

# **Guidelines**

on the discharge from hospital  
of children and young people  
with high support needs



These guidelines are written to assist staff in tertiary and local hospitals as well as the commissioners and providers in Primary Care Trusts in planning the discharge of children with high support needs. The purpose is to set down a framework that staff may find useful when negotiating and planning discharge.

The children and young people covered in these guidelines are those with the highest support needs – those children requiring an extensive care package during both the day and night in order to maintain their optimal health. It will probably include children with the following conditions: children on long-term ventilation (LTV) or requiring long-term respiratory support, children with acquired brain injury, children with neurological-degenerative conditions, children with Epidermolysis Bullosa, children with unstable respiratory conditions and children with tracheostomies or who need nasopharyngeal suction as they cannot independently manage their secretions.

The guidelines were written by Jeanne Carlin, disability consultant, in consultation with staff from hospital and primary care trusts and national organisations working with children who have palliative care needs. The work was funded and supported by the Council for Disabled Children and the Department of Health.

# Six basic principles

## **1. Different environments**

The child or young person with high support needs is moving from an environment where he/she is cared for by health staff to an environment where health agencies will provide support to a family to enable them to care for their child.

## **2. Family life**

The support provided should enable the family to lead as 'normal a life' as possible and should support the child to do the things that other children do, such as go to school or early years services, enjoy leisure and other activities, and access their local community facilities.

## **3. Supporting parents to be parents**

Support should be offered in a way and at a level which ensures that parents are supported to be parents and take responsibility for their child in the same way as other parents do. This role should not be undermined or usurped by care staff.

## **4. Recognising the parents' needs**

Parents have a right to an 'adult' life, and where this involves going to work, other avenues used by all parents, such as working tax credits, paid child care etc. should be explored and used. It is the additional costs, due to the child's condition, which may form part of the support package.

## **5. A safe environment**

Support should be offered in a way which makes parents feel that it is 'safe' to have their child at home. Parents will need a 24 hour contact link and care pathway for times when they have concerns about their child.

## **6. Partnership and trust**

Planning discharge should be done in partnership with the family so that they develop a trust in the ability of the PCT to meet their needs flexibly.

# Planning the discharge process

- 1.** The planning process should start as early as possible – as soon as it is likely that the child will need a home care package. This may be apparent before the child is medically stable.
- 2.** Parents and other family members should be offered support to come to terms with their child's condition and prognosis as early as possible. This support should look at the emotional issues, for example, many parents are frightened that their children are going to die if they take them out of a hospital setting and this often acts as a barrier to an appropriately timed discharge. This type of support should be offered on an ongoing basis.
- 3.** Prior to the planning meetings and assessment, hospital staff should not discuss the level of support (number of hours) a family should expect as this sets unrealistic expectations and may set up a conflictual relationship between the parents and the Primary Care Trust (PCT). It is important that support is not referred to in terms of 'nursing care' as parents will expect carers to be registered nurses.
- 4.** There is a recognition that PCTs work differently and that this may create problems in terms of the hospitals knowing who to contact in order to start the process. PCTs can assist by clarifying who the lead person is in terms of commissioning support packages. PCTs should have a clear process outlining who is responsible for negotiating discharge, who should be involved in the assessments and attend meetings, and who should put together the package of support.
- 5.** Some children will move from a tertiary hospital straight home while others will move first to the local district general hospital or to the children's hospice service before going home. If the child is moving to either a local hospital or hospice service then the service needs to be involved in the planning from an early stage.
- 6.** The children's hospice service may form part of the package of care being offered to the child and family. Children's hospice services provide palliative care for children and young people with life-limiting conditions and their families. Delivered by a multi-disciplinary team and in partnership with other agencies, children's hospice services aim to meet the needs of both child and family – physical, emotional, social and spiritual – through a range of services delivered in the home (commonly termed 'hospice at home service') and/or in a purpose built building. The range of services offered includes 24-hour end of life care; support for the entire family (including siblings, grandparents and the extended family); 24-hour access to emergency care; and planned, specialist short break care.
- 7.** The child's support package should be based on an individual assessment of need – of both the child and the family. Blanket rules about particular conditions requiring set levels of support are unhelpful. Appropriate staff from both the hospital and the PCT should be involved in carrying out this assessment. This may involve other agencies, for example, housing or social services. The Children's Continuing Care guidance sets out a useful process and assessment tool, with a nominated health assessor to take the lead and coordinate the assessment information.
- 8.** The assessment should recognise that the child's needs are likely to change and that the child may make progress between the time of the first meeting and the time they are discharged.

- 9.** House adaptations and the provision of equipment often takes a long time and the process of undertaking this work should run alongside the other aspects of putting together the care package. There should be local arrangements outlining a clear process for reaching agreement regarding funding.
- 10.** If the child is school-going age, his/her educational needs should be considered. Links to the child's school and peers is important to create a sense of 'normality'. For pre-school children, involving local portage or pre-school services should be considered.
- 11.** The process of applying for and agreeing the funding of the support package should be clear and transparent. The Children's Continuing Care guidance sets out a clear decision making phase with timescales, which follows the assessment phase. This guidance states that disputes between agencies should not delay the provision of the care package and a protocol should make clear how funding will be provided pending the resolution of any dispute.
- 12.** The PCT needs to set realistic time frames in order to recruit, check and train staff to support the child. The arrangements to offer support vary considerably and the support may be offered through the PCT's in-house provider; through a team from the local hospital or through an external private provider. In future this support may be offered through an individual health budget, controlled by the family.
- 13.** The initial and ongoing training of support staff is an essential element of a support package. The PCT has a responsibility to ensure that the provider has appropriate skills, competencies and governance structures to support safe and effective care. The discharging hospital should support the PCT in meeting this responsibility.
- 14.** Support packages need to be sustainable and integrated into the child's care pathway. Sustainability of provision is as important as speed of discharge.
- 15.** Where there are disagreements between the family and the PCT over the support package, resolution at a local level should be attempted as early as possible. Families should be offered support through advocacy services. The Children's Continuing Care guidance recommends that disputes between the family and an organisation should be dealt with promptly through a local complaints procedure.
- 16.** There needs to be clarity as to who has the ultimate responsibility when the child is at home. In some areas an agreement or contract is drawn up between the family, PCT and discharging hospital.
- 17.** The support package should be reviewed on an agreed regular and ongoing basis (at least once a year). Parents should be made aware that packages of support are likely to increase and decrease as needs change.

These guidelines should be read in conjunction with the guidance issued by the Department of Health (2010) *National Framework for Children's Continuing Care*.

# Checklist



Is the child likely to need a home care support package?

Have the parents and other family members been offered support to come to terms with their child's condition and prognosis?

Has the commissioning lead for the relevant PCT been identified and contacted?

Is the commissioning lead for the PCT involved in the discharge planning process?

If the child is likely to have a staged discharge from a tertiary hospital via a district general hospital or a children's hospice service – are these organisations involved in the discharge planning process?

Are the appropriate hospital and PCT staff involved in an assessment of the continuing health care needs of the child and family?

Is a multiagency plan for discharge in place which includes other key agencies, for example:

- housing
- equipment
- education
- children's services.

Have realistic time frames been set in order to recruit and train the support staff?

Has the funding of the support plan been agreed?

Is there agreement regarding continuing responsibility for the child following discharge?

Is the support package sustainable?

Is there ongoing support available to the parents and family?

Has a date been set for a regular review of the support package?

# Useful websites and helplines

**ACT** UK-wide charity working to achieve the best possible quality of life and care for every child and young person who is not expected to reach adulthood.

<http://www.act.org.uk/> Helpline – 0845 1082201

**Aiming High for Disabled Children (AHDC):** Better support for families, launched in May 2007, is the transformation programme for disabled children's services. AHDC is jointly delivered by the DCSF and the Department of Health (DH). The website is kept updated with programme developments and examples of best practice.

<http://www.dcsf.gov.uk/ecm/ahdc>

**British Association of Community Child Health (BACCH)**

<http://www.bacch.org.uk/index.php>

**Children's Hospices UK**

<http://www.childhospice.org.uk/>

**Council for Disabled Children**

<http://www.ncb.org.uk/cdc>

**Department of Health**

<http://www.dh.gov.uk/en/Healthcare/Children/Disabledchildrenandyoungpeople/index.htm>

**Every Disabled Child Matters (EDCM)** health campaign

<http://www.ncb.org.uk/edcm/campaigns/health/downloadsandresources.aspx>

**Royal College of Nursing (RCN)**

<http://www.rcn.org.uk/>

RCN guidelines on managing children with health care needs, delegation of clinical procedures, training and accountability issues:

[http://www.rcn.org.uk/\\_\\_data/assets/pdf\\_file/0020/145640/Clinical\\_proceduresfinal08.pdf](http://www.rcn.org.uk/__data/assets/pdf_file/0020/145640/Clinical_proceduresfinal08.pdf)

**UK Children on Long Term Ventilation (LTV)**

<http://www.longtermventilation.nhs.uk/>

**The Council for Disabled Children (CDC)** is the umbrella body for the disabled children's sector in England, with links to the other UK nations. CDC works to influence national policy that impacts upon disabled children and children with Special Educational Needs (SEN) and their families. CDC is a semi-independent council of NCB, and has a staff team reporting to its director. The CDC Council is made up of a wide range of professional, voluntary and statutory organisations, including disabled young people and parent representatives. CDC's broad based membership and extensive networks of contacts provides a unique overview of current issues. It also enables us to promote collaborative and partnership working among organisations. CDC hosts the following networks;

- The National Parent Partnership Network
- The Special Educational Consortium
- The Transition Information Network
- The Every Disabled Child Matters Campaign
- Making Ourselves Heard

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[www.ncb.org.uk](http://www.ncb.org.uk)