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We don't know how many summer days we have left together as a family, but our very best days are spent splashing around in the pool with our son Luke. Your support makes this possible.

Dear Friend,

My son Luke loves to make a 'Big Splash' at the pool. He's eight now and has been blind and deaf from birth – touch is by far his strongest sense. The feel of the water all over his body, it's a unique experience for him; we can see the pleasure he gets; his face just lights up. And the pool at Chestnut Tree House is the only place he can have this pleasure – because it's kept incredibly clean and at a constant body temperature.

Being together at Chestnut Tree House's pool has become the highlight of our summer, **thanks to the support of kind local people like you.**

Luke was born with a unique and abnormal chromosome 16 (I really do mean unique! He is the only child in the world with this condition). This fact has massively affected his ability to grow and develop like an average child would. He is fed through a tube directly into his stomach and he has a pacemaker to keep his heart going. He's had 17 operations so far in his little life (the first BIG operation was to repair a big hole in his heart and while they were in there, the surgeons also repaired a hole in his diaphragm when he was just nine weeks old). He has multiple epileptic seizures each day – any one of which could be fatal.

Luke's life is exceptionally delicate. We've spent a large part of his life in hospital – and **three times we've been told "this is the end"**, but he's pulled through.

Our lives are completely focussed around Luke's needs, 24 hours a day (getting more than a few hours sleep at a time is a luxury!). My husband Simon and I are full-time carers for him – and we are supported by the amazing James who works as Luke's 'Personal Assistant'. Between us we can give Luke the care he needs to stay alive. But this means that we really struggle to give Luke's sister Izzy (who's 11 now) the attention she needs and deserves.

It's been really tough on all of us, but perhaps Izzy the most. When I said I was going to be writing to you, I asked if she had any memories from when Luke was very young. She said, "You used to be upset and shout a lot!" – and she was right, I was so tired all the time. **But then, when Luke was nearly three, we found Chestnut Tree House – our sanctuary.**



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**{Children's
Hospice Care}**

Luke loves being at Chestnut. Even though he's deaf and blind he can walk – and he loves exploring. This means he has to have someone with him every minute to prevent him from bumping into doors, tables and other people, but Chestnut give him that freedom. When he's in hospital he can't do what he wants – it's too dangerous. **But at Chestnut they just say, "Why not?!"**

Chestnut is where we go to have a holiday together – time to just enjoy being a family together. We can completely hand over all of our care responsibilities. The nurses at Chestnut Tree House are amazing, caring and respond really well to all of Luke's medical needs. When he has seizures they help him recover, giving reassurance and hugs. They change him, feed him, keep his feeding tube clean, entertain him and keep him safe and happy. They're the only people apart from James, his Personal Assistant, that we trust with Luke's care.

Chestnut's care means we can have a break too; because for a few short hours we're free of the constant pressure and worry of Luke's care – and so we can spend time with Izzy and give her some much needed attention. Not only do they take care of Luke, they take care of us. We don't have to worry about a thing when we're there – the food just magically appears and it is wonderful! Chestnut is our summer sanctuary, so we can focus on being a family and enjoying this special time of year, together.

Like every family cared for by Chestnut Tree House, we're limited to a small number of days per year – so we're grateful for the days we do get at Chestnut, but there are so many children, like Luke, who need their attention too. So, when we can, Luke gets to spend a day at Chestnut whilst we spend some time with Izzy, which we always end together, by having a 'Big Splash' in their special pool.

In the morning we get Luke ready, loading him, his wheelchair and all his gear (there's loads!) into our converted Transit van and then we head off on the drive to Chestnut. Once there, we have a short handover with the nurses, bring them up to speed on Luke's health that day – and then we kiss him goodbye and we go off, just the three of us, for a few hours.

We use this time to do something that Izzy really wants to do. So, that could be shopping in Brighton, paddle boarding or a fish and chip lunch! (Izzy's favourite). Most importantly, we get back to Chestnut for about 4pm, because that means we've got time to go for a swim. The nurses book the pool and we all get changed and play in the pool together, splashing about. It's always great, one of the very few times when all four of us can be together as a family, all enjoying the same thing. Then we get changed and usually stay for dinner, all sat together with the nurses and other families there (we've made a lot of friends over the last four years at Chestnut). We pack up after dinner and head home.

Just that day, one day without the worry, the work, the stress – feels like a fortnight's holiday would feel to other families. For us, a day at Chestnut, making a 'Big Splash' and enjoying our summer is just perfect.

But we're totally aware how privileged we are to be able to go to Chestnut Tree House; the joy of swimming in their pool is only available to us because it is paid for by donations from amazing, caring local people like you. I cannot find the words needed to fully tell you how much it means to our family to have the support that you make possible. Thank you – you've helped my family and hundreds of others to have quite often the best times in our lives through your generosity.

Today, I want to ask if you could help to make a 'Big Splash' possible for other families this summer. The staff have told me it costs **£41.00** for Luke to spend a magical hour splashing about at Chestnut. That covers both the cost of running the pool and the time of a specialist nurse to be there with him, caring for his needs and keeping them safe. Every day of the year Chestnut has to find **£80.00** just to keep the pool clean, warm and ready for a family to use. It would be wonderful if we could raise the money they need to keep the pool running this summer – and make sure that every child has the chance of their own 'Big Splash'. Whatever you feel you could contribute would be wonderful and I know would be hugely appreciated by all families who rely on Chestnut's care as we do.

Lastly, I have another really special favour to ask you. This summer, we'd really like to brighten up the doorway to the pool with spectacularly colourful decorations, filled with kind words of love and support. So, when the kids make their way into the pool to make their own 'Big Splash', your lovely words will be the first thing they see – particularly for those families who are using the pool for the first time. Please, take a moment to send in your own words of encouragement, we'd really love it if you could be part of their experience!

Thank you again, so much, for your wonderful support. From my family to yours, I send you every best wish. I hope you get to make some 'Big Splashes' with your loved ones this summer.

A handwritten signature in black ink that reads "Liz" with a stylized flourish at the end.

Liz, Luke's Mum