

Children and young people
with acquired brain injury
*Current practice in
occupational therapy*

College of Occupational Therapists

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Therapists**



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Foreword



Royal College of
Paediatrics and Child Health
Leading the way in Children's Health

Acquired brain injury (ABI) is injury to the brain caused by an identifiable event such as trauma, hypoxia, metabolic disorders or infection. ABI in children and young people is an important health condition. The National Institute for Health and Care Excellence estimates around 3,500 children per 500,000 population attend accident and emergency with head injuries per year (NICE 2014). The consequence of ABI for many is lasting changed life circumstances.

From the moment of diagnosis, delivering care which is based on best available evidence is important in ensuring optimal outcomes for the child or young person, and their family. Following brain injury there is typically a multitude of health professionals engaging with patients and families during the long journey through recovery. Streamlined co-ordination of care is key to success, but it is essential that wherever possible there is active engagement of the child/young person or their carers in agreeing treatment priorities, and that a shared decision-making process puts their wishes at the centre of the planning process.

This guidance document has been developed by a group of occupational therapists working across a range of healthcare settings from acute through to community service providers. This guidance is aimed not only at occupational therapists but will also be of value to other allied health professionals working with this important group of children. It provides a superb learning tool for understanding some of the most important concepts underlying both acute and long-term care, and many of the topics covered in these pages will be transferable to other situations.

Occupational therapists share the goal of enabling and supporting a child's occupational performance in daily life activities. They can have a role in the early days after injury, from admission to an intensive care unit where maintaining physical and sensory functions such as joint range and muscle tone are a focus. Their role evolves over the weeks and months of recovery through to long-term support in enabling children to both recover their pre-injury skills and also to continue to acquire and develop skills through to adulthood. No two children with an acquired brain injury have the same needs or recovery path. This guidance document aims to provide a framework for therapists working with children after acquired brain injury, and support their clinical decision making. While it is critical that any therapist maintains up-to-date knowledge of the research literature and practice guidance throughout their career, this guidance aims to support those therapists who may be new to this field or see few children with such needs, in anticipating the longer-term support needs. Children and young people across the UK deserve the best possible care, regardless of where they live, and this is an excellent resource for ensuring consistency of approach across all settings.

Dr Hilary Cass
President

Royal College of Paediatrics and Child Health

1 Introduction

Occupational therapy is a person-centred profession concerned with promoting health and wellbeing, through enabling engagement and participation in the occupations of everyday living. Occupational therapists define an occupation as much more than a chosen career. Occupation refers to everything that people do during the course of everyday life, and for a child or young person this includes playing/socialising, doing school/college work and taking care of themselves. Occupations are key to people's health and wellbeing, because they make us who we are and shape our roles and responsibilities in life.

The role of the occupational therapist is to enable the participation of the child or young person in the life roles which are important for them and their family, such as being a son/daughter, sibling, school student, player, self-carer and friend. To do this the occupational therapist provides appropriate opportunities, strategies and techniques for the child to engage in occupations, for example getting dressed, listening to music, talking with family, which supports participation in these life roles. Through 'doing' activities, occupational therapists believe it will have a positive impact on the child's health and wellbeing (Wilcock 2006). How this is undertaken will depend on the child or young person's needs, the family's needs and the specific setting.

Following a head injury the child or young person's occupations will be severely disrupted. Acquired brain injuries (ABI) are a major cause of disability in children and youth in the United Kingdom. The causes of brain injury vary widely and are managed by different clinical teams depending on the cause, e.g. paediatric neurology and oncology. The causes include trauma (e.g. road traffic accidents, falls, blows to the head), strokes and non-traumatic comas (e.g. following a brain infection and brain tumours). While the causes are diverse, occupational therapy involvement will always focus on supporting the participation of the child and family in life roles through engagement in occupations.

Involvement of the child or young person's family is vital at each stage of the occupational therapy process. Working with the family of a child or young person with acquired brain injury requires sensitivity. The traumatic change in family circumstances will present in variable ways. It could impact on the presence or absence of family members during therapy sessions. Every situation is different and gentle introduction of information should be made. Some families will want information very soon after the child has been admitted, while others will not be ready for detailed information until a later stage. Careful communication of the purpose and nature of the occupational therapy intervention is paramount.

1.1 Incidences of brain injuries

1.1.1 Traumatic brain injury

'The incidence of hospitalisation for Traumatic Brain Injury (TBI) in England has been reported as ranging from 280–500 [sic] per 100,000 children aged < 16 years, implying that the total number of children admitted to hospital for TBI per annum in the UK is at least 35,000. Of these, approximately 2,000 will have sustained severe TBI, 3,000 moderate TBI and 30,000 mild TBI.' (NHS England 2013, p2)

1.1.2 Non-traumatic coma

'The total number of UK children aged 1–16 years who sustain non-traumatic coma associated with severe or moderate encephalopathy per year is of the order of 4,000' (NHS England 2013, p2).

1.1.3 Paediatric stroke

'The overall incidence of childhood stroke has been estimated to be of the order of 2–3 per 100,000 children per year, equating to approximately 200–300 cases in England' (NHS England 2013, p2).

1.1.4 Brain tumour survivors

'In the UK, data from the UK Childhood Cancer Study Group suggests that brain tumours occur in about 5 per 100,000 of children per year, equating to approximately 525 new cases in England' (NHS England 2013, p2).

1.2 About this resource

The aim of this resource is to guide occupational therapists working with children and young people with acquired brain injury (ABI). It is relevant for occupational therapists working in hospitals, community settings or rehabilitation facilities. The resource may also be of interest to other disciplines including physiotherapists, speech and language therapists, psychologists, social workers and play specialists, particularly those working in the United Kingdom.

The resource provides an overview of:

- The role of the occupational therapist working with children and young people with acquired brain injury.
- Assessments, goal setting, interventions and evaluation techniques used by occupational therapists and when these may be usefully applied within the care pathway.
- Links to existing resources for child/family/professional information about acquired brain injury, interventions and outcomes.

Although this document draws upon some literature from the fields of cerebral palsy and stroke, in the absence of evidence specific to children with acquired brain injury, this evidence may be relevant. When combined with thorough clinical reasoning, this evidence could be interpreted with caution to acquired brain injury patients presenting with similar impairments, acknowledging the potential limitations.

This document is intended to be used alongside the occupational therapist's clinical expertise and, as such, the practitioner is ultimately responsible for the interpretation of the information in the context of the specific circumstances, environment and service user's individual needs and preferences.

It is important that this document is read alongside relevant national guidelines and quality standards. It is recommended that knowledge of current literature is maintained to ensure practice is informed by relevant theory and research evidence. As a starting point for literature relevant for children with acquired brain injury, see the College of Occupational Therapists' hOT topic *Acquired brain injury in children*. Available at: <http://www.cot.co.uk/hot-topics/hot-topics>

1.2.1 Target population

This resource is intended to support occupational therapists new or returning to the field of paediatric neurology and working with children with acquired brain injury. It provides information relating to occupational therapy processes from acute presentation in hospital through to long-term community care.

Transitioning to adult services is also an important consideration. This guide can be read in conjunction with *Acquired brain injury: a guide for occupational therapists* (COT 2013) which focuses on adults (over the age of 16).

1.2.2 Terminology

The United Kingdom definition published by the World Federation of Occupational Therapists states that 'occupational therapy enables people to achieve health, wellbeing and life satisfaction through participation in occupation' (World Federation of Occupational Therapists 2013, p48).

The terminology used to present information is consistent with the World Health Organization's *International classification of functioning, disability and health* (ICF) (World Health Organization 2014).

The term 'child' is primarily used in this document. This refers to infants, children and young people. This guidance does not focus on the needs of neonates.

Other frequently used terms within this document include:

- **Occupation** – A group of activities that has personal and sociocultural meaning is named within a culture and supports participation in society. Occupations can be categorised as self-care, productivity and/or leisure (Consensus definition from the European Network of Occupational Therapy in Higher Education Terminology Project Group (ENOTHE) 2004).
- **Self-care** – Occupations for looking after the self. Examples include personal care, personal responsibilities, functional mobility and organisation of personal space and time (Canadian Association of Occupational Therapists 2002, p37).
- **Productivity** – Occupations that make a social or economic contribution or that provide for economic sustenance. Examples include play in infancy and childhood, schoolwork, employment, home making, parenting and community volunteering (Canadian Association of Occupational Therapists 2002, p37).
- **Leisure** – Occupations for enjoyment. Examples include socialising, creative expressions, outdoor activities, games and sports (Canadian Association of Occupational Therapists 2002, p37).
- **Occupational performance** – The results of a dynamic, interwoven relationship between persons, environment and occupation over a person's lifespan; the ability to choose, organise and satisfactorily perform meaningful occupations that are culturally defined and age appropriate for looking after oneself, enjoying life and contributing to the social and economic fabric of the community (Canadian Association of Occupational Therapists 2002, p181).

There are a variety of glossaries available which define terms used within acquired brain injury services. Examples of such glossaries can be found at the following websites:

- Neurologic Rehabilitation Institute at Brookhaven Hospital:
<http://www.traumaticbraininjury.net/brain-injury-terms/>

- The Children's Trust Brain Injury Hub:
<http://www.braininjuryhub.co.uk/information-library/glossary>
- Headway: <https://www.headway.org.uk/common-brain-injury-terms.aspx>
- Queensland Government, Queensland Health:
<http://www.health.qld.gov.au/abios/asp/glossary.asp>

All websites accessed on 21.01.15.

1.2.3 How to navigate this resource

The resource is divided into sections according to location of the child during their care pathway. It is understood that clinical settings, team composition and roles may differ between locations. Locations include:

- Paediatric intensive care unit (PICU)/high dependency unit – for children with acute presentation.
- Inpatient acute hospital ward – for children who are medically stable and do not require one-to-one nursing care.
- Inpatient rehabilitation – for example a neurology ward, rehabilitation bed in a hospital or a rehabilitation facility.
- Community-based rehabilitation – for the longer-term needs of the child or young person when they have returned home and are reintegrating into education and community life.

Disclaimer

The advice presented in this resource is intended as a general guide only, with examples of useful resources for occupational therapists. It is not a competency framework. The circumstances for every individual and their needs following acquired brain injury will differ. While care has been taken in preparation of this resource, the authors and publisher do not accept responsibility for the results of specific action taken on the basis of this information, nor for any errors or omissions. Any mention of products or interventions in this resource is not an indication of endorsement.

2 Occupational therapy models, frames of reference and evidence-based practice

Within all areas of occupational therapy practice, it is vital that the therapist is guided by a theoretical framework. It is recommended that occupational therapists working with children and young people with acquired brain injury (ABI) research and reflect on relevant occupational therapy model(s) and frame(s) of reference they are using prior to, during and following their occupational therapy involvement. Making the use of models and frames of reference explicit in practice through supervision and departmental discussions is considered good practice.

Occupational therapists must only 'provide services and use techniques for which they are qualified by education, training and/or experience', and within their professional competence (COT 2015, p32). This information should be used in conjunction with the therapist's clinical expertise and, as such, the clinician is ultimately responsible for the interpretation of the evidence-based recommendations in the context of their specific circumstances and the service user's individual needs.

In addition, this information should be read alongside current versions of the following professional practice documents; knowledge of and adherence to these are assumed:

- *Standards of conduct, performance and ethics* (Health and Care Professions Council (HCPC) 2012).
- *Standards of proficiency: occupational therapists* (HCPC 2013).
- *Code of ethics and professional conduct* (COT 2015).
- *Professional standards for occupational therapy practice* (COT 2011).

Occupational therapists should also be familiar with their relevant country-specific policy documents and performance measures.

2.1 Occupational therapy models and frames of reference

Occupational therapy models guide occupational therapists' practice and ensure that they remain within their professional domain and area of expertise (Crepeau et al 2009).

Frames of reference draw from multiple theories and offer an organising structure to facilitate the translation of theory into practice (Hinojosa et al 2010). Frames of reference are not used exclusively by occupational therapists; therefore an occupational perspective should be taken when using frames of reference.

When working with children and young people with acquired brain injury, the occupational therapist will need to decide on the model and, if appropriate, frame(s) of reference they will use to guide their practice. If using multiple frames of reference, it is essential to ensure consistency within the theoretical concepts so that practice is coherent and contradictions are avoided.

As a starting point, **models of practice** that could be considered include:

- Person-Environment-Occupation (PEO) Model (Law et al 1996)
<http://cjo.sagepub.com/content/66/3/122.short>
- Occupational Therapy Intervention Process Model (OTIPM) (Fisher 2009, 2013, Fisher and Griswold 2014a)
<http://www.innovativeotsolutions.com/content/otipm/>
- Canadian Model of Occupational Performance and Engagement (CMOP-E) (Polatajko et al 2007) <http://www.caot.ca/default.asp?pageid=3781>
- Model of Human Occupation (MOHO) (Kielhofner 2008)
<http://www.cade.uic.edu/moho/>
- Kawa model (Iwama 2006) <http://kawamodel.com/>

All websites accessed on 19.05.15.

Additional information on these models and others can be researched via the following texts:

- Schell BB, Gillen G, Scaffa M, Cohn E eds (2014) *Willard and Spackman's occupational therapy*. 12th ed. Philadelphia, PA: Lippincott Williams and Wilkins.
- Turpin M, Iwama M (2011) *Using occupational therapy models in practice: a field guide*. Edinburgh: Churchill Livingstone.

Frames of reference that could be considered include:

- The Four-Quadrant Model of Facilitated Learning (Greber et al 2007a, b).
- Enhancing Childhood Occupations: SCOPE-IT (Haertl 2010).
- Motor Control and Motor Learning Theories (including Dynamic Systems Theory and Neuronal Group Selection Theory) (see Cole and Tufano 2008, Law and Darrah 2014 for a description).
- Acquisitional Frame of Reference (Mosey 1986).
- Applied Behavioural Frames of Reference (see Cole and Tufano 2008).
- Cognitive Behavioural Frames (see Cole and Tufano 2008).
- Biomechanical and Rehabilitative/Compensatory Frames (see Cole and Tufano 2008).
- Lifespan Development Frames (see Cole and Tufano 2008).
- Psychodynamic Frame (see Cole and Tufano 2008).
- Neuro-Developmental Treatment (Bobath 1948).
- Sensory Integration and Processing (Ayres 1972a, b, 1979, 1989, Schaaf and Davies 2010).
- Theory of Occupational Adaptation (Schkade and Shultz 2003, Shultz 2014).

Additional information on these frames of reference and others can be researched via the following texts:

- Cole MB, Tufano R (2008) *Applied theories in occupational therapy: a practical approach*. Thorofare, NJ: Slack.
- Kramer P, Hinojosa J eds (2010) *Frames of reference for pediatric occupational therapy*. 3rd ed. Philadelphia, PA: Lippincott Williams and Wilkins.

2.2 Evidence-based practice

Alongside using an occupational therapy model and, if appropriate, frame(s) of reference, it is the responsibility of the individual occupational therapist to use research evidence to inform their practice (COT 2015, p37). Evidence-based practice is the 'conscientious, explicit, and judicious use of the current best evidence in making decisions about the care of individual patients' (Cochrane Community 2014, Sackett et al 1996, p71). Applying research evidence to practice is evolving. Constant review and reflection of occupational therapy interventions is an essential part of any occupational therapy process. This may involve service user feedback and practitioner experience as well as systematic evaluations and research trials.

As a starting point, see the College of Occupational Therapists' literature search on occupational therapy for children and young people with acquired brain injury available at: <http://www.cot.co.uk/hot-topics/hot-topics>

Additional information relating to the use of evidence-based practice can be found at the following websites:

- School for Rehabilitation Science, McMaster University: <http://www.srs-mcmaster.ca/>
- Evidence Based Nursing Practice: <http://www.ebnp.co.uk/>
- Centre for Evidence-Based Medicine: <http://www.cebm.net/>

All websites accessed 21.01.15.

3 Paediatric intensive care unit/high dependency unit

3.1 The role of the occupational therapist

When a child is first admitted to a paediatric intensive care unit (PICU) the immediate aim of the medical team is to stabilise the child's medical status and address any threats to his or her life and loss of function. During this time the child may be intubated and ventilated. The child will also be nursed in line with medical neuro-protection principles to reduce the risk of further complication. This is a medical approach using pharmacology and technology to prevent or slow disease progression and secondary injuries. It may or may not be possible to begin occupational therapy assessment during these early days. The initial role of the occupational therapist in the PICU includes the prompt identification of changes in body structures and functions that place a child at risk of longer-term impairments.

At an appropriate time, it is important to explain to the parents the involvement of the occupational therapist in their child's care and how the focus will be on enabling the child to engage in activities which are important for them and the family. The timing and nature of the information exchanged with families will need to be determined on an individual basis through building positive communication with the child and family. A key component of this is supporting children and their parents to express their priorities and have the opportunity to ask questions. Through active engagement in occupations of everyday living, occupational therapists believe this will have a positive impact on recovery (Wilcock 2006).

It is essential that all assessments and interventions are fully explained along with clear clinical reasoning to the parent/carer/young person and consent obtained. In some circumstances written consent may be required within the service, for example splinting or video/photographs to be used as an outcome measure.

Rehabilitation following an acquired brain injury (ABI) does not follow a set protocol due to the variety of mechanisms of injury and structures affected. Rather, rehabilitation is an individualised process that will often involve a multidisciplinary approach; how this will be done will change and evolve as the child's condition improves/changes.

For any child or young person who is in hospital following an ABI it will have an impact on their psychological wellbeing. The family including siblings will also be affected by this traumatic event. The occupational therapist needs to be mindful of this impact and support the child/young person and family through actively listening to concerns or worries, giving information when required and recognising when to give space. Written information, signposting to web-based resources, creating a dedicated time to sit and discuss plans, and setting up personalised timetabling can be helpful strategies for supporting families to manage the information they receive from the multidisciplinary team.

For an occupational therapist, in the initial stages of involvement it will be important to gain an understanding of the child's roles, interests and abilities prior to their injury, obviously being considerate of the family's emotional vulnerability at this time.

3.2 Assessment approaches

This section includes details of assessments that would be suitable in a PICU setting. Further information about relevant methods of assessment at this stage can also be found in section 4.2.

3.2.1 When to assess

Discuss with the child's medical team whether the child is stable enough for an initial occupational therapy assessment. This will usually be within their first week on the unit. Correct timing for assessment in PICU is important; it might be too early to assess the child if they are too medically unwell.

Any assessment should be undertaken with a nurse or doctor present who is familiar with the child. A child's condition in PICU can change rapidly, therefore regular review and liaison with the nursing and medical team are essential. In addition to stability of medical condition, considerations at this stage should include the level of distress, discomfort or fatigue a child may be displaying with basic care routines and potential impact of attempting further assessment requiring handling, moving, communication or sustained attention. The timing and prioritisation of the assessment should be carefully considered as part of the child's overall health management plan.

3.2.2 What to assess

The first stage in the assessment is to review the medical records. Always check with the medical team and note any contraindications prior to occupational therapy involvement. For example, there may be pelvic or other fractures that require bed rest or non-weight bearing. Also spinal fractures could be unstable, meaning that either the child should not be moved, or moved in a specific manner such as through log rolling and/or with the use of a neck collar. Children in these situations can still be assessed but be aware of the precautions.

A child's vital signs should be stable before getting involved. It is imperative to keep checking the vital signs during the session and be alert to the alarms of monitors and aware of any precautions as well as medical attachments (i.e. external ventricular drains (EVD), catheters and other medical attachments). Nursing staff will usually provide one-to-one care in this environment and be present during occupational therapy contact with the child; thus close collaboration with the nursing staff is essential.

At this stage it is important to gain an understanding of the child's level of functioning at present. This could be done through observing the child, interacting with the child (through using activities as appropriate) and speaking with the staff and family involved with the child's care. Consider the impact of the immediate environment and the hospital care routines on the child. In addition, more specific assessments of body functions may be carried out to help inform you of the child's ability to engage in occupations. It can be helpful to talk to family members about the child's abilities prior to injury and their interests and personality. This must be done with sensitivity and the timing judged on a case by case basis depending on factors such as the acuity and stability of the child's condition and family preferences. This information can be very helpful in communicating with the child and family around their preferred activities and in focusing attention on the child as a whole. There will be situations where this conversation in more detail may be more appropriate when the child's condition has stabilised and she or he has been transferred to the hospital ward.

Observations of the child are a critical part of the occupational therapy assessment. For example, observing a child's response to commands in semi-structured play, or interaction with their parents, can provide valuable information regarding cognitive, social, language and motor function. Other standardised assessment may also be valuable. Some examples of assessments which may be helpful at this stage are listed below. Please note that assessments may need to be completed in conjunction with other members of the multidisciplinary team.

Careful consideration should be given to the tolerance of a child or young person when completing assessments. Monitoring the child or young person's responses to assessment and using a graded approach will ensure that the child is appropriately challenged, but not made uncomfortable or overly fatigued. Fatigue can result from being within a stimulating environment (sound, light, social interaction) and/or physical effort. For a child soon after diagnosis, sitting up out of bed for example can be very fatiguing. A child may demonstrate fatigue by appearing physically tired, having disturbed sleep, and by having difficulty sustaining attention or readily becoming tearful, restless or irritable. It is important to work within a child's ability and to carefully grade the amount and nature of stimulation and demands a child is exposed to so that they do not over-tire. For further information see Royal Children's Hospital Melbourne Paediatric Rehabilitation Service (2010a) *Brain injury – cognitive fatigue*.

Level of awareness

When assessing a child or young person to establish their level of awareness, the following points should be considered:

- The child's responses via observations and discussions with those involved with the child's care routines. This could include their reactions to how they are handled and their response to the sensory environment, e.g. visual, auditory and tactile stimuli.
- The child's level of awareness and ability to communicate should be initially determined. This could include non-standardised observations and interactions as well as the administration of standardised assessments.

In collaboration with the multidisciplinary team, at this time also consider:

- The psychological impact of the child being in the PICU environment. The child's behavioural responses to care routines, including interaction with staff, will guide the team regarding priorities for essential care and how much active therapy intervention is clinically indicated.
- If the child is experiencing post traumatic amnesia (PTA). If so, consider formal assessment – refer to Marosszeky et al (1997) for details regarding this and current practice for a child in PTA. Also see Royal Children's Hospital Melbourne Paediatric Rehabilitation Service (2010b) *Brain injury – post traumatic amnesia PTA*.
- Whether the child is experiencing cerebral irritation (e.g. irritability, distress, headache), for example, having poor tolerance of stimulation or change in stimulation, and a need to have protected periods of quiet in a relatively low stimulation environment. If so, consider the effect of sensory stimulation on the child's functioning.
- If the child has comorbidities, e.g. seizures, soft tissue or musculoskeletal injuries, or premorbid conditions that may impact interaction or behaviour.

Assessments which could be considered at this stage include the following.

Assessment	Details	Age range	Reference
The Wessex Head Injury Matrix (WHIM)	Assessment of patients in and emerging from coma and those in the vegetative and minimally conscious states.	12 years and above	Shiel et al 2000
Children's Orientation and Amnesia Test (COAT)	Assesses cognition during the early stage of recovery from traumatic brain injury. Composed of 16 items evaluating general orientation, temporal orientation and memory.	3 to 15 years	Ewing-Cobbs et al 1990
Glasgow Coma Scale (GCS)	Discriminative measure. A standardised assessment to measure the child's level of consciousness. This is generally administered by the medical team. A paediatric version of this scale is used in some settings – refer to hospital protocol.	Unspecified	Teasdale and Jennett 1974
Rancho Los Amigos – Revised	Measure of cognitive functioning based on response to testing. Scale of 1 (no response) to 10 (purposeful, appropriate). Used to evaluate level of recovery.	Unspecified	Hagen 1998
Westmead Post Traumatic Amnesia Scale	Measure of post traumatic amnesia. Consists of 7 orientation questions and 5 memory items.	16 years and above	Marosszeky et al 1997

Further information on Glasgow Coma Scale and Rancho levels can be found in:

- LeBorgne A (2014) Traumatic brain injury. In: BAB Schell, G Gillen, ME Scaffa, E Cohn, eds. *Willard and Spackman's occupational therapy*. 12th ed. Philadelphia, PA: Lippincott Williams and Wilkins. 1184–1186.

Posture and positioning

It is key that while the child is immobile or experiencing difficulties with movement, comfort is maintained by regular changes in position. It is also essential that postural care is considered and range of movement is maintained so that functional potential is optimised as the child improves and becomes more active. Improving proximal stability can enhance distal movements. Proximal stability is also important in efficient upper limb use, for example in performance of activities of daily living, for improved endurance, pain reduction and as a significant component of respiratory function. Enhanced postural control can also maximise pressure distribution and so minimise pressure sores.

Initially evaluate posture and positioning of the child in the bed in collaboration with physiotherapists, paying careful attention to:

- Any risk of pressure areas.
- Passive and active patterns of movement.
- Current muscle tone, strength and range of motion in the joints which may include standardised assessments. Also consider the National Institute for Health and Care Excellence clinical guideline on *Spasticity in children and young people* (NICE 2012) for further information in relation to the assessment of the upper limb.

Assessment	Details	Age range	Reference
Modified Ashworth Scale of muscle spasticity (MAS)	A clinical measure of muscle spasticity which uses a scale from 0 (no spasticity) to 5 (rigid).	Unspecified	Bohannon and Smith 1987

Functional assessments

In conjunction with speech and language therapy, consider positioning to promote communication, eating and drinking. For example, the occupational therapist could assess the child's position to optimise their ability to look around the environment, ensure safe swallowing and enable the child or young person to feed themselves if appropriate. This may involve the provision of adaptive equipment, e.g. cutlery or cups.

Regular reviews are required at this stage as the child's condition is expected to improve, stabilise or evolve. Assessment findings may contribute to medical decisions (e.g. medication to address tone management), as well as influence daily interventions (e.g. positioning in bed, provision of seating). Good communication between members of the multidisciplinary team is therefore essential.

To facilitate this communication, all occupational therapy involvement including positional changes must be documented in the child's medical records. This is also a requirement in order to comply with the *Standards of proficiency* issued by the Health and Care Professions Council (2013), the *Code of ethics and professional conduct* (COT 2015) and the *Professional standards for occupational therapy practice* (COT 2011).

3.3 Goal setting and outcomes

Goal setting should be realistic given the acute nature and uncertainty of the child's condition in this setting. Goals should be written in relation to what you would expect the child or young person to be able to do following intervention (i.e. the intended outcome). It is an important process as it ensures a focus for involvement and offers a way of evidencing the effectiveness of an intervention.

Goals should be developed in collaboration with the child/young person (if possible), family and members of the multidisciplinary team. The focus could be on areas such as:

- Maintaining and developing routines for the child around periods of rest, mealtimes, social connection with family and significant others, washing and dressing, etc.
- Maintaining and developing effective posture(s) so that the child can engage in their surroundings as appropriate.
- Maintaining and developing a child's communicative behaviours.

3.4 Intervention approaches

Information from the assessment and goals of the child and family will inform the intervention strategies. Consider the child's condition overall, including their levels of fatigue, and work closely with the multidisciplinary team to inform decisions around tolerance, intensity and nature of occupational therapy interventions during the early stages of recovery.

Providing parents/carers with a role in their child's recovery may enable them to re-assume their parental role and adjust to this new situation. Keep in mind, however, that it is an emotional and traumatic time for the family. Offering opportunities for the family to be involved can support the health and wellbeing of the family unit. These opportunities, however, should not create an additional burden or feelings of guilt as for some families it may be difficult for them to engage at this stage.

With any family involvement, ensure that they are given appropriate information to support their child and understand their current condition. When doing this, remember that families will be processing a lot of information from different professionals at the same time. In line with the National Institute for Health and Care Excellence guideline (NICE 2014) for the *early management of head injury in children, young people and adults*, keep information clear and focused on the priorities for their child and be prepared to repeat information and/or provide it in a variety of formats (e.g. verbal and written) as the family requires.

With any intervention it is vital to record and document occupational therapy involvement accurately, concisely and in a timely way (COT 2015). Further information can be sourced from the College of Occupational Therapists' guidance on record keeping (COT 2010).

3.4.1 Interventions addressing body structures and functions

In the acute stages of recovery, it may be important to focus interventions on the maintenance and development of a child's body structure and functions so that they have the opportunity to participate in occupations when sufficiently recovered (for example stability of the child's medical condition, fatigue, post traumatic amnesia and their motivation to engage in particular occupations). While it is important to address needs in relation to body structures and functions, an occupational therapist should always link these interventions to maximising the potential of the child to further engage in occupations.

24-hour postural care/positioning

Early implementation of 24-hour postural care is included in the National Institute for Health and Care Excellence guidelines for the *diagnosis and initial management of acute stroke and transient ischaemic attack (TIA)* (NICE 2008) and *spasticity in children and young people with non-progressive brain disorders* (NICE 2012). In PICU it is common for children to remain sedated and intubated; therefore their active movement is limited. The nursing team often take the lead in positioning over the 24-hour period, alternating between supine and side lying positions mainly to prevent pressure sores. The physiotherapy team is also often involved in providing daily stretching exercises as changes in tone often affect the child's active and passive range of movement. The role of the occupational therapist at this stage is to promote postures and positions which will enable the child's involvement in their daily occupations to their level of ability in the recovery process. This could be through providing a supportive bed or chair sitting position so that the child can engage with their immediate environment, and to promote the maintenance of range of movement and comfort for the child at rest.

At this stage of recovery the occupational therapist will need to focus on using positioning and equipment to minimise joint deformities and contractures as well as promote a symmetrical posture. Initially children may demonstrate a degree of cerebral irritability which may exacerbate involuntary movements. Extra movements of the upper limbs can be reduced with use of containment/swaddling. This can also be addressed with positioning and handling advice. When providing advice on posture and positioning, be explicit about the intended functional outcome for the child such as engaging in mealtimes, leisure activities or self-care routines. Activities could also involve the speech and language therapist in supporting access to assistive and augmentative communication (AAC), such as eye pointing to a choice of two objects or simple communication boards. This is reliant on the child being able to show some early cognitive skills, e.g. object permanence and cause and effect.

Consider the environment and how this can be adapted to improve posture or provide a more/less demanding challenge. A photo programme can be used (provided consent is gained from parents/carers) and this can be annotated according to the aims of the therapists. This would consist of a series of photographs which demonstrate the child or young person in a suitable position and indicate how frequently they should change positions. It may be that the child would benefit from a particular position on their side or back with frequent changes between these positions. Photo programmes can also be useful in ensuring the child is sitting appropriately in their chair or wheelchair.

Careful consideration should be given to the tolerance of the child in a sitting position. Using a graded approach will ensure that the child is appropriately challenged, but not made uncomfortable or overly fatigued.

Upper limb management

Following an acquired brain injury, a child or young person may not be able to move their arms and hands with the quality and variety of movement they had prior to injury. Abnormal muscle tone and patterns of movement may emerge. Depending on the child's medical condition, tone modifying medication may or may not be prescribed. Consider the use of this medication and its effect during upper limb intervention.

Passive range of movement (PROM) stretches

PROM stretches involve the therapist or carer physically moving the child's joints through the full range of movement. While there is no evidence to support the notion that passive range programmes are effective in retaining range of movement, moving joints passively is required to maintain joint health and integrity (Copley and Kuipers 2014). Liaison with a physiotherapist would be appropriate. This passive stretching could offer parents/carers the opportunity to be actively involved in their child's care during this time, although this should not be insisted upon. If a stretch programme is put in place try to integrate it into daily care routines. Providing written information with diagrams or photos, giving demonstrations and allowing the parent/carers to practise with the support of the therapist enables them to become confident in this aspect of their child's routine. A child's patterns of movement and tone may change over a short period of time; therefore it is important to monitor range of movement and the need for intervention regularly.

This type of stretching (or ranging of joints) is often used alongside other interventions such as splinting. Splinting is considered a sustained stretch as it is maintained over a longer period of time. If a child is neuro-protected or has an intracranial pressure (ICP) monitoring system in place, check whether splinting is increasing distress to the child. See section 4.4.3 for information on resting splints.

3.4.2 Compensating to enable participation

A child or young person may be aided by changes to the environment and tasks. The occupational therapist should consider how routines and equipment can support a child or young person's participation.

Use of routines

While in PICU, children are exposed to a variety of stimuli due to the equipment and high staffing levels associated with this environment. Children after an acquired brain injury can perceive routine stimulation as distressing or noxious. This includes touch (such as handling needed for care and medical interventions), sound (observations machine, ventilators, intravenous lines) and light (bright artificial lighting, television, computer or phone screens). Minimising the visual, auditory and tactile stimulation a child experiences may assist in their rest and sleep routines. Gradually introduce stimulation during the occupational therapy intervention sessions by offering sensory experiences (consider tactile, auditory, visual and movement possibilities).

The use of a timetable may be helpful. The family and multidisciplinary team should agree on specific opportunities for intervention and 'time-off' periods where interventions are restricted to minimal (e.g. minimise conversation and activity by the bed). Frequency and length of intervention will depend on the child's state and rate of improvement/recovery. It is important to keep in mind that a child with an acute acquired brain injury will require considerable periods of rest, so this needs to be incorporated into any routines and carefully explained to family members. In some settings, timetabling may be standard multidisciplinary practice. If not, it would be useful to have the timetable clearly visible for staff and the family. Using colours, images and limiting the amount of text will help convey this information to a range of people in a busy setting.

The National Institute for Health and Care Excellence guideline for the *early management of head injury in children, young people and adults* (2014), recommends providing encouragement to family members and carers to talk with the child and make physical contact (such as hand holding). This should be balanced with periods of rest for the child and family. Families should not feel obligated to spend extensive periods of time at the bedside. Visitors should be limited during the early phases of admission so that the child is not over-stimulated.

PICU considerations for equipment

Necessary equipment to increase safety, independence or for rehabilitation, such as seating, wheelchairs and mobility equipment, should be provided as soon as appropriate, particularly if the child is unable to sit independently (Golisz 2009, NHS Clinical Advisory Group Report 2011, Royal College of Physicians and British Society of Rehabilitation Medicine 2003).

Before prescribing equipment in PICU, consider the reason and purpose of the equipment and how it supports the occupations of the child or young person. Children in PICU are often fully sedated or paralysed, therefore the use of equipment will be focused on promoting optimal positioning in preparation for occupation (see information on 24-hour postural care). In situations where a child is alert and able to initiate rehabilitation, supportive seating equipment to enable engagement and performance of activities could be introduced. The timing and suitability of transitioning to equipment and the support needs required will be based on clinical examination of the child's postural ability and response to environmental stimulation, e.g. ability to maintain head control and to use hands in play while in a supported sitting position.

When moving the child it is essential to comply with the manual handling requirements and risk assessment procedures of the PICU setting. Also, pay careful attention to the child's medical equipment (e.g. EVD) when moving the child or selecting equipment. Based on the assessment of the child consider the level of support needed in equipment prescription. For example, if it is observed that a child has poor head control consider a chair with a high back or head support. The multidisciplinary team may need to be guided by the occupational therapist in appropriate and safe transfers, as well as the duration and frequency of use of the equipment. This could be included in the child's timetable if appropriate.

3.5 Discharge planning

For children with acquired brain injury, their pace of recovery will vary greatly. Hospital settings will have their own protocols for transitioning children from PICU settings to inpatient acute hospital wards to continue early rehabilitation. If this is a different team in the hospital, ensure that a robust handover is provided to facilitate a smooth transition for children and their families to avoid unnecessary delays or incorrect information being received.

Handover information should include an outline of the child or young person's current functional ability and needs, the therapy goals which have been achieved and planned, and any postural care and equipment needs. Any pre-injury information related to the child's occupational engagement and performance will also be relevant. Consideration should also be given to liaison with other professionals such as clinical psychologists, community or social care occupational therapists, social workers, case managers, etc.

For additional information on discharge planning please see section 4.5.

4 Inpatient acute hospital ward

4.1 The role of the occupational therapist

The role of the occupational therapist is to maintain and develop the child or young person's engagement and participation in their daily life tasks. How occupational therapy input is undertaken will vary as the child or young person's condition at this stage can vary greatly, ranging from being minimally conscious to walking and talking. Examples of the occupational therapy role are described in the sections that follow.

Involvement of the child's family is vital at each stage of the occupational therapy process. Written information should be made available in addition to verbal information so that families can utilise it when required. Every situation is different; some families will welcome information very soon after their child is admitted, while others will not be able to read it for some time as they may be overwhelmed with their child's medical condition. Working with the family of a child or young person with acquired brain injury (ABI) requires sensitivity. The grief of family members will present in variable ways. This could impact on the presence or absence of family members during therapy sessions and their need for careful communication of the purpose and nature of the occupational therapy intervention.

4.2 Assessment approaches

Prior to beginning the assessment of a child, it is essential to liaise with the parents/carers and where possible the school, to gather pre-injury information about their developmental level, likes and dislikes and personality, to form a baseline. This information is key to ensuring that interventions are child-centred and meaningful, and to act as a guide for goal setting.

If a child is conscious, the occupational therapist may be able to begin their assessment at the level of occupational engagement and performance and then, if indicated, progress to impairment focused or environmental assessments. If the child is presenting in a vegetative state it may be necessary to focus on their impairments of body structures and functions (e.g. motor, cognitive, intrapersonal/interpersonal skills) and the impact of the environment.

At all times, consideration should be given to the child or young person's physical, mental and emotional needs. The child or young person has gone through a traumatic experience and the impact of this will be different for every person. The child or young person may also have issues with fatigue so the amount of activity expected should be carefully considered and a timetable for multidisciplinary intervention should be in place to enable sufficient rest periods. See section 3.2.2 for more information regarding fatigue and impact on functioning and intervention. Consider how fatiguing it can be for a child to attend to conversation or respond to commands in a noisy and busy ward environment.

Further information about relevant methods of assessment at this stage can also be found in section 3.2.

4.2.1 Level of consciousness

Children in a minimally conscious state will have periods of being awake. They also can show signs of ‘purposeful’ behaviour – things they have meant to do, rather than ‘autopilot’ reflexes. They might smile or cry in response to something, or reach out for an object. Some children in this state might be able to make some sounds or say words. All of these responses are limited, often subtle, and not consistent. This state may be permanent, or may be a stage that leads to further recovery.

Assessments which could be considered at this stage include the following.

Assessment	Details	Age range	Reference
The Wessex Head Injury Matrix (WHIM)	Assessment of patients in and emerging from coma and those in the vegetative and minimally conscious states.	12 years and above	Shiel et al 2000
Children’s Orientation and Amnesia Test (COAT)	Assesses cognition during the early stage of recovery from traumatic brain injury. Composed of 16 items evaluating general orientation, temporal orientation, and memory.	3 to 15 years	Ewing-Cobbs et al 1990
Glasgow Coma Scale(GCS)	Discriminative measure. A standardised assessment to measure the child’s level of consciousness. This is generally administered by the medical team. A paediatric version of this scale is used in some settings – do refer to your hospital protocol.	Unspecified	Teasdale and Jennett 1974
Rancho Los Amigos – Revised	Measure of cognitive functioning based on response to testing. Scale of 1 (no response) to 10 (purposeful, appropriate). Used to evaluate level of recovery.	Unspecified	Hagen 1998
Westmead Post Traumatic Amnesia Scale	Measure of post traumatic amnesia. Consists of 7 orientation questions and 5 memory items.	16 years and above	Marosszeky et al 1997

4.2.2 Sensory responses

Assessment of the child’s behavioural responses to visual, auditory, olfactory, oral, movement and tactile stimuli will be important as it can provide information on the child’s sensory state. Consider the impact of sensory stimuli within the child’s environment and implement appropriate strategies to assist the child to cope within their surroundings, e.g. decreasing the number of visitors at one time, decreasing noise or visual input. Assessment of responses to sensory stimuli at this stage would be through structured observation of single sense stimulation, e.g. when assessing vision, avoid noisy toys. Standardised assessments may also be useful.

Assessment	Details	Age range	Reference
Sensory Profile 2	This consists of standardised forms completed by caregivers and teachers to detect disorders in children's sensory processing patterns.	Birth to 14 years 11 months	Dunn 2014
Sensory Processing Measure (SPM)	A set of three integrated rating scales to detect and describe difficulties in sensory processing, praxis and social participation at home, in the classroom and in the school environments. The Home Form (75 items) is completed by the child's parent or home-based care provider. The Main Classroom Form (62 items) is filled out by the child's primary classroom teacher. The School Environments Form (10–15 items per environment) is completed by other school personnel who work with and observe the child.	5 to 12 years	Parham et al 2007

4.2.3 Comfort

It is essential to consider the comfort of the child, particularly as their mobility might be impaired. Observations of the child's reactions are an important indicator of their level of comfort. Also consider strategies to empower the child to communicate any pain or discomfort as they are able. Liaison with the speech and language therapist should be sought when the child's ability to communicate is impaired. If appropriate, a pain scale may be used (Royal College of Nursing 2009). Formal evaluation of pain should be undertaken in communication with the broader clinical team and in accordance with local protocols. It is important that pain ratings are reported in a standardised way for the whole team as the findings may influence the nature and intensity of intervention provided and inform medical and nursing staff regarding a child's need for analgesia.

Pressure management is vital in ensuring the child's comfort. This could involve a turning programme/regular change of position and use of a specialist pressure relieving mattress. Liaise with nursing and tissue viability staff as appropriate as part of this pressure management. See section 4.2.8 for further information.

4.2.4 Moving and handling

The child will often need to be supported to move and change positions to enable them to engage with the environment and their occupations. Consider the need for sliding sheets, sliding boards and/or hoist for transfers. Liaise with physiotherapy, nursing staff and manual handling adviser as appropriate. Assessment of the moving and handling needs should be assessed on admission and reviewed regularly as the child's needs change. This should be in accordance with local policy and procedures. Ensure the appropriate documentation is completed and the multidisciplinary team have an agreed moving and handling strategy for the individual child. The use of photographs and/or instruction sheets at the bedside may assist the staff and family to maintain these procedures.

4.2.5 Occupational performance

The goal of occupational therapy is to enable a child's occupational engagement and performance; therefore an assessment of the child's occupational performance should be carried out as soon as reasonably possible. This is likely to include an observation and/or standardised assessment of self-care, leisure, play, mealtimes and sleep routines. The use of activity analysis will be helpful to determine how occupations can be graded or adapted to support the child's performance. See sections 5.2 and 6.2 for further information.

4.2.6 Safety awareness

When carrying out any assessment it is vital to observe the child's emotional and behavioural responses and assess the child's safety awareness. For example, the child may have decreased balance, impaired condition (e.g. poor planning skills) or visual deficits which impact on their ability to carry out tasks safely. Always consider assessing safety awareness if the child/young person presents with post traumatic amnesia. Safety awareness is particularly important to consider for discharge planning and level of supervision available upon discharge.

4.2.7 Communication

In collaboration with the speech and language therapist assess the need for assistive technology (switches, communication boards) or low technology methods, e.g. indicating responses by blinking/eye pointing/gesturing at pictures/symbols/words for communication. Ensure the family are involved with the communication strategy and the multidisciplinary team are consistent in using the system. This will assist the child's learning and avoid confusion.

4.2.8 24-hour postural care/positioning

The role of the occupational therapist is to promote postures and positions which will enable the child's involvement in their daily occupations to their level of ability in the recovery process. This may include assessing the child's resting posture, their ability to actively change position or the ability for care providers (and families) to position the child in optimal anatomical or functional postures. When assessing the child's posture, many factors must be considered such as the child's ability to safely follow instructions, their alertness level, strength, tone and range of movement. The child may require assessment for equipment to support positioning such as sleeping systems, an indoor static chair and/or wheelchair for external use.

Seating

Seating should initially provide full postural support if required, with tilt in space, recline, head and thoracic support, hip guides, calf straps and suitable footplates (removable to assist with transfers). The pelvis should be anchored with hips at 90° or less where appropriate (this is particularly helpful in children with dystonia). A ramped cushion may be required to close the hip angle for children who tend to posture into a pattern of extension. It is important to monitor the child's alignment and changes in postural tone. Also see section 4.2.3 for further detail regarding the comfort of the child or young person. Considerations for the individual child in prescribing seating should include any medical or surgical precautions including presence of fractures and post-operative moving and handling protocols. Passive and active joint range, the child's response to handling and positioning when outside equipment and tolerance of seating equipment prescribed should be closely monitored and adjustments made when required. Frequently a child will require

regular review of their seating during their admission as their condition changes and their recovery progresses. A graded approach to tolerance of seating may be required with initially short bursts of sitting followed by more reclined sitting or return to rest in bed. This will need to be individually assessed considering the child's related medical and surgical condition.

Muscle tone

Tone can be defined as the muscle resistance to passive elongation or stretching. Generally, tone is described as normal, increased or decreased. Normal tone presents as a slight resistance to passive movement. Increased tone or hypertonia is defined as 'abnormally increased resistance to externally imposed movement about a joint' and is usually associated with spasticity (Sanger et al 2003, p89). Abnormal tone may be one factor which hinders a child or young person's ability to move their body and limits their opportunities to engage in occupations.

Hypotonia and hypertonia may need to be assessed when interventions involve medication, positioning and splinting/orthotic needs. Tone can be assessed by palpation of the muscles or by clinical observation of the response of muscles to passive stretching (Radomski and Latham 2008). This can be done by slowly ranging a joint through its normal movement and then moving it faster to detect any changes in resistance (e.g. spasticity is a velocity dependent presentation). It is important to check: shoulder flexion/extension and abduction/adduction; elbow flexion/extension; supination/pronation; finger flexion/extension. In the lower limbs it is important to check: hip abduction/adduction and flexion/extension; knee flexion/extension; and ankle flexion/extension. By checking different joints more information is obtained on the possible distribution of abnormal tone (i.e. predominately proximal or distal).

Tone evaluation remains an area of clinical examination where inter-rater differences are prevalent. It is recommended that the occupational therapist develop skills and knowledge in assessing tone through working alongside experienced colleagues. Every child is different and factors such as emotional stress, temperature, fatigue, changes in sensory stimulation, head position, alertness and medication can influence the assessment. Reviewing tone at similar times of the day and considering the factors above can help intra-rater reliability (Radomski and Latham 2008). Depending on the age of the child, at times they may actively resist passive ranging but this should not be confused with increased tone. Engaging with the infant/child first before assessing tone can help prevent the child actively resisting. Consider talking slowly/singing to relax the infant/child.

Newborns can present with increased resistance to passive stretching, and/or often present with fistled hands; however, this can be normal as long as it does not hinder passive/active movement. For more information on paediatric neurologic examinations for children up to 2½ years old see: http://library.med.utah.edu/pedineurologicexam/html/newborn_n.html Accessed on 19.05.15.

Assessments for tone could include the following.

Assessment	Details	Age range	Reference
Modified Ashworth Scale of muscle spasticity (MAS)	This clinical measure of muscle spasticity uses a scale from 0 (no spasticity) to 5 (rigid).	Unspecified	Bohannon and Smith 1987
Modified Tardieu Scale (MTS)	This scale assesses the muscle's response to stretch at various given velocities.	Unspecified	Haugh and Pandyan 2006
Hypertonia Assessment Tool (HAT)	Discriminates between dystonia, spasticity and rigidity in children.	4 to 19 years	Jethwa et al 2010

Passive and active range of movement

In collaboration with the physiotherapist, consider the need to establish a stretching programme, splinting and casting, with particular attention in the upper limbs to elbow flexors, supination, long finger flexors and thumb adductors. Record the joint range of motion measurements as this can be used to monitor change (Bukowski 2000, Latella and Meriano 2003, McMillan and Carin-Levy 2012).

Active range of movement will support the child's opportunities to participate in their occupations. If considered necessary, and in collaboration with the physiotherapist, assess the child's ability to actively move their upper limbs through all planes of movement, against gravity and against resistance. This may be one factor which is contributing to the child's challenges with engaging in occupations. When assessing active and purposeful movement consider the motivation of the child and try to use tasks which may be of interest or importance to them.

4.2.9 Cognition/perception

Depending on the presentation of the child, either a cognitive screening or a comprehensive cognitive assessment should be completed. This should include attention, memory, spatial awareness, apraxia and perception (NICE 2013). Information on the child or young person's pre morbid functional level should also be sought through discussion with parents and liaison with school as this will inform whether current impairments are acute or previously present.

It may be necessary to consider visual motor skills, visual fields and visual perception if there is an indication that this could be impacting on a child's occupational engagement or performance. This could be undertaken through using standardised assessments and/or clinical observations. Also if indicated, consider assessing for attention, orientation, memory, information processing and executive skills through clinical observation.

Assessments which could be considered include the following.

Assessment	Details	Age range	Reference
Beery-Buktenica Developmental Test of Visual–Motor Integration – 6th edition (VMI)	The VMI assesses visual–motor skills in children and adults that may be associated with learning, neuropsychological and behaviour problems. The Short Format and Full Format tests present drawings of geometric forms arranged in order of increasing difficulty that the individual is asked to copy. The Short Format is often used with children ages 2 to 8 years.	2 to 100 years	Beery et al 2010
Lowenstein Occupational Therapy Cognitive Assessment – 2nd edition (LOTCA)	Cognitive screening assessment. The LOTCA is a series of tests that evaluate abilities in four areas: orientation, visual and spatial perception, visual motor organisation and thinking operations.	6 to adult	Itzkovich et al 2000
Rivermead Behavioural Memory Test for Children (RBMT-C)	This test comprises a series of subtests spanning a range of everyday memory problems reported and observed in subjects with memory difficulties.	5 to 12 years	Aldrich et al 1991
Wide Range Assessment of Visual Motor Ability (WRAVMA)	Designed to evaluate three skills in a child’s visual–motor functioning.	3 to 17 years	Adams and Sheslow 1995
Developmental Test of Visual Perception 3 (DTVP-3)	Assess visual perception and visual–motor integration skills.	4 to 13 years	Hammill et al 2013
Test of Visual Perceptual Skills (non-motor) (TVPS3)	Standardised assessment of paper-based visual perceptual abilities.	4 to 13 years	Martin 2006

Liaise with the psychology team if there are concerns regarding a child’s cognitive skills and how these may impact the individual’s daily life abilities.

4.3 Goal setting and outcomes

Setting collaborative goals with parents and where possible the child or young person is a core occupational therapy skill (COT 2011) ensuring interventions are child and family centred (Rosenbaum et al 1998). Goals should be written in relation to what you would expect the child or young person to be able to do following intervention (i.e. the intended outcome). Goals should be based on the child’s occupational engagement and performance. Consider the child and family’s needs, current level of acceptance and motivation for areas such as self-care, productivity and leisure occupations.

General stages in the goal setting process include:

- Collaborating with parents/carers to develop the goal(s). This could include using tools such as the Canadian Occupational Performance Measure (COPM) (Law et al 2014).
- Involving the child/young person as much as possible such as through using the Perceived Efficacy and Goal Setting System (PEGS) (Missiuna and Pollock 2000) or COPM.
- Agreeing and recording goals with the child/young person, parent and team.
- Describing the baseline, i.e. what is the child/young person able to do now?
- Describing the expected level of achievement, i.e. what will the child/young person be able to do following occupational therapy intervention?
- Ensuring goals are SMART (Doran 1981).
 - S = Specific
 - M = Measurable
 - A = Attainable
 - R = Realistic
 - T = Timely.
- Planning intervention.
- Reviewing.

Assessment	Details	Age range	Reference
Perceived Efficacy and Goal Setting (PEGS)	The PEGS is a tool that enables young children to reflect on their strengths and abilities and identify areas of daily challenge. It provides young children with disabilities with the opportunity to share their perceptions of their current performance level on daily activities. It consists of picture cards that illustrate 24 tasks essential for daily living and participation in school. These tasks are age appropriate and reflect skills that have normally been acquired by children of this age.	6 to 9 years	Missiuna and Pollock 2000, Missiuna et al 2006
Canadian Occupational Performance Measure (COPM) 5th edition	The COPM is a client-centred tool to enable individuals to identify and prioritise everyday issues that restrict or impact their performance in everyday living. It has a broad focus on occupational performance in all areas of life, including self-care, leisure and productivity, taking into account development throughout the lifespan and the personal life circumstances.	Parent interview or child above the age of 8 years and parent	Law et al 2014

(Continued)

Assessment	Details	Age range	Reference
Goal Attainment Scaling (GAS)	GAS is a measurement approach that grades multiple levels of an individual person's goals, and has a scoring system which allows for comparisons between people.	Parent interview or child above the age of 8 years and parent	Turner-Stokes 2009

4.3.1 Goal Attainment Scaling

Goal Attainment Scaling (GAS) (Turner-Stokes 2009) can be a very useful way to set personalised goals that target functional goals of the child and family. During rehabilitation, 2–3 functional goals can be very helpful in measuring change that may be more difficult to capture using standardised measures, and are often more meaningful to families. Functional activities are observed and described in detail, placed on a five-point scale, and specific therapy aims are defined for future evaluation.

A variety of guides on writing GAS goals are available on the internet, for example:

- GAS in Rehabilitation: <http://www.bsrm.co.uk/>
- McMaster University Family Centred Resources: <http://canchild.ca/>
- Goal Setting Guide: <http://www.goal-setting-guide.com/>
- GAS Resource Book/Training Manual: <http://www.tvcc.on.ca/>

All websites accessed on 21.01.15.

4.4 Intervention approaches

It is widely understood that occupational therapy intervention is unique in its ability to make a difference to the child's occupational performance (Wilcock 2006). Occupational therapy at this acute stage may focus on maintaining a child's body function and structure so they have the opportunity to participate in their daily life tasks when their medical condition becomes stable. Occupational therapy interventions should be goal directed, functional and meaningful to the child and family.

In the acute stage most children will benefit from a therapy session on a daily basis, dependent on service capacity and the child's level of tolerance (NICE 2013). It may be that some children fatigue quickly so require shorter sessions. Other children will be able to tolerate longer daily sessions. According to the *Stroke rehabilitation* guidelines (NICE 2013), patients should be offered as a minimum a 45-minute session daily if tolerated, or daily shorter sessions as tolerated. As this guidance is not specific to people with acquired brain injury, it is important to use clinical reasoning and adjust the length and/or complexity of the sessions according to how the child or young person is presenting.

Priorities for intervention will be dependent on the goals you have set. When involving family members in the intervention strategies it will be important to include written information so they can refer back to it.

At all times, consideration should be given to the child or young person's physical, mental and emotional needs. The child or young person has gone through a traumatic experience and the impact of this will be different for every person. Enabling engagement in meaningful occupations is how the occupational therapist can support a child or young person's physical, mental and emotional recovery.

Intervention approaches should be theoretically and if possible evidence based (refer to section 2 for a detailed description) (Gordon and di Maggio 2012). The focus should remain on the child or young person's engagement and occupational performance.

4.4.1 Functional rehabilitation

As the child begins to regain active movement and respond to stimulation there are several approaches and interventions which can be used to improve the child's occupational performance. Familiarity with the principles of motor learning theory (Zwicker and Harris 2009) and dynamic systems theory (Cole and Tufano 2008, Law and Darrah 2014) can be useful in supporting and guiding intervention selection and delivery. The occupational therapist should determine a suitable approach depending on the child and their needs. Consideration should be given to the type(s) of occupation that are suitable for this stage in recovery. In particular it may be necessary to limit the use of mobile phones and tablets as they could be over-stimulating for the child or young person (CanChild 2014).

Options for intervention may include a focus on the following areas.

Self-care

Interventions for self-care may involve compensating to enable a child/young person to participate as appropriate in self-care occupations. For example:

- Adapting the routine so that activities are undertaken at the time of day which is most suitable for the child's tolerance levels and needs.
- Involving the family in helping complete some of the daily care activities for the child.
- Providing a wheelchair to enable access around the hospital.
- Providing a sliding board to assist transfers from bed to chair or toilet.
- Providing a bath board or shower chair to assist washing.
- Providing pressure relief cushions to ensure comfort while resting or participating in self-care tasks.

Sleep

Sleep hygiene is the control of behavioural and environmental factors that precede and may interfere with sleep (American Academy of Sleep Medicine 2001). Sleep-wake cycles are disturbed by the injury itself and by time spent in hospital. It is important to establish a bedtime and waking routine that is carried out consistently. This could be through the use of a timetable (see section 3.4.2 for further details). The timing of sleep, mealtime regimes and the actual sleep environment are important aspects of sleep hygiene. Pharmacological interventions may also be required.

Productivity

The child should have the opportunity to engage in productive occupations in a way which is appropriate for their stage of recovery. The child's cognitive skills can change significantly during the admission and fluctuate due to factors such as medication. In selecting appropriate tasks, the child/young person's age, interests, motivation and previous knowledge should be considered. This may include asking parents for the child's favourite toys, choosing favourite games or school activities or photographs of their pets. The tasks should be graded so that they are achievable for the child while maintaining a degree of challenge. Repetition and practice will be helpful for the child in developing their skills. Using a daily calendar as another cognitive rehabilitation technique will also help the child to establish their routines and orientate them to the time of day, etc. Also consider collaborating with education specialists if appropriate and available within the hospital setting.

Play/leisure

The child should have the opportunity to engage in leisure occupations and these could be included on the child's daily timetable. The types of task will depend on the child or young person's age, interests, motivation and stage in their recovery. For example, shape and colour matching games, popping bubbles, messy play, listening to an audiobook, origami, etc. Grading activities will be important so that the child is able to engage and participate. Equipment and postural support to promote engagement in leisure may be appropriate. Consider collaborating with play specialists if they are available within the hospital setting.

4.4.2 Environmental considerations

There are important considerations during the acute phase of recovery with regard to sensory responsiveness. At this stage of recovery a child may find the environmental stimulation challenging; a degree of confusion, irritability and impulsivity in behaviour may be present in some cases. In this situation, the impact of the environment on the child's safety should also be considered. A timetable to carefully grade the amount and type of stimulation can be useful in not over-stimulating a child. While many children are being cared for in a highly stimulating intensive care or ward environment, discussion with team members to allow rest when only essential observations are undertaken can support the opportunity for the child to have a more regulated sleep–wake cycle. Consider timetabling the child's intervention schedule to support the child's need for periodic rest, enable families to plan their day, streamline staff contact and therefore support a more controlled environment in terms of stimulation.

4.4.3 24-hour postural care/positioning

It is essential that the child's position for rest and function is maintained during the day and night. This could be through providing a supportive bed or chair sitting position so that the child can engage with their immediate environment. The occupational therapist will also need to focus on using positioning and equipment to minimise joint deformities and development of contractures as well as promote a symmetrical posture. For example, a child who tends to extend may prefer side lying and require suitable positioning equipment such as a sleep system. The importance of time out of the seating system should be communicated to the family and nursing staff. For further information on muscle tone, passive and active range of movement, see section 4.2.8.

Muscle tone

For an occupational therapist, intervention for tone management can include positioning, splinting and stretching in order to maintain range and prevent further deformities of the affected joints. If there is weakness from antagonist muscles, strengthening exercises could be considered through modified activities and play, in collaboration with the physiotherapist.

Intervention to address muscle tone issues may be indicated depending on:

- The severity (e.g. development of contractures).
- Significance (potential impairment to function).
- Area involved (focal versus generalised).
- The etiology (e.g. progressive versus stable).
- The impact of the medication side effects (e.g. time since onset and cost of intervention).

(High et al 2005)

Common medications for tone management are baclofen (oral or intrathecal), diazepam and gabapentin for spasticity (Stevenson 2010, Yelnik et al 2009) and trihexyphenidyl for dystonia (Delnooz and Van de Warrenburg 2012) as well as botulinum toxin for focal/segmental treatment (Jankovic 2006).

Resting splints

The use of splinting in neurorehabilitation has evolved through clinical experiences of therapists and an understanding of scientific theories to support clinical reasoning. Evidence, however, to support the use of splinting remains limited and there is a lack of consensus regarding design and wearing times. In their literature review, Lannin and Ada (2011) found that in the adult stroke population evidence did not support splinting to decrease spasticity or reduce contracture development, although Kanellopoulos et al (2009) found that combining splinting with botulinum toxin injections in children with cerebral palsy was effective in both reducing spasticity and improving function. Jackman et al (2013) reported some small benefits to the use of splinting alongside therapy; however, these studies were not conducted with children with ABI and as these are different conditions, comparisons may not be drawn.¹

Splinting in the acute phase following an acquired brain injury is most likely to be used for positioning, maintaining range of movement or hygiene (e.g. maintaining dry skin and preventing breakdown). Splints at this stage are likely to be resting splints and could be fabricated by the therapist. Consent for splinting should always be sought from the parent/carer and young person where possible. With any splints, ensure that they are comfortable for the child with smooth padded edges, particularly if the child has extra involuntary movements. If the child has poor skin integrity then caution should be used if considering splinting. Some prefabricated splints are available and these may be useful if the child would not tolerate the splinting process, e.g. if they are hypersensitive to sensory input. Guides are available to support therapists in the fabrication of splints, for example *The splint selection flow chart* (Copley and Kuipers 2014) and the *Problem-based splint selection table* (Hogan and Uditsky 1998).

¹ Although this document draws upon some literature from the fields of cerebral palsy and stroke, in the absence of evidence specific to children with acquired brain injury, this evidence may be relevant. When combined with thorough clinical reasoning, this evidence could be interpreted with caution to acquired brain injury patients presenting with similar impairments, acknowledging the potential limitations.

Cautions when using splints include the following:

- Prior to providing splints, consent should be sought from parent/carer and the child or young person as appropriate. This should involve a discussion of the splinting programme, clarification of purpose and goals, and agreement of who will be responsible for its delivery. A record of this discussion and subsequent actions must be documented in the medical notes, with a clear review procedure.
- Ensure that the splinting programme can be carried out by the family/carers and/or nurses on a daily basis.
- The child's hands or arms may be difficult to work with due to cannulas/lines. Should splinting be required, discuss with the medical team the possibility of re-siting the lines at the next opportunity.
- Splinting one part of the body can influence tone or posturing in another part of the body and therefore close monitoring will be required.
- As the cause of the limited range of movement and hypertonicity could be neural (spasticity) or non-neural (shortening of ligament, changes in muscle structures) (Copley and Kuipers 2014), both aspects need to be considered when splinting. The underlying cause will indicate the appropriate method of intervention, e.g. a combination of botulinum toxin and splinting or the need for surgical intervention.
- Evidence for specific wearing times of splints is inconclusive at this stage. It is the amount of time that the joint is held 'stressed' at near end of range by a splint (low load prolonged stretch) which is more important and this amount of time varies for each child. The 'total end range time' (TERT) is a term used by Flowers and Michlovitz (1988) and is determined by multiplying the frequency a splint is worn by the duration. When developing a wearing regime it is the intensity as well as the TERT which must be considered. Intensity is determined by the force or angle of the splint.
- Due to this uncertainty about splinting, it is important to introduce splints for a short period of time initially. Then check there are no pressure areas, oedema, marks or pain. If the child is appearing distressed due to the splint then alternative solutions should be sought.
- If the splint is tolerated and it is considered appropriate, small increases in TERT can then be considered. A therapeutic amount of TERT may result in increased range of movement; however, too much will result in pain or inflammation and too little in no change of range (remember intensity can be changed through the angle of the splint).
- Monitor frequently for pain and discomfort and for the effects of the splint on the child's positioning.
- Do not use splinting in the presence of fluctuating tone or severe tone.
- Do not use splinting if there is no identified goal or benefit.
- Advice should be sought from an experienced therapist if there is any uncertainty with the provision or monitoring of splints.
- Splinting guidelines/instructions should be issued with splints to ensure appropriate handover with carers/nurses and parents. Reinforce the clinical reasoning for the use of the splint and the rationale for the wearing regime.

4.5 Discharge planning

As the child progresses in their recovery, frequently medical staff decide when the child is medically fit for discharge. It is part of the occupational therapist's role, along with the other members of the multidisciplinary team, to determine if the child is ready and safe for discharge. Part of this determination will include communicating with the child, family/carers and other agencies, e.g. school and community therapy teams, to ensure the child's level of occupational performance is understood.

A child may be discharged home or they may be discharged to another hospital or rehabilitation centre. In either case, it will be necessary to contact local services to establish availability of occupational and other therapies and equipment as required.

It is often necessary to refer to social services and wheelchair services early after diagnosis, even if the child is going to a rehabilitation setting, as there are often waiting lists. Also consider referrals for community occupational therapy support, communication support (e.g. speech and language therapy) and an educational need assessment (e.g. educational psychologist). Family consent to referrals being made to other services is required. A copy of any referrals should be made available for the family, but be sensitive about the content. Signposting families to charities who support children and young people with acquired brain injury will also be appropriate.

In preparation for discharge to home, it is likely that a home visit will be necessary to consider the functional needs of the child and family, safety and provision of equipment. Involvement of the child and family is vital so that they feel confident to establish a daily routine which will continue to promote recovery and will fit in with family life. It will be important to ensure as far as possible that there is an efficient transfer of services from the acute setting to community services. Close liaison with community occupational therapy services is essential.

The child will also need to re-establish themselves in their school setting. This will require support from occupational therapy to enable the school to accommodate the child's ongoing needs and maximise the child's potential to participate in school life. A multiprofessional team meeting involving parents, teaching staff and health professionals can help ensure all relevant information is shared and a plan is in place to support return to (or commencement of) nursery, school or college.

Consideration will need to be given to how the child or young person will:

- Access and navigate around the school (particularly if they are now using a wheelchair or their mobility has changed).
- Manage the demands of the school day (e.g. a graded return to a full school timetable may be appropriate or rest periods throughout the day).
- Use the toilet.
- Get changed for sport.
- Manage playtime and friendships.
- Eat their lunch.
- Access the curriculum (e.g. physical education, science, maths, history, etc.).

Some children or young people may require ongoing postural care support. As a starting point for the conversation with school staff relating to this, the *A to Z of postural care* resource may be useful. This is available at: https://www.kent.ac.uk/chss/docs/A-Z_Posture_Booklet-v5c-pages-web.pdf Accessed 18.02.15.

A referral to educational psychology services may also be pertinent to help establish the child or young person's educational needs. It may also be useful for the school's special educational needs co-ordinator (SENCO) to visit the child prior to discharge to facilitate the transition back into school.

When planning discharge, the child or young person and their family may find contacting charitable organisations useful as they may be able to offer practical and emotional support (see Appendix).

5 Inpatient rehabilitation

5.1 The role of the occupational therapist

For children and young people who are medically stable following an acquired brain injury (ABI), it is appropriate that the focus shifts to rehabilitation. The role of an occupational therapist is to enable participation in daily occupations (COT 2015). This is achieved by undertaking the occupational therapy process where the child and family's priorities in relation to occupational performance are identified and assessed, goals are established and interventions to enable participation are carried out and evaluated.

It is also important to determine if rehabilitation can be completed in this environment or if a referral elsewhere should be made. Planning for transition/discharge from the rehabilitation setting should begin on admission. This will include liaison with community services for necessary home modifications, assistive equipment, wheelchair provision and preparing for home care support. Provision of these services/facilities can take considerable time, particularly if assistive equipment or home modifications are required for safe discharge.

5.2 Assessment approaches

The goal of occupational therapy is to enable a child's or young person's occupational engagement and performance, therefore an assessment of the child's occupational performance should be carried out as soon as reasonably possible. To determine the priorities for assessment it is important to collaborate with the family, child or young person and members of the multidisciplinary team. It may also be appropriate to liaise with the hospital school if the child or young person is able to access this provision. Any issues that may impact a young person's engagement with the hospital school programme, for example fatigue and the signs of this, should be explained to the school staff so the demands can be graded as appropriate.

At all times, consideration should be given to the child or young person's physical, mental and emotional needs. The child or young person has gone through a traumatic experience and the impact of this will be different for every person. Careful consideration should be given to the tolerance of a child or young person when completing assessments. Monitoring the child or young person's responses to assessment and using a graded approach will ensure that the child is appropriately challenged, but not made uncomfortable or overly fatigued.

Enabling engagement in meaningful occupations is how the occupational therapist can support a child or young person's physical, mental and emotional recovery.

Tools which may be useful in establishing priorities include the following.

Assessment	Details	Age range	Reference
Perceived Efficacy and Goal Setting (PEGS)	The PEGS is an innovative and motivating tool that enables young children to reflect on their strengths and abilities and identify areas of daily challenge. It provides young children with disabilities with the opportunity to share their perceptions of their current performance level on daily activities. PEGS provides colourful picture cards that illustrate 24 tasks essential for daily living and participation in school. These tasks are age appropriate and reflect skills that have normally been acquired by children of this age.	6 to 9 years	Missiuna and Pollock 2000, Missiuna et al 2006
Child Occupational Self-Assessment (COSA)	A client-directed assessment tool and an outcome measure designed to capture children's and youth's perceptions regarding their own sense of occupational competence and the importance of everyday activities. Using the instrument in therapy provides a young client with an opportunity to identify and address their participation in important and meaningful occupations. It is also useful to look at a child's self-awareness.	8 to 13 years	Keller et al 2005
Canadian Occupational Performance Measure (COPM) 5th edition	The COPM is a client-centred tool to enable individuals to identify and prioritise everyday issues that restrict or impact their performance in everyday living. It has a broad focus on occupational performance in all areas of life, including self-care, leisure and productivity, taking into account development throughout the lifespan and the personal life circumstances.	Parent interview or child above the age of 8 years and parent	Law et al 2014
Children's Assessment of Participation and Enjoyment (CAPE) and Preferences for Activities of Children (PAC)	CAPE and PAC are two companion measures of children's participation. Both are self-report measures of children's participation in recreation and leisure activities outside of school activities.	6 to 21 years	King et al 2004

Exercise caution when prioritising occupations as there may be contraindications based on the child or young person's injury. The type of activity and length of time spent on an activity will need to be closely monitored to ensure the child/young person has appropriate periods of rest to promote recovery. For guidelines on suitable activities for children and young people post-concussion, please see the webpage 'Activity suggestions for recovery stages after concussion', available from: http://www.canchild.ca/en/ourresearch/resources/activity_suggestion_recovery_stage_concussion.pdf

Accessed on 13.10.14.

5.2.1 Self-care

An assessment of self-care should include an observation and, if required, a standardised assessment.

Possible areas could include:

- Waking up and getting out of bed/going to bed and sleeping.
- Accessing and moving around the setting.
- Brushing teeth.
- Using the toilet (including managing menstruation).
- Having a bath or shower.
- Getting dressed.
- Eating breakfast/lunch/dinner/snack.
- Moving around the centre.

(Continued)

Standardised assessments of self-care may be appropriate and could include the following.

Assessment	Details	Age range	Reference
Assessment of Motor and Process Skills (AMPS)	AMPS evaluates activities of daily living (ADL) task performance. It is an observational tool which examines the transaction between the person, the ADL task, and the environment. It evaluates the quality of a person's ADL task performance, measured at the level of activity and participation and not underlying body functions, person factors, or environmental factors. There is a requirement for certification training to administer this tool.	2 years +	Fisher and Bray Jones 2010, 2012
Pediatric Evaluation of Disability Inventory (PEDI)	Parent/young person/clinician questionnaire. The PEDI measures abilities in the three functional domains of daily activities, mobility and social/cognitive. The PEDI's responsibility domain measures the extent to which the caregiver or child takes responsibility for managing complex, multi-step life tasks.	Birth to 20 years	Haley et al 1992
Pediatric Evaluation of Disability Inventory – Computer Adaptive Test (PEDI-CAT)	The PEDI-CAT is designed for use with children and youth with a variety of physical and/or behavioural conditions. Applications include: identification of functional delay; examination of improvement for an individual child after intervention; and evaluation and monitoring of group progress in programme evaluation and research.	Birth to 20 years	Haley et al 1992

5.2.2 Productivity

This is likely to include an observation and/or standardised assessment of productivity. Possible areas could include:

- Writing for school/college work task (including handwriting and using the computer).
- Completing craft or maths projects including the use of tools and equipment.
- Following directions for an activity.
- Reading a school textbook.
- Working with another person to do a project.

Standardised assessments of productivity may be appropriate, including the following.

Assessment	Details	Age range	Reference
School Assessment of Motor and Process Skills (ScAMPS)	ScAMPS evaluates schoolwork task performance. It is an observational tool which examines the transaction between the person, the schoolwork task and the environment. It evaluates the quality of a child or young person's schoolwork task performance, measured at the level of activity and participation and not underlying body functions, person factors or environmental factors. There is a requirement for certification training to administer this tool.	2 years+	Fisher et al 2007
Detailed Assessment of Speed of Handwriting (DASH)	Suitable for providing evidence for access arrangements for Key Stage 2 National Curriculum tests and for general qualifications. It can also be used to identify children with handwriting difficulties. The assessment includes five subtests, each testing a different aspect of handwriting speed. The subtests examine fine motor and precision skills, the speed of producing well-known symbolic material, the ability to alter speed of performance on two tasks with identical content and free writing competency.	9 to 17 years	Barnett et al 2007
School Function Assessment (SFA)	The SFA provides a structured method to evaluate and monitor a student's performance of functional tasks and activities that support his or her participation in school. It is designed to facilitate collaborative programme planning for children with a variety of conditions.	5 to 12 years	Coster et al 1998

5.2.3 Play/leisure

This is likely to include an observation and/or standardised assessment of leisure. Possible areas could include:

- Playing a game/doing a puzzle.
- Socialising with a sibling/friend.
- Playing/non-contact sport activities (in the gym or outdoors).
- Reading a book/listening to an audiobook.
- Listening to music.
- Using a mobile phone/tablet.
- Crafts (e.g. modelling clay, scrapbooking).
- Photography.
- Meditation.

Standardised assessments of play/leisure may be appropriate, including the following.

Assessment	Details	Age range	Reference
Evaluation of Social Interaction (ESI)	The ESI is an observational assessment designed to evaluate a person's quality of social interaction during natural social exchanges with typical social partners. The ESI is appropriate for use with any person who has or is at risk for experiencing challenges with social interaction and/or behaviour which will impact on their ability to engage in occupations in social contexts. There is a requirement for certification training to administer this tool.	2½+ years	Fisher and Griswold 2014b
Revised Knox Preschool Play Scale (RKPPS)	The RKPPS is a standardised instrument designed to evaluate play in children and is administered in environments familiar to the child. The scale includes two 30-minute observations of the child in different settings, one indoor and one outdoor. The four dimensions included in the RKPPS are the following: (1) space management, (2) material management, (3) pretense/symbolic, and (4) participation.	0 to 6 years	Knox 1997
Test of Playfulness (ToP)	The ToP is an assessment composed of 29 items that are scored following an observation of the individual's free play in both indoor and outdoor settings.	6 months to 18 years	Bundy 2005

5.2.4 Safety awareness

When carrying out any assessment it is vital to observe the child's emotional and behavioural responses and assess the child's safety awareness. For example, the child may have decreased balance or visual deficits which impact on their ability to carry out tasks safely. It may be that the child is unaware of safety risks and this should be considered in any risk assessment plan. Safety awareness is also particularly important to consider for discharge planning and level of supervision available upon discharge.

5.2.5 Moving and handling

The child may need to be supported to move and change positions to enable them to engage with the environment and their occupations. Consider the need for sliding sheets, sliding boards and/or hoist for transfers. Liaise with physiotherapy, nursing staff and manual handling adviser as appropriate. Assessment of the moving and handling needs should be assessed on admission and reviewed regularly as the child's needs change. This should be in accordance with local policy and procedures. Ensure the relevant documentation is completed and the multidisciplinary team have an agreed moving and handling strategy for the individual child.

5.2.6 Communication

In collaboration with the speech and language therapist assess the need for assistive technology (switches, communication boards) or low technology methods, e.g. indicating responses by blinking/eye pointing/gesturing at pictures/symbols/words for communication. Ensure the family are involved with the communication strategy and the multidisciplinary team are consistent in using the system. This will assist the child's learning and avoid confusion.

5.2.7 Tests of body functions

Standardised assessments may be useful if further information is required about the child's body functions in order to determine suitable interventions.

Assessments could include the following.

Assessment	Details	Age range	Reference
Beery-Buktenica Developmental Test of Visual-Motor Integration – 6th edition (VMI)	The VMI assesses visual-motor skills in children and adults that may be associated with learning, neuropsychological and behaviour problems. It helps assess the extent to which individuals can integrate their visual and motor abilities. The Short Format and Full Format tests present drawings of geometric forms arranged in order of increasing difficulty that the individual is asked to copy. The Short Format is often used with children ages 2 to 8 years.	2 to 100 years	Beery et al 2010

(Continued)

Assessment	Details	Age range	Reference
Lowenstein Occupational Therapy Cognitive Assessment – 2nd edition (LOTCA)	Cognitive screening assessment. The LOTCA is a series of tests that evaluate abilities in four areas: orientation, visual and spatial perception, visual motor organisation and thinking operations.	6 to adult	Itzkovich et al 2000
Rivermead Behavioural Memory Test for Children (RBMT-C)	This test comprises a number of subtests, each attempting to provide an objective measure of a range of everyday memory problems reported and observed in subjects with memory difficulties.	5 to 12 years	Aldrich et al 1991
Test of Everyday Attention – Children (TEA-Ch)	The TEA-Ch comprises nine subtests which measure a child's ability to: • Selectively attend. • Sustain their attention. • Divide their attention between two tasks. • Switch attention from one thing to another. • Withhold (inhibit) verbal and motor responses. The subtests are sensitive to the developmental progression of attentional skills.	6 to 16 years	Manly et al 1999
Behavioural Assessment of the Dysexecutive Syndrome for Children (BADSC)	BADSC is a battery of tests of executive functioning for children and adolescents with neuro-developmental disorder including traumatic brain injury.	8 to 16 years	Emslie et al 2003
Sensory Profile 2	The Sensory Profile is a questionnaire used to determine how well children process sensory information in everyday situations and to profile the sensory system's effect on functional performance. The profile contributes to a comprehensive picture of a child's performance. It can be combined with other evaluation data to create a complete picture of the child's status for diagnostic and intervention planning. It also includes a questionnaire filled in by the parent/carer.	Birth to 14 years 11 months	Dunn 2014

(Continued)

Assessment	Details	Age range	Reference
Sensory Processing Measure	The Sensory Processing Measure is a set of three integrated rating scales assessing sensory processing, praxis and social participation at home, in the classroom and in the school environments. The Home Form (75 items) is completed by the child's parent or home-based care provider. The Main Classroom Form (62 items) is filled out by the child's primary classroom teacher. And the School Environments Form (10 to 15 items per environment) is completed by other school personnel who work with and observe the child.	5–12 years	Parham et al 2007
Wide Range Assessment of Visual Motor Ability (WRAVMA)	Designed to evaluate three skills in a child's visual–motor functioning.	3 to 17 years	Adams and Sheslow 1995
Developmental Test of Visual Perception 3 (DTVP-3)	Assesses visual perception and visual–motor integration skills.	4 to 13 years	Hammill et al 2013
Test of Visual Perceptual Skills (non-motor) (TVPS3)	Assesses visual perceptual skills.	4 to 13 years	Martin 2006

5.3 Goal setting and outcomes

Setting collaborative goals with parents and where possible the child or young person is a core occupational therapy skill (COT 2011) ensuring interventions are child and family centred (Rosenbaum et al 1998). Goals should be written in relation to what you would expect the child or young person to be able to do following intervention (i.e. the intended outcome). Goals should be based on the child's occupational engagement and performance. The priorities identified for the assessment should form the basis for goal setting. Consider the child and family's needs and motivation for areas such as self-care, productivity and leisure occupations.

General stages in the goal setting process include:

- Collaborate with parents/carers to develop the goal(s). This could include using tools such as the Canadian Occupational Performance Measure (COPM).
- Involve the child/young person as much as possible such as through using talking mats, the Perceived Efficacy and Goal Setting System (PEGS) or COPM.

- Agree and record goals with child, parent and team.
- Describe the baseline, i.e. what is the child able to do now?
- Describe expected level of achievement, i.e. what will the child be able to **do** following occupational therapy intervention?
- Ensure goals are SMART (Doran 1981).
 - S = Specific
 - M = Measurable
 - A = Attainable
 - R = Realistic
 - T = Timely.
- Plan intervention.
- Review.

5.3.1 Goal Attainment Scaling

Goal Attainment Scaling (GAS) (Turner-Stokes 2009) can be a very useful way to set personalised goals that target functional goals of the child and family. During rehabilitation, 2–3 functional goals can be very helpful in measuring change that may be more difficult to capture using standardised measures, and are often more meaningful to families. Functional activities are observed and described in detail, placed on a five-point scale, and specific therapy aims defined for future evaluation. The process of setting goals with family members, and the child themselves whenever possible, is an important part of clarifying expectations and unifying the focus of rehabilitation. See section 4.3.1 for resources and guides on writing GAS goals.

Assessment	Details	Age range	Reference
Goal Attainment Scaling (GAS)	GAS is a measurement approach that grades multiple levels of an individual person's goals, and has a scoring system which allows for comparisons between people.	Parent interview or child above the age of 8 years and parent	Turner-Stokes 2009

5.4 Intervention approaches

The approach of the occupational therapist will reflect the model of occupational therapy being followed, frames of reference used and the research evidence (see section 2 for a description). For example, to support daily life activities the occupational therapist may employ a compensatory frame of reference (to enable participation in washing and dressing through the use of equipment) and use this in conjunction with a rehabilitation frame of reference (to develop skills needed for an aspect of dressing). It is important any approaches are carefully considered. Some approaches are not suitable to be undertaken together due to different theoretical bases, so a clear understanding of the rationale behind them is vital.

When involving family members in the intervention strategies it will be important to include written information so they can refer back to it and to signpost any appropriate online resources. With parental and as appropriate the young person's permission, liaising with and involving the school staff (such as the special educational needs co-ordinator (SENCO)) during the child's stay in the rehabilitation unit will be desirable to facilitate school reintegration.

It is important to use reasoning and consider the child's overall condition when making decisions around tolerance, intensity and nature of occupational therapy interventions. This will include consideration of how quickly the child or young person fatigues when engaged in activity. Close liaison with the multidisciplinary team is important to establish any contraindications for occupational therapy intervention.

5.4.1 Occupation-centred intervention approaches

As an occupational therapist, the priority is to focus on enabling participation in daily occupations (COT 2015). Occupational therapy during this rehabilitation stage should concentrate on working with the child or young person, family and hospital staff to engage in occupation. Occupational therapy interventions should be goal directed, functional and meaningful to the child and family.

Based on the assessment of the child's occupational needs and the goal specified, intervention will target participation in the areas of self-care, productivity and play/leisure. For example, if the assessment is related to eating and mealtimes, then the goal would also relate to participating in mealtimes. The occupational therapy intervention would focus on enabling participation in mealtimes, and the outcomes of the intervention would be evaluated.

The focus for intervention will be on preparing the child to reintegrate into their daily life on discharge. Establishing a routine for the child and family will be important. This will include the child or young person and family being able to undertake self-care and play activities and enabling the child or young person to eventually re-engage with school/community activities. Liaison with the child or young person's school will facilitate this reintegration. If possible, enabling the child or young person to have contact with relevant school staff (e.g. SENCO, teacher, school nurse) and friends could help transition from rehabilitation to the community setting.

Ensuring personal safety, encouraging positive behaviour and prevention of deterioration are key factors that need to be considered.

Intervention approaches to achieve goals include:

- Collaborating to produce compensatory strategies to enable a child/young person to undertake their occupation(s). For example:
 - Providing bathing/showering equipment.
 - Adapting the routine so that activities are undertaken at the time of day which is most suitable for the child's tolerance levels and needs.
 - Involving the family in helping complete some of the daily care activities for the child so that their energy can be focused elsewhere.
 - Grading a game so that the rules are simpler and the child can participate.

- Developing specific skills to enable occupational performance. For example:
 - Breaking down the task of dressing into discrete steps so that the child can practise the sequence. This could include written instructions, picture or symbol prompts.
 - Using backward chaining where the child is required to do only the last part of a task, providing a sense of achievement.
 - Developing a group activity to encourage the development of particular skills such as cooking or painting/drawing/writing skills.
- Remediating impairment through restoring body functions and structures. For example:
 - Encouraging the child to go for a walk or move about the hospital so that they develop and maintain their muscle strength.
 - Providing opportunities to contact their friends and family through telephone calls, emails/social media, or writing a letter so they can develop and maintain their social interaction skills.
 - Doing a craft activity to develop and maintain hand function.

(Fisher 2009)

5.4.2 Modified constraint-induced movement therapy (mCIMT) and bimanual therapy/hand-arm bimanual therapy (HABIT)

The focus of **mCIMT** is to combine restraint of the unaffected limb and intensive use of the affected limb. Various different restraints could be used, e.g. splint, mitt or sling on the unaffected hand, while the affected upper limb has to be used to complete unilateral activities/tasks.

Bimanual therapy aims to increase spontaneous use of the affected upper limb to support the unaffected hand in two-handed tasks through intense practice of bimanual activities.

mCIMT and bimanual therapy are intensive therapy interventions and current literature suggests that ideally children would participate in a measured dose of 60–90 hours of therapy across 2–6 weeks (Aarts et al 2012, Boyd et al 2010, Eliasson et al 2005, 2009, Gordon et al 2011, Hoare et al 2007, 2010, Sakzewski et al 2011, 2012). The evidence for the application of these interventions in the acute or inpatient rehabilitation setting early post-injury is lacking and clinically it may not be possible or appropriate at this stage. Therapists working in acute settings may use a modified constraint or bimanual approach in the hospital setting, e.g. 30 minutes daily followed up with a programme of bimanual activities for parents to carry out with the child depending on the individual's tolerance, needs and abilities. Blocks of intense therapy are more likely to be considered by community therapists to target specific skills or following botulinum toxin injections. It is important that a target dose is identified, regardless of the setting, and goals established to evaluate outcome.

The scientific literature in the field of neurorehabilitation for children is changing rapidly. It is strongly recommended that clinicians critically appraise the evidence to inform their clinical decision-making regarding rehabilitation prescription including both approach and intensity.

A website which hosts reviews of the literature and has reviewed constraint therapy in 2013 can be found at:

- Peninsula Cerebra Research Unit (PenCRU):
<http://www.pencru.org/evidence/constrainttherapy/> Accessed on 21.01.15.

An evidence-based care guideline for *Pediatric modified constraint induced movement therapy (mCIMT) plus bimanual training (BIT)* (2014) has been produced by the Cincinnati Children's Hospital Medical Center. It is available at:

- www.cincinnatichildrens.org/WorkArea/DownloadAsset.aspx?id=87897
Accessed on 05.03.15.

5.4.3 Interventions to prepare for occupational performance

Interventions which focus on preparing the child or young person for occupations may include the use of splinting and casting.

Functional splints

Functional splints are used to support or stabilise particular joints to enable functional movement in others, e.g. thumb spica to assist with grasping. These splints can be fabricated by therapists out of thermoplastic or neoprene or can also be purchased prefabricated. They can be used during therapy sessions, e.g. motor relearning or during daily activities.

Lycra/dynamic orthoses are made to measure garments, fabricated out of dynamic material such as lycra. There are several types including full body suits, vests, shorts, sleeves and gloves. Aims may include to reduce muscle tone, increase proprioception/stability, influence patterns of movement and to improve biomechanical alignment. The rationale for providing these different types of orthoses vary. At the time of writing this resource the evidence for orthoses was not specific to ABI, but has focused largely on the cerebral palsy population. Studies in general have also used small sample sizes which do not allow generalisations about effectiveness (Edmonson et al 1999, Nicholson et al 2001). As the evidence for orthoses improving occupational outcomes for children and young people with ABI is inconsistent, careful consideration of current literature is advised.²

Provision of dynamic orthoses is not standard across community teams and therefore may be recommended by therapists for parents to purchase privately, if required.

Casting

Casting refers to when a cast (hard or soft) is applied over one or more joints. It is essential that the occupational therapist has relevant training and skills before casting and there has been a clearly defined rationale for undertaking the procedure. There are different types of casting such as inhibitive and serial; these are used for different purposes such as tone reduction and contracture release. Casting should only be carried out by a person who has the appropriate skills and knowledge. There must be evidence of the occupational therapist's rationale for using this treatment modality.

² Although this document draws upon some literature from the fields of cerebral palsy and stroke, in the absence of evidence specific to children with acquired brain injury, this evidence may be relevant. When combined with thorough clinical reasoning, this evidence could be interpreted with caution to acquired brain injury patients presenting with similar impairments, acknowledging the potential limitations.

See the following text to further explore the potential reasons for undertaking casting:

- Copley J, Kuipers K (2014) *Neurorehabilitation of the upper limb across the lifespan: managing hypertonicity for optimal function*. Oxford: Wiley-Blackwell.

Splinting can be used between casts to maintain progress and casting can be used alongside therapy programmes.

If casting is going to be used post discharge, it is essential to consider the family's circumstances and their availability to attend regular appointments to have the cast removed and remade.

Botulinum toxin (BoNTx)

BoNTx is a medication for reduction of spasticity and/or dystonia. It is given in the form of an injection which can be used in overactive muscles, i.e. with significantly increased tone (hypertonus) and in some cases dystonia or a combination of these. The toxin blocks the release of acetylcholine and causes a temporary chemical denervation which inhibits muscle contraction and therefore 'weakens' the targeted muscle groups. This thereby provides a window of opportunity to strengthen/train weaker antagonist muscle groups and improve upper limb range and functional skills through intervention (Heinen et al 2009).

BoNTx is generally administered by a doctor or allied health professional who has completed relevant training. In the upper limb it is recommended that BoNTx is used as an adjunct to occupational therapy interventions (Hoare and Imms 2004) and it is not generally used as a standalone treatment. Adjunct therapy interventions which could be considered are splinting, casting, stretches, intense motor relearning programmes (e.g. constraint induced movement therapy), hand and arm bilateral intensive therapy (see section 5.4.2) and other activity-based programmes as described above.

In general, BoNTx has a quick effect (seen within 2–3 days). The effect peaks in the following weeks and effects should be assessed and intervention provided between 6 and 12 weeks by relevant medical and therapy staff. Following this, the effect of the BoNTx gradually ceases and patients should be reviewed between 12 and 26 weeks to assess whether repeat injections are required (NICE 2012).

The National Institute for Health and Care Excellence clinical guidelines for spasticity in children and young people (NICE 2012) suggest the indications for BoNTx injections at this stage would be:

- If the child has hypertonia and/or dystonia affecting specific muscle groups/joint range of movement that is not effectively being controlled with medication or occupational therapy intervention.
- If the muscle has a dynamic spastic component.

5.5 Discharge planning

Discharging the child or young person home will require careful planning and close liaison between the hospital and community occupational therapists. This will likely be an exciting, although anxious time for the child and family and their needs should be central to any arrangement made.

Building on the intervention progress made during their time in the rehabilitation unit, the child's current level of occupational functioning should be assessed. In addition to discharge planning information contained in section 4.5 the following points should be considered when planning the child or young person's discharge from hospital to home:

- Is the home suitable to enable the child and family to manage their daily occupations?
 - Is equipment or are adaptations required?
 - What are the timescales involved?
 - Do any interim arrangements need to be put in place?
 - Are services or referrals in place for the community occupational therapy team?
- Is the child/young person and family confident and safe in the use of any equipment provided (e.g. splints, seating, bathing equipment)?
 - Who will review the equipment as the child grows and changes?
- Is the family confident in supporting their child to do their daily occupations?
 - Do they have any concerns?
 - Has written information been provided to support the use of equipment, strategies or techniques (including moving and handling)?
 - Have any safety concerns been addressed?
 - Does the family know whom to contact should they have further questions or needs?
- Has the child got a programme for gradual reintegration back into school or home schooling?
 - Is the school aware of the child's current needs and potential future needs?
 - Is the child or young person known to the SENCO and have they visited the child in hospital?
 - Is referral to a neuropsychologist or educational psychology services required?
 - Is it necessary to initiate special educational needs support for the child when they re-enter school (e.g. Education, Health and Care Plan/Statement, etc.)?
- Have the needs of any siblings been considered in the transition of the child or young person returning home?
- Are there other community services (including charitable and voluntary organisations) which will support the child and family?
 - Does the hospital offer follow-up clinics which the child and family may attend (for example orthotics clinics)?
 - Are the child's GP and paediatrician aware of the child's progress and plans for continued rehabilitation?
 - Have all referrals been received by the local service and are their timelines for being able to commence seeing the child in line with the discharge plans?

When planning discharge, the child or young person and their family may find contacting charitable organisations useful as they may be able to offer practical and emotional support (see Appendix).

6 Community-based rehabilitation

6.1 What is the role of the occupational therapist?

The role of an occupational therapist is to enable participation in daily occupations (COT 2015). This is achieved by undertaking the occupational therapy process where the child/young person and family's priorities in relation to occupational performance are identified and assessed, goals are established, and interventions to enable participation are carried out and evaluated. At this stage the main focus for occupational therapy is to support the child/young person's integration into the home, community and school/education environment. Children are discharged to community services at different stages of their recovery; thus relevant content may be found in earlier sections of this resource.

The needs of children following an acquired brain injury (ABI) are diverse and influenced by many factors including age at injury, stage of development, time and degree of injury, family and education factors. In addition to this the personal goals of the child or young person and family are central to any occupational therapy involvement. Whatever the child or young person's stage in recovery or level of current functioning, the occupational therapist should focus on what they want to, need to or are expected to do.

Frequently the concerns of children and family focus on:

- **Productivity/education** – Occupational therapy may be required to support the child or young person participate in their school life. This could include special schooling or home schooling.
- **Self-care** – Enabling the child or young person and their family to carry out daily life activities is a focus for the occupational therapist.
- **Play leisure** – The occupational therapist will be supporting social and leisure opportunities for the child/young person. Consideration of the respite needs of carers is also a requirement.
- **Community participation** – Enabling the child or young person and their family to engage in community life is vital to promote long-term goals.
- **Transitions** – This may include working with the child/young person and family at times of change such as when moving from pre-school to primary school, to secondary school, and into adult life/work/tertiary education. The occupational therapist plays a vital role in identifying their goals well in advance of transitions in order to source facilities and resources to enable optimal choice and independence.

6.2 Assessment approaches

An occupational therapy assessment will always begin by finding out relevant background information and reason for referral. See section 5.2 for details on relevant assessment tools and procedures for establishing the context for the child and family.

The occupational therapist in collaboration with the child or young person and family will determine the priorities for their involvement. Often children with an acquired brain injury will have multiple areas that they find challenging; however, prioritising is important to ensure interventions are manageable for the child and family.

At all times consideration should be given to the child or young person's physical, mental and emotional needs. The child or young person has gone through a traumatic experience and the impact of this will be different for every person. Enabling engagement in meaningful occupations is how the occupational therapist can support a child or young person's physical, mental and emotional recovery.

It is realistic to set between one and four priorities at any time, reviewing as appropriate. Ensure that consideration is given to the child or young person's level of fatigue when assessing their needs.

Examples of a child's or young person's occupational needs could include the following.

Education setting	For example:
In the classroom	• Completing written work for various subjects (including using the computer). • Completing craft, science or maths projects including the use of tools and equipment. • Playing sport and participating in physical education. • Following directions for an activity. • Working in a group to do a school project. • Packing up and tidying a desk. • Following a timetable.
In the playground	• Playing/socialising in the playground at break time.
Arriving at and leaving school	• Arriving at school and carrying out the morning school routine. • Leaving school and getting home.
Self-care including toileting activities	• Going to the toilet. • Getting changed for sport.
Moving around the educational setting	• Finding the way around the school safely and on time. • Lining up to go back into the classroom.
Mealtime or snack time	• Participating in breakfast club. • Eating lunch/school dinner. • Carrying food in the school dining area.
Other school/ college participation	• Participating in assembly/school concerts/clubs. • Going on school trips. • Preparing a bag for school.

At home	For example:
Personal activities of daily living	• Waking up and getting out of bed/going to bed and sleeping. • Accessing and moving around the house and garden. • Brushing teeth. • Using the toilet (including managing menstruation). • Having a bath or shower. • Getting dressed. • Sexual awareness and sexual activity as appropriate. • Eating breakfast/lunch/dinner/snack. • Organising oneself to go out.
Doing homework	• Planning what to do and completing homework tasks.
Household chores	• Washing the dishes or loading the dishwasher. • Tidying a bedroom. • Setting the table. • Watering the plants. • Feeding/grooming/walking pets.
Play and leisure	• Playing a game or socialising with a sibling/friend. • Playing outside. • Using technology, i.e. tablet, computer or phone. • Reading a book. • Listening to music. • Riding a bike.
In the community	For example:
Moving around the community	• Using the bus or train. • Walking or cycling in the community.
Play and leisure	• Going to the cinema/shopping with friends. • Playing sport, going swimming or going to the gym. • Going on holiday. • Going on a date. • Attending Scouts/Guides/Brownies or other structured groups.
Work, appointments and errands	• Going to appointments or meetings. • Going to the supermarket/bank/post office. • Doing a part-time job/volunteering.

Transitions	For example:
Hospital to school	• Maintaining social contact between the child/young person and relevant school personnel (e.g. teacher or SENCO). • Planning for graded introduction/re-introduction to school. • Relevant information provided to school staff about the child's occupational performance.
Pre-school to primary school	In addition to the considerations from hospital to school: • Adapting to the changes in routine such as a lack of daytime sleep and increased demands of the tasks. • Managing self-care including toileting. • Considering lunchtime arrangements.
Primary school to secondary school	In addition to the considerations from hospital to school: • Navigating around the school classrooms and grounds. • Moving between classrooms and carrying books/materials. • Making friends and socialising at break times. • Using the library and canteen. • Managing self-care and changing for sports. • Managing the school day.
Secondary school to college/university/work	In addition to the considerations from hospital to school: • Preparation for interviews. • Planning, preparing and cooking meals. • Managing money. • Accessing support systems including adult health services, student support, etc. • Reasonable adjustments for the education setting or workplace.

(Adapted from COT 2014, p6)

For additional information on relevant occupations for children of different ages, see:

- Rodger S, Brown T (2006) I can do it: developing, promoting and managing children's self-care needs. In: S Rodger, J Ziviani, eds. *Occupational therapy with children: understanding children's occupations and enabling participation*. Oxford: Wiley Blackwell. 203–210.

Also consider the activity guidelines developed for children following concussion which may be appropriate for children recovering from a brain injury. These are available at: <http://canchild.calen/canchildresources/resources/RTAsuggestionsbystageindividual.pdf>
Accessed on 19.09.14.

Once the priorities are determined, the occupational therapist should assess the child's current level of performance in the chosen occupation(s). Observation is a key assessment tool for occupational therapists (Fisher 2009). In addition standardised assessments may also be appropriate. For a list of standardised assessments see section 5.2.

The assessment may also include assessing a child's body functions and structure in order to clarify reasons for impaired occupational performance. If a child is assessed in an unfamiliar context, such as in a clinic, consideration needs to be given as to how the child's performance would be different when they are in their usual context. For example, if a child was assessed for handwriting in a therapy clinic which is quiet and set up for their needs, their performance will be different from completing handwriting in their usual, perhaps noisy/distracting classroom. It is good practice to assess the child in the context where the challenges are arising.

6.3 Goal setting and outcomes

Based on the areas which have been prioritised and assessed, suitable goals should be established in collaboration with the child/young person and family. It will also be appropriate to involve the school staff if the goals are school based. It is reasonable to set one overall goal for each priority area and it should focus on what the child will be able to do following intervention. Goals need to be written in a way which is meaningful for the child and family and it also provides a measure of the success of occupational therapy intervention. Goals should be written in relation to what you would expect the child or young person to be able to do following intervention (i.e. the intended outcome). For guidelines on writing goals see section 5.3 and below are examples of how a goal could be written.

Occupations	Desired outcome: what this means for the child
Finding the way around the school	Tom will find his own way to his classrooms, by October 2014.
Getting changed for sport	Tom will keep all his belongings in one place when changing for sport, by November 2014.
Completing maths work	Tom will complete his maths papers within the class timeframe, by December 2014.
Leaving school and getting home	Tom will catch the school bus home, by May 2015.
Getting showered and changed at home	Tom will be able to transfer from his wheelchair to his shower chair and shower himself with supervision, by May 2015.

(Adapted from COT 2014, p4)

In addition to the goal for the child and family, the occupational therapist may also determine that sub-goals are useful to support the child and family see smaller stages of progress. The occupational therapist may also write an action plan/session plan of what they will do to support a child to reach their goals. This should not be confused with the overall goal.

6.4 Intervention approaches

The intervention provided will depend on the needs and priorities of the child or young person and family, including the impact on siblings. Consideration should be given to the child or young person's condition including any mood or behavioural changes and levels of fatigue. There are several models of occupational therapy and frames of reference (see section 2) and a combination of these may be used to guide occupational therapy intervention.

There are many factors to consider when selecting an approach for intervention. It is important to note that the available evidence may not be specific to the acquired brain injury population, although they may have some relevance to the child or young person's situation. Using reasoning and theory to inform decision making is essential to support occupational therapy intervention approaches.

Building on the goals set with the child/young person and family, intervention approaches could be compensatory, developing a skill or restoring a body function or structure (as described in section 5.4). For example:

Occupations	Desired outcome: what this means for the child	Intended actions: what will be done and who will do it?	Resources (including frequency)
Finding the way around the school	Tom will find his own way to his classrooms, by October 2014.	The occupational therapist in collaboration with the SENCO and Tom will develop a timetable and map for Tom which he can access on his mobile phone to support his navigation around the school.	The occupational therapist will visit the school up to four times during the Autumn term to develop the resources in collaboration with the SENCO and Tom.
Getting changed for sport	Tom will keep all his belongings in one place when changing for sport, by November 2014.	The occupational therapist, class teacher and learning support assistant will work together to establish a routine for Tom and designate a space for him to use when changing for sport.	The occupational therapist will collaborate with, and offer advice to, the school during the scheduled visits during the Autumn term.
Completing maths work	Tom will complete his maths papers within the class timeframe, by December 2014.	- Alternative materials will be trialled with Tom to determine the most appropriate tools to enable Tom to complete his maths work. - The maths teacher will grade the amount and difficulty of maths problems to enable Tom to achieve this goal.	The occupational therapist will collaborate with, and offer advice to, the school during the scheduled visits during the Autumn term. The maths teacher will provide daily support.

Occupations	Desired outcome: what this means for the child	Intended actions: what will be done and who will do it?	Resources (including frequency)
Leaving school and getting home	Tom will catch the school bus home, by May 2015.	- The occupational therapist will work together with Tom, his family and the school bus driver to make the task manageable for Tom to undertake with increasing independence. - The school counsellor will support Tom develop his confidence about using public transport.	The occupational therapist will visit the school up to three times during the Spring and Summer terms to devise a suitable plan with Tom and key people. The school counsellor will offer weekly support for ten sessions.
Getting showered and changed at home	Tom will be able to transfer from his wheelchair to his shower chair and shower himself with supervision, by May 2015.	The occupational therapist in collaboration with Tom and his family will redesign the downstairs bathroom to enable Tom's independence.	The occupational therapist will coordinate the modifications to the bathroom through two visits and monitoring as required.

(Adapted from COT 2014, p4)

Children and young people will have different trajectories of recovery following an ABI. For some children and young people, more intensive and long-term support at home and in the community will be required. Further examples and support can be found at:

- CanChild Center for Childhood Disability Research, Brain injury page:
<http://www.canchild.ca/en/childrenfamilies/braininjury.asp>
 - Headway Brain Injury Association, Caring for someone with a brain injury:
<https://www.headway.org.uk/caring.aspx>
 - The Children's Trust Brain Injury Hub, Back at home after a brain injury:
<http://www.braininjuryhub.co.uk/information-library/back-at-home>
- All websites accessed on 05.03.15.

6.4.1 Transitions

Effective transitions are an essential way of preparing children and young people for change, and occupational therapists can have an important role in this stage. Information for professionals working with young people with disabilities is available from the Transition Information Network website: <http://www.transitioninforonetwork.org.uk/home.aspx> (Accessed on 07.07.15)

Additional guidance on transition is available from some of the brain injury charity websites listed in the Appendix in section 7.

6.4.2 Daily living

As children and young people grow, changes may be seen in a child's muscle tone and altered patterns of movements which can lead to contractures and deformities over time. Compensatory strategies may need to be considered longer term to best support the child or young person, e.g. access to a computer/laptop to facilitate learning (rather than just focusing on improving handwriting) or adaptive kitchen aids to enable the child to become more independent with daily living skills.

If contractures/deformities develop, pain can become problematic and long-term surgery may need to be considered (e.g. wrist arthrodesis). Referrals should be made to an orthopaedic surgeon following discussion with the child's paediatrician/GP.

Body image and peer socialisation are an important part of growing up. Compliance with splint wearing and therapy programmes will often reduce as young adults want to be the same as their peers. Therapists should consider this when fabricating splints and developing programmes. Being flexible with wearing regimes and incorporating activities meaningful to the young person in their programmes, e.g. age appropriate exercise in the gym, sports or yoga, will encourage engagement. Botulinum toxin injections and/or corrective surgery can be considered to improve the cosmetic appearance of affected limbs.

A child or young person's behaviour and mood may have altered as a result of their ABI. This could impact on the relationships they have with their parents/carers and siblings as well as friendships. Intervention will need to include the child or young person's wider context to support daily living activities.

6.5 Discharge planning

It is important to assess how a child has progressed by completing goals and monitoring progress in these to determine the appropriate discharge time. It is also vital that children/parents/carers and school/nursery are informed about the needs of the child or young person and whom to contact should needs change, or when approaching a transition (e.g. into primary or secondary school, home schooling, employment or college).

When planning discharge, the child or young person and their family may find contacting charitable organisations useful as they may be able to offer practical and emotional support (see Appendix).

For children and young people with an acquired brain injury the full impact may only become apparent several years after the injury. For example, difficulties may become more apparent as the child transitions from primary to secondary school and tasks become more demanding and priorities change. It is therefore recommended that the family/carers are made aware of this and if possible a child is reviewed in a follow-up clinic at key stages in their lives or alternatively provided with details of a professional who can be contacted for advice. In some circumstances it will be adequate for the family/carers to be educated and empowered to contact their GP and advocate for assistance and advice as needed.

If the occupational therapist is working with a young person with ongoing needs it will be necessary to consider the transition to suitable adult services, which may vary in different areas. The Children's Trust Brain Injury Hub website provides a range of useful information about this important stage (<http://www.braininjuryhub.co.uk/information-library/moving-on-adulthood>). Specific areas covered include:

- *Moving to adult services* – information about adult healthcare and the differences involved in these services.
- *Transition to adulthood* – covering areas such as education, driving, relationships and sexuality.
- *Employment and acquired brain injury* – information on the schemes and support available when taking the first steps into the workplace.
- *Looking after yourselves* – provides information on the way acquired brain injury can affect the rest of the family.
- *Talking to others about brain injury: a guide for young people* – gives young people ideas for talking to friends and family about brain injury.

The Directgov website (www.direct.gov.uk) provides useful information about jobs, careers and education and how to access these services. For young people wishing to go on to higher education a Disabled Students' Allowance may be an option to consider. Information on the support available, eligibility criteria and how to apply is available from Disability Rights UK website: <http://www.disabilityrightsuk.org/applying-disabled-students%E2%80%99-allowances-dsas>

7 Appendix – Charitable organisations

When working with children, young people and their families, it may be necessary to put them in contact with charitable organisations that can offer further support. Organisations may be able to offer practical and emotional advice for children/young people and their families such as providing finances or access to equipment, home adaptations, wheelchairs, counselling, etc. Listed below is a starting point for charities which may offer services for children with acquired brain injury (ABI) and their families. Some of these organisations also provide support for adults following brain injury and can support and guide transitions to adulthood. All websites accessed on 09.04.15 unless otherwise indicated.

Barnardos

National children's charity providing services including: counselling, fostering and adoption, vocational training and disability inclusion groups.
<http://www.barnardos.org.uk/>

Brain and Spine Foundation

Charity set up to develop research, education and information programmes relating to disorders of the brain and spine. <http://www.brainandspine.org.uk/>

Brain Injury Rehabilitation Trust (BIRT)

National organisation providing specialist assessment, rehabilitation and community-based services to adults with acquired brain injury. Part of national charity *The Disabilities Trust*. <http://www.thedtgroup.org/brain-injury/>

Brain Tumour Charity

A charity which provides practical and emotional support to those affected by brain tumours through a helpline and information service.
<http://www.thebraintumourcharity.org/>

Brake

Charity which provides support to victims of road traffic collisions and their families.
<http://www.brake.org.uk/>

British Association for Counselling and Psychotherapy (BACP)

BACP can provide advice on a range of services to help meet the needs of anyone seeking information about counselling and psychotherapy.
<http://www.bacp.co.uk/>

Cerebra

Charity helping to improve the lives of children with brain-related conditions through researching, educating and directly supporting children and their carers.
<http://www.cerebra.org.uk/>

Child Brain Injury Trust

A charity that supports children, young people, their families and professionals and helps them come to terms with what has happened and how to deal with the uncertainty that the future may hold. <http://childbraininjurytrust.org.uk/>

Child Death Helpline

The helpline is a partnership between professionals and bereaved parents working together to provide a professional Freephone service to anyone affected by the death of a child of any age. <http://childdeathhelpline.org.uk/>

The Children's Trust

Charity providing care, education and therapy to children and young people with multiple disabilities and complex health needs and rehabilitation services to children and young people with acquired brain injuries. <http://www.thechildrenstrust.org.uk/>

The Compassionate Friends

Charity of bereaved parents, siblings and grandparents dedicated to the support and care of other bereaved parents, siblings and grandparents who have suffered the death of a child/children. <http://www.tcf.org.uk/>

Contact a Family

A UK charity providing advice, information and support to the parents of all disabled children – no matter what their disability or health condition. <http://www.cafamily.org.uk/>

Council for Disabled Children (CDC)

The CDC is the umbrella body for the disabled children's sector in England, with links to other UK nations. <http://www.councilfordisabledchildren.org.uk/>

Different Strokes

Run by stroke survivors for stroke survivors, the charity provides a free service offering self-help and mutual support to younger stroke survivors throughout the UK. <http://www.differentstrokes.co.uk/>

Disabled Living Foundation

Charity providing free, impartial advice, information and training about all types of disability aids and independent living. <http://www.dlf.org.uk/>

Encephalitis Society

Charity to support adults and children, their families and carers by providing advice and information to improve the quality of life for all people affected directly and indirectly by encephalitis. <http://www.encephalitis.info/>

Epilepsy Action

A UK organisation which exists to improve the lives of everyone affected by epilepsy. Free helpline available: 0808 800 5050. <https://www.epilepsy.org.uk/>

Every Disabled Child Matters (EDCM)

EDCM is a campaign to get rights and justice for every disabled child. <http://www.edcm.org.uk/>

The Family Fund

Provides timely grants to low income families raising disabled and seriously ill children and young people. <http://www.familyfund.org.uk/>

Florence Nightingale Aid in Sickness Trust

Grants to provide medical and household aids to people in need who are ill, convalescent or disabled. <http://www.fnaist.org.uk/>

Headway

Provides support, services and information to brain injury survivors, their families and carers, as well as to professionals in the health and legal fields.

<https://www.headway.org.uk/>

Help the Hospices – Hospice UK

Enabling hospice and palliative care professionals to keep their skills and knowledge up to date as they support patients, their families and carers.

<http://www.hospiceuk.org/>

I CAN

Charity working to support the development of speech, language and communication skills in all children, with a special focus on children with a communication disability.

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

Information, Advice and Support Services Network (IASS)

Previously known as the National Parent Partnership Network, the IASS Network provides information, advice and support to disabled children and young people, and those with special education needs, and their parents.

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

Meningitis Now

Meningitis Now (formerly the Meningitis Trust and Meningitis UK) supports bereaved families, individuals and families with after-effects and anyone who has been touched by the disease. <http://www.meningitisnow.org/>

Meningitis Research Foundation

Information on meningitis, a 24-hour helpline, a befriending programme and other services. <http://www.meningitis.org/>

National Alliance of Childhood Cancer Parent Organisations (NACCPO)

An umbrella charity of support groups and charities helping children and young adults with cancer and their families. www.naccpo.org.uk/

National Association for Special Educational Needs (NASEN)

A UK organisation supporting those who work with or care for children and young people with special educational needs or disabilities (SEND).

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

Sibs

Sibs is a UK charity supporting siblings of all ages who are growing up with or who have grown up with a brother or sister with any disability, long-term illness or life-limiting condition. <http://www.sibs.org.uk/>

Stroke Association

Charity providing support to those who have experienced stroke, their carers and families. Includes a dedicated child stroke support service.

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

Together for Short Lives

A UK charity for all children with life-threatening and life-limiting conditions and all those who support and care for them. <http://www.togetherforshortlives.org.uk/>

Transition Information Network (TIN)

The network aims to improve the experience of disabled young people's transition to adulthood. TIN is a source of information and good practice standards for disabled young people, families and professionals.

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

Whizz-kidz

A national children's charity working to give disabled children and young people independent mobility; supporting them to become confident and independent young adults. <http://www.whizz-kidz.org.uk/>

Winston's Wish

Winston's Wish is a childhood bereavement charity offering practical support and guidance to bereaved children, their families and professionals across the UK.

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

Young Epilepsy

The national charity working exclusively on behalf of children and young people aged 25 and under with epilepsy and associated conditions. They aim to improve the lives of children and young people to enable them to fulfil their potential and ensure they have the best quality of life. <http://www.youngpilepsy.org.uk/>

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Children and young people with acquired brain injury *Current practice in occupational therapy*

This publication is a practical resource to guide occupational therapists new or returning to the field of paediatric neurology and working with children with acquired brain injury.

It provides information relating to occupational therapy processes from acute presentation in hospital through to long-term community care. Divided into sections according to the location of the child during the care pathway, it provides an overview of:

- The role of the occupational therapist working with children and young people with acquired brain injury.
- Assessments, goal setting, intervention approaches and evaluation techniques used by occupational therapists and when these may be usefully applied within the care pathway.
- Links to existing resources for child/family/professional information about acquired brain injury, interventions and outcomes.



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