NHS
The Leeds
Teaching Hospitals
NHS Trust

Acquired brain injury in children

The early rehabilitation stage

Information for parents & carers

leeds children's
hospital
caring about children

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Introduction

This booklet has been written for you, as a parent or carer of a child who has injured their brain following an accident or illness.

Children's Neurosciences ward

The ward cares for children who have a brain injury following an accident or illness as well as children with other neurological problems. Children from infancy to 16 years are admitted can be admitted to the ward.

The aim is to provide you with information about your child's stay whilst on the ward.

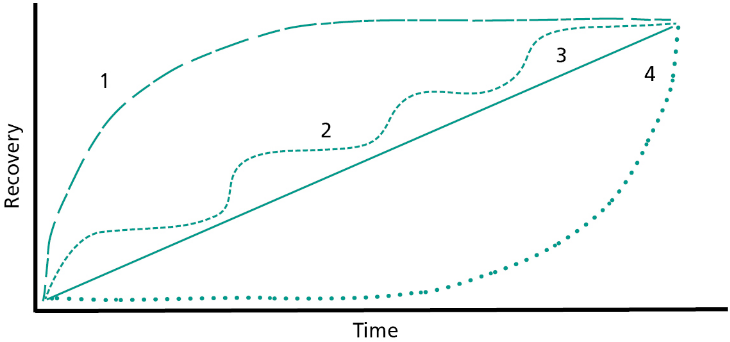
The booklet will be concentrating on:

- The early rehabilitation stages - the process, the people involved and what to expect when your child is on the ward.
- The planning and preparation for discharge home.

Important points to remember

Recovery

Each child will progress in a different way following a brain injury and will experience different problems. It is not possible for anyone to predict exactly how well or how fast your child will recover. We understand that it is really hard for parents when we cannot give a clear idea about what the future might look like.. One of the reasons for this is that your child could take one of the many paths in recovery as shown in the following diagram:



1. Fast recovery in early stages which then slows down.
2. Periods of fast recovery followed by periods of slow progress.
3. Steady progress in recovery.
4. Slow recovery in early stages which then speeds up but eventually your child will reach their potential in rehabilitation.

As you can see, every child progresses differently and at varied speeds. There are many factors which impact a child's rehabilitation including a child's age, a child's engagement in sessions and the area of the brain that's been impacted.

It is important to mention that some difficulties may arise later as the brain continues to develop throughout childhood and adolescence. At the time of injury only problems present can be detected. As children get older and are expected to acquire new skills, problems may then become apparent. One example is that we are often aware of difficulties with movement earlier than difficulties with how are brain is thinking , these difficulties can sometimes take longer to emerge.

Rest

Rest is important. The brain needs rest to recover from an injury. Stimulation and activity must be balanced with lots of rest to be effective. This is because rest is important: rehab takes a great deal of work and time to redevelop skills that have been affected by a brain injury.

How will this affect you and your family?

The most important thing for you to know is that you are not alone, we try our best to support family members as well as the child. We know that when a child's experienced a brain injury, it doesn't just impact the child but can have far reaching impact on parents, siblings, family members and communities.

It is normal and common for parents and family members to not feel quite themselves during this time, particularly at the beginning. However, every family responds slightly differently. Some family members feel very overwhelmed, might become tearful or upset and feel they can't cope. Some family members focus on the day to day and settle into a routine on the ward.

It is really important that family members look after themselves too so that they are to be able to provide the best care for their child. Members of the neuro-rehab team and ward team will check in with you and ask how everyone is doing. Please do speak to us about how you're feeling so that we can listen or help problem solve anything we can.

We ask parents to try and do the following:

- Try to get enough sleep, although this may be difficult if you're sleeping on the ward. Some families feel better sleeping on the ward whilst others feel better sleeping at home or in parent accommodation. It's normal for sleep to be impacted after a frightening experience howeverif you are finding it difficult to sleep longer term, speak to your GP.
- Try to eat regularly. If you can, familiar food can be helpful or eating small regular foods can be more manageable. A balanced diet will help with your energy levels up but we know sometimes this isn't always possible when a child's in hospital.
- Overtime, we support families to try and get into a routine on the ward. This includes waking up at a similar time, washing/showering, having regular meals and trying to go sleep at the same time. We know these things won't always be possible and if there's anything we can do to help, please let us know.
- We understand that families who have other children at home can find it particularly difficult both practically and emotionally to manage a neuro-rehab admission. We always encourage families to think about who can help with childcare. It can be helpful to let the siblings' school know about an admission so that the school can provide additional support if needed.

- Make a list of any problems you are facing while you are in hospital and try to resolve them one at a time. Think about whether friends, other members of your family or members of the team can help you with these problems.
- Try to find time for yourself, whether this is a few minutes to make a cup of tea or to go for a walk. We will always try to support family members to have a break from the ward where staffing allows. Sometimes members of the team can see children for sessions on their own e.g. school or physio and this can be a good time for family members to have a break.
- You might want to think about joining a support group, e.g. Children's Brain Injury Trust (CBIT) to talk with parents who have been in similar situations (see details at the back of this booklet).

The Team on the ward

The Multi-Disciplinary Team (MDT) Involves:

Nurses: plan care programmes and provide physical care for children such as washing and feeding. They also check on them throughout the day and night. Each child has a named nurse who will look after your child whenever they are on duty. Parents are encouraged to do as much as they want or feel able to do in the day-to-day care of their child (e.g. washing etc). However, you should remember that the nursing staff are always there to care for your child and you should only do as much as you feel happy with. The nurses will provide support and teach families about aspects of care.

Doctors: are responsible for the medical management of your child. This includes investigations and assessments, the prescribing of drugs and the co-ordination of all aspects of care.

Trauma and rehabilitation co-ordinator: Supports you and your child during your inpatient admission. They provide a link to the medical and rehabilitation team, provide information and advice and will make referrals for additional support and information. They will arrange and chair meetings with the rehabilitation team to discuss discharge home and your child/ young persons' rehabilitation journey.

Physiotherapists: are specialists involved in the rehabilitation of movement and mobility. They will use specific positioning, stretches, facilitation techniques and exercise to help your child achieve their best possible function. The activities and treatment will depend on your child's individual ability and the physiotherapist will advise you on what you can do to help while visiting and caring for your child. They may also work with your child to help them maintain a clear chest if this is appropriate.

Occupational Therapists (OT): are specialists who are involved in supporting daily functioning such as your child's abilities in self-care, leisure and educational activities. They use specific techniques, equipment and / or activities to maximise your child's abilities. They can also assess your home circumstances and offer advice regarding any equipment / alterations needed to enable your child to return home.

Dietician: establishes nutritional needs and recommends appropriate nutritional treatment tailored to each child. They will monitor dietetic interventions to help ensure a positive effect on your child's nutritional status and aid the recovery process.

Speech and Language Therapists (SALT): are specialists focusing on swallowing and communication. Firstly, they may need to assess your child's swallowing skills and whether they are ready for eating and drinking. They may advise modification of food / fluid consistency or specialised equipment. It may be necessary for them to also assess communication skills. This area includes your child's ability to understand language and their ability to express themselves appropriately. If it is appropriate to help support your child's understanding, or ability to express themselves a speech and language therapist may introduce an augmentative or alternative form of communication such as picture communication symbols.

Hospital Teacher: provides education for children in hospital, and in some cases temporarily after discharge. They also assess educational needs and liaise with your child's own school to help them go back to school as smoothly as possible.

Clinical Psychologist: provides a space to talk about the child's admission and brain injury. The psychologist often starts with family support, meeting with family members to provide a space to talk through any concerns and identify the best way of supporting your child and family. . Overtime, if your child is able to communicate, the psychologist may meet with your child to talk about his or her feelings about what has happened to them and to work through any problems.

Alongside this, the psychologist will identify any early concerns about cognition. Formal cognitive assessment may be offered as an outpatient following discharge.

Play Specialist: uses play as a resource to encourage the holistic development of your child whilst in hospital. They are also available to prepare your child for any forthcoming medical interventions and to provide diversional therapy during painful or invasive procedures.

Social Worker: Some patients may be referred to a social worker if the team feels this is appropriate. This may be especially important nearing discharge as they will know what help and support is available locally.

Other people: Your child may sometimes have to be seen by specialists. Any care given by these people will be co-ordinated by the team. This may include eye and ear specialists, dentists, radiographers, neuro-surgeons, and orthopaedic surgeons.

The team works together to provide joined up care, endeavouring to involve the family at all times.

What happens on the ward

Once on the ward your child will start the process of assessment and rehabilitation. Rehabilitation is the term we use for starting the process of recovery. It is a shared approach between your child, your family and a team of specialised professionals. This can include direct sessions with your child as well as exercises or strategies suggested for you to complete with your child outside of therapy sessions. It may involve considering adaptations and planning support that may help or be needed.

We support children to start their rehabilitation whilst admitted however it is a long process which will continue after discharge from the ward.

Ward Rounds

Each morning your child will be seen by the doctors on the daily ward round. On a Tuesday a larger team ward round takes place attended by the Lead Consultant and the therapy team. The purpose of these ward rounds is to review your child’s rehabilitation progress, not only medically but from all the therapy perspectives. The team are happy to answer any questions you may have. They may also arrange to meet with you at another convenient time.

Timetables

Each child has their own weekly timetable which is designed to meet their individual needs. It can usually be found on the wall beside your child’s bed. All therapy, school and rest times are included. The therapy and school sessions are as long as the team feel your child can cope with at that stage of their recovery. At first these are often as short as 10 minutes because your child will tire easily. This may seem a short amount of time, but it is important to remember that overstimulation is unhelpful. Rest is just as important as activity. As your child progresses, therapy and school sessions will become longer.

Goal Planning

As part of rehab, we will set goals for your child’s recovery. This is to help your child, you and the team have a focus for your child’s recovery. We will discuss these goals with you and your child (if appropriate). This may include both short-term goals and long-term goals. We will review your child’s progress towards their goals every one to two weeks in the weekly team meeting.

Questions

If you have any questions or concerns please do not hesitate to contact any members of our team. You may find it useful to write down any questions you may have and then discuss these with the team or your key worker as you see them.

Other Information You May Need

Parking permits: These are available, please ask nursing staff or ward clerk regarding the application process. These are only valid within the hospital grounds/car parks.

Food and drink: Toast is provided for all resident parents for breakfast, please speak to the housekeepers. there is a canteen on C floor in clarendon wing and shop on A floor. There is a large selection of sandwich shops opposite the Great George Street entrance. At the Jubilee Wing entrances you will also find newsagents and coffee shops.

The Leeds Hospitals Charity brings a snack trolley on the ward at around 2pm also providing tea and coffee.

Parents kitchen on ward 52: Tea, coffee, sugar and milk is provided within the parents kitchen. Parents can help themselves but ask that parents keep this tidy and wash up. A fridge and freezer is available in the kitchen, please label with your name and date. Home made food can be kept for 1 day. Some snacks are provided in the parents kitchen from the Millie Wright Charity.

Visiting times: Unlimited for parents. Anyone else may visit between **11am – 7pm.** Only 4 visitors are allowed per bed. Press the buzzer to enter the ward which is locked for security reasons.

Quiet hour: To aid rest and recovery the ward has a quiet hour 3-4pm. At these time the lights will be lowered and we ask to keep noise to a minimum.

Helpful Contacts

Child Brain Injury Trust

The Child Brain Injury Trust supports children and young people with an acquired brain injury (a brain injury acquired after birth), their families and the professionals involved with them.

Website: www.childbraininjurytrust.org.uk

Email: info@cbituk.org

Helpline: 0303 308 2248

Leeds Headway

Headway aims to promote understanding of all aspects of brain injury and to provide information, support and services to people with a brain injurytheir families and carers.

Website: www.headway.org.uk

Email: helpline@headway.org.uk

Helpline: 0808 800 2244

The Children's Trust

For children with brain injury.

Website: www.thechildrenstrust.org.uk

Email: enquiries@thechildrenstrust.org.uk

Helpline: 0173 736 5000

Notes

What did you think of your care?

Scan or click QR code, or visit **bit.ly/nhs leeds fft**

Your views matter

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