# 2021

# Guidance for Paediatric Physiotherapists Managing Children and Young People with Acquired Brain Injury





Association of Paediatric Chartered Physiotherapists Neurodisability Committee

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# Introduction to the guidance document

The purpose of this guidance document is to support paediatric physiotherapists working with children and young people (CYP) with acquired brain injury (ABI) in both acute and community settings. The document provides key points to consider at each stage of a CYP's rehabilitation journey from time of admission through to their return to home, school and community leisure activities. Foundation level knowledge and skills required to assess and treat a CYP in each phase are discussed, as well as more advanced knowledge and skills for more senior clinicians working in hospital or community settings.

The guidance is based on clinical knowledge and expertise, with reference to current research and evidence from the field of ABI and neurorehabilitation. It is written by members of the Association of Paediatric Chartered Physiotherapists (APCP) Neurodisability Group, in collaboration with experienced clinicians working in a range of hospital and community settings.

We encourage physiotherapists working with CYP after ABI to work towards enabling full participation in all aspects of family, school and community life through appropriate assessment, goal setting, intervention and review. The World Health Organisation (WHO) International Classification of Function, Disability and Health (ICF) (2001) is a useful framework to support this holistic process and is commonly used internationally within research and clinical practice. It is outlined in Figure 1 below:

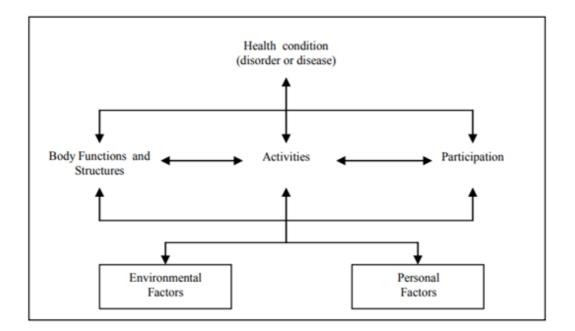


Figure 1. The ICF (World Health Organisation, 2001)

While this document focuses on aspects relating primarily to physiotherapy, there is an underpinning assumption that physiotherapists will work hand in hand with the wider multidisciplinary team to support CYP at all stages of recovery and rehabilitation after ABI.

It should be acknowledged that this guidance document is not a systematic review, checklist or audit tool, but provides a framework of the core elements of physiotherapy management of paediatric ABI in the UK. It is recommended that clinicians use this document in association with other learning resources and professional guidance, including APCP's 'Working with children' document (2016). Respiratory management of CYP with severe ABI is not covered within this guidance document. For further advice and information regarding respiratory physiotherapy management please see local policy guidelines, the APCP respiratory committee website and the Association of Chartered Physiotherapists in Respiratory Care (ACPRC) website.

# Introduction to acquired brain injury

Acquired brain injury (ABI) during childhood refers to a range of individual presentations and injury mechanisms, following a period of normal development (Forsyth & Kirkham, 2012). It causes sudden disruption to normal developmental processes spanning physical, cognitive and psychosocial domains (Braga et al., 2005). It typically does not include antenatal or perinatal brain injuries, nor those linked to genetic or neurodegenerative causes. The term ABI encompasses traumatic brain injuries (TBI) including those due to falls, road traffic collisions and non-accidental injuries; and non-traumatic causes including infection, cerebrovascular events, hypoxia/anoxia, tumour or metabolic causes. There are approximately 35,000 new childhood TBI in England per year, of which 2,000 are considered to be severe, 3,000 are of moderate severity, and the remainder are classed as mild. Moderate-severe encephalopathy affects around 4,000 children per year in the UK, childhood tumours around 500 per year, and stroke approximately 200-300 per year (National Health Service [NHS] England, 2013).

ABI is a chronic condition with life-long consequences (McKinlay et al., 2016; All Party Parliamentary Group [APPG] on Acquired Brain Injury [ABI], 2018). Current literature suggests that difficulties linked to childhood ABI may persist into adulthood (McKinlay et al., 2016), with TBI affecting educational achievement, employability and social interaction (APPG on ABI, 2018; De Netto & McKinlay, 2020). Given the potential impact of ABI on a CYP's future development, and the potential for physiotherapists to encounter CYP at various stages after ABI (Young et al., 2020), it is important for physiotherapists to be aware of the factors which may influence recovery, rehabilitation and outcomes. These factors are summarised briefly in the following section and can be categorised as factors related to A. the injury, B. the CYP and family, and C. organisation of the professional network surrounding them.

# A. Injury-related factors

#### Age at injury

Age at time of injury is an important factor in recovery and outcome following ABI. Infants may be at risk of a poorer outcome following severe TBI compared to older children, due to relative immaturity and vulnerability of the developing brain at the time of injury (Anderson et al., 2005; Giza et al., 2009). This may lead to a derailing of the usual developmental processes and a change in developmental trajectory over time (Anderson et al., 2011; NHS England, 2013). As adolescence is also a time of critical neurodevelopment, it is vital to consider the impact of ABI during teenage years on all domains of function and participation in relation to development of skills for adulthood (Ciccia & Threats, 2015). Regardless of the age at injury, greater severity of injury may lead to reduced quality of life and functional outcome in adulthood (Anderson et al., 2011).

#### Non-linear pattern of recovery

Recovery may follow a non-linear pattern, with a slow initial phase, followed by rapid progress leading to a plateau phase (Forsyth et al., 2010). Improvement in motor skills may be noted up to five years post-injury (Beretta et al., 2018). Additionally, the consequences of an injury may evolve over time (Royal College of Paediatrics and Child Health [RCPCH] & The Stroke Association, 2017). Parents may be concerned about their CYP's progress several years after the initial injury (Hawley et al., 2002);

difficulties may only become noticeable when skills, particularly cognitive, fail to emerge at the expected developmental point (Braga et al., 2005; Thompson et al., 2009; Anderson et al., 2011).

It is therefore important that ABI should be regarded as a lifelong disability with the potential to affect the ability of the CYP to meet anticipated developmental norms in a variety of functional domains (Anderson et al., 2011). Repeated evaluation is recommended across all domains of the ICF (WHO, 2001) to highlight changing needs (RCPCH & The Stroke Association, 2017). It is important to consider the dynamic interplay between the individual and their environment as part of development, particularly during adolescence, and the impact of this on their overall participation (Stewart et al., 2012). Where a CYP has independent mobility and can join in with usual levels of physical activity, there may still be reduced participation compared to pre-injury. In these cases, further exploration of causes may be relevant, including high-level balance skills (Kelly et al., 2019). CYP should be able to access therapeutic intervention including physiotherapy at timely moments reflecting their developmental stage, their movement through key points of transition in education, and in preparation for adulthood (Braga et al., 2005; McKinlay et al., 2016).

While recovery after mild TBI is often spontaneous, symptoms may have a prolonged duration (Hawley et al., 2002; Dahl et al., 2006) and it is important to ensure that any persisting difficulties are addressed in a timely manner to facilitate a positive recovery (McKinlay et al., 2016).

#### Area and extent of ABI

An ABI comprises both primary and secondary injury components. In TBI, primary injury occurs at the moment of impact due to external mechanical forces, and includes diffuse axonal injury, intra- or extra-cerebral haemorrhage or a focal cortical contusion; primary injury leads to irreversible cell damage and is the main determinant of clinical outcome (Yokobori & Bullock, 2013). Secondary injury after TBI evolves over the time following impact, and also contributes to overall outcome. It is related to ischaemic, inflammatory and neurotoxic responses triggered by the primary injury, as well as the impact of wider systemic factors including hypotension or hypoxaemia (Kochanek et al., 2013). Primary and secondary injuries may interact in a complex pattern of evolving damage (Sharp & Jenkins, 2015). Critical care intervention is often focused on managing aspects related to the secondary injury as well as the primary mechanical insult; an appreciation of methods of neuroprotection is important for physiotherapists and is discussed later in section F. Special considerations.

An ABI may affect any area of the brain and therefore any functions it controls, leading to a range of emotional, cognitive and physical impairments (McKinlay et al., 2016). Knowledge of the roles and functions associated with each area of the brain is important to give an understanding of the potential impact of the individual CYP's injury. However, young brains have not completed their full localisation, so it is more difficult to predict what the functional outcome will be after ABI (Anderson et al., 2011). It is thought that the amount of damage to the brain has a greater impact on neurobehavioural outcomes than the site of injury (Power et al., 2007). Likewise, initial injury severity descriptor by Glasgow Coma Scale of mild, moderate or severe brain injury may not relate to future functional outcome (Volpe et al., 2017).

#### Non-motor deficits

Physiotherapy will focus primarily on motor deficits, but it is also expedient to consider sensory, behavioural, communication and cognitive changes, and the implications of these for goal setting, treatment planning and overall social participation (RCPCH & The Stroke Association, 2017; Ryan et al., 2019). For example, a CYP with attention difficulties may walk well in a quiet clinic setting but may struggle to complete the same activity in a busy school corridor. A CYP with reduced processing speed may find it hard to participate in a treatment session or PE lesson due to difficulties following multiple or rapid instructions. A CYP with social communication and self-regulation difficulties may find it hard to join in with peers at sports clubs. Additionally, a CYP with a new visual impairment may present with falls or unsteadiness. These examples underpin the need for multidisciplinary collaboration and discussion across different settings as the nature of the CYP's injury and patterns of impairment, activity limitations and participation restrictions become more evident over time.

#### Fatigue

Fatigue after ABI is well recognised, but few studies consider post-ABI fatigue in children. It is thought to have complex multidimensional causes (Ponsford et al., 2015; Crichton et al., 2018a), and it is important to consider fatigue linked directly with ABI within an array of comorbidities including pain, mood and mental health changes, changes in sleep and the impact of medication (Mollayeva et al., 2014). An individual's perception of fatigue can be influenced by the balance of physical effort, cognitive effort, and rest time, and should not be considered as a unidimensional entity at only one time point (Molleyeva et al., 2014). Predictors for fatigue at 12 months after childhood ABI include injury severity, time since injury, changes to sleep-wake cycles, pre-injury mood changes and the presence of pre-injury fatigue (Crichton et al., 2018b). Physical or motor difficulties at six months after ABI has been identified as a predictor of fatigue at 12 months post-injury (Crichton et al., 2018b).

#### **B.** Child and family factors

#### **Psychological aspects - CYP**

Psychological aspects should be considered at all stages of treatment. For the CYP, there may be elements of post-traumatic stress (Nelson and Gold, 2012; Rhine et al., 2017) and the need for new coping strategies to aid adjustment to new disability (Ciccia and Threats, 2015). These aspects may need to be considered in the light of cognitive changes affecting, for example, memory, insight and inhibition. It is important to remember that needs for the CYP may change over time, with acceptance in adolescence being viewed as a fluid and changeable concept, affected by developmental, individual and experiential factors (Cartwright et al., 2014).

#### Psychological aspects - family

For the family, who have journeyed with their child through a period of often life-threatening illness, it is important to recognise significant psychological reactions which may require specific support, including guilt (Savage et al., 2005) and post-traumatic stress disorder (Nelson and Gold, 2012; Muscara at al., 2015). There may also be ongoing stress as families cope with the demands of long-term rehabilitation and consider the implications of the injury on their child's future (Backhouse and Rodger, 1999; Bray, 2015). Helping parents maintain a sense of hope during recovery and rehabilitation is vital (Bray, 2015), contributing to their resilience and coping mechanisms. Families may require support to help them recognise the dynamic process of grief, which may re-emerge at

different points in a "non-finite" pattern of loss (Collings, 2008). Additionally, there may be strains on the parental relationship and wider family networks (Savage et al., 2005; Forinder and Norberg, 2010; Tyerman et al., 2017). Siblings may be impacted by the changes in the CYP with an ABI, disruption to usual family routines during hospital admission and transition home, and changes in family dynamics if parents need to focus more on the care and rehabilitation needs of the CYP with ABI (Forinder and Norberg, 2010), which may lead to sibling behavioural change (Ciccia and Threats, 2015).

#### **Psychosocial risk factors**

Careful consideration of psychosocial risk factors which may have a negative influence on recovery and family functioning post-injury is required (Anderson et al., 2001, Savage et al., 2005; Renaud et al., 2019). These may include pre-morbid family and CYP functioning, including pre-injury emotional needs and comorbidities such as attention deficit hyperactivity disorder (ADHD) (Rhine et al., 2017). Family cohesion, secure family relationships and effective family communication are associated with positive family outcomes following childhood ABI (Rivara et al., 1992). As part of a multidisciplinary approach, physiotherapists may have a role in highlighting psychological needs or contributing to referral for appropriate psychosocial support.

## C. Professional network organisation

#### Multidisciplinary working and communication

Multidisciplinary communication is vital to the ongoing management and treatment of children and young people after ABI. This includes communication and clear referral pathways between tertiary care, specialist rehabilitation services, local hospital and community paediatric services (NHS England, 2013; Scottish Acquired Brain Injury National [SABIN] Clinical Network, 2018). There may also be active safeguarding concerns, so liaison with social care may be an important part of a physiotherapist's work. The CYP may have input from multiple paediatric physiotherapists; liaison with joint goal setting and monitoring may be required across NHS, private and specialist centre contexts. As ABI is regarded as a life-long condition, it is important to respond to a CYP's changing needs. Involvement of the specialist neurorehabilitation team may be beneficial at different points of age and developmental stages (NHS England, 2013).

In some cases, a key worker or case manager may be appointed to coordinate and facilitate the CYP's ongoing rehabilitation needs; this may be extremely beneficial when planning for discharge and in managing the transitions between hospital, specialist rehabilitation centre and home (McKinlay et al., 2016). A case manager or key worker may be appointed from within health, social care, education or medicolegal teams. Close liaison with the school setting is vital both in the early stages of recovery and as the CYP grows (Semrud-Clikeman, 2010; APPG on ABI, 2018; SABIN Clinical Network, 2018).

#### Family-centred care

Family-centred care has been shown to significantly improve CYP's functional and psychological outcomes (Braga et al., 2005). Family-centred care also empowers families to be involved in all aspects of assessment, goal setting, identification of rehabilitation priorities, discharge planning and ongoing review of recovery and development (RCPCH & The Stroke Association, 2017). It is important for families to be given relevant information about their child's ABI and recovery, being mindful of family psychological stress, as described above. Information should be given several times in different

contexts and formats at every point in the rehabilitation pathway (Hawley et al., 2002; Savage et al., 2005; McKinlay et al., 2016; SABIN Clinical Network, 2018). Where English is not the first language, information should be shared in culturally relevant ways using qualified translators.

#### Liaison with education settings

Education settings represent a unique neurorehabilitation environment for children after ABI (APPG on ABI, 2018; N-ABLES, 2021). Navigating the return to education and the possibility of special educational needs processes may be a new and potentially confusing activity for the family of a CYP for whom this was not previously required, especially for CYP discharged home from hospital relatively quickly without a comprehensive support structure in place (Savage et al., 2005). Hidden and subtle changes in cognition or behaviour, and failure of skills to emerge at the required developmental stage, may be misinterpreted within the school setting (APPG on ABI, 2018). As part of a multidisciplinary approach to neurorehabilitation, physiotherapists have a role in contributing to a school's holistic understanding of ABI and its impact on the child.

## Conclusion

While working with CYP following ABI may present unique and complex challenges for paediatric physiotherapists due to variables around the recovery pathway and the ongoing impact on a CYP's overall development, it is important to look ahead and to keep re-evaluating the hopes and desires of the CYP and their family. In collaboration with the CYP's multidisciplinary team, physiotherapists are encouraged to keep in mind their role in providing opportunity for development across a wide range of physical and social domains, enhancing a CYP's quality of life and working towards the fullest participation possible (Rosenbaum and Gorter, 2011).

# **Rehabilitation pathway**

The information in this section is designed to highlight aspects of the CYP's journey important to physiotherapists working in various settings. It is crucial to note that a CYP will not necessarily follow the whole pathway as described below - some will not require time in critical care, and some may not require a hospital admission at all, if an ABI has been identified in a community setting. It is important, however, that physiotherapists understand the whole range of rehabilitation settings, the important considerations for physiotherapy intervention in each setting, and the impact of rehabilitation on the CYP and family at any time point following an ABI. It is imperative that physiotherapists are flexible and responsive in their approach to the CYP and their family at whatever point of the rehabilitation journey they encounter them. It is recommended that a CYP's family and carers are well informed of the physiotherapist's professional role and that they understand the intervention being given - section 1.6 of the National Institute for Clinical Excellence (NICE) head injury guideline (2014) makes recommendations on information and support for families and carers. While not stated explicitly in every section below, multidisciplinary team working is vital for CYP after ABI and should be the norm at each stage.

The rehabilitation pathway is summarised in Fig. 2 before examining the key consideration for physiotherapists, focus of physiotherapy assessment, focus of physiotherapy intervention and communication with the CYP and their family at each stage.

CYP diagnosed with an ABI	<ul> <li>CYP may be diagnosed with ABI through sudden-onset of symptoms or clinical history, or they may have symptoms of ABI for some time prior to diagnosis</li> <li>Diagnosis is likely to involve investigations and imaging as well as input from a range of members of the multidisciplinary team</li> </ul>
A. Paediatric critical care	<ul> <li>Initial management is often time-sensitive and may involve admission to the paediatric intensive care unit (PICU) where they may be intubated</li> <li>Care will be led by intensivists with input from a range of different teams - for a CYP with an ABI this is likely to include paediatric neurosurgeons and/or neurologists among others, depending upon the CYP's individual needs</li> </ul>
B. Transition from critical care	<ul> <li>CYP will be transferred when they are sufficently stable to no longer require care within the PICU environment</li> <li>They may be repatriated to their local hospital or be transferred to a ward within the same hospital - in either case, communication with the CYP and family as well as colleagues receiving the CYP is essential</li> </ul>
C. Ward setting	<ul> <li>When the CYP is on the ward, further physiotherapy assessment and intervention can be offered as part of their acute rehabilitation</li> <li>Communication with the CYP and family, as well as colleagues in the multidisciplinary team remain essential</li> </ul>
D. Transition from the ward	<ul> <li>Discharge from hospital ward to community, ward to specialist inpatient rehabilitation unit or specialist inpatient rehabilitation unit to community</li> <li>Support by summarising physiotherapy assessments, intervention to date and treatment plans, communicating clearly with physiotherapy colleagues in the next setting and referring on in good time</li> <li>CYP and family should also be supported to continue their rehabilitation</li> </ul>
E. Community	<ul> <li>Community physiotherapy may be required once the CYP has returned home from hospital or a specialist inpatient rehabilitation unit</li> <li>Physiotherapy assessment and intervention may take place within a variety of settings, including home, nursery, school or clinic and should be based around the CYP's changing needs and/or progress being made</li> </ul>
F. Discharge	<ul> <li>Discharge from physiotherapy may happen following intensive input from community physiotherapists or intervention blocks</li> <li>Self-management advice and recommendations are important to share with CYP and family as part of discharge planning</li> <li>Advice for requesting re-referral for physiotherapy and signposting to charities for ongoing family support may be important at this stage</li> </ul>
G. Re-referral and transition	<ul> <li>ABI is a lifelong injury and a CYP may encounter new and emerging difficulties some time after injury - smooth referral back to physiotherapy for further assessment and intervention is important</li> <li>CYP may benefit from review in transition clinics, or be referred directly into adult physiotherapy teams</li> </ul>



# A. Paediatric critical care

Key considerations for physiotherapists

• Before any assessment or intervention ensure familiarity with the CYP's current Glasgow coma score (GCS), level of sedation, level of neuroprotection and relevant critical parameters

including intracranial pressure (ICP), cerebral perfusion pressure (CPP), seizure status, ventilation requirements and cardiovascular status - see Special Considerations section, F. Neuroprotection, for further detail.

- CYP who have sustained a TBI may also have other trauma, including but not limited to musculoskeletal or abdominal injuries. Following completion of the primary survey, early resuscitation and stabilisation of vital signs, a secondary survey will be carried out by a doctor, to identify other possible injuries.
- Be aware that bruising over the mastoid process may indicate a fracture of the middle cranial fossa (Battle's sign), periorbital bruising may indicate basal skull or facial fracture ('raccoon eyes'), and evidence of cerebrospinal fluid (CSF) or blood drainage from the ear may indicate a possible basal skull fracture. Head and scalp examination should be completed by the medical team and will also include assessment of eye and pupil responses.
- The chest, abdomen and limbs will also be examined by the medical team in the secondary survey. Swelling or bruising due to fractures may only develop over time and may have been missed in the primary survey. It will be important to check for any signs of pain including facial grimace, increased heart rate, increased blood pressure, or increased ICP in response to active or passive movement. The secondary survey should also include skin examination: friction burns may be present after a road traffic accident, and a plastic surgery opinion may be required.
- It is essential that the physiotherapist is aware of the findings of primary, secondary and ongoing surveys, and recognises there may still be unidentified injuries. Assessment and intervention may need to be adjusted according to local policy, for example, hip flexion limitations in the presence of a pelvic fracture (trauma injuries), restrictions due to drains or neuroprotection.
- For CYP with a TBI, a rehabilitation prescription or plan should be started within 72 hours of admission and this document should follow the CYP at all stages of rehabilitation.
- Be aware of medications, and the potential impact on physical examination findings: a patient who is fully paralysed and sedated will not have any movement or reflexes. Consider also the impact of sedation withdrawal as medication can take time to move out of a CYP's system and this may influence the context of assessment findings.
- Consider a differential diagnosis of critical illness polyneuropathy when patients display unexplained weakness and difficulty in weaning from mechanical ventilation.
- The impact of prolonged bed rest on muscle strength and subsequent weakness needs to be taken into account during assessment and intervention.
- A risk assessment including the following considerations may be beneficial to determine how many therapists are required for safe assessment and treatment:
  - Behavioural factors
  - Agitation may be nursed on the floor, 1:1 supervision, bed side padding
  - Aggression and disinhibition
  - Unpredictability CYP could be mobile
  - Postural control
  - Level of consciousness
- Paroxysmal sympathetic hyperactivity (PSH), also known as dysautonomia or sympathetic storming, is a severe, debilitating sequela of ABI, characterised by dysfunction of the autonomic nervous system resulting in fever, tachypnoea, hypertension, tachycardia,

diaphoresis (excessive sweating) and/or dystonia. PSH occurs in 8-33% of adults following brain injury and in 13% of paediatric patients following ABI (Kirk et al., 2012), with a higher incidence of 31% following anoxic brain injury (Krach et al., 1997; Kirk et al., 2012). Episodes appear unprovoked and can last hours or days and then end abruptly (Lemke, 2007), and most reports focus on the first few weeks after injury. Kirk et al. (2012) suggest children with PSH have longer hospital stays and worse scores on standardised assessment. Physiotherapists working in paediatric critical care should be aware of this phenomenon and recognise the symptoms following ABI. Both pharmacological and environmental interventions are used to manage the individual's symptoms.

 Post intensive care syndrome - paediatrics (PICS-p) is an area of current research interest. PICS is recognised in adults and its application to the paediatric setting is relevant to all CYP who have a stay in critical care, along with their families. It can lead to a range of physical, psychological and cognitive changes affecting recovery, even without a primary neurological injury (Hartman et al., 2020). It is important for the physiotherapist to understand local protocols in place within critical care to manage potential PICS-p risks.

#### Focus of physiotherapy assessment

- Assessment at this stage is initially about monitoring body structure and function, and mitigating the effects of immobility, taking into consideration all relevant systems including respiratory, neurological, musculoskeletal and sensory functions. Early functional assessment may be indicated on a case-by-case basis; early mobility can be beneficial and is an area of current research interest.
- Discuss with nursing staff how the CYP responds to handling during routine care and other interventions such as suction, personal care and procedures. This should inform your assessment before any specific objective assessment is carried out.
- Close monitoring of critical parameters is required throughout assessment, with a pause or discontinuation of assessment if these are breached, the CYP becomes unstable or has a seizure. Be aware of possible physiological responses to pain, including increased heart rate and blood pressure, even when there is a low level of consciousness.
- Each contact with the CYP should be considered as part of the assessment, adding to the clinical picture over time. There may be times when the CYP is too unstable to be assessed or treated this should still be documented in the physiotherapy records.

#### Focus of physiotherapy intervention

- The focus of intervention at this stage will be on maintaining body structure and function, managing range of movement and muscle tone, and encouraging early mobility where possible.
- Treatment sessions may be short and may be managed by different specialties within the physiotherapy team, including the critical care respiratory or neurorehabilitation teams.

#### Communication with CYP and family

- Ensure that you are speaking to the person with parental responsibility.
- Be aware that there may be active safeguarding concerns.
- Admission to critical care following an ABI may be upsetting, shocking or frightening to families and the CYP (if conscious). It is vital to introduce yourself at every visit, reminding

them of your role and expectations for the session. Liaising with medical and nursing teams can be crucial in understanding the emotional wellbeing of the family, and whether a physiotherapy session is appropriate at any given time. Situations can change quickly, and family priorities may not include a lengthy physiotherapy session if they have received new updates on diagnosis, prognosis or medical treatment plans.

- Speak to the family or carers about what they observe in their CYP.
- Give a summary of findings to the family during and after each session.
- Ensure the CYP and family know when the next physiotherapy session will be and how they can make contact should queries arise.

# **B.** Transition from critical care

Key considerations for physiotherapists

- Critical care stays may be very brief or extended. Some CYP are repatriated to their local district general hospital directly from the critical care setting, so be prepared to handover to a local team in a timely manner.
- Ensure that the receiving physiotherapist (whether within the same hospital or not) is informed of progress while in critical care, and that any particular instructions or parameters for ongoing assessment including limb injuries, weight bearing status or sensory changes are shared.
- Timely updates to the CYP's rehabilitation prescription (where applicable) are important to consider.

#### Communication with CYP and family

• Communication with both CYP and family is vital at this point - moving out of critical care to a ward setting is a positive step, but it can feel terrifying to move from one-to-one support to a different model of nursing care and monitoring. Parents can find having fewer monitors attached disconcerting, particularly if the critical care stay has been prolonged. Contribute to multidisciplinary communication to prepare families (and CYP, if appropriate) for the transition. Ensure they are aware of what physiotherapy intervention to expect when on the ward, and who is going to provide this.

# C. Ward setting

Key considerations for physiotherapists

- After TBI, a CYP may have post-traumatic amnesia. This may affect their short-term memory, orientation and behaviour.
- PICS-p may be present.
- Raise any concerns about decline in respiratory status, neurological function (including seizures) or independence to ward nursing or medical staff promptly. New neurological symptoms including seizures or an acquired hydrocephalus may emerge in these early phases of rehabilitation so close observation, assessment and communication of assessment findings to the multidisciplinary team is required.
- Continue to consider medication effects, pain, tertiary survey results and behavioural factors, as noted above.

- Consider the impact of the environment and the CYP's condition on their presentation including frequency of observations, quality of sleep, noise and external distractions.
- Use an interdisciplinary assessment format where possible. Consider assessing jointly with occupational therapy, speech and language therapy, orthotics, hospital play team or hospital school colleagues, to ensure maximal therapy observation/input while mitigating for likely fatigue and processing difficulties.
- Early identification of ongoing rehabilitation needs and liaison with local physiotherapy teams is essential. It is important to highlight the likelihood of continued support when the CYP is discharged from hospital. Discharge location may vary regionally and knowledge of pathways and processes for smooth and supported transition is important - see also section D. Transition from the Ward, below.

#### Focus of physiotherapy assessment

- The ward assessment builds on previous findings, with increasingly detailed assessment of body structure and function, moving through activity and into participation domains, according to the CYP's progress and developmental stage. It is also important to consider what ongoing rehabilitation a CYP may need in the medium to long term.
- Range of movement and tone, strength, selective and purposeful movement, functional mobility, impact of cognition and sensory functions on mobility, and impact of fatigue should be assessed.
- Risk assessment, including the following factors, is essential in determining therapist numbers/skill mix for safe intervention:
  - Behavioural factors
  - Agitation may be nursed on the floor, 1:1 supervision, bed side padding
  - Aggression and disinhibition
  - Unpredictability CYP could be mobile
- Use play and other activities as soon as possible as part of assessment.
- Consider early assessment and referral for equipment that the CYP may require, including specialist seating, standing frames, sleep systems, wheelchairs, orthotics, lycra suit, spinal bracing, ankle-foot orthosis.
- Consider whether additional specialist inpatient neurorehabilitation is likely to be indicated this should be considered by the whole MDT. For some families, such a placement can be a vital step in maximising outcomes, adjusting to new situations and allowing additional time for comprehensive community support to be arranged.

Focus of physiotherapy intervention

- The focus for intervention in the ward setting is to progress a CYP's physical mobility and function, taking into account changes in muscle strength and tone, range of movement, communication, cognitive and sensory changes.
- For CYP with polytrauma, confirm weight-bearing status with the medical or orthopaedic teams as well as any other restrictions on mobility (e.g., bed rest due to abdominal injuries) prior to getting out of bed.
- Involve parents or carers in treatment sessions if possible, to build confidence in assisting and handling their CYP in preparation for the eventual move to the community setting and home-based therapy programmes.

- As for assessment, aim for interdisciplinary intervention formats, working towards joint goals with other disciplines including occupational therapy, speech and language therapy, orthotics, hospital play, psychology or hospital school. The latter two teams can be extremely effective in promoting activity and participation.
- Use play and other activities as soon as possible as part of intervention. Make use of varied locations once the CYP is stable (check with the medical team before taking off the ward for the first time) the therapy gym, hospital school, hospital canteen or outside garden areas may be suitable environments. Ensure the environment ambience is appropriate for the CYP's status: for example, if the CYP has poor attention or processing speed, aim for a quiet, calm environment to begin with.
- Monitor throughout for signs of fatigue and modify intervention time accordingly.

#### Communication with CYP and family

- During intervention sessions, ensure instructions are given simply and clearly by one designated team member to avoid giving conflicting information, or multiple processing requirements at any given time. It is important to explain this to the family as well.
- To help manage post-traumatic amnesia, it is important to communicate clearly, ensuring the CYP knows who each member of the team is, with names being repeated each time. An orientation board and photos of MDT members may be beneficial.
- Continue to consider family wellbeing parents or carers may benefit from ongoing reassurance that the CYP is making progress and no longer requires the critical level of monitoring and nursing care.
- Begin goal-setting with the family. This may be a new skill for families to learn and may require time, practice and reassurance. MDT approaches will be beneficial, including clinical psychology where appropriate to support discussions around adjustments to potential long term changes while remaining hopeful for progress in rehabilitation.
- Explain observations and session findings to the family, giving clear instructions for activities to try between sessions (if appropriate it may be more important to give instructions to rest or manage fatigue), and when the next session is planned for.
- Timetables can be an effective tool for the MDT to use throughout the CYP's hospital stay to ensure good communication between the CYP, family and teams. They can ensure that therapy interventions, schooling and rest times are appropriately allocated to help minimise impacts of fatigue or overload.

# D. Transition from the ward

This transition may be from a hospital ward setting to the community, from a hospital ward to a specialist inpatient rehabilitation unit, or from a specialist inpatient rehabilitation unit to the community. The role of the 'discharging' physiotherapist and the 'receiving' physiotherapist will be detailed.

#### 'Discharging' team preparation

Key considerations for physiotherapists

- This stage should start early on in a CYP's hospital stay either because they are making rapid
  progress and are likely to be discharged quickly, or because there are anticipated obstacles to
  discharge including housing, care or educational requirements and family factors. It is
  important to be aware of the likely course of the hospital stay and to be aware of factors likely
  to delay discharge.
- Where appropriate, contribute to the assessment of the CYP's level of rehabilitation need (Turner-Stokes, Krägeloh and Siegert, 2018), rehabilitation prescription or plan to help support ongoing rehabilitation in the community setting. For CYP in a major trauma centre this is standard practice (check local policy and paperwork), and while it may not be mandatory for CYP with non-traumatic ABI, a similar approach may be relevant.
- Consider referral to a specialist neurorehabilitation centre when a CYP may benefit from ongoing intensive rehabilitation in a non-acute environment. Early discussion of this option is advised, involving the family (and CYP where appropriate), with prompt referral to the specialist centre to ensure timely assessment and transfer if appropriate.
- Check the referral criteria and process for the community physiotherapy team, initiating referral as early as possible. Where possible, arrange a joint appointment with community counterparts to ensure smooth transition and handover. Take time to understand the intervention packages offered by different community teams as these may vary depending on location, to help manage CYP and family expectations.
- Outcome measures and goals initiated in the ward setting should be passed on to community teams. Ensure there is clear documentation and communication of abilities and progress during inpatient intervention. Progress documentation is also important for those patients who do not require community follow up and especially those with more moderate injuries as this is a group with greater risk of future unmet need (Hawley et al., 2002).

Focus of physiotherapy assessment

- Consider early assessment and referral for equipment that the CYP may require on discharge or whilst staying in hospitals, including specialist seating, standing frames, sleep systems, wheelchairs, orthotics, including lycra suit, spinal bracing, ankle-foot orthoses.
- It may be necessary to contribute to a multidisciplinary assessment/request for a continuing health care plan, including long term equipment needs. Contribution to an application for a statutory assessment of educational needs may also be required if this was initiated while the CYP was an inpatient.

Focus of physiotherapy intervention

- Increase involvement of parents and family during the CYP's physiotherapy sessions to build their confidence in handling and transferring skills and to prepare them for delivering home therapy programmes.
- Provide education for the CYP and family on 24-hour postural care if appropriate.
- Continue with ongoing education to family, and CYP where appropriate, to increase awareness of ABI, rehabilitation progress and to build their confidence with advocating for their child's needs. Ensure written condition-specific information is given for future reference (see Appendix D). Education should include discussion about possible long-term impacts of ABI with emerging difficulties across childhood and adolescence, balancing hope with clear awareness of likely progress.

- Consider a written or photographic diary/journal to help family and community teams understand the progress made by the CYP in the hospital or specialist inpatient rehabilitation unit. Ensure these are within data protection, record keeping and clinical governance frameworks in your workplace.
- Consider the use of days out, day visits home and weekend leave as part of treatment planning, to help parents prepare for taking their CYP home and allow for problem-solving around participation prior to discharge. Consider local policies and procedures to help guide this.

#### Communication with CYP and family

- Introduce the concept of referral to community therapy teams to families during hospital admission. This should be discussed with families as part of ABI education and with reference to anticipated clinical progress and rehabilitation expectations.
- It is important to prepare families for moving from a more acute setting with perhaps daily
  multidisciplinary therapy, to sub-acute and long-term settings where therapy intervention
  may reflect the steady but slower-paced gains expected in the months and years following
  ABI. In the latter settings, there may be greater emphasis on home programmes, intervention
  blocks and use of daily activities as part of therapy provision, which may be an unfamiliar
  process to many CYP and families. This conversation should highlight the positive progress
  made in rehabilitation, and that CYP is ready to move to the next rehabilitation setting.
- In certain cases, a CYP will not be returning to his/her original home following their admission: this may relate especially to babies and young children with non-accidental injuries. In these cases, liaise with the hospital and local authority safeguarding and social work teams, and foster carers or extended family members as to who will be taking on responsibility for daily care of the child. Physiotherapists should ensure they are clear who has parental responsibility, that rehabilitation plans are sufficiently detailed and that contact details for further advice are provided.

#### 'Receiving' team preparation

Key considerations for physiotherapists

- Consider early initiation of new referral.
- You may wish to consider whether intervention can be delivered in a multidisciplinary format in conjunction with other therapy disciplines, to reduce the burden of appointments during the initial return home and the significant family adjustment this requires.
- Ensure that you have received copies of rehabilitation prescription or plan (where appropriate), outcome measures and goals initiated in the acute setting, for ongoing completion and review as required.

Focus of physiotherapy assessment

• Discuss with the hospital or rehabilitation centre team what ongoing intervention may be indicated, and how this may be delivered to CYP in the community setting. This will help the hospital team as they prepare the family and manage expectations for the transition home - use rehabilitation prescription or plan to guide this where appropriate.

• Contribute to continuing health, care and statutory educational needs assessments as required.

Focus of physiotherapy intervention

- The focus for intervention at this point is largely establishing a therapeutic relationship with the CYP and family. If possible, consider visiting the CYP in the hospital or rehabilitation setting, or attending a multidisciplinary planning meeting either face to face or through virtual meeting. This may help to build confidence at this time of transition and ensure a consistent message is given to the CYP and family in preparation for discharge, in relation to expectations of therapy intervention and future plans.
- The CYP may be negotiating their return to school while simultaneously settling into the home setting. It may be beneficial to make early contact with the CYP's school to support staff (including teachers, SENCo and educational psychologist) to ensure the return to school plan is appropriate for the CYP's current physical needs, thereby promoting their participation (N-ABLES, 2021). Areas to cover may include mobility around school, physiotherapy programmes to be completed within school, participation in PE/sports, and fatigue management.

#### Communication with CYP and family

- As part of the CYP's multidisciplinary team, consider the next steps for follow up and allocate a keyworker or case manager to act as a single point of contact for the family as they prepare to go home (McKinlay et al., 2016). Ensure the family has the receiving physiotherapist's contact details as well as those for the keyworker during transfer of treatment location from hospital to community setting.
- Consider the emotional/psychological needs of the family at the time of returning home. At times, they may be limited in their ability to take in new information or complex treatment programmes. Reinforce verbal information with written resources and allow time for discussion and questions.

# E. Community

It is acknowledged that service provision will vary between individual community physiotherapy teams. The information below provides guidance on aspects to consider, but should be applied according to your local policies and practice.

Key considerations for physiotherapists

- Timely intervention for children with ABI is important. Regular review is essential to monitor the progress of the children once they have settled into their home environment. Consider treatment provision creatively and flexibly to meet the needs of the individual child.
- A CYP may be seen by a physiotherapist in a variety of settings including home, nursery, school and clinic. It can be helpful to be flexible around which setting to see a CYP in, taking into account their physical condition, rehabilitation progress, cognitive and community needs, plus family needs including transport requirements, parental working patterns, or parental/CYP emotional wellbeing.
- As discussed in the introduction, recovery may take place over many years thus physiotherapy assessment and intervention should be available to the CYP on an ongoing basis. Recovery in

the initial phase may see skills returning and improving very quickly; in later phases these may emerge more slowly. Where a CYP has had a critical care stay, it may be useful to consider the possible contribution of PICS-p.

#### Focus of physiotherapy assessment

- The focus of assessment in the community setting is on the CYP's activity and participation, and how changes in body structure and function contribute to this. Needs may change over time and will be impacted by usual developmental processes including growth and weight changes, as well as by changes related to the ABI including muscle strength and tone, motor control, sensation, cognition and communication.
- Assessment may also include higher-level mobility needs: for example, a CYP may be able to walk, but may have difficulty running due to high-level balance and coordination changes. Subtle muscle strength or tone changes should also not be overlooked. Visual changes may also impact negatively on higher-level mobility skills.
- Part of the ongoing assessment may include reviews of equipment for including specialist seating, standing frames, and wheelchairs. Knowledge of local equipment providers and pathways is necessary to ensure no undue delay in provision and to maximise the CYP's participation.
- Contribute to continuing health, care and education needs assessments as required. It is essential to liaise with the CYP's educational setting.

Focus of physiotherapy intervention

- The focus of intervention in the community setting includes maximising activity and participation across home, school and community domains: promoting physical activity and return to school (or entry, for those with ABI in pre-school years) alongside management of body structure and function including muscle tone and strength, balance and coordination. This involves understanding usual developmental processes, and how the CYP's ABI and neurological deficits may impact on these over time.
- It is important to involve the CYP's school when setting and reviewing goals, emphasising the nature of the educational environment as a rehabilitation setting. It presents opportunity for rehearsal and repetition, application of emerging skills to a variety of contexts, every-day and real-life situations, plus the impact of social interaction on wellbeing and progress.
- It is common for a CYP to have a phased return to school, as part of managing fatigue. Physiotherapists have a key role in advising on strategies to pace activity and manage fatigue across home and school settings.
- From an early point in community therapy intervention, it is important to promote physical activity due to its long-term health and wellbeing benefits for all children. A CYP may have been extremely physically active prior to their ABI and may wish to return to this level of participation. The physiotherapist is uniquely placed to support this by liaising with school and community activity providers, supporting modified involvement as part of the CYP's therapy programmes. For CYP with significant changes to motor or cognitive skills, who are unable to return to the same sport or level of competition, this may require specific goal setting, referral into local community disability sports clubs, plus specific advice for safe involvement in PE lessons at school.

Communication with CYP and family

- Involve the CYP in the intervention programme as much as possible. Make use of pre-injury hobbies and preferences to inform intervention approaches and invite the CYP to participate in goal setting and review.
- Ensure that the CYP's cognitive needs are considered in the context of their therapy provision: for example, a CYP with verbal memory difficulties may need written instructions/pictures of a simple home exercise programme, with frequent reinforcement of what is required.
- Close liaison with parents remains vital, to address and manage their expectations regarding therapy intervention, including intensity and frequency. It is important to explain the process of treatment blocks, or packages, and how these fit together over time. If a CYP is seen at school, ensure that a session summary is sent to the family afterwards, or parents are updated by phone call, to allow for regular review of progress and expectations.
- Families may be overwhelmed with paperwork and appointment letters, so it is important to ensure parents are clear about therapy team expectations of them (for example, timescales for changing appointments, opt-in requirements, policies for discharge if a CYP is not brought to an appointment). Given the sudden, shocking impact of the ABI on the family's wellbeing, it is important to offer understanding of the family's situation and some flexibility with expectations, if possible.
- Family-centred goal setting should be the standard, with multidisciplinary goal setting wherever possible.

# F. Discharge

Key considerations for physiotherapists

• Ideally, treatment should be continued until the CYP and family are able to self-manage, the CYP has stopped making progress, or requires no ongoing management for neurological impairments resulting from the ABI.

Communication with CYP and family

- It is important to prepare the CYP and family for discharge, whether this comes after an extended period of community-based intervention, or at the end of a block of treatment.
- It is important to ensure the family knows how to request a re-referral should new difficulties emerge or concerns around physical abilities arise.
- Ensure that discharge reports are sent to families in a timely manner, and are copied to the multidisciplinary team including school, with permission of the family and CYP where indicated. Discharge reports should contain clear recommendations and indicate who the family should talk to if they have concerns in the future.
- Signpost to relevant charities for ongoing family support, see Appendix D.

# G. Re-referral and transition

Key considerations for physiotherapists

• ABI is a lifelong injury and a CYP may encounter new and emerging difficulties some time after injury. It is vital that they can be referred back to for further physiotherapy assessment and intervention easily.

• Where indicated, it will be important to refer to a transition clinic, or directly into adult physiotherapy teams. Timely referral will help support the young person at this time, with joint appointment as part of the handover if possible.

#### Focus of physiotherapy assessment

- The focus of assessment for a re-referral is on identifying what is different compared to the time of previous assessment, why the CYP's function and participation may have changed, and the identification of new goals. There may be physical change (e.g. through natural growth or onset of adolescence), new communication or emerging cognitive difficulties affecting participation with peers or team activities, or it may be that the environment around the CYP has changed.
- Often, times of transition in education may prompt re-referral to physiotherapy: for example, moving from primary to secondary school, from there into college, and then into tertiary education or work (RCPCH & The Stroke Association, 2017). The complexity of demand and expectation changes, and the CYP's motor or cognitive skills may fail to meet these. A CYP may present with increased fatigue, new musculoskeletal pain, difficulties participating in usual sporting activities both within and outside of school, increased cognitive difficulties or a rise in anxiety.
- A CYP may be less likely to participate in physical activity after ABI so it is important to assess a CYP's ability to participate in physical activity to promote long term good health. It is important to review the physiotherapy advice in a statutory education, health or care plan at the time of re-referral or long-term review also.
- Factors to consider, at time of re-referral or long-term review, include:
  - Age at injury
  - Age at time of re-referral
  - Normal developmental milestones and growth changes
  - Pre-morbid health/learning
  - Impact of any sensory changes on function and participation e.g visual changes
  - Possibility of emerging difficulties in any area of function, and the impact of this on social and school participation e.g. high level cognitive-communication changes which may be extremely subtle
  - Current environmental demands
  - Ongoing psychological adaptation and mental health

Focus of physiotherapy intervention

- Should new needs be identified, intervention programmes should be re-initiated, with the
  usual family and CYP education required to support this, liaison with the multidisciplinary
  team, and consultation with school as appropriate. Attention should be given to promoting
  physical activity as discussed above, including signposting to relevant local play, sporting and
  leisure activities for children with disability where indicated.
- If indicated, refer or request referral back to neurology, neurosurgery, community paediatrics, orthopaedics or adult neurorehabilitation teams for medical review and medication adjustments/management of tone changes or limb positioning.
- Intervention should have a strong focus on anticipating future needs: for example, advice about driving options, or developing increased independence with public transport.

Communication with CYP and family

- The CYP and family may notice subtle changes it is important to listen to the information they share to identify unmet needs and ask questions based on physiotherapy clinical expertise to identify potentially unrecognised needs. It may be important to consider emotional and wellbeing aspects as a route into discussing what the specific difficulties are for example, a CYP may be feeling upset or frustrated, and on further discussion may indicate they are unable to keep up with friends as they used to. It is the skill of the physiotherapist to then work with the CYP and family to work out why participation has changed.
- It remains important to manage expectations, particularly when considering transition to adult services. Transition to a 'new' adult team can be worrying for parents and young people.

# **Physiotherapy assessment**

Guidance for physiotherapy assessment is noted below and is mapped to the ICF as described earlier in this document (see Fig. 1). It may not be necessary to assess all ICF elements at all assessments: clinical judgement is required to determine what may be needed at each stage of the CYP's recovery and rehabilitation, in combination with best available evidence. Additional sources of guidance on aspects around assessment include:

- Cerebral Palsy Integrated Pathway
- Children and young people with acquired brain injury: Current practice in occupational therapy (College of Occupational Therapy, 2015)
- Paediatric acquired brain injury best practice statements (SABIN, 2018)
- Spasticity in under 19s: management (CG145) (NICE, 2016)
- Stroke in childhood: Clinical guideline for diagnosis, management and rehabilitation (RCPCH & The Stroke Association, 2017)

It may be relevant to consider assessment related to other frameworks or approaches, including neurodevelopmental therapy/Bobath or motor learning. All your physiotherapy assessment skills and experience will be relevant for the progressive and dynamic assessment of CYP after ABI, selecting suitable approaches based on the needs of each unique CYP. It is important to begin assessment as soon as the CYP is medically stable.

#### Personal factors

Personal factors including gender, age, education, past and current experience, character and other factors can influence how disability is experienced by the individual. For example, a CYP may be frightened due rapidly changing situations; a CYP may be inherently shy and not outspoken prior to injury. For a CYP with ABI, fatigue can influence performance during assessment.

Timing of assessment may be relevant to consider - a CYP may not show the full range of their abilities if they have had a busy morning of medical procedures on the ward, or completed an exam in school prior to your appointment.

#### **Environmental factors**

The physical, social and attitudinal environments in which people live and conduct their lives are either barriers to, or facilitators of, an individual's functioning. For example, being in hospital may reduce a CYP's ability to reach the bathroom independently, compared to being at home. It is important to consider the various environments the CYP may experience, particularly in relation to physical access and equipment provision.

#### **Outcome measures**

The use of standardised outcome measures as part of the assessment process provides a common language with which to evaluate a CYP's progress. There are a large number of outcome measures relevant to physiotherapy available, although they may not all be validated for use with CYP following ABI. Some may measure specifically within one ICF domain whilst others may cross a number of

domains, and there is no single standardised measure which will adequately reflect change at all stages of rehabilitation.

Results from outcome measures and indeed any other assessments should be shared and explained with parents/carers in order to help them understand their CYP's condition. They can also be used to assist with family-centred goal setting during intervention planning. McCauley et al (2012) summarise outcome measures used in childhood TBI research, highlighting the broad range of domains benefitting from standardised assessment. More detail on <u>paediatric outcome measures</u> is available on the APCP website.

#### Assessment of impairments to body structure and function

Consider key elements including muscle tone, range of movement, power, sensory function and pain. A brief summary of assessments and outcome measures related to impairments of body structure and function is found in Table 1 below, with more detail provided in Appendix A.

Example area	Specific examples of assessment and outcome measures	Descriptor
Muscle tone	Modified Ashworth Scale (Bohannon and Smith, 1987)	A clinical measure of muscle spasticity which uses a scale from 0 (no spasticity) to 5 (rigid).
	Tardieu Scale (Boyd and Graham, 1999) Modified Tardieu scale (Yam and Leung, 2006)	This scale assesses the muscle's response to stretch at various given velocities
	Hypertonia Assessment Tool (HAT) (Jethwa et al, 2009)	A 7-item instrument that discriminates between spasticity, dystonia, and rigidity.
Deep tendon reflexes	Babinski Sign	A reflex characterized by upward movement of the great toe and an outward movement of the rest of the toes, when the sole of the foot is stroked. It is a normal reflex up to the age of two. Its presence beyond that age indicates neurological damage.
	For example, patella, tendo-achilles,	A stretch reflex, when the stretch is

 Table 1. Examples of assessment and outcome measures for impairments to body structure and function

	biceps, triceps reflexes	created by a blow upon the muscle tendon.
Ankle clonus	Ankle clonus test	Involuntary rhythmic contractions and relaxations of a muscle indicates upper motor neuron damage
Range of movement	Goniometry	Use of a goniometer to measure range of active and passive motion in joints
Muscle strength	Oxford Scale also known as the Medical Research Council (MRC) Scale for Muscle Strength	Muscle power graded on a scale 0-5 Grade 5: Muscle contracts normally against full resistance
	(MRC, 1981)	Grade 4: Muscle strength is reduced but muscle contraction can still move joint against resistance.
		Grade 3: Muscle strength is further reduced such that the joint can be moved only against gravity with the examiner's resistance completely removed.
		Grade 2: Muscle can move only if the resistance of gravity is removed.
		Grade 1: Only a trace or flicker of movement is seen or felt in the muscle or fasciculations are observed in the muscle.
		Grade 0: No movement is observed
	Sunnybrook facial grading system (SFGS) (Ross, Fradet and Nedzelski, 1996)	The SFGS is used in the clinical evaluation of facial nerve function. The SFGS comprises three areas of assessment:
		<ul> <li>Resting symmetry</li> <li>Voluntary excursion of facial muscles</li> <li>Synkinesis associated with specific voluntary movement</li> <li>The regions of the face are evaluated separately using five standard expressions.</li> </ul>

NACK		
MSK alignment	Chailey Levels of Ability (Pountney et al., 1999)	An assessment tool to measure postural ability, covering theoretical aspects of posture management and its practical application through treatment and equipment.
Postural control	Chailey Levels of Ability (Pountney et al., 1999)	An assessment tool to measure postural ability, covering theoretical aspects of posture management and its practical application through treatment and equipment.
	Segmental Assessment of Trunk Control (SATCo) (Butler et al., 2010)	Provides segment by segment assessment of trunk control. Assesses static, active and reactive control in sitting.
Balance	Berg Balance scale (Berg, Wood-Dauphine and Williams, 1992)	Test of a person's static and dynamic balance abilities. There are 14 items assessed and scored on a five-point ordinal scale ranging from 0 to 4, with 0 indicating the lowest level of function and 4 the highest level of function.
	Paediatric Balance Scale (Franjoine, Gunther and Taylor, 2003)	A modified version of the Berg Balance Scale. Used to assess functional balance skills in school-aged children.
Coordination	Scale for the Assessment and Rating of Ataxia (SARA) (Schmitz-Hübsch et al., 2006)	Assesses a range of different impairments in cerebellar ataxia. The scale is made up of 8 items related to gait, stance, sitting, speech, finger- chase test, nose-finger test, fast alternating movements and heel-shin test.
	Brief Ataxia Rating Scale (BARS) (Schmahmann et al., 2009)	A shorter assessment of ataxia developed from Modified International Cerebellar Ataxia Rating scale.

Sensation	Superficial Sensation	Pain perception - sharp/dull
		discrimination Temperature awareness - hot/cold discrimination
		Touch awareness - light touch (cotton wool) Pressure perception
	Deep sensation	Kinesthesia awareness - movement awareness Vibration perception - tuning fork Stereognosis perception- object recognition
	Combined cortical sensation	Tactile localization Two-point discrimination
Pain	Visual analogue scale (VAS) (Wewers and Lowe, 1990)	A self-reported tool that tries to measure a characteristic or attitude that is believed to range across a continuum of values and cannot easily be directly measured e.g. pain.
	Paediatric Pain profile (Hunt et al., 2004)	The Paediatric Pain Profile (PPP) is a 20- item behaviour rating scale designed to assess pain in children with severe neurological disability.
	Faces Pain Scale (Hicks et al., 2001)	The scale consists of six faces that range from no pain at all to the worst pain imaginable. The emotional faces range from smiling to grimacing. Children aged 3+ years match their level of pain to a face on the scale.
Involuntary movement	Barry Albright Dystonia Rating Scale (Barry, VanSwearingen and Albright, 1999)	A 5-point, criterion-based, ordinal scale designed to assess dystonia in eight body regions: eyes, mouth, neck, trunk, and the four extremities. The examiners score dystonia as none (0), slight (1), mild (2), moderate (3), or severe (4)
	Burke-Fahn-Marsden Dystonia Rating Scale (Burke et al., 1985)	Consists of the Burke-Fahn-Marsden Movement Scale (BFMMS) and Burke- Fahn-Marsden Disability Scale (BFMDS).

		BFMMS measures dystonia in nine body regions including the eyes, mouth, speech and swallowing, neck, trunk, arms, and legs, with scores ranging from 0 (minimum) to 120 (maximum). BFMDS is a functional marker consisting of parental- or self-reported daily activities involving speech, handwriting, feeding, eating, swallowing, hygiene, dressing, and walking, with scores ranging from 0 (completely independent) to 30 (completely dependent).
Level of consciousness	Wessex Head Injury Matrix (WHIM) (Sheil et al., 2000)	Assessment of patients in and emerging from coma and those in the vegetative and minimally conscious states. 12 years +
	Ranchos Los Amigos (Hagen, Malkmus and Durham, 1972; Lin and Wroten, 2021)	Scale used to measure and track cognitive and behavioural presentation as they emerge from coma following TBI.
	Glasgow Coma Scale (Teasdale and Jennett, 1974; see also <u>www.glasgowcomascale.org</u> )	A standardised discriminative assessment to measure the child's level of consciousness. The sum of the eye response, motor response, and verbal response are recorded.
Vision	Visual field and tracking	Visual field is tested in all four quadrants. Visual tracking occurs with movement of the eyes to follow a moving object and not movement of the head. The eyes have the ability to track an object in the vertical and horizontal, diagonal, and circular planes.
Fatigue	Visual analogue scale (VAS) (Wewers and Lowe, 1990)	A self-reported tool that tries to measure a characteristic or attitude that is believed to range across a continuum of values and cannot easily be directly measured e.g. fatigue

#### Assessment of activity limitations

CYP may have had considerable physical skill prior to their ABI which facilitated their involvement in a wide range of home, school and community-based activities and this should be included as part of a comprehensive history-taking. It is vital to consider the CYP's age at injury, plus age and developmental stage at assessment when evaluating activity limitation, as well as their pre-injury developmental and activity history. We would examine a CYP's physical and cognitive capacity to carry out an activity, the way they carry it out and the quality of their movement. Areas to consider are not limited to but may include:

- Bed mobility including transfers from bed to chair or commode
- Transfers e.g., lying to sitting, on/off the floor, crawling, high kneeling, half kneeling, sitting to stand
- Appropriate functional skills e.g. rolling, sitting balance, crawling, walking, running
- Indoor and outdoor mobility, use of aids
- Wheelchair use and mobility
- Stairs skills
- Balls skills, throwing catching, kicking
- Activities of daily living

There are a number of outcome measures for assessment of functional activity. Be aware that some areas may overlap with impairments to body structure and function, for example, bladder and bowel function in the FIM+FAM. The assessments will guide you towards areas to focus physiotherapy intervention on, taking CYP goals into account. Assessment examples are provided in Table 2.

Generalised assessment and outcome measures	Descriptor	Age
Alberta Infant Motor Skills (AIMS) (Piper and Darrah, 1994)	Assesses gross motor skills and evaluates weight bearing, posture, and antigravity movements of infants	0-18 years
Assisting Hand Assessment (AHA) (Louwers et al., 2016)	A tool to evaluate hand function, measuring and describing how a CYP with an UL disability in one hand, uses their affected hand (assisting hand) combined with the non- affected hand in bimanual play.	18 months to 12 years

Bayley Scales of Infant and Toddler development, Third Edition (Bayley III) (Bayley, 2005)	A norm-referenced measure for assessing the development of infants and toddlers, covering five domains: cognitive, language, motor, adaptive, and social-emotional development.	1 month and 42 months.
Functional Independence Measure Functional Activity Measure (FIM+FAM) (Turner-Stokes et al., 1999)	Measures disability in the brain-injured population. FIM is an 18-item global measure of disability, with an ordinal scoring system for 30 items from 1-7 (1 = complete dependence and 7 = fully independent) providing a motor score in areas of self- care, transfers, mobility and cognition. FAM adds 12 items to the FIM addressing cognitive and psychological function. It does not stand alone.	8 years +
Functional Independence Measure for Children (WeeFIM <sup>®</sup> ) (Chen et al., 2005)	Measures functional ability in 3 domains including self-care, functional mobility, and cognition.	6 months through 7 years in typically developing children. Children 7+ years with disabilities and delays in functional development
Gait analysis	Systematic study of human motion, measured through observation or augmented by instrumentation for measuring body movements, body mechanics, and the activity of the muscles. Types include video analysis (e.g. 2D, 3D, motion capture systems), visual gait analysis (e.g. Edinburgh Gait scale), gait analysis walkways (e.g. GAITRite)	Any age once walking

Goal Attainment Scale (GAS) (Turner-Stokes, 2009)	Individualised goal selection and scaling with a 5-point measurement and scoring system, allowing the degree of attainment to be captured for each goal area.	Parent interview or child above the age of 8 years and parent
Gross Motor Function Measure (GMFM) (Russell et al., 2002)	Standardised assessment tool measuring changes in gross motor function over time or with intervention in children with cerebral palsy. The GMFM-88 has 88 items spanning the spectrum of gross motor activities. GMFM-66 is a subset and provides information on the level of difficulty of an item and can help with goal setting.	5 months to 16 years
High level Mobility Assessment Tool (HiMAT) (Williams, Robertson and Greenwood, 2004)	A unidimensional measure of high-level mobility for people with TBI, and includes items assessing high-level walking tasks, the ability to negotiate stairs, and the ability to run, skip, hop, and bound.	The CYP must have the ability to walk more than 20m independently without a walking aid and with or without orthoses
Melbourne assessment of unilateral upper limb function (Johnson et al., 1994)	A test of quality of unilateral upper limb function. It is a criterion based tool, providing measurement of four elements of upper limb movement quality: range of movement, accuracy, dexterity and fluency.	2.5- 15 years old
Movement Assessment Battery Children (MABC) (Henderson, Sugden and Barnett, 2007)	Identifies delays or impairments in childhood motor development, divided into three age bands (3–6, 7– 10, and 11–16 years). There are eight tasks per age band, divided into three domains: (a) manual dexterity,	3–16 years

	(b) balls skills, and (c) balance	
Peabody Developmental Motor Scale (PDMS-2) (Folio and Fewell, 2000)	Assesses motor skills in children including reflexes, grasping, locomotion, object manipulation and visual-motor integration.	0-6 years
Paediatric Evaluation of Disability Inventory (PEDI) or PEDI CAT (computer adaptive test) (Haley et al. 1992; Dumas et al., 2019)	An interview-based assessment where the parent or caregiver answer questions about the CYP's performance in self-care, mobility and social abilities. 4-point scale ranging from 'unable' to 'easy' and can be repeated to gauge and measure progress over time.	PEDI 6 months - 7.5 years PEDI-CAT newborns to 21 years
Physical Abilities and Mobility Scale (PAMS) (Trovato et al., 2014)	A brief and repeatable measure of physical skills and mobility changes in a child's status, including items reflecting the degree of caregiver burden, in relationship to goals for an inpatient rehabilitation admission.	2 -18 years
6 Minute Walk Test (6MWT) (American Thoracic Society, 2002)	A standard method for measuring the distance CYP walked in 6 minutes on a 30 m corridor.	Any age once walking
Timed up and go (Podsiadlo and Richardson, 1991)	Used to assess mobility and requires both static and dynamic balance. It measures the time that a person takes to rise from a chair, walk three meters, turn around 180 degrees, walk back to the chair, and sit down while turning 180 degrees.	Any age once walking

#### Assessment of participation - involvement in life situations

Participation should be the focus of rehabilitation in order to make it meaningful to the CYP and their family. Assessing and measuring participation may be especially relevant within the community setting rather than in the acute setting. As with assessment of activity limitation, it is important to consider pre-injury participation and interests and what is important for the CYP at this point in their rehabilitation. For some, returning to school or sport may be important, for others it may be the ability to join their friends in online gaming. Examples of assessment for participation can be found in Table 3.

Generalised assessment and outcome measures	Descriptor	Age
Canadian Occupational Performance Measure (COPM) (Law et al., 1990; Law et al., 2014)	A client-centred outcome measure, used to enable individuals to identify and prioritise everyday issues that restrict their performance and participation in everyday living. It focuses on occupational performance in all areas of life, including self-care, leisure and productivity.	Parent interview or child above the age of 8 years and parent
Child and adolescent scale of participation (CASP) (McDougall, Bedell & Wright, 2013)	Measures the extent to which children participate in home, school, and community activities as reported by family caregivers.	All ages
Children's assessment of participation and enjoyment (CAPE) (King et al., 2004)	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
FIM+FAM (Turner-Stokes et al., 1999)	The UK FIM+FAM is designed for measuring disability in the brain-injured population. The FIM is an 18-item global measure of disability. It has an ordinal scoring system for all	8 years +

Table 3. Examples of assessment and outcome measures for participation

	30 items from 1-7 (1=complete dependence and 7 fully independent). FAM adds 12 items to the FIM addressing cognitive and psychological function. It does not stand alone.	
Functional Independence Measure for Children (WeeFIM®) (Chen et al., 2005)	Measures functional ability in 3 domains including self-care, functional mobility, and cognition.	6 months through 7 years in typically developing children. Children 7+ years with disabilities and delays in functional development
Goal Attainment Scale (GAS) (Turner-Stokes, 2009)	GAS is a measurement approach that is individualised and involves goal selection and goal scaling and has a 5 point scoring system, which allows the degree of attainment to be captured for each goal area.	Parent interview or child above the age of 8 years and parent
Preferences of activity for children (PAC) (King et al., 2004)	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
Participation and Environment Measure for Children and Youth (PEM-CY) (Coster, 2011)	Evaluates participation in the home, at school, and in the community, alongside environmental factors within each of these settings.	5-17 years

# **Physiotherapy intervention**

Physiotherapy intervention for CYP with ABI can be complex and wide ranging, due to factors including age, developmental stage, injury type and severity. This section aims to provide an overview of the complexity of physiotherapy interventions for CYP with ABI, rather than recommend or prescribe a specific treatment approach or programme. It is acknowledged that the current evidence base is limited with research findings mainly drawn from small heterogeneous patient populations allowing only limited interpretation and generalisability of the findings (Meyling et al., 2021). Currently, there is preliminary evidence supporting the use of functional strength training, gait and balance training, and hippotherapy for improving gross motor function following childhood ABI, as well as treadmill walking with virtual reality (Baque et al., 2016; Meyling et al., 2021). It is recommended that this physiotherapy intervention section is used in conjunction with Appendix B which provides one approach to considering groups of interventions for CYP with ABI within broader categories. We also recommend that information in this section is used alongside guidance and protocols in your local contexts.

Three case examples are included in Appendix C to bring the rehabilitation pathway, physiotherapy assessment and intervention sections to life. Given the unique nature of each CYP's injury and personal circumstances the examples are not exhaustive, but aim to show how the information above fits together. We have included CYP and family goal preferences but not converted these to specific goals within the text. GAS goals may be a useful framework to consider in clinical practice.

#### Rehabilitation and habilitation

You should use all your knowledge of normal development to guide physiotherapy intervention after ABI. You may be working on skills that had not been achieved prior to ABI due to the CYP's age at injury, and particularly when ABI took place during the first few years of life. This can be considered as habilitation rather than rehabilitation. Within this guidance document we use the term 'rehabilitation' to cover both situations, referring to the regaining of lost skills or functioning as well as working on developmentally new skills. It is therefore essential that you have a clear understanding of the CYP's baseline function prior to their ABI. At any stage of rehabilitation, physiotherapy should follow a comprehensive assessment and focus on the needs of the CYP and their family, working towards meaningful participation.

Rehabilitation should be offered to CYP appropriately for their age, ability to engage with or tolerate sessions, at an intensity and frequency which promotes lasting change and enables them to meet their goals; it is important to base rehabilitation on principles of motor learning, repetition and application to everyday life (RCPCH & the Stroke Association, 2017). Work is ongoing to understand the impact of intervention dosage on outcome (Forsyth et al, 2018).

Establishing a trusting relationship with the family is important. Consider the use of coaching strategies to assist parents/carers and the CYP with adjustments to their new situation. This may help to support goals and rehabilitation priorities for the CYP and family at the most appropriate time for them.

#### Intervention based on ICF domains

As with the assessment section, interventions should aim to address all domains of the ICF including impairments to body structure and function, activity limitation and participation, and should be focused towards real-life and everyday situations taking into account the environment and individualised personal factors. Joint family-centred and multidisciplinary goal setting is a very important part of the intervention process, to ensure a clear framework for involvement and to facilitate cooperation and participation from the CYP and their family. Goal setting will help to inform the direction and focus of physiotherapy intervention at any stage of a CYP's rehabilitation. Progress against goals should be monitored regularly, with intervention plans being adjusted accordingly. Outcome measures are a useful tool alongside intervention as well as within assessment, to help determine and compare progress linked to different intervention approaches.

Describing disability through the ICF model gives a holistic picture of the health condition. Rosenbaum and Gorter (2011) describe an additional "F words" viewpoint grounded in the ICF model, using the words function, family, fitness, fun, friends and future as a framework supporting intervention. This moves slightly from the biomedical model towards meaningful strength-based interventions that are personalised to the individual's situation. Incorporating the "F-words" into intervention planning should be considered when working with a CYP with a long-term disability following ABI.

## Impairment to body structure and function

Interventions to address impairments in body structure and function are wide-ranging, relying on accurate assessment and clinical reasoning to create a suitable programme which will engage the CYP at any point in their rehabilitation. Table 4 below summarises intervention suggestions for addressing changes in body structure and function.

Example area	Specific examples of intervention	
Muscle tone - may want to increase or decrease	<ul> <li>Therapeutic handling can influence tone e.g. tapping, sweeping, trunk mobilisation, facilitated movement</li> <li>Choice of position (e.g. lying, sitting, standing) will affect muscle tone as adjustments to the base of support can increase or decrease muscle tone, dependent on desired effect</li> <li>Use of splinting, orthotics, serial casting to provide prolonged stretch</li> <li>Use of Lycra e.g. upper limb sleeve, trunk vest, shorts to influence muscle tone</li> <li>Hydrotherapy or movement in water</li> <li>Electrical stimulation to increase or decrease muscle tone</li> <li>Sensory influences, e.g. vibration, thermal with ice or heat, proprioception e.g. weighted blankets</li> </ul>	
Clonus	Weight bearing can reduce clonus	

Table 4. Examples of interventions for impairment to body structure and function

	<ul><li>Application of a slow stretch can reduce clonus</li><li>Orthotic provision</li></ul>
Range of movement	<ul> <li>24-hour postural management through use of appropriate seating, sleep systems etc. in a consistent manner</li> <li>Upper or lower limb splinting, serial casting may be appropriate</li> <li>Orthotics, use of AFOs, gaiters etc.</li> <li>Stretches of joints and muscles at risk of developing contracture (taking a joint through range on a regular basis may help ascertain whether a contracture or reduction in range is developing)</li> <li>Joint mobilisation - physiological and accessory movements</li> <li>Use of standing frame, supine or prone</li> <li>Active exercise in all relevant muscle groups</li> <li>Electrical stimulation can be used to assist with maintaining range of movement</li> <li>Hydrotherapy or water-based activities</li> </ul>
Muscle strength	<ul> <li>Isometric, concentric and eccentric activities</li> <li>Repetition of exercise or action</li> <li>Open and closed chain activities (weight bearing and non-weight bearing)</li> <li>Gait training e.g. using coloured circles pads, parallel lines, ladders, cones, obstacle courses</li> <li>Treadmill training e.g. varying speed or incline</li> <li>Static or assisted cycle or cycling e.g. varying resistance, time or interval training</li> <li>Functional electrical stimulation (FES) can help during functional activities</li> <li>Modified constraint induced movement therapy (mCIMT) encourages repetitive activity of affected limb and is tailored to the individual child</li> <li>Hydrotherapy/water-based activity/swimming utilising the buoyancy and resistance of water</li> <li>Resistance and/or weight bearing activities</li> <li>Core strengthening exercises</li> <li>Use of gym-based equipment e.g. rowing machine, crosstrainer, weight machines</li> <li>Pilates</li> </ul>
MSK alignment	<ul> <li>24-hour postural care, sleep systems</li> <li>Seating, orthotics, lycra, splinting</li> <li>Supine or prone standing frame</li> <li>Mirror work can aid conscious visual prompting to adjust</li> </ul>

	posture/alignment
Postural control	<ul> <li>Head and trunk control activities - consider a variety of positions including prone, four-point kneeling, sitting and standing</li> <li>Weight bearing through upper and lower limb</li> <li>Encourage co-contraction and stabilisation activities</li> <li>Sitting and standing balance activities</li> <li>Core stability exercises</li> <li>Seating with or without head support, lateral trunk supports, ramped cushion, knee blocks</li> <li>Lycra (e.g. full suit, short suit, shorts)</li> <li>Spinal bracing or abdominal support</li> <li>Upper or lower limb splinting</li> <li>Supine or prone standing frame</li> </ul>
Balance	<ul> <li>Head and trunk control activities</li> <li>Weight bearing through upper and lower limb</li> <li>Sitting and standing balance activities i.e. gradual reduction in base of support</li> <li>Core stability exercises</li> <li>Use of wobble boards, gym balls etc.</li> <li>Perturbation in different postures e.g. in sitting, kneeling, high kneeling, standing, tandem standing, one leg standing</li> <li>Consider the visual component of balance - working with eyes open/closed.</li> <li>Both anticipatory and reactive balance training</li> <li>Progression to uneven surfaces - grass, slopes, trails etc.</li> </ul>
Coordination	<ul> <li>Hand-eye coordination e.g. reach and grasp activities, throwing and catching, skittles, throwing into targets, clapping games, dot to dot, fishing game</li> <li>Foot-eye coordination e.g. ball skills, dance mats, stepping stones, shooting at goal, hopscotch, dribbling around obstacles, jumping in out of hoops, skipping</li> <li>Graded activity including distance, size of ball or balloon, speed of task, dual tasking or simultaneous physical and cognitive challenges e.g. counting backwards whilst throwing and catching, naming footballers whilst passing ball between partners</li> <li>Fine motor skills - threading, weaving, use of pencil, grading size and shape of objects being handled or moved</li> <li>Gait training</li> <li>Consider the visual component of coordination - train with eyes open/closed</li> </ul>

	<ul> <li>Consider working a joint in isolation, limiting degrees of freedom and working distal to proximal when treating ataxia</li> </ul>
Sequencing and motor planning	<ul> <li>Obstacle courses, crawling under, over and around, Twister, Simon says game, climbing frames, skipping</li> </ul>
Level of consciousness	<ul> <li>Gradual verticalisation using standing frames</li> <li>Sitting out of bed into chair, sitting over the edge of the bed</li> <li>Vibration plate can improve level of awareness</li> </ul>
Vision	<ul><li>Tracking games</li><li>Consider eyes closed/eyes open</li></ul>
Fatigue	<ul> <li>Activity modification / Pacing</li> <li>Diary/daily timetable ensuring planned rest</li> <li>Environmental modification</li> </ul>

## **Activity limitations**

Thorough assessment will likely highlight activity limitations in both the CYP's capacity (what the CYP can do at their best) and performance (what they actually do day to day) as well as an impact on the quality of their movement during performance. Once an activity limitation has been identified, the physiotherapist must break down the task to address which impairment to body structure and function is limiting the performance of the activity. Breaking down the task in this way will allow accurate clinical reasoning for therapy intervention. For example, the CYP may report and the physiotherapist may observe a limitation in their ball skills, being unable to kick a football without losing balance. In order to address this limitation the physiotherapist must assess the components of the task to determine if this is due to one or a combination of factors including balance, strength, coordination, muscle tone, vision, proprioception, motor planning and sequencing, fatigue, or their ability to concentrate in that environment. Findings from this assessment will inform goal setting and programme planning to improve the CYP's abilities in specific body structure and function domains, to enhance overall performance during the activity.

It is important to recognise that 'fixing' the impairment may not automatically lead to improvements in activity and participation. It is likely to be more complex, involving the child's individual motivators and environmental factors (Wright, 2008). A physiotherapy intervention programme needs to therefore incorporate an awareness of personal and environmental factors.

### **Participation**

Participation is defined as involvement in life situations (WHO, 2001). CYP with ABI are more restricted in their ability to participate than their peers (Law et al., 2011), and physiotherapists need to plan intervention to include the CYP's participation environment. As well as the physical environment of school and home, this includes the social environment of family and peer support, the attitudes of others, and the availability and cost associated with activities.

Discussing the CYP's individual participation goals in collaboration with the family and MDT will be helpful to identify suitable intervention options. Knowledge of recreational and social opportunities in the local area will be helpful, whether these are specific for CYP with disabilities or not. Remember that friends are extremely influential in a child's life, so giving opportunities to participate alongside friends may be a strong motivator for encouraging longer-term participation in recreation, social and skill-based situations. Broadening the social network of CYP with ABI should be a major goal of rehabilitation.

<u>CanChild</u> offers a variety of tip sheets to help with planning participation activities.

### Multidisciplinary intervention

Physiotherapy intervention will ideally form part of a multidisciplinary approach focusing on the agreed goals. For example, when addressing spasticity in the upper limb which is limiting the CYP's ability to hold a cup to drink, a joint management approach may include medical management with Baclofen and Botulinum toxin A injections, splinting and seating, orthotics support, physiotherapy and occupational therapy (OT) interventions such as constraint-induced movement therapy (CIMT) or functional electrical stimulation (FES) to promote functional movement and motor control. Another example of MDT focused intervention to address the goal of eating and drinking may require joint management from physiotherapy, speech and language therapy (SLT) and OT to work on head and trunk control, provide appropriate seating, address pacing and fatigue, alongside SLT assessment of swallow.

#### **Environmental considerations**

It is important to consider the intervention environment, in the light of the CYP's individual needs after ABI. Their ability to concentrate on activities may be impacted by how many people are in the room, the level of background noise (including music or a radio on), time of day, fatigue or pain levels. They may struggle with dual tasking or following very complex, multi-step instructions. Understanding their needs in relation to their environment will help them participate as fully as possible. Environmental considerations can also be context dependent. For example, school and home settings may present very different opportunities or challenges to intervention. Neither is better or worse than the other; ensure the correct context is chosen for the goals and aims of the session or intervention focus, paying close attention to the CYP's age and developmental stage, willingness to engage, levels of comfort and confidence, and overall wellbeing.

#### Wraparound aspects

All intervention should be considered in the context of graded facilitation and include principles of exercise, cardiovascular conditioning and strength training as relevant to the CYP's individual needs. The physiotherapist should aim for concurrent assessment and treatment, with ongoing evaluation of the CYP's response and reaction to an intervention. Children should be actively involved in their intervention, with active participation based on the level of their function and awareness. Tasks which are put in context or framed around favourite toys, characters or activities may help to promote engagement and motivation.

# **Special considerations**

Certain presentations, pathologies or contexts require special consideration, including unrecognised TBI, mild TBI, non-accidental injuries, brain tumours, disorders of consciousness and neuroprotection. Key points are noted below to aid understanding and clinical reasoning.

## A. Unrecognised TBI

Following polytrauma, CYP who do not return to school as rapidly as expected, have persistent fatigue, or whose performance does not meet their pre-injury standard could have an unrecognised TBI, in the absence of other physical or psychological factors. CYP with a major associated injury (for example, multiple limb fractures) may be two times more likely to report unmet needs at one-year follow up compared to those who did not, and these are likely to centre around cognitive changes (Slomine et al., 2006).

Physiotherapists working within trauma centres and orthopaedic outpatient settings should check the clinical history carefully and consider a possible TBI (even if the head CT scan was normal during the early part of admission). Should concerns be raised by the treating physiotherapist, parents or CYP, or if difficulties with participation in education are noted, referral to a paediatrician or neurology team for further assessment should be made, usually via the CYP's GP.

### B. Mild TBI

The severity of a TBI can range from mild to severe. Mild injury has often been described as 'concussion' but this term may suggest a benign condition with spontaneous recovery, which may not be helpful for CYP experiencing persistent symptoms. Instead, the term 'mild traumatic brain injury' (mTBI) may be more helpful in describing symptoms and ongoing recovery (Sharp & Jenkins, 2015).

## Clinical course of mTBI

Mild TBI occurs when a direct external force, or an indirect acceleration-deceleration force, is applied to the brain. Symptoms may include dizziness, headaches, sleep changes and fatigue. There may be cognitive changes including reduced concentration and attention, memory or processing speed. CYP with mTBI may or may not seek emergency medical help; if they do, investigations are likely to be normal, with no changes on CT scan if one is performed. A CT scan rules out significant structural changes requiring emergency attention but is unlikely to be sensitive enough to detect any micro-changes (Sharp & Jenkins, 2015). Rather than macroscopic changes, there may be physiological alteration to the brain including oxidative stress, impaired axonal function and altered neurotransmission (Lumba-Brown et al., 2018). CYP may return home from hospital quickly, with families responsible for managing symptoms and navigating a return to school or sport. It is therefore important that relevant information is given to both CYP and parents at the time of injury to explain symptoms, mechanism of injury and anticipated recovery progress. This can reduce both parental and CYP stress, and optimise early management (Ponsford et al., 2001; Choe et al., 2016). A phased return to school and sport is advocated (for up-to-date advice see <a href="https://canchild.ca/en/diagnoses/brain-injury-concussion">https://canchild.ca/en/diagnoses/brain-injury-concussion</a>).

While most mTBI symptoms resolve spontaneously after a period of recovery, symptoms may persist for several weeks or months after injury, and individual recovery trajectories may vary (Lumba-Brown et al., 2018). Failure to recognise and manage symptoms after mTBI may lead to prolonged symptoms, which are potentially detrimental to a CYP (Choe et al., 2016). Physiotherapy review may be indicated in these cases, along with referral to a GP, paediatrician or paediatric neurologist. The pathogenesis for post-traumatic headaches is not well understood - there may be local trauma or pain of a musculoskeletal origin, but this does not account for all cases of headache after mTBI (Sharp & Jenkins, 2015). In persistent cases, referral to paediatric neurology may be indicated.

### Physiotherapy assessment and intervention

Wide-ranging physiotherapy assessment and intervention skills will be relevant for treating the symptoms of mTBI as described and identified by the CYP and family, including musculoskeletal assessment and intervention, neurological examination including balance, intervention approaches including a graded approach to exercise and return to sport, headache management, and vestibular symptom management.

There may be sensori-motor changes including visual acuity, balance, and finger dexterity (Lambregts et al., 2018). It is possible that clumsiness or visual acuity difficulties may have been present prior to the mTBI but were not previously detected (Lambregts et al., 2018). In cases of protracted dizziness and imbalance, assessment to detect the presence of a peripheral vestibular disorder may be beneficial (Brodsky et al., 2018).

Symptoms may be exacerbated by anxiety so it may be valuable to address this through the intervention approach, or refer for psychological support.

#### Health promotion

Physiotherapists have a role in health promotion, including pitch side identification of possible mTBI, advising on safe return to sport and consideration of sport retirement in the case of multiple mTBIs. <u>The England Rugby Headcase</u> contains valuable resources for schools, young people and families about mTBI. Promotion of safety equipment including helmets for cycling and scooter use is recommended in the course of usual paediatric practice.

#### C. Non-accidental injury

Non-accidental injury (NAI), sometimes known as abusive head trauma (AHT), is a cause of TBI. The injury is usually sustained through shaking or impact when a CYP is at a very young age, when the brain is extremely vulnerable to injury and it is possible for a diffuse injury to be inflicted. Shaking or impact may have a more significant effect due to poor head control and a relatively large head size compared to the rest of the body. Normal developmental processes may be significantly disrupted with a range of difficulties in motor, sensory, communication and cognitive domains, which may or may not be apparent at the time of injury.

#### **Emerging difficulties**

Some CYP may present with clear neurological deficits including changes in muscle tone, vision or microcephaly, and physiotherapy intervention may have a clear focus. Other CYP with TBI due to NAI

may have a period of typical development and only present with difficulties some time later (Chevignard and Lind, 2014), which suggests that long term follow up is indicated to monitor skills and possible emerging difficulties. As the CYP gets older, other factors may emerge including the impact of emotional trauma, attachment needs, complex family needs or care arrangements. It is possible that the TBI could be overlooked, but it remains an important part of the CYP and family's life story, medical and developmental history. The combination of an underlying TBI plus social and emotional factors may lead to complex behavioural, sensory, learning and social interaction needs. A thorough knowledge of childhood development will be vital for physiotherapists working with this group of CYP to ensure subtle physical needs are identified and addressed promptly.

#### Challenges of follow up

It is recognised that, despite the critical need for long term follow up, there is often a high attrition rate for this group (Chevignard & Lind, 2014). CYP who have a TBI due to NAI will often be discharged from hospital to foster care, or care arrangements with other relatives. It is important that physiotherapists are fully aware of who is caring for the child and who has parental responsibility, usually by checking with hospital safeguarding or local social care teams. There may be multiple changes in carer, social worker, or geographical location and it is important for physiotherapists to ensure the primary carer can get in touch when needed, that the CYP can receive the follow up indicated, and that care is transferred between teams promptly and smoothly. Physiotherapists will need compassionate communication skills for liaising with a wide range of carers and family members who may also have been directly affected by the circumstances of the CYP's injury. Some CYP will be adopted, and adoptive parents may have limited details about the injury sustained. It may be useful to liaise with community paediatrics colleagues to find out if it is possible to request more precise information, and work with them to provide adoptive parents with advice about the long-term impact of TBI with sensitivity.

#### **D.** Brain tumours

CYP may have an ABI due to a brain tumour, of which there are different subtypes. On diagnosis, each tumour is classified based on histology and graded I-IV using the standard WHO grading system (Louis et al., 2016).

CYP with a brain tumour may present with a wide range of signs and symptoms. It is possible that the symptoms are related directly to the location of the tumour, or are a secondary symptom of the tumour, for example, hydrocephalus secondary to a posterior fossa tumour. Symptoms may also occur as a result of medical treatment that the CYP has received.

#### Medical and neurosurgical management

The CYP will require a range of investigations including a CT scan or an MRI scan, to support the initial diagnosis of a space occupying lesion or a suspected brain tumour. If a brain tumour is confirmed, oncology treatment will be unique for each CYP, it is therefore important to have a clear understanding of what investigations and treatments they are likely to receive. The CYP may require intervention from the neurosurgical team for a biopsy, debulk or resection of the tumour, or related to concerns about hydrocephalus. Examples of surgical management for hydrocephalus to redirect or remove extra cerebrospinal fluid include an endoscopic third ventriculostomy (ETV), an external

ventricular drain (EVD), or a shunt (e.g. ventriculoperitoneal shunt). General surgery teams may also be involved for the insertion of peripheral lines (e.g. Hickman lines or ports) to support regular blood tests and delivery of medication. Following formal diagnosis of the brain tumour including grade and sub-type, care will be managed by a paediatric oncologist who will lead with further treatments such as chemotherapy, including high dose chemotherapy with stem cell rescue (HDCSCR), radiotherapy or proton beam therapy. In some cases the CYP may only require surgery followed by monitoring; in other cases, the CYP may not require any surgery at all.

Side effects are very common during treatment for a brain tumour and are dependent upon the types and intensity of treatment that the CYP receives. While different side effects occur with different types of chemotherapy, side effects experienced by CYP are individual. Common side effects are mucositis, fatigue, nausea and hair loss. One side effect often brought to the attention of the physiotherapist is peripheral neuropathy related to the chemotherapy medication Vincristine. Although this process is not fully understood it is important for physiotherapists to be aware of this potential side effect. Physiotherapists may be requested by the oncology team to review the severity or change in neuropathy presentation to inform decisions about medication dosage; this should be done through close monitoring of reflexes, muscle strength, range of movement, sensation and function. Physiotherapists working with CYP with a brain tumour should remain updated about blood counts, including but not limited to haemoglobin, platelets, white blood cell count, neutrophils. These may be affected directly by oncology treatment for brain tumours and could impact clotting factors, levels of fatigue experienced by the CYP, the need to isolate due to severely affected function of the immune system, which in turn could influence physiotherapy intervention selection and intensity.

In some circumstances, the focus may change from active to palliative treatment. Close MDT communication across acute and community settings will be essential to ensure up to date information is exchanged, appropriate equipment supplied and that goals can be adjusted in line with the CYP and family's wishes.

### Inpatient physiotherapy

A baseline physiotherapy assessment may be completed prior to commencement of the CYP's surgery or treatment (see physiotherapy assessment section above). It is essential to take a thorough clinical history and close liaison with the MDT is extremely important. Following neurosurgical intervention or during ongoing treatment, the CYP may need rehabilitation during their inpatient stay in critical care, the ward or both settings. As outlined previously, physiotherapy intervention should follow a thorough assessment and be based around patient-centred goals with the aim of increasing the CYP's participation in everyday activities. In cases of peripheral neuropathy as described above, consider management of muscle length, posture and mobility, with referral to orthotics and orthopaedics as necessary.

### **Outpatient/community physiotherapy**

Physiotherapy may be required at any point during or after neurosurgical or oncological treatment for the brain tumour. Physiotherapy intervention may be adversely impacted by response to treatment, general health, psychological needs or reduced exercise tolerance which may not be primarily due to the ABI. As for all CYP with any type of ABI, intervention should include support for school reintegration and referral to community teams may be required. Due to the unique needs of this

particular group, individualised assessment and intervention offered with flexibility and smooth rereferral routes will be beneficial to meet the changing needs of the CYP and their family over time. Treatment for CYP with brain tumours can be very prolonged over many months or years, with physical condition deteriorating at different points. Therapy blocks in the community may be beneficial in reducing the extent or impact of these periods of deterioration. It is known that chemotherapy and radiotherapy can lead to late effects on physical and psychological function. These may be physical such as peripheral neuropathy, thyroid dysfunction or secondary cancers, or psychological or cognitive, including altered educational performance, peer relationships or life skills (Children's Cancer and Leukaemia Group [CCLG], 2021). It is therefore important to promote positive health behaviours for the future.

### Posterior fossa syndrome

Posterior fossa syndrome (PFS, also known as cerebellar mutism syndrome) is a term used to describe a range of symptoms which can occur following surgery to the cerebellum and brainstem, an area known as the posterior fossa (CCLG, 2016). Tumours in this region are the most common CNS tumour in CYP. Symptoms of PFS include movement difficulties affecting all limbs and trunk, difficulties controlling eye movement, reduced speech or complete mutism, emotional lability and cognitive difficulties (CCLG, 2016). Ataxia is a very common symptom in this patient population; see Table 1 for further details. Initial symptoms of PFS tend to present 24-72 hours post-op and it can be hard to predict the duration or severity of symptoms, although support may be required for years following the initial onset of symptoms (CCLG, 2016).

For CYP and their families, a coordinated MDT approach is essential within and across the inpatient and community settings, involving the lead paediatric oncologist as well as a local paediatrician. Following discharge from an inpatient setting, community referrals may be needed and additional support may also be required in school to optimise reintegration and learning, as outlined above.

### E. Disorders of consciousness

An ABI may lead to a period of loss of consciousness, which could last for seconds or extend to weeks and months. Consciousness encompasses two distinct aspects. 'Wakefulness' is a state in which the eyes are open and there is a degree of motor arousal; it contrasts with sleep – a state of eye closure and motor inactivity. 'Awareness' is the ability to have, and the having of, experience of any kind. Any disorder of consciousness (DOC) is due to difficulties in one or both of these aspects.

## Types of DOC

Coma is characterised by absent wakefulness and absent awareness. It is a state of unrousable unresponsiveness, lasting more than six hours in which a person is unconscious and cannot be wakened, fails to respond normally to painful stimuli, light or sound, lacks normal sleep-wake cycle, and does not initiate voluntary actions. Coma lasting more than four weeks is described as a prolonged disorder of consciousness (PDOC), with the following definitions:

• Vegetative state (VS) is characterised by wakefulness with absent awareness. There is preserved capacity for spontaneous or stimulus-induced arousal, evidence of sleep-wake cycles and a range of reflexive and spontaneous behaviours. VS is characterised by the

absence of awareness of self and the surrounding environment. A CYP in VS may still cry, grunt, chew or move their limbs, but without any discernible reason. Visually, they may be able to track or fix on an object but usually only for a few seconds.

- Minimally conscious state (MCS) is characterised by wakefulness and minimal awareness. It
  is a state of severely altered consciousness in which minimal but clearly discernible awareness
  of self or the surrounding environment is demonstrated. MCS is characterised by inconsistent
  but reproducible responses above the level of spontaneous or reflexive behaviour, which
  represents a degree of interaction with the CYP's surroundings. This may include episodes of
  crying, smiling, or laughter in response to words or the visual content of an emotional topic,
  vocalisation in direct response to a question or comment, reaching for objects in a manner
  that demonstrates a clear relationship between object location and direction, or having
  different responses to different people.
- MCS can be further categorised as MCS- and MCS+. MCS- is used to indicate individuals who show only non-reflex behaviour such as visual tracking or localisation to stimuli. MCS+ is used to indicate individuals where more complex behaviours are observed including command following, for example attempting to nod their head in response to a question.

There is no simple single clinical sign or laboratory test of awareness. Its presence must be deduced from a range of behaviours which indicate that an individual can perceive self and surroundings, frame their intentions, and interact with others. Formal assessments include the JFK Coma Recovery Scale (Giacino, Kalmar and Whyte, 2004), WHIM (Sheil et al, 2000) and SMART (Gill-Thwaites & Munday, 2004). For further information please refer to the Royal College of Physicians (2020) PDOC clinical guidelines.

CYP presenting with PDOC following TBI have lower mortality rates, improved outcomes for consciousness, longer term function and independence than those with PDOC following other causes of ABI (Houston et al., 2020).

### A note about locked-in syndrome

Locked-in syndrome usually results when brainstem pathology disrupts the voluntary control of movement without abolishing either wakefulness or awareness. CYP who are 'locked-in' are substantially paralysed but fully conscious and can usually communicate using movements of the eyes or eyelids. Locked-in syndrome is therefore not a PDOC and must be seen as a distinct presentation.

### Physiotherapy assessment and intervention for CYP with DOC

Assessing a CYP's level of consciousness should be carried out by the whole MDT and include observations from the family. Assessment will identify when a CYP is emerging from the different states of DOC (see Royal College of Physicians, 2020).

Goal setting can be difficult within this group: MDT approaches to rehabilitation including sensory stimulation may be particularly beneficial to CYP with PDOC. (Houston et al., 2020). As part of the physiotherapy approach, regular assessment of muscle tone, range of movement (ROM) and postural alignment is vital. Postural management will be at the forefront of intervention, using orthotics and splints to maintain joint ROM and muscle length. Advice should be given to family members and staff regarding positioning in postural management equipment including sleep systems, standers and

seating. Photo charts with clear instructions may help with a consistent approach. Verticalisation through the use of a tilt table or supine stander may help to raise the CYP's level of arousal and should be considered within a rehabilitation programme (Elliot et al., 2005; Riberholt, 2013; Wilson et al., 2013).

PDOC in a CYP will have a profound effect on the family and the MDT need to be supportive to help them address the long-term implications including housing suitability, the need for care and respite arrangements, and a possible change in education placement.

## **Emerging from PDOC**

As consciousness occurs along a continuum, determining emergence is not straightforward (Pundole et al., 2021). To confirm emergence, a CYP in PDOC must demonstrate functional object use or functional communication with 100% accuracy. A multidisciplinary approach to assessing this should be employed, including speech and language therapy, occupational therapy as well as the family's observations and reports over time.

Further information on assessment of PDOC can be found on the following website: www.rhn.org.uk/professionals/research/putney-prolonged-disorder-of-consciousness-toolkit/

### F. Neuroprotection

CYP with any form of ABI may be admitted to critical care, and neuroprotection is an important aspect of their management. It is important that physiotherapists understand concepts of neuroprotection and a brief summary is included in this Special Considerations section to support this. It should be read in conjunction with the Rehabilitation Pathway section on critical care, and alongside local protocols.

### Intracranial pressure, mean arterial pressure and cerebral perfusion pressure

The skull is a rigid fixed volume compartment, containing the brain parenchyma, blood and cerebrospinal fluid. Any increase in volume of these constituents will increase the intracranial pressure (ICP). As skull volume increases, ICP increases, first at a slow rate and then to the critical point of decompensation where ICP rises rapidly. This increased ICP can severely affect cerebral blood flow. Raised intracranial pressure (ICP) plays a key role in secondary brain injury.

Adequate cerebral blood flow is required to keep up with the brain's constant demand for oxygen, nutrients and glucose. It is therefore essential that steps are taken in the paediatric critical care setting to maintain optimal cerebral perfusion and reduce cerebral metabolic demands. Physiotherapy intervention such as suction, repositioning or passive movements may increase intracranial pressure or blood pressure which directly influences perfusion. Specific parameters may be given by the critical care team to manage ICP and it is vital to be aware of these at all times:

 Blood pressure will be monitored continuously, and ICP may be monitored via the insertion of an ICP bolt by the neurosurgical team. This allows for a more accurate measurement of cerebral perfusion pressure (CPP), the net pressure gradient causing cerebral blood flow (perfusion).

- The CPP is calculated by subtracting the intracranial pressure from the mean arterial blood pressure (MAP): MAP ICP = CPP.
- If the CPP is too high, the ICP will increase; if the CPP is too low then the brain will become ischaemic.
- The medical or neurosurgical team will document the recommended CPP for each patient; if ICP is not monitored, a recommended MAP value will be noted.

## **Glasgow Coma Scale**

The Glasgow Coma Scale (GCS) is used as an objective assessment of conscious level. Eye opening, verbal and motor responses to specific stimuli are measured, with scores ranging from 3 at worst to 15 at best (Teasdale & Jennett, 1974; see also <u>www.glasgowcomascale.org</u>). Severity of TBI can be classified using the GCS scale:

- 13-15 mild
- 9-12 moderate
- 8 and below severe

The CYP's GCS may vary over time, with a decrease in GCS indicating a deterioration in neurological status. Physiotherapists must be aware of the trend in a CYP's GCS recordings and recognise any signs of deterioration in consciousness.

It is recognised that the standard GCS measure is not effective for children under the age of 5 years, particularly as they may not yet have developed the verbal skills required to be successful in the test, or they may be frightened. Various alternative scales have been proposed, with the Child's Glasgow Coma Scale recommended by the British Paediatric Neurology Association (Kirkham, Newton & Whitehouse, 2008).

## Neuroprotective measures

The management of severe ABI involves a number of neuroprotective measures. These measures are aimed at managing the patient's physiology to optimise cerebral perfusion and oxygenation. It is important to follow local policies and work with the wider multidisciplinary team to manage neuroprotection successfully. It is essential that all physiotherapists treating CYP with ABI in critical care settings are aware of these protective measures and why they are in place, to assess the stability of the patient for physiotherapeutic input. Neuroprotective measures involve management of physical and physiological factors, and are summarised in Table 5 and 6 below:

Measure	Comments	
Airway control and ventilation	<ul> <li>Avoid hypoxia, hypercapnia, aspiration</li> <li>Maximise cerebral oxygenation</li> </ul>	
Circulatory support	<ul> <li>Avoid hypotension leading to decreased cerebral blood flow and further ischaemia</li> <li>Maintain cerebral perfusion</li> </ul>	

Sedation, analgesia, neuromuscular blockade	<ul> <li>Noxious stimuli and anxiety lead to increased ICP and increased cerebral O2 demand.</li> <li>Neuromuscular paralysis reduces airway and intrathoracic pressure which improves cerebral venous return; use of this may mask clinical seizures</li> </ul>
Fluids and nutrition	<ul> <li>Maintains circulating volume and hence blood pressure</li> <li>Nutrition is essential for tissue repair, wound healing and general organ function</li> </ul>
<ul> <li>Positioning and manual handling:</li> <li>Neutral head position</li> <li>15-30° head up tilt on bed</li> <li>Avoid hip flexion</li> <li>Spinal protection if TBI</li> </ul>	<ul> <li>Improves cerebral venous drainage</li> <li>Hip flexion may increase intra-abdominal pressure, increase intrathoracic pressure leading to reduced cerebral venous return.</li> <li>Regular repositioning will be required; log rolling is necessary if the spine has not been cleared as stable by appropriate medical team (seek local policies and procedures regarding this)</li> </ul>
Deep vein thrombosis prophylaxis	Follow local protocol

Table 6: Neuroprotective measures specific to critical care

Measure	Comments
ICP monitoring	<ul> <li>Gold standard intraventricular monitoring</li> <li>Accurate continuous monitoring</li> </ul>
Cerebral perfusion pressure monitoring	<ul> <li>MAP – ICP = CPP</li> <li>Limits set by intensivist or neurosurgeon</li> </ul>
Hyperosmolar therapy	<ul> <li>Creates osmotic gradient across cerebral vascular bed which decreases cerebral oedema</li> </ul>
Temperature control	<ul> <li>Avoid hyperthermia, as this increases cerebral metabolic demand, promotes inflammation and decreases the seizure threshold</li> </ul>
Hyperventilation	<ul> <li>Only with advanced monitoring ie ICP monitor</li> <li>Carbon dioxide is a potent determinant of cerebral vascular diameter</li> <li>Increased carbon dioxide leads to vasoconstriction which decreases ICP, but may cause cerebral ischaemia with reduction in cerebral blood flow</li> </ul>
Anti-seizure medication	Seizures will increase cerebral metabolic demand
<ul> <li>Surgical management:</li> <li>CSF diversion</li> <li>Evacuation of haematoma or space occupying lesion</li> <li>Decompressive craniectomy</li> </ul>	<ul> <li>May be indicated in situations where there is significant compromise of brain function</li> </ul>

# **Summary**

This guidance document has introduced childhood ABI and aspects which may influence recovery and outcome, including factors relating to the injury, the CYP and family, and the professional network around them. The journey from critical care through to community follow up has been described and principles for physiotherapy assessment and intervention outlined, culminating in case examples to bring these principles together (see Appendix C). The document is designed as a tool to support understanding, clinical reasoning and high-quality intervention.

Physiotherapists play a pivotal role for children after ABI, supporting them at every stage after injury throughout childhood and into adulthood. Physiotherapists have the opportunity to make a positive impact on the outcome of a CYP's ABI, contributing to their life-long health, wellbeing and participation at all levels of society. Physiotherapists also have a crucial role in supporting family wellbeing by empowering parents, carers and siblings to contribute to rehabilitation in meaningful ways. We hope that this guidance document has inspired you to see each CYP as unique, and that you are equipped with knowledge and skills to personalise your physiotherapy intervention to their aims and goals, age and educational stage, keeping the holistic picture of needs and abilities in view. Ultimately, we hope you will find working with children after ABI rewarding and uplifting.

## **References**

- All Party Parliamentary Group on Acquired Brain Injury (2018) *Time for change*. Retrieved from <u>https://www.bsrm.org.uk/downloads/appg-on-abireporttime-for-change2018.pdf</u> (accessed 06 August 2021)
- American Thoracic Society (2002) 'ATS statement: Guidelines for the six-minute walk test', American Journal of Respiratory and Critical Care Medicine, 166, pp. 111–117. doi.org/10.1164/ajrccm.166.1.at1102
- Anderson, V., Brown, S., Newitt, H. and Hoile, H. (2011) 'Long-term outcome from childhood traumatic brain injury: intellectual ability, personality, and quality of life', *Neuropsychology*, 25 (2), pp. 176– 184.
- Anderson, V., Catroppa, C., Haritou, F., Morse, S., Pentland, L., Rosenfeld, J. and Stargatt, R. (2001) 'Predictors of acute child and family outcome following traumatic brain injury in children', *Pediatric Neurosurgery*, 34 (3), pp. 138-148.
- Anderson, V., Catroppa, C., Morse, S., Haritou, F. and Rosenfeld, J. (2005) 'Functional plasticity or vulnerability after early brain injury?', *Pediatrics*, 16 (6), pp. 1374-1382.
- Anderson, V., Spencer-Smith, M. and Wood, A. (2011) 'Do children really recover better? Neurobehavioural plasticity after early brain insult', *Brain*, 134, pp. 2197–2221.
- Association of Paediatric Chartered Physiotherapists (2016) *Working with children guidance on good practice.* Retrieved at <u>https://apcp.csp.org.uk/system/files/working\_with\_children\_2016\_1.pdf</u> (accessed 06 August 2021)
- Backhouse, M. and Rodger, S. (1999) 'The transition from school to employment for young people with acquired brain injury: parent and student perceptions', *Australian Occupational Therapy Journal*, (46), pp. 99-109.
- Baque, E., Sakzewski, L., Barber, L. and Boyd, R. N. (2016) 'Systematic review of physiotherapy interventions to improve gross motor capacity and performance in children and adolescents with an acquired brain injury', *Brain Injury*, 30 (8), pp. 948-959. doi: 10.3109/02699052.2016.1147079
- Barry, M., VanSwearingen, J. M. and Albright, A. L. (1999) 'Reliability and responsiveness of the Barry-Albright Dystonia Rating Scale', *Development Medicine and Child Neurology*, 41, (6), pp. 404-411.
- Bayley, N. (2005) *Scales of Infant and Toddler Development 3rd edition (Bayley-III).* Pearson Clinical UK.
- Beretta, E., Molteni, E., Galbiati, S., Stefanoni, G. and Strazzer, S. (2018) 'Five-year motor functional outcome in children with acquired brain injury: yet to the end of the story?' *Developmental Neurorehabilitation*, 21 (7), pp. 449-456. doi: <u>10.1080/17518423.2017.1360408</u>
- Berg, K., Wood-Dauphine, S. L. and Williams, J. L. (1992) 'Measuring balance in the elderly: validation of an instrument', *Canadian Journal of. Public Health*, 83 (S2), pp. S7-S11.
- Bohannon, R. W. and Smith, M. B. O. (1987) 'Inter-rater reliability of a Modified Ashworth Scale of muscle spasticity', *Physical Therapy*, 67, pp. 206–7.

- Boyd, R. and Graham, H. K. (1999) 'Objective measurement of clinical findings in the use of Botulinum toxin type A for the management of children with cerebral palsy', *European Journal of Neurology*, 6, pp. S23-S35.
- Braga, L. W., Da Paz Junior, A. C. and Ylvisaker, M. (2005) 'Direct clinician-delivered versus indirect family-supported rehabilitation of children with traumatic brain injury: a randomized controlled trial', *Brain Injury*, 19 (10), pp. 819-831.
- Bray, L. (2015) 'Parents' experiences of hope following a child's brain injury', *Nursing Children and Young People*, 27 (7), pp. 22-26.
- Brodsky, J. R., Shoshanyi, T. N., Lipson, L. and Zhou, G. (2018) 'Peripheral vestibular disorders in children and adolescents with concussion', Otolaryngology–Head and Neck Surgery, 159 (2), pp. 365–370.
- Burke, R. E., Fahn, S., Marsden, C. D., Bressman, S. B., Moskowitz, C. and Friedman, J. (1985) 'Validity and reliability of a rating scale for the primary torsion dystonias', *Neurology*, 35, pp. 73–77.
- Butler, P. B., Saavedra, S., Sofranac, M., Jarvis, S. E. and Woollacott, M. H. (2010) 'Refinement, reliability and validity of the Segmental Assessment of Trunk Control', *Pediatric Physical Therapy*, 22, pp. 1-13.
- Cartwright, T., Fraser, E., Edmunds, S., Wilkinson, N. and Jacobs, K. (2014) 'Journeys of adjustment: the experiences of adolescents living with juvenile idiopathic arthritis', *Child: Care, Health and Development*, 41 (5), pp. 734-743.
- Chen, C., Bode, R., Granger, C. and Heinemann, A. (2005) 'Psychometric properties and developmental differences in children's activities of daily living item hierarchy: a study of the WeeFIM instrument', *American Journal of Physical Medicine Rehabilitation*, 84, pp. 671–679.
- Chevignard, M. and Lind, K. (2014) 'Long term outcome of abusive head trauma', *Pediatric Radiology,* 44 (Supplement 4), pp. 548-558. DOI: 10.1007/s00247-014-3169-8
- Children's Cancer and Leukaemia Group (2016) *Posterior fossa syndrome Information for parents of a child with PFS.* Retrieved from <u>https://www.cclg.org.uk/write/MediaUploads/Publications/PDFs/Posterior\_Fossa\_Syndrome\_F</u> <u>actsheet.pdf</u> (accessed 06 August 2021)
- Children's Cancer and Leukaemia Group (2021) *Late effects of treatment*. Retrieved from <u>https://www.cclg.org.uk/CSOIR/Late-effects-of-treatment</u> (accessed 24 August 2021)
- Choe, M. C., Valino, H., Fischer, J., Zeiger, M., Breault, J., McArthur, D. L., Leung, M., Madikians, A., Yodovin, S., Lerner, J. T. and Giza, C. C. (2016) 'Targeting the epidemic: interventions and followup are necessary in the pediatric traumatic brain injury clinic', *Journal of Child Neurology*, 31 (1), pp. 109-115.
- Coster, C., Bedell, G., Law, M., Khetani, M. A., Teplicky, R., Liljenquist, K., Gleason, K., and Kao, Y.. (2011) 'Psychometric evaluation of the Participation and Environment Measure for Children and Youth', *Developmental Medicine and Child Neurology*, 53, pp. 1030-7.

- Crichton, A., Anderson, V., Oakley, E., Greenham, M., Hearps, S., Delzoppo, C., Beauchamp, M. H., Hutchinson, J. S., Guerguerian, A., Boutis, K. and Babl, F. E. (2018a) 'Fatigue following traumatic brain injury in children and adolescents: a longitudinal follow-up 6 to 12 months after injury', *Journal of Head Trauma Rehabilitation*, 33 (3), pp. 200-209.
- Crichton, A., Oakley, E., Babl, F. E., Greenham, M., Hearps, S., Delzoppo, C., Beauchamp, M. H., Hutchinson, J. S., Guerguerian, A., Boutis, K. and Anderson, V. (2018b) 'Predicting fatigue 12 months after child traumatic brain injury: child factors and postinjury symptoms', *Journal of the International Neuropsychological Society*, 24, pp. 224–236.
- Ciccia, H. A. and Threats, T. (2015) 'Role of contextual factors in the rehabilitation of adolescent survivors of traumatic brain injury: Emerging concepts identified through modified narrative review', *International Journal of Language and Communication Disorders*, 50 (4), pp. 436–451.
- College of Occupational Therapists (2015) *Children and young people with acquired brain injury: Current practice in occupational therapy.* Retrieved from <u>Children and young people with</u> <u>acquired brain injury Current ...www.rcot.co.uk > file > download</u> (accessed 06 August 2021)
- Collings, C. (2008) 'That's not my child anymore! Parental grief after acquired brain injury (ABI): incidence, nature and longevity', *British Journal of Social Work*, 38, pp. 1499-1517.
- Dahl, E., von Wendt, L. and Emanuelson, I. (2006) 'A prospective, population-based, follow-up study of mild traumatic brain injury in children', *Injury*, 37 (5), pp. 402-409. https://doi.org/10.1016/j.injury.2005.09.008
- De Netto, R. K. and McKinlay, A. (2020) 'Impact of childhood traumatic brain injury on educational outcomes and adult standard of living', *Disability and Rehabilitation*, 42 (17), pp. 2444-2450. https://doi.org/10.1080/09638288.2019.1637948
- Dumas, H. M., Fragala-Pinkham, M. A., Rosen, E. L. and Ni, P. (2019) 'A content validity evaluation of the PEDI-CAT Speedy Mobility domain', *Physiotherapy Theory and Practice*, 24, pp. 1-10.
- Elliot, L., Coleman, M., Shiel, A., Wilson, B. A., Badwan, D., Menon, D. and Pickard, J. (2005) 'Effect of posture on levels of arousal and awareness in vegetative and minimally conscious state patients: a preliminary investigation', *Journal of Neurology, Neurosurgery and Psychiatry*, 76 (2), pp. 298– 299.
- Folio, M. R. and Fewell, R. R. (2000) *Peabody Developmental Motor Scales, Second Edition (PDMS-2)*. Pearson Clinical UK.
- Forinder, U. and Norberg, A. L. (2010) "Now we have to cope with the rest of our lives": existential issues related to parenting a child surviving a brain tumour', *Supportive Care in Cancer*, 18 (5), pp. 543–551.
- Forsyth, R. and Kirkham, F. (2012) 'Predicting outcome after childhood brain injury', *Canadian Medical Association*, 184 (11), pp. 1257 1264.
- Forsyth, R. J., Salorio, C. F. and Christensen, J. R. (2010) 'Modelling early recovery patterns after paediatric traumatic brain injury', *Archives of Disease in Childhood*, 95 (4), pp. 266–70.

- Forsyth R., Young D., Kelly G., Davis K., Dunford C., Golightly A., Marshall L. and Wales L. (2018) 'Paediatric Rehabilitation Ingredients Measure: a new tool for identifying paediatric neurorehabilitation content', *Developmental Medicine and Child Neurology*, 60 (3), pp.299-305.
- Franjoine, M. R., Gunther, J. and Taylor, M. J. (2003) 'Pediatric Balance Scale: a modified version of the Berg Balance Scale for the school-age child with mild to moderate motor impairment', *Pediatric Physical Therapy*, 15, pp. 114–128.
- Giacino, J. T., Kalmar, K. and Whyte, J. (2004) 'The JFK Coma Recovery Scale-Revised: measurement characteristics and diagnostic utility', *Archives of Physical Medicine and Rehabilitation*, 85, 2020-2029.
- Gill-Thwaites, H. and Munday, R. (2004) 'The sensory modality assessment and rehabilitation technique (SMART): a valid and reliable assessment for vegetative state and minimally conscious state patients', *Brain Injury*, 18 (12), pp.1255–1269.
- Giza, C. C., Kolb, B., Harris, N. G., Asarnow, R. F. and Prins, M. L. (2009) 'Hitting a moving target: Basic mechanisms of recovery from acquired developmental brain injury', *Developmental Neurorehabilitation*, 12 (5), pp. 255–268.
- Hagen. C., Malkmus, D. and Durham, P. (1972) *Levels of cognitive functioning*. Downey, CA: Rancho Los Amigos Hospital.
- Haley, S.M., Coster, W. J., Ludlow, L, H., Haltiwanger, J. T. and Andrellos, P. J. (1992) *Pediatric Evaluation of Disability Inventory (PEDI): Development, standardization and administration manual*. San Antonio, TX: Harcourt Assessment Inc.
- Hartman, M. E., Williams, C. N., Hall, T. A., Bosworth, C. C. and Piantino, J. A. (2020) 'Post-intensivecare syndrome for the pediatric neurologist', *Pediatric Neurology*, 108, pp. 47-53.
- Hawley, C. A., Ward, A. B., Magnay, A. R. and Long, J. (2002) 'Children's brain injury: a postal follow up of 525 children from one health region in the UK', *Brain Injury*, 16 (11), pp. 969-85.
- Henderson, S., Sugden, D. and Barnett, A. (2007) *The Movement Assessment Battery for Children-2*. Minnesota: Pearson Education, Inc.
- Hicks, C. L., von Baeyer, C. L., Spafford, P. A., van Korlaar. I. and Goodenough, B. (2001) 'The Faces Pain Scale–Revised: toward a common metric in pediatric pain measurement', *Pain*, 93 (2), pp. 173-183.
- Houston, A. L., Wilson, N. S., Morrall, M. C. H. J., Lodh, R. and Oddy, J. R. (2020) 'Interventions to improve outcomes in children and young people with unresponsive wakefulness syndrome following acquired brain injury: a systematic review', *European Journal of Paediatric Neurology*, 25, pp. 40-51.
- Hunt, A., Goldman, A., Seers, K., Crichton, N., Mastroyannopoulou, K., Moffat, V., Oulton, K. and Brady,
   M. (2004) 'Clinical validation of the Paediatric Pain Profile', *Developmental Medicine and Child Neurology*, 46 (1), pp.9-18.
- Johnson, L. M., Randall, M. J., Reddihough, D. S., Oke, L. E., Byrt, T. A. and Bach, T. M. (1994) 'Development of a clinical assessment of quality of movement for unilateral upper-limb function', *Developmental Medicine Child Neurology*, 36, pp.965–73.

- Kelly, G., Davis, K. and Wales, L. (2019) 'The presence of high level physical difficulties in children and young people with severe acquired brain injuries who regain independent mobility', *International Journal of Therapy and Rehabilitation*, 26 (11), pp. 1-12. <u>https://doi.org/10.12968/ijtr.2018.0087</u>
- King, G., Law, M., King, S., Hurley, P., Hanna, S., Kertoy, M., Rosenbaum, P., and Young, N. (2004). *Children's Assessment of Participation and Enjoyment (CAPE) and Preferences for Activities of Children (PAC)*. San Antonio, TX: Harcourt Assessment, Inc.
- Kirk. K., Shoykhet, M., Jeong, J., Tyler-Kabara, E., Henderson, M., Bell, M. and Fink, E. (2012) 'Dysautonomia after pediatric brain injury', *Developmental Medicine and Child Neurology*, 54, pp. 759-764.
- Kirkham, F. J., Newton, C. R. and Whitehouse, W. (2008) 'Paediatric coma scales', *Developmental medicine and child neurology*, *50* (4), pp. 267–274. <u>https://doi.org/10.1111/j.1469-8749.2008.02042.x</u>
- Krach, L. E., Kriel, R. L., Morris, W. F. and Warhol, B. L. (1997) 'Central autonomic dysfunction following acquired brain injury in children', *Neurorehabilitation and Neural Repair*, 11, pp. 41-45.
- Kochanek, P. M., Clark, R. S. B. and Jenkins, L. W. (2013) 'Pathobiology of secondary brain injury', in Zasler, N. D., Katz, D. I. and Zafonte, R. D. (eds.) *Brain injury medicine: Principles and practice* (chapter 12). Publisher: Demos Medical Publishing.
- Lambregts, S. A. M., Van Markus-Doornbosch, F., Catsman-Berrevoets, C. E., Berger, M. A. M., De Kloet, A. J., Hilberink, S. R. and Roebroeck, M. E. (2018) 'Neurological outcome in children and youth with acquired brain injury 2-year post-injury', *Developmental Neurorehabilitation*, 21 (7), pp. 465-474. doi:10.1080/17518423.2018.1460770
- Law, M., Baptiste, S., Carswell, A., McColl, M. A., Polatajko, H., Pollock, N. (2014) Canadian Occupational Performance Measure (COPM). 5th ed. Ottawa, ON: Canadian Association of Occupational Therapists.
- Law, M., Baptiste, S., McColl, M., Opzoomer, A., Polatajko, H., and Pollock, N. (1990) 'The Canadian Occupational Performance Measure: An outcome measure for occupational therapy', *Canadian Journal of Occupational Therapy*, 57 (2), pp 82-87. doi:10.1177/000841749005700207
- Law, M., Anaby, D., DeMatteo, C. and Hanna, S. (2011) 'Participation patterns of children with acquired brain injury', *Brain Injury*, 25 (6), pp. 587-95.
- Lemke, D. (2007) 'Sympathetic storming after severe traumatic brain injury', *Critical Care Nurse*, 27 (1), pp. 30-37.
- Lin, K., and Wroten, M. (2021) *Ranchos Los Amigos*. Retrieved from <u>https://pubmed.ncbi.nlm.nih.gov/28846341/</u> (Accessed 20 October 2021)
- Louis, D. N., Perry, A., Reifenberger, G., von Deimling, A., Figarella-Branger, D., Cavenee, W. K., Ohgaki, H., Wiestler, O. D., Kleihues, P. and Ellison, D. W. (2016) 'The 2016 World Health Organization classification of tumors of the central nervous system: a summary', *Acta Neuropathologica*, 131 (6), pp. 803–820. doi.org/10.1007/s00401-016-1545-1

- Louwers, A., Beelen, A., Holmefur, M. and Krumlinde-Sundholm, L. (2016) 'Development of the Assisting Hand Assessment for adolescents (Ad-AHA) and validation of the AHA from 18 months to 18 years', *Developmental Medicine and Child Neurology*, 58 (12), pp. 1303-1309.
- Lumba-Brown, A., Yeates, O., Sarmiento, K., Breiding, M. J., Haegerich, T. M., Gioia, G. A., Turner, M., Benzel, M. C., Suskauer, S. J., Giza, C. C., Joseph, M., Broomand, C., Weissman, B., Gordon, W., Wright, D. W., Moser, R. S., McAvoy, K., Ewing-Cobb, L., Duhaime, A-C., Putukian, M., Holshouser, B., Paulk, D., Wade, S. L., Herring, S. A., Halstead, M., Keenan, H. T., Choe, M., Christian, C. W., Guskiewicz, K., Raksin, P. B., Gregory, A., Mucha, A., Taylor, H. G., Callahan, J. M., DeWitt, J., Collins, M. W., Kirkwood, M. W., Ragheb, J., Ellenbogen, R. G., Spink, T. J., Ganiats, T. G., Sabelhaus, L. J., Altenhofen, K., Hoffman, R., Getchius, T., Gronseth, G., Donnell, Z., O'Connor, R. E. and Timmons, S. D. (2018) 'Diagnosis and management of mild traumatic brain injury in e182847. children а systematic review', JAMA Pediatrics, 172 (11), doi:10.1001/jamapediatrics.2018.2847
- McCauley, S. R., Wilde, E. A., Anderson, V. A., Bedell, G., Beers, S. R., Campbell, T. F., Chapman, S. B., Ewing-Cobbs, L., Gerring, J. P., Gioia, G. A., Levin, H. S., Michaud, L. J., Prasad, M. R., Swaine, B. R., Turkstra, L. S., Wade, S. L., Yeates, K. O., and Pediatric TBI Outcomes Workgroup (2012) 'Recommendations for the use of common outcome measures in pediatric traumatic brain injury research', *Journal of neurotrauma*, 29 (4), pp. 678–705. <u>https://doi.org/10.1089/neu.2011.1838</u>
- McDougall, J., Bedell, G., and Wright, V. (2013) 'The youth report version of the Child and Adolescent Scale of Participation (CASP): assessment of psychometric properties and comparison with parent report', *Child: Care, Health and Development*, 39, pp. 512-522. doi: 10.1111/cch.12050
- McKinlay, A., Linden, M., DePompei, R., Jonsson, C. A., Anderson, V., Braga, L., Castelli, E., de Koning, P., Hawley, C. A., Hermans, E., Kristiansen, I., Madden, A., Rumney, P., Savage, R. and Wicks, B. (2016) 'Service provision for children and young people with acquired brain injury: Practice recommendations', *Brain Injury*, 30 (13-14), pp. 1656-1664. doi: 10.1080/02699052.2016.1201592
- Medical Research Council (1981) *Aids to the examination of the peripheral nervous system*. Memorandum no. 45, Her Majesty's Stationery Office, London.
- Meyling, C. G., Verschuren, O., Rentinck, I. R., Engelbert, R. H. H. and Gorter, J. W. (2021) 'Physical rehabilitation interventions in children with acquired brain injury: a scoping review', *Developmental Medicine and Child Neurology*. doi: 10.1111/dmcn.14997
- Mollayeva, T., Kendzerska, T., Mollayeva, S., Shapiro, C. M., Colantonio, A. and Cassidy, J. D. (2014) 'A systematic review of fatigue in patients with traumatic brain injury: the course, predictors and consequences', *Neuroscience and Biobehavioural Reviews*, 47, pp. 684-716.
- Muscara, F., McCarthy, M. C., Woolf, C., Hearps, S. J. C., Burke, K. and Anderson, V. A. (2015) 'Early psychological reactions in parents of children with a life threatening illness within a pediatric hospital setting', *European Psychiatry*, 30, pp. 555-561.
- National Acquired Brain Injury in Learning and Education Syndicate (2021) *ABI return children and* young people with acquired brain injury - guiding their return to education. Retrieved from www.ukabif.org.uk/ABIReturn (accessed 06 August 2021)

- National Health Service England (2013) 2013/14 NHS standard contract for paediatric neurosciences:neurorehabilitation.Retrievedfrom<a href="https://www.england.nhs.uk/wp-content/uploads/2018/09/Paediatric-Neurorehabilitation.pdf">https://www.england.nhs.uk/wp-content/uploads/2018/09/Paediatric-Neurorehabilitation.pdf</a> (accessed 06 August 2021)
- National Institute for Clinical Excellence (2014) *Head injury: Assessment and early management.* Retrieved from <u>https://www.nice.org.uk/guidance/cg176/chapter/1-Recommendations</u> (accessed 06 August 2021)
- National Institute for Clinical Excellence (2016) *Spasticity in under 19s: Management*. Retrieved from <u>https://www.nice.org.uk/guidance/cg145/chapter/1-Guidance#physical-therapy-physiotherapy-andor-occupational-therapy</u> (accessed 06 August 2021)
- Nelson, L. P. and Gold, J. I. (2012) 'Posttraumatic stress disorder in children and their parents following admission to the pediatric intensive care unit: a review', *Pediatric Critical Care Medicine*, 3 (3), pp. 338-347.
- Piper, M. C and Darrah, J. (1994) *Motor Assessment of the Developing Infant*. USA: WB Saunders Company.
- Podsiadlo, D. and Richardson, S. (1991) 'The timed "up and go": a test of basic functional mobility for frail elderly persons', *Journal of the American Geriatrics Society*, 39 (2), pp. 142-148.
- Ponsford, J., Willmott, C., Rothwell, A., Cameron, P., Ayton, G., Nelms, R., Curran, C. and Ng, K. (2001) 'Impact of early intervention on outcome after mild traumatic brain injury in children', *Pediatrics*, 108 (6), pp. 1297-1303.
- Ponsford, J., Schönberger, M. and Rajaratnam, S. M. (2015) 'A model of fatigue following traumatic brain injury', *Journal of Head Trauma Rehabilitation*, 30 (4), pp. 277-82. doi: 10.1097/HTR.000000000000049
- Pountney, T. E., Cheek, L., Green, E., Mulcahy, C. and Nelham, R. (1999) 'Content and criterion validation of the Chailey Levels of Ability', *Physiotherapy*, 85 (8), pp. 410-416.
- Power, T., Catroppa, C., Coleman, I., Ditchfield, M. and Anderson, V. (2007) 'Do lesion site and severity predict deficits in attentional control after preschool traumatic brain injury (TBI)?', *Brain Injury*, 21 (3), pp. 279-92.
- Pundole, A., Varley, R. and Beeke, S. (2021) 'Assessing emergence from prolonged disorder of consciousness: current opinion and practice in the UK. *Neuropsychological rehabilitation*, 31, (7), pp. 1003-1027.
- Johnson, L. M., Randall, M. J., Reddihough, D. S., Oke, L. E., Byrt, T. A. and Bach, T. M. (1994) 'Development of a clinical assessment of quality of movement for unilateral upper-limb function', *Developmental Medicine and Child Neurology*, 36, pp. 965–73.
- Renaud, M. I., Lambregts, S. A. M., van d Port, I. G. L., Catsman-Berrevoets, C. E. and van Heughten, C. M. (2019) 'Predictors of activities and participation six months after mild traumatic brain injury in children and adolescents', *European Journal of Paediatric Neurology*, 25, pp. 145-156. <a href="https://doi.org/10.1016/j.ejpn.2019.11.008">https://doi.org/10.1016/j.ejpn.2019.11.008</a>

- Rhine, T., Cassedy, A., Yeates, K. O., Taylor, H. G., Kirkwood, M. W. and Wade, S. L. (2017) 'Investigating the connection between traumatic brain injury and post traumatic stress symptoms in adolescents', *Journal of Head Trauma Rehabilitation*, 33 (3), pp. 1-9.
- Riberholt, C. G., Thorlund, J. B., Mehlsen, J., and Nordenbo, A. (2013) 'Patients with severe acquired brain injury show increased arousal in tilt-table training, *Danish Medical Journal*, 60 (12), A4739.
- Rivara, J. B., Fay, G. C., Jaffe K. M., Polissar, N. L., Shurtleff, H. A. and Martin, K. M. (1992) 'Predictors of family functioning one year following traumatic brain injury in children', *Archives of Physical Medicine and Rehabilitation*, 73 (10), pp. 899-910.
- Rosenbaum, P. and Gorter, J. W. (2011) 'The 'F-words' in childhood disability: I swear this is how we should think!', *Child: care, health and development,* 38 (4), pp. 457-463.
- Ross, B. G., Fradet, G. and Nedzelski, J. M. (1996) 'Development of a sensitive clinical facial grading system', *Otolaryngology-Head and Neck Surgery*, 114, pp. 380–6.
- Royal College of Paediatrics and Child Health and The Stroke Association, (2017) *Stroke in childhood: clinical guideline for diagnosis, management and rehabilitation*. Retrieved from <u>https://www.rcpch.ac.uk/resources/stroke-in-childhood-clinical-guideline</u> (accessed 06 August 2021)
- Royal College of Physicians (2020) *Prolonged disorders of consciousness following sudden onset brain injury: national clinical guidelines*. Retrieved from <a href="https://www.rcplondon.ac.uk/guidelines-policy/prolonged-disorders-consciousness-following-sudden-onset-brain-injury-national-clinical-guidelines">https://www.rcplondon.ac.uk/guidelines</a> policy/prolonged-disorders-consciousness-following-sudden-onset-brain-injury-nationalclinical-guidelines (accessed 06 August 2021)
- Russell, D. J., Rosenbaum, P. L., Avery, L. M. and Lane, M. (2002) *Gross Motor Function Measure* (*GMFM-66 and GMFM-88*) *User's Manual*. London, United Kingdom: Mac Keith Press.
- Ryan, N. P., Reyes, J., Crossley, L., Beauchamp, M. H., Catroppa, C. and Anderson, V. (2019) 'Unraveling the association between pediatric traumatic brain injury and social dysfunction: the mediating role of self-regulation', *Journal of Neurotrauma*, 36, pp. 1-9. doi: 10.1089/neu.2018.6308
- Savage, R. C., DePompei, R., Tyler, J. and Lash, M. (2005) 'Paediatric traumatic brain injury: A review of pertinent issues', *Pediatric Rehabilitation*, 8 (2), pp. 92-103. doi: 10.1080/13638490400022394
- Schmahmann, J., Gardner, R., MacMore, J. and Vangel, M. G. (2009) 'Development of a Brief Ataxia Rating Scale (BARS) based on a modified form of the ICARS', *Movement Disorders*, 24, pp. 1820– 1828.
- Schmitz-Hübsch, T., Tezenas du Montcel, S., Baliko, L., Berciano, J., Boesch, S., Depondt, C., Giunti, P., Globas, C., Infante, J., Kang, J-S., Kremer, B., Mariotti, C., Melegh, B., Pandolfo, M., Rakowicz, M., Ribai, P., Rola, R., Schöls, L., Szymanski, S., van de Warrenburg, B. P., Dürr, A., Klockgether, T. and Fancellu R. (2006) 'Scale for the assessment and rating of ataxia: development of a new clinical scale', *Neurology*, 66, pp. 1717–1720.
- Scottish Acquired Brain Injury National Clinical Network, NHS Scotland (2018) *Paediatric acquired* brain injury best practice statements. Retrieved from <u>https://www.sabin.scot.nhs.uk/wp-</u> <u>content/uploads/2018/06/Paediatric-ABI-Standards-April-2018.pdf</u> (accessed 06 August 2021)

- Semrud-Clikeman, M. (2010) 'Pediatric traumatic brain injury: rehabilitation and transition to home and school', *Applied Neuropsychology*, 17 (2), pp. 116-22.
- Sharp, D. J. and Jenkins, P. O. (2015) 'Concussion is confusing us all', *Practical Neurology*, 15 (3), pp. 172–186.
- Shiel, A., Wilson, B. A., McLellan, L., Horn, S. and Watson, M. (2000) 'The Wessex Head Injury Matrix (WHIM) main scale: a preliminary report on a scale to assess and monitor patient recovery after severe head injury', *Clinical Rehabilitation*, 14, pp. 408–416.
- Shumway-Cook, A. and Woolacott, M. (2001) *Motor control theory and practical applications*. 2nd edition. Lippincot, Williams and Wilkins.
- Slomine. B., McCarthy, M., Ru, D., MacKenzie, E., Jaffe, K., Aitken, M., Durbin, D., Christensen, J., Dorsch, A. and Paidas, C. (2006) 'Health care utilization and needs after pediatric traumatic brain injury', *Pediatrics*, 117 (4), e663-e674.
- Stewart, D. A., Lawless, J. J., Shimmell, L. J., Palisano, R. J., Freeman, M., Rosenbaum, P. L. and Russell,
   D. J. (2012) 'Social participation of adolescents with cerebral palsy: trade-offs and choices',
   *Physical and Occupational Therapy in Pediatrics*, 32 (2), pp. 167-179.
- Teasdale, G. and Jennett, B. (1974) 'Assessment of coma and impaired consciousness: a practical scale', *The Lancet*, 304 (7872), pp. 81-84.
- Thompson, K., Biddle, K. R., Robinson-Long, M., Pager, J., Wang, J., Yang, Q. X. and Slinger, P. J. (2009) 'Cerebral plasticity and recovery of function after childhood prefrontal cortex damage', *Developmental Neurorehabilitation*, 12 (5), pp. 298-312.
- Turner-Stokes, L., Nyein, K., Turner-Stokes, T. and Gatehouse C. (1999) 'The UK FIM+FAM: development and evaluation. Functional Assessment Measure', *Clinical Rehabilitation*, 13 (4), pp. 277-87.
- Turner-Stokes, L. (2009) 'Goal Attainment Scaling (GAS) in rehabilitation: A practical guide' *Clinical rehabilitation*, 23 (4), pp.362-70.
- Turner-Stokes, L., Krägeloh, C. U. and Siegert R. J. (2018) 'The patient categorisation tool: Psychometric evaluation of a tool to measure complexity of needs for rehabilitation in a large multicentre dataset from the United Kingdom', *Disability and Rehabilitation*, 18, pp. 1-9.
- Trovato, M. K., Bradley, E., Slomine, B. S., Saloria, C. F., Christensen, J. R. and Suskauer, S. J. (2013) 'The Physical Abilities and Mobility Scale (PAMS): Reliability and validity in children receiving inpatient brain injury rehabilitation', *Archives of Physical Medicine Rehabilitation*, 94 (7), pp. 1335–1341.
- Tyerman, E., Eccles, F. J. R. and Gray, V. (2017) 'The experience of parenting a child with an acquired brain injury: a meta-synthesis of the qualitative literature', *Brain Injury*, 31 (12), pp. 1553-1563.
- Volpe, D. S. J., Oliveira, N. C. A., Carlos Santos, A., Linhares, M. B. M. and Carlotti, A. P. C. P. (2017) 'Neuropsychological outcome of children with traumatic brain injury and its association with late magnetic resonance imaging findings: a cohort study', *Brain Injury*, 31 (12), pp. 1689-1694.

- Wewers, M. E. and Lowe, N. K. (1990) 'A critical review of visual analogue scales in the measurement of clinical phenomena', *Research in Nursing & Health*, 13, pp. 227–236.
- Williams, G., Robertson, V. and Greenwood, K. (2004) 'Measuring high-level mobility after traumatic brain injury', *American Journal of Physical Medicine Rehabilitation*, 83 (12), pp. 910-20.
- Wilson, B. A., Dhamapurkar, S., Tunnard, C., Watson, P. and Florschutz, G. (2013) 'The effect of positioning on the level of arousal and awareness in patients in the vegetative state or the minimally conscious state: a replication and extension of the previous findings', *Brain Impairment*, 14 (3), pp. 475–479.
- World Health Organisation, (2001) International Classification of Functioning, Disability and Health. Retrieved from <u>https://apps.who.int/iris/bitstream/handle/10665/42407/9241545429.pdf;jsessionid=3099758</u> <u>991248C046FD6563996F8A522?sequence=1</u> (accessed 06 August 2021)
- Wright, F. V., Rosenbaum, P. L., Goldsmith, C. H., Law, M. and Fehlings, D. (2008) 'How do changes in body functions and structures, activity and participation relate in children with cerebral palsy?', *Developmental Medicine and Child Neurology*, 50 (4), pp.283-9.
- Yokobori, S. and Bullock, M. R. (2013) 'Pathobiology of primary traumatic brain injury', in Zasler, N. D., Katz, D. I. and Zafonte, R. D. (eds.), *Brain injury medicine: Principles and practice* (chapter 11). Publisher: Demos Medical Publishing.
- Yam, W. K. and Leung, M. S. (2006) 'Interrater reliability of Modified Ashworth Scale and Modified Tardieu Scale in children with spastic cerebral palsy', *Journal of Child Neurology*, 21, pp. 1031–5.
- Young, D. K., Starace, H. E., Boddy, H. I., Connolly, K. M. D., Lock, K. J. and Hamilton, C. R. E. (2020) 'Evaluating functional change using the Physical Abilities and Mobility Scale in acute paediatric neurorehabilitation', *International Journal of Therapy and Rehabilitation*, 27 (12), pp, 1-11. <u>https://doi.org/10.12968/ijtr.2019.0144</u>
- Young, D. K., Forsyth, R. and Mares, K. (2019) 'Development of a consensus classification of physiotherapy interventions in paediatric neurorehabilitation', *APCP Journal*, 10 (2).

# Appendix A – Foundation/advanced level physiotherapy assessment guide

The table below sets out in more detail some of the considerations for assessing the ICF body structure and function domain, for CYP with an ABI. It draws on all areas of physiotherapy assessment techniques and skills. 'Foundation' assessment suggestions are relevant to all physiotherapists working with children after an ABI. The suggestions in the 'advanced' column are extension assessments which may add more specific detail to the overall physiotherapy assessment. For all areas, it is important to know if there were any pre-existing deficits prior to the ABI - this will help to determine what is different post-injury and inform goal setting and intervention planning. Ensure you get a detailed history from the family, carers or staff working with the CYP to aid with your assessment.

Area for assessment	Foundation	Advanced
Muscle tone	<ul> <li>Clinical skills for assessment of muscle tone will be relevant throughout the CYP's rehabilitation pathway as changes occur throughout recovery - regular assessment is necessary to inform ongoing management</li> <li>Knowledge of neural and non neural components of hypertonia will help inform management options</li> <li>Abnormal muscle tone varies in appearance, and can include hypertonia, hypotonia and dystonic presentation alone or in combination. Presentation is likely to change daily in the early post-injury phase. Distribution of abnormal tone should be assessed in all body areas including upper and lower limb, trunk, neck and face and any asymmetries.</li> <li>Decorticate or decerebrate posturing indicate the severity of injury; the presence of these abnormal postures can be seen in response to intervention or as a consequence of cerebral irritability and may be transient or persistent. The latter indicates severe injury and is seen more frequently following a</li> </ul>	<ul> <li>Consider symptoms which might suggest paroxysmal sympathetic hyperreflexia (PSH), sympathetic storming, dysautonomia or autonomic storming. Presentation may include episodes of hypertension, tachycardia, tachypnea, muscle overactivity or dystonia, fever without source of infection and agitation. Liaison with medical colleagues is necessary.</li> <li>Consider that critical illness polyneuropathy can be difficult to distinguish alongside the ABI presentation - careful assessment including lower motor neuron (LMN) and upper motor neuron (UMN) differentiation is needed and may require formal testing with deep tendon reflexes and nerve conduction studies.</li> </ul>

	<ul> <li>prolonged hypoxic insult e.g. hanging or drowning.</li> <li>Consider the influence of factors including pain, position, state of awareness, agitation, bladder and bowel function, and environment on muscle tone.</li> <li>Consider the impact of sedation withdrawal on the muscle tone of the CYP e.g. fluctuating tone, jitteriness, increase in tone.</li> <li>Refer to Spasticity in under 19s: management (CG145) (NICE, 2016)</li> <li>Measurement tools include Modified Ashworth Scale, modified Tardieu</li> </ul>	
Deep tendon reflexes	<ul> <li>Assessment should compare one side to another, establishing the symmetry and strength of response.</li> <li>Typical assessment includes tendo- achilles, patella, biceps and triceps tendons</li> <li>Hyperreflexia is a feature of upper motor neurone (UMN) syndrome, indicating the level of excitation in the neural pathways.</li> <li>Absent reflexes indicate a lower motor neurone (LMN) injury or flaccid paralysis in the cases of acute spinal cord injury</li> </ul>	
Clonus	<ul> <li>Involuntary rhythmic contractions and relaxations of a muscle indicates UMN damage, except in neonates where it is a normal finding.</li> <li>Most commonly tested and observed in gastroc-soleus complex but can be present in any muscle group as a positive feature of UMN syndrome.</li> <li>Record if absent or present, ill sustained or sustained (&gt; 10 beats), symmetrical or asymmetrical.</li> </ul>	

Range of movement (ROM)	<ul> <li>Knowledge of normal joint ROM and goniometry skills to measure and record them accurately is essential.</li> <li>Both active and passive ROM should be assessed in upper and lower limbs.</li> <li>Frequency of assessment will be dependent on presentation and stage of rehabilitation.</li> <li>Monitor for development of joint contractures - these are common in CYP with an ABI and can lead to complications with posture, ADLs, upper limb function, mobility, seating and skin management as well as functional attainment.</li> </ul>	<ul> <li>The Cerebral Palsy Integrated Pathway (CPIP) should be considered as a model of good practice to monitor hip migration in children with severe spasticity or dystonia causing imbalance of muscles around the pelvis and hips, leading children to be at risk of development of hip migration.</li> <li>Be aware of the possibility of development of heterotopic ossification (HO) especially in children who have a brain injury as a result of trauma. HO in CYP with severe TBI may result in joint restriction or swelling; it is often seen after long bone fractures and can be mistaken for increased tone or development of joint contractures; early identification is necessary, and x-rays are required for diagnosis.</li> </ul>
Muscle strength	<ul> <li>Assessment of strength through observation of active movements and level of assistance required for functional tasks should be noted in all body areas including upper and lower limb.</li> <li>Formal assessment may need to be adapted for different age groups (e.g. younger children) or depending on clinical setting as a more functional assessment of power may be appropriate. This should be undertaken as appropriate within your clinical setting.</li> </ul>	

	<ul> <li>Tools for assessment include the Medical Research Council (MRC) and Oxford scales. Note that it may be more difficult to use the MRC scale to test strength in this group of patients due to age, level of understanding, muscle tone, level of fatigue and arousal.</li> </ul>	
Postural control	<ul> <li>Postural control is the ability to maintain controlled upright posture. Assessment should include both static and dynamic control (anticipatory and reactive). It may be impacted by the presence of involuntary movements and the CYP's abilities for volitional movement.</li> <li>The level of challenge for the assessment will be informed by skilled observation and knowledge of normal movement patterns and normal postural control development.</li> <li>Early assessment may include sitting over the edge of a bed/plinth with support of several therapy team members may be the first opportunity to assess head control and sitting balance.</li> <li>Progression in the assessment will include reduction in base of support, varying the stability of supporting surface, degree of verticalisation.</li> <li>Be aware of postural hypotension when moving against gravity, particularly in the early stages - proceed with caution and consider simultaneous blood pressure monitoring.</li> <li>Assess and record the impact of fatigue on postural control</li> </ul>	<ul> <li>Consider the variability in postural control at different ages - note that the system is not mature until 7-10 years of age, with particular variability in postural control responses and an apparent regression at age 4-6 years (Shumway-Cook &amp; Woollacott, 2001).</li> <li>Use of standardised measurement tools may be used, for example the Chailey Levels of Ability and the Segmental Assessment of Trunk Control (SATCo). These may help in providing a common language with other members of the MDT including health or social care OT, and wheelchair services.</li> </ul>
Balance	<ul> <li>Balance is dependent upon the interplay between visual, vestibular and proprioceptive input alongside</li> </ul>	

	<ul> <li>postural control. Deficits in any of these systems will affect balance ability.</li> <li>Assessment should include anticipatory and reactive balance skills in different postures including sitting, standing and during movement.</li> <li>The level of challenge of assessment will vary according to the CYP's ability. Progression in the assessment will include reduction in base of support, varying the stability of supporting surface, degree of verticalization.</li> <li>Note which strategies are used to maintain balance or in reaction to any perturbation, including saving reactions, head righting reactions, lateral trunk righting, weight transference and any asymmetry.</li> <li>Note changes in muscle tone and any associated reactions.</li> <li>In standing note the size of the base of support e.g. single leg, tandem, wide; note postural sway or any asymmetry.</li> <li>Note variation in balance control with eyes open and closed.</li> <li>Assess and record the impact of fatigue on postural control</li> <li>There are a number of standardised tests that can be used in the assessment of postural control and balance, eg. Romberg test, paediatric balance scale.</li> <li>Higher level balance skills may also be assessed in standing e.g. tandem stand, one leg stance.</li> </ul>	
MSK alignment	<ul> <li>Knowledge of normal gait and movement patterns and their assessment is vital.</li> </ul>	<ul> <li>Advanced knowledge of gait analysis and use of assessment tools e.g.</li> </ul>

	<ul> <li>Some CYP may experience asymmetry or neglect of a limb which will impact on their body alignment and awareness.</li> <li>MSK alignment should be observed and assessed in all positions including supine, prone, and side-lying, sitting and standing, depending on the CYP's level of functioning and safety.</li> </ul>	<ul> <li>Edinburgh Gait score, GAITRite, video gait analysis</li> <li>Be aware that due to immobility and non-weight bearing, antiepileptic drugs, use of steroids or poor nutrition there is a risk of developing osteoporosis.</li> </ul>
Coordination	<ul> <li>Assessment of fine and gross motor coordination should be included at an age-appropriate level. Standardised assessments may be useful including Movement ABC, Bayley Scales of Infant and Toddler Development, Peabody Developmental Motor Scales</li> <li>Scale for the Assessment and Rating of Ataxia (SARA), the Brief Ataxia Rating Scale (BARS) may be beneficial.</li> <li>Assessments including nose-finger test, finger chase test, fast alternating movements and heel-shin test may help to ascertain specific coordination issues including dysmetria, dysdiadochokinesis, or an intention tremor.</li> <li>Results may be abnormal if there is loss of motor strength, proprioception or a cerebellar lesion.</li> <li>Impairments in strength, tone, motor control cognition and fatigue may lead to difficulty completing standardised assessments.</li> <li>Consider using video to assist with description of movement and assess change over time.</li> <li>Check eye movements including tracking of objects left, right, up, and down.</li> <li>Liaise with OT colleagues, particularly when considering assessment of</li> </ul>	<ul> <li>Coordination may be affected by altered cognition and understanding, leading to motor planning and sensorimotor perceptual difficulties.</li> </ul>

	coordination in relation to functional activities.	
Sensation	<ul> <li>Consider the influence of age - younger children may not be able to communicate effectively to inform assessment.</li> <li>Check light touch, pin prick, two- point discrimination, vibration sense, joint position sense, temperature - document distribution clearly.</li> <li>Knowledge of sensory dermatomes is important</li> <li>Note physiological responses if CYP in low state of arousal</li> </ul>	
Pain	<ul> <li>Be aware of the CYP's response to pain. Pain responses can be exhibited in many ways e.g. involuntary movement patterns, alteration in tone, physiological changes, alteration in heart rate, respiratory rate, sweating, tears and skin erythema.</li> <li>Ensure that pain responses are noted in all interactions including during handling, stretches, passive movements, change of position, personal care.</li> <li>Early stimulation to elicit a reaction can be used to determine level of responsiveness e.g. pinch on trapezius muscle, supraorbital pressure or sternal rub.</li> <li>Consider MDT working and potential side effects of analgesia (e.g. alertness, constipation etc.)</li> <li>If appropriate plan physiotherapy sessions around timing of analgesia to optimise effect and minimise the effect of pain on function.</li> <li>Consider the presence of other unidentified injuries e.g. wrist fractures - common when treating patients with polytrauma.</li> </ul>	<ul> <li>Consider the development of heterotopic ossification, especially in adolescents following a traumatic brain injury.</li> <li>Consider other potential less obvious sources of pain e.g. constipation, pressure areas, headaches etc.</li> </ul>

	<ul> <li>Consider standardised assessment measures as appropriate for age or developmental stage including FLACC (face, legs, arms, cry, consolability), Faces pain scale, visual analogue or numerical rating scale</li> </ul>	
Involuntary movements	<ul> <li>Presence of involuntary movement is common in CYP with ABI, including tremor, fasciculations, associated reactions, spasms, clonus.</li> <li>Note if present at rest or on movement; type, distribution and frequency; impact on function including balance, fine motor skills or ADLs.</li> </ul>	
Level of consciousness	<ul> <li>Note Glasgow Coma Scale (GCS) level on critical care neuro observation chart; CYP are often paralysed and sedated in an induced coma as a neuroprotective measure</li> <li>GCS may fluctuate – be aware of any reduction in GCS as this may be an indication of further CNS involvement e.g. increased ICP due to hydrocephalus, further haemorrhage etc.</li> <li>Consider use of standardised measures e.g. WHIM (Wessex Head Injury Matrix) 12 years and over or the Rancho Los Amigos scales.</li> </ul>	<ul> <li>Have a knowledge the disorders of consciousness (DOC) including coma, vegetative state, minimally conscious state</li> <li>Consider role of physiotherapy in multidisciplinary assessment of DOC</li> <li>Be aware that medication or sedation levels may be altered by medical teams to assess level of stability - level of consciousness may fluctuate</li> <li>Be aware that some children may experience unusual behaviours during medication withdrawal</li> </ul>
Orientation and memory	<ul> <li>It is not uncommon to present with disorientation or post traumatic amnesia (PTA) following an ABI - be aware of how this may affect the assessment, engagement or carry over.</li> <li>Liaise with psychology and OT as part of MDT approach to assessment and</li> </ul>	<ul> <li>Consider the presence of PTA; liaise with MDT regarding the use of PTA screening tools including Westmead PTA scores</li> </ul>

	supporting the CYP's orientation to self, place and time.	
Vision	<ul> <li>Visual impairment is common in children with ABI - consider whether there is a visual loss or impairment as it may impact on the subsequent planning of therapy input.</li> <li>Look at control of eye movements, ability to fix and follow, visual field, double vision</li> <li>Common sensorimotor visual symptoms include blurred vision, reading problems, double vision or eye strain, dizziness or disequilibrium in visually-crowded environments, visual field defects, light sensitivity, and colour blindness.</li> <li>Consider referral to ophthalmology</li> </ul>	<ul> <li>Consider the site of injury on visual function i.e. cranial nerves, occipital lobe, cerebellum, to help focus your clinical inquiry and reasoning.</li> </ul>
Hearing	<ul> <li>CYP with ABI may have hearing difficulties due to damage of auditory pathways.</li> <li>Note response to sound - ensure the auditory stimulus is outside the CYP's visual field when testing.</li> <li>Check with parents/carers, note if they feel the CYP responds to their familiar voices.</li> <li>Liaise with medical team re referral for audiology if concerns raised</li> </ul>	
Communication	<ul> <li>Communication problems are common in children following an ABI, including expressive or receptive communication difficulties, dysphasia, perseveration, dysarthria, cognitive-communication disorder and facial palsy</li> <li>As a physiotherapist you will need to have an awareness of any communication difficulties as these will directly affect accurate assessment and treatment, including the CYP's ability to follow</li> </ul>	

	<ul> <li>instructions, respond to verbal questioning etc.</li> <li>Ensure close liaison with speech and language therapy (SLT) if any problems are suspected, to establish a consistent strategy to support effective communication.</li> <li>Be cognisant of the language most familiar to the CYP.</li> </ul>		
Cognition	<ul> <li>Knowledge of age-appropriate cognitive development and understanding is relevant throughout</li> <li>Consider previous cognitive ability – liaise with education and psychology team</li> <li>When assessing understanding, consider the use of your own language and choice of questions. – keep simple and allow time for slow processing.</li> <li>Be aware that fatigue may have a negative impact on understanding and speed of processing</li> </ul>	<ul> <li>Consider prompt liaison and referral to psychology for assessment</li> </ul>	
Behaviour	<ul> <li>Behaviours may alter post ABI. This may be transient or more long lasting.</li> <li>Be aware of any preinjury behaviors which may influence your assessment.</li> <li>Assessment regarding changes in behavior should include looking at triggers – unfamiliar environment, and unfamiliar people, level of cognition, fatigue, pain etc - this should be part of an MDT approach.</li> </ul>	<ul> <li>Liaise promptly with clinical psychology team for advice on approaches to use physiotherapy assessment</li> </ul>	
Swallowing function	<ul> <li>If CYP is noted to be coughing during or immediately after eating or drinking, liaise with MDT to request urgent referral to SLT as CYP may be at risk of aspiration; poor oromotor control or drooling (if not age appropriate or usual for that child)</li> </ul>		

	may indicate reduced management of oral secretions and require SLT referral also.	
Bladder and bowel function	<ul> <li>Review nursing charts to be aware of any altered signs of bladder or bowel function. Urinary retention may be caused by spinal cord involvement (risk in polytrauma). Constipation can lead to increasing symptoms such as increased hypertonia, difficulties with behavioural regulation or attention, irritability and pain.</li> </ul>	
Sleep	<ul> <li>Sleep patterns can be disturbed significantly after an ABI with an impact on the CYP's functioning and fatigue</li> <li>Discuss with parents and nursing staff regarding sleep-wake patterns, length of sleep, frequency of naps, aiming to build physiotherapy sessions around this patten</li> <li>Note any changes compared to premorbid levels and age appropriateness.</li> </ul>	<ul> <li>Refer to medics to consider introduction of melatonin</li> <li>Discuss with MDT regarding use of a sleep diary and importance of sleep hygiene</li> <li>Liaise with OT and psychology colleagues</li> </ul>
Fatigue	<ul> <li>Note fatigue levels – both physical and cognitive</li> <li>Consider fatigue response to physiotherapy sessions to guide future sessions, plus be aware of other activities - if CYP has had lots of other appointments on the same day, may not see the true picture of physical activities due to fatigue.</li> <li>Visual analogue scales can be useful tool to assess fatigue</li> </ul>	<ul> <li>Knowledge of long-term aspects of fatigue with ABI, contribution of psychological, cognitive, social and emotional factors as well as physical</li> </ul>

# **Appendix B - Physiotherapy intervention categories**

The table below provides a summary of proposed physiotherapy intervention categories, rationale and example options of how these might be applied for CYP following ABI (Young et al., 2019). It is not anticipated that these 'intervention categories' are delivered in isolation or one at a time, but rather it offers a way to think about groups of interventions based on common essential ingredients, plus aims and rationale about how they are working through mechanisms of action. For further detail about this approach to categorising treatment approaches according to common essential ingredients and mechanisms of action, please see the paper by Forsyth and colleagues (2018) detailing the development of the Paediatric Rehabilitation IngredientS Measure (PRISM) tool.

Please note, this list is not exhaustive - as described previously, physiotherapy intervention for children after ABI is often complex, requiring a combination of approaches.

Category	Description	Rationale	Examples
1.	Enabling implicit learning (learning-by- doing)	Providing feedback regarding body position, movements, forces generated	Hippotherapy Biofeedback Mirror therapy Lycra suits Virtual reality
2.	Provision of explicit feedback (providing knowledge that can be understood and repeated back)	Learning through conscious, intentional thought; the provision of knowledge which can be understood and, where possible, repeated back	Giving written or verbal advice Cueing Mental practice Strategies
3.	Alteration of the properties of tissues through passive application of external forces	Utilise external forces to maintain or improve range of movement and function as well as aid and manage secondary complications from tonal changes	Serial casting +/- prior to botulinum toxin-A injections Use of specialist seating to maintain alignment Use of standing frames for weight bearing
4.	Alteration of the dynamics of movement	Compensation for an impairment through the action of altering natural pattern of movement using an external aid or device	Ankle-foot orthoses Functional electrical stimulation

5.	Use of task-specific, functional goals which are meaningful to the patient	Completing tasks which have a purpose within the daily life of the patient	Sitting and transfer practice Reach-to-grasp tasks
6.	Use of tailored progression	Graded exposure to tasks whereby the difficulty, intensity or complexity is tailored to provide the optimal level of challenge for the patient	Partial body weight device Strength training Aerobic training
7.	Repetition of movement	Completing treatments which require multiple repetitions of specific movements	Constraint induced movement therapy Treadmill walking
8.	Sensory integration	Treatments which aim to stimulate sensory systems and enable adaptation	Vestibular rehabilitation

# **Appendix C - Case studies**

## A. Yusuf - physiotherapy during the acute admission

Yusuf was 15 years old when he was admitted to hospital. He was previously fit and well, enjoyed sport and was doing well at school. He lived at home with both parents and his siblings. The story below describes the pertinent parts of his physiotherapy assessment and intervention during the acute part of his rehabilitation.

## **Clinical history**

Yusuf had a basilar artery stroke, presented with GCS 7 after collapsing at home. An MRI scan showed acute thalamic and pontine infarcts. He was intubated and ventilated for 4 days on PICU before transferring to the neurosciences ward on day 7 of admission, with GCS 10 (visual 4, verbal 2, motor 4). He required a nasogastric tube for nutrition, hydration and medication due to an unsafe swallow.

## Time point: day 7 of admission

Initial assessment concentrated on ICF body structure and function. Muscle tone assessment (MAS and Tardieu) highlighted increased lower limb tone with strongly evident extensor patterning; in the upper limbs, spasticity was evident only in the biceps bilaterally. Voluntary movement was limited to Yusuf's eyes and head turn to the left only, with some emerging consistency using lateral eye movements to point to yes-no cards to communicate; verbal communication was limited to crying. Movement patterns and postures were observed at rest and during personal care; joint ROM and muscle length were recorded. The Wessex Head Injury Matrix was used in conjunction with the MDT to assess level of responsiveness. Assessment of sensation was difficult due to communication inconsistency, fatigue and level of responsiveness. Baseline FIM-FAM and RCS were completed.

Physiotherapy goals:

- For the family to understand the role of the physiotherapist
- Maintenance of muscle length and ROM
- Establish 24-hour positioning schedule

Physiotherapy intervention to support the goals above included:

- Time with family to explain the physiotherapy role within Yusuf's MDT and start to develop a family-centred relationship family had been given photos of MDT members to help them recognise the team and their roles
- Referral to orthotics for lower limb resting splints and liaison with OT for upper limb splinting
- Preparation of positioning photo chart (with parental consent) to manage lower limb extensor patterns including use of large T roll to flex, abduct and laterally rotate hips; hip flexion in side lying; use of his sleep system's lateral trunk supports when lying supine or supported sitting in bed
- Training parents to carry out gentle limb passive movements, building on their desire to be involved and contribute to Yusuf's rehabilitation
- Joint working with OT on Yusuf's sensory profile and stimulation parental advice given on stimulation with different textures, use of oil or moisturiser to massage skin

- Use of FES to maintain range of movement in the ankle family were taught how to use and given a regime to follow
- Liaison with MDT regarding timetable of team interventions including rest times

## Time point: week 5 of admission

By this point, Yusuf was consistently using eye-gaze technology for communication facilitated by SLT, and could supplement this with a head shake or nod. He had developed some asymmetrical active control of his lower limbs. Muscle tone had increased in his upper limbs; he could actively flex his right elbow and had some emerging finger flexion and extension. Yusuf had no abdominal muscle activity to assist with rolling; lack of activity also affected his bowel motility leading to episodes of constipation. Baclofen had been considered to help with the spasticity but not initiated due to the potential negative effects on his swallowing function and head control. He required supportive seating due to poor trunk control and adopted a chin poking posture and right sided trunk flexion.

Yusuf's goals were to:

- be independent in toileting
- stand up without help
- play on his X box
- propel his wheelchair
- speak rather than type or use eye-gaze
- eat again

The physiotherapists explained to Yusuf and his family that physiotherapy intervention would work towards these goals by working on his motor control and strength (ICF body structure and function) progressing from movement in bed to sitting and standing (ICF activity limitations). Due to Yusuf's age and height, physiotherapy sessions required three therapists for safe handling. Sessions were long to accommodate communication through eye-gaze technology and he had five sessions of physiotherapy per week. Clear instructions were given by one therapist with demonstration of movements, verbal and tactile prompts to assist movement.

Physiotherapy intervention to support the above goals included:

- Tilt table work, using weight bearing to offer stretch and increase muscle control through active knee relaxation and extension whilst standing, and increase trunk activation through assisted forward reaching
- Plinth work, including supine with chin tucked to flex upper cervical spine, assisted active rolling to activate abdominals, supported sitting on plinth during joint sessions with OT working on reach and upper limb movements
- Transfers to plinth with hoist and sling parent competencies completed
- Assisted active upper and lower limb movements, with exercise plan to continue with parents
- Application of FES in standing to a variety of muscle groups including trunk, upper and lower limbs parents were also trained to apply this to abdominals and back extensors prior to therapy sessions; FES bike was also used to activate lower limb movement
- Hydrotherapy to increase limb movement and trunk activation
- Continued use of orthotics and sleep system to support maintenance of postural alignment

The whole MDT met weekly to discuss progress and goals, and a weekly timetable was drawn up with Yusuf and his parents including hospital school, therapy, leisure and rest times. Yusuf's physiotherapists contributed to MDT discharge planning by referring to and liaising with the local community physiotherapy team and discussing whether referral to a specialist rehabilitation centre or bespoke locally commissioned rehabilitation package would be beneficial.

## Time point: week 12 of admission

Yusuf's fatigue had now improved and he could manage 45-minute sessions of physiotherapy, OT, SLT and psychology. He was able to use his right hand to type and with some assistance he could reach and grasp with two hands. His trunk control was improving and he could roll from supine to the right side without assistance by pulling on the side of the bed, assist with lying to sitting, and sit on the plinth with minimal trunk support with his feet flat on the floor. When in the tilt table Yusuf could bring his trunk forwards away from the supporting surface and maintain active knee extension. A PEG had been inserted as his swallow was still not safe.

Yusuf worked hard in sessions but was reluctant to spend time out of his room or go to the gym. The psychologist had a good relationship with him and Yusuf reported he felt that people were staring at him when he was out of his room. Yusuf's OT had sourced an adapted Xbox controller so he was able to game with his peers; eye-gaze technology gave him access to his peers through social media (ICF participation limitations). He was able to indicate when he needed the toilet, and was able to use a bottle for toileting, with assistance.

Yusuf's goals were now to:

- stand and step for transfers
- use a toilet independently
- walk independently
- go home

Physiotherapy intervention focused mainly on the ICF Activity and Participation domains to support the above goals and included:

- Sitting to standing work including transfers with assistance of three and practice moving from sitting on plinth to standing with another high plinth in front
- Supported standing with standing hoist
- Rotunda transfers with assistance of two and training nursing team and family members to use this for transfers on/off toilet, which meant Yusuf was practicing this multiple times per day
- Sitting balance work, including reaching around base of support, perturbation responses, anterior-posterior pelvic tilt control in sitting, unstable surface work on a balance cushion; sessions also included games in sitting to give opportunity to practice these skills, for example reaching to place a Connect 4 piece, balloon tennis, punching balloon
- Prone lying working on back and neck extensor strength
- Continued use of FES and FES bike
- Hydrotherapy to promote general strengthening, reciprocal stepping, balance in standing -Yusuf found this a fun activity with a positive effect on mood
- Continued use of lower limb splints for 24-hour postural management and during treatment

• A whole-body strengthening exercise programme was written for Yusuf, and his family were shown how to supervise this during evenings and weekends

Weekly hospital MDT meetings continued, with review of goals and adjustment of weekly programmes. Referrals had been made to local services for all therapy disciplines and the local teams were updated on progress at each monthly discharge planning meeting. Housing adaptations were underway following assessment by the social care OT, and an application had been made to the local education authority for statutory assessment. Wider family needs were also discussed, and the psychologist continued to meet with them regularly to help with the adjustment to their lives following Yusuf's ABI.

While Yusuf's goals included walking and going home, it was recognised that he would benefit from further intensive rehabilitation, outside of an acute hospital ward. He met the criteria for a placement at The Children's Trust and so plans were made for him to transfer there to continue his rehabilitation.

### B. Jack - return to sport

### **Clinical history**

Jack, a 12-year-old boy, sustained a left sided traumatic subarachnoid haemorrhage (tSAH) and left parietotemporal fracture following a road traffic accident, bike vs bus; Jack was not wearing a helmet. His initial GCS was 14, dropping to 4 during initial medical assessment. He was intubated and transferred to his nearest major trauma centre. He was admitted to critical care and was managed conservatively by neurosurgery; extubation the following day was uneventful. An MRI head scan four days after injury confirmed the initial CT head scan findings of tSAH and skull fracture; there was no evidence of diffuse axonal injury.

### Time point: day 5 of admission

The inpatient physiotherapy team assessed Jack. Tone, active range of movement, power, sensation, proprioception and coordination were all normal. Jack was mobile on the ward with distant supervision, with a steady reciprocal gait. Jack made good physical progress and on balance assessment using the Pediatric Balance Scale (an adapted version of the Berg Balance Scale) he had only mild deficits, scoring 53/56. Challenges identified through assessment were standing on one leg at a time for longer than five seconds, standing with one foot in front of the other on a line, and he was slow when turning through 360°. Prior to discharge Jack and his parents were provided with a leaflet describing daily balance exercises and advice was given about who to contact if there were any concerns following discharge.

### Time point: six months after discharge

Jack attended an ABI clinic review six months later. At the appointment he told the paediatric neurologist that he had not gone back to playing local club football and cricket yet and was missing joining in with his friends. He got tired moving around school during lesson changes and when walking to or from school along a main road. He said that he participated in parts of PE, including warm up drills, however he no longer enjoyed the lessons and would often 'forget his kit'. On further questioning the paediatric neurologist identified that Jack still found standing with one foot in front of the other and balancing on one leg difficult. Jack also reported dizziness and mild headaches on

sudden head movements, looking up and running. Jack said he was frustrated at not being back at his usual levels of activity but was also keen to avoid running or sudden movements which made him feel dizzy. These difficulties identified at the ICF impairment level had a direct impact on Jack's participation in PE and extracurricular sports.

Jack was referred to outpatient physiotherapy by the paediatric neurologist following the ABI clinic; he was also referred to the vestibular clinic regarding his continued presentation of dizziness. Following physiotherapy assessment and liaison with the vestibular clinic, intervention focused on supporting Jack to move his head in all directions, reduce dizziness and improving his balance (ICF - body structures and function), facilitating Jack's return to more complex activities (ICF - activity) and a graded return to sport (ICF – participation). The following represent some of the education and interventions which were delivered:

- Education and advice around fatigue management, pacing and graded return to exercise, and provision of a diary for monitoring patterns and achievements
- General conditioning work strength plus exercise tolerance, including a home exercise program which could be built into PE lessons too
- Progressive difficulty of challenge slow to fast movement; unidirectional movement to
  multidirectional plus frequency of changing direction; simple to complex context (noise, visual
  stimuli, other people); working at different heights (e.g. standing to crouching); stable to
  unstable surface; simple instructions/drills to more complex instruction/drills (e.g. several
  components); shorter to longer sessions; training to match conditions
- Goal setting, including participating in a cricket tournament and preparing for the next football season
- Advice to school PE teacher and cricket/football coaches specific drills and activities to work on, brain injury education, advice on symptom management and what to look out for, ways to involve Jack in sessions to maintain social and peer contacts even on reduced activity levels
- Psychoeducation raising Jack's awareness of abilities and areas of need, empowering him in self-management and self-advocacy, promoting motivation, support to address fears/concerns and a referral on to clinical psychology
- Health promotion on long-term benefits of exercise and activity including wearing a helmet when on his bike

Jack made good progress and three months later was discharged from physiotherapy as he made significant progress, was participating in school PE, cricket and football clubs although he was not yet back to playing full cricket matches. A clear plan was in place to support his ongoing return to cricket and Jack, his family and club coaches were happy to monitor this. They were encouraged to contact the physiotherapist if problems arose with the plan, and the family were confident that Jack could be referred back to physiotherapy in the future through further ABI clinic reviews.

## C. Sophie - early years intervention

## **Clinical history**

Sophie is a 3-year-old child who had a spontaneous pontine haemorrhage and right parieto- occipital infarct at 13 months of age. Right-sided tone and movement changes were noted during admission,

and she was diagnosed with a left hemianopia. She developed hydrocephalus and required a VP shunt insertion. and stayed in hospital for three months before being discharged home with input from community therapists. Sophie was previously fit and well with normal developmental milestones, proficient in crawling and able to cruise, stand and take some steps independently.

## Time point: 2 years after injury, start of nursery year

Sophie was reviewed by her community physiotherapy team as part of their early years programme. She presented with a right hemiplegia with increased tone affecting her trunk and right upper and lower limbs, and left facial weakness with 5<sup>th</sup>, 6<sup>th</sup> and 7<sup>th</sup> cranial nerve palsies. Sophie wore a right AFO and a protective helmet as she frequently bumped into furniture due to her hemianopia and reduced spatial awareness. She was able to sit independently and had started to use her right arm to save herself when her balance was challenged. She moved around the floor with a modified crawl, with her right hand held in a fist with elbow flexion. She was able to pull herself to stand at a sofa or low table. When standing at the low table, she was unable to cruise, bearing weight mainly through her left leg and resisting shifting weight over to the right.

Sophie was highly motivated to play but struggled with bimanual tasks due to visual impairment and increased tone in her right arm and hand. She tended to neglect her right arm (learned non use) and used her left to play, adopting compensatory strategies to achieve a task and becoming frustrated if the compensation was unsuccessful. She had good cognitive and social skills during play and was able to plan, problem solve, share and enjoy success.

She attended a playgroup for children with visual impairment and had started to attend nursery in the mornings.

Joint goal setting and collaboration with other members of Sophie's MDT including her mum, occupational therapist, teacher for children with visual impairment and nursery staff was imperative to ensure goals were addressed by the whole team, encouraging practice and repetition in different contexts.

Sophie's mum wanted her to be able to:

- Use a walker for short distances indoors safely by end of Reception class at school
- Have means to be independently mobile around her home and community
- Play using both hands to hold and manipulate a toy
- Dress and undress herself for PE classes by end of Reception class
- Hold a book and turn a page
- Climb stairs safely and independently
- Access the local soft play centre, using all slides, tunnels and stairs without assistance

Assessments included those around ICF domains of body structure/function and activity, and included range of movement with CPIP, modified Tardieu for tone, PEDI-CAT, AHA and video analysis to look at movement quality.

Physiotherapy intervention to support the goals above was targeted to include all domains of the ICF and included:

- Weight bearing activities to promote lateral weight shift to the right, progressing to stepping with left foot, and then to standing and assisted stepping with a walker
- Use of standing frame in nursery and home to during play e.g. painting at easel, water or sand play
- Right-hand splint for overnight immobilisation to provide passive prolonged stretch.
- Modified constraint induced movement therapy (mCIMT) to improve right upper limb active movement and function, in collaboration with Sophie's OT
- Tone management assessment for Botulinum Toxin-A injections for right hand/biceps to improve posture for crawling, and right gastrocnemius to improve balance and weight transfer
- Assessment for daytime lycra splint to improve body awareness and function during activity and continued monitoring for orthotic requirements
- Discussion with Sophie's mum and education about independent mobility, consideration of Wizzy Bug early powered chair to support Sophie's independence in play, socialisation and cognition while still learning to stand and walk
- Close liaison with Sophie's OT regarding daily activities including eating, drinking, dressing, toileting and transfers, to promote as much independence as possible
- Assessment in the nursery included access, transfers and mobility around the environment
- Intervention in the nursery included training for nursery staff on their role in Sophie's ongoing rehabilitation and development
- Context-specific interventions included a therapy session at the local soft play centre where ideas for progressing independence were shared; this helped to increase Sophie's mum's confidence within different settings, increasing Sophie's opportunities to meet with and play alongside her peers.

A request for statutory assessment of educational need was made to establish if Sophie met the criteria for early years support in the nursery setting, and in preparation for starting Reception class. Her physiotherapist contributed a report to support this, in line with local policy. Progress of therapy goals was monitored through profession-specific sessions and MDT meetings, and these were adjusted over time to accommodate progress and emerging needs. By the Spring of Sophie's nursery year, the nursery staff were proficient with including her in all activities, and she was joining in more social activities with her peers outside of the nursery setting.

Plans were made for the physiotherapy team to reactivate Sophie's intervention in preparation for transition to Reception class, and a home programme was set up for her mum to continue with her. Sophie's mum felt motivated to continue this and was happy to manage things alongside the nursery team for the second half of the nursery year. Sophie's mum knew that she could contact the physiotherapy team at any time, and that future physiotherapy plans would include packages of intervention to address specific needs at any one point in time. Nursery staff were also confident to continue Sophie's rehabilitation through the educational setting and were planning to start liaison with the primary school as soon as the place was confirmed, enabling Sophie to achieve her goals and be an active participant in all aspects of her life.

# **Appendix D - Third-sector organisations**

Third-sector organisations provide excellent information and support for children and families after ABI. Please take time to explore the resources and support options to which you can direct families, schools or other professionals. The list is not exhaustive and APCP does not endorse these organisations specifically.

Organisation	Website	
Brain Tumour Charity	www.braintumourcharity.org	
Cerebra	www.cerebra.org.uk	
Child Brain Injury Trust	www.childbraininjurytrust.org.uk	
The Children's Trust (Tadworth)	www.thechildrenstrust.org.uk	
The Encephalitis Society	www.encephalitis.info	
Headway	www.headway.org.uk	
Little Brains Trust	www.brainstrust.org.uk/little-brainstrust/	
Macmillan Cancer Support	www.macmillan.org.uk	
Meningitis Now	www.meningitisnow.org	
Stroke Association, Childhood Stroke Project	www.stroke.org.uk/childhood-stroke	
Teenage Cancer Trust	www.teenagecancertrust.org	
Young Epilepsy	www.youngepilepsy.org.uk	
Young Lives vs Cancer	www.younglivesvscancer.org.uk	

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Dedicated to the children, young people and families with ABI who have inspired us through their tenacity and courage.