

## Magic Moments – feedback report, February 2017

Thank you for the £1,200 in August 2016 towards a specialist pressure relieving mattress, which is making a difference for children staying at Little Havens Children's Hospice.

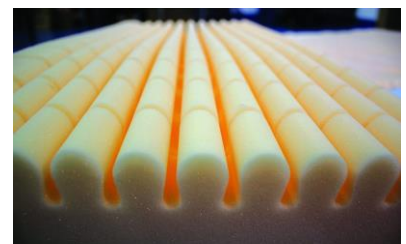
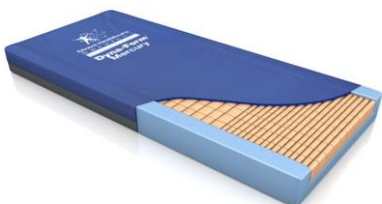


Some of our patients often spend long periods of time resting and being cared for in bed. We are now able to give them the safest and most advantageous care possible by utilising the best equipment in palliative care thanks to Magic Moments and other funders. The mattress is specifically designed as an aid in the prevention and treatment of pressure ulcers and for pain therapy.



One of the bedrooms at Little Havens Children's Hospice

I recently met with a colleague; Little Havens Ward Sister, Birgit Duellberg-Webb, who told me *"The mattress has made a huge difference. It is more comfortable for patients, especially as some conditions can cause a patient to become marked by their bed, but these don't. They are quieter as well and there are more settings so the patients have more control. For example, they have the option to have an increased anti-pressure setting by using the air pump. This way we are able to make the set up suitable for the different range of children. We currently have a young person who is known to develop pressure areas and the mattress is very beneficial to him. We can also clean the covers easily in the washing machine too which is obviously better for maintaining the highest standards of hygiene."*



To illustrate how supporters like you and the care provided by Little Havens makes a positive difference to patients, here is Charlie Batten's story:

Four-year-old Charlie has so far not been diagnosed with a condition. He has lung disease, can't swallow safely and has a gastrostomy and uses an oxygen machine to help him breathe, but no cause has been found for his medical conditions. He has been visiting Little Havens with his mum, dad and big brother Alfie, eight, since November 2015.



When Charlie was first referred to Little Havens the family were initially refused, as Charlie was undiagnosed it was difficult to show what his specific needs were. However, after Charlie deteriorated the family turned to Little Havens again and were invited in for a stay.

"The only thing I was worried about before we came to Little Havens was explaining it to Alf, because he's so sensitive. I didn't want to worry or upset him or for him to think Charlie wouldn't be around for very long. They can be quite boisterous and loud too and I was worried it might not be appropriate, I don't know what I imagined but I don't think I imagined it to be as relaxed as it is."

Charlie and his big brother Alf are very close and during Charlie's often long stays in hospital the brothers talk over Facetime and Charlie shows Alf his room.

"They're very different but I think they complement each other and they miss each other a lot when Charlie's in hospital."

Charlie loves superheroes and the picture of him flying into the ball pool – just like a superhero – is one of his favourites! "I always assumed that if you had a child with a disability someone would tell you what you're meant to say but they don't so we're kind of winging it. Charlie has started to ask a few awkward questions. He asked me if he takes his cannula off is he going to die? I think as children get older they become more aware of their own mortality.

"Coming to Little Havens has been amazing. The kids love it and what's so nice is that the kids think it's a holiday and I love that. Alf has just started going to a support group for siblings and Charlie loves the ball pool. Russ and I are able to actually get some sleep as well and properly relax. We can ask for advice too; we get so many letters and often we don't fully understand what they mean and some of the medical terminology so the Care Team can explain.

"During our stays so far Charlie has been well and able to enjoy it and I'm really grateful for that because he knows the hospice now and he'll be really comfortable here when he's not well. He feels confident and has been able to enjoy it.

"The bit I find hard is not knowing. Do I plan for years and years? Is he going to become an adult? But then when he's so well none of it feels real because he doesn't look sick, he's happy and chatty. Then it comes as a bit of a shock when he goes downhill, particularly when you start to see his body start to give up, you realise that he is actually quite sick and you've got to remember that."

*Emma, Charlie's mum*

Sarah Macdonald, Trust Officer, Havens Hospices  
01702 221656 [smacdonald@havenshospices.org.uk](mailto:smacdonald@havenshospices.org.uk)