Integrated Care Pathway for the Management of Spinal Cord Injury

National Clinical Programme for Rehabilitation Medicine
CLINICAL STRATEGY & PROGRAMMES DIVISION, HEALTH SERVICE EXECUTIVE , 2018

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INTRODUCTION

The annual incidence of traumatic spinal cord injury (SCI) in Ireland is approximately 12-15 per million population per year[1]. In 2017, there were 125 new cases of NTSCI recorded in Ireland (incidence of 26.1 per million). The 2 most common causes of NTSCI are degenerate spinal conditions (due to spinal stenosis or disc prolapse) and cancer metastases[2]. Incidence of non- traumatic spinal cord injury is impacted by population age, with incidence steadily increasing in an older population. What we know from an Irish perspective is derived from data from the Spinal Cord System of Care (SCSC) Programme at the National Rehabilitation Hospital. In 2015, the SCSC programme had 157 discharges, of which 125 were new admissions, with 70 of these suffering a traumatic spinal cord injury (56%)[3] with the other 44% presenting with non-traumatic onset. Of those presenting with traumatic injury, 47% had a diagnosis of tetraplegia and those with non-traumatic onset, 16% had a diagnosis of tetraplegia.

Evidence from international studies show that tetraplegia is the outcome for approximately half of all spinal cord injured patients, and the majority of these patients will have injuries to the cervical spine and consequently some degree of respiratory insufficiency and potential need for a degree of respiratory support. Many patients with high cervical lesions are anticipated to be ultimately weaned from requiring long term ventilator assistance. However international data would indicate that of these, 3.5% will be dependent on lifelong ventilator assistance[4]. If these figures are applied to the estimated Irish incidence figures, it can be anticipated that there could be up to 62 patients presenting with tetraplegia annually and of those, 1- 2 patients could potentially be dependent on long term ventilation post spinal cord injury. It should be noted that all these figures are cumulative. While NRH data for 2015 is given here as an estimate of incidence, the number of patients requiring long term supports post SCI increases year on year.

This relatively small cohort of people poses particular challenges currently with respect to ***rehabilitation and long term care***. The unfortunate outcome for these patients is all too often long term care in an acute hospital. This is wholly unacceptable for the person, and also for the health service where acute beds are in huge demand.

The International Classification of Functioning (ICF) should be used as a framework when considering the needs of these patients. ICF belongs to the WHO family of classifications and presents taxonomies of functioning and disability associated with health conditions. Since 2001 it is the recognised framework describing functioning and health[5]

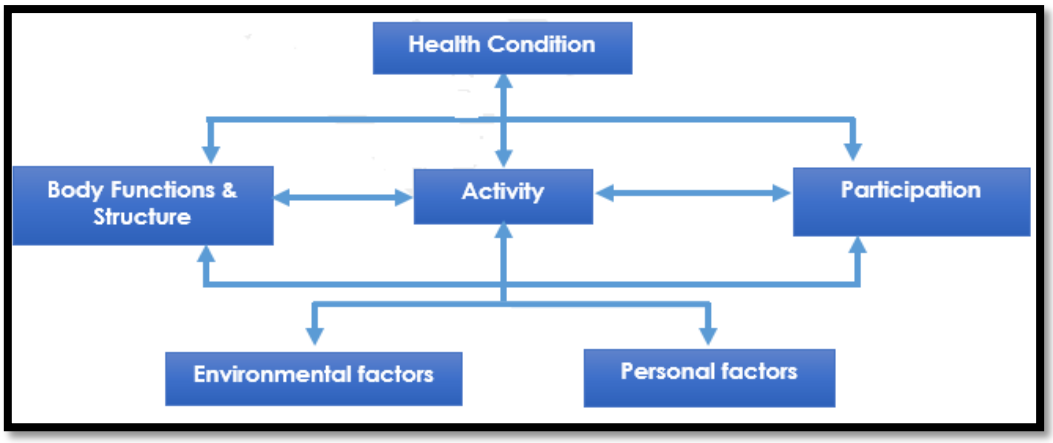


Fig1: Model of disability forming the basis of the ICF

The ICF provides a more comprehensive model of disability than medical or social models in isolation. It recognizes that disability is an interaction between the features of the person and elements of the overall context in which the

[1] International perspectives on Spinal Cord Injury, WHO, ISCoS, 2013
[2] Smith, E et al, 2018. Epidemiology of non-traumatic spinal cord injury in Ireland – A prospective population-based study. ISCoS annual scientific meeting
[2] Smith, E et al, 2018. Epidemiology of non-traumatic spinal cord injury in Ireland – A prospective population-based study. ISCoS annual scientific meeting September 2018, Sydney
[3] National Rehabilitation Hospital, Annual Report 2015
[4] NSCISC National Spinal Injury Statistical Centre, Spinal Cord Injury Model Systems, 2015 Annual Report – Public Version.
[5] Cieza A et al (2004). Development of ICF Core Sets for Patients with Chronic Conditions. *J Rehabil Med 2004; Supp.44:9-11*

person lives. Disability and functioning are viewed as outcomes of interactions between health conditions and contextual factors in the ICF framework.

Within this framework, the human experience of functioning is not considered as the consequence of a disease, but the result of the interaction between a health condition and both personal attributes and environmental influences (contextual factors)[i]. The impact of these contextual factors is important, since they can act as facilitators or barriers for functioning. Contextual factors are crucial when describing a care pathway for patients who are dependent on ventilator support.

A ***safe*** return to home with an appropriately funded care package would be considered the ideal for many patients with this level of high dependency needs. Currently the funding of such care packages is a challenge as they are funded out of local budgets for all disability services or the older person and budget holders need to be cognizant of the many demands on a limited budget**.**

CONTEXT

The HSE Clinical Strategy & Programmes Division was developed to improve and standardize care throughout the organisation by bringing together clinical disciplines and enabling them to share innovative solutions to deliver greater benefits to every user of HSE services. The National Clinical Programme for Rehabilitation Medicine (NCPRM) is tasked with describing how Specialist Rehabilitation Services should be configured nationally, in line with best practice. The NCPRM, along with all National Clinical Programme has overarching aims with respect to;

- Quality
- Access
- Value

The main recommendations from the model of care for the NCPRM which are all applicable to this pathway include;

- **Person centered approach to patient care**
    - The International Association Patient Organisations (IAPO) Declaration on Patient-Centered Healthcare[6] outlines five key principles against which models of care can be measured to determine the degree to which they are patient-centered. In clinical practice, the rehabilitation cycle of assessment, collaborative goal-setting, treatment plan and intervention, and goal review attempts to mirror these 5 principles
        - Respect
        - Choice & Empowerment
        - Patient Involvement in Health Policy
        - Access and support
        - Information
- **Development of appropriately resourced interdisciplinary inpatient, outpatient and community based specialist rehabilitation teams across Ireland supported by education and training**
    - Traditional multidisciplinary team (MDT) models involve professionals working independently to achieve discipline specific goals. Individual team members may not communicate directly with all other team members in care planning. Members working independently often lack a common understanding of issues that can influence interventions[ii].
    - The key factors distinguishing the IDT from the MDT is that team members work together closely in goal setting, treatment, decision making and ongoing problem solving to ensure continuity of care and a more holistic approach[iii]. From the time of admission, and in some cases from the time of referral, to the point of discharge the patient, family and the team are working on mutually agreed goals to achieve the optimum outcome.
- **Case management of patients**
    - Intensive, ongoing and personalised case management can improve quality of life and outcomes for individuals with complex or ongoing needs and those who care for them. Case management can

[6] www.patientsorganizations.org accessed 15th October 2014

enable patients to return home after hospital admission for a life-changing illness more quickly with a coordinated support package

- **Managed Clinical Networks**

The NCPRM recommends in its model of care the establishment of managed clinical rehabilitation networks (MCRNs) for specialist neurological and limb absence rehabilitation services. Organised care will be developed based on a hub and spoke model, and services will be provided through a national system comprising a tertiary center with a number of population based MCRNs. This is reflective of the model proposed in the National Strategy & Policy for Neuro-rehabilitation services in Ireland, 2011-2015. It is also reflective of the model proposed by the National Clinical Programme for Critical Care who describe a similar hub and spoke model of patients with critical care needs including those who require long term ventilator support.

MCRNs should consist of linked groups of health professionals and organisations from primary, secondary and tertiary care working in a coordinated manner. Once established, inpatient and community based specialist rehabilitation services will function together as a managed clinical network.

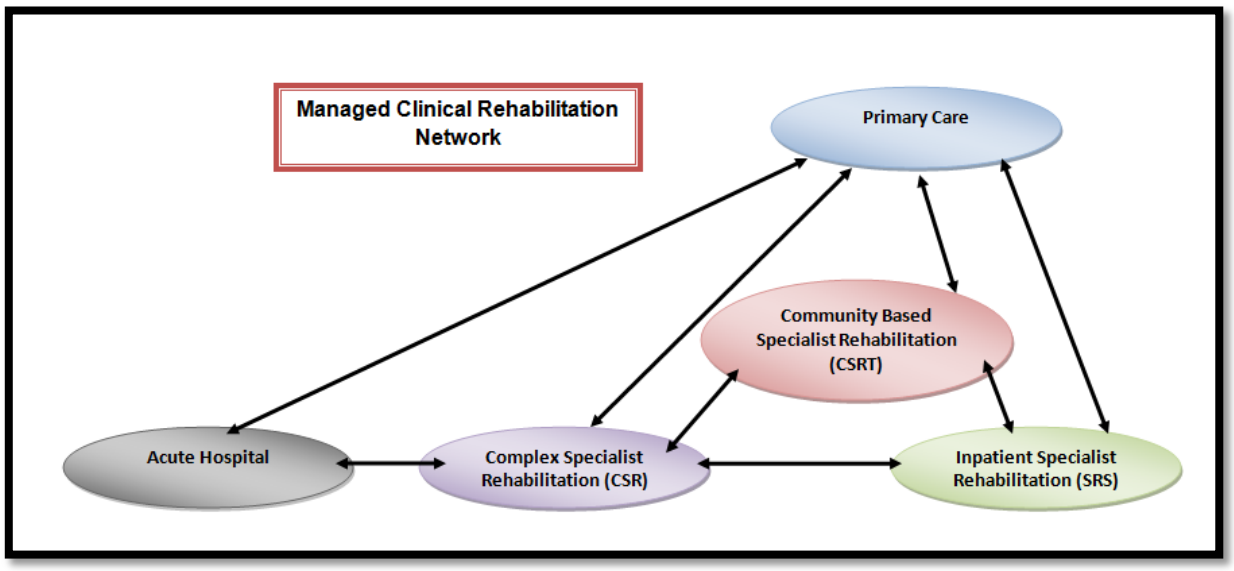


Fig 2; MCRN model

This model acknowledges the fact that different service users need different input and different levels of expertise and specialisation at different stages in their rehabilitation journey is fundamental to the development of specialist rehabilitation services. The critical point of this model is that, although service users may need to access different services as they progress, the transition between services should be facilitated by appropriate communication and sharing of information between services so that they progress in a seamless continuum of care through the different stages[7].

- **The three-tier model of complexity-of-need**

Specialist rehabilitation services are led or supported by a consultant trained and accredited in rehabilitation medicine, who may work in both hospital and community settings. These services often support rehabilitation across a range of conditions including neurological, musculoskeletal, amputee rehabilitation, provide advice and support for local general rehabilitation teams [26] and can deliver both inpatient and outpatient programmes. There are three recognised levels of specialist rehabilitation described for the Irish context (from NCPRM, adapted from the British Society of Rehabilitation Medicine (BSRM) :

[7]Model of Care, National Clinical Programme for Rehabilitation Medicine 2018

- **Complex Specialist service:** serves a national population and manages a high proportion of complex cases (60-70% have complex needs).
- **Local specialist rehabilitation service:** serves a population of up to 1 million and manages fewer complex cases (up to one third or 25-33% will have complex needs).
- **Community rehabilitation services:** serves a CHO population (usually <500,000) and comprises a wide range of therapy services including specialist and generic, and statutory and voluntary.

Complex specialist rehabilitation services
These are high cost/low volume services, which are provided for patients with highly complex rehabilitation needs that are beyond the scope of their local services. These specialised services should be provided through coordinated service networks planned over a regional population of 1- 3 million through collaborative specialised commissioning arrangements. Typically, they would include units specialising in spinal cord injury, brain injury etc., but some units could cater for a range of conditions.

Specialist regional rehabilitation services
Suitable post-acute specialist regional services should be developed to build capacity for specialist rehabilitation and complex specialist rehabilitation for patients, enhancing patient care and flow through the system and reduce waiting times for rehabilitation across the network. Clinical services should be provided by trained rehabilitation staff led by a consultant in rehabilitation medicine.

Community-based specialist rehabilitation

For a successful rehabilitation system to function, a coordinated development of community rehabilitation services and long-term support is required to meet the long-term and on-going needs of patients. Best practice includes active case management. Case managers with the appropriate training, clinical expertise and knowledge of services should be appointed to co-ordinate patient care post initial rehabilitation and ensure on-going personalised case management for patients with complex or on-going needs.

The development of community specialist rehabilitation teams within each community healthcare organization (CHO), as described in the National Strategy & Policy for Neurorehabilitation Services in Ireland (2011-2015) is supported strongly by the NCPRM. Specialist rehabilitation services are best able to determine the care needs of patients with complex conditions, such as cervical level spinal cord injury and complex traumatic brain injury in the community. These service providers will be aware of the potential health and social complications that can arise and this guidance should translate directly into timely funding for adequate supports such as home care packages. Community specialist rehabilitation teams will include a range of health and social care professionals, and a case manager, with support from a rehabilitation medicine specialist, and prosthetic and orthotic expertise.

Other services within the network

In addition to the multi-disciplinary rehabilitation teams described above, a range of other services will be required to meet patients' rehabilitation, health and social care needs. These services can be provided at either a local or network level. They include: integrated equipment services for temporary or permanent provision of assistive equipment and technologies, including telecare and communication aids; social work and social care services; bladder & bowel management (clear and responsive pathways in the community related to kidney infections and care of skin would reduce hospital re-admissions as well as improve the quality of life for the person with SCI), sexuality, psychology and mental health/psychiatry services, including drug and alcohol services; prosthetics, orthotics, surgical appliances, and seating and wheelchair services, vocational and educational supports, family support; uni-disciplinary or other/stand-alone rehabilitation services e.g. outpatient physiotherapy, hand therapy, pain management; specialist and community nursing services and sensory impairment teams.

Voluntary and third sector organisations

Voluntary and third sector organisations have an important role to play in the rehabilitation of patients. They can often provide additional support and clinical care to patients and their families, friends and carers. Any teams delivering health and social care services should liaise with those voluntary and third sector organisations, which may be relevant and distribute the necessary information about them to patients and their families, friends and carers. These organisations should feature in the proposed directory of services. Statutory and voluntary agencies crucially also support people who have sustained spinal cord injuries to participate in sporting and recreation activities, promoting social participation, physical activity and associated health and secondary prevention benefits. Spinal Injuries Ireland, the primary support group of patients with spinal cord injury also provide;

- Goal setting to re-engage service users back into community, social, educational and working life. Ongoing support to set and achieve person centered goals and to address barriers that may prevent achievement of goal.
- Advocacy where appropriate and referral to National Advocacy Service where appropriate.
- Peer support programme
- 'Meet Up's' – support groups / information sessions for people with SCI and their family members.
- Counselling service
- Support into activities and sports and support to those clubs.
- Family support.

- **<u>Outcome Measurement & data collection</u>**

  In terms of the continuum of care, it is necessary to know about process data (i.e. what is being done where, by whom and treatment outcome). At present, such data is not available. The task of determining the gap between Rehabilitation Services provided in Ireland and internationally recognised best practice is significant, particularly in relation to quality of service and outcomes. This will be an essential requirement of the programme as the health care system moves towards a system of costing bundles of treatment in preparation for activity based funding.

The pathway described in this document is;

a) In line with the care pathway for patients with spinal cord injury as described in the Model of Care for the National Clinical Programme for Rehabilitation Medicine
b) Reflective of a MCRN network which sees care providers across the continuum of care working together to provide optimum life-long care for those with Rehabilitative Needs
c) Reflective of the recommendations in the National Strategy & Policy for Neurorehabilitation Services in Ireland, 2011-2015
d) Reflective of the recommendations trauma network steering group

Specific supports are required to provide care to this cohort of patients, who have particularly high care support needs including patients who are dependent on ventilator support. The focus of the pathway is to support these patients to advance through the continuum of care from hospital to rehabilitation and on to appropriate long term placement, ideally at home, as indicated. The principles reflected in this pathway are applicable to all those with spinal cord injury, however, it is noted that those with co-morbidities may require additional supports at all levels, for example, those with an acquired brain injury and spinal cord injury. In these instances, every effort should be made to support collaborative working among service providers

The pathway should also be considered in the context of improving quality for patients in line with the Framework for Improving Quality in our Health Service developed by the Quality Improvement Division. In this framework, quality improvement is considered to be 'the combined and unceasing efforts of everyone – healthcare

professionals, patients and their families, researchers, commissioners, providers and educators – to make the changes that will lead to

- Better patient outcomes
- Continued development and supported staff
- Better Experience of care

WHAT IS A CARE PATHWAY?

An integrated care pathway (ICP) is an interdisciplinary outline of anticipated care, placed in an appropriate timeframe, to help a patient with a specific condition or set of symptoms move progressively through a clinical experience to positive outcomes.

While variations from the pathway may occur as clinical freedom is exercised to meet the needs of the individual patient, ICP's can help to reduce unnecessary variations in patient care and outcomes. They support the development of care partnerships and empower patients and their carers.

ICPs can also be used as a tool to incorporate local and national guidelines into everyday practice, manage clinical risk and meet the requirements of clinical governance[8].

The ICP for patients with spinal cord injuries span numerous service delivery sites, beginning at the time of initial presentation through to long term management in an appropriate setting.

The ICP should be able to address the following issues;

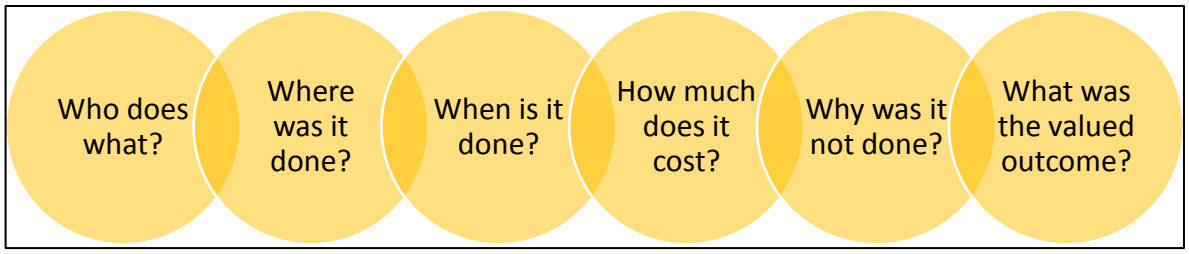


Fig 3: What an ICP should be able to address

The ICP will include reference to the breadth of the patient journey and address issues under the headings of;

- Network
- Pre-hospital care
- Reception & Intervention
- Reconstruction & ongoing care (including acute rehabilitation)
- Post-Acute Rehabilitation
- Life-long care

Issues not addressed within this care pathway but which need to be explored and addressed fully to be able to answer the questions above include;

[8] *http://www.medicine.ox.ac.uk/bandolier/booth/glossary/ICP.html*

- Governance;

- Corporate Governance & clinical Governance structures need to be considered. The pathway will see patients move across the pathway. The clinical governance of the patients, both as they transition through the pathway and in the longer term when in the community needs to be determined.

- With respect to implementation of the pathway, clear governance structures need to be considered. There will need to be an overarching steering group with appropriate representation from all stakeholders. Implementation of this pathway will involve a new way of collaborative working across HSE divisions and organizational boundaries.

- The steering group will need to be supported by an operational working group who will have roles and responsibilities for monitoring of progress, clinical audit, date gathering etc. This group should also have a significant role in developing the required protocols and policies which will link the pathway with ongoing developments across the health service which will directly impact on the pathway i.e.

    - Proposed development of a national trauma network
    - Planned implementation of the National Strategy & Policy for Neuro-rehabilitation Services in Ireland

- Subgroups of the National Steering Group will need to be established to work on specific supporting requirements for implementation of the pathway. Examples of such could include;

    - Development of competencies for management of patients who require long term ventilation for both hospital and community staff
    - Development of competencies for acute rehabilitation of patients with spinal cord injury

INTEGRATED CARE PATHWAY FOR PATIENT'S WITH SPINAL CORD INJURY

NETWORK

The Network refers to the entire patient pathway as outlined in the Model of Care for the National Clinical Programme for Rehabilitation Medicine. Clear protocols need to be developed that clarify the relationships and integration across all service providers supporting the patient across the network. This should include Service Level Agreements to support the repatriation of patients, when appropriate.

The pathway within the model of care describes the pathway for all patients with a spinal cord injury. While patients who are ventilator dependent require additional specialist services, the principles of the pathway should be consistent for all patients with a Spinal Cord Injury and indeed other neurological conditions.

National pathways and recommendations need to be made that address the specific needs of this cohort of individuals. These pathways will need to be developed with representation from all key stakeholders including;

- Critical care
- Anesthesiology
- Neurology
- Otolaryngology
- Respiratory Medicine
- Spinal cord injury specialists
- Acquired Brain injury specialists

- Rehabilitation Specialists
- Health & Social Care Professionals
- Long term care providers
- Primary Care
- Patient representatives
- Nursing
- Respiratory services
- HIQA
- National Transport Medicine Programme
- HSE Quality Improvement Division

The pathways will need to take into account all the necessary requirements to provide a safe and effective clinical intervention. The pathways will also need to be holistic and consider the patient's choice and preferences.

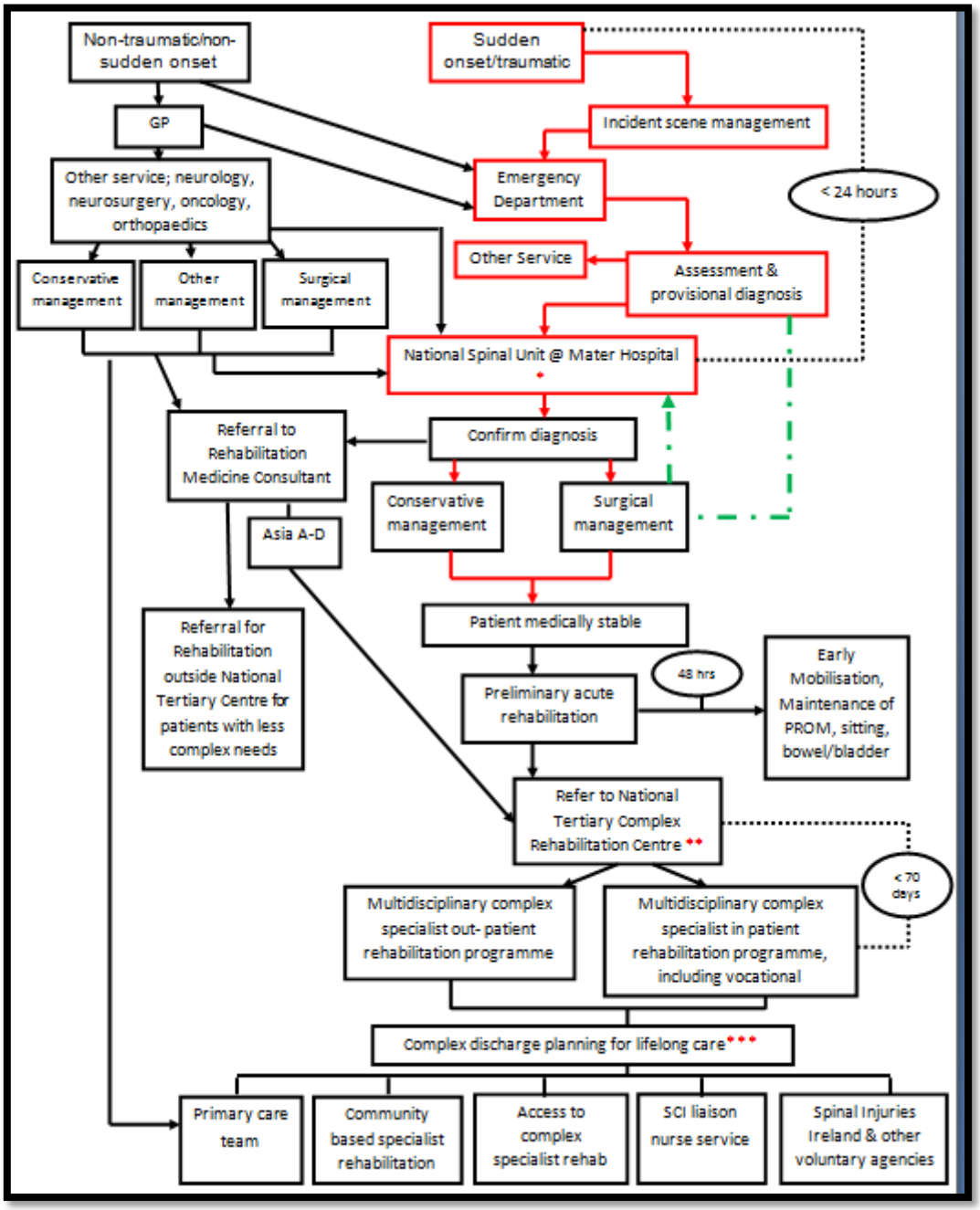


Fig 4; Pathway of care for patients with Spinal Cord Injury, Model of Care, National Clinical Programme for Rehabilitation Medicine

PRE-HOSPITAL CARE

- Hospital bypass protocols for those with suspected spinal cord injury need to be considered. Patients should be admitted to hospitals where their immediate needs can be met and their condition managed appropriately, this should include:
    - 24 Access to MRI/CT Scanning
    - Access to appropriate critical care services

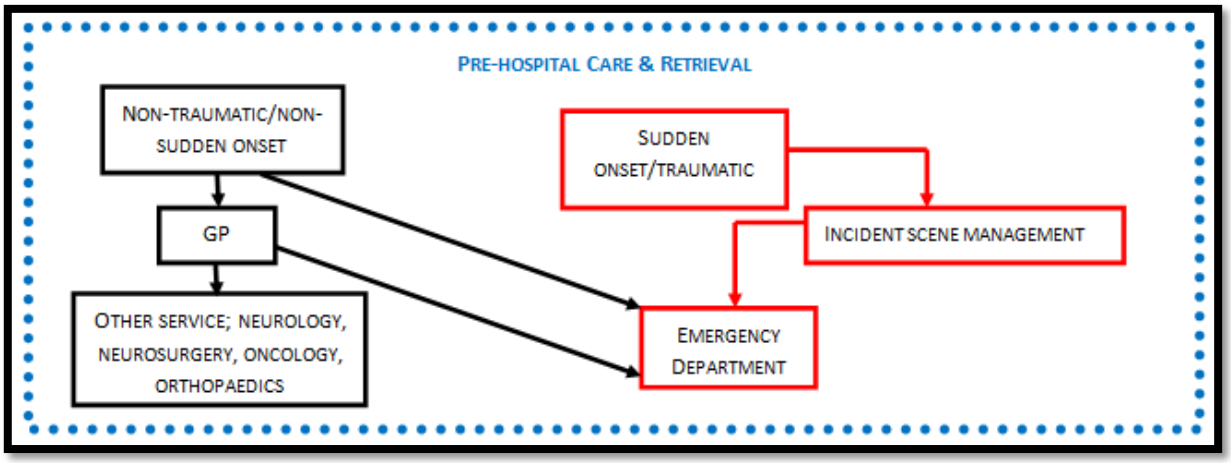


Fig 5; Pre-hospital stage in patient pathway

Supporting protocols in line with the NICE Guideline for the management of patients with spinal cord injury are included in appendix 4. These protocols reference;

- Assessment for spinal cord injury
- Assessment for cervical spine injury
- Assessment for thoracic or lumbosacral spine injury
- When to carry out or maintain full in-line spinal immobilisation
- How to carry out full in-line spinal immobilisation
- Extrication
- Pain management in pre-hospital setting
- Immediate destination after injury

RECEPTION & INTERVENTION

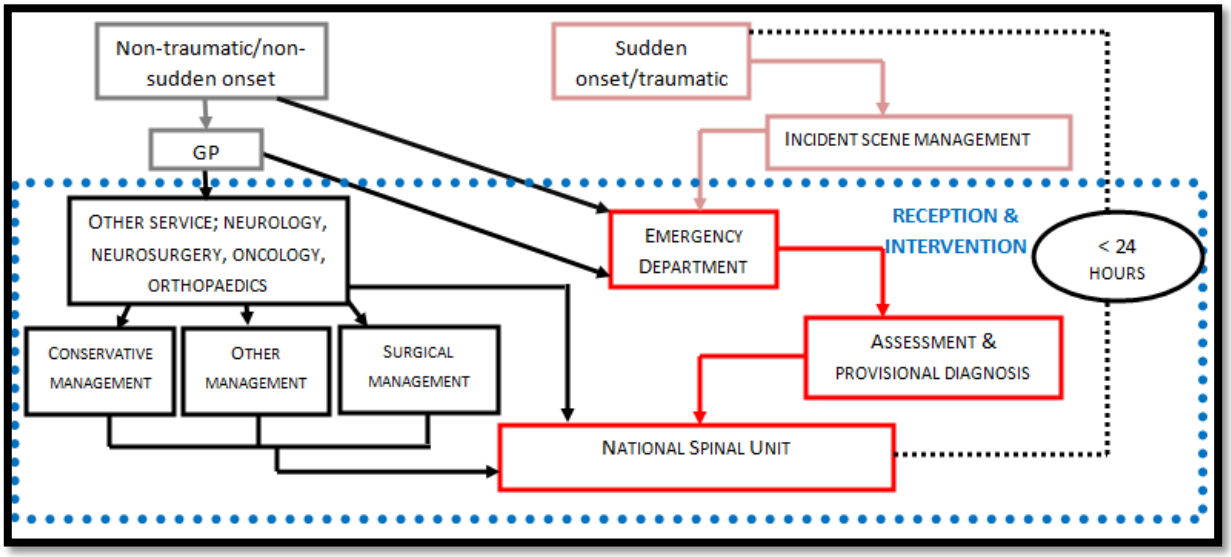


Fig 6; Reception and Intervention stage to include retrieval of patient in patient pathway

This section will consider;

- pre-alert system
- admission to major trauma center (MTC) for those whose injury is traumatic and onward referral to National Spinal Injury Unit (NSIU)
- Admission to NSIU or Neurosurgical/Neurology center for those with non-traumatic presentations

Patients with high cervical spinal cord injury, in particular those who are ventilator dependent require critical care support. Those who receive their injury through a traumatic event should be transferred to a major trauma center where their care will be managed in hospitals with all essential services in-situ to support them. Those whose onset is acute, but not necessarily through a traumatic event need to be managed in a hospital with appropriate critical care services. If the major trauma center does not have a specialist spinal cord injury center, then the NSIU should be contacted for guidance on the physiological stabilization of the patient. The NSIU should have a complete protocol on acute management.

Critical Care Services (HDUs and ICUs) are located in aligned Model 3 or Model 4 hospitals. The National Clinical Programme for Critical Care adopts the Prospectus Critical Care 'hub-and-spoke' configuration as its service delivery and organisational model for critical care services with connectivity across Hospital Groups in the acute hospital system[9].

There is evidence that multidisciplinary, multispecialty critical care in centralised (or regionalised) high-volume Critical Care Units is associated with superior outcomes (Kahn (2006); Hutchings (2009); Davenport (2010); Kim (2010).

The HSE (through the National Clinical Programme for Transport Medicine) is implementing the National Adult Critical Care Retrieval Service. This service is developing the existing retrieval service for critically ill adult patients, which is currently provided by Mobile Intensive Care Ambulance Service (MICAS). The remit of the Service is to ensure the timely 'hospital to hospital' transfer of Level 3 ICU critically ill patients as needed and as appropriate.

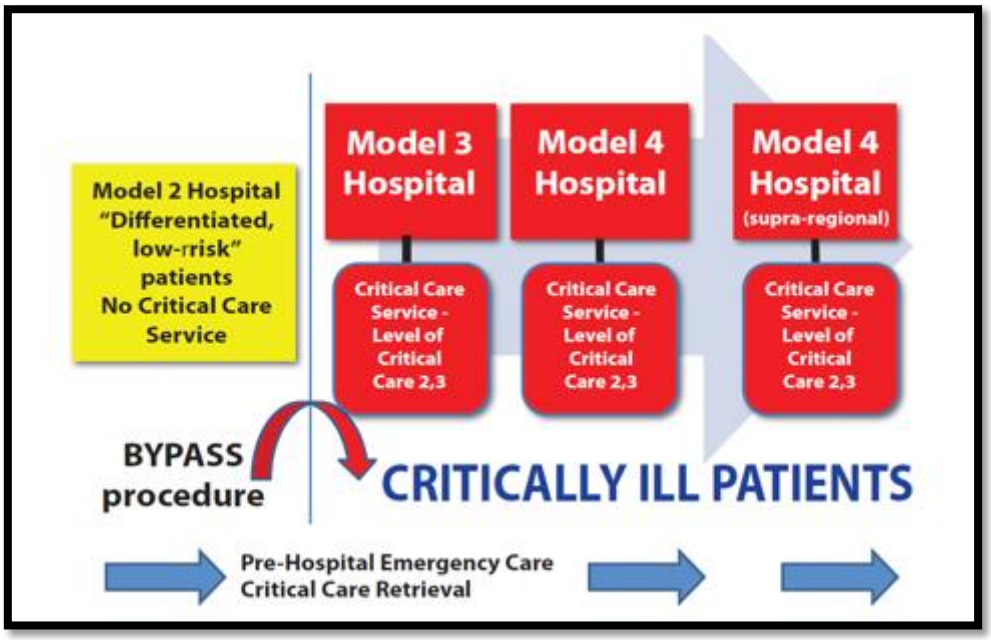


Fig 7; Model of care for Adult Critical Care, National Clinical Programme for Critical Care

RECONSTRUCTION & ONGOING CARE

Reconstruction and on-going care starts following urgent surgery and continues until discharge from an acute setting. The prevention of complications arising from spinal instability or neurological compromise must begin immediately and involves all members of the multi-disciplinary team. If there is significant spinal cord injury, early

[9] National Clinical Programme for Critical Care, Model of Care Oct 2014

contact should be made with a spinal cord injury centre for advice and to plan strategy which should include contacting the adult critical care retrieval service MICAS to enable transfer to the centre as soon as possible, ideally within 24 hours. MICAS provide a fully trained team proficient in the stabilisation and transfer of critically ill patients who require a higher level of care or definitive care not available at the centre the patient is in.

- Ongoing appropriate physiological management particularly for patients with cervical level SCI
- Prevention of secondary complications arising associated with the absence of specialist nursing
- Assessment of rehabilitation needs (see appendix 1) within 48 hours with initiation of rehabilitation interventions as early as possible, preferably in the critical care unit. The completion of the rehabilitation needs assessment should be the trigger to the instigation of future care planning and the assignment of a rehabilitation coordinator
- Engagement with NSIU re; recommendations on acute rehabilitation for those with spinal cord injury
- Engagement with National Rehabilitation Hospital and Consultant in Rehabilitation Medicine
- Specialist rehabilitation is essential to address the physical and psychosocial needs of patients that result from their injuries and experiences. Without a well-defined and adequately funded pathway, patients will not achieve their optimal function.
- There should be cross network agreements and adequate resources to ensure that once specialist medical care has been completed, patients can be transferred to the care of a service which can meet their ongoing care and rehabilitation needs.

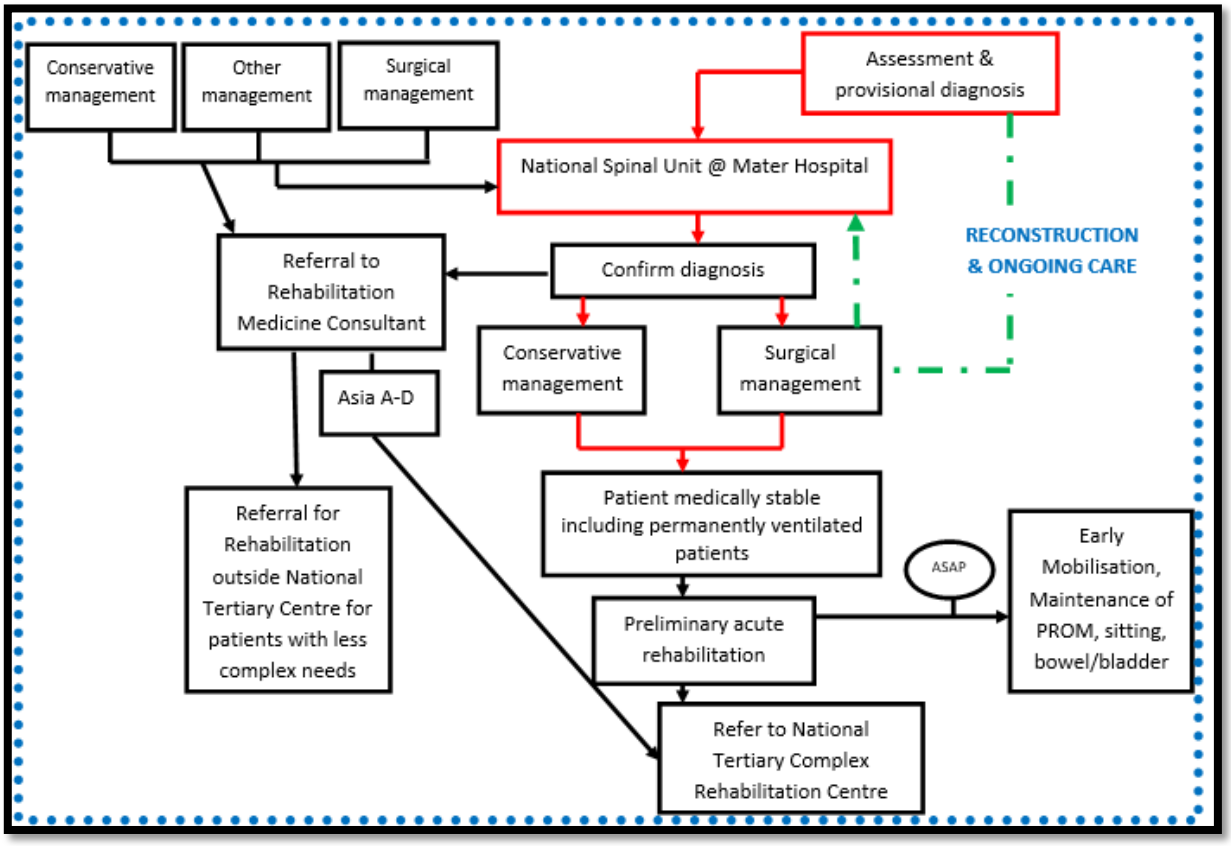


Fig 8; Reconstruction and Ongoing Care phase of patient pathway

Early rehabilitation is essential. 'Early' refers to rehabilitation interventions that commence immediately after stabilization (Parker et al, 2013[10]). A multidisciplinary team-based approach is paramount to the successful incorporation of early rehabilitation into routine practice in the ICU.

[10] Parker et al. Early Rehabilitation in the Intensive Care Unit: Preventing Physical and Mental Health Impairments. Curr Phys Med Rehabil Reports. 2013 December; 1 (4): 307-314

Early rehabilitation is important to utilise plasticity as effectively as possible and to reduce the potential for complications[11]. There is strong evidence (Grade A) that early access to rehabilitation leads to reduced length of stay in hospital and improved outcomes[12].

There are many examples of patients who have arrived to the NRH with pressure marks from skin not being adequately cared for in the acute setting. These patients end up in bed for many weeks in the NRH, unable to engage with therapies. This increases length of stay in NRH and compromises patient outcomes.

Early intervention from a social worker / case worker is also key in relation to applications for the medical card and support to the family / individual with SCI regarding adaptation of housing. Delayed discharges can occur because of housing not being ready so the earlier this process begins the better. Medical card applications can be lengthy and people who are entitled to one can be discharged from the NRH without this being in place.

POST ACUTE REHABILITATION

This cohort of patients require access to Complex Specialist Rehabilitation Services, with transfer to the National Rehabilitation Hospital as soon as the patient is deemed to be 'ready' to engage in rehabilitation.

Delayed transfer to rehabilitation is a significant problem within the NSIU. Delays may result from waiting lists for rehabilitation services or genuine medical/surgical instability requiring longer lengths of stay. Some patients may fluctuate over time between instability and fitness for rehabilitation. Daily recording of the (Rehabilitation Complexity Scale Extended version) RCS-E **M-scores**, may be used to assist with informing decisions on fitness for transfer.

Complexity: Rehabilitation Complexity Scale Extended (RCS-E)

	0	1	2	3	4
Care	Independent	1 carer	2 carers	≥ 3 carers	1:1
Risk	None	Low	Medium	High	Very high
Nursing	None	Qualified	Rehab nurse	Specialist nursing	High dependency
Medical	Non active	Basic	Specialist	Potentially unstable	Acute medical/surgical
Therapy disciplines	None	1	2-3	4-5	≥ 6
Therapy intensity	None	Low level (< daily)	Moderate (eg daily)	High (+ assistant)	Very high (>30 hours/week)
Equipment	None	Basic	Specialist	-	-

RSCE: C _____ N_____ M_____ Td_____ Ti_____ E_____ Total_____/22

Fig 9: Rehab Complexity Scale Extended Version

Acute

- At M = 4, the patient still requires acute medical/surgical care in the specialist setting
- At M = 3, they require ongoing acute medical care as they are potentially unstable
- At M = 2, they may still have acute medical/surgical needs requiring out of hours' care in an acute care setting, or acute rehabilitation unit

At M0-1 they are ready for transfer to a post-acute rehabilitation service with the following levels of medical care:

Post -Acute

- M = 1 - routine medical monitoring/surveillance
- M = 0 their medical/surgical trauma needs could be met at home.

[11] Gutenbrunner C et al. White Book on Physical and Rehabilitation Medicine in Europe. Journal of rehabilitation medicine. Supplement No. 45, Jan 2007

[12] Turner-Stokes L. Evidence for the effectiveness of multidisciplinary rehabilitation following acquired brain injury: A Synthesis of Two Systematic Approaches. J Rehabil Med 2008; 40: 691-701

Those patients who are ventilator dependent, cannot currently access complex specialist rehabilitation services in Ireland. From the patient and family perspective it is better to offer rehabilitation services in this country than sending patients to the UK for an inpatient rehabilitation programme with little or no onward planning possible other than discharge back to MMUH/NSIU or their local hospital. Out of country rehab is expensive and leaves no legacy of skills/infrastructure in Ireland. The most challenging part of rehab for these patients involves coordination with local/social/community care and this cannot happen while abroad. It can happen simultaneously with medical rehab if the patient is in Ireland.

The long-term impact of rehabilitation abroad on the family both in terms of family relations and financial strain has lead in some cases to family breakdown. This further compounds the devastation and psychological trauma of the SCI both for the person with SCI and the surrounding family members. The stress of these circumstances has also lead in some cases to ill health of the primary carer for the person with SCI, again compounding and complicating the impact of the initial diagnosis.

The key gap in the management of ventilated spinal cord injured patients in the Republic of Ireland is a gap at NRH in the clinical governance for the safe and effective management of the patient during the inpatient rehabilitation phase and the discharge planning phase.

Transfer to the National Rehabilitation Hospital requires the development of a pathway in itself. Considering both the preadmission planning and discharge preparation required, this pathway spans several stages in the overall Integrated Care Pathway.

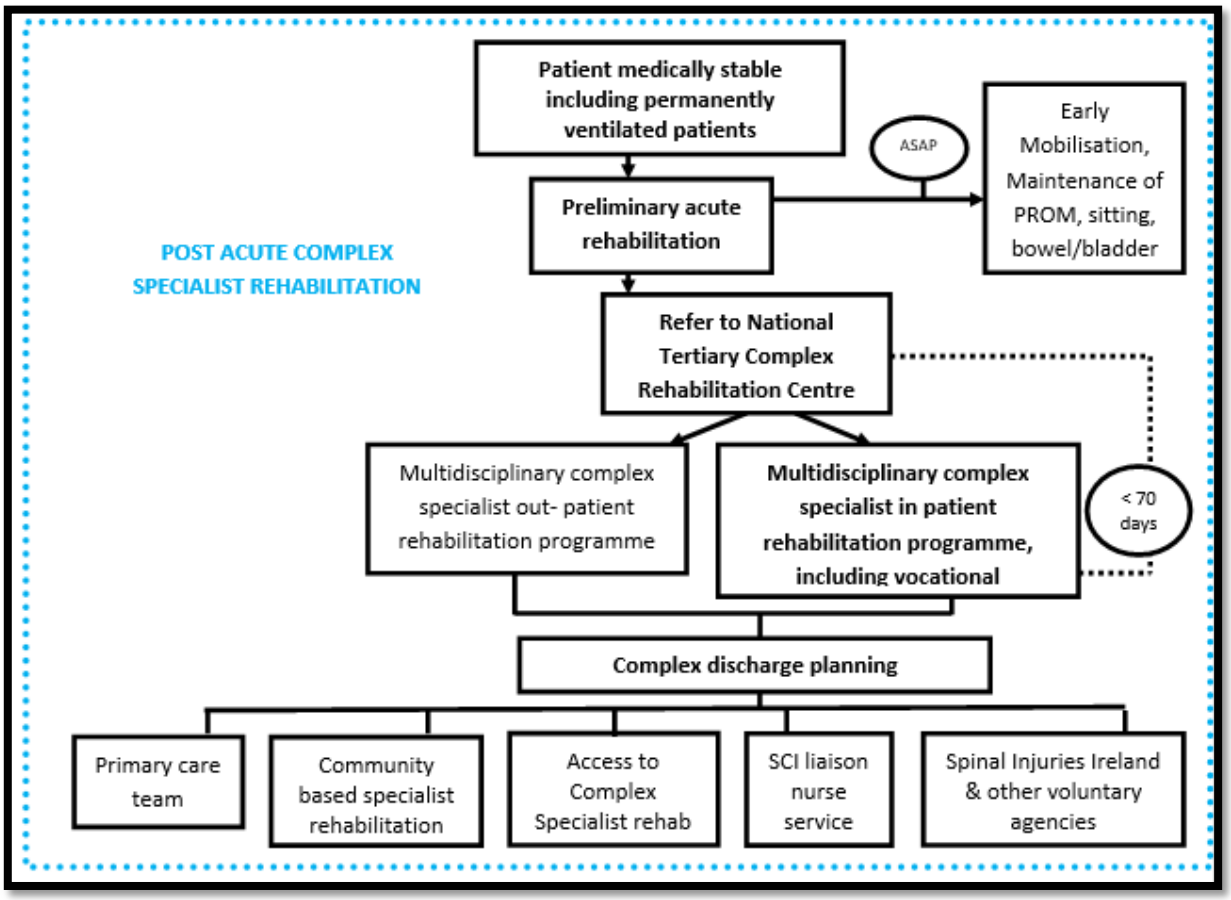


Fig 10; Post Acute Rehabilitation phase of patient pathway

COMPLEX DISCHARGE PLANNING

Discharge planning for patients with complex needs should be a network wide process and mirror the existing system within paediatric services, supported by appropriate policy and standard operating procedures.

Within paediatric services, complex discharge planning is a 6-stage process, overseen by a governance group and a complex child care group. The complex child care group has representation from all key stakeholders including specialist hospital services, local hospital services and community based organisations. The roles and responsibilities of all parties are clear. The complex child care group has access to a ring-fenced budget from which funding of home care packages is provided.

Each child is assessed by a national standard assessment tool to determine their level of complexity. The tool supports clinical decision making processes and helps develop and tailor services by directing resources more appropriately, economically and effectively. Once complexity is confirmed, the child falls under the remit of complex childcare system. Exact levels of support are determined by the multidisciplinary team led by a nominated key worker/coordinator. Following this, a business case is developed and submitted to the complex childcare group for consideration and approval.

This process is initiated once the lead clinician has determined that home care is the preferred option for the child. The discharge planning stage is a defined process with associated recommended timeframes. This is the model that should be modified and applied to discharge planning for adults with complex care needs such as those with cervical spinal cord injury.

LIFE LONG CARE

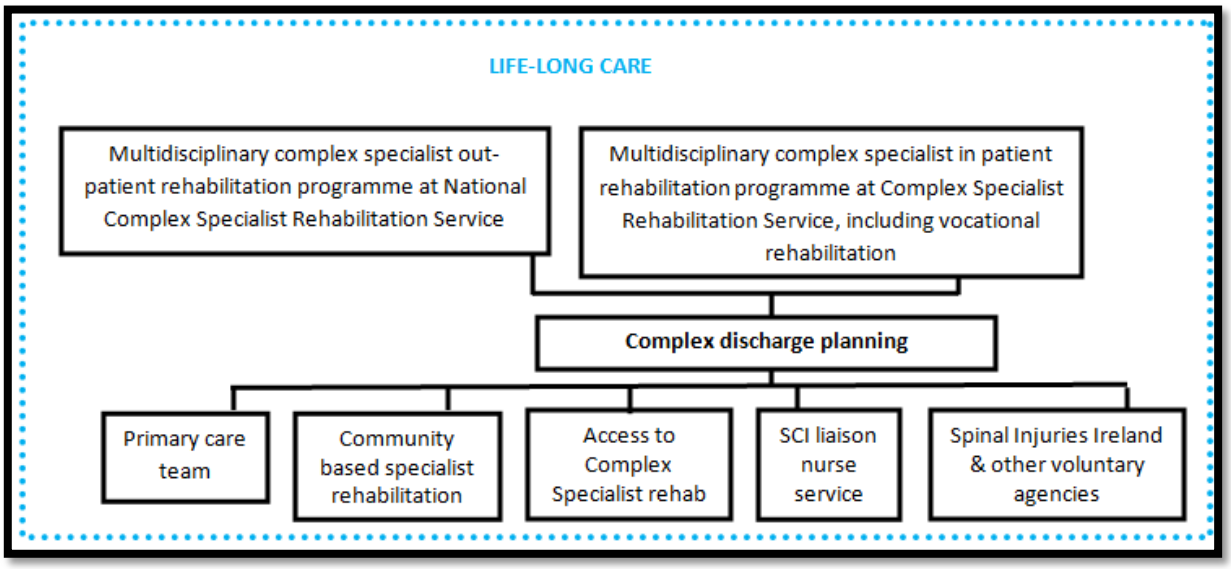


Fig 11; Life-long care phase of patient pathway

A return to home with an appropriately funded care package would be considered the ideal for many patients with high dependency needs. People with spinal cord injury have many needs and face wide-ranging, long-term restrictions in their ability to live independently, drive or use public transport, return to work or education, participate in leisure and social activities. [13] As such, the support needs of these patients are significant and should include;

- Domestic assistance
- Educational/vocational support
- Night time care
- Personal assistance
- Medical care

The level of attendant care required for each level of spinal cord injury is described later in this document, however, every situation is different and so individual circumstances and how care needs are affected must be considered. In

[13] Adapted attendant care guidelines, Dr Eimear Smith, NRH

addition, a person's attendant care needs may change and at certain times, increased or decreased support will be required.

Currently the funding of home care packages is a challenge as they are funded out of local budgets and budget holders need to be cognisant of the many demands on a limited budget. In addition, there is no consistency country-wide in the response to requests for care in the community or regarding what is an acceptable level of care to be requested in the home versus that which suggests that nursing home is more appropriate.

Efforts should be made to review alternative funding systems, particularly systems wherein patients' needs and goals are aligned with funding. Such systems are used around the world, and while no perfect model exists, services which allocate funding based on need determined by a universally acceptable assessment tool should be considered preferable to block funding. Payment should also be dynamic with reassessments of need and adjustment of funding determined by the patients changing needs over time.

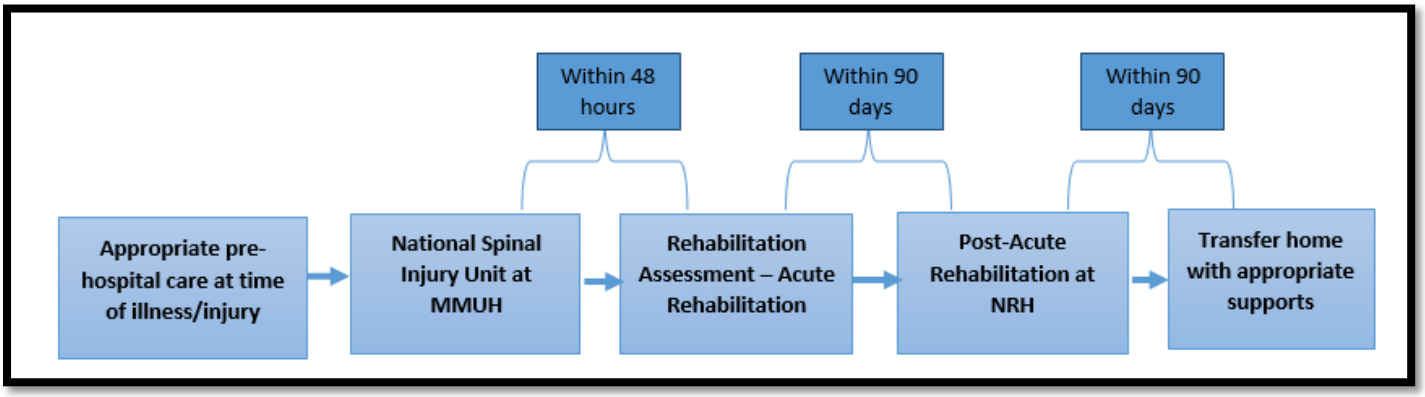
In addition to funding issues, there is a significant requirement for the training and education of families and carers. Care-staff attrition and re-training of new staff also need consideration. Home support teams should consist of a team of competent health care assistants who are trained and supported by qualified nurses.

LIFE LONG CARE FOR THE VENTILATOR DEPENDENT PATIENT

Mechanical Home Ventilation as a treatment of choice and therefore best practice for chronic respiratory failure has been employed for many decades in countries such as Germany, Austria, the USA, Canada and now Australia as well. In the past two decades, there has been an increased interest in mechanical home ventilation for several reasons, including improved survival following episodes of acute respiratory failure as a direct result of advanced treatment options in Intensive Care[14].

It is important that families and carers are made aware of the increased risks involved in managing a ventilator-dependent individual at home, compared to supporting the same individual in an acute hospital setting. Leaving hospital will inevitably increase some risk factors: it will significantly reduce access to skilled medical support and emergency treatment, for example. But this is balanced by the delivery of one-to-one care by people who know the person well. Managing the sometimes conflicting issues of risk and quality of life is fundamentally important. For both families and professionals there is a need for open and honest discussion based around the best interests of the person and their family. The threshold of acceptable risk will differ in each case[15].

CURRENT STATUS



[14] Mechanical Home Ventilation Guidelines. https://intensivecareathome.com/mechanical-home-ventilation-guidelines/ Accessed Feb 2017
[15] Supporting information LTV – 'Toolkit to support ventilated children and young people in children's hospices' – Cooke, A et al, Children's Hospices UK

Fig 12; Ideal progression through care pathway

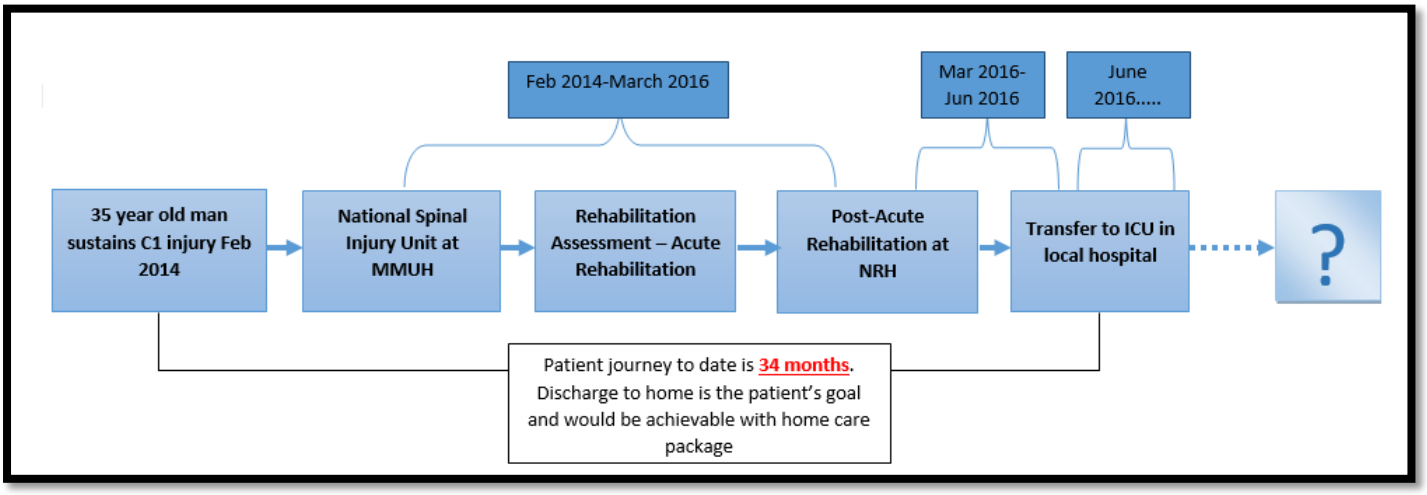


Fig 13; Actual example pathway for one tetraplegic SCI patient

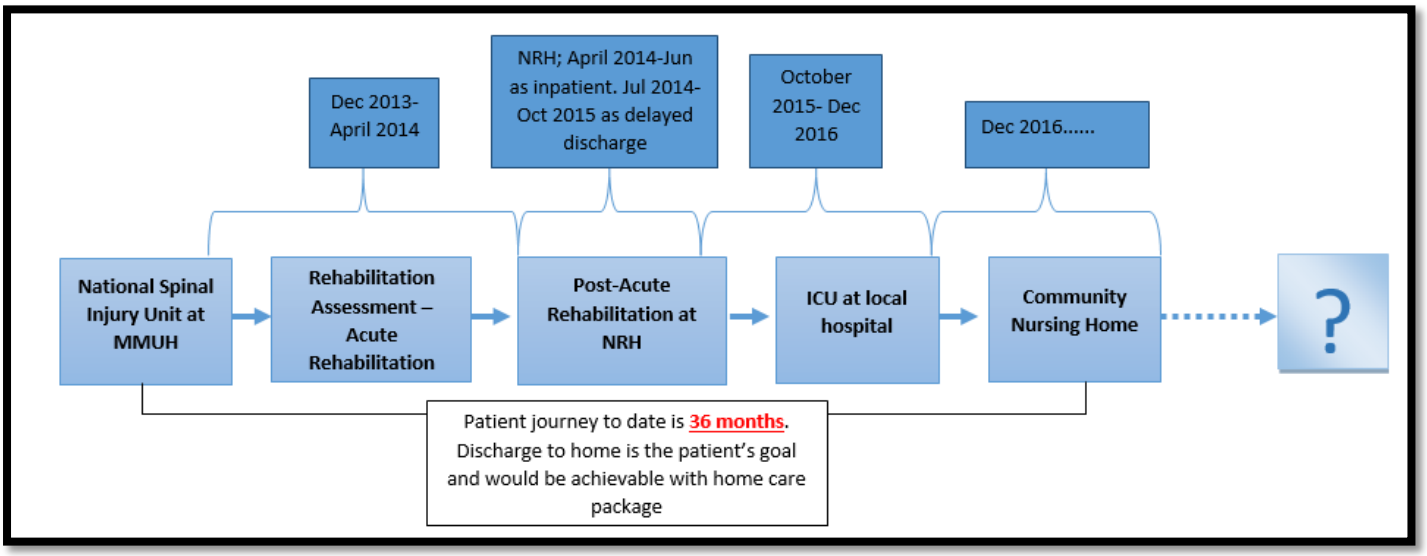


Fig 14; Actual example pathway for one tetraplegic SCI patient

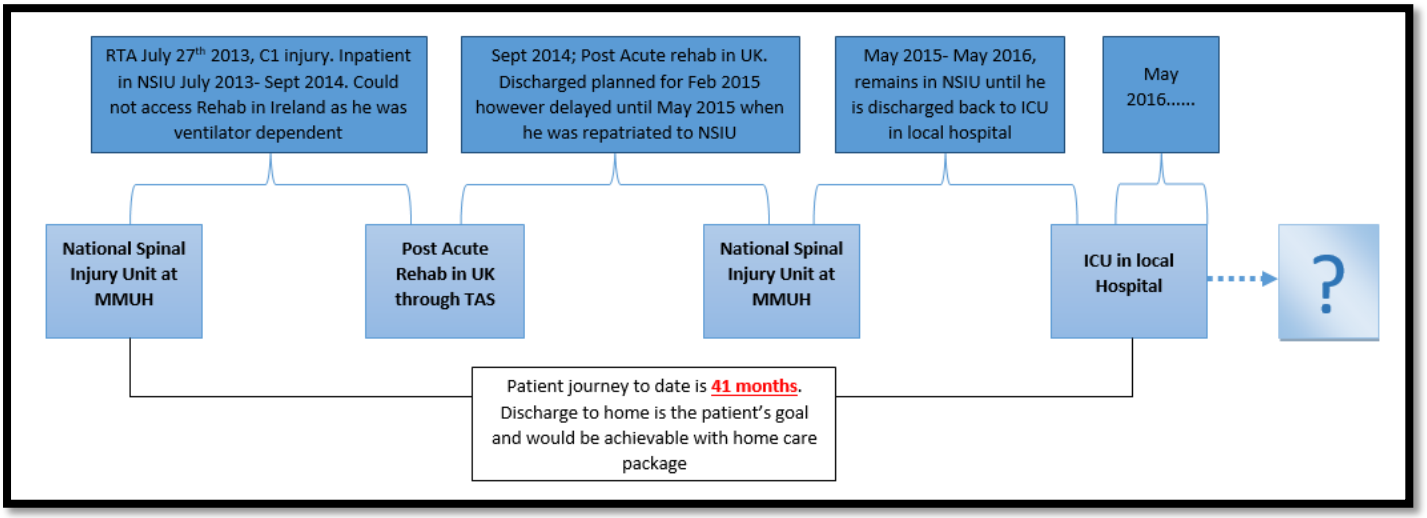


Fig 15; Actual example pathway for one patient who is ventilator dependent post SCI

While elements of the ideal pathway function effectively, the unfortunate reality is that the pathway ends following a period of post-acute rehabilitation at the NRH for most, but for those who are ventilator dependent, the pathway ends following a period of acute rehabilitation at the NSIU. For these patients, many are discharged back to their local hospital while awaiting access to post acute rehabilitation in the UK through the Treatment Abroad Scheme (TAS).

Those who do get to benefit from post-acute specialist rehabilitation often have their functional gains negated by a discharge back to the critical care unit at their local hospital post rehabilitation owing to lack of funding for appropriate long term care.

With an 'appropriate' admission for acute management and post-acute rehabilitation being estimated at approximately 180 days, anything above this (+/- 30 days) should be considered an inappropriate and costly use of services. In figure 12 above, the time spent in the acute hospital setting was 1,609 days. 1,489 of these days were most likely not clinically indicated. These days have an associated cost of over €2,000,000. 335 days were also lost to delayed discharge at the National Rehabilitation Hospital at a further cost of €268,000.

In figure 13 above, this patient is still accumulating days within the acute hospital system. Except for the 302 days the patient & their family had to spend in the UK, this patient has so far been in the acute hospital setting (critical care) for 793 days. These examples, while they may appear extreme, are unfortunately not atypical for patients with high support needs following a spinal cord injury.

The average length of stay for a patient with tetraplegia in the NRH in 2015 was 107 days with a range of 36 days – 523 days.

As of 18.8.16, there are 29 patients with spinal cord injury awaiting admission to the spinal injury programme at the NRH. 9 of these are patients with tetraplegia, i.e. 31%. These patients are currently accumulating days in the acute hospital system. The NRH aims to admit patients to the spinal injury programme within 90 days of referral. While this target is achieved for many patients, the numbers of beds lost to delayed discharge has a direct impact on the ability of NRH to admit new patients. At present, the longest waiting patient has been waiting since 15.6.16.

From a patient perspective, a recent survey undertaken by Spinal Injuries Ireland, outlines some of the biggest challenges/issues as identified by those with spinal cord injury. These issues, while reflective of issues addressed through the pathway, includes the issue of medical cards. This is a significant issue for patients, and is generally seen as the primary obstacle to accessing services within the community.

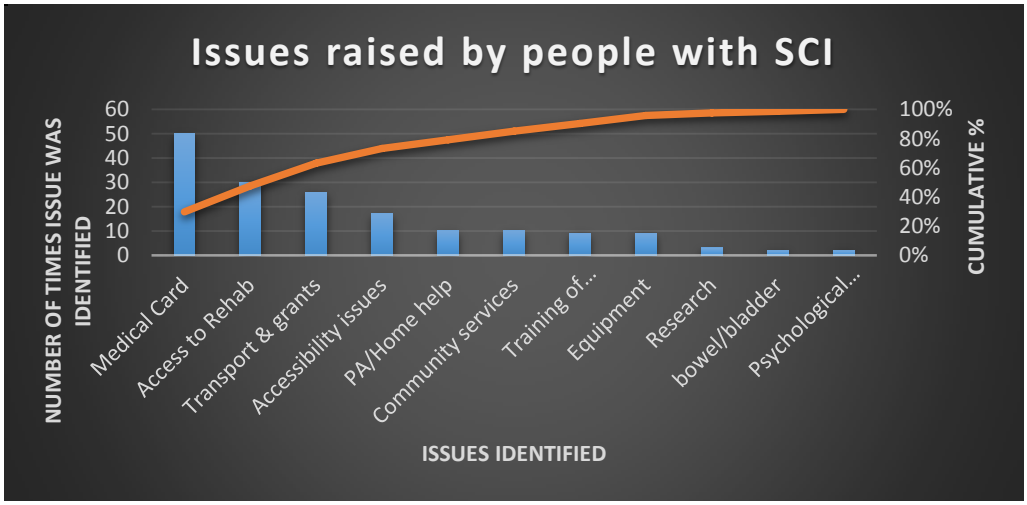


Table 1; Issued raised by people with SCI

In additional to the survey conducted by Spinal Injuries Ireland which related to living with a Spinal Cord Injury, an additional patient questionnaire was circulated to clients of SII in an attempt to establish a baseline with respect to patient experience of the care pathway. Results from this survey revealed the following;

- When asked about their discharge destination post-rehabilitation, 60% of respondents reported that their discharge destination was not their choice.
- Significant variance in length of stay at all levels of service provision i.e. acute hospital, rehabilitation hospital etc
- When asked about 'clear pathway with smooth transitions across services', respondents 67% felt that this was not their experience.
- When asked whether the pathway proposed within the ICP was reflective of their own experience the following results were observed;

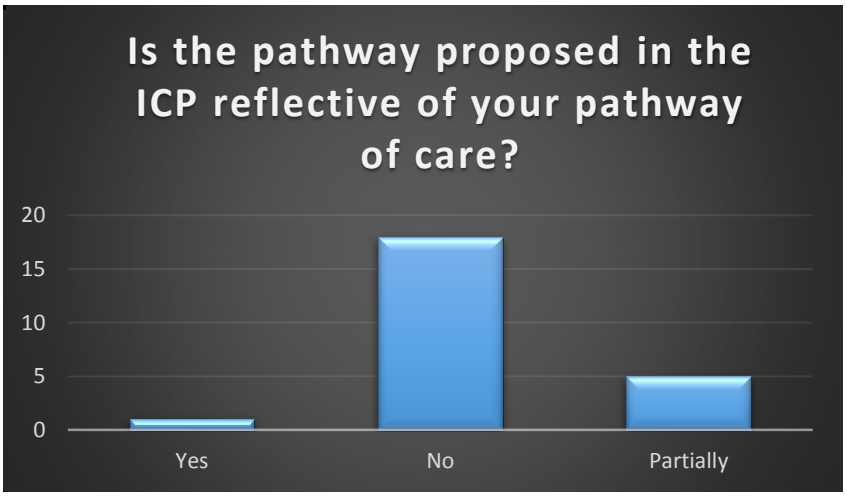


Table 2; Patient feedback on their pathway of care versus proposed pathway of care

- When asked about negative and positive aspects of their continuum of care, the following word clouds were generated based on patient responses;

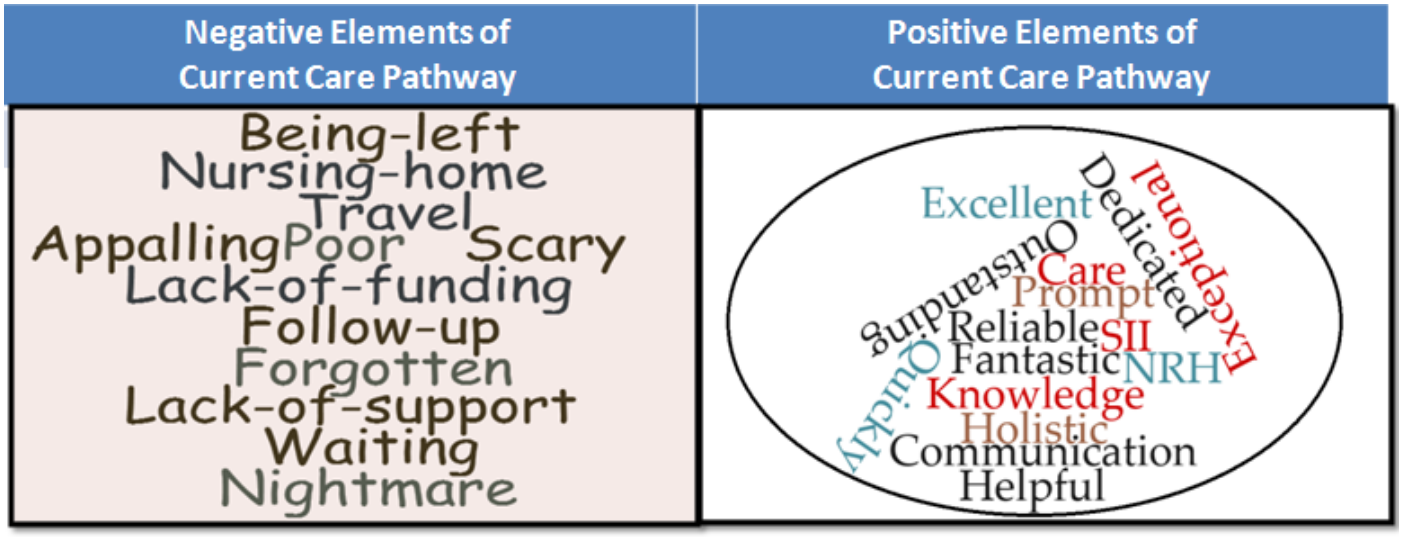


Fig16; Word cloud based on recurrent themes

- When asked to identify what changes could be made to improve the patient pathway, the following themes were noted and reflected in the Pareto Chart below;

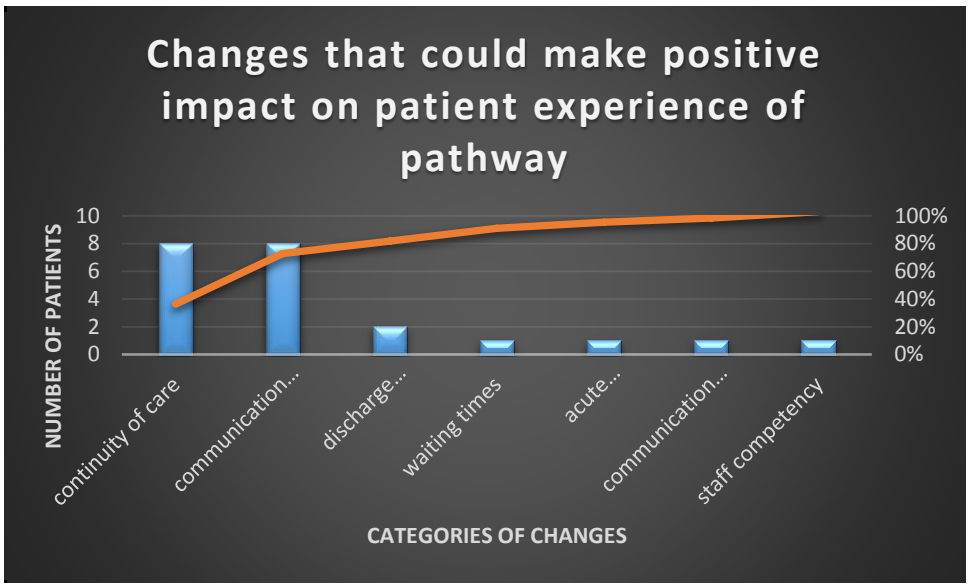


Table 3; Changes which could make a positive impact on experience

REQUIREMENTS

REQUIREMENTS FOR ACCESS TO POST-ACUTE SPECIALIST REHABILITATION SERVICES AT THE NATIONAL REHABILITATION HOSPITAL FOR PATIENTS WHO ARE VENTILATOR DEPENDENT

There are some of the key points to be considered in the process flow for the management of ventilated spinal cord injured patients in the Spinal Cord System of Care (SCSC) Programme at NRH.

- The input of critical care medicine from MMUH to NRH needs to be a regular and sustained service with a weekly ward round at NRH. *(Although the SCSC Programme regularly admits patients with compromised respiratory status, including patients with a tracheostomy, the incidence of ventilated spinal cord injured patients is very low)*.
- Consideration needs to be given as to how a new Intensivist Consultant post at MMUH would collaborate on an ongoing basis with NRH and not just for an admission period.
- Consideration also needs to be given to access to MMUH ENT or other services if required by the Intensivist Consultant.
- Education for NRH staff by critical care medicine would ensure a level of competency and comfort in the management of ventilated patients. This could take place on a regular basis and stepped up on a formal basis prior to any planned admission. In addition, some SCI nurses at NRH have completed further training courses in 'tracheostomy and airway interventions' and management of 'NIPPV ventilation'.
- Telemedicine link. A camera and a communications link between St Margaret's Ward NRH and MMUH have been installed and the IM&T Department at NRH is finalising this project.
- The creation of a liaison/coordinator nurse post at NRH would facilitate the development of a clinically case managed pathway from admission to MMUH to the community setting post discharge.
- Agreement with the Ambulance Service to return critically ill ventilated patients to MMUH rather than SVUH. This was previously agreed as part of the care plan of another patient who was due to attend NRH.

- There is a need for the development at NRH of documented Policies and Procedures and Standard Operating Procedures to address the governance and operational management of ventilated patients.
- A programmatic national approach is required to develop and resource the needs of the long term ventilated spinal cord injury patient, including an agreed transparent funding mechanism to meet the patient's lifelong care needs in the community. Critical Care Medicine Consultant(s) appointment and engagement with such programmatic development is recommended.

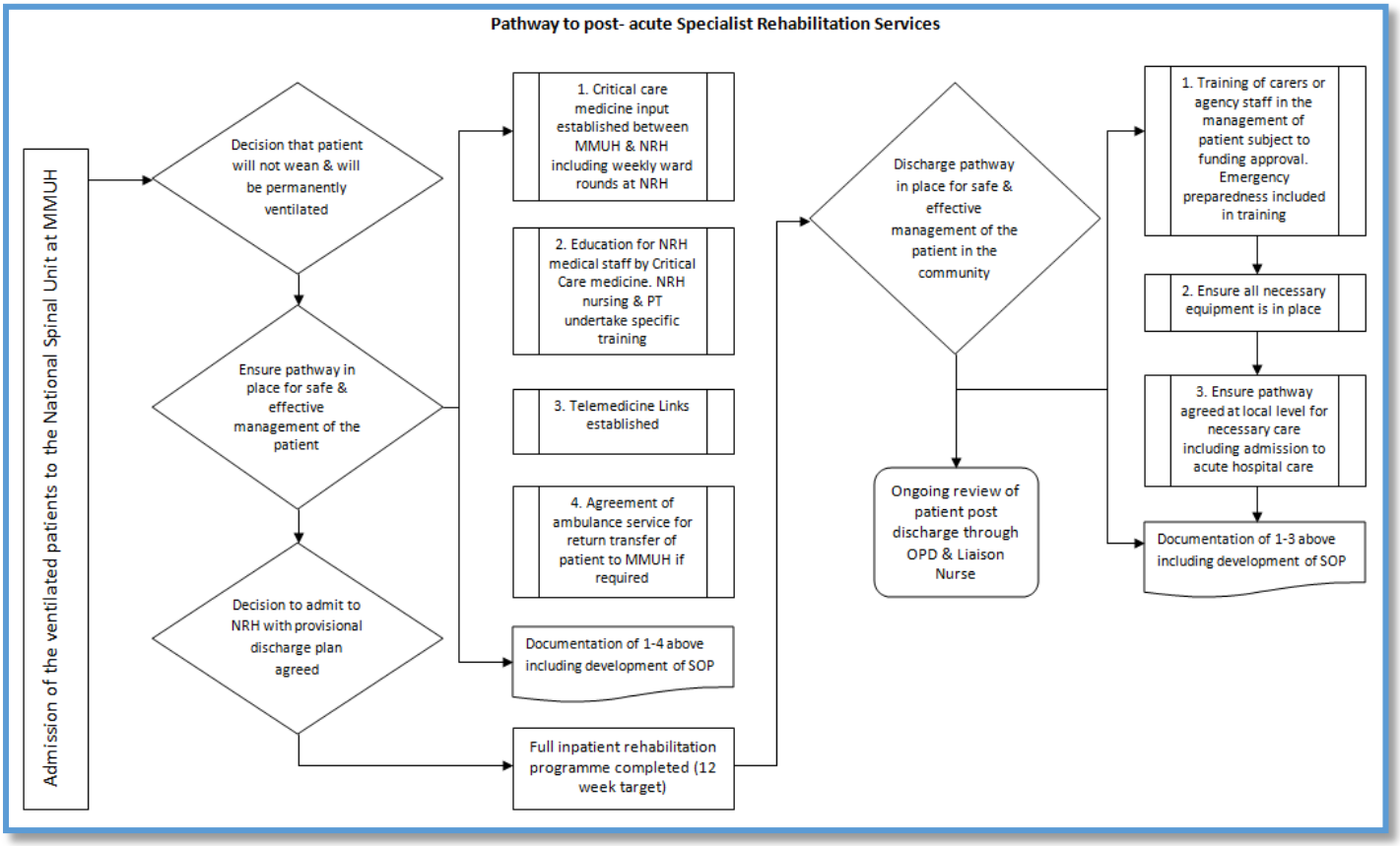


Fig 17: Pathway to post acute rehabilitation for patients who require long term ventilation

REQUIREMENTS FOR THE MANAGEMENT OF PATIENTS WITH CERVICAL CORD INJURIES AT HOME/IN THE COMMUNITY

Full details outlining the care needs for patients with spinal cord injury is detailed per level of injury in the Attendant Care Guidelines developed at the National Rehabilitation Hospital (see appendix 2). This guideline is based on Australian *Guidelines for levels of attendant care for people with spinal cord injury* produced by The Lifetime Care and Support Authority of NSW and the Motor Accidents Authority. They have been adapted for use in Ireland by the NRH with an advisory committee with a wide range of experience with the needs of people with a spinal cord injury and in the delivery of attendant care services.

Described within that document are the care needs based on;

- Impairment to body system
    - Mobility
    - Respiration
    - Autonomic dysfunction
- Activity limitations
- Activities of Daily Living; personal assistance
- Domestic assistance
- Participation support

The care needs have been developed as they apply to 'typical' patients. Periodic clinical reassessment is required to ensure the level of care is appropriate to the patient need, and reassessment at times of changing circumstances,

especially as the person ages, will ensure the current attendant care needs are being provided. Factors, other than level of injury, which can impact on a person's care needs can include;

- Age at time of injury
- Ageing
- Appropriate support (eg home modifications)
- Assistive technology and modified equipment
- Autonomic dysreflexia
- Body weight, strength and body shape
- Discharge from hospital
- Driving and transport
- Energy conservation
- Geographical location
- Hospitalisation, surgery or acute treatments
- Increased independence
- Living situation
- Major life transitions
- Medication
- Pre-existing or co-morbid conditions
- Respiratory care
- Responsibility for children, pregnancy, parenthood
- Work, school or study
- Young adulthood[16]
- Support Network
- Addictive Conditions

REQUIREMENTS FOR THE MANAGEMENT OF VENTILATOR DEPENDENT PATIENTS AT HOME/IN THE COMMUNITY

In addition to the requirements for management of a patient with a spinal cord injury in the home, patients who are dependent on ventilation require specific additional supports.

The transition phase from the clinical to the non-clinical environment is highly vulnerable for the patient. The correct time point for discharge is reached only when the underlying and secondary illness(es) are deemed stable, and when the meeting of costs as well as the provision of the necessary equipment, resources and materials have been secured. Intensive Home Care programs have been successfully developed in countries like Australia, the United Kingdom, Germany, Austria or the US and Canada, where proof of concept has been established decades ago.

The specific equipment requirements for the management of a patient who is ventilator dependent are detailed in appendix 3

In order to safely look after ventilated patients in the home, a number of prerequisites and minimum skills must be available before the person can be safely transitioned into the home. This includes family support system.

In order to provide nursing care for ventilated adults& children in the home, a designated specialist nurse must be assigned in order to organize and manage the care of a particular client[17].

The shared care of a home-ventilated patient should include;

[16] Australian *Guidelines for levels of attendant care for people with spinal cord injury* produced by The Lifetime Care and Support Authority of NSW and the Motor Accidents Authority. They have been adapted for use in Ireland by the NRH with an advisory committee with a wide range of experience with the needs of people with a spinal cord injury and in the delivery of attendant care services

[17] Nottingham University Hospitals, NHS Trust. Clinical Guidelines/Nursing. Guideline for the care of adult patients with a tracheostomy. Feb 2012

- Ongoing clinical supervision (usually overseen by Intensivists, Respiratory physicians, anaesthetists, paediatricians or neurologists) in cooperation with home care providers.
- A care team, with highly skilled staff to support patient and family
- Education, training and up skilling of care team annually or as required
- Technical support from equipment providers for machines and accessories.
- Access to therapy services including;
    - Speech & Language Therapy
    - Occupational Therapy
    - Physiotherapy
    - Dietitian
    - Respiratory therapy
    - Medical Social Work
- A qualified care team as well as a representative from the equipment provider should always be contactable 24/7
- Social care and family support

All staff caring for patients with tracheostomies and laryngectomies must be trained and assessed as competent to safely deliver care to these patients within the clinical area and during transfer. Training and competency is assessed locally within specific clinical areas (NHS, 2012) but should include the following areas;

- Physiology and Anatomy of the Respiratory system and mechanical ventilation
- Understanding and knowledge about mechanical ventilation and mechanical ventilators
- Monitoring
- Oxygen therapy
- Knowledge and understanding about tracheostomy and mask ventilation
- Tracheostomy management
- Management of secretions
- Management of inhalation and nebuliser management
- Humidification management of the respiratory system
- Tracheostomy care
- Bedside equipment
- Inner tube cleaning
- Dressing and tapes
- Infection control considerations
- Cuff pressure checks
- Dysphagia
- Communication
- Transferring
- Resuscitation
- Emergency planning/preparedness

FUNDING

Appropriate rehabilitation services are effective in reducing the burden of disability and enhancing opportunities for people with disabilities. Its cost is frequently no greater than would have otherwise been incurred by health services had such services not been provided.

A central theme of post-acute rehabilitation is early, targeted intervention to restore independent function. If effective, this should lead to cost benefits in terms of reduced length of stay in hospital and reduced needs for long-term care in the community[18].

[18] Turner-Stokes L, The evidence for the cost effectiveness or rehabilitation following acquired brain injury. Clinical medicine Vol 4 No1 Jan/Feb 2004

The cost saving that can be achieved both in terms of lessening the burden of need in the more highly dependent patients and return to work/productivity/community participation / active citizenship for those with lower dependency cannot be ignored and should be taken into account when planning service development.

Current funding and payment structures do not incentivise the delivery of rehabilitation in a timely or comprehensive manner. Current funding streams lead to delayed rehabilitation and delayed transfers within the system, which leads to suboptimal outcomes, inappropriate care in the wrong setting and increased stresses on patients and families.

A funding structure, which reflects ethical principles and supports desirable patient pathways is essential. Similar to paediatric services, t**he completion of a specialist rehabilitation needs assessment/prescription should trigger the commencement of a planned release of funding to ensure timely care for those patients with severe and major injuries/illness most at need of multiagency input. It is recommended that patients with complex needs require a centralised funding stream.** In the UK, there is a trust payment for each rehabilitation prescription completed, as it is seen as a vital component of the process. This may be of particular benefit for activity based funding or patient-costed care in the Irish context.

Funding of rehabilitation services across the continuum of care, including care packages for long term care should not be impacted by the separate HSE divisional budgets. There needs to be a whole system approach to funding which supports the patient journey from acute hospitals, disability services and long term care. Currently, funding to support the discharge of patients home is applied for through social care division. Without this funding in place, patients remain in either acute hospitals or National Rehabilitation Hospital as a delayed discharge. This is an inappropriate use of both these resources and an unacceptable outcome for patients. Disability services are dependent on local services/budgets funding care packages, which can often be considerable. This local decision making leads to significant variance in patient experience, as local managers struggle to absorb these often-time high cost packages while continuing to fund routine services. This variation can be seen as an injustice to those who don't receive funding and are thus forced to remain in an acute hospital setting in the long term. It could be considered an affront to personal autonomy, as it would not be expected that patients would identify the acute hospital setting as a desirable discharge destination. It can also be interpreted as an injustice for those patients awaiting access to inpatient beds in the hospital ED which are blocked as a result of these inappropriate placements of patients.

COSTS FOR PATIENTS WITH HIGH SUPPORT NEEDS

While costings for a home care package are significant, they should not be considered in isolation. Every day a patient is at home, is another acute hospital bed day released into the system for the appropriate management of acutely ill patients. Everyday a patient is supported at home instead of remaining in the NRH as a delayed discharge means access to rehabilitation services for another patient in need. In 2015, 2155 days were lost to delayed discharge. This equates to full inpatient rehabilitation services for an additional 33 patients. With demand far outweighing capacity at the NRH, this is a very significant issue.

The care of these patients presents a significant challenge on acute care wards due to the high burden of care i.e. nursing and therapy. These factors increase the average cost per day in acute hospitals. These added pressures can ultimately lead to less staff and therefore staff time, to provide acute medical care to medically unwell patients in the unit and have increased care costs.

With respect to actual monetary value, the direct cost of maintaining a patient in an acute hospital, particularly in the NSIU or in an ICU (for ventilated patients) ranges from €1,000 per day to €1,800 per day (up to €657,000 per year). Another very real cost with respect to inappropriate management of these patients is that associated with pressure wounds. It is reported that the cost to the health service to successfully treat on patient with a grade 4

pressure wound is €119,000[19]. Patients with SCI are a particularly vulnerable population for developing ulcers and are at high risk for recurrent ulcers. The incidence of pressure ulcers in SCI population is 25-66%.[20]

While data is limited in terms of costing of home care packages for adults with highly complex needs, costings for Paediatric Home Care Packages can be considered. In these instances, costings for 'complex home care packages' for children with spinal cord dysfunction range from €20,000 to €347,573.93 (child who is ventilator dependent) per year.

This should be considered however in comparison with costs associated with acute hospital admissions. With an 'appropriate' admission for acute management and post-acute rehabilitation being estimated at approximately 180 days, anything above this (+/- 30 days) should be considered an inappropriate and costly use of services.

It needs to be noted also, that people with spinal cord injury, in particular tetraplegia have a complicated presentation with all body systems included. They can also develop unpredictable complications that are potentially life threatening in nature. Managing these patients requires a dedicated care routine. This additional level of care needs to be considered when making comparisons between cost of funding a home care package versus funding placement in a residential setting. **Average costings for placement in residential setting are not applicable in these cases.** Residential care settings generally provide room, board, housekeeping, supervision, and personal **care** assistance with basic activities like personal hygiene, dressing, eating, and walking. This level of support is not adequate for patients with tetraplegia. To place people with tetraplegia in a residential setting without the appropriate or adequate level of care can result in damage their physical health and lead to costly readmissions to specialist services for example admission to hospital for pressure wound management.

COSTS FOR PATIENTS WHO ARE VENTILATOR DEPENDENT

While cost is of course a significant consideration when planning longer term care and management of patients who are ventilator dependent, it cannot be the only determining factor. The patient's rights and preferences need to be acknowledged and supported. Long term care in an acute hospital is not an acceptable outcome.
Cost will be dependent on individual's specific needs including the level of ventilation they require.

Level 1
The person is able to breathe unaided but needs to go onto a ventilator for *supportive* ventilation. The ventilation can be discontinued for up to 24hours without clinical harm. Ventilation is 'life enhancing' not 'life sustaining'.

Level 2
The person requires ventilation at night for very poor respiratory function; has respiratory drive and would survive accidental disconnection, but would be unwell and may require hospital support.

Level 3
The person is unable to breathe independently and requires permanent mechanical ventilation or has no respiratory drive when asleep or unconscious and requires ventilation and one-to-one support while asleep (as disconnection would be fatal)[21].

Those patients who are considered 'level 3' will require 2 carers continuously over a 24 hour period, 7 days a week, 52 weeks a year.

There is little supporting data currently available that describes the cost of maintaining a person who is ventilator dependent in their home. Available data references paediatric cases from both Ireland and the UK however it can be assumed that generally speaking, the direct care costs should not differ significantly between paediatric and adult

[19] M Flynn. 'The 'Pressure ulcers to zero collaborative'. HSE Quality & Safety Division. WIN Vol 22 No 9, Nov 2014
[20] Kruger et al. Comprehensive management of pressure ulcers in spinal cord injury. The Journal of Spinal Cord Medicine, 2013, vol 36, No 6.
[21] Toolkit to support ventilated children and young people in children's hospices' – Cooke, A et al, Children's Hospices UK)

patients. The predominant difference is generally relating to informal care i.e. that provided by parents/families which is often more apparent in paediatric patients.

Noyes *et al* (2006)[22] examined care packages for 35 ventilator dependent children and young people aged between one and 19 years from the caseloads of 11 consultants across England and Scotland. Some were supported in hospital, some at home and some were in the care of their local authority. The researchers found that caring for ventilator dependent children and young people at home is usually, but not always, cheaper than supporting them in hospital or long stay units, with the majority of the cost being picked up by the NHS[21].

The annual cost per child ranged from £10,000 to £633,700, excluding the cost of informal care. Home care costs included medical equipment, pharmaceutical products, and professional care. This included qualified nurses, nursery nurses and unqualified carers. Some teams were made up of a combination of skilled and unskilled staff and some parents or health care assistants were supported at a distance by qualified nurses[21].

This compared with an average annual cost of £155,158 for care on a children's ward, £301,888 in a long-term ventilation (LTV) unit and £630,388 in a children's intensive care unit. This data is supported by Murphy (2008)[23] who found that the average cost of caring for a child in a paediatric intensive care unit was £2,067 per day, equating to £754,455 annually, in contrast with £100,000 - £250,000 for a community package[21].

Both Noyes *et al* and Murphy identified additional issues to consider when caring in a hospital setting for children and young people who are medically fit for discharge. Important areas to consider include emotional, social and psychological implications for the children/young people and families and the impact of blocking an acute bed that could be required urgently by another patient[21].

Other data sources available include a German study completed by Geiseler et al (2010)[24]. While their study focused predominantly on neuromuscular conditions, they observed that 'in comparison to the costs that accumulate in the intensive care unit of a hospital, a reduction from 62% to 74% for the in-home care via an ambulatory nursing service is reported'.

In Ireland, the cost of a critical care bed is approx. €1,316 on top of the general cost for admission to an acute medical ward. Access to these beds is also a significant issue. In Ireland, we currently have 178 ICU beds and 55 HDU beds (National Critical Care Capacity and Critical Care Nursing Staff Establishment Provision 2014 Census). With critical care beds limited, they should not be used for the long-term care of patients who could be discharged home safely with an appropriately funded care package9.

HSE must reach a decision regarding the oversight of trained carers by a nurse, rather than these patients requiring 24hour nursing, as is the case in the UK & other developed countries.

Within paediatric services, work has been undertaken looking at the role and competencies of a nurse along with the role and competencies of a healthcare assistant. An educational module on the care of children who are ventilator dependent has been developed in collaboration with Temple Street Hospital along with a competency framework and assessment tool. This would support both nurses and healthcare assistants in achieving the appropriate level of competence in managing ventilated patients in the home. This would apply to service providers be they direct HSE employees or providing care as a preferred partner through a service level agreement. This work could and should be applied to adult services.

Similar educational modules could be developed addressing other care needs of those requiring a high level of support in the community. Any such undertaking would need to include all appropriate key stakeholders at both hospital, community and academic levels

[22] Noyes, J; Godfrey, C & Beecham J 2006. 'Resource use and service costs for ventilator-dependent children and young people in the UK'. *Health and Social Care in the Community* 14 (6) pp 508–522.
[23] Murphy J 2008. 'Medically stable children in PICU: better at home'. *Paediatric Nursing*.
February, vol 20, no 1 pp 14 – 16.
[24] Invasive home mechanical ventilation(HMV) , mainly focused on neuromuscular disorders. Geiseler J, Karg O, Börger GMS Health Technology Assessment 2010, Vol. 6, ISSN 1861-8863

GLOSSARY OF TERMS

Spinal Cord Injury (SCI)	Spinal cord injury (SCI) is damage to the spinal cord that causes changes in its function, either temporary or permanent. These changes translate into loss of muscle function, sensation, or autonomic function in parts of the body served by the spinal cord below the level of the lesion.
Spinal Cord System of Care (SCSC)	The Spinal Cord System of Care Programme at the National Rehabilitation Hospital (NRH) provides comprehensive inpatient and outpatient services to patients who, as a result of an accident, illness or injury, have acquired a spinal cord injury, or spinal cord dysfunction, and who require specialist medical rehabilitation.
Tetraplegia	TETRAPLEGIA**,** also known as quadriplegia, is paralysis caused by illness or injury that results in the partial or total loss of use of all four limbs and torso;
Paraplegia	Paraplegia is similar to tetraplegia but does not affect the arms. The loss is usually sensory and motor, which means that both sensation and control are lost.
ASIA impairment scale	The American Spinal Injury Association Classification of spinal cord injury**.** This is a clinical assessment tool used to DEFINE and describe the extent and severity of a person's spinal cord injury
Incidence	INCIDENCE in epidemiology is a measure of occurrence of a given medical condition in a population within a specified period of time i.e. the number of new cases during a specified time period
Prevalence	The percentage of a population that is affected with a particular disease at a given time
Respiratory insufficiency	The condition in which the lungs cannot take in sufficient oxygen or expell sufficient carbon dioxide to meet the needs of the cells of the body. Also called pulmonary INSUFFICIENCY. IT CAN BE A COMPLICATION OF A CERVICAL OR HIGHER THORACIC LESION
Weaning	Weaning from mechanical ventilation can be defined as the process of abruptly or gradually withdrawing ventilatory support, allowing the patient to assume a greater proportion of the ventilatory effort.
Cervical spinal injury	SPINAL CORD injuries at the CERVICAL **(**NECK**)** level
Thoracic spinal injury	Spinal cord Injuries at the level of T1 to T12 (chest & abdominal area)
Lumbosacral spinal injury	SPINAL CORD INJURY AT OR BELOW LEVEL L1 (the small of the back and the back part of the pelvis between the hips)
Complete spinal injury	A complete spinal cord lesion results in full, outright and usually permanent loss of ability to send sensory and motor nerve impulses below the level of the injury
Incomplete spinal injury	An incomplete lesion is the term used to describe partial damage to the spinal cord. With an incomplete lesion, some motor and sensory function can remain below the level of the injury
International Classification of Functioning (ICF)	ICF belongs to the WHO family of classifications and presents taxonomies of functioning and disability associated with health conditions. Since 2001 it is the recognised framework describing functioning and health
managed clinical rehabilitation networks (MCRNs)	Linked groups of health professionals and organisations from primary, secondary and tertiary care, working in a coordinated manner, unconstrained by professional and health board boundaries, to ensure equitable provision of high-quality, clinically effective rehabilitation services
Highly complex needs	Patients with profound disabilities e.g. severe physical, cognitive communicative disabilities or challenging behaviours.
Voluntary agency	Autonomous non-profit and non-statutory organisation providing a social or

	community service. In the context of the Programme, a voluntary agency is a specialist non-profit provider of neurological or disability services or supports.
HDUs	A high dependency unit is an area in a hospital, usually located closely to the intensive care unit, where patients can be cared for more extensively than on a normal ward, but not to the point of intensive care
ICU	INTENSIVE CARE UNIT**. (**ICU**)** a hospital UNIT in which is concentrated special equipment and specially trained personnel for the CARE of seriously ill patients requiring immediate and continuous attention **(**INTENSIVE CARE**).** Called also critical CARE UNIT**.**
Model 3 hospital	General Hospital. Model 3 hospitals will provide 24/7 acute surgery, acute medicine, and critical care
Model 4 hospital	Tertiary Hospital. Model 4 hospitals will be similar to model 3 hospital but will provide tertiary care and, in certain locations, supra-regional care.
Specialist rehabilitation	Specialist rehabilitation is the total active care of patients with a complex, disabling condition by a multi-professional team who have undergone recognised specialist training in rehabilitation, led or supported by a consultant trained and accredited in rehabilitation medicine
Autonomic dysreflexia	Autonomic dysreflexia is a syndrome in which there is a sudden onset of a range of symptoms and signs including excessively high blood pressure, precipitated by a stimulus below the level of the SCI that would usually cause pain It is occurs in people with spinal cord injuries at the T6 neurological level or above).
Mechanical ventilation	MECHANICAL VENTILATION is the medical term for ARTIFICIAL VENTILATION where MECHANICAL MEANS are used to assist or replace spontaneous breathing
Tracheostomy	A TRACHEOTOMY or a TRACHEOSTOMY is an opening surgically created through the neck into the trachea (windpipe) to allow direct access to the breathing tube
Laryngectomies	Laryngectomy is the removal of the larynx and separation of the airway from the mouth, nose and oesophagus. In a total laryngectomy the entire larynx is removed and in a partial laryngectomy only a portion is taken out. The laryngectomee breathes through an opening in the neck known as a stoma
Dysphagia	DYSPHAGIA is the medical term for the symptom of difficulty in swallowing

DRAFT

Rehabilitation Needs Assessment

Part A; A Needs Assessment should be completed for all patients with rehabilitation needs admitted to the hospital, within 48 hours. It should be completed with input from the rehabilitation team, and can be updated at regular time intervals. It may be used to signpost ongoing rehabilitation requirements and act as a discharge summary for patients with non-specialist ongoing rehabilitation needs.

Part B; For patients with specialist rehabilitation needs requiring bed-based post acute care rehabilitation services. This should include patients with estimated ISS ≥9 or RCSE > 13/22. The specialist rehabilitation prescription should be completed/signed off by a Consultant in rehabilitation or designate at discharge

Pages 1-3 to be completed for all patients assessed

Patient Name: **DoB:** **Address:** **MRN:** **GP:** **Current Location:**	**Date of Injury: ___/___/___** Injury Type (tick all that apply) □ Musculoskeletal □ Neurological □ Abdominal □ Amputation □ Burns □ Vascular □ Thoracic □ Brain Injury □ Spinal Cord Injury □ Other Other detail of Injury:
Family Contact/NOK:	**Consultant:** **Key worker:**
Estimated ISS:	
Date of initial rehabilitation needs assessment; ___/___/___	

Clinical needs assessment: Does the patient have any of the following needs?	
□ Musculoskeletal	□ Mood evaluation
□ Neuro-rehabilitation	□ Communication
□ Amputee rehabilitation	□ Challenging behaviour
□ Complex mental health	□ Cognitive assessment
□ Profound disability	□ Low awareness state
□ Complex pain management	□ Emotional support
Other needs;	

Please indicate professions required to support identified needs and ensure referral to same;
□ Physiotherapy □ Occupational Therapy □ Dietician □ Speech and Language Therapy □ Pain Team □ Clinical Nurse Specialist □ Orthotics □ Psychology □ Social services □ Rehab medicine □ Tissue Viability □ Palliative Care □ Psychiatry Additional Therapies/information:

Pre-injury Information:	
Home Support/ADL function;	Previous Mobility;
Housing/Accommodation;	Employment/Leisure;
Additional Medical History;	Alcohol/smoking;

TARN minimum dataset	
A) Rehabilitation prescription	□ No □ Yes □ Not required
B) Presence of physical factors affecting activities/participation	□ No □ Yes □ Not required
C) Presence of cognitive factors affecting activities/participation	□ No □ Yes □ Not required
D) Presence of psychosocial factors affecting activity/participation	□ No □ Yes □ Not required

Complexity: Rehabilitation Complexity Scale Extended (RCS-E)

	0	1	2	3	4
Care	Independent	1 carer	2 carers	≥ 3 carers	1:1
Risk	None	Low	Medium	High	Very high
Nursing	None	Qualified	Rehab nurse	Specialist nursing	High dependency
Medical	Non active	Basic	Specialist	Potentially unstable	Acute medical/surgical
Therapy disciplines	None	1	2-3	4-5	≥ 6
Therapy intensity	None	Low level (< daily)	Moderate (eg daily)	High (+ assistant)	Very high (>30 hours/week)
Equipment	None	Basic	Specialist	-	-

RSCE: C _____ N_____ M_____ Td_____ Ti_____ E_____ Total_____/22

FIM			
Motor items		12. Tub, shower transfer	/7
1. Eating	/7	13. Car transfer	/7
2. Swallowing	/7	14. (i) locomotion – walking "w"	/7
3. Grooming	/7	(ii) locomotion – wheelchair "c"	/7
4. Bathing	/7	Preferred mode of locomotion (w or c)	
5. Dressing Upper Body	/7	15. Stairs	/7
6. Dressing Lower Body	/7	16. Community mobility	/7
7. Toileting		Preferred mode; c=care; t=taxi; p=public transport	
8. (i) Bladder – level of assistance	/7	Total Scores;	
(ii) Bladder – frequency of accidents	/7	Self Care (7-49)	
9. (i) Bowel – level of assistance	/7	Bladder/Bowels (2-14)	
(ii) Bowel – frequency of accidents	/7	Locomotion (7-49)	
10. Bed, chair, wheelchair transfer	/7	Total Motor Sub-score (16-112)	
11. Toilet transfer	/7		

FAM			
Cognitive Items			
17. Comprehension	/7	26. Problem Solving	/7
18. Expression	/7	27. Memory	/7
19. Reading	/7	28. Orientation	/7
20. Writing	/7	29. Concentration	/7
21. Speech Intelligibility	/7	30. Safety Awareness	/7
22. Social Interaction	/7	Total Scores;	
23. Emotional Status	/7	Communication (5-35)	
24. Adjustment to limitations	/7	Cognitive/psychosocial (9-63)	
25. Leisure Activities	/7	Total Cognitive Sub-score (14-98)	

For patients with Spinal Cord Injury, please use SCIM, see appendix 2.	
Self-Care Sub-total	___/20
Respiration & Sphincter Management	___/40
Mobility	___/40
Total SCIM SCORE	___/100

GCS: E ..../V. .../M .... Total: ...../15	Motor Loss: □ Yes □ No	Sensory Loss: □ Yes □ No

Equipment Needs;	
□ Orthotics/Prosthetics/Splints: □ Mobility aids/transfer equipment: □ Specialist seating	□ Bed/posture Management: □ Activities of Daily Living equipment □ Other (eg Environmental controls)

Anticipated Rehabilitation services required;	
1. Complex Specialist Inpatient Rehabilitation	□ Yes □ No
2. Specialist Inpatient Rehabilitation	□ Yes □ No
3. Community based specialist Rehabilitation	□ Yes □ No
4. Non-specialist Inpatient Rehabilitation	□ Yes □ No
5. Community based non-specialist rehabilitation	□ Yes □ No
IF COMPLEX SPECIALIST OR SPECIALIST REHABILITATION SERVICES ARE INDICATED, PLEASE REFER PATIENT TO CONSULTANT IN REHABILITATION MEDICINE AND PROGRESS TO PAGE 6 FOR COMPLETION OF REHABILITATION PRESCRIPTION	

Progress/Complications

Functional Status at discharge/transition another facility for post-acute rehabilitation:		
Injuries still requiring active management;		GCS: E ..../V. .../M .... Total: ...../15 Motor Loss: □ Yes □ No Sensory Loss: □ Yes □ No RCS- E: M.../C.../N.../Td.../Ti.../E... Total: ..../22

PLEASE COMPLETE AT LEAST ONE GLOBAL OUTCOME MEASURE SPECIFIC TO PERSONS DIAGNOSIS	
OUTCOME MEASURE	SCORE

Date: / / Role:	Completed by: Signature

Name of service/unit to where patient has been referred; Date referral acknowledged; Anticipated waiting time for transfer;

PART B; REHABILITATION PRESCRIPTION

Patient Name: **DoB:** **Address:** **MRN:**

Summary of current impairments/function					
Neurological	**Consciousness**	**Motor Loss**	**Sensory Loss**	**Vision**	**Hearing**
	GCS ..../15	Yes □ No □	Yes □ No □	Intact □ Impaired □	Intact □ Impaired □
	Muscle Tone	**Behaviour**	**Cognition**	**Mood**	**Anxiety/depression**
	Normal □ Impaired □	Normal □ Impaired □	Normal □ Impaired □	Normal □ Impaired □	Normal □ Impaired □
Respiratory	**Oxygen support**	**Tracheostomy**	**Assisted ventilation**	**Management/ weaning plan**	
	Yes □ No □ Type:	Yes □ No □ Type:	Yes □ No □	Yes □ No □ Details:	
Mobility	**Sitting out**	**Transfers**	**Walking**	**Washing & Dressing**	

	Standard Chair □ Special seating □ Unable □	Independent □ Assist + 1 □ Assist + 2 □ Hoisted □	Independent □ Assist + 1 □ Assist + 2 □ Unable □	Independent □ Assist + 1 □ Assist + 2 □
Weight Bearing	**Upper limbs**			
	Lower limbs			
Continence & skin	**Bladder**	**Bowel**	**Skin**	
	Catheter Yes □ No □ Independent with: Toilet/commode/urinal □ Requires assistance; Assist + 1 □ Assist + 2 □	Independent with: Toilet/commode □ Requires assistance; Assist + 1 □ Assist + 2 □	Waterlow □ Braden □ Score: Pressure Sore: Yes □ No □ Grade/location:	
Nutrition	Special Diet; Yes □ No □	Diabetic; Yes □ No □	MUST Score	
	Swallowing	Normal □ Impaired □ Nil by mouth □		
	Food consistency	Normal oral fluid & diet □ Modified oral fluid & diet □ Pureed/soft diet □ PEG/NG fed □		
	Feeding	Independent □ Requires assistance □		
Expected Duration of admission		Rapid intervention (2 weeks) □ Short stay (2-6 weeks) □ Medium stay (6-12 weeks) □ Long stay (+12 weeks) □		
Equipment	□ Orthotics/prosthetics/splints □ Mobility aids/transfer equipment □ Specialist seating □ Bed/posture management □ Activities of daily living equipment □ Other (eg environmental controls)			

Current Rehabilitation Needs:		**Details:**
Medical	□ Neurosurgery □ Orthopaedic □ Surgical □ Cardiothoracic □ Amputee □ Spinal Injuries □ Not yet assessed □ Other	
Physical	□ Mobility □ Limb function □ Splinting/orthotics □ Spasticity/Tone □ Pain □ Postural support □ Not yet assessed □ Other	

Nursing/ Communication	□ Tracheostomy □ 1:1 supervision □ Continence □ Wound Management □ Pressure area care □ Infection Control □ Swallow □ Nutrition □ Communication □ Not yet assessed □ Other	
Functional	□ Personal care □ Transfers □ Extended ADL □ Vocational □ Educational □ Not yet assessed □ Other	
Cognitive/ psychosocial	□ Sensory □ Cognitive/perceptual □ Behavioural □ Mood/emotional □ Psychological □ Mental Health □ Family Support □ Not yet assessed □ Other	
Discharge Planning	□ Housing/Placement □ Benefits/Finances □ Equipment/Adaptation □ Community Visit □ Funding □ Not yet assessed □ Other	
Other on-going risks	□ Capacity concerns □ Medico legal	

Rehabilitation Goal/s	Summary of Treatment and Plan	Achieve By
Discharge planning and referrals made:		
Current outstanding rehabilitation needs:		

Name of service/unit to where patient has been referred; Date referral acknowledged; Anticipated waiting time for transfer;	
GCS: E ..../V. .../M .... Total: ...../15 Motor Loss: □ Yes □ No Sensory Loss: □ Yes □ No	RCS- E: M.../C.../N.../Td.../Ti.../E... Total: ..../22
PLEASE COMPLETE AT LEAST ONE GLOBAL OUTCOME MEASURE – OUTCOME MEASURE TO BE DETERMINED BY PATIENTS DIAGNOSTIC CRITERIA	
OUTCOME MEASURE	SCORE

Date of prescription: / /

Completed by:

Role:

Signature

APPENDIX 2; FROM ATTENDANT CARE GUIDELINES

CONSIDERATIONS IN PROVIDING AND DELIVERING ATTENDANT CARE

Consideration should be given to issues relating to the provision and delivery of care. While these may often differ from person to person, several key issues to consider have been identified.

• **Access:** The highest level of care and hours indicated will not be required by everyone. However, those living independently, particularly at level C6 and above, require easy access to assistance for emergencies.

• **Combined tasks:** There may be times when personal care duties may also include some simple household activities that can be undertaken in conjunction with personal care, e.g. soaking / washing personal clothing items. There may also be times when the person wishes, for convenience or to reduce the number of attendant care workers coming into their home, to combine some personal assistance, domestic assistance and community access tasks. It cannot, however, be assumed that certain tasks will be combined. The combining of tasks must be negotiated between all parties.

• **Day services:** Day services in the community can enhance quality of life and reduce support hours required in the home. It is subject to individual local services and availability, but should be explored as an option.

• **Effective case management**: Has the potential to reduce overall care hours by: ensuring a coordinated approach to services delivery; implementing goal-directed interventions that increase independence; and ensuring a focus on promoting health. The number of attendant carers required must be taken into consideration, particularly for high level injuries when two or more may be necessary for some tasks. Case management may be intermittent or ongoing.

• **Emergency care:** The category of respite care does not include emergency care, e.g. if there is the need to recall a personal assistant due to a fall or other unforeseen event. Emergency care should not have a limit; however, if emergency support hours are high it indicates that a reassessment may be required as support hours being provided in another category may be inadequate.

• **Equipment:** Should be maintained and / or replaced according to the manufacturers' specifications and treating therapists' recommendations. All requests for new equipment and maintenance should be evaluated against the documented assessment of need.

• **Family or friends:** It may be appropriate for family or friends to receive training if they choose to have a more integrated role in the person's attendant care, or be relied on to provide care in an emergency.

• **Occupational Health and Safety requirements:** Management and operation of all equipment should comply with health and safety regulations. Regulation health and safety equipment must be provided and are considered necessary to maintain the "typical" level of care. These requirements are not factors that will decrease care hours.

• **Qualifications:** It is necessary that nursing or other qualifications are designated on a task basis to ensure that certain levels of training are mandated by the nature of the activity. For example, the necessity of a Registered Nurse for some wound dressing procedures. Bowel care should be performed by a Registered Nurse, a trained attendant, or carer.

• **Reasonable and necessary:** What is **"**reasonable and necessary**"** relates to a person and their specific circumstances and therefore varies from person to person. Factors that may be considered include the pre-injury lifestyle of the person and the availability and cost of new technology.

Respite Care: Refers to a flexible short-term break from the regular care routine for the person or their family / carer. It can be provided at home or in a separate location. It is subject to local services and availability.

• **Risk management plan:** Spinal Cord Injury is a complex condition and can bring about many medical conditions and complications. An individualised risk management plan should be developed for each person, outlining the identified risks directly related to their care needs and detailing how each risk will be managed.

COMPLETE CERVICAL 1–3 (C1–C3)

REQUIRES VENTILATOR SUPPORT

SUMMARY OF IMPAIRMENT TO BODY SYSTEM

Mobility

- Total paralysis of all limbs and trunk.
- Limited active head and neck movement.

Respiration

- Respiratory muscle function impaired and respiratory capacity and endurance compromised.
- Requires ventilator support; inability to clear secretions and intermittent suction required.
- Ventilator is necessary; however portable ventilator will attach to back of chair.
- Oxygen and humidification are also required.

Autonomic dysfunction

- Vulnerable to autonomic dysreflexia and orthostatic hypotension.
- Vulnerable to impaired thermoregulation.

Other

- Neurogenic bladder and neurogenic bowel.

SUMMARY OF ACTIVITY LIMITATIONS AND ASSISTANCE REQUIRED

MOBILITY

- Full assistance required for all transfers, including use of a hoist with 1–3 assistants, due to a range of factors, e.g. the weight of the person, spasticity, assist with head support.
- Possible ability to manoeuvre power chair with chin control or other adaptive device.
- Full assistance required with transport.
- Wheel-in vehicle necessary for transport.

ACTIVITIES OF DAILY LIVING

- Full assistance required for bowel / bladder management, bathing / showering, lower body dressing and upper body dressing, feeding.

Support Hours: Personal Assistance | Minimum of 196 hours per week / 28 hours per day

- Full assistance required with personal care.
- Level of care for adults is based on 24-hour active care plus additional:
  - 2 hours (morning care – for bowel management, showering, grooming, transfers)
  - 1 hour (afternoon – for transfers and skin integrity)
  - 1 hour (at night – transfers, skin integrity, and settling).
- Total required care is 28 hours daily.
- If the person is medically stable, care is generally provided under the supervision of a Qualified Nurse by personal care attendants who have successfully completed training. Training is generally provided by the discharging rehabilitation hospital and then sustained by the service provider at community level. Training modules required include:
  - administration of medication • bowel management • respiratory function
  - autonomic dysreflexia • emergency tracheostomy change • skin integrity
  - bagging • equipment use and maintenance • spinal cord injuries
  - bladder management – female / male catheterisation and supra pubic catheterisation • oxygen therapy • suctioning • percutaneous endoscopic gastrostomies (PEG) feeding • tracheostomy care • ventilator management and failure.

- If the treating team identifies that the person is significantly medically unstable (e.g. with severe dysreflexia) this situation may best be managed with appropriately Qualified Nurses providing all attendant care. However, there may be some circumstances where this level of care is not available (e.g. in remote geographic areas). In all cases, access to a Qualified Nurse for support and advice is required 24 hours / 7 days with all programs routinely and regularly reviewed by an appropriately skilled Registered Nurse.
- Each situation requires individual assessment of needs and circumstances. Support arrangements should always be negotiated with the family as they may wish to have some family time with minimal staff disturbance.

OTHER ACTIVITIES OF DAILY LIVING

- Range of abilities varies from limited to good use of mouth stick for computers, keyboards, telephones, turning pages and environmental controls.
- Range of assistance required varies from full assistance to independent in communication technology, depending on workstation setup and equipment availability.
- Full assistance required with all domestic duties.

Support Hours: Domestic Assistance | 5 to 21 hours per week

- At this level of injury (assuming the person is medically stable), it is appropriate that routine daily domestic duties can be attended to by personal care attendants.
- These duties may include meal preparation, personal laundry, shopping (with the person) and specific household tasks. It is recommended that the person be provided with a contact system (e.g. transportable intercom / monitor) that the personal care attendant carries with them.

PARTICIPATION

Support Hours: Community Access | 0 to 7 hours per week

- A second person is required as a driver for all community access for people who require ventilator support. The other hours are highly variable depending on the person's age, lifestyle and the amount of support the activity requires, e.g. playing cards, fishing, going to the movies, socialising with friends.
- The categories of child-care services, educational support and vocational support have not been allocated a range of support hours. The support requirements in these categories are very specific to a person's circumstances and should be based on an assessment of the person's need.

SUMMARY OF SUPPORT HOURS REQUIRED

	Hours per week
Activities of Daily Living – Personal Assistance	**196**
Other Activities of Daily Living – Domestic Assistance	**5 - 21**
Participation – Community Access	**0 - 7**
Participation – Child-care/Educational/Vocational	**Variable**
Total Hours	**201 - 224**

COMPLETE CERVICAL 4 (C4)

SUMMARY OF IMPAIRMENT TO BODY SYSTEM

Mobility

- Total paralysis of trunk and lower extremities.
- No elbow, wrist or finger movement.
- Can move head and neck. Minimal movement of shoulders – may shrug.

Respiration

- Respiratory muscle function impaired and respiratory capacity and endurance compromised.
- May require non-invasive / invasive ventilator support for part of the day. Able to breathe without a ventilator.

- Will require assistance to clear secretions, assisted cough and / or suctioning, which may be through a tracheostomy.

Autonomic dysfunction

- Vulnerable to autonomic dysreflexia and orthostatic hypotension.
- Vulnerable to impaired thermoregulation.

Other

- Neurogenic bladder and neurogenic bowel.

SUMMARY OF ACTIVITY LIMITATIONS AND ASSISTANCE REQUIRED

MOBILITY

- Full assistance required for all transfers, including use of a hoist with 1–2 assistants, due to a range of factors including the weight of the person and spasticity.
- Full assistance required for propelling a manual wheelchair.
- Can use chin control for power wheelchair on flat ground and ramps of low gradient.
- Full assistance required with transport.
- Wheel-in vehicle necessary for transport.

ACTIVITIES OF DAILY LIVING

- Will require arm supports.
- Full assistance required for bowel / bladder management.
- Full assistance required for bathing / showering, dressing and grooming.
- Full assistance required for food / meal preparation, cutting food and eating.

Support Hours: Personal Assistance | 49 to 91 hours per week /7 to 13 hours per day

- Full assistance is required with personal care.
- If the person is medically stable, care is generally provided under the supervision of a Qualified Nurse by personal care attendants who have successfully completed training. Training is generally provided by the discharging rehabilitation hospital and then sustained by the service provider in the community. Training modules required include:
  • administration of medication • bowel management • respiratory function
  • autonomic dysreflexia • emergency tracheostomy change • skin integrity
  • bagging • equipment use and maintenance • spinal cord injuries • bladder management – female / male catheterisation and supra pubic catheterisation • oxygen therapy • suctioning • percutaneous endoscopic gastrostomies (PEG) feeding • tracheostomy care • ventilator management and failure.
- If a person is not living with someone in attendance, then the maximum level of adaptive environmental equipment is necessary including access to a personal alarm and security and environmental control systems.
- The higher range of care hours should apply where the person is older, requires more regular turning, or has any of the following: spasticity, postural hypertension, wound care requirements, pain, or autonomic dysreflexia.

Nighttime Cover:| 56 hours per week / 8 hours per day

- Attendant care worker required to sleep at the workplace and be available to deal with any urgent situation which cannot be dealt with by another worker or be dealt with after the end of the sleepover period.
- Some people may prefer not to have an inactive sleepover. If so, a personal alarm system, full environmental control for lights / TV, air conditioning, etc. would need to be fully operational and the person able to independently access a drinking system overnight.

OTHER ACTIVITIES OF DAILY LIVING

- Range of abilities varies from limited to good use of mouth stick for computers, keyboards, telephones, turning pages and environmental controls.
- Range of assistance required varies from full assistance to independent in communication technology, depending on workstation setup and equipment availability.
- Full assistance required with domestic duties.

Support Hours: Domestic Assistance | 18 to 21 hours per week

- The range at this level includes total assistance with washing and ironing, shopping etc.
- There may be negotiated times between the person and their personal, domestic and community access assistants where there is some sharing of tasks to allow a more flexible routine or to limit the number of support staff coming into their home.

PARTICIPATION

Support Hours: Community Access | 7 to 10 hours per week

- The 7-hour lower range is for transport, including to medical and other personal appointments, e.g. dentist etc.
- The other hours are highly variable depending on the person's age, past social habits and the amount of support the activity requires e.g. playing cards, fishing, going to the movies, socialising with friends.
- Child-care services, educational support and vocational support have not been allocated a range of support hours. The support requirements in these categories are very specific to the person's circumstances and should be based on an assessment of the person's needs.

SUMMARY OF SUPPORT HOURS REQUIRED

The upper range of personal assistance hours allows for 24-hour care when combined with domestic services and an inactive sleepover. When 24-hour care is provided, additional care hours will not be necessary for community access.

	Hours per week
Activities of Daily Living – Personal Assistance	**49 - 91**
Nighttime Cover	**0 - 56**
Other Activities of Daily Living – Domestic Assistance	**18 - 21**
Participation – Community Access	**7 - 10**
Participation – Child-care/Educational/Vocational	**Variable**
Total Hours	**74 - 178**

COMPLETE CERVICAL 5 (C5)

SUMMARY OF IMPAIRMENT TO BODY SYSTEM

Mobility

- Total paralysis of trunk and lower extremities.
- Limited movement in elbow and forearm.
- No wrist or finger movement.
- Can move head and neck with moderate shoulder control.

Respiration

- Respiratory muscle function impaired and respiratory capacity and endurance compromised.
- Will require assistance to clear secretions, assisted cough and / or suctioning, which may be through a tracheostomy.

Autonomic dysfunction

- Vulnerable to autonomic dysreflexia and orthostatic hypotension.
- Vulnerable to impaired thermoregulation.

Other

- Neurogenic bladder and neurogenic bowel.

SUMMARY OF ACTIVITY LIMITATIONS AND ASSISTANCE REQUIRED

MOBILITY

- Full assistance required for all transfers, including use of a hoist with 1–2 assistants, due to a range of factors including the weight of the person and spasticity.
- Range of assistance required varies from full assistance with manual chair with capstans, pushing uphill, downhill, on rough surfaces and outdoors.
- Able to use power wheelchair with hand control.
- Rarely able to drive motor vehicle but possible with appropriately modified vehicle, adaptive equipment and assistance with transfer and positioning chair.
- Full to moderate assistance required with transport.

ACTIVITIES OF DAILY LIVING

- Splints or palmar straps will be needed for any activity needing hand or digital grip.
- Full assistance required for bowel / bladder management, bathing / showering, lower body dressing and upper body dressing.
- Range of assistance required varies from full to minimal assistance for grooming with adapted equipment.
- Full assistance required with bed / wheelchair transfers and assistance in positioning with equipment.
- Full assistance required for food / meal preparation and cutting food.
- Range of assistance required varies from full assistance to moderate in eating with equipment / splints.

Support Hours: Personal Assistance | 42 to 49 hours per week / 6 to 7 hours per day

- Full assistance required with personal care.
- If the person is not living with someone in attendance, the maximum level of adaptive environmental equipment is necessary, including access to a personal alarm system and environmental control systems.
- The higher range of care hours should be applied where the person is older, requires more regular turning or has any of the following: spasticity, postural hypertension, wound care requirements, pain, or autonomic dysreflexia or physique which requires 2 attendants for transfers e.g. extreme obesity.

Support Hours: Nighttime Cover | 56 hours per week / 8 hours per day

- An attendant is required to sleep at the workplace and be available to deal with any urgent situation which cannot be dealt with by another worker or be dealt with after the end of the sleepover period.
- Some people may prefer not to have an inactive sleepover. If so, a personal alarm, full environmental control for lights / TV, air conditioning, etc. would need to be fully operational and the person able to independently access a drinking system overnight.

OTHER ACTIVITIES OF DAILY LIVING

- Range of assistance required varies from full assistance to independent in communication technology, depending on workstation setup and equipment availability.
- Can turn pages and use computers, keyboards, telephones and environmental controls with adaptive equipment / devices.
- Full assistance required with all domestic duties.

Support Hours: Domestic Assistance | 18 to 21 hours per week

- The range at this level includes full assistance with tasks such as washing, ironing, shopping, etc.
- There may be negotiated times between the person and their personal, domestic and community access assistants where there is some sharing of tasks to allow a more flexible routine or to limit the number of support staff coming into their home.

PARTICIPATION

Support Hours: Community Access | 7 to 10 hours per week

- The 7-hour lower range is for transport, including to medical and other personal appointments, e.g. dentist etc.
- The other hours are highly variable depending on the person's age, past social habits and the amount of support the activity requires.
- Child-care services, educational support and vocational support have not been allocated a range of support hours. The support requirements in these categories are very specific to the person's circumstances and should be based on an assessment of the person's needs.

SUMMARY OF SUPPORT HOURS REQUIRED

	Hours per week
Activities of Daily Living – Personal Assistance	**42 - 49**
Nighttime Cover	**0 - 56**
Other Activities of Daily Living – Domestic Assistance	**18 - 21**
Participation – Community Access	**7 - 10**
Participation – Child-care/Educational/Vocational	**Variable**
Total Hours	**67 - 136**

COMPLETE CERVICAL 6 (C6)

SUMMARY OF IMPAIRMENT TO BODY SYSTEM

Mobility
- Total paralysis of trunk and lower extremities.
- Minimal movement in elbow, forearm and wrist.
- Can move head and neck with moderate shoulder control.

Respiration
- Respiratory muscle function impaired and respiratory capacity and endurance compromised.
- May require assistance to clear secretions.

Autonomic dysfunction
- Vulnerable to autonomic dysreflexia and orthostatic hypotension.
- Vulnerable to impaired thermoregulation.

Other
- Neurogenic bladder and neurogenic bowel.

SUMMARY OF ACTIVITY LIMITATIONS AND ASSISTANCE REQUIRED

MOBILITY
- Full assistance required for floor to chair transfer.
- Range of assistance required varies from moderate assistance to independent with wheelchair to bed and bed to commode transfer.
- Minimal to moderate assistance required with other transfers depending on a range of factors including age, strength, upper torso mobility, size, other disability, hand function, upper limb length and current well-being.
- Independent using manual wheelchair on even surfaces. (Sometimes requires capstans on hand rims).
- Range of assistance required varies from full to moderate assistance with manual wheelchair outdoors. Independent with standard hand-control power wheelchair on all surfaces.
- May choose to use a power wheelchair with hand control for long distance travel.
- Can drive an appropriately modified vehicle using hand controls but may require assistance with transfer in / out of vehicle, clamping / unclamping and loading / unloading chair.

ACTIVITIES OF DAILY LIVING
- Minimal assistance may be required with applying adaptive bands although this may not be necessary when using appropriately engineered bands.
- Palmar straps needed for writing, typing, grooming, feeding etc.
- Full to moderate assistance required with bowel management.
- Range of assistance required varies from full to moderate assistance with bladder management.

- Emptying own leg bag may be possible but usually requires assistance.
- Range of assistance required varies from full to moderate assistance with lower body bathing and lower body dressing.
- Range of assistance required varies from minimal assistance to independent with bathing upper body and grooming using adaptive equipment.
- Moderate assistance required with upper body dressing.
- Full assistance needed with cutting food and independent eating with adaptive equipment.

Support Hours: Personal Assistance | 28 to 35 hours per week / 4 to 5 hours per day

- On average, 4 hours per day is usual; however, there are some circumstances where the upper range will be necessary – for example where assistance with bladder management does not fit into a 4 hour per day routine.

OTHER ACTIVITIES OF DAILY LIVING

- Independent in communication technology, depending on workstation setup and equipment availability.
- Can prepare basic meals using adaptive equipment. Requires assistance with complex meal preparation.
- Moderate to full assistance required with all other house-cleaning and domestic duties.
- Full assistance required with home maintenance.

Support Hours: Domestic Assistance | 18 to 21 hours per week

- A breakdown of the hours could be interpreted as 2 hours per day meal preparation, 3 hours week shopping, 4 hours cleaning, washing, ironing and other domestic duties per week.

PARTICIPATION

Support Hours: Community Access | 7 to 10 hours per week

- This is for transport including medical and other personal appointments, e.g. dentist etc. If a person has a fully modified vehicle that they can access and drive independently, then transport hours would be reduced.
- The other hours are highly variable depending on the person's age, past social habits and the amount of support the activity requires, e.g. playing cards, fishing, going to the movies, socialising with friends.
- Child-care services, educational support and vocational support have not been allocated a range of support hours. The support requirements in these categories are very specific to the person's circumstances and should be based on an assessment of the person's needs.

SUMMARY OF SUPPORT HOURS REQUIRED

	Hours per week
Activities of Daily Living – Personal Assistance	**28 – 35**
Other Activities of Daily Living – Domestic Assistance	**18 - 21**
Participation – Community Access	**7 – 10**
Participation – Child-care/Educational/Vocational	**Variable**
Total Hours	**53 – 66**

COMPLETE CERVICAL 7–8 (C7–C8)

SUMMARY OF IMPAIRMENT TO BODY SYSTEM

Mobility

- Total paralysis of trunk and lower extremities.
- Full shoulder and elbow movement.
- Moderate arm, wrist and finger control. A person with an injury at C7 has movement in thumbs and gross grip.

- Can move head and neck, with good shoulder control.

Respiration

- Respiratory muscle function impaired and respiratory capacity and endurance compromised.
- May require assistance to clear secretions.

Autonomic dysfunction

- Vulnerable to autonomic dysreflexia and orthostatic hypotension.
- Vulnerable to impaired thermoregulation.

Other

- Neurogenic bladder and neurogenic bowel

SUMMARY OF ACTIVITY LIMITATIONS AND ASSISTANCE REQUIRED

MOBILITY

- Moderate assistance to independent with floor-to-chair transfers.
- Usually independent in transferring to and from level surface with aid of transfer board. May require moderate to minimal assistance with uneven transfers.
- Independent using manual wheelchair on indoor surfaces and level outdoor terrain.
- Range of assistance required with manual wheelchair on uneven surfaces.
- Independent using power wheelchair on outdoor surfaces. May choose to use a power wheelchair with hand control for long distance travel.
- Can drive an appropriately modified vehicle. Independent with transport if able to transfer, load and unload wheelchair or able to wheel directly into an appropriately modified vehicle (e.g. a van). Some people may require assistance with transfer, clamping / unclamping and loading / unloading wheelchair.

ACTIVITIES OF DAILY LIVING

- Moderate assistance to independent for bowel / bladder management.
- Independent in upper body, showering / bathing and dressing; may require assistance in lower body showering/dressing.
- Independent in grooming.
- Range of assistance required varies from moderate to minimal assistance with complex meal preparation.
- Independent with light meal preparation and eating.
- Independent in most other activities with minimal use of adaptive equipment.

Support Hours: Personal Assistance | 14 to 21 hours per week / 2 to 3 hours per day

- Generally requires 2 hours assistance in the morning and 1 hour in the evening; this may vary depending on individual needs.

OTHER ACTIVITIES OF DAILY LIVING

- Independent with light house duties. Full assistance required with heavy housework and home maintenance. Other domestic duties possible if living in an appropriately modified house.

Support Hours: Domestic Assistance | 7 to 21 hours per week

- A break down of the hours could be interpreted as 2 hours per day meal preparation (assuming breakfast is independent), 3 hours shopping and 4 hours cleaning, washing, ironing and other domestic duties per week. Less than 2 hours meal preparation may be required on some days if lunch is prepared beforehand or purchased while out.

PARTICIPATION

Support Hours: Community Access | 0 to 10 hours per week

- The lower range only applies to people who are independent in transfer.
- This figure includes transport assistance. Although some people may be independent with transfer and wheelchair loading / unloading and be able to drive an appropriately modified vehicle, there is still an allowance of 7 hours per week assistance with transport. Assistance with transport will still be necessary for those who do not have a licence and / or do not have access to an accessible vehicle. A reduction in transport assistance would be justified if the person has an accessible vehicle and is an independent driver.

- The other hours are highly variable depending on a person's age, past social habits and interests, e.g. playing cards, fishing, going to the movies, socialising with friends.
- Child-care services, educational support and vocational support have not been allocated a range of support hours. The support requirements in these categories are very specific to the person's circumstances and should be based on an assessment of the person's needs. For example, if 8 hours educational / vocational support is required at an education facility or work then it is likely there may be a reduced need for domestic meal preparation during the day.

SUMMARY OF SUPPORT HOURS REQUIRED

	Hours per week
Activities of Daily Living – Personal Assistance	**14 - 21**
Other Activities of Daily Living – Domestic Assistance	**7 - 21**
Participation – Community Access	**0 - 10**
Participation – Child-care/Educational/Vocational	**Variable**
Total Hours	**21 - 52**

COMPLETE THORACIC 1–4 (T1–T4)

SUMMARY OF IMPAIRMENT TO BODY SYSTEM

Mobility
- Total paralysis of the lower trunk and lower extremities.
- Limited upper trunk stability. Impaired sitting balance.
- Full control of upper limbs. (A person with an injury at the T1 level may not have fine hand control.)

Respiration
- Respiratory muscle function impaired. Compromised respiratory capacity and endurance.

Autonomic dysfunction
- Vulnerable to autonomic dysreflexia and orthostatic hypotension.
- Vulnerable to impaired thermoregulation.

Other
- Neurogenic bladder and neurogenic bowel.

SUMMARY OF ACTIVITY LIMITATIONS AND ASSISTANCE REQUIRED

MOBILITY
- May require assistance with floor-to-chair transfer due to a range of factors including age, strength, upper torso mobility, size, other disability, hand function, upper limb length and current well-being.
- Independent in transfer with or without equipment on level surface. Minimal assistance with uneven transfers.
- Independent using manual wheelchair. May choose to use a power wheelchair hand control for long distance travel.
- Can drive an appropriately modified vehicle. Independent with transport if able to transfer, load and unload wheelchair or able to wheel directly into an appropriately modified vehicle (e.g. a van). Some people may require assistance with transfer, clamping / unclamping and loading / unloading wheelchair.

ACTIVITIES OF DAILY LIVING
- Minimal support in all personal care is required if the person has no other complicating factors, e.g. health, weight, or other disability and living in an appropriately modified environment.

Support Hours: Personal Assistance | 0 to 14 hours per week

- There is a wide variation in the level of personal assistance required for this level of injury. Generally, the higher level of support hours refers to the higher level of injury.

OTHER ACTIVITIES OF DAILY LIVING

- Will need assistance with heavy housework and home maintenance.
- Other domestic duties are possible if the person lives in an appropriately modified environment.

Support Hours: Domestic Assistance | 0 to 14 hours per week

- The range of support hours is due to the large variance in function at this level of injury. The 14 hours per week would be required if the person has poor trunk control, balance, or hand control.
- Domestic assistance required, including shopping, cleaning, washing and ironing. If assistance with shopping is required then the upper level of support hours would be necessary.

PARTICIPATION

Support Hours: Community Access | 0 to 7 hours per week

- This figure reflects transport assistance. Although some people may be independent with transfer and wheelchair loading / unloading and able to drive there is still an allowance of 7 hours per week assistance with transport.
- Assistance with transport is still necessary for those who do not have a license and / or do not have access to an accessible vehicle. No transport assistance may be justified if the person had an accessible vehicle and is an independent driver.
- Child-care services, educational support and vocational support have not been allocated a range of support hours. The support requirements in these categories are very specific to the person's circumstances and should be based on an assessment of the person's needs.

SUMMARY OF SUPPORT HOURS REQUIRED

	Hours per week
Activities of Daily Living – Personal Assistance	**0 - 14**
Other Activities of Daily Living – Domestic Assistance	**0 - 14**
Participation – Community Access	**0 - 7**
Participation – Child-care/Educational/Vocational	**Variable**
Total Hours	**0 - 35**

COMPLETE THORACIC 5–9 (T5–T9)

SUMMARY OF IMPAIRMENT TO BODY SYSTEM

Mobility

- Total paralysis of the lower trunk and lower extremities.
- Moderate upper trunk stability. Moderately impaired sitting balance.
- Full control of upper limbs.
- Full control of shoulder, elbow, wrist and hand.

Respiration

- Compromised respiratory capacity and endurance.
- May need assisted cough strategy.

Autonomic dysfunction

- People with spinal cord lesions at T6 and above are vulnerable to autonomic dysreflexia and orthostatic hypotension.
- Vulnerable to impaired thermoregulation.

Other

- Neurogenic bladder and neurogenic bowel.

SUMMARY OF ACTIVITY LIMITATIONS AND ASSISTANCE REQUIRED

MOBILITY

- May require assistance with floor-to-chair transfer due to a range of factors including age, strength, upper torso mobility, size, other disability, upper limb length and current well-being.
- Independent in transfers on level surface. Minimal assistance to independent with uneven transfers.
- Independent using manual wheelchair on indoor surfaces. May require assistance on some outdoor surfaces.
- Can drive an appropriately modified vehicle. Independent with transport if able to transfer, load and unload wheelchair or able to wheel directly into an appropriately modified vehicle (e.g. a van). Assistance may be required for clamping and unclamping of the wheelchair in the vehicle. Some people may require assistance with transfer and loading / unloading wheelchair.

ACTIVITIES OF DAILY LIVING

- Minimal support is required with personal care if the person lives in an appropriate accessible environment and has no other complicating factors, e.g. health, weight, or other disability.

Support Hours: Personal Assistance | 0 to 10 hours per week

- There is a wide variation in the level of personal assistance required for this level of injury. Generally, the higher level of support hours refers to the higher level of injury.

OTHER ACTIVITIES OF DAILY LIVING

- Will need assistance with heavy housework or home maintenance.
- Other domestic duties are possible if the person lives in an appropriately modified environment.

Support Hours: Domestic Assistance | 0 to 10 hours per week

- The range of support hours is due to the large variance in function at this level of injury. The 10 hours per week would be required if the person has poor trunk control and needs greater assistance with heavy domestic duties e.g. pushing and loading a shopping trolley, carrying and hanging washing etc.

PARTICIPATION

Support Hours: Community Access | 0 to 7 hours per week

- Assistance with transport would not usually be required at this level of injury. The upper range may be required for assistance with transport where the person is unable to transfer, clamp and unclamp the wheelchair in the vehicle, or load and unload the wheelchair.
- Child-care services, educational support and vocational support have not been allocated a range of support hours. The support requirements in these categories are very specific to the person's circumstances and should be based on an assessment of the person's needs.

SUMMARY OF SUPPORT HOURS REQUIRED

	Hours per week
Activities of Daily Living – Personal Assistance	**0 - 10**
Other Activities of Daily Living – Domestic Assistance	**0 - 10**
Participation – Community Access	**0 - 7**
Participation – Child-care/Educational/Vocational	**Variable**
Total Hours	**0 - 27**

COMPLETE THORACIC 10 – LUMBAR 1 (T10–L1)

SUMMARY OF IMPAIRMENT TO BODY SYSTEM

Mobility

- Partial paralysis of lower trunk.

- Total paralysis of lower extremities.
- Minimally impaired balance in sitting.
- Full control of upper limbs.
- Full control of shoulder, elbow, wrist and hand.

Respiration

- Minimal compromise to respiratory capacity and endurance. However, may need assisted cough strategy.

Other

- Neurogenic bladder and neurogenic bowel.

SUMMARY OF ACTIVITY LIMITATIONS AND ASSISTANCE REQUIRED

MOBILITY

- May require assistance with floor-to-chair transfer due to a range of factors including age, strength, upper torso mobility, size, other disability, upper limb length and current well-being.
- Independent in all other transfers with or without equipment.
- Independent using manual wheelchair on indoor surfaces. May require assistance on some outdoor surfaces.
- Independent in driving an appropriately modified vehicle including loading and unloading wheelchair. However, a car hoist may be required to facilitate this.

ACTIVITIES OF DAILY LIVING

- Minimal support is required with all personal care if the person lives in an appropriate accessible environment and has no other complicating factors, e.g. health, weight, or other disability.

Support Hours: Personal Assistance | 0 to 7 hours per week

- At this level the person is usually independent but may require up to 1 hour per day personal assistance, e.g. bowel / bladder management.

OTHER ACTIVITIES OF DAILY LIVING

- Will need assistance with heavy housework and home maintenance. Other domestic duties are possible if the person lives in an appropriately modified environment.

Support Hours: Domestic Assistance | 0 to 10 hours per week

- The range of support hours is due to the large variance in function at this level of injury. The 10 hours per week would be required if the person had poor trunk control / balance and needed greater assistance with heavy domestic duties e.g. pushing and loading a shopping trolley, carrying and hanging washing etc.

PARTICIPATION

Community Access | 0 to 7 hours per week

- Assistance with transport would not usually be required at this level of injury. The upper range may be required for assistance with transport where the person is unable to transfer, clamp and unclamp the wheelchair in the vehicle, or load and unload the wheelchair.
- Child-care services, educational support and vocational support have not been allocated a range of support hours. The support requirements in these categories are very specific to the person's circumstances and should be based on an assessment of the person's needs.

SUMMARY OF SUPPORT HOURS REQUIRED

	Hours per week
Activities of Daily Living – Personal Assistance	**0 - 7**
Other Activities of Daily Living – Domestic Assistance	**0 - 10**
Participation – Community Access	**0 - 7**
Participation – Child-care/Educational/Vocational	**Variable**
Total Hours	**0 - 24**

COMPLETE LUMBAR 2 – SACRAL 5 (L2–S5)

SUMMARY OF IMPAIRMENT TO BODY SYSTEM

Mobility

- Good trunk stability.
- Moderate to good control of the lower extremities. Unimpaired sitting balance.
- Variable hip, knee, ankle control and foot movement, may use option of knee-ankle-foot orthoses.
- Full control of upper limbs.
- Full control of shoulder, elbow, wrist and hand.

Respiration

- Intact function.

Other

- Neurogenic bladder and neurogenic bowel.

SUMMARY OF ACTIVITY LIMITATIONS AND ASSISTANCE REQUIRED

MOBILITY

- May require assistance with floor-to-chair transfer.
- Independent in other transfers with or without equipment. May be independent in standing.
- May require moderate assistance to independent in walking with aids.
- Independent in using a manual wheelchair on all surfaces.
- Independent in driving an appropriately modified vehicle, including loading and unloading wheelchair.
- There is a broad range of abilities at this level, from completely wheelchair dependent to being independent in walking. Even if the person can walk they may still have difficulty walking quickly and need assistance with lifting objects.

ACTIVITIES OF DAILY LIVING

- Minimal support is required with all personal care if the person lives in an appropriate accessible environment and has no other complicating factors, e.g. health, weight, or other disability.

Support Hours: Personal Assistance | 0 to 7 hours per week

- At this level the person is usually independent but may require up to 1 hour per day personal assistance, e.g. bowel / bladder management.

OTHER ACTIVITIES OF DAILY LIVING

- May need assistance with heavy housework and home maintenance. Other domestic duties possible if lives in an appropriately modified environment.

Support Hours: Domestic Assistance | 0 to 10 hours per week

- The range of support hours is due to the large variance in function at this level of injury. The 10 hours per week would be required if the person requires mobility aids or has impaired balance e.g. for pushing and loading the shopping trolley and carrying and hanging washing.

PARTICIPATION

Support Hours: Community Access | 0 hours

- Assistance with transport would not be required at this level of injury.
- The categories of child-care services, educational support and vocational support have not been allocated a range of support hours. The support requirements in these categories are very specific to the person's circumstances and should be based on an assessment of the person's needs.

SUMMARY OF SUPPORT HOURS REQUIRED

	Hours per week
Activities of Daily Living – Personal Assistance	**0 - 7**
Other Activities of Daily Living – Domestic Assistance	**0 - 10**
Participation – Child-care/Educational/Vocational	**Variable**
Total Hours	**0 - 17**

APPENDIX 3

Equipment needs

EQUIPMENT: COMPLETE C1 – S5

Equipment recommendations are for a "typical" person with a spinal cord injury who lives independently in the community, in an appropriately modified environment. Each person will need to be assessed to determine if there are any factors that would put the person outside the range of the "typical", for example, their age or any co-existing injuries.

Equipment should be maintained and / or replaced according to the manufacturers' specifications and treating therapists' recommendations. All requests for new equipment and maintenance should be evaluated against the documented assessment of need.

The Equipment chart indicates requirement of domestic aids, dressing aids, shower aids and splints. These are detailed on page 36. However, even where aids are indicated, not every aid will be needed and individual requirement should be assessed.

Additional equipment may be needed for social participation, recreation and leisure pursuits. These would reflect the persons' individual tastes and lifestyle choices, and the inclusion of specialist adaptations and equipment to return a person to their pre-injury activities or substitute. This may include items such as a sports or recreational wheelchair, adapted sports equipment, adapted computer hardware and software or games, club or other memberships, etc. Hire and trial of equipment could be considered.

	C1-3	C4	C5	C6	C7-8	T1-4	T5-9	T10-L1	L2-S5
Airvo									
Bath seat									
Bathmaster									
Domestic aids [*See Note A*]									

Dressing aids [*See Note B*]									
Easystand									
ETCO2 monitor, Obs monitor, SPO2 monitor									
Plinth									
Electronic adaptive technology									
Hoist and sling									
Leg lifter									
Long handled reacher									
Long handled sponge									
Manual wheelchair									
Motomed									
Neuromuscular electric stimulation									
Phrenic nerve stimulator									
Power wheelchair									
Pressure relieving mattress									
Profiling bed									
Propelling shower commode chair									
Recliner shower chair									
Respironics cough assist machine and circuits and stand									
Heated humidifier / NIPPV and trolley									
Roller board									
Shower trolley									
Sliding sheets									
Splints [*see Note C*]									
Suction machine and trolley									
Tilt table									
Transfer Board									
Wheelchair cushion									

Equipment required indicated by grey box	

NOTES: For recommendation on individual assessment by the treating therapist:

Note A: Domestic Aids	**Note B: Dressing Aids**	**Note C: Splints**
Adapted cutlery	Adaptive clothing	Catheter splint
Dycem bottle opener	Coiler shoe laces	Elbow splint
Dycem met	Leg lifter	Knee extension splints
Jar opener	Long handed aids and button hook	Resting hand splints
Plate guard	Long handed comb	Resting ankle splints
		Typing splints

DISPOSABLE SUPPLIES

The disposable supplies list is designed as a general guide only, and an individual nursing or other assessment would be necessary for individual needs and requirements. This list details all possible supplies that may be required for these injury levels and is not designed to replace an individual assessment.

COMPLETE C1-3

- **Alcohol wipes**
- **10ml Ampoules normal saline**
- **Antimicrobial filters suitable for use with ventilator as ordered and HME type**
- **1 box nebuliser with T piece mouthpiece**
- **Catheter night bag – 2 liters**
- **15mm x 22mm Connectors (fifty)**
- **Cotton and velcro tracheostomy tapes**
- **Disinfectant hand-wash lotion**
- **Disposable Yankauer sucker**
- **Gauze squares**
- **1 Inch micropore tape**
- **Incontinence sheets**
- **Instillagel pre-loaded syringes**
- **Large dressing packs**
- **Leg straps for catheter**
- **4 Litre jug for catheter emptying**
- **Non-sterile gloves**
- **Normal saline sterile sachets**
- **Plastic disposable aprons**
- **Sterile gloves, all sizes**

- **Sterile H2O nebs**
- **Sterile lubricant gel tubes**
- **Sterile pipe cleaners**
- **50ml Syringes**
- **Thermovents**
- **Tracheostomy care suction catheters. All sizes: standard and extended length, cuffed and uncut**
- **Tracheostomy tubes (identical size as patient currently has in situ and one size smaller than patient currently has in situ). Check with ward staff and / or physiotherapist for exact type (i.e. LPC, cuff less, fenestrated / non-fenestrated) prior to ordering**
- **Urinary catheters (identical to current catheter being used by patient)**
- **Urinalysis dipsticks**
- **Urinary drainage 750ml long tube leg bags**

COMPLETE AND INCOMPLETE C4–S5

Catheters – in-dwelling catheter or supra-pubic catheter

- As per patient

Catheter accessories

- Catheter valve
- Connector
- Spiggot
- Catheter straps
- Adhesive catheter anchor
- Catheter introduction set
- Normal saline ampoules
- Normal saline sachets
- 10ml syringe
- Split gauze / drain sponge
- Alcohol swabs

Catheters for intermittent catheterisation

- As per patient

Intermittent catheterisation accessories

- Clothing hook
- Splint
- Mirror
- Extension tubing
- Glycerine
- Baby wipes

External condom drainage

- As per patient

Drainage bags / bottles

- PVC leg bag – long tube
- PVC leg bag – short tube
- Night bottle
- Night bag – drainable

Drainage bag accessories

- Leg straps
- Night bottle connector / tubing
- Night bag holder / stand
- Leg bag holder

Continence pads

BOWEL MANGAGEMENT SUPPLIES

- As per patient

SKIN CARE SUPPLIES

Wound management (appropriate to size of wound)

- As per patient

Skin care

- Moisturising lotion
- Barrier cream
- Skin cleanser lotion / wipes
- Medical sheepskin
- Adhesive wipes / brush on / dab on
- Adhesive remove wipes

Miscellaneous items

- Flexible straws
- Antibacterial hand wash
- Antibacterial hand gel / lotion
- Air freshener spray

RESPIRATORY CARE

The basic requirements for ventilators were determined according to ISO-Standards, distinguishing between „Home care ventilators for ventilator-dependent patients "(ISO 10651-2: 2004) and „Home-care ventilation support devices "(ISO 10651-6:2004). In life-supporting ventilation, or for Clients unable to remove their own face masks, a ventilation machine with an internal battery is required (ISO 10651-2: 2004). If the Client's ability to breathe spontaneously is greatly reduced (daytime ventilation time > 16 hours), an external battery pack with a capacity of at least 8–10 hours is required. If the duration of mechanical home ventilation exceeds 16 hours/day, an additional identical ventilator must be provided. The replacement of the existing ventilator with a different type of machine or the adjustment of the ventilation mode must each take place under hospital conditions[i].

Invasively/ Tracheostomy ventilated Adults or Children require high-performance, battery- supplied suction devices as well as a replacement machine and ventilation bag.

For home invasive Tracheostomy ventilation, the Tracheostoma must be stable. In ventilation via a tracheal cannula, either a blocked or an unblocked cannula can be used; the use of a blocked cannula requires a cuff pressure gauge. In addition to the required reserve cannula of the same size, one smaller reserve cannula must also be at hand to aid emergency cannulation in difficult cases of cannula exchange
Invasive ventilation (Tracheostomy ventilation) always requires a humidifying system

Daily checks of equipment are essential to ensure patient safety at all times. Equipment should be checked at least once per day and documented as checked with replacements requested for any missing or malfunctioning equipment.

The following equipment should also be available at all times:

- Tracheal dilators
- Spare tracheostomy tubes (one of the same size and one a size smaller) usually the same type but must be a type that can easily be inserted in an emergency situation
- Functioning suction unit
- Appropriate sized suction catheters
- Oxygen with tracheostomy mask
- Non-rebreathe circuit and/or adult bag-valve-mask with reservoir with tubing
- 10ml syringe
- Stitch cutter (if sutures present)
- Water soluble gel (The Intensive Care Society, 2008)

- Sputum traps
- Guedel airways
- 500mls sterile H2O
- Suction bottle chamber
- Suction tubing circuits
- Surgeons face masks
- NIPPV full face masks – small, medium, large
- NIPPV nasal masks – small, medium, large
- NIPPV nasal pillows
- NIPPV tracheal interface
- Box oxygen tubes
- Connection for oxygen from NIPPV circuit

- Disposable bottle for tracking supplies
- Disposable trays for clearing suction
- Tracheal Dilator
- Ambu bag
- Incentive spirometer
- Fisher – Paykel circuits – for ventilator / for aivro
- Nasal airvo mask
- Tracheal airvo mask
- Oxygen connectors for thermovents
- Bacterial viral filter for NIPPV circuit
- Catheter mount for tracheal connection – nebuliser etc
- Aerosol hose for cough assist machine
- Connector 22m – 22m
- Shiley caps 15mm cap
- Bags for waste disposal
- Box for disposal of suction bottle when full

APPENDIX 4 NICE GUIDANCE FOR SPINAL CORD INJURY

ASSESSMENT FOR SPINAL INJURY

1.1.1 On arrival at the scene of the incident, use a prioritising sequence to assess people with suspected trauma, for example <C>ABCDE:
- catastrophic haemorrhage
- airway with in-line spinal immobilisation (for guidance on airway management refer to the NICE guideline on major trauma)
- breathing
- circulation
- disability (neurological)
- exposure and environment.

1.1.2 At all stages of the assessment:
- protect the person's cervical spine with manual in-line spinal immobilisation, particularly during any airway intervention and
- avoid moving the remainder of the spine.

1.1.3 Assess the person for spinal injury, initially taking into account the factors listed below. Check if the person:
- has any significant distracting injuries
- is under the influence of drugs or alcohol
- is confused or uncooperative
- has a reduced level of consciousness
- has any spinal pain
- has any hand or foot weakness (motor assessment)
- has altered or absent sensation in the hands or feet (sensory assessment)
- has priapism (unconscious or exposed male)
- has a history of past spinal problems, including previous spinal surgery or conditions that predispose to instability of the spine.

1.1.4 Carry out full in-line spinal immobilisation if any of the factors in recommendation 1.1.3 are present or if this assessment cannot be done.

ASSESSMENT FOR CERVICAL SPINE INJURY

1.1.5 Assess whether the person is at high, low or no risk for cervical spine injury using the Canadian C-spine rule as follows:
- the person is at high risk if they have at least one of the following high-risk factors:
  - age 65 years or older
  - dangerous mechanism of injury (fall from a height of greater than 1 meter or 5 steps,
  - axial load to the head – for example diving, high-speed motor vehicle collision, rollover motor accident, ejection from a motor vehicle, accident involving motorised recreational vehicles, bicycle collision, horse riding accidents)

- paraesthesia in the upper or lower limbs…

• the person is at low risk if they have at least one of the following low-risk factors:
  - involved in a minor rear-end motor vehicle collision
  - comfortable in a sitting position
  - ambulatory at any time since the injury
  - no midline cervical spine tenderness
  - delayed onset of neck pain …
• the person remains at low risk if they are:
  - unable to actively rotate their neck 45 degrees to the left and right (the range of the neck can only be assessed safely if the person is at low risk and there are no high-risk factors).
• the person has no risk if they:
  - have one of the above low-risk factors and − are able to actively rotate their neck 45 degrees to the left and right.

1.1.6 Be aware that applying the Canadian C-spine rule to children is difficult and the child's developmental stage should be taken into account.

ASSESSMENT FOR THORACIC OR LUMBOSACRAL SPINE INJURY

1.1.7 Assess the person with suspected thoracic or lumbosacral spine injury using these factors:

• age 65 years or older and reported pain in the thoracic or lumbosacral spine
• dangerous mechanism of injury (fall from a height of greater than 3 meters, axial load to the head or base of the spine – for example falls landing on feet or buttocks, high-speed motor vehicle collision, rollover motor accident, lap belt restraint only, ejection from a motor vehicle, accident involving motorised recreational vehicles, bicycle collision, horse riding accidents)
• pre-existing spinal pathology, or known or at risk of osteoporosis – for example steroid use.
• suspected spinal fracture in another region of the spine
• abnormal neurological symptoms (paraesthesia or weakness or numbness)
• on examination: − abnormal neurological signs (motor or sensory deficit) − new deformity or bony midline tenderness (on palpation) − bony midline tenderness (on percussion) − midline or spinal pain (on coughing)
• on mobilisation (sit, stand, step, assess walking): pain or abnormal neurological symptoms (stop if this occurs).

1.1.8 Be aware that assessing children with suspected thoracic or lumbosacral spine injury is difficult and the child's developmental stage should be taken into account.

WHEN TO CARRY OUT OR MAINTAIN FULL IN-LINE SPINAL IMMOBILISATION

1.1.9 Carry out or maintain full in-line spinal immobilisation if:

• a high-risk factor for cervical spine injury is identified and indicated by the Canadian C- spine rule
• a low-risk factor for cervical spine injury is identified and indicated by the Canadian C-spine rule and the person is unable to actively rotate their neck 45 degrees left and right
• indicated by one or more of the factors listed in recommendation 1.1.7.

1.1.10 Do not carry out or maintain full in-line spinal immobilisation in people if:

• they have low-risk factors for cervical spine injury as identified and indicated by the Canadian C-spine rule, are pain free and are able to actively rotate their neck 45 degrees left and right
• they do not have any of the factors listed in recommendation 1.1.7.

HOW TO CARRY OUT FULL IN-LINE SPINAL IMMOBILISATION

1.1.11 When immobilising the spine tailor the approach to the person's specific circumstances (see recommendations 1.1.12 and 1.1.16 to 1.1.18).

1.1.12 The use of spinal immobilisation devices may be difficult (for example in people with short or wide necks, or people with a pre-existing deformity) and could be counterproductive (for example increasing pain, worsening

neurological signs and symptoms). In uncooperative, agitated or distressed people, including children, think about letting them find a position where they are comfortable with manual in-line spinal immobilisation.

1.1.13 When carrying out full in-line spinal immobilisation in adults, manually stabilise the head with the spine in-line using the following stepwise approach:

- Fit an appropriately sized semi-rigid collar unless contraindicated by: − a compromised airway − known spinal deformities, such as ankylosing spondylitis (in these cases keep the spine in the person's current position).
- Reassess the airway after applying the collar.
- Place and secure the person on a scoop stretcher.
- Secure the person with head blocks and tape, ideally in a vacuum mattress.

1.1.14 When carrying out full in-line spinal immobilisation in children, manually stabilise the head with the spine in-line using the stepwise approach in recommendation 1.1.13 and consider:

- involving family members and carers if appropriate
- keeping infants in their car seat if possible
- using a scoop stretcher with blanket rolls, vacuum mattress, vacuum limb splints or Kendrick extrication device.

EXTRICATION

1.1.15 When there is immediate threat to a person's life and rapid extrication is needed, make all efforts to limit spinal movement without delaying treatment.

1.1.16 Consider asking a person to self-extricate if they are not physically trapped and have none of the following:

- significant distracting injuries
- abnormal neurological symptoms (paraesthesia or weakness or numbness)
- spinal pain
- high-risk factors for cervical spine injury as assessed by the Canadian C-spine rule.

1.1.17 Explain to a person who is self-extricating that if they develop any spinal pain, numbness, tingling or weakness, they should stop moving and wait to be moved.

1.1.18 When a person has self-extricated:

- ask them to lay supine on a stretcher positioned adjacent to the vehicle or incident
- in the ambulance, use recommendations 1.1.1 to 1.1.13 to assess them for spinal injury and manage their condition.

1.1.19 Do not transport people with suspected spinal injury on a longboard or any other extrication device. A longboard should only be used as an extrication device.

1.2 PAIN MANAGEMENT IN PRE-HOSPITAL AND HOSPITAL SETTINGS

PAIN ASSESSMENT

1.2.1 See the NICE guideline on patient experience in adult NHS services for advice on assessing pain in adults.

1.2.2 Assess pain regularly in people with spinal injury using a pain assessment scale suitable for the patient's age, developmental stage and cognitive function

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1.2.3 Continue to assess pain in hospital using the same pain assessment scale that was used in the pre-hospital setting.

PAIN RELIEF

1.2.4 Offer medications to control pain in the acute phase after spinal injury.

1.2.5 For people with spinal injury use intravenous morphine as the first-line analgesic and adjust the dose as needed to achieve adequate pain relief.

1.2.6 If intravenous access has not been established, consider the intranasal1 route for atomised delivery of diamorphine or ketamine. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented.

1.2.7 Consider ketamine in analgesic doses as a second-line agent.

1.3 IMMEDIATE DESTINATION AFTER INJURY

1.3.1 Be aware that the optimal destination for patients with major trauma is usually a major trauma center. In some locations or circumstances intermediate care in a trauma unit might be needed for urgent treatment, in line with agreed practice within the regional trauma network.

SUSPECTED SPINAL CORD INJURY

1.3.2 Transport people with suspected acute traumatic spinal cord injury (with or without column injury) to a major trauma center irrespective of transfer time, unless the person needs an immediate lifesaving intervention.

1.3.3 Ensure that time spent at the scene is limited to giving life-saving interventions.

1.3.4 Divert to the nearest trauma unit if a patient with suspected acute traumatic spinal cord injury (with or without column injury), with full in-line spinal immobilisation, needs an immediate life-saving intervention, such as rapid sequence induction of anaesthesia and intubation, that cannot be delivered by the pre-hospital teams.

1.3.5 Do not transport people with suspected acute traumatic spinal cord injury (with or without column injury), with full in-line spinal immobilisation, directly to a spinal cord injury center from the scene of the incident.

SUSPECTED SPINAL COLUMN INJURY

1.3.6 Transport adults with suspected spinal column injury without suspected acute traumatic spinal cord injury, with full in-line spinal immobilisation, to the nearest trauma unit, unless there are prehospital triage indications to transport them directly to a major trauma center.

1.3.7 Transport children with suspected spinal column injury (with or without spinal cord injury) to a major trauma center.

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