2017

Guidance for Paediatric Physiotherapists Managing Childhood Onset Spinal Cord Injuries

Written and compiled by the APCP Neurodisability Committee

Contents

Where the document refers to 'child' throughout, this means child or young person (CYP)

Spinal Cord Injuries (SCI) in Children

Introduction

This document recommends good practice in the management of **childhood (0-18 years) onset spinal cord injury (SCI),** traumatic (i.e. following injury) and non-traumatic (i.e. transverse myelitis, spinal tumour, spinal infarct). It is based on clinical knowledge and experience, as well as current research in SCI and recognised child SCI literature

The models of management may also be appropriate for some congenital cord injury i.e. spina bifida. Clinicians should however be mindful of the limitations associated with hydrocephalous and anencephaly.

The intention of this document is to create a learning resource for the physiotherapy assessment and management of children and young people with SCI. This guidance is not intended to replace other standards and learning resources for SCI, it is not a prescription to practice and does not cover the entire scope of MDT involvement. This document should be used in conjunction with all other learning resources and professional guidance such as the APCP (Association of Paediatric Chartered Physiotherapists) Working with Children Document 2016

The document is divided into foundation knowledge and more advanced knowledge. Both are relevant to physiotherapists; the foundation module being aimed at both community paediatric clinicians and those in tertiary centres. The advanced module is aimed at tertiary centres referring on to specialist SCI centres experienced in the care of children after acute SCI diagnosis.

Considerations for childhood onset SCI:

Age at injury is significantly related to deformity management and age appropriate function/function acquisition. 100% of children injured with a SCI < 5 years will develop some level of deformity as they grow/develop. (Parent 2010, Mulcahey et al 2013, Betz & Herndon 2014)

Every child with a SCI should be encouraged and supported to lead a fulfilling life; most regular life events can be experienced with a SCI and this should always be encouraged and facilitated. The International Classification of Functioning, Disability and Health (ICF) is a framework for describing and organising information on functioning and disability. It provides a standard language and a conceptual basis for the definition and measurement of health and disability and familiarity with this can help guide physiotherapy goal setting around issues concerning function and participation.

Red flags: SCI should be considered with progressive neurological symptoms unrelated to brain injury, unexplained persistent low back pain with change in neurology, unexplained respiratory deterioration and/or urinary retention

Benchmarking: Normal life milestones should be expected of the child living with a SCI. This would include attendance at mainstream school and meeting peer academic and developmental milestones

	Foundation Module	Advanced Module
Initial Management and Referral to Specialist Services	Every child living with a SCI should be under the direct care of a spinal cord injury specialist service experienced in the on-going management of the child with SCI. "Standards for children and young people (<19 yrs.) requiring SCI care". Found in the document store of www.spinalcordinjury.nhs.uk Incidence of children with SCI is low (Parent S et al, 2011). There is no UK incidence data but it is estimated that approx. 60 children/year under 14 yrs. suffer an acute SCI. (Augutis M et al 2006). Best practice dictates they should be referred to a SCI centre able to manage the lifelong needs of SCI and the unique needs of the child with SCI. (Standards for children and young people requiring SCI care) Higher functional, educational and social outcomes have been shown to result with specific group peer delivered rehabilitation therapy. Referral to a specialist centre can occur at any time after diagnosis but it is highly recommended this occurs at the time of diagnosis; this will help minimise the known secondary complications associated with childhood onset SCI. If the child is already supported by a SCI centre, it is highly recommended that physiotherapists make contact with the SCI centre physiotherapy team for advice on the individualised management and on-going care of the child they are responsible for. The child with SCI under the care of a SCI centre will be reviewed every 6-12 months throughout their childhood and their care tailored accordingly.	Please refer to document; "The Management of Children with SCI, Advice for Major Trauma Networks and SCI Centres, on the Development of Joint Protocols, With Advice for Clinicians in Acute Hospitals". Found in the document store of www.spinalcordinjury.nhs.uk This document covers numerous clinical aspects for the acute care of the child with SCI including: • Initial Patient Assessment • Spinal Shock • Airway and Cervical Spine Control • Breathing, Ventilation and Weaning • Circulation • Neurological Assessment • Steroid Therapy • Handling The Child With a Spinal Cord Injury • Imaging • Deep Venous Thrombosis • Skin • Paralytic Ileus • Stress Ulceration • Bladder • Bowel • Spinal Surgery • Anaesthesia • Autonomic Dysreflexia • Transfer to the Spinal Centre including transfer checklist The following information will help guide the treating physiotherapist to the most usual acute areas of care experienced by the child with SCI and aims to help highlight areas of further learning in the topics they are not familiar with.

	The UK spinal centres can also offer help and advice about the referral process if the child is not under the care of a SCI centre. Alternatively make contact with the APCP Neurodisability Committee Spinal Cord Injury Representative via the APCP website – they can also offer help and advice regards the referral process. **Referral to a specialist SCI centre – England:** Acute children's services can refer the acute/newly diagnosed child via the NHS England spinal injury referral portal, any healthcare practitioner can complete the forms found in the referral portal – www.spinalcordinjury.nhs.uk **Referral to a specialist SCI centre for NON-ACUTE SCI in England and referral for all other areas in the UK i.e. Scottish/ Irish/N. Ireland/ Welsh children with SCI**: Referral is via medical to medical referral, i.e. paediatrician/ GP/ oncologist, to the lead consultant at the relevant spinal injury centre. **NB: Not all spinal cord injury centres in the UK are able to admit children**. In the UK, the National Spinal Injury Centre (Stoke Mandeville Hospital) houses the only child specific spinal cord injury ward. Most spinal injury centres manage their children in the host Trust's children's ward until the age of 16 years (with support provided by the Trust Spinal Injury Centre during this period). After the age of 16 years the young person will be managed via the Spinal Injury Centre. **ENGLAND – spinal centre details:** Specialised health care services for the management of spinal cord injury is provided in the eight specialist centres in England, offering support for patients sustaining spinal cord injury through the initial period of treatment and	**Spinal shock** - In the acute stage there may be total, flaccid paralysis of all skeletal muscle and loss of all spinal reflexes below the level of the lesion. This is referred to as spinal shock. It may last from several hours to several weeks depending on the severity. The return of the bulbo-spongiosus (previously referred to as the bulbo-cavernosus) reflex denotes the end of the spinal shock period. The physiotherapist should be mindful of this period and when it lifts, as incomplete neurological function may be noted after this period. **Paralytic ileus** is common during spinal shock. There is a risk of vomiting/aspiration. Paralytic Ileus usually occurs immediately in thoraco-lumbar injuries but can be delayed for anything up to 48 hours in cervical injuries. Abdominal distension may impede breathing by splinting the diaphragms and also compromising respiratory management. Gastric dilatation may occur even if bowel sounds are present. The physiotherapist should be mindful of this period as this will affect the respiratory management that is delivered. **Hypercalcemia** - is a condition during which the calcium level in the blood is above normal due to increased bone reabsorption following immobilisation. Hypercalcemia occurs in 10 - 23% SCI – mostly adolescent males during first 3 months after injury (Vogel 1997). Signs include abdominal pain, nausea, vomiting, malaise, polyuria, polydipsia, dehydration, fever and lethargy. Management of hypercalcemia - encourage oral fluids, IV fluids, bisphosphonate, and weight bearing activities to encourage calcium to stay in the long bones – for the physiotherapist this may include leg cycling or standing activities. **Heterotopic Ossification** - The incidence of heterotopic ossification in children with SCI is rare, approximately 3% compared with approximately 20% in adults with SCI (Vogel 1997). The average onset is 14 months after injury

	rehabilitation and on-going lifelong support. **Duke of Cornwall Spinal Treatment Centre** Salisbury District Hospital, Oddstock, Salisbury. Tel: 01722 336262. Paediatric Service: Unable to admit under 16 years **Golden Jubilee Spinal Cord Injuries Centre** James Cook University Hospital, Middlesbrough. Tel: 01642 850850 Paediatric Service: All ages of children and young people admitted for initial management and on-going rehabilitation on the children's ward. **London Spinal Cord Injuries Centre** Royal National Orthopaedic Hospital NHS Trust, Stanmore. Tel: 020 8954 2300 Paediatric Service: All ages of children and young people admitted for initial management and on-going rehabilitation on the children's ward **Mersey Regional Spinal Injuries Centre** Southport & Formby Hospital, Southport. Tel: 01704 547471. Paediatric Service: All ages of children and young people admitted for initial and on-going rehabilitation on the children's ward **Midlands Centre for Spinal Injuries** Robert Jones & Agnes Hunt Orthopaedic Hospital, Oswestry. Tel: 01691 404655. Paediatric Service: Most children and young people can be admitted for initial and on-going rehabilitation on the children's ward. Do not admit ventilated children. **National Spinal Injuries Centre** Stoke Mandeville Hospital, Mandeville Road Aylesbury HP21 8AL. Paediatric Service: Via St Francis Ward 01296 315805. All ages (0-18 yrs.) of children and young people admitted for initial and on-going rehabilitation in dedicated SCI children and young person's ward.	for children and adolescents with SCI compared to 1-4 months after injury in adults (Betz R, Herdon H, 2014). If heterotopic ossification is suspected (either by a change in end feel of joint range – often termed 'spongy' – or via radiographic imaging) then care with passive movements and ranging is required to maintain as much range of motion as possible but not promote further bone formation via aggressive pressure end of range. The physiotherapist is often the first person to identify the presence of heterotopic ossification. **Skin Management** – see description in Foundation Module. **Acute Outreach Support:** After referral of the child into the SCI data base, the acute outreach liaison staff from the link specialist SCI centre can liaise with the team providing care during the acute phase and/or provide a support visit to help support areas of acute care management. The Spinal Injuries Association (SIA) can also provide help and advice via their SCI nurse team. (SIA contact details can be found in the Resources section at the end of this document). This team is vital for the child who is NOT referred on to specialist services.

	Princess Royal Spinal Injuries Centre Northern General Hospital, Sheffield. Tel: 0114 2715644. Paediatric Service: Children under 16 years admitted to Sheffield Children's Hospital and the spinal injury centre offer advice and support. Over 16 years. admitted to the spinal injury centre. **Yorkshire Regional Spinal Injuries Centre** Pinderfields General Hospital, Wakefield. Tel: 0844 8118110. Paediatric Service: children under 16 years managed in the children's ward (Gate 46) and over 16 years via the spinal injury centre. **SCOTLAND:** **Queen Elizabeth National Spinal Injuries Centre** Queen Elizabeth University Hospital, Govan Road, Glasgow, UK, G51 4TF. Tel: 0141 201 2555. Children under 14 years treated on children's ward, over 14 years at the spinal injury centre. **WALES:** **Welsh Spinal Injuries and Neurological Rehabilitation Centre** Rookwood Hospital, Cardiff CF5 2YN, Tel: 029 2031 3732 and 029 2031 3833. Paediatric Services: via The Noah's Ark Children's Hospital based at Heath Hospital, over 16 years at the spinal injury centre. **NORTHERN IRELAND:** **The Spinal Cord Injuries Centre** Musgrave Park Hospital, Belfast BT9 7JB, Telephone: 02890903041. Children under 14 years treated at Belfast Children's Hospital, over 14 years at the spinal injury centre. **REPUBLIC OF IRELAND:** **The National Rehabilitation Hospital** Rochestown Avenue, Dun Laoghaire, Co Dublin, Telephone: 003 531 2355000. Paediatric Service: via St Agnes children's rehabilitation ward. Over 16 years at the spinal injury centre.	

Determining level and incompleteness of SCI	SCI is determined via assessment using the ISNCSCI scale (International Standards for Neurological Classification of Spinal Cord Injury) to determine the neurological impairment. This assessment is generally (but not uniquely) performed by a medical practitioner (or anyone trained in the assessment procedure). Online learning is available here. ISNCSCI online algorithm calculators can also be found on the website which can be useful in determining the impairment classification. The ISNCSCI assessment will determine the: • Neurological level. This is a descriptor of the last fully functioning area of the cord i.e. C6 = neurological function at the level of the 6th cervical nerve in the neck. NB the level of damage/injury and neurological level may be different. Typically the neurological level is the descriptive term used. However the last level of intact function may be hard to accurately assess in the young child and as such often the child is initially described by the level of damage to the cord/ vertebrae/ level of surgery and later by neurological level. • Incompleteness of injury (how much preservation of function is intact below the neurological level). This is described as a letter: A= Complete lesion (no function below the level of injury), B= Incomplete sensory sparing but no motor function (sensation requires to extend through the sacral segments S4-S5), C= Incomplete motor function below the neurological level. This reflects key muscles grade 3 or less but other criteria apply (see guidance on the assessment proforma), D= Incomplete motor function below the neurological level in the majority of key muscles (grade 4 or above), E= Motor and sensory function are normal.	

	• If the neurological presentation is best described by a SCI syndrome. Please see information on the ASIA website for more detail. Recent work with children showed that the ISNCSCI motor and sensory scores can be obtained in children as young as 6 years of age with moderate to strong reliability (Mulcahey et al 2007 & 2011). Despite the potential limitations of the ISNCSCI its use is recommended for children over 6 years. For children younger than 6 years, observational motor assessment may facilitate the assessment of muscle strength and motor activity (Calhoun et al 2009). The WeeSTeP incorporates the paediatric considerations for the assessment of the child with SCI and is recommended when performing the ISNCSCI examination on children. WeeSTeP is also freely available on the ASIA website. **Secondary pathologies** and underlying conditions will also affect the outcome and prognosis of the SCI. It is not unusual to treat childhood onset SCI with secondary pathology. Some childhood pathologies are predisposed to the development of a SCI and some childhood pathologies will undergo necessary spinal surgery that may result in the development of neurological loss. **Dual diagnosis** can also be apparent in the child with trauma i.e. ABI and SCI. More usually the more significant trauma will lead rehabilitation outcomes and the choice of specialist service involvement. More normally SCI is not a condition that deteriorates over time, however secondary pathologies may impact this	

Autonomic Dysreflexia (AD):	This is a life-threatening condition associated with SCI. All children who are at risk of Autonomic Dysreflexia (AD) and under the care of SCI specialist services will know about the condition, how susceptible they are, what their symptoms are and how to manage these symptoms (or their care giver will if they are very young). **AD is NOT a reason to exclude a child from day to day activities** and should be considered similar to the child with allergies or diabetes – both of which can result in an acute medical incident if not managed appropriately. AD is reported to occur in 40-70% of adults with an SCI at or above the level of T6 (6th thoracic vertebrae) (Karlsson 2006). The syndrome occurs as a result of uncontrolled reflex sympathetic activity below the level of injury and a parasympathetic response above the level of injury. An AD episode will occur when there is a painful or irritating stimulus below the level of the injury (e.g. blocked catheter, full rectum, tight clothing or orthotics). This produces sensory impulses which ascend the spinal cord but are blocked at the level of injury, causing a mass sympathetic response below the level of injury (vasoconstriction resulting in increased BP). In response to this rise in BP, the cardiovascular centre in the medulla oblongata sends out parasympathetic impulses via the vagus nerve that decreases heart rate and causes vasodilation above the level of injury. The symptoms of AD are: Pounding headache, flushing and blotching of the skin above the injury, nasal congestion and pale, cold skin below the injury. Untreated this can lead to stroke or cardiac arrest and therefore must be dealt with as an emergency. The young child may not be able to express or describe these symptoms and as such **an awareness of normal BP for the child with SCI should be known so changes can be noted**. **A**	

	rise of 15 mmHg above the baseline for the child with SCI under 13 years or over 20 mmHg for the child with SCI over 13 years old may be a sign of AD. The unusually grizzly and irritable young child should also be considered as potentially suffering from AD and appropriate checks made. **Management of AD:** The patient should be sat up to drop blood pressure and checks of bowel, bladder and skin made. Essentially, to treat autonomic dysreflexia the irritating stimulus must be rapidly identified and removed. If a painful stimulus cannot be immediately corrected, is delayed or cause cannot be traced, an appropriate dose of sublingual Nifedipine should be given to reduce a prolonged raised blood pressure and medical help sought. For further information contact your link SCI centre. AD alert cards can be obtained via the Spinal Injuries Association. (See Contacts at the end of this document). Additionally individuals with SCI can be registered on a medical profile (see alert services addresses in Resource section at the end of this document). The physiotherapist plays a role in helping the child and family understand what may induce AD during daily activities and how to manage the condition if this occurs. AD symptoms may also occur during therapeutic activities that cause discomfort e.g. stretching tight muscles; in this instance the physiotherapist will need to be aware who is susceptible to AD and why in order to tailor treatment accordingly.	

Skin and Pressure Areas	The risk of developing a skin insult e.g. non-blanching pressure areas or pressure ulcers following SCI is extremely high due to:- • Lack of sensation below the level of injury – the patient is unaware that there may be a problem (includes awareness of pressure and temperature) • Lack of muscle activity below the level of injury – resulting in a reduced ability to move away from/off pressure areas. • Impaired circulation below the level of injury – reducing amount of oxygen to the skin • Poikilothermia- the inability to regulate body temperature A pressure ulcer will delay mobilisation and may later limit functional attainment while the area heals; this will result in a permanently vulnerable scar. The risk to formation of pressure areas is a lifelong complication following spinal cord injury. In children, pressure ulcers may develop due to pressure from equipment such as orthosis/splints as well as toys which may get lost or forgotten in the bed or on the wheelchair cushion. Regions of the body that are prone to pressure area formation (below the level of injury) include bony prominences i.e. heels, sacrum, occiput, shoulder blades, elbows, pelvis, greater trochanters. The risks of developing pressure areas and how to minimise their formation should be reiterated to children and families once established in the community to support the education received during rehabilitation. Knowledge of vulnerable areas and how to position the child to prevent formation is essential as well as education to perform regular skin checks of vulnerable areas. Skin checks are recommended first thing in the morning prior to dressing and in the evening in bed after the day's activities as well as	

	following any insult to the skin caused by activity during the day. It is also important to establish the reason for pressure areas to minimise this over time. Always remember the child is changing and growing; a pressure area that occurs out of the blue is likely to suggest something has changed in the child's routine or their shape or ability has changed i.e. growth or postural deterioration/ contracture development. In the acute stages of care the child will be turned in bed safely and regularly to relieve pressure on the dependent area. Over time the turning regimes are progressed to increase skin tolerance time until the individuals turning regime for home/discharge is established i.e. 6 hourly turns in bed overnight. **It is absolutely contra-indicated for a SCI individual to sit / lay / maintain pressure on a non-blanching or open pressure ulcer.** Once discharged home, advice and information can be provided, to the child/family or attending healthcare professional, either via the link spinal injury centre or charities such as the Spinal Injuries Association. (see Contacts at the end of this document) Aspects of physiotherapy management for skin will be targeted at functional movements (when functional potential allows) as part of pressure care and skin care management. Movements such as actively rolling side to side, prone lying, forward leaning in sitting or side to side lean in sitting as well as correct postural alignment in sitting and in bed will all become part of pressure care management. Children will, regardless of level of injury, take part in visual inspection of the skin (observing for skin insult or injury) using mirrors and assistance when required (becoming verbally independent in their care if not physically able to be independent) and may need physiotherapy to achieve functional movements and to reinforce	

	knowledge to facilitate this (i.e. rolling, prone lying and dynamic movements in sitting). Lifting in the wheelchair using the upper limbs (to relieve pressure under the ischial areas) is NOT recommended due to the long term impact on weight bearing through the upper limbs. Forward leaning in sitting or side to side lean in sitting is recommended as an alternative.	
Respiratory	**The respiratory assessment** - All of your current physiotherapy skills are relevant to this type of assessment. More generally the child with SCI will have normal lungs but the mechanics/ neurological ability to inhale/ exhale and/ or cough may be impaired. Monitoring of respiratory function in the acute stages is vital – especially if the child with neurological signs has not yet received a formal diagnosis. The respiratory assessments performed by the physiotherapist may be the first indicator of acute deterioration For the child with SCI, respiratory strength training is an essential aspect of physiotherapy management to maintain respiratory function. Knowledge of normal vital capacity for varying ages/ heights of children is essential as well as the ability to record and monitor this with a spirometer. Children with injury at C2 or higher will have no function of the diaphragm or intercostal or abdominal muscles; neck muscles may also be weak or non-functional. In this instance respiration will need to be supported 24 hours a day. For further standards in the management of the child requiring domiciliary ventilation please refer to Appendix to: Standards of care for Spinal Cord Injured children and young people (0-19 yrs.) 'Children requiring domiciliary/long term ventilation' found in guideline folder of http://www.spinalcordinjury.nhs.uk/	In the acute phase of care, for the child with an undetermined presentation of neurological weakness, the respiratory skills and knowledge of the physiotherapist are essential. Creeping respiratory deterioration may be the first indicator of an ascending cord injury or the presence of a non-traumatic spinal cord injury i.e. transverse myelitis or Guillain-Barre syndrome.

	Children with injuries at C3-C4 may have partial function of their respiratory musculature which may mean they have potential to sustain unsupported respiration while awake but not asleep. Weaning from the ventilator may be possible for some children with high tetraplegia especially those who have a C4 level of motor function. Weaning should start when the child is medically stable and can tolerate rehabilitation in a seated position. Initial weaning should not occur during therapies/ activities that require more energy and endurance than resting in bed or wheelchair. Children with injuries at C5 and below, despite having full use of their diaphragm, may struggle with respiration in the acute phase of their care due to lack of other secondary respiratory muscle groups i.e. intercostals and abdominals and/or other related trauma to the thorax. Respiratory strength training is an essential component to their rehabilitation to maximise their residual respiratory function. As weaning for SCI is a form of muscle strengthening it must follow general principles of exercise to gradually build strength with appropriate monitoring of vital signs; the physiotherapist's skills are ideally placed to support this need. For advise on how to commence or carry out a weaning programme contact your local link SCI centre. Phrenic or diaphragm pacers may also be used but are still not widely available for those children requiring full time ventilation. (Onders et al 2011). Children with injuries at or above T6 will have full diaphragm function and intercostal function but will not have intact abdominals (required to affect a full strength cough). These children will require help and support to increase their vital capacity to compensate their cough strength as well as advice on performing, or assistance to provide, 'manual assisted coughs' to replicate the action of the lost abdominals.	

	In the acute phase the physiotherapist should be mindful of fractured ribs and paralytic ileus when considering the use of manual assisted coughs. Performing manual assisted coughs on the very young child/ infant may also not be indicated due to the risks of abdominal trauma. In this instance, abdominal support/bracing and/ or positioning as well as mechanical assisted cough devices may be more appropriate under the guidance of the local respiratory team and/ or SCI centre. For manual assisted cough techniques contact your link SCI centre or refer to respiratory chapter in Ida Bromley, '*Tetraplegia and paraplegia a guide for physiotherapists'*, Churchill and Livingstone **Things to consider include:** • Respiratory capacity related to the child's age/ height and neurological function – what can they achieve versus what would you expect of a child of similar age and height. • Ability to cough (NB if abdominals are impaired so will be their ability to cough). The measurement of cough strength is useful to monitor change. Secretion clearance may be difficult without cough strength. • Limitations caused by possible rib fractures caused at the time of injury as well as paralytic ileus. • Teaching assisted coughs' (without equipment i.e. manually / via attendant) and with the use of equipment i.e. cough assist device. • The greater the vital capacity the greater the child's ability to clear secretions with or without abdominal ability therefore respiratory muscle training is essential. • The impact on deformity (especially in the trunk e.g. scoliosis) to current and future respiratory function and management.	

Range of movement, 24 hour positioning and use of orthoses	**Measuring joint range of motion** - All of your current physiotherapy skills are relevant to this type of assessment. The younger a child is injured and the more asymmetrical their preserved neurological function the more potential they have to develop deformity and contracture. Limitations of as little as 5° will magnify enormously with growth and should be prevented wherever possible with positioning and orthotic regimes to maintain flexibility. Knowledge of normal joint range is therefore essential as well as the ability to measure and record accurately with a goniometer. In the very acute phase of care (when handling limbs during joint management), the physiotherapist should be mindful of areas of swelling, bruising and skin insult. The physiotherapists may be the first to note secondary areas of trauma when the focus remains on the spine trauma in the first hours or days following injury. Certain levels of SCI will develop known and typical contracture and deformity over time due to the child's level of preserved function. There are specific tricks and styles of functioning specific to the neurological losses acquired by SCI that require the fullest joint range of motion. Loss of joint range will adversely affect functional gains Hypermobility may also need to be managed. Certain levels of SCI will develop known and typical joint hypermobility which over time will impact on the stability of the skeleton (limiting or preventing future functional attainment). Referral on to a spinal centre with experience treating the child with SCI will help you monitor and maintain joint range of motion. **Hip dislocation, subluxation and contractures** are extremely common in the child growing with SCI especially among children injured at younger ages (Betz & Herndon 2014). Leading to complications with posture, seating and skin management as well as functional	

	attainment. Because of this high incidence an aggressive prevention approach is recommended; including soft tissue stretching, control of spasticity, prophylactic hip abduction, a standing programme and sleeping prone. Referral on to a spinal centre with experience treating the child with SCI will help you monitor and limit this. The prevalence of **neuromuscular scoliosis** in childhood onset SCI is high, especially when an injury occurs in a younger patient. Scoliosis will lead to complications with posture, seating, skin management, respiration, digestion and functional attainment of skill. Age at injury has been reported as the single predictive factor of scoliosis in children with SCI. (Mulcahey 2013). Scoliosis will also predispose the child to the development of hip subluxation. Because of this high incidence an aggressive prevention/ prophylactic approach is taken including stretches, control of spasticity, the use of orthoses, a standing programme and sleeping prone. Referral on to a spinal centre with experience treating the child with SCI will help you monitor and maintain this **Splinting and the use of orthoses** – Use of orthoses are based on age and level of injury, medical status and social issues. Abdominal bracing, is specific to childhood onset SCI and can be different to other types of childhood scoliosis management. Referral to an orthotics service used to managing the ongoing needs of the child with SCI is essential (if not found locally contact with your link SCI unit will help you source an appropriately experienced orthotic service). Abdominal bracing for the child with SCI has been proven to slow down the development of curvature and maintain the flexibility of the spinal column (Mehta et al, 2004), this allows any potential surgical input to be postponed until skeletal maturity is achieved or at least significant spinal column growth has been achieved.	

	Abdominal bracing is indicated for the child with SCI who does not have full complement of neurology intact in the trunk and is commenced when upright sitting starts (prior to deformity manifestation). The physiotherapist's skills of assessment and seating will complement the assessment and need for orthotic intervention. Other areas of muscle asymmetry or lack of muscular control below the level of injury should also be considered for orthotic support (refer to equipment section for a list of common orthotic provision following SCI). **Postural management** - All of your current skills are relevant to this type of assessment. Early postural prophylactic intervention is indicated for the child with SCI. **Standing:** It is the sitting posture that is felt to be contributory to the development of deformity in the child with SCI therefore upright weight bearing/standing is a highly recommended and a significant part of the child with SCI's postural management programme. The aim is to provide as much standing as the child would have received prior to the SCI. This upright loading of the skeleton will also aid skeletal development (particularly of the hip joints) and the laying down of bone density, which will impact postural management and prevention of long bone fractures as the child ages into and beyond adulthood. Studies have demonstrated daily standing for more than 1 hour a day 5 days a week maintained bone density in comparison to children who did not perform standing. (Alekna et al 2008). Weight bearing in the late teenage years has also been shown to be a key period for bone growth (McCormack et al 2017). Dependent on the level of absent neurology, the child with SCI is recommended to stand in a full supportive orthosis (supporting trunk and lower limbs), especially if injured pre adolescence. E.g. in a full calliper and	

	brace set- thoraco-lumbo-sacro-hip-kne ankle-foot orthosis (TLSKAFO). This will help contain and control the weight bearing skeleton especially the hip joint position and will enable specific anatomical positioning on every application regardless of the extent of activity performed by the child or the skill of the attendant supporting the child.	
Strength & Tone	**Knowledge of MRC grades** - All of your current skills are relevant to this type of assessment. However if muscle strength is recorded below a grade 5, neurological deficit is expected by the SCI clinician reading your scores. Therefore if pain or lack of ability has led to weakness, but you know the patient is neurologically intact, always record as a 5 with a comment added to describe the weakness. During conventional SCI rehabilitation the preserved strength is used to compensate for the lost strength. However today rehabilitation for the child with SCI includes attainment of strength that may appear lost. Most SCI literature is based on an adult model that does not always reflect the potentials of the child with SCI. Referral to a SCI centre used to the treatment of the child with SCI can help advise strengthening and future neurological potential. Children have great neuroplastic ability (Mundkur 2005). As such more restorative therapeutic approaches are applied to the rehabilitation of the child with SCI regardless of their abilities (or lack of). Early intervention via the use of electrical stimulation is recommended as well as weight bearing regimes and continuous, repetitive, patterned programmes of activity. For further reading refer to chapter 28 'neurological recovery and restorative rehabilitation' Spinal Cord Injury in the Child and Young Adult - Lawrence Vogel, Kathy Zebracki, Randal Betz and MJ Mulcahey 2014. A sound knowledge in the application of rehabilitation technology including	

	electrical stimulation is of benefit to the physiotherapist treating the child with SCI. Often in the management of the very young child, paralyses may occur before the child has learned how to move functionally. Therapy therefore focusses on habilitation- teaching skills not yet developed, as well as rehabilitation- regaining lost skills. Below the age of 6 yrs. the ISNCSCI examination cannot be relied upon to capture accurately all areas of preserved function and as such areas of motor power that appear absent may later prove otherwise. Accordingly efforts to involve the child in participatory functional activities can be useful i.e. use of a tricycle with a fixed wheel (so the pedals move while the wheels turn and as such the child's legs move regardless of their volition) or electrical stimulation leg ergometery may be useful to motivate the child to try and move their legs independently with the device. **Tone** – your current skills and knowledge are relevant to this type of assessment. Tone is recorded via the Modified Ashworth Scale and Modified Tardieu Scale. The management of spasticity should include a thorough history and physical examination with attention directed to potential exacerbating factors. Goals should be to improve function, prevent complications, and alleviate pain. Conservative means to manage spasticity is the preferred management strategy for the child with SCI e.g. weight bearing, stretches and reciprocal limb activities. If conservative management is insufficient to manage problematic increased tone in the child with SCI and systemic drug treatment must be used, medication can be considered. For spasticity unresponsive to standard management, the primary options are intrathecal baclofen and localized	

	injection of botulinum toxin. Intrathecal baclofen is beneficial in managing severe spasticity in children with SCI; however, it is expensive and occasionally associated with adverse reactions.	
Functional Ability of the SCI Child	**Function attainment** in the child with SCI is in accordance with normal child development. All age appropriate function can be replicated for the child with SCI. Areas included in the attainment of ability include: • Mat (bed mobility) skills • Standing regimes • Transfer skills e.g. movement from wheelchair to bed/ toilet/ car/ floor/ bath/ sofa/ chair etc. • Wheelchair use/ skills e.g. ascent/ descent of kerbs and back wheel balancing • Gait (for the complete and incomplete lesion). A useful prediction paper that may help consider your child's potential gait abilities can be found via Van Middendorp et al 2011. Teaching and advice on these areas and expected levels of independence/ potential can be best addressed through the specialist skills at a spinal injury centre experienced in the treatment and management of the child with SCI. If you are managing a child in the community with SCI and need help and advice about what their potential is and how to gain this, contact your local link spinal injury centre for help and advice. Information can also be found in the resources recommended at the end of this document. **Integration into school PE programmes** is possible, for all children with SCI regardless of level, and is highly recommended. Your link spinal injury centre as well as the SCI charities noted at the end of this document can advise how to integrate the child fully	**Getting out of bed for the first time** – Decision to mobilise is led by the medical team and is based upon spine stability, state of the spinal cord and cardiovascular stability as well as the condition of the skin and other presenting injuries. Liaise with your link SCI centre for help and advice before and during this period if additional information or support is required. Generally the bed head is inclined progressively until upright sitting is achieved NB care of skin on the sacral area while sitting inclined in bed to minimise sheer forces. **Mobilisation** in a suitably supportive wheelchair is advised as opposed to sitting up in a conventional supportive chair or over the side of the bed, as the child with SCI is unlikely to have sufficient core neurological function to be able to achieve this. Sudden drops in blood pressure should be avoided, with the use of medication, abdominal binders (if abdominal function is lost) and anti-embolism stockings/ compression garments (if full leg function is lost) to prevent sudden drops in blood flow to the recovering cord. **Standing/ weight bearing** – This decision is led by the medical team and is based upon how medically fit and well the child is after mobilisation in a wheelchair. More generally, once the child can sit up in a wheelchair for over 4 hours without drops in blood pressure, standing can commence. A gradual incline via a tilt table will be the first phase of a standing programme (supported by abdominal binder and anti-embolism/ compression stockings avoiding sudden drops in BP). Liaise

	into school and home life. Most sports and leisure pursuits carried out at school can also be adapted to include the child with SCI. **Aquatic Therapy:** All levels and ages of children with SCI can benefit from aquatic therapy including the ultra-high lesion requiring domiciliary ventilation and the child with a tracheostomy. Strength training, maintenance of joint range, respiratory training and fitness as well as the acquisition of functional skills can all be maximised in the pool. For some children the benefits gained in the water may require to be offset by any potential nuisances experienced e.g. the lack of temperature control experienced after treatment (i.e. some may take a long time to warm up after getting out of the pool and remain lethargic for the rest of the day). Your link SCI centre can provide help and advice as required. **The psychological Impact on the child and family.** This should not be underestimated following SCI; a full description of how this is managed is beyond the scope of this document but further information can be found in the resources and reading available at the end of this document (particularly ' Spinal Cord Injury in the Child and Young Adult'). SCI is a huge life event and will impact on every aspect of family life and as such can be a major source of stress, anxiety and turmoil. Support, structure and advice, on how to manage this life change, is available for the child, siblings and family during the care they receive in specialist SCI services. During care in specialist SCI services families benefit from the support provided by the whole MDT (including the knowledge provided by the physiotherapist) and the support and experience of families going through (or who have already gone through) similar life events. Vital support can also be provided via the SCI charities noted at the end of this document (e.g. The SIA & The BackUp	with your link SCI centre for help and support. **Early Functional Skill Acquisition**: This list is a general guide to factors to consider during the early rehabilitation of a child with SCI. This is not an exhaustive list and treatment must be based on a thorough neurological assessment. Principles of treatment: • Encourage symmetry and postural alignment - 24 hour postural management • Promote normal skeletal development and growth • Scoliosis prevention • Stretch tight/ active muscles to maintain ROM and flexibility. • Teach bed mobility/ mat skills • Sitting balance (static/ dynamic) • Promotion of upper limb and hand activity/ function • Basic wheelchair skills • Basic lifting and transfer techniques • Start and progress a standing regime • Gait re-education where appropriate • Promotion of functional participation and verbal/ physical independence

	Trust). These charities can get involved and benefit at any stage of the child and families journey after SCI diagnosis. For some families this may be in the very early acute phase and for others later on in their journey. These charities can also provide vital support and education to the professional looking after the child with SCI.	
Equipment & Mobility Needs of the SCI child	All of your current skills are relevant to this type of assessment. Means of independent mobility should be provided as soon as the able bodied child would be freely moving around and exploring their environment; approximately 12-18 months (Calhoun et al 2013). However this may mean at a young age the child will require independent mobility equipment as well as a buggy. Children with injuries C6 and below will generally gain full independent mobility using a lightweight manual wheelchair and injuries above C6 powered mobility. The use of power-assisted mobility applied to a light weight manual wheelchair may also be useful if a child is on the cusp of ability using a lightweight manual wheelchair. Early contact with the local wheelchair services is essential however often below the age of 5 years provision via children's charities is common place due to the lack of suitably sized or light weight equipment via full NHS prescription. Equipment Needs include: • Wheelchair (powered and/ or light weight manual) • Scooter/ prone board • Pressure relieving cushion (and some may also require a backrest) • Postural orthoses- abdominal brace/ thoraco-lumbo-sacral orthosis (TLSO), collar, ankle-foot	

	orthosis (AFO), calliper/ knee-ankle-foot orthosis (KAFO), arm/ leg gaiters. • Standing frame (more often mobile) e.g. R82 Rabbit or Todd Stander. • Standing orthosis- full calliper and brace set (TLSKAFO), calliper (KAFO) • Walking aids • Night time positioning equipment/orthosis • Restorative therapy equipment e.g. electrical stimulation • Sports and recreational equipment • Equipment to adapt environment If you are managing a child in the community with SCI and need help and advice about equipment and mobility potentials, contact your local link spinal injury centre for help and advice. Information can also be found in the resources recommended at the end of this document.	
Charities and other supporting organisations		
	• Spinal Injuries Association (SIA) - www.spinal.co.uk • BackUp Trust - www.backuptrust.org.uk • Aspire - www.aspire.org.uk • Wheelpower- http://www.wheelpower.org.uk/ • International Spinal Cord Society (ISCoS) - www.iscos.org.uk • Multidisciplinary Association of SCI Professionals (MASCIP)- www.mascip.co.uk • International Spinal Research Trust (ISRT) - www.spinal-research.org • Regain - www.regainsportscharity.com • ICORD (International Collaboration of Repair Discoveries) - http://icord.org • Christopher & Diana Reeve Foundation – www.christopherreeve.org • Medical profile registration for SCI- www.alertservices.co.uk/SCI	
Useful Resources		
Spinal Cord Injury in the Child and Young Adult - Lawrence Vogel, Kathy Zebracki, Randal Betz and MJ Mulcahey. MacKeith Press, 2014. ISBN: 978-1-909962-347 The Child with Spinal Cord Injury, 1996, Betz & Mulcahey Published by American Academy of Orthopaedic ISBN 10: 0892031468 ISBN 13: 9780892031467 (updated now to the version above but still available in some medical library's and includes relevant information)		

'Wha' ever' The teenagers guide to SCI. Spinal Injuries Association (UK). Free to those under 18 years. with a SCI or to download. Website: https://www.spinal.co.uk/product/whaever-meg-harper/

Tetraplegia and paraplegia a guide for physiotherapists: Chapter - Spinal Cord Injury in Children and Chapter- Respiratory Therapy. Churchill and Livingstone. Author: Ida Bromley, eBook ISBN: 9780702032394, Hardcover ISBN: 9780443101809, Paperback ISBN: 9780702055263

Management of Spinal Cord Injuries – A Guide for Physiotherapists, Churchill Livingstone. Author: Lisa Harvey. ISBN: 9780443068584 (no information specific to childhood onset SCI but good participation and functional teaching advice and information).

England SCI Referral portal and document store: http://www.spinalcordinjury.nhs.uk/

American Spinal Injury Association Learning Portal: http://asia-spinalinjury.org/learning/

Don't Call it a Miracle – The Movement to Cure Spinal Cord Injury, Kate Willette – Free to download via Amazon

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Dedicated to

Ms Ebba Bergstrom MPhil, Clinical Specialist Physiotherapist (now retired) – who inspired, educated and supported my passion for childhood onset spinal cord injury and who paved the way for the care of the child with spinal cord injury at Stoke Mandeville Hospital

Acknowledgements

With thanks and acknowledgement to the staff at the National Spinal Injuries Centre, Stoke Mandeville Hospital, Buckinghamshire Healthcare NHS Trust, the APCP Neurodisability Committee and the Spinal Cord Injury Therapy Leads (SCITL) who provided advice, information, support and critique during the writing of this document.