

Delivering the shift from hospital to community for children and young people with complex medical needs.

November 2025

Contents

1. Our vision – Hospital to home
2. WellChild Nurses – Specialist children’s nurse workforce
 - a. Growing numbers and complexity of need
 - b. Delivering the hospital to home vision
3. Equipment, resources and safe spaces for training
 - a. Upskilling parents, carers, professionals and communities
 - b. Variety of skills required
4. Complex discharge best practice and principles
5. Summary & recommendations

WellChild is the national charity for children and young people with complex medical needs. Last year, through our work we enabled more than 589 children and young people with highly complex medical needs to be discharged home from hospital. We also prevented more than 16,000 hospital readmissions. Our Section 1 evidence summarises data, case studies and family insights on how this has been achieved, the professionals and skills that made it happen.

With the numbers of children living longer with increasingly complex medical needs, caseloads are rising. We passionately believe that the role of specialist Children’s Nurses and investment into the training and development of specialist complex care workforce and skills is key to delivering the hospital to community vision.

1. Our vision – Hospital to home

Our vision as a national charity is for every child with complex medical needs to be thriving at home, instead of hospital.

Our hypothesis and supporting evidence demonstrates that upskilling parents, carers, community professionals and local NHS teams with the skills and confidence to meet the clinical needs of this growing population is key to ensuring that these children and young people can be not only cared for at home instead of hospital, but also key to ensuring that they can access services such as education, respite and other local services.

The following services are examples of the specialist work that we have undertaken to enable the realisation of the hospital-to-home vision over the last 20 years.

2. WellChild Nurses – Specialist children’s nurse workforce

WellChild has funded 53 specialist, band 7 children’s nurses, working within the NHS in hospitals and communities in every country of the UK. WellChild Nurses are experts in the field of children’s complex medical care with specialisms that cover Complex Discharge, Long Term Ventilation (LTV) and Parent Educators.

There are currently WellChild Nurses working within 38 NHS Hospital Trusts, including Great Ormond Street Hospital, St George’s Hospital, Alder Hey Children’s Hospital, Edinburgh Hospital for Sick Kids and Birmingham Children’s Hospital.

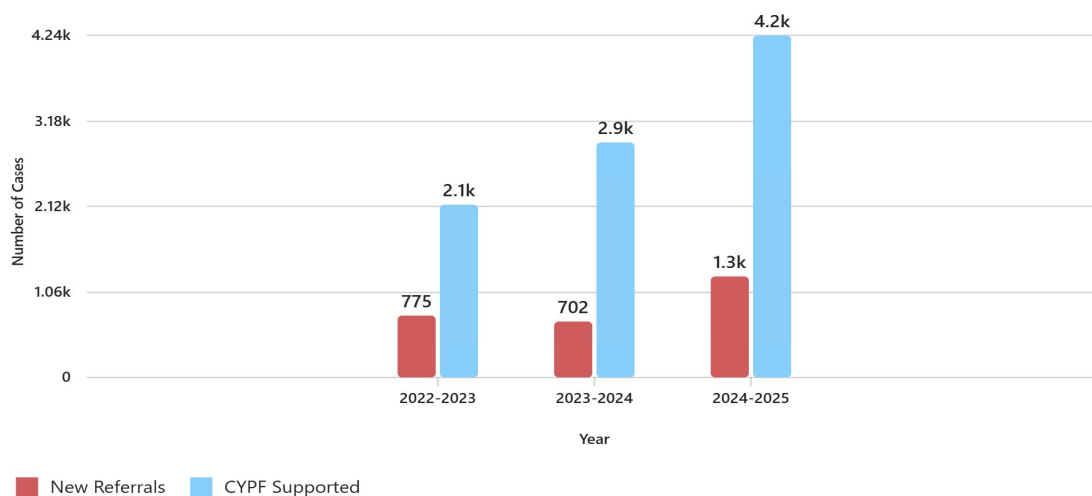
WellChild Nurses provide the specialist practical, emotional support and training to facilitate quicker hospital discharge, build parental and carer clinical confidence and to act as a central coordinator of care.

WellChild Nurses are empowering parents and carers, but they are also building clinical and skills confidence in family members, local NHS, education and community professionals to ensure that these children can be cared for closer to home when needed and access basic services such as education, or respite.

“If I could put into perspective my child’s life with and without the support of a WellChild Nurse, I would tell you that before we met our nurse, our child would have been in hospital an average of 10 times a year, with discharge always being complicated and lengthy. Since the involvement of our WellChild Nurse, our child spends more time at home than hospital and hasn’t had a lengthy stay in hospital since 2017.”

2a. Growing numbers and complexity of need

Advances in medicine and technology means that children and young people with complex medical needs are living longer - often into adulthood. WellChild is seeing the numbers of these children and young people growing in parallel with a growing complexity of their clinical need. This can be seen in the rise of WellChild Nurse caseloads and referrals over the last three years.



Many of these children and young people require round-the-clock specialist medical care. Many will stay in hospital for months and years simply because there isn't the support to get them home. One of the biggest barriers to hospital discharge is a lack of skills and clinical confidence amongst parents, carers and those around them to meet the intensive, round the clock, clinical needs of these children – from tracheostomy care to basic life support.

Other barriers to hospital discharge include the availability of specialist equipment and the suitability of housing for these children, young people and their families. The complexity of their respective long-term conditions can also mean that even when nothing is acute, getting discharged is difficult, leading to unnecessarily long hospital stays.

Those who are being cared for at home will face regular and sometimes unnecessary admissions to hospital, which can often be a long way from the family home. Particularly those families who live in rural areas, who can live hours from the nearest specialist paediatric hospital and who don't have access to a WellChild Nurse.

Workforce and local skills shortages are leaving parent carers left to deliver round-the-clock care single handedly to unsafe and unsustainable levels.

“There is a serious lack of complex care carers available. The agency cannot fill the package, so we are scraping by on minimal amounts now”

“I am having to do sometimes 4 or 5 nights in a row. Every week. I am exhausted. I am tired and could fall asleep at any moment. The amount of caffeine that I have to have sometimes makes me feel sick and shakey...I worry about what would happen if I collapsed because of exhaustion. There is no agency back up plan so I'm just hoping things get better very soon although I know they won't. There are no staff coming through and they would have to complete training when they do get here.”

“I do think that it's a recruitment issue but yes they know that I'll have to cover. I could take the PHB and I'd be able to do it but now I have no capacity for any more work and I don't know if I'd be able to recruit any easier, so I feel like I'm just stuck here doing their job always. It's not that I don't want to look after my child, it's that I'm not physically able to do 24/7. As well as their medical and emotional needs to which are very warring. It would actually be easier mentally for me not to have to rely on the agency, but I have to have help. I have had meetings with group directors of care and the commissioner. There are always false promises of things picking up. There is a lack of staff and a lack of money.”

‘When our overnight carer is ill and there is no cover, I have to stay up to do an awake all night ‘shift’. I need to make sure my child's airway is safe and that his ventilator that helps him breathe stays attached. On nights like that, with only a few hours warning, there's no time to stock up on sleep so by 7am I am exhausted. I can only go to bed the next day if my child is at school otherwise, being their main carer I can be up without sleep for a couple of days.’

2b. Delivering the hospital to home vision

With expertise and specialisms in complex discharge planning and coordination; and by helping parents and carers to develop the clinical confidence to care at home and in the community, WellChild Nurses are leading the delivery of the hospital to home vision for children and young people with complex medical needs within their regions.

Indeed, last year, WellChild Nurses enabled **573 children to be discharged home** from hospital and **prevented 15,865 hospital readmissions**. They trained and upskilled 1,623 parents and carers and spent 1,790 hours upskilling other teams and supporting more than 2000 other professionals and teams.

Case study

Accelerating hospital discharge

One WellChild Nurse supported a baby born in Wales with Congenital Central Hypoventilation Syndrome (CCHS), meaning that the baby had a tracheostomy inserted at five weeks old, and will require ventilatory support for life.

Training with the parents began immediately once the tracheostomy was inserted. Due to the training the parents received, the parents were deemed competent 7 weeks after training began. After 16 weeks in hospital the baby was able to be discharged to go home.

Being able to train the parents immediately on how to take care of the baby, has allowed the baby to thrive at home.

3. Equipment, resources and safe spaces for training

In parallel, we have funded and established 18 Better At Home parent carer training simulation units and resources within NHS Trusts across the UK.

The key aim - to provide parents, carers, local professionals and communities with safe spaces and resources to learn the key skills (and more importantly, the confidence) to meet the clinical needs of the children and young people with complex medical needs in their care.

Building confidence in skills such as tracheostomy care and tube feeding, to basic life support and emergency procedures are key to realising the hospital to home vision. The more people around a child and family who have these skills, the more likely they are to stay out of hospital and access community services such as education, or respite.

Without these resources, parents and carers have to learn the life-critical skills such as tracheostomy care at the bedside in busy hospital environments and on their own child. Once home they would be the only person with that confidence, leading to burnout, social isolation and hospital readmissions.

Thanks to our state-of-the-art simulation suites and community mobile training kits and resources, we have made it possible for training in these complex procedures to be carried out in 'home-from-home' safe spaces, and in the home itself.

These spaces and resources have been used to build clinical confidence of parents, carers and wider family members. They have also been used to train local NHS professionals and community professionals such as school staff to help ensure that these children's needs can be met not only closer to home, but also in the community in which they live.

"Thank you [WellChild Nurse] Nicky for coming out to school. The workshop you have run for our class has been fantastic. We can't wait to continue our training and get [the child] back into school as soon as is safely possible."

Case study

Training at home instead of hospital

In this case, the boy has an immune deficiency syndrome and received a bone marrow transplant in a tertiary centre.

Unfortunately, he suffered many complications following this resulting in a major change to his everyday life. He required feeding through a jejunostomy tube along with a complex medication regime. He was unable to function independently following his transplant and required careful moving and handling.

The boy lives with his family and two of his brothers also have additional needs making hospital visiting and training in the tertiary centre very difficult for the family.

The WellChild Nurse was able to work with colleagues in the tertiary centre to develop a joint training plan for the family. She used the Better at Home mobile equipment to allow training at home.

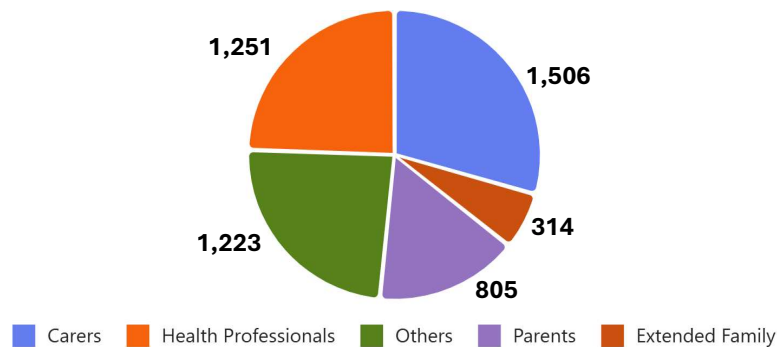
The mother also has difficulties retaining information around complex procedures, so it was invaluable to have the equipment to enable her to practice the skills when she had the time to do so.

Only with the help of the WellChild Better at Home mobile kit, the mother was trained and her son was discharged and able to come home.

3a. Upskilling parents, carers, professionals and communities

WellChild Better At Home Units and Mobile Resources have been used to build the clinical confidence of parents, carers and wider family members. They have also been used to train local NHS professionals and community professionals such as school staff to help ensure that these children's needs can be met not only closer to home, but also in the community in which they live.

Last year, WellChild Better At Home resources were used to train and upskill more than 5,000 parents, carers, family members, health professionals and others (including student nurses).



Case study

Upskilling carers to ease the pressure at home

Toby suffered an injury at birth resulting in cerebral palsy, microcephaly and inability to feed. He suffers frequent chest infections and has had several admissions to intensive care.

He had been commenced on non-invasive ventilation overnight in the tertiary centre recently but his tolerance of this was poor. This was leading to extreme fatigue for Mum (Dad works away from home) as she was up frequently during the night trying to maintain his ventilation.

WellChild Nurses were able to provide training for carers to care for Toby overnight and maintain ventilation while allowing the parents to sleep. The nurses used the WellChild Better At Home mobile training resource to provide training in the child's home using his own equipment.

This allowed the carers to practice fitting the mask correctly without having to put it on and off the boy, which he would not have tolerated well. The carers were also able to gain confidence in using the machinery in a supportive environment.

This has led to a better quality of life for the family as a whole, as Mum is able to have more sleep and is better able to cope with Toby's needs during the day. Mum has also reported that she feels that the boy's tolerance of the ventilation has increased, as carers are responding immediately to any movement of the mask and settling the boy back down with reassurance.

3a. Variety of skills required

The children and young people supported by WellChild have multiple and complex conditions, often rare or undiagnosed. They will have a complex array of medical needs that require clinical skills training across a range of medical procedures for them to live at home. Often these will change over time as children grow and their needs change. WellChild Better At Home resources

delivered an average of 9 different skills per project last year, from tracheostomy care and tube feeding, to basic life support and emergency scenarios.

Below is a list of the skills one of our Educator/Parent Trainer WellChild Nurses delivered with the help of the Better at Home Simulation Suite and the Mobile Simulation Kit within one year.

Type of training delivered e.g. BLS, suction	Numbers trained				
	Parents	Other family members	Health Professionals*	Carers	Other**
A – E Assessment			3		
Basic Life Support	29	10	15	2	
Oxygen					
Oxygen Saturation Monitoring	3	2			
Suction	15	6		4	12
Administration of Nebuliser	1				
Tracheostomy Training	5	2	16		12
Transition to 'Marpac Twill Ties' for Tracheostomies	7	10	46		12
Virtual Tracheostomy Update (via Microsoft Teams)			14		
Long-Term Ventilation (via NIPPY)	4	1	24		12
Nasogastric Tube Training	3				
Gastrostomy Training	2			1	
Mic-Key Button Changes			2		
Feed Pump Training (Abbott Pump)	8	1		1	
Aseptic Non Touch Technique			8		
Seizure Management					12
Rectal Irrigation (Using 'Qufora Mini')			4		
Intravenous Medication Administration Update	1				
TOTAL	78	32	132	8	60

4. Complex discharge best practice and principles

WellChild Nurses, in partnership with The Pan Thames LTV collaborative, a collaboration between the South Thames Paediatric Network, the North Thames Paediatric Network and Paediatric Pan London Long Term Ventilation Group brings together the skills and knowledge of clinicians and commissioners from across London and the South East of England who have extensive experience in working with children with complex medical needs.

It is acknowledged that complex discharge is carried out differently depending on where you are in the UK and who or what is available to support the process. WellChild and the Pan Thames LTV collaborative recognised their joint aims to improve family experience and came together to co-produce a set of principles and best practice around children's complex discharge.

You can read the full set of principles here (also attached with this submission): [10 Principles for Complex Discharge: Guidance & Toolkit](#)

Complex discharge refers to the process of safely transitioning children and young people with significant medical needs from hospital to home. This requires a structured, multi-disciplinary approach to ensure continuity of care, family readiness, and patient safety. The WellChild framework, developed with the Pan Thames LTV Collaborative, sets out ten guiding principles to standardize best practice across the UK.

1. Early Preparation and Planning

Discharge planning should begin as soon as possible, ideally at admission. Clear timelines, expectations, and responsibilities must be agreed upon early to avoid delays and ensure readiness.

2. Governance and Accountability

A designated discharge lead or coordinator should oversee the process, supported by a multi-disciplinary team (MDT). Governance structures ensure compliance with safeguarding, clinical standards, and local policies.

3. Comprehensive Assessment

Holistic assessment of the child's medical, social, and environmental needs is essential. This includes evaluating home suitability, equipment requirements, and family capacity to provide care.

4. Environment and Adaptations

Home adaptations and equipment provision must be planned well in advance. Safety, accessibility, and infection control considerations are critical for a successful transition.

5. Communication and Collaboration

Transparent, ongoing communication between professionals and families is vital. Families should be fully informed, involved in decision-making, and supported throughout the process.

6. Family-Centred Approach

The child's family is central to discharge planning. Emotional support, practical guidance, and involvement in care decisions help build confidence and reduce stress.

7. Training and Competency

Families and carers must receive tailored training to manage complex care safely at home. Competency assessments ensure readiness before discharge.

8. Capability Assessment

Formal evaluation of family and carer capability ensures they can meet the child's needs. Additional support or respite should be arranged where gaps are identified.

9. Partnership Working

Collaboration across health, social care, education, and voluntary sectors ensures continuity of care and access to community resources.

10. Final Discharge and Ongoing Support

The discharge process does not end at hospital exit. Clear plans for follow-up, emergency protocols, and ongoing MDT involvement safeguard the child's long-term wellbeing.

Case study

Enabling discharge home and back to school

A young girl from Birmingham had previously been fit and well. However, following development of a tumour they required extensive airway surgery and tracheostomy formation.

The girl was extremely fearful of their airway and therefore WellChild Nurses worked closely with the hospital play specialists during routine cares/ changes of tube etc in order to ensure their confidence developed.

Training for all 4 parents started immediately with a structured timetable to ensure when fit of discharge the girl could return to their usual home routine of shared care across 2 homes. Unfortunately, her condition worsened, and further surgery was required, this in turn led to all 4 parents requiring retraining.

This happened rapidly and all 4 parents were signed off prior to the girl being medically fit for discharge. Because of this they were allowed to take the girl out of hospital and on home leave. There was no delay in discharge once medically fit.

The girl is of school age and was keen to get back into school as quickly as possible. Training for the school team could not be accommodated by the community nurses and therefore A WellChild Nurse went out to the schools and trained the teachers on care too.

The girl was discharged from hospital in January, was back in school part time by February half term and in full time, fully by Easter. The WellChild Nurse works alongside the school to ensure no breaks in education occur due to lack of trained staff. Family also requested support for further training of a parent of her friend to further widen her independence allowing her to access socialising without parents present whilst still being safe. This work is ongoing.

5. Summary & Recommendations

We need a complex care workforce within and outside the NHS that has the confidence to meet the clinical needs of a growing population of children and young people living longer with complex medical needs. Workforce and skills confidence is critical to successfully achieving the hospital to community vision for this group of children and young people.

However, as the national charity, we fear that this vision is currently challenged and undermined by a lack of recognition and understanding of the needs of this growing population.

In particular, we fear that whilst the need is growing, the specialist complex care workforce and skills required to support these children, young people and families is diminishing, leading to inevitable hospital readmission, longer hospital stays, parent burnout and significant (and unnecessary) extra pressure on our health and social care system. We worry that this is driven by the following key undermining factors.

- Increasing generalisation of nurse training.
- Loss of experienced specialist children's nurse workforce through retirement.
- Low children's nursing recruitment and retention.
- Staff and complex care skills shortages within care agencies, leading to continuing care package breakdowns and a postcode lottery of out of hospital support.
- General lack of complex care skills within local communities, including schools.
- Additional workforce challenges within social workers for housing, occupational therapy and other related allied health professionals.
- Nurses remaining accountable for delegated tasks, causing reluctance to train families in the community and shifting responsibility to parents.

Through the work of WellChild Nurses and our Better At Home Training Units and resources, we are seeing first-hand the impact that can be achieved with the right workforce and the upskilling of those around the family. This impact spans reduced hospital stays, prevented readmissions, NHS cost savings, parental resilience, family wellbeing and most importantly, the chance for these children and young people to thrive at home, in their communities and into adulthood.

Sadly, there are many areas across the UK without access to a WellChild Nurse and/or Better At Home training resources. Meanwhile, many areas that do employ a WellChild Nurse are facing devastating staff cuts. Investment in national complex care workforce and skills development is the only way to realise the NHS hospital to community vision for these children and families.

“Now we are home, despite some recent trips back to hospital with a virus, our child is really thriving. They are just amazing and is the happiest little child. They don't ever seem to cry and just wants to play and smile all the time. They're developing well and manages to play and move even attached to all the equipment. They're hitting milestones and now weighs 7Kg whereas they were only 580g at birth! They have an older sibling it's great they can finally be a big sibling to them as it's so difficult when in hospital.”

About WellChild

WellChild is the national charity for children and young people with complex medical needs. Through our national network of children's nurses, training and family support programmes, our vision is for these children and young people to thrive at home, instead of hospital.

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