

**We need to talk about Palliative Care**  
**Children's Hospice Association Scotland**  
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**Parent using Rachel House**

## **HARRY'S STORY**

Harry was our three year old little boy who was born with a range of very complex medical needs. It's a miracle that he survived the first few weeks of his life but he did and he went on to learn to walk and communicate. He spent most of his short life in and out of hospital, including spells at Edinburgh Sick Kids and Great Ormond Street in London. He had a complex syndrome of congenital anomalies called "Vacteral Association" and in Harry's case they were overwhelmingly serious leading to organ failures.

As parents it became quite evident to us there isn't any palliative care for children with Harry's complex needs in hospital – to us it seemed that palliative care happened through in the oncology ward but there wasn't any in the medical ward where Harry was staying. Even after Harry was fully dependant on Total Parenteral Nutrition and tests showed that he was in complete intestinal failure, the hospital still didn't consider putting Harry in a palliative care bracket. It seemed as though there was a fear in the ward of even mentioning palliative care – perhaps due to the inexperience of hospital staff and a financial block to re-direct the financial support elsewhere. It was a daily challenge to battle for everything and do a lot of Harry's care ourselves, committing to the point we had to split our family up to manage Harry's care. As time went on we felt more and more that we were stuck. Harry was slowly deteriorating and no-one was ready to talk about what the ongoing plan for Harry was even after Great Ormond Street provided information from tests conducted there. We felt that we weren't being listened to and that communication between staff was breaking down. If only they had taken Harry's pain seriously. And if only palliative care had been put in place Harry would have been medicated correctly and had the dignity to do it in private.

After talking recently with the management in the hospital I asked them if they receive funding for palliative care to which they replied "Yes"..... but they choose NOT to apply it as a service to patients. Again if you're an oncology patient and you enter this stage you get offered the option to go home. Harry was declined this by our local community team at home mainly because we had the wrong postcode and also not a correct diagnoses to fit accordingly. Sadly when we were at Rachel House and pushing to get Harry home under palliative care we received a phone call from the hospital to say it would be pointless to order any equipment to accommodate Harry at home as he probably wouldn't live much longer, again a huge lack of understanding of what palliative care actually is.

Getting a referral to CHAS was initially difficult – we were turned down the first time because the surgeon at RACH had said that Harry 'could be fixed'. We felt devastated because we didn't know where else we could turn to for support.

Harry spent all of the last year of his life in hospital before being transferred to Rachel House for end of life care. The Diana Children's nurse based locally in Aberdeen was able to work with the hospital and hospice teams to ensure palliative care was at the heart of his care as he deteriorated. Coming to Rachel House, Harry had the best end of life he could have had.

It was difficult being such a long way from home but Rachel House provided a place where we could be a family together. Harry's brother Sam and sister Kaidey were able to be there with us, as were his grandparents. We had the opportunity to make memories and for the first time we were able to just be Harry's mum and dad. Each member of the family had a lead person – including Sam and Kaidey – who made sure their needs were considered. Sam and Kaidey were given help with staying connected with school and school work.

Harry died peacefully on 6 September 2015 with all his family round him. We were then able to take him home to Buckie and to his own bedroom where he stayed until his funeral. Harry was a big Fireman Sam fan and so his 'special box' was a Fireman Sam design.

It's good to know that Rachel House can provide ongoing bereavement support if we need that – specially as some of the staff who were most involved in Harry's care at the hospital have not even acknowledged his death or been in touch to see how we're doing or offered us a debrief.

It would have been good if we could have had an earlier referral to Rachel House instead of waiting for the situation to reach crisis point as Harry's suffering was out of control to the point that we were transferred to High Dependency. If there could have been more parallel planning so that palliative care was offered alongside any curative options as a family we would not now be feeling that we were completely robbed of Harry's remaining time. In contrast Rachel House were able to parallel plan to a level exceeding any 5 star rating.

Harry was such a source of inspiration and love in our family and he taught us so much. He touched the hearts of everyone who met him. We hope to show some of his strength, determination and courage to make a difference so that anyone faced with a similar situation can enjoy the remaining time of life left instead of battling to keep a child comfortable and pain free. If this can't be met, then in our experience it would be better that they didn't take on the care of complex needs patients at all and that families like ours were referred elsewhere for care.