Wessex Children's and Young Adults' Palliative Care Network

Hampshire and Isle of Wight

Isaac's Story

Please be aware, you may find this story distressing.
Isaac'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 Isaac's and his family.

Background

Maxine fostered Isaac from 8 months old, at this time Isaac did not have a diagnosis, Maxine was just aware that Isaac was having seizures and had special needs. As time passed and Isaac's needs for medical decisions were proving too difficult to navigate as a foster parent, Maxine applied to become his special guardian, as Maxine wanted Isaac to remain with her.

There is no contact with Isaac's birth parents.

Maxine has 4 grown-up children, one who lives away and three who live locally.

Isaac was diagnosed with Allan-Herndon-Dudley syndrome, a neurological condition that affects mobility, cognition, and general health – affects males and disrupts development from before birth.

Isaac is unable to move independently, has a tracheostomy, requires constant oxygen therapy, occasional additional bagging*, has monitoring on at night, which will alarm if observations alter, has no facial expressions, and needs 24/7 care, which is provided predominantly by his mum, with support 3 times a week from his nurse (which has been in place for the last 3 months).

Maxine had discussed and agreed an advance care plan (ACP**) and do not attempt cardiopulmonary resuscitation (DNACPR***).

*application of respiratory support via a sealed face-mask, nasal mask, mouthpiece, full face visor or helmet without the need for intubation.

**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/

Child and Young Person's Advance Care Plan Collaborative

***means if your heart or breathing stops your healthcare team will not try to restart it.

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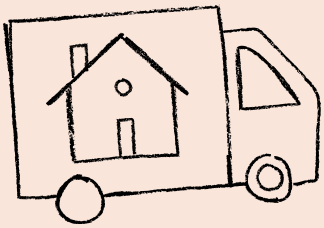
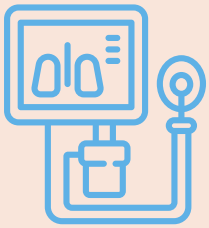
Hampshire and Isle of Wight

In March 2023, a week after moving house, mum went to bed as normal, Isaac had monitoring on at night to alert if there were any issues. Mum was awoken by the monitoring alarm in the early hours, Isaac had respiratory arrested. This happened periodically and mum would bag Isaac until he started breathing again, this could take up to 30 mins. However, this evening was different, mum was bagging for nearly 2 hours, Isaac wasn't recovering, he was blue, no respirations, not in distress, just asleep and mum could not feel a pulse.

The ACP stated DNACPR and this was all documented. Mum felt Isaac had made his choice, however she hadn't had the conversation about who to call when it happened. In that moment, she called 999, she needed someone to be with her and confirm that Isaac had died and explain what to do next. Mum was clear in the ACP that she wanted Isaac to die at home.

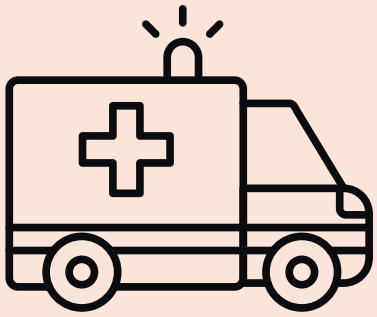




The 999 call handler asked questions and instructed mum to start cardiopulmonary resuscitation (CPR), mum refused as this was not part of their wishes or inline with Isaac's ACP. The 999 call handler kept trying to persuade mum to do CPR, mum explained her son was dead.

The ambulance crew members arrived (1 & 2); mum explained she needed to know if Isaac had 'gone' and reiterated that Isaac had a DNACPR. The ambulance crew asked for a copy of the DNACPR document but mum could not find it. They had moved the previous week and mum could only find the old one.

2 more ambulance crews arrived (3 & 4) along with 4 policemen. Ambulance crew member 1 who was with Isaac said that he would have to resuscitate Isaac as there was no documented DNACPR. Mum tried to stop him, however the police advised her that they would have to arrest her if she did not move. Isaac had no respiratory rate at this time however he had a faint heart rate.



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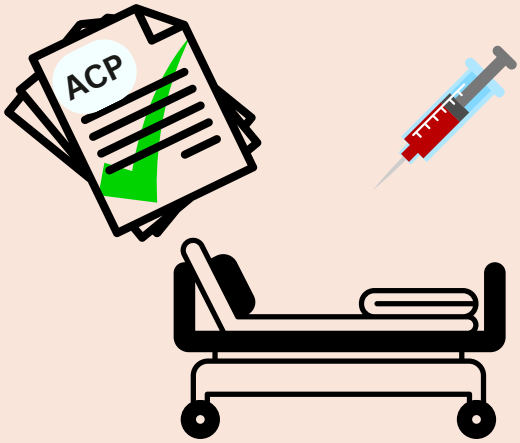
Hampshire and Isle of Wight

Mum called the local hospital and spoke to the Consultant, who found Isaac's DNACPR on the system and mum put the consultant on with ambulance crew member 1. However, the ambulance crew advised they could not stop.

Mum felt that ambulance crew member 1 was very condescending, referring to mum as 'the carer', despite her correcting him. It made her feel that as Isaac was not her flesh and blood she did not care.

The ambulance crew spoke with their fast response medical director who advised the crew to take Isaac to hospital.

Ambulance crew 1 asked mum if she was coming to hospital with Isaac. It was the way she was asked that upset her, with or without her or her consent, mum felt totally helpless as if after caring for Isaac for 10 years, she wasn't going to go with him.



Isaac and mum were taken to local hospital resus and mum describes that they were amazing. They had Isaac's ACP and DNACPR and aware that he was not for resus and therefore stopped. Isaac's temperature was very low and his respirations were 3 per minute, without any bagging. They asked mum if she was ok if they took bloods to see if there was an underlying issue and put a warming blanket on, both of which mum understood and agreed too.

The ambulance crew member 2 apologised to mum, that they had not been able to follow her wishes. Mum was really touched by this.

Isaac had no oxygen for approximately 6 minutes, no one knew how he was still alive, however he was still breathing and appeared to be improving and mum just wanted to take him home. Consultant agreed with her, however they were concerned Isaac would die on the way and they agreed to look for somewhere quiet.

As all this was occurring, Maxine's grandson had been born the previous evening by caesarean and her daughter-in-law and son were also at the hospital. This meant that her grown up son was able to come and be with her and Isaac during this time.

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Hampshire and Isle of Wight

The team at the local hospital obtained special permission to go to the new adult hospice, which are on the grounds of the hospital. They were moved to the hospice, with a Sister from the children's ward and Maxine's older son was able to join them.

Whilst at the hospice they were quietly sat, Isaac was not being bagged, no oxygen and his respirations were down to 3 per minute. Although Isaac was really blue and mum thought he was going to die, his breathing started to improve and increased to 9 per minute. Mum asked her older son to get the Sister. The Paediatric Consultant and community children's nurse had arrived and took over Isaac's care.

Mum wanted to take Isaac home, the team agreed with mum to reinstate Isaac's medication, as a number of these had sedative effects, and monitor before arranging an ambulance home. They explained they didn't want mum to be distressed by Isaac dying enroute and mum agreed. Isaac continued to pick up, so the consultant travelled with Isaac, mum and the team home with the nurse following behind.

Isaac has had a few more episodes like this since and he is not the same child.

Isaac no longer reaches out to touch his mum, he sleeps most of the time.

Mum feels that when she asked for someone to come and confirm that Isaac had died, they took away their perfect death and this can never happen again.

Mum didn't sleep for weeks after and 10 months after still thinks about it every day. Mum shared that what happened 'keeps relaying on a loop, I am positive I have PTSD'.

As a result of what happened, mum stated that she will never dial 999 again, she felt that they took away their choice, which mum is still angry about.

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.

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Hampshire and Isle of Wight

Mum is keen to understand that if the hospital have the ACP and DNACPR, why didn't the ambulance crew? If there is a flag on the system, where is the paperwork to go with it? Why wouldn't the crew take the verbal notification from the consultant? The key for mum is to ensure that this does not happen to someone else.

The local ambulance provider has been liaising with mum to help her understand the decisions they made.

Mum has the ACP to hand now and ensures it is always available, however feels that moving house should not have resulted in this situation occurring.

What Matters Most

Some reflections from Maxine about what really mattered most and the learning she hopes can be taken away from Isaac and her experience ...

- Empathy and compassion – cost nothing and means the earth. Although an apology cannot take away what happened, it really meant something.
- Being heard – parents need to be heard, they know their child, what their norm is and when things are not right.
- Paperwork – only as good as the systems that record it – need to ensure these are up to date and if someone moves this is easily updated.
- Consistency in approach – for one ambulance crew member to apologise and another to say nothing, the inconsistency showed starkly the different approaches and impact.
- Environment – obtaining a quiet space for someone when they are end of life, families do not always wish to go to areas they have been cared for previously.