Acquired Brain Injury - Rehabilitation

A guide for families

A word of explanation

The words “family” and “parents” are used often in this booklet. They are used in a general sense and are intended to include all parents whether married, single, widowed or divorced. We also wish to include families where parenting is carried out by step-parents, partners, grandparents, adoptive parents, foster parents, close friends, aunts, uncles and cousins. Families have many different members and living arrangements and not all children live with both parents. We hope you will apply the words “family” and “parents” to your situation.

Introduction

Your child has been admitted into hospital for a period of observation, assessment and rehabilitation following their brain injury. This booklet is designed to explain more about the possible effects of brain injury and what treatments and therapies your child may have during their stay. This booklet gives advice about ways in which you can help your child’s recovery and introduces the staff who may be involved in their care.

At the back of the booklet you will find spaces to make notes of questions you may wish to ask staff and also a personal diary for you to record events, feelings, etc. Finally we have contact numbers for organisations you might find helpful.

What is a brain injury

The medical staff will have already discussed your child’s injury. With brain injury, the major concern is the degree of damage to the brain itself. Your child may not have any visible signs of a serious injury to their head, such as cuts or bruises, but this does not mean that their brain has not been injured.

An acquired brain injury (ABI) is any kind of injury to the brain that occurs after birth. Common causes include accident, illness (such as. meningitis or encephalitis), stroke or tumour. When an injury occurs suddenly or results from a knock to the head, it can also be known as a traumatic brain injury.

The recovery process

All children recover at different rates from a brain injury and to a different level. It depends on many things, including how old the child is, how severe the injury, which part of the brain is damaged and to what extent. In early stages of recovery it is difficult to predict how your child will be affected in the future. Over the next days and weeks, we will assess your child’s progress. The most rapid recovery will occur in the first few months and continue for up to a year or two after the injury. Learning and emotional functions may take longer to improve and may need ongoing monitoring and therapy, sometimes over a number of years.

What is rehabilitation in acquired brain injury?

Rehabilitation is the processes of helping your child achieve the highest level of function, independence and quality of life possible after their ABI. Rehabilitation does not reverse or undo the damage caused, but rather helps your child achieve optimal health, functioning and wellbeing.

The rehabilitation programme

The rehabilitation programme is designed to meet your child's specific needs so each programme is different. Some general treatment components for rehabilitation programmes include the following:

- Treating the basic disease and preventing complications
- Treating the disability and improving function
- Providing adaptive tools and altering the environment.

How successful rehabilitation will be for any child or young person depends on many different things including:

- The type and severity of the ABI
- What type of impairments are present and how severe they are
- The overall health of your child
- Family support.

Aspects covered in your child's rehabilitation program may include:

- Mobility skills, communication skills, self-care skills and activities of daily living
- Nursing and medical care including nutrition, medication and pain management
- Psychology support and support in developing cognitive skills
- Support with school reintegration
- Family support and education.

The rehabilitation team

Your child will have been admitted under the care of a Consultant Neurosurgeon (Surgical) and/or Consultant Neurologist (Medical) and a Specialist Neurodisability Consultant (Medical).

The surgical and medical team will treat medical problems and will monitor your child's progress and care on a daily basis. Once your child has been linked in with the Neurodisability Consultant who specialises in management of brain injury, they will supervise the rehabilitation plan, working closely with the full team.

When your child is stable medically and ready to go home, the medical team will arrange follow-up/ward review and outpatient appointments. If you do not live in Edinburgh, your child may be referred to your local medical team (and therapy team if necessary) for continuing care.

Our Specialist Neurodisability Consultant has shared responsibility for co-ordinating the multidisciplinary team.

Rest

It is vital that your child is allowed to have adequate amounts of rest each day in between activities to aid their recovery. This is particularly important in the early phase of recovery and they may require more rest than previously.

Rehabilitation team meetings

Our team meet weekly on the ward to discuss your child's progress and, if required, an update will be placed in their nursing folder. If you have anything you would like to discuss with the team, please let a member of the nursing staff know.

Following assessment and discussion of your child's needs, a rehabilitation timetable will be drawn up. This timetable allows for you and your child to know when planned activities and rest are scheduled into their day.

Medical team

Your child will be admitted under the joint care of the Neurosurgical and Neurology Team.

They will see your child on a daily basis, monitor their progress and care and prescribe any medication that is required, e.g. to help sleep or treat any muscle stiffness or movement problems that your child may have.

When your child's condition is stable and they are ready to start their rehabilitation programme, our Neurodisability specialist will become the lead medical professional coordinating the rehabilitation programme and the multidisciplinary team.

The Neurodisability consultant works closely with the neurology nurse specialist to support your child and family in their rehabilitation journey from hospital to home.

Nursing team

The nursing team are experienced in caring for children and young people who have different types of brain injuries and would like to reassure you that we are fully committed to helping your child make the best recovery as possible throughout your stay on the ward. The nursing staff work day shifts (7.30am - 8pm) and night shifts (7.30pm - 8am). The nurse responsible for caring for you and your child will introduce themselves to you at the beginning of each shift. Different grades of nurses work in Neurology (Borthwick ward). The Senior Charge Nurse wears navy blue, the registered nurses wear blue uniforms and non registered nurses wear light blue uniforms. A team effort is made on the ward and although you may have a specific nurse allocated to care for your child, the other nurses may help throughout the shift, to ensure that treatments and important aspects of care are provided in a timely manner.

As previously mentioned, every child and young person with a brain injury is different and will exhibit different care needs, depending on their injury. It is the job of the nursing staff to identify these needs and work with you to develop an individualised plan of care that will not only meet your child's needs but those of the family. Parental/family involvement in providing cares is encouraged, where appropriate. A folder is available by your child's bedside, should you wish to read the nursing reports and observations made by the nurses.

The nursing staff will help the wider team assess your child's progress through observation of your child's skills and their ability to cope with specific daily activities, for example; eating, washing, toileting, dressing. The nursing staff will provide feedback to other team members and adjust plans of care, to take account of any changes in your child's condition.

The nursing team will provide you with support and advice throughout your child's hospital stay. It is important to maintain good communication with the nurses. We are happy for you to speak to us or raise any issues for discussion, which are important to you, your child or family. In addition to the nurse looking after your child, there is a nurse in charge (wearing a red badge) or the Senior Charge Nurse (weekdays 8am -5pm) for you to speak to. Please feel free to speak to any of us or provide feedback on your hospital experience.

The neurology nurse specialist

The Neurology Nurse Specialist will be involved in your child's care to help support recovery from their brain injury and give advice about the recovery process, returning home, school and sports/ activities.

Our Nurse Specialist works closely with the Neurodisability Consultant and the Clinical Neuropsychologist. Part of the Nurse Specialist's role is to link in with your child's school and support the staff and to help them understand the impact a brain injury can have on a developing brain. The Neurology Nurse Specialist will liase with the school and where appropriate attend any meetings to help with the move from hospital to home to school. A phased return is usually appropriate to help ease back into normal school activity.

Each child's journey is different, however there are common themes and sometimes if return to school is too quick or not supportive enough, the child may not manage.

The school will be provided with the Nurse Specialist’s contact details should any queries or concerns arise.

The physiotherapist

The physiotherapists work as part of the team helping to improve your child’s physical abilities.

In intensive care the physiotherapist will have worked to prevent your child’s joints and muscles becoming too stiff as well as keeping their chest clear.

Following the transfer to Neurology (Borthwick ward), physiotherapy will continue. The physiotherapist’s treatment is specifically related to the difficulties your child has, and this is reviewed daily as they start to change and develop.

Treatment sessions may at times appear quite challenging both physically and emotionally. The treatments are designed to help recovery. Your child may find sessions very tiring.

Treatment will initially take place in the ward but as your child improves, and can leave the ward, they will visit the physiotherapy department. We very much welcome and encourage families to participate in physiotherapy sessions.

Some of the types of treatment your child may have are:

- Chest Physiotherapy - if they have continuing chest/breathing problems
- Positioning Programme - a variety of positions may be recommended to keep your child comfortable and help their recovery
- Leg/Arm and trunk movements/stretches - to prevent muscles and joints from getting stiff and tight
- Splinting - occasionally splints need to be made to hold joints in a better position usually for the ankles
- Exercises - to teach your child to “relearn” how to move in a normal way, build up strength and balance. The physiotherapist will often help to guide your child’s movements to help them to relearn to sit, stand and walk.
- Equipment provision - your child may require a wheelchair or standing aid to help with rehabilitation and enable you to have time out of the ward together.

The Physiotherapist will explain what they are doing and why but if you have any questions or worries concerning treatment please ask.

In addition to treatment, the physiotherapy sessions are designed to continually assess and advise parents and staff how to handle and care for your child to enable the best possible recovery to take place. Parental involvement is therefore very important. The

Physiotherapist will let you know what you can do to help with your child's recovery and advise you when it is safe to try new activities.

Your child may continue to require physiotherapy after they are ready to go home - this will be discussed with you and organised well in advance.

The occupational therapist

In Neurology (Borthwick ward) the Occupational Therapist (OT) specialises in the treatment of children who have had traumatic injuries, especially head injuries.

The goal of occupational therapy is to enable your child to engage in everyday activities and an assessment will be carried out as soon as reasonably possible.

Assessment may involve observation or standardised assessment of self care, leisure, play, meal times and sleep routines. The use of activity analysis will help decide how occupations can be graded or adapted to support your child's performance. As your child improves, the occupational therapist will begin sessions, usually for short periods at first and then for longer periods.

Following assessment, the types of activities you may see the occupational therapist carrying out with your child include:

- Self-care: dressing, feeding
- Cognitive: memory, problem solving, perceptual activities and opportunities to engage in productive occupations
- Play/leisure: handwriting/drawing, including grading of activities
- Postural care and positioning: functional hand splints and stretching in order to maintain range and prevent deformities
- Environmental considerations: therapy timetables are often used to plan your child's day to ensure recovery/rest periods are included
- Discharge planning; the occupational therapist will attend progress meetings about your child. When your child is ready to go home either for a day or weekend, at first the occupational therapist will assess what help or equipment may be needed (e.g. toileting, equipment, ramps or rails) and will work with your local community occupational therapist to enable your child to go home
- Following discharge home the occupational therapist may continue to help your child's return to nursery or school by helping teachers to understand the problems your child may have.

The occupational therapist is always happy to answer any of your questions or queries and parental involvement is encouraged.

The speech and language therapist

The Speech and Language Therapists will contribute to the overall assessment of your child. We have a specific responsibility for the assessment, treatment and management of any communication problems or feeding/swallowing difficulties they may have resulting from their acquired brain injury.

Some children may experience disturbance of language affecting their ability to understand language, remember words, say words and sentences clearly and with reading and writing. Following an acquired brain injury your child may have difficulty swallowing. This could be due to the muscles they use for speech and feeding/ swallowing being affected or to your child being weak and tired.

The Speech and Language Therapist will assess your child and plan a programme of therapy to achieve the best possible recovery. The sessions will start as soon as your child is ready. These will initially be on the ward but as your child improves and is able to leave the ward they will visit the department. The Speech and Language Therapists participate in multi-disciplinary meetings and are always happy to answer any questions or queries you may have.

If your child requires further support when discharged home this may be arranged as an outpatient at the hospital or in your local health clinic. This will be discussed with you so you know who you will be seeing for continued therapy support.

The paediatric neuropsychology team / psychiatrist

The Paediatric Neuropsychology team is made up of Clinical Psychologists, a Paediatric Neuropsychologist and Assistant Psychologists. They work closely alongside Psychiatry to promote psychological wellbeing and reduce psychological distress in people with physical or mental health problems. They may work directly with the person and their family or indirectly by advising or teaching other professionals involved.

Because the brain is responsible for so many different functions, brain injury can affect children and young people in many different ways. Changes in behaviour, personality, concentration, memory and other thinking abilities are commonly reported following a brain injury.

Paediatric Neuropsychology team

In some cases, the Paediatric Neuropsychology team may be involved in observing a child’s behaviour in order to assess the effect of the brain injury on their thinking and emotional functioning. They can then provide advice and guidance around how to support any difficulties that are identified.

Sometimes it is useful for the Paediatric Neuropsychology team to test a child’s thinking skills using standard tests. This type of detailed assessment is not usually completed until at least six months after a significant brain injury. The assessment helps the team to understand any ongoing problems with thinking abilities, as well as any changes in mood and behaviour. This information can help the family and school understand how the brain injury is affecting the child's day-to-day learning and behaviour. The Neuropsychology team will liaise with the school and Educational Psychology to help the school support your child's continued learning.

You are welcome at any time to contact the Paediatric Neuropsychology team about issues or questions. They may continue to provide input after discharge from hospital.

The Psychiatrist

Sometimes changes in mood, anxiety, behaviour, attention and other thinking abilities following a brain injury may be related to chemical changes in the brain. A Psychiatrist may work with the rehabilitation team to prescribe medication to try to manage symptoms associated with these chemical changes.

The Psychiatrist may continue to provide input after discharge from hospital. You are welcome to contact them at any time.

The play specialist

Play forms an important part of the rehabilitation process as it is both familiar and non-threatening to the child and it is an activity that the whole family can participate in.

Neurology (Borthwick ward) Play Specialists work alongside the other professionals as part of the rehabilitation team in assessing the needs of your child. They are on the ward Monday to Friday.

Your child's individual needs programme will be designed after discussion with other professionals and family, taking into account your child's preferences and favourite activities before admission and any difficulties they may be experiencing. This programme will be updated daily to take into account your child's progress and assist in maintaining their all round developmental needs.

The Play Specialist is always happy to discuss the programme with both staff and family to advise on how others can become involved in the therapeutic play activities.

The dietitian

Dietitians help to ensure that each child has an adequate nutritional intake whilst they are recovering from an injury. Once a child's nutritional needs have been established the Dietitian reviews these regularly and recommends dietary changes as needed. The child's preferences are taken into consideration as much as possible.

Following an assessment from the speech and language therapists, foods of a suitable texture or thickened drinks will be available as necessary to help make eating and drinking easier. If your child is unable to eat and drink enough, the Dietitian can advise on dietary supplements as required.

If your child has problems with chewing and swallowing they can be given food in a liquid form via a tube which is passed down your child's nose into the stomach. The Dietitian will discuss with you which feed is best for your child's needs and how much is required each day and will monitor intake and progress for however long tube feeding is required.

If your child is discharged home with tube feeds the feed is available on prescription via your GP. The feed and equipment needed is delivered to your house every month. Progress is then monitored by the community dietetic team, community nurse and health visitor.

The teaching service

A teaching service, staffed by qualified primary and secondary specialists, is available within the hospital for children who are admitted for a prolonged stay. Every child/young person's educational needs are assessed and an individual educational programme is planned in conjunction with their own school. This is to ensure continuity and progression. Progress is monitored and plans changed accordingly to suit the child/young person's needs as they recover.

Young people can be supported to sit their National Qualifications in hospital if this is recommended by medical staff.

Educational needs will be assessed nearer to your child/young person's discharge. Where appropriate, a referral can be made for educational support in the community. Medical staff/Neurology Nurse Specialist will liaise with you to advise on your child's return to school.

The Social Worker

There are social workers linked to Neurology (Borthwick ward) who can provide advice and support regarding information about relevant services. Where appropriate, our social worker assesses children and their family's needs so that consideration can be given to accessing related services.

Discharge liaison

The purpose of the Discharge Liaison Nurse is to oversee and facilitate the discharge of children and young people who are in a long term rehabilitation programme following a brain injury. The role involves working very closely with families and all members of the multi-disciplinary team within the hospital and in the community.

Often parents/carers of children and young people with additional needs have or will need multi-agency support for the rest of their life, which includes additional support to promote family life and ensure safety at home.

To ensure the appropriate level of support and service provision, detailed planning within a multi-agency process is required.

This process is called Child or Young Person Planning and should start as early as possible, ideally from the time of admission.

The Discharge Liaison Nurse is normally notified by the Lead Consultant, and has responsibility to ensure there is a co-coordinated approach to planning for your child’s return home.

This process can involve multi-interagency team meetings, including Social Work and Education professionals. These meetings result in action plans with identified timescales to be met by the relevant professional in order to ensure timely and safe discharge.

As part of this integrated working, this role and the process for discharge is further being developed using the Getting it Right framework (GIRFEC) as a standard of practice in communicating and sharing information about your child.

Getting it Right for Every Child (GIRFEC) is a Scottish Government-led agenda that all Health Boards have agreed to. This is to ensure that anyone providing support puts the child or young person and their family at the centre. It has been put in place to allow early intervention and to work across organisational boundaries.

All children by law will have a Named Person; this is the Health Visitor or a teacher nominated by the Head teacher at your child’s school. Children or young people with additional support needs will have a Lead Professional who will work in partnership with you as the parents and the Named Person.

The Lead Professional is the single point of contact for parents/ carers and professionals involved to share information.

The family’s feelings

It is a difficult time for families when your child is badly injured. Your emotional reaction may begin with shock and anxiety. You may feel frightened or panic. Your concentration may be poor and you may feel unable to make decisions.

Some people feel like crying, shouting or talking a lot. Others want to be left alone or to spend time with the injured child. It is important to remain optimistic but not unrealistic.

You will be encouraged to help with your child’s care, however, some tasks have to be carried out by the professionals. To help you be involved as much as possible, visiting is allowed at any time on the ward and provision can be made for you to stay overnight.

Recovery following a head injury can be lengthy, therefore it is very important to look after your own health and strength by taking sufficient breaks and rest. You may feel guilty about leaving your child. This is a common reaction. It is difficult to think of yourself at a time like this.

Any questions you will have will be answered as truthfully as possible at any stage, but sometimes it is too early to be able to give definite answers. Sometimes it is helpful to write down any questions you may have.

You may feel frustrated and short-tempered at times. We understand this may happen and that it is a natural reaction.

People have a lot of different feelings which are difficult to cope with. It is not just parents who are affected. Other relations, especially brothers and sisters, may experience strong feelings too. If you are worried about your own or your relatives' ability to cope with the situation, please tell us.

We are aware that you may find it hard to remember and concentrate with all that is going on. Space is available at the end of this booklet for you to write down questions you may wish to ask or information given.

The rate of improvement in your child can sometimes be so gradual that it seems that nothing is happening. To help you realise what changes have occurred we have also included space for a diary of your child's progress which you can fill in if you wish.

What you can do while your child is in the hospital

It is important to look after yourself. Here are a few suggestions for parents:

- Eat regularly - have nutritious meals
- Take regular rest periods for yourself
- Take time for yourself if that is what you need; some people prefer to have someone with them all the time, while others need some space
- If you cannot stay at the hospital, telephoning your child's nurse may help you to worry less
- Ask for help from friends, relatives and extended family. People often want to help in any way they can - let them. One thing that can be helpful is to ask someone to be a telephone "buddy" - someone who can ring around other family and friends with information so that you don't have to keep repeating the story over and over, which can be exhausting.

Conclusion

When a child has a brain injury we know that it can have an impact on the whole family. The members of the team in Neurology (Borthwick ward) are available to help you and your child while you are in the hospital and after discharge.

We hope this booklet has helped you to understand what is happening, but if you have more questions, please do not hesitate to talk to our staff. Remember there are also organisations and support groups available to help you - details of some of these are supplied at the end of this booklet.

Helpful contacts:

Paediatric Neurology Nurse Specialist
Royal Hospital for Children and Young People
50 Little France Crescent
Edinburgh
EH16 4TJ
0131 312 0636

Child Brain Injury Trust
Norton Park
57 Albion Road
Edinburgh
EH7 5QY
0131 475 2598 or **0303 303 2248**
www.childbraininjurytrust.org.uk
helpline@cbituk.org

The Child Brain Injury Trust provides free emotional and practical support as well as information on topics including acquired brain injury, returning to school, social opportunities, and peer support. Anyone can call **0131 475 2598** for details on how we can support your family.

Kindred
Supporting families of children and young people with additional needs
helpline - **0131 536 0583** or email us directly at kindred.enquiries@gmail.com

Headway House - adult services
Astley Ainslie Hospital
Canaan Lane
Edinburgh
EH9 2HL
0131 537 9116

Vocal
Carers Centre
For support or information contact: **0131 622 6666**
or email centre@ vocal.org.uk

Diary Page:

Date	Comments

Notes Page:

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