



BETTER AT HOME CAMPAIGN

MP Reception

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House of Commons

Hosted by Tom Clarke MP

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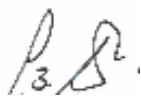
Foreword

Every Child and young person has the right to expect care to be provided at home unless they need to be admitted to a hospital environment. The recently published Child Health Strategy states that:

“Community children’s nurses have a role in working with schools, primary care and families in supporting children with identified health needs outside hospital. They provide advice and treatment and monitor progress – and are the bedrock of local service provision for children and young people with disabilities, long-term conditions and complex health needs. They are often best placed to take on the role of a lead professional, liaising with other agencies on behalf of, or in collaboration with, the child and family to ensure that their wishes, views and choices inform their ongoing care and to explore how best to move towards a multi-disciplinary approach and a more integrated care package in the location of the child and family’s choice”

(Healthy lives: Brighter futures: The strategy for children and young people’s health 2009)

It is clear that there is currently inequity in service provision, with a need to increase the number of community children’s nurses and to ensure availability 24/7. Improved communication and better co-ordinated services are vital between health and social care to meet the needs of children with complex health care needs. The community children’s nurse is often the lynch pin in the provision of seamless care.



Dr Peter Carter
Chief Executive & General Secretary
Royal College of Nursing



Kedge Martin
Chief Executive
WellChild

Executive Summary

In 2007 the Royal College of Nursing debated the need for the expansion of resources within community settings for technologically dependent babies, children and young people. The debate highlighted the:

- lack of community children's nursing and other resources including equipment to support children at home
- need for foster and respite care for children with complex and special needs
- the cost implications of failing to enable timely discharge from children's intensive care units
- the negative emotional and psychological distress and impact on children and young people, as well as social and financial strain on parents and other family members of prolonged hospitalisation

The RCN has lobbied Ministers, written letters outlining discussion points and held discussions with Chief Nursing Officers. Members have participated in work around the development of a child specific continuing care framework in England, as well as contributing to a review of services for children with complex health care needs in and the development of an integrated care pathway in Northern Ireland. The Royal College of Nursing joined forces with WellChild in 2008 to raise the needs of children and young people with complex health care needs.

An Early Day Motion was placed by Tom Clarke MP in June 2008. 84 signatories have pledged support to bring attention to:

- the disparity in service provision across England for children and young people with long-term complex care needs and their families
- the need for timely and effective care packages to be delivered at home for children and young people with long-term complex health care needs ensuring that their health, social care and education needs are met
- the need for greater financial investment in the provision of specialist children's nurses to work specifically with this group of vulnerable children and young people to bridge the gap between hospital and community services.

A Freedom of Information request to hospitals and Primary Care Trusts found that there are currently **186** children across England who have been in hospital for more than 3 months duration.

Key barriers to discharge include the:

- lack of staff to support parents and families, particularly community children's nurses
- delays in sorting out and funding for care packages at home
- availability of equipment and suitable housing
- availability of social care and psychological support

Introduction

The prevalence of children with long term complex health needs has increased over the last 10 years, with the survival of pre-term babies and with advances in medicine leading to earlier diagnosis of congenital and genetic conditions, as well as better life expectancy following severe illness or injury. It is estimated that there are 6,000 children who are dependent on assistive technology including respirators (long term ventilation).

It has been recognised since the 1960's that children are better cared for at home. Government policies have continuously reinforced the importance of reducing hospital admissions and managing care at home wherever possible. Most parents would prefer to care for their child at home, where this is an option. A child's admission and stay in hospital can be particularly draining on the family, emotionally and financially with extra costs associated with time off work, travel, car parking and child care for other siblings. Children who experience long term hospitalisation tend to:

- do less well than children cared for at home as a result of less stimulation essential for normal development
- are often cared for in inappropriate care settings such as Paediatric Intensive Care Units
- miss out on family life, events, school and leisure activities
- are at increased risk of hospital acquired infections

The 'Better at Home Campaign'

We are calling for:

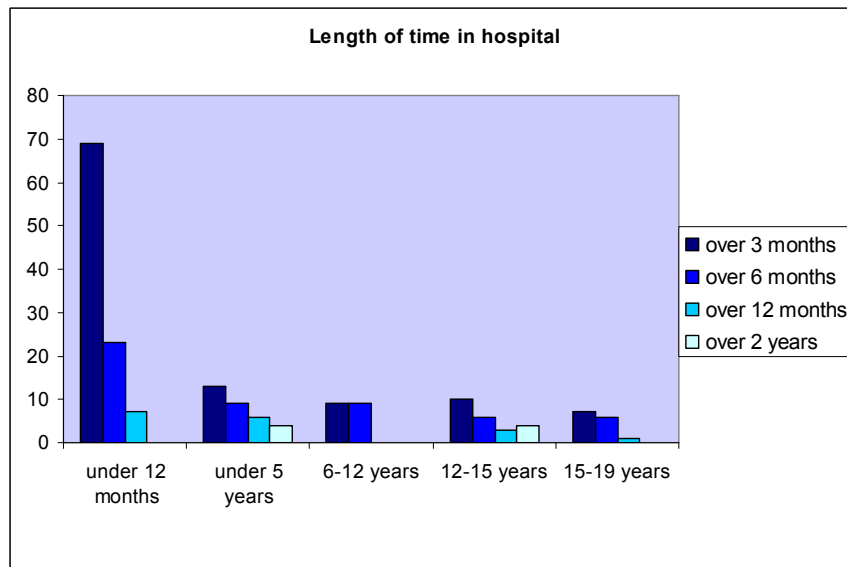
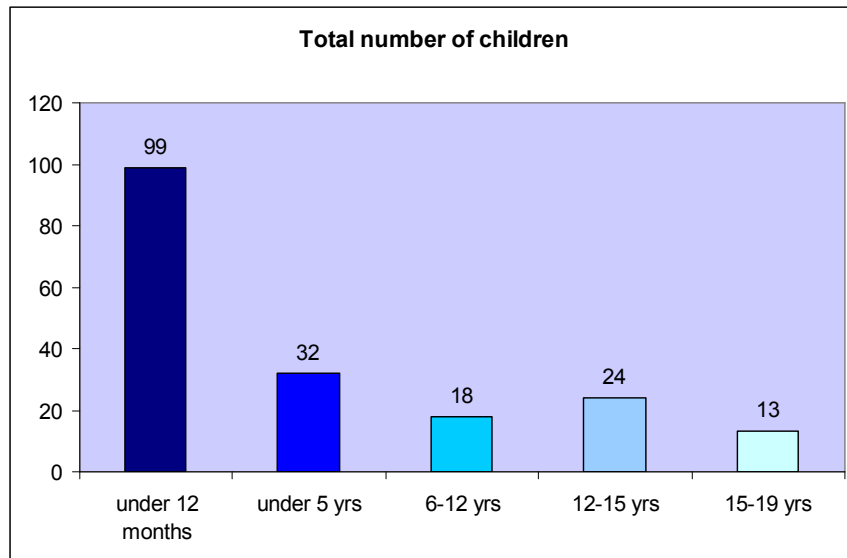
- Timely, high quality and effective care to be delivered in the home where possible.
- Packages of care which co-ordinate health, social care and education in a way that meets their individual and ongoing needs of the children and their families.
- The government's commitment to support greater financial investment in the provision of community children's nurses to work specifically with this group of vulnerable children and bridge the gap between hospital and community services.

Evidence to support the campaign

Using the Freedom of Information Act 2000 and Environmental Information Regulations 2004, a total of 582 hospitals and Primary Care Trusts across England were contacted to:

- Establish the number of children and young people in hospital three months and longer'
- Identify the barriers to preventing the discharge of these children home
- Identify what would be needed to facilitate earlier discharge for these children

A total of 149 responses were received and these showed that **186** children currently remain in hospital for a period of more than 3 months.



The following key barriers to discharge have been identified:

Lack of staff to support parents and families

- Limited, under resourced or no community children's nursing teams
- Lack of trained carers or delays in recruitment

Delays in sorting out and funding for care packages at home

- Delay in decision-making about the funding of care packages
- Time delay in implementing continuing care packages

Availability of equipment and housing

- Limited availability of specialist paediatric medical equipment within the community such as portable ventilators, lifting hoists and feeding tubes
- Awaiting home adaptations such as downstairs toilets and bedrooms

Availability of social care and psychological support

- Lack of psychological care and counselling for children and families
- Awaiting foster care or beds at rehabilitation centres

The financial cost of delayed discharge

Example 1

Caring for a medically fit ventilator dependent child in Paediatric Intensive Care versus caring for them at home (1)

- The national average cost of caring for a child in PICU is £2,067 per day equating to £754,455 annually
- The average cost of caring for a child in the community is £100,000-£200,500 annually

It is estimated that 12% of all available PICU beds are occupied by children who are medically fit and who could be cared for at home

(1) Murphy J (2008) Medically stable children in PICU: Better at home, *Paediatric Nursing*, vol 20, no 1 14-16

Example 2

Two children requiring Long term ventilation (2)

- One child was cared for on a Paediatric Intensive Care Unit for 12 months at a total cost of £630,388
- Once child was cared for on a High Dependency Unit for 12 months at a total cost of £301,888

Care could have been provided at home at a total cost of £161,174 per child

2) Noyes, J (2004) *Evaluation of Health and Social Care Provision for Ventilator-Dependent Children in the UK*. PhD thesis, University of York.

Example 3

Between 2002 and 2004 four children who sustained significant acquired brain injuries (ABI) required intensive rehabilitation in one PCT area. (3)

Although the children were treated in three different hospitals they were all transferred to a residential rehabilitation centre as no other option was available. Units such as these cost in excess of £220k per annum per child plus equipment costs. The children required between six months and 2 year stays. The subsequent transfer of the children's care to the community was not begun until they were ready for discharge and as such there was no overall coordination and reintegration was complicated and prolonged as there were minimal links between the unit and community provision. The cost to the PCT for these 4 children was £550,000 plus equipment costs.

In July 2005 a Community Matron for Children was appointed with one of her key targets being to case manage this group of children. Since that time there have been 8 children with significant ABIs. The management of these children included:

- Support and advice to the child and family
- Early liaison with the acute services – weekly attendance at neurology team meetings when they have a child with a significant ABI
- Communication across all agencies, providing early warning of child's need
- Co-ordination of multi-agency services
- Facilitation of creative solutions
- Design of packages, including identifying extra resources when needed
- Ongoing oversight of child's progress and care
- Identification of lead professional once Community Children's Matron is no longer providing this role

Once assessed the majority of the children were able to receive their care at home at a total cost of £65,000 a total saving to the PCT of £490,000

(3) Brombley K, (2008) Better at home? Benefits of case management for children with complex needs. *Paediatric Nursing*, vol 20, no 9 24-26

The family experience

Families have highlighted positive and negative experiences of having a child in hospital long-term. The financial impact on the family can also be tremendous. Loss of earnings, increased travel costs, car parking charges and increased child care costs for siblings are common issues for families who find themselves in this situation. Many report experiencing great financial hardship at a time when the health of their child is their main concern.

Example 1

Charley-Ann was admitted to her local hospital in June 2003, at the age of 22 months. She had been unwell for a couple of weeks but her parents became concerned when her condition rapidly deteriorated. Despite numerous tests and scans, Doctors were unable to make a definite diagnosis but suspected that she may have Tuberculosis.

Following her transfer to a large Children's Hospital, Charley-Ann's lung collapsed and she was moved to intensive care, given a tracheostomy and put on a ventilator. Despite attempts to wean her off, it became clear that Charley-Ann was going to remain on the ventilator for the long-term. Planning for Charley-Ann's discharge started in October 2003 but she was not able to return to home until 2007.

Charley-Ann's parents describe the discharge process as extremely drawn out with a large number of professionals, training and equipment to co-ordinate. The four years waiting for their daughter to return home presented many challenges for the whole family and in particular, her younger brother, who had to live with relatives for much of this time. With Charley-Ann now cared for at home by a team of trained carers and her parents, the family are able to reflect on the benefits of her being in a familiar environment with people that she knows and trusts.

Example 2

10 year old Emily was born with a Tracheo-Oesophageal Fistula (TOF), a rare congenital condition requiring emergency surgery immediately following birth. Since coming home from hospital at the age of three months, Emily has been re-admitted many times often with severe chest infections and has spent time in intensive care.

Two years ago Emily's parents were told that she was unlikely to survive and she was transferred to the local children's hospice. Despite the poor prognosis that she had been given Emily began to get stronger and was able to return home just three weeks later. Her parents believe that this timely discharge was solely due to the support they receive from the Star Project Community and Home Support Team. Despite the overwhelming amount of equipment and medication that Emily requires, the team were able to co-ordinate and manage all of this at home whilst training Emily's parents to care for her.

The Star Project Team, consisting of Nurses, Care Assistants and Play Specialists help to keep Emily at home even when she becomes unwell and this has in turn alleviated the stress on the whole family. They offer emotional as well as practical support and have helped Emily's younger brother to feel like a valuable part of his sister's care team.

"The Star Project team is a priceless gift and a lifeline and we feel privileged to be under their care. We wish all families could have this experience with an inspirational team, they have enhanced the quality of life for our children and our family and we are eternally grateful." (Emily's parents)

Supporting care at home – the role of Community Children’s Nurses

Every Child and young person has the right to expect care to be provided at home unless they need to be admitted to a hospital environment. Appropriate help and support from a children’s community nursing team should be available for parents/families to enable them to care for their child at home.

Community children’s nurses are a diverse workforce with a variety of models currently in existence. The model of provision provided has evolved to address the needs of children and young people locally. Community children’s nursing teams are able to provide:

- emergency care and triage, support for early discharge and assessment at home
- care and support for children and young people in the community with long term conditions, as well as those with complex health and palliative care needs

Community children’s nurses have the potential to reduce and prevent hospital admissions, as well as attendances at outpatient clinics. The role of the community children’s nurse encompasses acting as the child and family’s advocate.

Numerous government policy initiatives and studies of service provision have highlighted the importance of the community children’s nursing role, the shortfall in the number of community children’s nurses across the UK, as well as the need to increase funding for this service.

The Royal College of Nursing recommends that for an average sized district with a child population of 50,000 a minimum of 20 WTE community children’s nurses are required to provide a holistic community children’s nursing service in addition to any child specific continuing care investment.

The Royal College of Nursing has produced several position statements in relation to community children’s nursing. Copies can be found in this pack.

References

Department of Health (2004) *National Service Framework for Children, Young People and Maternity Services*, HMSO, London

Department of Health (2006) *Making it Better for Children and Young People. Clinical Case for Change*. Report by Dr Sheila Shribman, Clinical Director for Children, Young People and Maternity Services, HMSO, London

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Noyes J, Lewis M (2005) *From Hospital to Home, Guidance on discharge management and community support for children using long-term ventilation*, Barnardo's

