise to him.

Anna, Sebby's Mum

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