

A young girl with a white headscarf and a light blue hospital gown is lying in a bed. She is smiling and looking to the left, holding a large, light brown teddy bear. The background is a plain white hospital sheet.

Pulse

Nursing at Home

Part of Acacium Group

**End of life care
Paediatric**

Your choice, our commitment

Snapshot

- Pulse Nursing at Home was the number one choice of care provider
- A seamless discharge home in just six days
- Pulse Nursing at Home provided consistent and effective support on both clinical and non-clinical issues
- Post bereavement care provided to team of nurses
- Excellent feedback received for Pulse Nursing at Home from all stakeholders

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Zara’s* background

Zara was originally born in Tiabego but spent her whole life as an inpatient in multiple hospitals around the world. She was misdiagnosed with cancer at birth and treated with chemotherapy. Shortly after being transferred to Toronto hospital, she was correctly diagnosed with interstitial lung disease, a condition that causes scarring of the lungs, making it difficult to breathe. Zara was reliant on continuous non-invasive ventilation and had a significant oxygen requirement. Due to Toronto hospital being unable to meet the complexity of Zara’s needs, she was eventually transferred to Great Ormond Street where she stayed for the final years of her life.

Six-day turnaround

Whilst at Great Ormond Street, Zara was rapidly deteriorating. Pulse Nursing at Home was approached to put together a package of care that would provide stability and continuity for the last couple of weeks of her life. Due to our strong relationship with the CCG, we were the only care provider that they trusted to effectively step in and achieve such a tight turnaround. We carried out clinical assessments and within six days, Zara was discharged home with one-to-one paediatric nurses caring for her, seven nights a week. With the support of the nurses at night, Zara’s parents were well-rested to spend quality time with their daughter during the day. This did come with its struggles as they had no prior experience of caring for Zara outside of a hospital environment, however the nurses were on hand to provide on-going support whenever it was needed.

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Providing non-clinical support

Zara was admitted back to Great Ormond Street several times after being discharged home. Due to the complexity of her condition, our team of nurses provided additional care during her time on the ward. Our nurses also worked with the family on non-clinical issues too. Due to Zara being an international patient, her parents had no understanding of the UK health system, so a lot of education was delivered around the NHS and its systems and processes. The majority of communication was with Zara's father as her mother's English wasn't good. With five other siblings to take care of, there was understandably a lot of pressure on the family and we needed to ensure this was alleviated as much as possible.

The outcome

During her short time spent at home (ten days in total), Zara enjoyed a party and quality time with her parents and siblings. Shortly after, at just six year's old, Zara sadly passed away in hospital, with her family at her bedside. Our team supported Zara's family following her death and we received a personal thank you for all of the support we had given them. Our nurses were also provided with post bereavement care after playing such a key role in the final stages of Zara's life.

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***Name has been changed for data protection**



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020 7959 1003

info@pulsenursingathome.co.uk
pulsenursingathome.co.uk

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