Care Pathway For Discharge of Leeds Children With Complex Needs
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CarolineJames/MLB/Care Pathway - 26th Feb 2007
Introduction

This care pathway has been produced to facilitate a seamless, co-ordinated, multi-disciplinary approach to discharge of Leeds children with complex needs from hospital to the community. It is a generic pathway which maps the process from admission to discharge. It does not attempt to go into minute detail and some additional information to support the pathway is included in this document.

Research has shown that poor discharge planning can cause problems such as discharges that occur too soon, are delayed, are poorly managed from the patient/carer perspective, and are to unsafe environments (DOH, 2003).

The National Service Framework for Children Standard for Hospital Services (DOH, 2003) suggests that there should be:

‘... an agreed process to plan care, involving primary care, and all relevant hospital departments and other agencies, including education and social services, to provide a joined up, co-ordinated care package so that children, young people and their parents can access different services easily.’

It is hoped that this pathway will clarify the process and improve the experience of young people, children and their parent/carers in the transition from acute services into the community. The main focus is good communication, early identification of complexity, working in partnership with families and good multidisciplinary and multi-agency working.
From Admission to Referral

**Admission** - There are many sources of admission to hospital, acute admission through A/E, transfer from another hospital, the child newly diagnosed, admission through outpatients and planned admissions. It is good practice for all planned admissions to have a pre-admission assessment which will start to address any discharge requirements (DOH, 2003). It is important at this stage to involve partner agencies such as Education Leeds in planning for the child’s discharge.

**Previous Assessments** - Many children are already known to the service and on admission staff should access previous multi-disciplinary assessments such as the Integrated Needs Assessment (INA) (appendix one), or Early Support Programme (ESP) (appendix two). Some parent/carers may also carry an updated medical summary that documents the child’s medical history and current treatment. This valuable information reduces the need for parent/carers to constantly repeat the same information (identified in standard 3 & 6 of the NSF for children and Young People, DOH, 2004). It is good practice with all children to check whether previous assessments have been carried out, particularly the Common Assessment Framework (CAF) (appendix three).

**Reason for Admission** - Although many admissions are necessary and appropriate, consideration must be given to the reason for admission. Is the admission due to breakdown in the care package, poor care management or social care issues, consider if the plan of care is working. Any issues highlighted should be incorporated into the review of the plan of care.

**Communication** - The Leeds Children’s Nursing Team (LCNT)/ Neonatal Outreach Team (NOT) must be notified of any admission of a child / neonate with potential complex needs. Ideally this should be done within 24-48 hours of admission. If the child is a new child with potential long term needs a formal referral must be made to the team. Known children usually have a long list of professionals involved in their care, it is important that the key person co-ordinating the care is notified of the child’s admission by the admitting nurse, so that everyone involved in the care is informed that the child is in hospital. This includes informing the Community Paediatrician involved in the child’s care. This information can be obtained from the INA or ESP, specialist areas also have contact lists for the children accessing their service.
From Admission to Referral

**Specialist Pathways** – Some specialist areas have well developed pathways for example the acquired head injury pathway, long term ventilation pathway and the care programme approach used within mental health services. These pathways will continue to be used but should embrace the principles within this document.

**Early Identification of Complexity** – One of the key principles of good discharge planning is early identification of complexity (for definition see protocol in appendix eight) and intervention (Standard One, NSF for Children and Young People, DOH, 2004). It is often difficult to identify the stage at which a child may have longer term needs, however it is important that as soon as there is an indication, this is discussed with the family and a referral for assessment made. Too often identification and referral is left until there is certainty about the child’s longer term needs, and this can lead to a delay in discharge home. For children already known to the service, any changes in their condition or their plan of care must trigger a referral to their key professional to review their existing assessment. The senior ward nurse as well as medical staff are best placed to fulfil this role.

**Discussion with Family** – Standard two of the NSF for Children and Young People (DOH, 2004) emphasizes the need to provide up to date information and support to parent/carers. Any discussion with the family regarding their child’s condition needs to be a face to face discussion in privacy and should be handled with respect, honesty and sensitivity (ACT, 2004). Written information which supports the discussion should be given to the family (e.g. information on the condition, support for families, and information on the discharge planning process).

**Referral** – Within 24 hours of discussion with the family, a referral must be made to one of the services responsible for co-ordinating the discharge of children from hospital. A brief description of each service and their contact details are listed on the following pages. The majority of children 0-13 yrs, who are not known to services or who do not have an existing social worker will be referred to the Family Keyworker Service, for children aged 14-18 yrs the appropriate service for referral is the Transitions Team. It is the responsibility of the senior ward nurse to facilitate the referral.

**Referral to the Community Paediatrician**
A child with potential long term needs must be referred to the Community Paediatrician. It is the lead medical professional for the child who initiates the referral.
From Admission to Referral

Key Points

- It is good practice for planned admissions to have a pre admission assessment that starts to address discharge requirements.
- Good discharge planning starts as early as possible.
- On admission previous assessments and medical summaries need to be utilized.
- Good communication is essential and the key professional for the child must be contacted on admission.
- The Leeds Children’s Nurse Team / Neonatal Outreach Team must be notified of the child’s / neonate’s admission.
- Parent/carers are central to the discharge planning process.
- Early identification of complexity and referral for multi-disciplinary assessment is essential.
- There must be early referral to community paediatricians.

Summary of responsibilities

Checking for previous assessments – A/E nursing staff and admitting ward nurse
Reasons for admission – lead medical professional
Communication – admitting ward nurse
Early identification of complexity – lead medical professional, senior ward nurse
Discussion with family – lead medical professional
Referral to community paediatrician – lead medical professional
Main services co-ordinating discharge planning and completion of INA.

**Family Keyworker Team – Main service completing INA**
The Family Keyworkers are an integrated referral and assessment team working within social services. The team consists of specialist workers who aim to provide a ‘needs led’ proactive service for families. The team works with children and young people aged from 0-13 years, who live in Leeds and who have a complex health need and/or disability which significantly affect the child’s functioning. Anyone can make a referral to the team. The family must give consent for the referral to be made. This is the main team taking referrals for discharge planning for children who do not already have an allocated social worker.

Tel: 0113 2063479
Social work department, Seacroft Hospital, York Rd, Leeds. LS14 6UH

**The Leeds Interagency Transitions Team – Main service completing INA**
The Transitions Team work with young people aged 14-18 yrs who are Leeds residents and have a disability, impairment or a complex health need. Together with the young person and their parent/carers they plan for the future. They aim to ensure a smooth transition to adulthood. The team offers specialist assessment, advice and support. Anyone can refer to the service. The Transitions Team work closely with Social Services, Health, Education and a range of independent and voluntary agencies.

Tel: 0113 3951736
Hough Lane Centre, Hough Lane, Bramley, Leeds. LS13 3RD

**Regional Paediatric Specialist Team**
The Social Workers offer a comprehensive service to children, young people and their families who have been referred to the hospital for specialist treatment. The specialist areas covered are Oncology, Haematology and Haemophilia, Renal, Liver and Cystic Fibrosis. The team offers a high quality support service. Anyone can refer to the team.

Oncology, Haematology, Haemophilia; 0113 2064975  
Renal; 0113 2066636  
Liver; 0113 2064387  
Cystic Fibrosis; 0113 2066102

St James’ Hospital, Beckett Street, Leeds. LS9 7TF
Other teams which may lead discharge planning in specialist areas.

**The Neonatal Outreach Team**
The Neonatal Outreach Service provides on going support to babies and their families who require specialist nursing care when they go home from hospital for up to 6 weeks post discharge. They are based either at the LGI or St James’ Hospital on the Neonatal Units.

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<tr>
<th>LGI</th>
<th>SJUH</th>
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<tr>
<td>Sue Peak</td>
<td>Anne Wood</td>
</tr>
<tr>
<td>Debbie Woodward</td>
<td>Ann Towers</td>
</tr>
<tr>
<td>Gail Ellis</td>
<td>Louise Nettleton</td>
</tr>
<tr>
<td>Tel: 0113 3925148</td>
<td>0113 2065020</td>
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Andrea Mills, Discharge Planning Clerk, Peter Congdon Neonatal Unit, C floor, Clarendon Wing ext 25148

**The Children’s Nurse Specialist**
Many specialist services within the hospital have a Children’s Nurse Specialist (CNS) who provides ongoing support for children and their families. Children’s Nurse Specialists can be found in specialties such as cardiology, endocrinology, epilepsy, hepatology and nutrition. In some services specialist nurses will play a key role in advising on discharge planning.

Contact
CNS can be contacted through the main hospital switchboards
St James’ Hospital – 0113 2433144
Leeds General Infirmary – 0113 2432799

**The Long Term Ventilation Team**
This team is lead by a Children’s Nurse Specialist (CNS) who has specialist knowledge of conditions requiring ongoing assistance from a portable ventilator. The CNS will lead the discharge of children who require this level of support, from the Paediatric Intensive Care Unit to their own home, and provide ongoing support to community teams and families. Within this team there is a staff nurse and a group of trained carers who will provide consistent care, training and support to the child and family, thus enabling them to care for their child both in hospital and at home whilst awaiting discharge.

CNS: Sarah Cozens:  Tel: 0113 3923220 Mobile: 07899 988712
**Hospital Occupational Therapy**

This team is concerned with enabling children to participate more successfully in daily life. The focus is to assess and improve/develop occupational performance in self-care, leisure and educational tasks prior to discharge. Equipment and adaptation needs for home and education settings are identified and provision facilitated. Training for carers is provided on performance areas and the use of equipment. The Occupational Therapist may lead the discharge planning of a child who requires this level of service.

Tel: 0113 3926610 or Bleep 80 1026.
Child Therapy Department, A Floor, Clarendon Wing,
CDC, SJUH tel: 0113 2065839 Bleep 80 1243

**The Hospital Social Work Team**

This is the Child Health Assessment Team employed by Leeds Social Services based at 10 Clarendon Road. They provide the social work service to children and families at both hospitals. Their main function is to coordinate Initial and Core Assessments of children in need, particularly those children in need of protection. They take referrals directly from hospital staff and aim to respond within 4 hours. A duty social worker is available from Mon. to Fri. 9.00am to 12.30 and 1.30pm to 4.30pm. The duty service also provides general advice and information. Duty tel: ext. 26850.

Tel: 0113 392 6663
Child Health Assessment Team, 10 Clarendon Road, LS2 9NS

**Children’s Disability Team**

The Children’s Disability Team is a care management team of specialist social workers covering the city of Leeds. The team offers long term support to disabled children and their families following the initial referral and assessment by the Keyworker Team. The team works with children and young people up to the age of 18 who have a severe disability and complex needs. CDT social workers are responsible for ongoing assessment and the implementation, monitoring and review of care plans. They would also be the likely co-ordinators for discharge planning for children they are already working with. Staff are based at -

- White Rose SSD (for NW and NE) Tel: 3951965
- York Towers SSD (for E) Tel: 2143074
- St James Hospital SSD (for S) Tel: 2064316
- Hough Lane SSD (for W) Tel: 3951617
## Community Paediatricians

Children with potential long term needs should be referred to community paediatricians. There are community paediatricians covering the five areas of the city.

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<tr>
<td>East</td>
<td>Dr John Roper</td>
<td>Community Paediatrics SJUH</td>
<td>0113 2064327</td>
</tr>
<tr>
<td>N/East /East</td>
<td>Dr Sheila Puri</td>
<td>Community Paediatrics SJUH</td>
<td>0113 2064591</td>
</tr>
<tr>
<td>North West</td>
<td>Dr Sarah Lee</td>
<td>Belmont House, Belmont Grv</td>
<td>0113 3926100</td>
</tr>
<tr>
<td>West</td>
<td>Dr Arnab Seal</td>
<td>Belmont House, Belmont Grv</td>
<td>0113 3926100</td>
</tr>
<tr>
<td>South</td>
<td>Dr David Cundall</td>
<td>St Georges Centre Middleton</td>
<td>0113 3929848</td>
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<tr>
<td>South</td>
<td>Dr Gill Robinson</td>
<td>St Georges Centre Middleton</td>
<td>0113 3929848</td>
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From Referral to Discharge

**Working in Partnership with Families** – Parent/carers are central to the discharge planning process. Some parents will be ‘experts’ in their child’s care and some will be at the start of this process. Support should always be given to parent/carers as they encounter the many professionals that may be involved in their child’s care (DOH, 2004). Parents must be given information about the discharge planning process (appendix four).

**Multi-disciplinary Meeting** – Once the referral is made to the service coordinating the discharge or one of the assessment teams, they are responsible for arranging a multi-disciplinary meeting. This will be within two weeks of receiving the referral for new children, meetings for review of existing assessments for known children must be held sooner, as the discharge process is likely to be quicker. At the meeting the care coordinator and chair of the meetings are agreed. The care pathway outlines some of the services that may be invited to attend, this will depend on the child’s diagnosis and long term needs. Information on these services can be found at the end of this section. At the end of the meeting an action plan is formulated and dates for further meetings agreed. At follow up meetings the action plan is reviewed and a potential discharge date is agreed with parent carers. Guidance for discharge planning meetings is also included in appendix five.

**Training of Parent Carers** – It is important that parent carers are given the opportunity to learn how to carry out nursing tasks for their child as early as possible. The training given and competencies achieved must be documented. Parent carers need to feel completely confident in these tasks before they should be expected to do these at home. The progress will be reviewed at discharge planning meetings.

**Integrated Needs Assessment (INA)** – This is a specialist assessment for disabled children and children with a health condition. Its purpose is to provide all agencies with a core assessment, communication and information tool which provides a complete picture of a child’s needs. It aims to prevent parents having to repeat basic information about their and their child’s circumstances to different professionals. The INA should be completed in conjunction with the parent-carers assessment which ensures that agencies listen to parent carers and assess the help that they need to carry on caring for their child. Copies of these assessments can be found in appendix one. The completion of the INA is not a prerequisite for discharge.
Final Discharge Planning Meeting – This meeting is the last meeting prior to discharge home. There will be a final review of the action plan and agreement of the individual plan of care. A phased discharge may be part of the planning process and this must be identified in the plan.

Individual Plan of Care – This is an agreement about the care of the child. An example is medical oversight, some children will have more than one consultant but it may be the community paediatrician who will take the lead in caring for the child in the community. Sometimes it may be the consultant from Martin House who takes the lead, but it is also important to acknowledge the General Practitioner’s role. There may be specific arrangements to prevent the admission of a child to hospital in the event of an acute illness, and there may be guidelines regarding the appropriate treatment for a child. All these elements of the plan will need to be agreed before discharge. The principles of assessment, identification of need, and setting and reviewing goals should be embraced. The key person to review the plan of care needs to be agreed. Parent carers will be given a copy of the plan and ideally an updated medical summary prior to discharge.

Checklist – It is good practice to use discharge checklists to ensure that all elements are in place prior to discharge, this covers organising medications, drug charts, equipment, outpatient follow up, transport etc.

Ready for Discharge – At this point all arrangements are in place and the child is ready for discharge. However in the event of unforeseen circumstances which brings a change in the needs of the child, the planning would start again with the multidisciplinary meeting.

Discharge – If the discharge care pathway has been followed, the parent carers will be able to go home confident in the care of their child and clear about the plan of care for their child. The INA/ESP may be completed or in the process of completion. A contact sheet in the INA/ESP lists all professionals involved in the child’s care and their contact numbers. If the INA/ESP is not complete, the parents must have a completed contact list to take home.
From Referral to Discharge

Key Points

- Work in partnership with families
- The multi-disciplinary meeting will be held within two weeks of referral
- The chair of the meetings and care co-ordinator must be agreed at the first meeting
- An action plan will be formulated and reviewed in subsequent meetings
- The INA is started
- Training for parent carers is started, documented and reviewed
- A discharge date is agreed with parent carers
- The individual plan of care is agreed
- All elements of the plan of care are in place
- Final discharge planning meeting
- Relevant written information given to parent/carers
- Discharge

Summary of responsibilities

Arranging multidisciplinary meeting – service co-ordinating the discharge
Support to family – ward staff, service co-ordinating discharge
Training of Parent/carers – ward staff
Completing Integrated Needs Assessment – keyworker, transitions team, social worker
Individual plan of care – lead medical professional with the family
Checklist – nursing staff in conjunction with service co-ordinating discharge
Contact list – nursing staff in conjunction with service co-ordinating discharge
Support for Families

ParentCarer Action (PCA)
ParentCarer Action Leeds is a non-political, independent voluntary organisation that exists to support families of disabled children and young people. PCA advocate that disabled children and young people are first and foremost children, with all the rights, needs and aspirations of all children and young people. Parent/carers are experts on their children’s needs and they feel passionate about services and policies meeting those needs. PCA believe that parent/carer views and experience are vital to provide better services for disabled children and their families. PCA believe that families of disabled children can cope if they get the right support at the right time.
Tel: 0870 420 2355
Round Foundry Media Centre Foundry Street LEEDS LS11 5QP

Discharge Planning Meetings
Services to consider for discharge planning meetings

Leeds Continuing Health Care Policy for Children
This policy aims to provide additional support (nursing respite) to children who are cared for at home and have ongoing complex health needs. The policy identifies those children with the most extreme needs. Continuing care for children is jointly commissioned between the NHS and the Local Authority. No provision is available through continuing care other than that which is outlined in the policy. Referral to the service is via an Integrated Needs Assessment.

Contact:  Caroline James, Case Manager on 0113 3059391
Children’s Case Management, Oaktree House, 418 Oakwood Lane, LS8 3LG.

The Leeds Children’s Continuing Care Team (LCCCT)
The team works in partnership with the family to provide a child focused, family orientated service which aims to meet the families needs by providing nursing care and respite, to children 0 – 18 (up to 19th birthday) with complex health care needs, in the community setting. The children accessing this service are those who meet the Leeds Continuing Health Care Criteria for Children.

Contact:  Helen Hartley, Respite Co-ordinator on 0113 2771811
Hunslet Health Centre, 24 Church Street, LS10 2PT
Leeds Children’s Nursing Team (LCNT)
The team helps to support families/carers to care for children 0 -18 (up to 19th birthday) with nursing needs, predominantly to enable the child to remain at home whenever possible and where this is not possible, to ensure the smooth transition from home to hospital and hospital to home by working collaboratively with other professional and agencies to provide support, advice, knowledge and skills to empower the family.

Contact: Karen Eaton, Professional Lead/Team Lead on 0113 2723759
Bridge House, Balm Road, LS10 2TP

The Butterfly Team
The aim of the team is to support children 0 – 18 (up to 19th birthday) with life limiting/life threatening conditions and to help support parents and the wider family network to promote optimum quality family life within the home by providing a combination of both health and social care. The Butterfly Team and LCNT work side by side in providing care and support to these children and families.

Contact: Karen Eaton, Professional Lead/Team Lead on 0113 2723759
Bridge House, Balm Road, LS10 2TP

Hannah House Health Respite Unit
Hannah House is a purpose built respite unit which provides nursing respite for children 0 - 18 (up to 19th birthday) with complex health needs. It provides the family with a break from the stresses of caring 24 hours a day by putting children first in a ‘home from home’ environment where children feel secure and loved, are happy and can have fun. There are eligibility criteria for this service. Referral to the service is via an Integrated Needs Assessment.

Contact: Jo Dodd, Home Manager on 0113 2829173
Hannah House, Coppice Head, Rothwell, LS26 0DX
**Martin House**
Martin House provides family led care for children and young people with life limiting conditions. The care includes symptom control, emergency care, respite care, terminal care and bereavement support. Care can be provided at Martin House or in the home. Children who access Martin House must have a life limiting condition such as progressive disorders or malignancy. Referrals can be made directly to Martin House. Anyone can refer.

Tel: 01937 844836
Martin House, Grove Road, Clifford, West Yorkshire. LS23 6TX

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**Children’s Learning Disability Nurse Team**
This is a community team of registered specialist learning disability nurses who assess and develop action plans to meet a child’s needs. They work with children aged 0—5 years who have global developmental delay and 5-18 years who have a severe learning disability. They can provide advice and develop plans to address a range of behaviours such as sleep difficulties, toileting, behavioural difficulties, epilepsy management and puberty and sexuality advice.

Tel: 0113 295 4100
Parkside Health Centre 311 Dewsbury Road, Beeston, LS11 5LQ. Beeston

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**Leeds Community Children’s Physiotherapy service**
The Leeds Community Children’s Physiotherapy service is a city-wide team and is part of Children’s Services. The service addresses the needs of children with neurological and neuromuscular conditions resulting in long term physical disabilities from 0-19 yrs. (Except pre-school children in the North East and the East of the city who will be seen by the Child Development Centre at St James Hospital).

The Service aims to work in partnership with the child, family and other agencies to enable the child to maximize their physical potential. The Leeds Community Paediatric Physiotherapy service is managed by Helen Dowden.

Tel: 0113-3055307
St Mary’s Hospital Admin Block Greenhill Road Leeds LS12 3QE
SJUH – Regional Child Development Centre – 0113 2065836
**Occupational Therapy (OT)**
The focus of Occupational Therapy is to assess and improve/develop occupational performance in self care, leisure and educational tasks. OT's will assess a child's abilities and identify equipment and adaptation needs for home/school/nursery. Hospital OT's will liaise with their community colleagues during the discharge planning process as appropriate.

Contact
LGI – Child Therapy Department A Floor Clarendon Wing – 0113 3926610 or Bleep 80 1243
SJUH – Regional Child Development Centre – 0113 2065839
Community – St Mary’s Hospital 0113 3055149
Social services - 79 Roundhay Road 0113 3951888

**Speech and Language Therapy**
Speech and Language Therapists help children with speech, language and communication difficulties and / or feeding difficulties. Speech and Language Therapists will liaise with community colleagues during the discharge planning of a child.

Contact:
LGI – Child Therapy Department A Floor Clarendon Wing – 0113 3926610
SJUH – Regional Child Development Centre – 0113 2065838
Community – St Mary’s Hospital 0113 3055308

**Dietitian**
The dietitian is concerned with the nutritional status and growth of children with complex clinical conditions. There are hospital and community dieticians for children. The hospital dieticians should liaise with community colleagues during the discharge planning of a child. They will also liaise with GP’s, home care company and pharmacist re feed prescriptions. They will also have links with the LCNT and the Children’s Nutrition Nurse Specialist.

Contact:
LGI: 0113 3923507 SJUH: 0113 2065188
Community: St Mary’s Hospital 0113 3055144
General Practitioner (GP)
The General Practitioner should be informed about the child’s requirements and plans for discharge. They will need to know the key person who is coordinating the child’s care and their contact number. They should receive medical summaries and updates, some may attend discharge planning meetings and should be invited. The GP usually will keep the child’s prescription chart up to date and will need to have information on what prescriptions are necessary (medications, oxygen).
The child’s GP should be recorded on the INA contact sheet.

Health Visitor
Health Visitors are involved with promoting the health of children from 0-5 years and their families, part of which is delivering the child health surveillance programme. They also provide support to families and are a link to other resources in the community. Health Visitors are usually based in health centres or local children’s centres, some work geographically and some are attached to GP practices. Child Health at St Mary’s Hospital has information on all Health Visitors and will be able to tell you who the Health Visitor for the child is.

Contact: Child Health 0113 3055274

Child and Adolescent Mental Health Services (CAMHS)
The Child and Adolescent Mental Health Service (CAMHS) is provided for children and young people up to the age of 17. The service is delivered on a tiered basis, Tier 1- Primary care services such as those offered by GP’s, Health Visitors, School Nurses, etc. Tier 2 - Locality based early intervention services delivered by the 0-16 Teams, Tier 3 - Multi-disciplinary CAMHS Outpatient Teams, Tier 4 - Inpatient and Day Services. For information on any of the services and contact numbers:

Laraine Hudson – Clinical Services Manager
Tel: 0113 3055269
School Nurse
School nurses are specialist practitioners who work with school aged children from 4-18 yrs, to help them and their families to achieve optimum health. School nurses work with other agencies to promote the five outcomes in ‘Every Child Matters’. Every main stream school and SILC (Specialist Inclusive Learning Centres previously special schools) has a named nurse. School nurses are based in local health centres and clinics, except in SILC’s where they are based on site. To find information on a named school nurse contact:

Helen Hudson Tel: 0113 3055250
St Mary's Hospital, Greenhill Road, Armley, Leeds, West Yorkshire. LS12 3QE

Young Adult Team
This is a team who work with physically disabled young people, aged between 16 and 25, to help them achieve the lifestyle they want. Young adults can self refer or any other agency can refer to the team.
To be eligible for the service a young person must:
• Be between 16 and 25 years old
• Have a physical impairment
• Be living within the Leeds boundary
• Have a Leeds GP
Contact 0113 3055388
St Mary's Hospital, Greenhill Road, Armley, Leeds, West Yorkshire. LS12 3QE

Head Injury Team
The team works with clients and their carers/relatives who have experienced a traumatic brain injury within the past five years and demonstrate rehabilitation potential. Goals will be established aiming to increase independence and improving quality of life. Client’s progress will be reviewed regularly and goals adapted as needs change over time. This is a rehabilitation service, which means that input is time limited and dependent on clients making progress towards their goals.
Contact: 0113 3055387
St Mary’s Hospital, Greenhill Road, Armley, Leeds, West Yorkshire. LS12 3QE
**The Medical Rehousing Service**  
The Medical Rehousing Service is based within Neighbourhoods and Housing Department. We operate a Medical Priority scheme to assist families in need of rehousing when their present home is no longer suitable to meet their child’s health needs. We accept referrals direct from families or health professionals.

For information or advice on housing issues.  
Contact: -  
Medical Housing Team – 0113 2141807 or via email infomedical@leeds.gov.uk

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**Education Leeds**  
Health to Education Notification Forms (H-EN) are completed by health professionals to alert Education Leeds to children who have complex physical and medical conditions that would impact on their attendance at school. These are completed for pre school children and for school age children who have acquired injuries.

The Hospital Teaching Service operating in St James’ Hospital and the LGI works as appropriate with school age children who have been admitted to hospital and some day patients.

Educational services for children with complex physical or medical needs are provided by schools who are advised and supported by a commissioned service operated by the East SILC/John Jamieson School and called the Physical Difficulties and Medical Service (PD&M). The PD&M Service working with Education Leeds supports mainstream schools (and hence children and families) with the provision of necessary aids and equipment, adaptations to schools, the provision of care facilities and advice and training on care, safe movement and access to the curriculum etc.

The PD&M Service should be alerted to the needs of all Leeds’ children with physical difficulties or complex medical needs being discharged from hospital.

Contact  
PD&M Medical Service – John Chadwick, Ed Leeds 0113 395 1035 or East SILC 0113 293 0236  
Hospital Teaching Service – Penny Woodhead, East SILC 0113 293 0236
Appendix One

Integrated Needs Assessment
And
Parent Carers Assessment
Appendix Two

Early Support Programme
About the Early Support Programme

The Early Support Programme is the central government mechanism for achieving better co-ordinated, family-focused services for young disabled children and their families across England.

Early Support builds on existing good practice. It facilitates the achievement of objectives set by broader initiatives to integrate services, in partnership with families who use services and the many agencies that provide services for young children.

Core Standard 8 of the National Service Framework for Children, Young People and Maternity Services stipulates:

"Children and young people who are disabled or have complex health needs receive co-ordinated, high quality child and family-centred services, which are based on assessed needs, which promote social inclusion and where possible, enable them and their families to live ordinary lives."

Early Support facilitates service development to achieve this objective by well co-ordinated, multi-agency support that is family focused, flexible and which offers practical help underpinned by better information. The programme is particularly relevant for families who use a number of services provided by different agencies.

The Early Support Programme provides a range of materials which help professionals and families to achieve this objective.

- Early Support Family pack
- Early Support Information for parents booklets
- Early Support Professional guidance
- Early Support Service audit tool
- Early Support Monitoring protocol for deaf babies and children
- Early Support Developmental journal for babies and children with Down syndrome
- Early Support Developmental journal for babies and children with visual impairment

This information has been taken from the early support website: www.earliesupport.org.uk
Appendix Three

Common Assessment Framework

The Common Assessment Framework for children and young people (CAF) is a shared assessment tool used across agencies in England. It can help practitioners develop a shared understanding of a child’s needs, so they can be met more effectively. The CAF is an important tool for early intervention. It has been designed specifically to help practitioners assess needs at an earlier stage and then work with families, alongside other practitioners and agencies, to meet them.

The CAF is not for when you are concerned that a child may have been harmed or may be at risk of harm. In those circumstances you must follow the procedures established by your local safeguarding children board (LSCB) immediately.

We all want better lives for children. Most children do well, but some have important disadvantages that currently are only addressed when they become serious. Sometimes their parents know there is a problem but struggle to know how to get help. We want to identify these children earlier and help them before things reach crisis point. The most important way of doing this is for everyone whose job involves working with children and families to keep an eye out for their well-being, and be prepared to help if something is going wrong.

The CAF is one way to help you do this. It is a tool to identify unmet needs. It covers all needs, not just the needs that individual services are most interested in. Even if you are not trained to do a common assessment yourself, knowing about the CAF will help you recognise when it might help so that you can arrange for someone else to do the assessment. There is also an easy-to-use CAF pre-assessment checklist, which can be used by any practitioner at any time, to help decide whether there should be a common assessment.

www.ecm.gov.uk/caf
Appendix Four

Information for Parent Carers
Information for Parent/Carers

This information aims to help you understand the discharge planning process for your child. Parent/carers are central to the discharge planning process and you should be involved every step of the way.

When your child/baby has been admitted to the ward, staff will contact the Leeds Children’s Nursing Team (LCNT) / Neonatal Outreach Team to let them know your child/baby has been admitted.

If your child is already known to services, the ward will contact the key professional co-ordinating your child’s care to let them know of the admission. You can help by remembering to tell the ward staff the name of your child’s care co-ordinator and asking them to let the co-ordinator know that your child is in hospital.

It is important that any potential long term needs are identified early (the medical staff will talk to you about this), so that planning for your child to go home can start as soon as possible.

You will be referred to a service that will co-ordinate the discharge planning of your child so that everything can be put in place to enable you and your child/baby to go home with the right support. If you already have a professional co-ordinating the care s/he will review this support to ensure that it is still what you require.

There will be a meeting with all professionals that may be involved with your child’s care, this can sometimes be quite daunting at first, but will ensure that everyone works together to plan for your child’s discharge home. There may be a series of these meetings before your child is ready to go home.

If you need to learn how to do some nursing tasks for your child, the ward staff will help you to do this. You will need time to gain confidence in these skills and the staff are there to support you.

A potential discharge date will be agreed with you, although this may be revised during the discharge planning process. Before discharge an individual plan of care for your child should be agreed. This identifies professionals involved in your child’s care and the role that they will play, it also includes any guidelines or agreements about the care of your child.

Once you have been discharged home, it is useful to keep a separate copy of assessments, individual plan of care and any medical summaries, to bring into hospital with you should your child need to be admitted in the future. This will provide invaluable information on admission.
Care Pathway for Discharge of Leeds Children with Complex Needs
Parent/Carer Information

Admission to Ward/PICU/NNU

Leeds Children’s Nursing Service, Neonatal Outreach Team and Key Professional contacted

Early identification of possible long term needs or review of existing needs

Discussion with Family

Referral to service leading discharge and community paediatrician

Family informed of service leading discharge and named person

Multi-disciplinary Meeting with family and all professionals. Assessment started/ reviewed

Training of parent/carers

Discharge planning meetings to review progress and to set discharge date with parent/carers.

Final Discharge Planning Meeting

Individual Plan of Care agreed with family

Ready for discharge

Home
Appendix Five

Discharge Planning Meeting Guidelines
Guidelines for Discharge Planning Meetings

**Care Co-ordinator**
At the first meeting clarify who is co-ordinating the discharge process and the Integrated Needs Assessment.

**Chair**
At the first meeting identify who will chair the meetings, usually the person most involved with the child - e.g. key worker / discharge co-ordinator

**Introductions**
All present should provide name, speciality and contact details.

The person taking minutes should be identified, any apologies given and anything arising from previous minutes (if not first meeting) discussed.

**Agenda / Discussions**
A summary should be given from each speciality involved with the child, and any concerns or actions addressed at this time.

For example:
- Medical
- Nursing
- Therapies
- Social
- Housing
- Education
- Community Services
- Family

**Close and Action Plan**
Any Other Business should be discussed and the Action Plan reviewed before a date for the next meeting is set.

**Action Plan** -

There may need to be an action for each speciality, or just one. These should be set out clearly with the following details:
Name of responsible person / Action to be achieved / Date to be achieved by.
Appendix Six

Housing
Procedures for Children in Hospital Requiring Rehousing.

Application
• All families requesting rehousing must firstly register with Leeds Homes.
• If not registered the family can request an application form from their local Housing Office, One Stop Centre, Medical Housing Team, or on line at www.leeds.org.uk.
• The application form once registered will automatically send out an HO30 form with guidance notes (this is a self referral medical form). Once the form has been completed by the family this is returned to the Medical Housing Team for assessment for medical priority and a housing recommendation.
• If the child is in hospital the Children’s planned hospital discharge form can be used and faxed to the Medical Housing Team direct.
• If the family is already registered with Leeds Homes the Social Worker can refer to the MHT via the Children’s Planned Hospital discharge form. You can request the form via email at infomedical@leeds.gov.uk or by contacting the team direct on tel- 2141801.
• If the family’s reasons for move do not fall within the medical criteria for rehousing we will sign post the family to the appropriate department.
• All referrals via the hospital to the MHT are inputted onto the Medical database and Council computer within 2 working days of receiving the referral and allocated to Medical Visitor within 5 working days if the case falls within our criteria. (The medical criteria and guidance notes can also be requested via email at infomedical@leeds.gov.uk).
• A Medical Visitor will arrange to visit the family and the child in hospital within 5 working days of receiving the case.

Assessment
• A Medical Visitor will visit the child in hospital to assess the level of difficulty the child and family have coping in the dwelling.
• We will then discuss with the family housing options including adaptations to present dwelling if this is feasible.
• An advice and guidance leaflet will be given to the family at the visit to assist them to identify a suitable home advertised through the Choice Based Lettings scheme.
• If the child requires an adapted home and has an Occupational Therapist we will liaise with them on behalf of the family for a housing recommendation and viewing any suitable properties identified.
• Following the hospital visit we will write to the family and Social Worker within 2 working days with a decision on the level of priority awarded, priority limit expiry date and the housing recommendation.
• The Medical Visitor will then update the Councils medical data base and Councils computer system with the decision and the housing recommendation.
• If they require an adapted home and do not have an Occupational Therapist we will refer to the Occupational Therapists within the Children Housing Support Group.
• **Rehousing**
  - The Children’s Occupational Therapist to view any suitable offers of accommodation for suitability/adaptations.
  - The Children’s Housing Support Group will meet monthly to discuss and track children’s cases on their lists that have not been rehoused.
  - The Children Housing Support Group will also through its monthly meetings identify any changing needs of the families they are supporting and update the Councils computer system accordingly.
  - The MHT will liaise on a regular basis with the ALMO’s on outstanding children cases that need adapted homes.

**Priority extensions**
- Priorities will be extended to children requiring adapted properties when none have been advertised within the 3 month period.
- Requests for extensions can be made by the first choice housing office or direct to the MHT within 3 weeks of the expiry date.
- We will respond to all priority extensions within 2 working days and inform the family by letter of our decision within 2 working days.
- If the customer has been awarded priority on homeless or additional needs grounds by housing, but requires a housing recommendation for a disabled child the MHT team will provide a housing recommendation on behalf of the family.

**Glossary of terms**

**MHT (Medical Housing Team)**

**HO30 (Medical referral form)**

**Leeds Homes Register (LHR)** – a register of housing applications reflecting the needs of customers in the Leeds area. The register provides details of the Council’s register as well as the waiting list for 14 Registered Social Landlords with properties within the Leeds area.

**Leeds Homes membership number** – a unique reference number for housing application held on the Leeds Homes Register.

**Arms Length Managing Organisation (ALMO)** – an ALMO is a company set up by the council to manage and improve its housing stock. There are six ALMOs in Leeds which operate under a management agreement with the council.

**Belle Isle Tenant Management Organisation (BITMO)** – the BITMO is a tenant-controlled organisation which provides management and maintenance services to tenants under a management agreement with their landlord.

**Choice based lettings scheme (CBL)** – CBL is a way of giving customers greater choice about where they would like to be rehoused, by enabling them to make expressions of interest in advertised properties.
Planned Hospital Discharge (Children)

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<tr>
<th>Leeds Homes Register Number</th>
<th>…………………………………………………………………………………</th>
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If case not registered please complete the Leeds Homes application form and return with this form to Medical Housing Team. 100 Middleton Park Grove, Middleton, Leeds, LS10 4BG

Telephone; 0113 2141801, Fax: 0113 2141802

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<tr>
<th>Parents/ Guardian Name</th>
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<th>Home Telephone number</th>
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<tr>
<th>Childs full name</th>
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| Date of birth | ……………………… | Gender Male ☐ Female ☐ |
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<th>Preferred first language</th>
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| Name of hospital | ……………………… | Ward……………………………… |
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<th>Hospital Social Worker and contact number</th>
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Give details of any household members moving with the patient.

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<th>Age</th>
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<th>Relationship to patient</th>
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CarolineJames/MLB/Care Pathway - 28th Feb 2007
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<th><strong>Name</strong></th>
<th><strong>Age</strong></th>
<th><strong>Relationship to patient</strong></th>
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<tr>
<th><strong>Date admitted to hospital?</strong></th>
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<tr>
<th><strong>Medical Reason for admission to hospital?</strong></th>
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<th><strong>Is the above medical condition stable □</strong></th>
<th><strong>likely to improve □</strong></th>
<th><strong>likely to deteriorate □</strong></th>
<th><strong>don’t’ know □</strong></th>
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<tr>
<th><strong>Expected date of discharge from hospital?</strong></th>
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Please list any other health problems or impairments (Physical, mental, learning or sensory) which restricts or prevents the child from returning to live in their home.

Why does the child need to move from their present home? *(Please use the parents/guardians own words to complete this box)*
If the patient has a permanent address, but is unable to return to this address on discharge from hospital, please state reasons why, (Social Worker or Health Professional to complete this box).

Is the patient blocking a hospital bed? Yes ☐ No ☐

**Give details of present dwelling.**

House ☐ Maisonette ☐ Bungalow ☐ Flat ☐ Mobile Home ☐ Hostel ☐

Beds ☐ other ☐……………………………………………………………………………………………………

If living in a flat on which floor?…………………Is there a lift access Yes ☐ No ☐

Is it Council ? ☐ Owner occupied? ☐ Privately rented? ☐ Housing Assoc.? ☐ Other? (please specify) ……………………………………………………………………

How long have they lived at the present property?………………………………………..

Previous address (if moved within last 5 years)………………………………………..

…………………………………………………………………………………………………………………………

Access:  Level ☐ Ramp ☐ Lift Access ☐ Steps (No)……………………………………

Terrain:  Flat location ☐ Hilly Location ☐ Very Hilly location ☐

Is there a vehicular access to the property? Yes ☐ No ☐

If no, state the approximate distance from the property to the road ………………

Are there adjacent /hard standing parking facilities? Yes ☐ No

Do they have transport ? Please specify………………………………………………………………

Has the property had any adaptations? Yes ☐ No ☐

If yes, please specify:
………………………………………………………………………………………………………………………………

Is the applicant on a waiting list for any adaptations to be carried out on the property ? If yes please specify…………………………………………………………
Can the applicant manage stairs? Yes □ No □
Walk up slope? Yes □ No □
Walk on the level? Yes □ No □

WIC  Upstairs □ downstairs □ both levels □ Outside □

Do they use any aids to assist them with their mobility? Yes □ No □
If yes, please specify  e.g. walking stick, zimmer frame, etc.

Type of current heating in property, please specify……………………………………………………………………………………………………
………………………………………………………………………………………………………………………………………………………………………………

Do they have pets? Yes □ No □ If the answer is yes, please specify…………………………………………………………………………………………

Does the family receive any of the following benefits? If yes please tick the relevant boxes.

Disability living allowance, Mobility component  High rate □ Low rate □

Disability living allowance, Care component  High □ Medium □ Low □

Housing benefit  Yes □ No □

Other, please specify……………………………………………………………………………………………………
………………………………………………………………………………………………………………………………………………………………………………

Are you applying for any benefits on the patients behalf? If yes, please state……………………………………………………………………………………………………
………………………………………………………………………………………………………………………………………………………………………………

Has an Occupational Therapist carried out a home visit?
Yes □ No □ If Yes. Please give name and telephone number

………………………………………………………………………………………………………………………………………………………………………………

Occupational Therapists Housing Recommendation if known.
Declaration

To be signed by the parents/guardian

I understand that you may need to share personal information about me, and that it may be held and processed by Leeds City Council and Leeds Homes Register Social Landlords.

Name………………………..Signed……………………Dated………………

Please note if you give consent but want to put a limit on the type of personal information that is shared or who it is shared with, please write in the details below.

………………………………………………………………………………
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So that a planned discharge can be arranged, please list names and contact numbers of the persons who will be co-ordinating the patients discharge from hospital.

………………………………………………………………………………
………………………………………………………………………………
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………………………………………………………………………………

A Medical Visitor will be assigned to the patient to co-ordinate a planned discharge from hospital within 48 hours of receiving this form.
Appendix Seven

Education
HEALTH TO EDUCATION NOTIFICATION FORM
(H-EN FORM)

This form should be used by the Health Authority to notify Education Leeds of any children or young people who, throughout their school life, may require access to additional educational resources or support.

PLEASE COMPLETE ALL SECTIONS USING BLOCK CAPITALS AND BLACK INK

<table>
<thead>
<tr>
<th>CHILD DETAILS</th>
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<tbody>
<tr>
<td><strong>SURNAME:</strong> ……………………………………<strong>OTHER NAMES:</strong>…………………………………</td>
</tr>
<tr>
<td><strong>DATE OF BIRTH:</strong> ……………………………………<strong>MALE/FEMALE:</strong>…………………………………</td>
</tr>
<tr>
<td><strong>ADDRESS:</strong> …………………………………………………………………………………………</td>
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<tr>
<td><strong>POSTCODE:</strong> ……………………………………<strong>TEL:</strong> ……………………………………………</td>
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Is the child in the care of a Local Authority? **YES/NO**
If yes which one?
…………………………………………………………………………………………………
Name of any Early Years provision/Educational setting child is attending
……………………………………………………………………………………………………………
Does the Referrer need to be contacted before the home visit is made? **YES/NO**

<table>
<thead>
<tr>
<th>FAMILY/CARER’S DETAILS</th>
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<tbody>
<tr>
<td><strong>Mother’s/Carer’s name:</strong> ………………………………………………………………………</td>
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<tr>
<td><strong>Address (if different from above):</strong> …………………………………………………………………</td>
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<td><strong>Father’s/Carer’s name:</strong> ………………………………………………………………………</td>
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<tr>
<td><strong>Address (if different from above):</strong> …………………………………………………………………</td>
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<tr>
<td><strong>Preferred language at home:</strong> …………………… <strong>Other language/s:</strong> ……………………</td>
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<tr>
<td><strong>Interpreter required?</strong> <strong>YES/NO</strong></td>
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<tr>
<td><strong>Other person/s with parental responsibility</strong></td>
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<td><strong>Name:</strong> …………………………………………………………………………………………</td>
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<tr>
<td><strong>Relationship:</strong> ………………………………………………………………………………………</td>
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<td><strong>Address (if different):</strong> ………………………………………………………………………………………</td>
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| DETAILS OF ANY DIAGNOSED SYNDROME / CONDITION: |

**PROGNOSIS / DETAILS OF POSSIBLE LONG TERM EDUCATIONAL IMPLICATIONS**
### AREA/S OF NEED
*Please provide details where relevant about the developmental or medical concerns that may have educational implications*

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<tr>
<th>Area</th>
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<tbody>
<tr>
<td>Cognition and Learning</td>
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<tr>
<td>Vision</td>
</tr>
<tr>
<td>Hearing</td>
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<tr>
<td>Physical</td>
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<tr>
<td>Communication and Interaction – Expression, comprehension or pronunciation</td>
</tr>
<tr>
<td>Communication and Interaction – Pragmatic difficulties</td>
</tr>
<tr>
<td>Behaviour</td>
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<tr>
<td>Medical/Nursing</td>
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**Name/s, designation/s and contact details of the professionals who are currently involved with the child**

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<thead>
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<th>Name/s, designation/s and contact details of the professionals who are currently involved with the child</th>
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**Family agree to professionals being contacted**

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<th>Family agree to professionals being contacted</th>
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<tr>
<td>YES/NO</td>
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</table>
DECLARATION BY HEALTH PROFESSIONAL
Parents/carers have been given a copy of this form.

Name of health professional making this notification

Designation: ........................................ Signature: ........................................

Contact Address: .................................................................

Tel: .......................................................... Date: ........................................

Data Protection Act 1998
The Data Protection Act 1998 requires that the health professional informs you why we need to share information about your child. Powers under the Education Act (Section 332) require the local health and education authorities to share this information if, in the opinion of the health authority, your child has special educational needs (SEN). This is for the purposes of ensuring that your child receives adequate SEN support throughout his or her educational career. As part of this process, the information may be shared with other Leeds City Council Services e.g. professionals and services. The information will only be used by Education Leeds in connection with education services. We will comply fully with our obligations under the Data Protection Act 1998 and acknowledge your rights under this.

Please sign to acknowledge you understand the above statement

Signed* ....................................................... Date ........................................

Name .................................................................

*PARENTS/CARERS SIGNATURE REQUIRED

PLEASE RETURN THIS FORM TO:
Senior Responsible Officer
Psychology and Assessment Service
The Blenheim Centre
Crowther Place
Leeds

LS6 2ST
Tel: 0113 3951030 / 0113 3951033
Fax: 0113 3951099

Version 7 2/11/05

CarolineJames/MLB/Care Pathway -28th Feb 2007
“Meeting your child’s individual needs”.

This leaflet will have been given to you by a health professional because your child may have special educational needs and may need additional resources in school.

**Working Together**

The person who gave you this leaflet will have asked your permission to fill in a Health to Education Notification Form (H-EN Form) to inform Education Leeds about your child. You will be given a copy of this form to let you know what has been written about your child.

**Education Leeds**

Education Leeds is the organisation responsible for schools, school nurseries and specialist educational provision in Leeds.

Education Leeds is committed to supporting children who may need additional help with their learning. There is a range of specialist services available to provide this support.

**Health to Education Notification Form (H-EN FORM)**

When Education Leeds receives the H-EN Form from Health about your child, they will want to offer a service that meets your child’s particular needs. The person who will contact you about the services available is called the Responsible Officer.

**Next Steps**

Within four weeks of Education Leeds receiving the H-EN Form, you will get a letter from one of the Responsible Officers telling you who will be the named contact person for you and your child.

If you have any questions or concerns before this, please contact the Senior
Appendix Eight

Protocol for Discharge of Leeds Children with Complex Needs
# Protocol for Discharge of Leeds Children with Complex Needs

<table>
<thead>
<tr>
<th>Author</th>
<th>Caroline James – Service Development Manager for Children with Complex Needs.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Corporate Lead</td>
<td>Sarah Sinclair – Director of Planning and Commissioning for Children and Maternity Services.</td>
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</table>
Protocol for Discharge of Leeds Children with Complex Needs

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1.0 Purpose Page 3
2.0 Scope Page 3
3.0 Why is a discharge protocol necessary Page 3
4.0 Principles Page 3
5.0 Definition of Complex Need Page 4
6.0 Pre-admission and Admission Page 4
7.0 Planning Process and Responsibility Page 4
8.0 Dissemination and Implementation Page 6
9.0 Evaluation and Review Page 6

Appendix one: Care Pathway for Discharge of Leeds Children with Complex Needs
Appendix two: Information for Parents
Appendix three: Long Term Ventilation Discharge Care Pathway
Appendix four: H-EN Form
Protocol for Discharge of Leeds Children with Complex Needs

1.0 Purpose

This purpose of this protocol is to facilitate a seamless, coordinated, multi-disciplinary, multi-agency, approach to discharge of Leeds children with complex needs from hospital in to the community. This protocol is a joint protocol between the Leeds Primary Care Trust and The Leeds Teaching Hospitals Trust.

2.0 Scope

This protocol sets out the process for those involved in the discharge of children with complex needs from hospital to a community setting. This protocol relates to children registered with a Leeds GP or resident within the Leeds boundary but not registered with a GP, and supports the care pathway for discharge of children with complex needs (appendix one).

3.0 Why is a discharge protocol necessary?

‘Getting the right start: National Service Framework for Children, Standard for Hospital Services’ (DOH, 2003), states that;

For children and young people requiring more than just the simplest of care, there should be an agreed process to plan care, involving primary care, and all relevant hospital departments and other agencies, including education and social services, to provide a joined-up, co-ordinated care package so that children, young people and their parents can access different services easily.’

Research has shown that poor discharge planning can cause problems such as discharges that occur too soon, are delayed, are poorly managed from the patient/carer perspective and are to unsafe environments (DOH, 2003). Development of a discharge protocol aims to prevent the problems arising from poor discharge planning by setting out the discharge process and highlighting key principles essential to good discharge planning.

4.0 This protocol embraces the following principles

- Working in partnership with the child and parent/carers at all stages in the process, recognising that some parents will already be ‘experts’ in their child’s care and others are just at the beginning of the journey.
- Agencies working in close collaboration to manage all aspects of the discharge process.
- Discharge planning starts at the earliest opportunity.
- Good communication is essential to the process.
- Equity and accessibility regardless of race, gender or background.
5.0 **Definition of Complex Need**

For the purpose of this protocol ‘a child with complex needs’ is defined as a child whose ongoing care and support requires input from more than one agency, or from more than one group of professionals where communication will be assisted by robust discharge arrangements.

6.0 **Pre-admission and Admission**

6.1 Discharge planning must commence as early as possible in the course of the admission. For planned admissions pre admission assessments need to start to address discharge requirements.

6.2 On admission consideration must be given as to whether the child has had a previous Common Assessment Framework (CAF), Integrated Needs Assessment (INA) or Early Support Programme (ESP). This information may provide valuable information about the child and the professionals involved in his/her care.

6.3 For children known to services, the admitting nurse must contact the key professional co-ordinating the child’s care (e.g. social worker, keyworker, community nurse) to inform them of the child’s admission. This information can be found in the INA/CAF/ESP, or from the parent/carer.

6.4 It is then the key professional’s responsibility to inform all other services involved in the child’s care of the child’s admission, ensuring that the community paediatrician is informed.

6.5 The Leeds Children’s Nursing Team / Neonatal Outreach Team need to be informed of all children/neonates admitted with complex needs, and where appropriate referred to the service.

7.0 **Planning Process and Responsibility**

7.1 Key to the discharge process is early identification of complexity, this responsibility lies with the senior ward nurse in liaison with medical staff.

7.2 Following discussion with the family, a referral will be made to the appropriate service to update/complete an INA/ESP and to arrange a multidisciplinary meeting. For the majority of children the appropriate service is the Family Keyworker (Team 0-13 yrs), or the
Transitions Team (14-18 yrs). Specialist areas may have their own referral arrangements. The process of identification of complexity and discussion with the family to referral to the appropriate service to co-ordinate discharge must happen within 24 hours. It is the senior ward nurse’s responsibility to initiate the referral.

7.3 Once the referral is made to the service co-ordinating the discharge or to one of the assessment teams, they are responsible for arranging a multidisciplinary meeting within two weeks of receiving the referral. Meetings for review of existing assessments for known children must be held as soon as possible after admission, to enable the care plan to be reviewed before discharge.

7.4 It is the lead medical professional’s responsibility to make a referral to the relevant community paediatrician. This must be done as soon as it has been identified that the child will have complex needs and after discussion with the family.

7.5 A referral must be made to Education Leeds via a Health to Education Notification Form (H-EN) (appendix four)

7.6 Discharge planning must always be in partnership with parent/carers. Some parent/carers will already be ‘experts’ in their child’s care, others will need more support during this process. Parent/carers can be overwhelmed by the number of professionals involved in multidisciplinary meetings, they must be fully prepared by the person co-ordinating the discharge prior to the meeting.

7.7 It is good practice for Parent Carers to be given written information on the discharge planning process (appendix two).

7.8 At the first multidisciplinary meeting the care co-ordinator and the chair of the meeting must be agreed. The INA will be started or reviewed and an action plan agreed.

7.9 Parent/Carers and all professionals who are involved in the child’s care or planning for the child’s care will be invited to the multidisciplinary meeting. This includes services from other agencies e.g. Education, Social Services and Housing. Interpretation services must be provided as required.

7.10 Further discharge planning meetings will be held to review progress, set a potential discharge date and to update the action
7.11 The discharge date must be planned for a date agreed with the parent carer, and which takes into account support services available.

7.12 Training for the parent/carer in the child’s nursing needs must start as soon as possible so that they can be confident in these tasks before the child is discharged home. Ward staff are responsible for training the child’s parents/main carers whilst the child is on the ward, the community nurse team are responsible for providing training in the community. Children who require long term ventilation have separate arrangements according to the long term ventilation discharge pathway (appendix three). Training given and skills demonstrated and practiced must be documented.

7.13 Agreement of the Individual plan of care is vital by the final discharge planning meeting. This plan should outline who is involved with the child’s care and who is the lead medical professional. Any agreements for readmission or preventing admission should be made clear as well as any guidelines for treatment.

7.14 The final discharge planning meeting ensures that all elements of the child’s care in the community is in place. Some services may use a discharge checklist to ensure that all aspects of the discharge have been addressed, e.g. transport, medication, outpatient appointments etc.

7.15 The ward nurse caring for the child should ensure that the Parent/carer have copies of all plans, guidelines and assessments, they must have written information with contact details of key professionals involved in their child's care. Ideally the parent/carer should have an updated medical summary which outlines the child’s medical history and current treatment so that this information can be shared when necessary. Copies of clinic letters should be sent to parent carers to ensure an up to date record of care is maintained.

8.0 Dissemination and Implementation

The protocol will be disseminated with the information supporting the care pathway and will be able to be accessed on the Leeds Health Pathways. The protocol will be distributed following approval, to all ward areas and there will be a programme of localised training for staff. This will be provided by the Case Manager for Children’s Continuing Care, who will also be responsible for evaluating and updating the pathway.
9.0 **Evaluation and Review of Care Pathway and Protocol**

The care pathway and protocol should be evaluated and reviewed after a period of one year from dissemination and implementation. The evaluation will be in the form of an audit undertaken by the Case Manager for Children’s Continuing Care.
Care Pathway for Discharge of Leeds Children with Complex Care Needs

**Admission**
- Consider why admitted
- Is the individual plan of care working?
- Child should already have Integrated Needs Assessment/ESP Blue Box

**PICU/NNU Wards**
- Early identification of complexity or possibility of long term needs
- Discuss with family

**Referral**
- Referral to Education Levels
- Referral to Family
- Referral to community paediatrician

**Main Services Co-ordinating Discharge Completing INA**
- Family Keyworker Team 0-13 yrs
- Transitions Team 14-18 yrs

**Other Teams which may lead discharge planning in specialist areas**
- Specialist Social Worker
- Hospital Social Work Team
- Child's Allocated Social Worker
- Children’s Nurse Specialist
- Neonatal Outreach Team
- Hospital Occupational Therapy

**Multidisciplinary Team - (see supporting information)**
- Parents
- Case Manager/Continuing Care
- Leeds Children’s Nurse Team
- Respite Coordinator
- Martin House
- Hannah House
- Occupational Therapy (Hosp/Comm, SS)
- Physiotherapy (Hosp/Comm)
- Dietitian (Hosp/Comm)
- Speech and Language Therapy
- General Practitioner
- Hospital Consultant
- Community Paediatrician
- Children's Nurse Specialist
- Housing
- Education/School
- Ward Nurse/Sister
- Young Adult Team
- Head Injury Team
- Children with Learning Disabilities Nurse
- CAMHS
- Health Visitor
- School Nurse
- Interpreting services

**Multidisciplinary Meeting**
- Agreement of care coordinator and chair of the meetings
- Formulation of action plan
- New or update of Integrated Needs Assessment/ESP and Parent Carer Assessment started

**Discharge Planning Meetings**
- Review progress and work towards potential discharge date agreed with parent/carer
- Action plan updated

**Final Discharge Planning Meeting**
- Final review of action plan
- Agreement of individual plan of care prior to discharge

**Community**

**Read for Discharge**
Information for Parent/Carers

This information aims to help you understand the discharge planning process for your child. Parent/carers are central to the discharge planning process and you should be involved every step of the way.

When your child/baby has been admitted the ward, staff will contact the Leeds Children’s Nursing Team (LCNT) / Neonatal Outreach Team to let them know your child/baby has been admitted. If your child is already known to services, the ward will contact the key professional co-ordinating your child’s care to let them know of the admission.

It is important that any potential long term needs are identified early (the medical staff will talk to you about this), so that planning for your child to go home can start as soon as possible.

You will be referred to a service that will co-ordinate the discharge planning of your child so that all services can be put in place to enable you and your child/baby to go home with the right support. If you already have a professional co-ordinating the care s/he will review this support to ensure that it is still what you require.

There will be a meeting with all professionals that may be involved with your child’s care, this can sometimes be quite daunting at first, but will ensure that everyone works together to plan for your child’s discharge home. There may be a series of these meetings before your child is ready to go home.

If you need to learn how to do some nursing tasks for your child, the ward staff will help you to do this. You will need time to gain confidence in these skills and the staff are there to support you.

A potential discharge date will be agreed with you, although this may be revised during the discharge planning process. Before discharge an individual plan of care for your child should be agreed. This identifies professionals involved in your child’s care and the role that they will play, it also includes any guidelines or agreements about the care of your child.

Once you have been discharged home, it is useful to keep a separate copy of assessments, individual plan of care and any medical summaries, to bring into hospital with you should your child need to be admitted in the future. This will provide invaluable information on admission.
Care Pathway for Discharge of Leeds Children with Complex Needs

Parent/Carer Information

- Admission to Ward/PICU/NNU
- Early identification of possible long term needs or review of existing needs
- Discussion with Family
- Referral to service leading discharge and community paediatrician
- Family informed of service leading discharge and named person
- Multi-disciplinary Meeting with family and all professionals. Assessment started/ reviewed
- Training of parent/carers
- Discharge planning meetings to review progress and to set discharge date with parent/carers.
- Final Discharge Planning Meeting
- Individual Plan of Care agreed with family
- Ready for discharge
- Home
## Long Term Ventilation
### Discharge Care Pathway

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<thead>
<tr>
<th>Key Area</th>
<th>Expected Week</th>
<th>Date Completed</th>
<th>Actual Week</th>
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<tbody>
<tr>
<td>Referral to Children’s LTV Nurse Specialist.</td>
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<tr>
<td>Meeting with family and child to discuss LTV / home ventilation.</td>
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<tr>
<td>Initiation of Domiciliary ventilation</td>
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<tr>
<td>LTV Nurse establish key personnel in discharge planning.</td>
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<td>Home assessment community OT / LTV Nurse Specialist</td>
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<tr>
<td>Integrated Needs Assessment, social worker/ LTV nurse specialist /community team (if available).</td>
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<tr>
<td>Referral to housing if applicable.</td>
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<tr>
<td>1&lt;sup&gt;st&lt;/sup&gt; Discharge planning meeting.</td>
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<td>17</td>
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<tr>
<td>Educational links identified (referral made where appropriate).</td>
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<tr>
<td>O&lt;sub&gt;2&lt;/sub&gt; concentrator delivered to home.</td>
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<td>18</td>
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<tr>
<td>1&lt;sup&gt;st&lt;/sup&gt; visit home with LTV Team if medically stable (day).</td>
<td>18</td>
<td>18</td>
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<tr>
<td>Draft business case/SLA/protocols of care.</td>
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<td>20</td>
<td>21</td>
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<td>2&lt;sup&gt;nd&lt;/sup&gt; Discharge planning meeting.</td>
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<tr>
<td>Equipment delivered to home.</td>
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<tr>
<td>Development of business case.</td>
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<tr>
<td>Housing adaptations (bed, hoist), access / doorway / basic adaptations.</td>
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<tr>
<td>Home visits arranged weekly (if medically stable) overnight.</td>
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<td>Service level agreement signed.</td>
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<td>Protocols of care agreed / treatment guidelines drawn up.</td>
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<td>Discharge home or recharging of LTV carers</td>
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### FOLLOW UP PLAN

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<td>3-6 mths</td>
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HEALTH TO EDUCATION NOTIFICATION FORM
(H-EN FORM)

This form should be used by the Health Authority to notify Education Leeds of any children or young people who, throughout their school life, may require access to additional educational resources or support.

**PLEASE COMPLETE ALL SECTIONS USING BLOCK CAPITALS AND BLACK INK**

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<td><strong>DATE OF BIRTH:</strong> ............................................. <strong>MALE/FEMALE:</strong> ...........................................</td>
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<tr>
<td><strong>ADDRESS:</strong> ...............................................................................................................................</td>
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<td><strong>POSTCODE:</strong> .......................................................... <strong>TEL:</strong> ...............................................................</td>
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Is the child in the care of a Local Authority?  **YES/NO**
If yes which one?
........................................................................................................................................................................

Name of any Early Years provision/Educational setting child is attending
........................................................................................................................................................................

Does the Referrer need to be contacted before the home visit is made?  **YES/NO**

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<tr>
<td><strong>Father’s/Carer’s name</strong> ..................................................</td>
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<tr>
<td><strong>Address (if different from above)</strong> ...............................................................</td>
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Preferred language at home .................................. Other language/s ..................................
Interpreter required?  **YES/NO**

Other person/s with parental responsibility
Name.......................................................... Relationship ............................................

Address (if different)...............................................................................................................................

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<th>DETAILS OF ANY DIAGNOSED SYNDROME / CONDITION:</th>
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<tr>
<td><strong>PROGNOSIS / DETAILS OF POSSIBLE LONG TERM EDUCATIONAL IMPLICATIONS</strong></td>
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## AREA/S OF NEED

*Please provide details where relevant about the developmental or medical concerns that may have educational implications*

<table>
<thead>
<tr>
<th>Area/Health Professional</th>
<th>Details</th>
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<tbody>
<tr>
<td><strong>Cognition and Learning</strong></td>
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<td><strong>Vision</strong></td>
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<td><strong>Hearing</strong></td>
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<tr>
<td><strong>Physical</strong></td>
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<tr>
<td><strong>Communication and Interaction – Expression, comprehension or pronunciation</strong></td>
<td></td>
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<tr>
<td><strong>Communication and Interaction – Pragmatic difficulties</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Behaviour</strong></td>
<td></td>
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<tr>
<td><strong>Medical/Nursing</strong></td>
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</table>

**Name/s, designation/s and contact details of the professionals who are currently involved with the child**

……………………………………………………………………………………………………………………
……………………………………………………………………………………………………………………
……………………………………………………………………………………………………………………

**Family agree to professionals being contacted**

YES/NO

**DECLARATION BY HEALTH PROFESSIONAL**
Parents/carers have been given a copy of this form.

**Name of health professional making this notification**

........................................................................................................................................

**Designation:** .................................................. **Signature:** ........................................

**Contact Address:** ........................................................................................................

**Tel:** ..................................................  
**Date:** ..................................................

**Data Protection Act 1998**
The Data Protection Act 1998 requires that the health professional informs you why we need to share information about your child. Powers under the Education Act (Section 332) require the local health and education authorities to share this information if, in the opinion of the health authority, your child has special educational needs (SEN). This is for the purposes of ensuring that your child receives adequate SEN support throughout his or her educational career. As part of this process, the information may be shared with other Leeds City Council Services e.g. professionals and services. The information will only be used by Education Leeds in connection with education services. We will comply fully with our obligations under the Data Protection Act 1998 and acknowledge your rights under this.

Please sign to acknowledge you understand the above statement

**Signed*** ..........................................................  **Date** ........................................

**Name** ..........................................................

*PARENTS/CARERS SIGNATURE REQUIRED

**PLEASE RETURN THIS FORM TO:**
Senior Responsible Officer  
Psychology and Assessment Service  
The Blenheim Centre  
Crowther Place  
Leeds  

**LS6 2ST**
Tel: 0113 3951030 / 0113 3951033  
Fax: 0113 3951099  

Version 7 2/11/05
LEAFLET 1 – INTRODUCTION TO EDUCATION LEEDS

“Meeting your child’s individual needs”.

This leaflet will have been given to you by a health professional because your child may have special educational needs and may need additional resources in school.

Working Together

The person who gave you this leaflet will have asked your permission to fill in a Health to Education Notification Form (H-EN Form) to inform Education Leeds about your child. You will be given a copy of this form to let you know what has been written about your child.

Education Leeds

Education Leeds is the organisation responsible for schools, school nurseries and specialist educational provision in Leeds.

Education Leeds is committed to supporting children who may need additional help with their learning. There is a range of specialist services available to provide this support.

Health to Education Notification Form (H-EN FORM)

When Education Leeds receives the H-EN Form from Health about your child, they will want to offer a service that meets your child’s particular needs. The person who will contact you about the services available is called the Responsible Officer.

Contact the Senior
Acknowledgements

This care pathway has built on previous work by Barbara Shaw (Team Manager Social Services) and Gill Lazonby (Children’s Nurse Specialist) on the Children’s Complex Discharge Planning Project (2001), and work led by Doreen Escolme (Clinical Services Manager), on ‘Care Pathway – Children with Complex Discharge and Ongoing Needs’ (2005).

The following people contributed or were involved with the development of the care pathway:

- Caroline James Service Development Manager Children with Complex Needs
- Steve Lister ParentCarer Action
- Ann Salter ParentCarer Action
- Doreen Escolme Clinical Services Manager Children’s Community Nursing
- Karen Eaton Professional Lead Leeds Children’s Nursing Team
- Helen Hartley Respite Co-ordinator Children’s Continuing Care Team
- Jill Asbury Matron Children’s Medical Services
- Alison Conchie Matron Paediatric Critical Care Services
- Siobhan Conlin Senior Sister Ward 51/52
- Yvette Barlett Matron Neonatal Services
- Anne Wood Neonatal Outreach Team
- Jo Dodd Home Manager, Hannah House, Health Respite Unit
- Sarah Cozens Long Term Ventilation Nurse Specialist
- Gill Lazonby Specialist Nutrition Nurse
- Barbara Shaw Social Work Manager, Family Keyworker Service
- Meryll Wilford Children with Disabilities Team Manager
- Linda Randall Transitions Team Manager
- John Blythman Transitions Team
- Keith Riach Social Services Team Manager
- Judith Kahn Service Delivery Manager (Health and Disability) Social Services
- Julie Bringloe Specialist Social Work Team
- Jessica Mudd Head Occupational Therapist - Children’s services LTHT
- Lisa Smith Occupational Therapist LTHT
- Julie Cliffe Community Paediatric Physiotherapy
- Sharon Linter Deputy Chief Nurse Children’s Services Leeds Teaching Hospitals Trust
- Dr Mike Miller Consultant Paediatrician Martin House Children’s Hospice
- Dr David Cundall Consultant Community Paediatrician
- Dr Arnab Seal Consultant Community Paediatrician
- Dr Ian Lewis Consultant Paediatric Oncologist
- Dr Mike Clarke Consultant Paediatric Neurologist
- Kim Chappell Medical Housing Department
- Lorraine Anderson Medical Housing Department
### Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>INA</td>
<td>Integrated Needs Assessment</td>
</tr>
<tr>
<td>ESP</td>
<td>Early Support Programme</td>
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<tr>
<td>CAF</td>
<td>Common Assessment Framework</td>
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<tr>
<td>LCNT</td>
<td>Leeds Children’s Nursing Team</td>
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<tr>
<td>NOT</td>
<td>Neonatal Outreach Team</td>
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<tr>
<td>NSF</td>
<td>National Service Framework</td>
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<tr>
<td>DOH</td>
<td>Department of Health</td>
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<td>ACT</td>
<td>The Association for Children’s Palliative Care</td>
</tr>
<tr>
<td>CSN</td>
<td>Children’s Nurse Specialist</td>
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<tr>
<td>PCA</td>
<td>ParentCarer Action</td>
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<tr>
<td>LCCT</td>
<td>Leeds Children’s Continuing Care Team</td>
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<td>OT</td>
<td>Occupational Therapy</td>
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<td>Child and Adolescent Mental Health Services</td>
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<td>GP</td>
<td>General Practitioner</td>
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<td>SILC</td>
<td>Specialist Inclusive Learning Centre</td>
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<tr>
<td>LSCB</td>
<td>Local Safeguarding Children Board</td>
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This care pathway has been developed by Caroline James – Service Development Manager for Children with Complex Needs, on behalf of Making Leeds Better and the Leeds Primary Care Trust.

If you have any comments or questions please contact: - 
Caroline James 
Service Development Manager for Children with Complex Needs 
Stockdale House, Victoria Road, Headingley, Leeds, LS6 1PF. 
Tel: 0113 2033 406 
caroline.james@leedspct.nhs.uk