

Better at Home training suite offers vital support for sick children

focus

WellChild 
the national charity for sick children

Seriously ill children and their families in South West London will be getting vital help as their parents receive training to care for them at home at a new Better at Home training suite, supported by a WellChild nurse.

The suite, the first of its kind in London, is funded by WellChild, the national charity for seriously ill children, and is situated at St George's University Hospitals NHS Foundation Trust. The project was made possible by a grant from the Sir Jules Thorn Charitable Trust.

WellChild has also funded Charlie Perth, long-term ventilation (LTV) and Better at Home clinical nurse specialist to work alongside Alex McClements, the current WellChild LTV nurse specialist, to develop this training facility.

WellChild Better at Home training suites provide home-from-home spaces where parents and carers can learn life-saving interventions in a safe environment using simulation equipment. They also provide the opportunity to train extended family members to widen the support network. Set up like a child's bedroom, they provide a safe space to prepare for providing care in the home.

The aim of clinical skills training for parents and carers is to supportively nurture their competence and confidence in caring for their child and thus support early discharge from hospital and prevent hospital readmission. The training aims to empower families and unpaid carers to provide safe and effective, evidenced-based care for a child with complex and frequently changing medical needs.

Training for parents and carers usually takes place at a child's hospital bedside prior to discharge home. In some cases, this does not prepare parents and carers for crisis or emergency situations that might arise, and the delivery of the training can be inconsistent, limited and delivered by more than one professional. This can prolong discharge from hospital settings. That's why parent trainers like Charlie and the WellChild Better at Home training suites are such an important resource for families with children with complex needs.

Charlie Perth has been a qualified nurse for almost nine years. Starting out with a BSc in adult nursing, her clinical experience is based in the acute medical unit and then intensive care, working in both district general hospitals and tertiary centres. After undertaking a secondment in paediatrics, she developed a passion for supporting children with complex medical needs and their families and undertook a PG(Dip) in children's nursing. After that, she completed the specialist paediatric critical care course, and worked as a sister in children's critical care.

Charlie says: "Being a WellChild nurse means listening, supporting and engaging families and children with long-term ventilation needs. My role gives me the ability to help transition a child and their family from hospital to the community. The Better



Clinical nurse specialist Charlie Perth in the Better at Home training suite.

at Home suite at St George's provides a supportive and safe environment for parents and carers to gain the invaluable specialised skills required to care for their child at home.

"I enjoy this dynamic role, working clinically with children that require long-term ventilation in acute areas, facilitating training for parents and carers in the suite and seeing patients in clinic. It is an immense privilege to be able to support these families and navigate the challenges faced by having a child who requires long-term ventilation and I'm proud to call myself a WellChild nurse."

One child who is already benefitting from the extended support WellChild has enabled is Dexter Adu. Dexter was born premature at 23 weeks' gestation and has severe chronic lung disease, he needs oxygen during the day and is on ventilation at night with a BiPAP (bilevel positive airway pressure) machine. He was in hospital for nine months following his birth and was given steroids to help his lungs grow stronger and had surgery for patent ductus arteriosus (PDA) to close an open vessel in his heart. His situation improved a little after surgery but not enough to come off the oxygen. The team supporting him introduced the family to the LTV team to start conversations about Dexter being put onto a form of ventilation.

WellChild nurse Charlie spent lots of time talking to the family about what being ventilated would mean for Dexter. When it was agreed that he would have non-invasive ventilation using a BiPAP machine, they knew what to expect and had Charlie with them to support them throughout.

When Dexter had improved and was ready to go home, Charlie started to prepare the family for what life at home would be like. They needed training on how to use the equipment he needed. There was a lot to learn as this was all very new to them. Charlie organised for the family to use the Better at Home suite, which Dexter's mum Holly describes as amazing. Holly says: "It's set up

like a child's bedroom with a cot and everything so we could see first-hand what it would be like when we went home, how much space the equipment took up but most of all it allowed us to role play and practise lots of different scenarios so when we went home, we were very well prepared. It was such a great place to learn as it can be difficult when on the ward surrounded by other parents, you always feel like they are watching. Having the privacy of the suite meant we could relax and really focus on learning the skills we needed. Charlie was with us, and we were able to ask questions there and then and keep going over and over everything until we were confident and competent. We had a WhatsApp group we could contact her on and she was there to help. She did everything she could to take the pressure off us as a family so we could focus on our training and Dexter. She even organised our discharge and for all our equipment to be sent to our home ready for Dexter."

Holly added: "Our world changed completely when Dexter was born and the support of Charlie and the team of professionals at the hospital who worked with Dexter have made life that bit easier. Even now we are home, Charlie continues to support us and ensure Dexter stays well at home. Dexter is really thriving. He's just amazing and the happiest little boy. He's developing well and manages to play and move even attached to all his equipment."

WellChild now has seven Better at Home training projects across the UK and this year will see the opening of another three. The Sir Jules Thorn Charitable Trust is fully funding this project as part of a £350,000 investment in the nationwide programme.



Dexter, his mum Holly and his brother.

Better at Home meets a huge unmet need and the training suite at St George's has the potential to deliver transformational, practical support for families in London.

For further information visit www.wellchild.org.uk

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100% human milk derived powdered fortifier



WHO recommendations on type of fortifiers

VLBW infants who fail to gain weight despite adequate breast-milk feeding should be given human-milk fortifiers, preferably those that are human milk based*



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*www.who.int/elena/titles/feeding_vlbw_infants/en/

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