Service provision

Complex care packages: supporting seamless discharge for child and family

Nikki Stephens discusses a framework set up to smooth the transition from hospital to home for children with complex needs which could provide a benchmark for community teams

Navigating a discharge from hospital to home can be a protracted process fraught with difficulties for a child with complex care needs. Poorly co-ordinated planning prolongs the discharge process (Edwards et al 2004, Ludvigsen and Morrison 2003, Noyes 2002). Primary care trusts (PCTs) and hospitals do not seem to have established frameworks to help ensure a smooth transition from hospital to home for this group of children. Ludvigsen and Morrison (2003) suggest that a framework known to both the community and hospital settings would offer better co-ordination and overcome major barriers to timely discharge such as funding and housing issues, and recruitment of supporting staff (Jardine et al 1999, Noyes 2002). Lack of collaboration between services and issues of parental, medical and nursing responsibility also hinder the discharge process.

Complex care
Advances in medical technology have pushed the boundaries of life expectancy (Kirk 1999, Edwards et al 2004) and resulted in many children with complex care needs/technology dependence being cared for at home. Kirk and Glendinning (1999) define a child as technology-dependent if he or she is dependent on a technological device to sustain life or optimise health. Children requiring complex care are described as those who may not be technology-dependent but require jointly commissioned health, education and social services, ie they require greater resources than those available within individual services (Lenton et al 2004). Both these definitions are used as part of the referral criteria in our team to assess children with complex care needs/technology dependence requiring continuing care at home.

Over the last five to ten years a number of teams have been set up across the UK to respond to the demand for caring for children with complex care needs in the community. The complex care team within the community children’s nursing service of Islington PCT team evolved to embrace these challenges. Each primary nurse is responsible for a number of children’s care packages and is supported by the complex care and respite team co-ordinator, with additional support from a senior practitioner, nurse consultant and administrative staff.

The team provides overall co-ordination of the care package, planning and delivery of nursing care. Team activities include recruiting, training and assessing the competency of carers who work alongside the family for up to 24 hours a day.

The framework
Planning for any child to go home begins on admission to hospital (Charlesworth and McKenzie 1996), particularly if the child has complex care needs. The Department of Health (1996) and the Audit Commission (2003) reported that a quality service for children is only achievable by providing a ‘seamless web of care’. According to Heywood (2002), the main feature of a seamless service is a multi-professional team with no boundaries but with clear roles and responsibilities.

Central to a seamless discharge process is the child and family with the various services and professionals all working collaboratively towards a common goal: to ensure early planned discharge and continuing home care. To aid the smooth transition of children from hospital to home the team devised a discharge flowchart (Figure 1) which is discussed below.

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Care plans and planning
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Once a referral is made from the hospital to the community children’s nursing service a meeting of professionals is arranged. The suggested invitation list includes parents and all relevant professionals from the acute and community sector who will be involved with the child and family (Box 1). This should be initiated by hospital staff but they may have limited experience or knowledge of the process and management of such a meeting. Aims of the professional meeting include:

- introducing the multi-disciplinary team to each other and to the family
- developing an early understanding of the child’s underlying condition, i.e., the current nursing/medical/social needs and the anticipated level of home nursing and personal support
- developing an action plan of professional responsibilities and roles
- identifying a key worker for the family who will coordinate the case and be their contact/link
- establishing a funding pathway.

The meeting strengthens communication between professionals and enables the identification of potential obstacles to early discharge (Smith and Daughtrey 2000). A key worker should be identified at the outset of the referral process; our experience supports Bewley’s (2002) and Gatford’s (2004) view that the most appropriate person for this role is the complex care team co-ordinator who has the relevant knowledge and experience of local services. The co-ordinator also arranges a comprehensive nursing needs assessment.

A joint home assessment is completed with the complex care primary nurse and occupational therapist (OT). Ludvigsen and Morrison (2003), Noyes (2002) and Jardine et al (1999) have all highlighted that hospitalisation can be prolonged due to inadequate or inappropriate housing such as lack of accessibility, cramped conditions, damp interior, or the need of major adaptations such as hoists and lifts. Such challenges not only prolong the discharge process but also cause friction between parents and professionals. Parents need to be kept up to date at every point of the discharge process to minimise their frustration (Smith 2000).

Funding

It is important to establish funding for the care package as early as possible as this can be one of the biggest obstacles in the provision of ongoing care (Murphy 2001). The cost of these care packages (£150,000 to £250,000)
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£200,000 on average) can lead to disputes between health and social services which need to be overcome by organising joint funding between the two services (Edwards et al 2004). Once funding is approved the process of purchasing the relevant medical equipment, ordering supplies and recruiting staff can begin.

The Islington PCT employs healthcare assistants and nursery nurses, many of whom have no previous healthcare knowledge or experience, to provide support and care for the child and family at home. Comprehensive training is provided by children's nurses and allied health professionals and covers the specific healthcare needs of the child they will be caring for. There is a recognised training package, which is assessed and reviewed regularly to ensure it continues to meet the needs of the carers.

While the child is waiting for discharge, day release home can be supported by the complex care team. This helps parents gain control by empowering them and increasing their confidence in caring for the child at home. It will also alert the family and the team to the practicalities of caring for a child with complex care needs in the home setting.

Agreeing responsibilities

Responsibilities need to be negotiated and agreed between all parties. Arrangements must be made and agreement reached about which local hospital will provide direct access for admission if required, and a named hospital paediatrician identified. The responsibility for parental resuscitation training lies with the unit where the child is currently an inpatient. Islington PCT’s complex care team has responsibility for offering support, parent/child education, service co-ordination and recruitment and training of staff.

An understanding should be reached with parents concerning their responsibility when taking their child home, and the role of the health care assistants (carers) should be made clear, which is to help support the parents in the clinical care of their child. The child’s parents are responsible for making clinical decisions not covered by routine procedures and guidelines written for the health care assistants, with advice and support from the complex care team co-ordinator. For example, the decision to take the child to accident and emergency is made by the parents not the carers.

Following training, equipment purchases and so on, staff and parents set a final discharge-planning meeting to address final discharge points and provide an update on the child’s medical and nursing needs. An anticipated date for discharge should be negotiated and agreed with the child/young person, parents, hospital consultant and complex care team.

Conclusion

Smith and Daughtrey (2000) recommends that there should be a co-ordinated and reliable approach to discharge in preparing and setting up complex care packages for children/young people requiring technological and clinical care at home. This framework is a structure for the team to follow and has led to safe discharge home for many children. However, obstacles such as inadequate housing and insufficient funding still prolong discharge. Our team has benefited from this framework but we recommend that adequate funding should be allocated for all children with complex care needs who need continuing care at home.

The main feature of a seamless service is a multi-professional team with no boundaries but with clear roles and responsibilities.

Further reading


REFERENCES


Noyes J (2002) Barriers that delay children and young people who are dependent on mechanical ventilators from being discharged from hospital. Journal of Clinical Nursing. 11, 1, 2-11.