



PROGRESS REPORT

October Club/WellChild Better At Home Training Units

Partnership aim:

- to fund four units (year 1) in England, Scotland, Wales and Northern Ireland
- to fund (minimum) two further units (year 2)
- to help provide/gather evidence for the future roll-out of the programme across the UK

In addition to the six Better At Home Training units funded, October Club will also be supporting WellChild on a cross Trust collaboration in London (involving King's College Hospital, Evelina Children's Hospital, St. George's Hospital and The Royal Brompton).

Progress to date – Year 1:

- Two units (Coventry and Ayrshire & Arran) operational
- Third unit (Cardiff), expected to be operational before summer 2019

Coventry:

- Launched January 2019
- Based at The Birches (pictured right) – a respite care centre for children with complex needs and learning disabilities
- Part of an exciting new service development, seeing all nursing and professional services (including social care and education) for children with complex needs come together across community, school and respite care
- Providing an opportunity to develop a bespoke/specialised training centre for parents and professional staff who care for children across the region
- Number of carer training days held to date, including CPR sessions (for families). Longer-term, looking to provide CPR training once a month (demand pending)
- Initial 150 families identified who will benefit from this service



Ayrshire & Arran:

- Launched February 2019
- Building on the work of and managed/overseen by WellChild Nurse Aileen Crichton (in post since September 2010), pictured right
- Training delivered both static (based at University Hospital Crosshouse Kilmarnock) and mobile (for use in homes, GP surgeries, schools, respite care centres, district general hospitals, etc.
- Specific focus given to all children who experience complex and additional health conditions from birth to 19 years (whilst still in education and under the care of a paediatrician)
- An initial cohort of 280 beneficiaries has been identified, comprising of children and young people with multiple and complex needs; parents, extended family members; and carers



- Mobile resource – ideally suited to Ayrshire & Arran’s rural location and large physical area, supporting a wide geographical spread of families
- Preventing inconsistencies and mixed messages given to those providing a child’s care

Cardiff:

- Both a static (based at a future children’s complex needs respite centre) and mobile resource (small mobile hand-held kit supporting families at home)
- In order to get this service rolling out now, we’re intending to use (in the interim) a temporary location at one of the Children’s Centres (in University Hospital Llandough), and until such a time a permanent venue is confirmed
- Facility will comprise of two rooms – one room imitating the home environment i.e. a child’s bedroom, whilst adjoining room will be utilised as a family meeting/training/discussion area whereby video captured scenarios will be replayed and aid discussions to support learning
- Includes a WellChild Parent Educator Nurse post whose role is to...
 - deliver training at the Better At Home unit, hospital, home and other community settings
 - provide ongoing educational support for children and families receiving continuing care from the Children’s Community Nursing Service
 - support the Children’s Community Nursing Service regarding assessments in changing needs of the child
- Estimated (initial) 345 beneficiaries identified (comprising of new family referrals, professionals and ongoing training)

Advance discussions with two further units (in 2019)...

Manchester:

- Static resource, based at Royal Manchester Children’s Hospital
- Supporting children and young people on long-term ventilation
- Estimated (initial) 170 beneficiaries identified (comprising of new family referrals, introductions via other services and professionals)

Belfast:

- WellChild’s new Director of Programmes is planning to meet the team in Belfast to explore options – potential mobile resource

Year 2 (2020) – potential unit(s) identified from...

- Cambridge – static – based within Addenbrooke’s Hospital
- Cumbria – mobile
- Edinburgh – static – based within new Royal Hospital for Children and Young People
- Nottingham – static – based within Nottingham Children’s Hospital
- Southampton – mobile
- Wales – static – Abertawe Bro Morgannwg University Health Board (covering Swansea, Bridgend, Neath and Port Talbot) – location to be confirmed
- West Sussex – mobile

And including London (supported by The October Club):

- Meetings held with a number of teams in London where there are existing WellChild Nurses (King’s College Hospital, Evelina Children’s Hospital, St. George’s Hospital and The Royal Brompton) to discuss their training needs as part of the development of the Better At Home programme. The plan is to bring together the leads from each Trust and also commissioners for a workshop to discuss potential for a cross Trust collaboration. It is hoped this sort of approach will provide the best access to training for many more families across the region

Summary:

The Better At Home Training programme is designed to reduce the practical and emotional impact on a family delivering 24/7 care through a safe and supportive training environment.

Thanks to the amazing partnership alongside The October Club, we will begin the creation/roll-out of a sustainable network of Better At Home Training units, empowering thousands of families (and equipping them with the critical skills) across the country for years to come.

Background:

WellChild has spent the past 10 years helping thousands of children with exceptional healthcare needs leave hospital as quickly as possible through our unique network of WellChild Nurses – transforming support for parents who desperately want to care for their children at home.

That network has been created using a sustainable model – with the charity fully funding each post for three years before the NHS takes over. There are now 40 WellChild Nurses (working across the country), making a huge impact for families, saving the NHS a significant sum of money, and freeing up much-needed bed space.

Following extensive consultation, building on that success, and using a similarly sustainable model, our next step is to transform training for those families through the creation of a network of Better At Home training units designed to make parents more confident and competent in the critical care of their children. That care often includes potentially life-saving procedures such as CPR, clearing blocked tracheostomy tubes, dealing with unexplained apnoea, etc. – acknowledged by...

Department of Health (2011) NHS at Home: Community Children’s Nursing Services identifies the necessity for training and ensuring ongoing competence of parents and carers and also the increasing need for skilled practitioners to deliver that training

Parents are increasingly involved in performing highly technical procedures that would formerly have been considered part of professional, particularly nursing, practice (Kirk 2001; Hewitt-Taylor 2005) and in some cases performing clinical procedures that would be considered extended nursing roles

NHS England Quality Standards – ***“Parents, primary carers and immediate family should be provided with a competency training programme facilitating safe care at home.”***

The need:

Health Secretary Jeremy Hunt (2018) – ***“The NHS in England is facing completely unacceptable problems. The key is to treat more people at home and in the community to ease the burden on hard-pressed hospitals.”***

Training for parents caring for children with exceptional health needs is increasingly inconsistent and incomplete – while support for families in the home has reached crisis point...

- 32% of parents caring for a seriously ill child suffer with acute stress, with 62% of that group prescribed medication
- 47% of parents have been to see their GP, with 62% of that group prescribed medication

Lack of training remains a huge barrier to discharge for many families who spend months, often years in hospital...

- Current training methods rarely focusing on a parent’s ability to deal with an emergency situation
- Lack of opportunities for parents to update or review their skills – especially if their child’s condition deteriorates

- Training only available to parents and not to other family members or friends who might be part of the support network
- Parents with no access to training and information outside of normal working hours
- Paid carers (who are often the most consistent source of support for the families – especially in providing overnight care) receiving limited training and not being equipped to deal with emergencies or manage equipment
- Lack of training tailored for those families where end-of-life care is being managed at home

A large group of isolated, partially or un-trained parents are, therefore, providing 24-hour, often invasive, care to their children – made worse by the stresses and expense of transport (often long distances) to and from hospital for procedures that could be carried out at home.

WellChild Better At Home Training Units:

- Mimicking a home-from-home setting, introducing parents, carers, extended family members, etc. to a wide range of emergency scenarios, and the mechanisms to safely deal with these
- Piloted by WellChild at Edge Hill University in partnership with Alder Hey Children’s Hospital (pictured right), with an evaluation study report recording parents’ feedback after interviews...

“I would go there every day, just to get that confident feeling. Feeling that confident, you feel on top of the world and ready for anything.”

“So, I’ve started college on a Monday evening, but I can also relax now when I’m not there because I trust family members.”

Benefits of these units/the programme...

- improved confidence, competence and emotional resilience of parents providing 24/7 care at home (including support at each stage of the journey home)
- improved health outcomes for children through the availability of better training for all care givers
- providing parents with access to high-quality training in a safe and supportive environment delivered by skilled trainers
- providing parents with opportunities to review and update their skills
- extending opportunities to other family members and care givers as well as other professionals involved in supporting the family
- impact on NHS, speeding up discharge and freeing resources: average annual cost of a child on PICU (£700,000) vs. £200,000 (max) in the community
- enabling families to care for their child at home

Care at home has a huge impact:

- Children thrive
- Reduces cost for families
- Extended family and friends can support
- Parents can return to work
- Important impact on siblings

