



Dylan's Story

Please be aware, you may find this story distressing.

Dylan's story is a reflection of what occurred from mum's perspective and is being shared with the intent to improve the lives of children and young adults, their loved ones, families, carers, and support those working in Palliative and End of Life Care, as to what was and continues to be important to Dylan's and his family.

Until May 2015, Dylan was a very healthy, sporty, happy 11-year-old boy. The first thing we knew was that Dylan kept falling over, which given Dylan was so sporty was strange. We went to the GP several times, however no reason was found. Finally, a GP agreed that there was something seriously wrong and we were referred to a teaching hospital, as things were getting worse, and Dylan had developed a limp. At the hospital after numerous scans and tests we were told that Dylan had an ependymomas on his spinal cord and needed an urgent operation, so he was admitted to the children's neurology ward. We were never told at this stage it was cancer. The ward had TV and air con, so although not great, it had some perks.



Doctors explained the operation and Dylan signed the consent form; we were not asked to. Seven and a half-hours later, Dylan soon realised he was left paraplegic, and wheelchair bound. The ependymomas was entangled. Dylan only spent a few weeks on the children's neurology ward as he caught a diarrhoea and vomiting bug, so he was moved onto children's medical unit (CMU), on the promise he could return to neurology, which never happened. There were also no beds on the oncology unit. CMU didn't have air con, no dedicated hoist and no free TV. These may seem like little things, however when you need a hoist every day and it takes an hour to locate one, an hour staff do not have time to look for, so we did, so an hour away from Dylan.

Dylan later found out from a local news programme on TV, that another child with an ependymomas had had a biopsy prior to surgery and due to stage of the ependymomas didn't proceed with the operation. If Dylan had known this and it was offered, he may have asked for this – missed opportunity.

Things were made a little trickier as the family found our relationship with Dylan's consultant difficult, we felt the consultant just didn't seem to have a lot of empathy.



We knew that we were about to be told bad news as we heard a doctor, who we met when Dylan was having tests (before admission) speaking to staff loudly on the ward about Dylan and whether the family and Dylan had been told the news.

About 2 hours after hearing the conversation we were called into a different room as histology had been received, the consultant came and told us Dylan had stage 3 cancer, maximum of 18 months. All they could do were things to support however these would not be curative. We later found out that his case had been raised at a multi-disciplinary team meeting and most agreed that this was all they could do.



Dylan was sent for daily radiotherapy, which in an ideal world would have been easy however Dylan had to go on his hospital bed which was highly embarrassing for him. Majority of the time the porters didn't turn up so we were having to go against hospital protocol and take him ourselves along with the play specialist. The radiologist consultant was amazing but could see that the treatment was causing Dylan a lot of pain as he could not lay for long on the table as it was a solid surface, and the transfer from bed to table was stressful.

This relationship with the oncologist was tested further when we asked for a second opinion, who wouldn't when it is their child? The second opinion consultant said the same. Dylan's consultant wanted to share with Dylan the results and what this meant, however we didn't want to, as we did not feel this was right for Dylan.



We were introduced to a wonderful children's palliative care consultant who worked at the teaching hospital and children's hospice. So compassionate, supportive and present. Dylan went to school at the teaching hospital, he could be challenging at times, had a great sense of humour and fun.

The play therapist was brilliant in hospital, as were the Pat Dog visits – Leo in particular.

Dylan went to his prom whilst in hospital, then staff enabled him to be supported, have transport and make a wish come true – to be at his prom with his girlfriend .

Whilst in hospital, we had visits to the children's hospice, which was great. They have all the kit needed and we could stay with Dylan.

308 days in hospital, why?... the operation left Dylan wheelchair bound and we lived in a house not suitable for a wheelchair and the equipment needed for Dylan's care. We had to have our garage converted into a room for Dylan, so he could come home. Simple things like, we couldn't get Dylan's electric wheelchair over our doorstep at home.





When Dylan came home, April 2016, his school (mainstream) made contact and came home with a tie for him as a welcome and they said they could accommodate all his needs. So, I brought all his school kit, he went in, and they had a fire alarm test and realised they could not accommodate and refused access. We approached other schools; his catchment school didn't return calls and local education authority did not offer any help. He had to do online lessons which most of the time were for infant school age children. One school, slightly further away were fantastic and said they had completed a risk assessment and could take Dylan, however by this time Dylan had deteriorated further and so Dylan never got to go to school again.



With the support of the children's hospice in March 2016 we completed an advance care plan* (ACP), they were brilliant.

Whilst at home Dylan had the support from carers, well, when they turned up, some were very good, others less reliable. An example of this was the day when Dylan died in the night, the carers didn't come, which of course we were very glad. However, the next day they turned up, which was very distressing.

Community nursing support was sometimes difficult too, no children's nurse, occasionally a district nurse, so we tended to take Dylan to the hospital to help with his catheter and sores on his feet. We did however have amazing support from our Occupational Therapist and Physio.

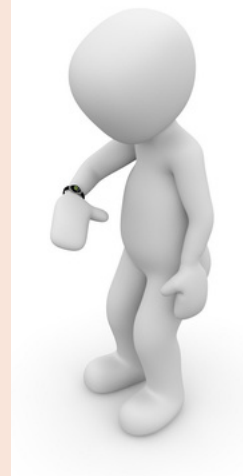
One month prior to Dylan's death, Dylan lost the use of his arms. This affected his independence and mental health, he could not play X box and connect with his friends, or do things like feeding himself etc. A couple of weeks later his breathing also started getting laboured. The palliative care consultant came to visit us and had a frank conversation with Dylan. Dylan was a very intelligent boy, we believe he knew that the ending was near. It was too late and Dylan gave up two days later, enough was enough. Had Dylan asked about his prognosis etc we would have discussed this with him. We constantly asked how he was doing and whether he wanted to talk about anything which he always refused.

*Child and Young Person's Advance Care Plans, also referred to as ACPs, have been standardised across the country and a blank one can be found on:
<http://cypacp.uk/>





When Dylan died, it was not what anyone would have expected. We had not really been told what to do when it happened, just that it would at some point. So, when he did, dad tried to revive whilst mum called 999 as they didn't know what else to do. Well, what happened next...



... armed response turned up at our door! They were apparently the closest responders carrying resuscitation equipment. Two burly chaps with guns at your door and your son has just died... well they were amazing. They asked about our other son, who was 10 and sleeping. We were with Dylan, they went and got his brother and were just great. The paramedics were also very good.

What followed was not as great. Undertaker arrived about half an hour later, not sure who contacted them. He stood just looking at his watch and said, we are here to 'take the body'. No compassion, no realisation that this was our precious boy who had just died. We thought we would have a few hours with him. I had to go and remove all bags etc (suprapubic catheter) as it was not something they do!



After Dylan died, we were offered bereavement support from the children's hospice, which we took up, however at different stages. Dylan's brother needed something else, the school were amazing, did a memory box and checked in. We were offered other support however the timing wasn't right for us.

Sadly, Dylan died in September 2016, a week after his 13th birthday.
Dylan was never told; however, he knew, Dylan never asked, that was right for our family.

What Matters Most

- Communication is key, open them and keep the channels open.
- Respect parents' wishes, they know their child.
- Timings and positions of treatments tricky – need to adapt as much as possible re ability of the child.
- Milestones are important – enable and mark them.
- Steps into physio... not thought through re people accessing who are in wheelchairs.
- Not all the curbs around the hospital have dropped sections.
- Awareness for families that they can get support from council with home adaptations.
- Do a full risk assessment before making promises.
- Preparation for when a child dies, simple processes and numbers to call.
- One message to all services to stop/inform services.
- Compassion and kindness costs nothing and is remembered forever.



The story does not end there..... Dylan's Quest

During Dylan's prolonged stay in hospital, Dylan decided that he wanted to help children in a similar situation, as there was so little activity for them on the ward. In a little over a year, he achieved the truly incredible feat of raising over £10,000 for the teaching hospital.

We set up a charity in Dylan's name, continuing 'Dylan's Quest' to help families like ours, with children and young adults who have life limiting illnesses.

You can find more out by clicking - [Dylan's Quest](#).



It is appreciated that you may have been affected by reading this story, if so, and you would like to speak with someone, please reach out.

This may be someone you know, or if not, you can call the Samaritans, they offer a 24-hour confidential emotional support, call free on **116 123** or email jo@samaritans.org.uk.

Just remember... you are never alone.