NSW ACI Pain Network & NSW State Spinal Cord Injury Service

Chronic Pain & Spinal Cord Injury Project
LTCSA Report 3: Development of the SCI PAIN NAVIGATOR

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Report 3: The following report summarises the process of developing the SCI Pain Navigator as part of the Chronic Pain and Spinal Cord Injury Project. This project is being conducted through the NSW Agency for Clinical Innovation (NSW ACI) with financial support from the NSW Lifetime Care and Support Authority (NSW LTCSA).
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1. BACKGROUND

Pain is defined by the International Association for the Study of Pain (IASP) as “an unpleasant sensory and emotional experience, associated with actual or potential tissue damage, or described in terms of such damage”. Chronic pain after spinal cord injury (SCI) is defined as pain persisting for greater than 6 months duration. Chronic SCI pain is particularly refractory to treatment, often leading to high levels of distress and disability.

The Lifetime Care and Support Authority (LTCSA) have funded a project being conducted through the NSW Agency for Clinical Innovation (ACI) to develop a resource for people with SCI who experience chronic pain, including development of resources and tools to support the clinicians who work with these individuals. Clinician resources will include an online clinical decision support system (CDSS) to assist in the management of chronic SCI pain, as well as access to a series of internet based resources and the development of a specialist SCI pain service.

This report forms the third in a series, detailing the progression of The SCI Pain Project.

- **Report 1 - Consumer Needs Analysis** includes responses from over 100 consumers who contributed to an online survey, attended one of two regional focus groups, or participated in interviews either in person or via phone.
- **Report 2 - Clinician Needs Analysis** includes information from over 200 clinicians via focus groups, interviews or participation in an online survey.
- **Report 3 – Development of the SCIPAIN NAVIGATOR** is a tool will assist health professionals working with individuals with SCI to navigate the often complex clinical picture of chronic SCI pain. The following report details how this tool was developed.

![Figure 1: Reports detailing progression of resource development](image-url)
2. INTRODUCTION

Chronic pain is common after SCI with approximately 70% of people with SCI reporting pain persisting >6 months and it is frequently reported as one of the most distressing and long term features of the injury (Spinal Cord Injury Research Evidence, SCIRE 2014). Local and international literature concur that of the 70% of people who experience pain, 30% experience severe symptoms, over 50% of people experience neuropathic pain (Bonica 1991) and 83% of people in employment report that SCI pain affects their ability to work. (Rose 1988)

Individuals with SCI may experience a range of different pain types, and these may occur at different points in time after the SCI, from the acute pain of the initial trauma to chronic pain, overuse injury and pain associated with aging. Pain may arise from irritation of the nociceptors of the musculoskeletal system or the viscera. Pain may also arise from damage to the central nervous system via trauma or secondary neuroplastic changes.

Most clinicians believed that neuropathic pain is the most problematic, with 65.1% reporting below level neuropathic pain and 36.8% reporting at level pain as the most distressing symptom for their clients.

After discharge from the specialist spinal injuries unit, individuals with SCI are largely managed in the primary care environment, where specialist spinal cord injury experience is rare. Clinicians in the community often report being under-resourced to manage the myriad of secondary health conditions that arise subsequent to SCI and similarly, individuals with SCI often report frustration and anxiety when working with health professionals who do not have a thorough understanding of SCI.

The SCI Pain project aims to build capacity in both primary care and in tertiary centres by developing the SCI Pain Navigator - a freely accessible web-based resource to facilitate access to information, to guide decision making and treatment planning for the management of persistent pain after spinal cord injury.
PAIN AFTER SCI

Chronic pain after SCI has been reported to be difficult to manage from a clinician’s perspective, being ‘particularly refractory to intervention’ (SCIRE project 2014). In a recent online survey conducted by the NSW Agency for Clinical Innovation, 83% of clinicians reported feeling under-resourced to manage SCI pain.

Historically, there has been a lack of consensus even as to the definitions and classification of pain after SCI. Recently, international consensus has been established through a working group representing 6 countries and a variety of stakeholders including researchers, clinicians and consumer advocates. The classification system was then endorsed by major Pain and SCI organisations such as the International Association for the Study of Pain (IASP), International Spinal Cord Injury Association (ISCOS), and American Spinal Injuries Association (ASIA). Classification of pain is an essential link between assessment and treatment for persistent SCI pain.

Despite advances in SCI pain research over the past 20 years, data obtained from the research is slow to filter into standard clinical practice and a comprehensive tool such as an endorsed clinical practice guideline in the area of SCI pain remains lacking. Due to the widespread but often fragmented resource material and at times restricted access to certain tools, even a conscientious clinician may struggle to navigate the plethora of variable quality research evidence in order to guide their clinical practice.

The Spinal Cord Injury Research Evidence (SCIRE) Project provides a high quality and comprehensive summary of the literature in key topic areas for spinal cord injury care, including spinal cord injury pain. This online publication is updated regularly by a skilled and dedicated team, and currently the 2014 revised version may be found at http://www.scireproject.com/rehabilitation-evidence/pain-management. This resource provides a strong evidence base for clinical decision making. The development of the SCI Pain Navigator aims to translate this evidence into practical tools that will help to integrate research findings into clinical practice. Information from the SCIRE literature summary will be incorporated into the SCI pain Navigator framework, and the opportunity for collaboration with the Canadian-based SCIRE project is being explored via A/Prof James Middleton’s current work “Implementation of a decision support tool and web-based resources for managing chronic pain after spinal cord injury.”

Recent publication of the International Spinal Cord Injury Pain Classification (Bryce et al 2012) and the SCI Pain Basic Data Set (Widerstrom Noga et al 2014) provide significant
advancement in the opportunity to relate research findings to clinical practice, by providing a common language and indeed fundamental definitions regarding chronic SCI pain. It is essential that all future SCI pain resources and research efforts are complementary to these efforts to standardise assessment, data collection and classification, and the SCI Pain Navigator will refer directly to these tools where possible.

The need for clinicians to be supported to make more informed decisions regarding SCI pain management in the long term, requires a comprehensive and sustainable solution with the capacity to appeal to clinicians with a range of experience and disciplines, linking what is known from clinical practice and what is known from clinical research. During the diagnostic phase of the project, clinicians discussed barriers to the implementation of best practice such as resource limitation (staffing, time & cost), insufficient knowledge of clinical practice guidelines and insufficient high quality evidence in the field of SCI research in general. From the online survey, 75.7% of clinicians responding reported being unaware of clinical practice guidelines for chronic SCI pain and few were aware of evidence summaries such as the Spinal Cord Injury Research Evidence SCIRE Pain Management resource nor the NSW SSCIS document “Managing Pain for Adults with a Spinal Cord Injury”.

Regarding resource development, the Clinician Needs Analysis identified that health professionals would benefit from facilitated access to the following resources to support their ability to work with clients with SCI pain:

- Access to a web site which hosts an interactive resource for SCI pain
- Access to resources for consumers that clinicians can use to support their practice
- A spinal cord injury pain interactive clinical algorithm tool for decision support
- Access to SCI pain assessment tools and pain management plans to support practice

The SCI Pain Navigator will link evidence based resources with practical tools to assist implementation. The tool will be located on a freely accessible internet based platform, and will be promoted with a strategic and targeted marketing strategy to increase exposure and uptake of the tool.
3. **THE SCI PAIN NAVIGATOR**

The SCI Pain Navigator has been developed to provide a framework for the screening, assessment, accurate classification, treatment planning and re-assessment for individuals experiencing chronic pain after SCI.

The SCI Pain Navigator has been designed upon the basic principles of clinical decision support systems, ‘linking health observations to health knowledge to influence health choices by clinicians to improve clinical care’ (Hayward, R 2004), mindful of the need to build into the system convenience, applicability to a variety of clinical settings, and integration of the tool into current workflow and work practices where possible.

The SCI Pain Navigator aims to guide clinicians through a practical clinical pathway, providing a systematic approach to treatment and management using the best current evidence available. The tool is designed with the capacity to be modified and updated in the future as additional evidence becomes available. The SCI Pain Navigator will draw on the earlier work of A/Professor James Middleton and Professor Phillip Siddall from their 2006 publication “A proposed algorithm for the management of pain following spinal cord injury” - refer to Appendix 1 for details of the 2006 published algorithm.

The online interactive “SCI Pain Navigator”, designed combining the principles of evidence based practice as well as the benefit of real-world clinical experience shaping the content of the tool, aims to provide health professionals in clinical practice access to a range of helpful tools to support their clinical care. A draft of the SCI Pain Navigator (see Figure 3) will be used throughout this report and the tool is currently in the design phase with Limelight Creative Media.

Essential elements of the SCI Pain Navigator were established in consultation with a variety of clinicians through a series of surveys, interviews and focus groups of SCI specialist and Pain specialist clinicians, as well as clinicians in primary and community care. The SCI Pain Navigator was designed by Associate Professor James Middleton, Professor Philip Siddall, Lyndall Katte and Associate Professor Kathryn Nicholson Perry, with support from the ACI Pain Management Network. The tool was developed over a period of 7 months whereby the project management group met monthly to work on the tool development, with weekly email correspondence regarding changes, updates and additions. Evidenced based recommendations and extensive clinical experience underpins the treatment recommendations and management plans at each level.
The SCI Pain Navigator is currently in the design phase where content will be put into an appropriate interactive platform for use on the ACI Pain Network website.

The structure of the SCI Pain Navigator was structured around the following five key domains:

1. Screening
2. Assessment
3. Pain Classification
4. Treatment
5. Re-Assessment

Figure 2: SCI Pain Navigator – Domains

“I think that a one off information service is never enough - rather people need a range of support services including written information, internet access or app sources as well as access to specialists and education of GP because it takes time to accept firstly that you have had an injury which is going to be permanent and secondly that the pain may be long term without any answers or magical cures. This is particularly so when the person is back home and their acute rehab has finished”
Each element of the Navigator will now be explored in greater detail:

1. Screening

As a result of the consultation with inpatient, outpatient and community based multi-disciplinary services involved in the management of individuals with SCI, it was established that SCI pain was not necessarily screened for prior to discharge, and that discharge plans inclusive of comprehensive pain management plans were not routine practice. There is an identified need for a standardised approach to screening prior to discharge for individuals with a newly acquired spinal cord injury. In addition, it is recommended that all individuals with a spinal cord injury who are readmitted to hospital for management of a medical condition, that may or may not relate to their pain, should also be screened for problematic persistent pain. For individuals in the community, it is recommended that participants in the LTCSA scheme, be screened periodically for pain during the development of their community living plans, and for individuals not covered by the scheme, it is recommended that they be screened by their primary health care workers or at spinal specialist reviews, at least on a yearly basis.

In the first instance, the screening question is simply; “Have you had any problems with pain in the past 3 months?” If the answer is “yes”, clinical staff are encouraged to proceed to pain assessment to further explore this pain. For non-clinical staff involved in the patient’s care, which may include LTCSA Co-ordinators, further exploration of aspects of the pain are recommended to guide referral for further assessment and services. These questions have been taken directly from the International Spinal Cord Injury Pain Basic Data Set* (with permission).

**Pain Intensity:**

1. What is the AVERAGE intensity of pain on a scale of 0 – 10 / 10?*

**Pain Interference:**

2. In general, how much has pain interfered with your day to day activities in the last week?*
3. In general, how much has pain interfered with your overall mood in the last week?*
4. In general, how much has pain interfered with your ability to get a good night’s sleep?*

From consultation with the project management group, stakeholder engagement and review of the literature, a score of 5 or more out of 10 for pain intensity and 4 or more out of 10 for pain interference measures, would support timely referral for further assessment of pain. However, a lower score on these items does not automatically exclude an individual from
accessing further services for pain assessment and follow up and this can be initiated at the discretion of the case manager and treating team.

2. Assessment

The use of appropriate assessment tools and outcome measures are essential elements in the clinical management of chronic pain after SCI. They assist in defining symptoms, completing the SCI pain classification, and ultimately support goal setting and clinical decision making.

The assessment of every person with SCI and chronic pain requires a detailed history that describes the onset of the pain and its quality, distribution and relieving or aggravating factors. It is also important to ascertain how intervening surgeries and treatments have influenced the pain, and the physical examination must precisely describe the person’s neurological status (Siddall and Middleton 2006). All these factors combined lead the health professional to accurately identify and classify the pain type.

The first level of classification into pain types as per the International Spinal Cord Injury Pain Classification - ISCIPC (Bryce et al 2012), is the link between assessment and treatment phases in the pain management plan. However, the ISCIPC as a stand-alone tool, requires significant assumed knowledge to identify the key features of the pain and further skill to progress to the classification phase.

The International Spinal Cord Injury Pain Basic Data Set - ISCPBDS (Widerstom-Noga et al 2014) describes anatomic location, pain severity, temporal pattern of pain and pain interference, which are all key aspects of assessment of pain after SCI. It also provides a domain for pain classification, however does not guide the clinician to establish a classification, with a degree of knowledge about SCI pain once again assumed.

It is imperative that any assessment tools recommended as part of this project, is compatible with these two essential developments in SCI pain research, but also with the capacity to guide relatively inexperienced clinicians towards accurate assessment and classification of SCI pain.

It was believed that a practical SCI Pain Assessment Tool, combining elements of the recent ISCIP-Classification and the ISCPBDS, with the addition of health screening questions and also functional prompts, may assist clinician’s to gather the information that they require to then classify SCI pain and progress towards developing a pain management plan.
Permission was requested from the publishing authors, by co-author Prof Phillip Siddall to amalgamate elements of the ISCIPBDS and the ISCIPC to form a practical clinical SCI Pain Assessment Tool (Appendix 2). This tool may be filled in directly by the person with pain, or delivered by the clinician or LTCSA coordinator. It can be emailed from participants to case managers prior to reviews or performed in readiness for a medical appointment to facilitate communication with health professionals. The domains of the assessment tool are designed to screen for SCI pain related red flags via a series of introductory health screening questions, in addition to assessing key features of the pain that will then lead to accurate classification and diagnosis. The tool is being developed in a number of formats for ease of access eg: printable paper versions, pdf fillable forms, and word document format. The SCI Pain Assessment Tool is one method to gather essential information to input into the SCI Pain Navigator.

i) **RED FLAGS**

The first phase of assessment is to perform a series of health screening questions to screen for red flags. **Red flags are defined as symptoms that may be associated with pain after SCI that may indicate the presence of a serious underlying health condition that requires urgent attention.** These red flags may be identified via the SCI Pain Assessment Tool or via direct patient interview, with the health professional working through the SCI Pain Navigator at the point of care. Red flags associated with SCI pain include:

- Onset of new or acute pain suggestive of a new pathology
- New or more severe neuropathic pain, associated with increased spasticity and deterioration of motor or sensory function suggestive of extension of neurological deficit (eg: syringomyelia)
- Systemic symptoms such as fever, chills, night sweats or unexplained weight loss suggesting the need to rule out systemic disease such as cancer, infection or osteomyelitis.
- Pain associated with symptoms of Autonomic Dysreflexia (AD) requires urgent medical attention of the Dysreflexia episode followed by exploration regarding potential triggers.
- Pain associated with altered bladder function eg: leakage or UTI may suggest the presence of urological or renal complications requiring further attention
Pain associated with bowel function may indicate complications with bowel function that require review and modification to bowel routines.

The presence of SCI pain may also be associated with a new skin breakdown or exacerbation of an existing wound, and skin integrity, particularly bony prominences should be inspected if concerns exist for skin.

A recent history of a minimal trauma or a fall, in addition to altered range of motion or localised symptoms of oedema, heat or discolouration of the skin, with an increase in neuropathic pain or increased Autonomic Dysreflexia for example, may signify the presence of a fracture, or other orthopaedic complications such as heterotopic ossification.

If the health professional identifies any of these issues during their assessment or as a result of using the SCI Pain Assessment Tool, they will enter the information into the SCI Pain Navigator, and they will be directed toward appropriate action, investigations and referrals. Access to further resources including links and downloadable material will also be possible from the SCI Pain Navigator.

**ii) PAIN INTENSITY & INTERFERENCE**

Similar to the further questions in screening for the non-clinicians, to guide referral for pain assessment by a treating health professional, the International Spinal Cord Injury Pain Basic Dataset (*) items for average pain intensity and average life interference from pain need to be evaluated as part of the pain assessment proper. As described above, these questions include:

**Pain Intensity:**
1. What is the AVERAGE intensity of pain on a scale of 0 – 10 / 10?*

**Pain Interference:**
2. In general, how much has pain interfered with your day to day activities in the last week?*
3. In general, how much has pain interfered with your overall mood in the last week?*
4. In general, how much has pain interfered with your ability to get a good night’s sleep?*

These questions are key features of the assessment and re-assessment and provide a concise and informative way to measure impact of pain on activities of daily living.

**iii) PAIN FEATURES**

Assessing the features of pain after spinal cord injury will provide crucial information required to classify pain, identify functional impact and plan for treatment.
Questions should include:

- **Where** is the pain located?
- Is this **above** or **below** the level of the spinal cord injury?
- **When** did the pain start?
- Was there an event that **triggered** the pain?
- Has the pain **changed**?
- What is the **intensity** of the pain?
- What activities **aggravate** the pain?
- What things **ease** the pain?
- What are the **temporal features** of the pain?
- What words best **describe** the pain?

The SCI Pain Assessment Tool provides a series of prompt questions to establish this clinical picture. However, clinicians may also proceed with their assessment in the absence of this tool if they are confident to cover these key areas, and input the assessment items directly into the SCI Pain Navigator tool.

### iv) YELLOW FLAGS

Yellow flags are defined as indications that psychological or social factors may be **contributing to the clinical presentation**. Psychosocial aspects of pain management will be addressed for all individuals presenting with pain of greater than 6 months duration as a matter of course, due to the impact of chronic pain on daily life and the importance of psychological techniques in the successful management of chronic neuropathic pain. However, pain presentation that is complicated by concerns for new or deterioration of mental health condition, drug and alcohol dependence, severe activity interference, significant unhelpful cognition or concerns for mood requiring screening during this assessment phase. Addressing such issues prior to implementation of a pain management approach is important to optimise outcome and the safety of the individual.

Once the screening and assessment phases have been completed, the SCI Pain Navigator directs the user to the all-important phase of SCI Pain Classification of pain type.
As advocated by Siddall and Middleton (2006), before examining treatments, consideration should be given to the classification of SCI pain and achieving optimal relief of pain is reliant on the accurate identification of the type of pain that is present. Until 2012 there existed 26 published methods to classify SCI pain, making classification complex. The International Association for the Study of Pain (IASP) classification system has recently been further refined by a group of published researchers in the field of SCI pain to reach international consensus. The International Spinal Cord Injury Pain Classification (Bryce et al 2012) will be used to define the many types of pain after SCI referred to in the SCI Pain Navigator Tool.

The ISCIP Classification is described in figure 4, and if multiple pain types are present, it is important to classify each pain separately and if pain has both nociceptive and neuropathic elements you should also classify both pains separately.

<table>
<thead>
<tr>
<th>Tier 1: Pain Type</th>
<th>Tier 2: Pain Subtype</th>
<th>Tier 3: Primary pain source and/or pathology</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nociceptive pain</td>
<td>Musculoskeletal pain</td>
<td>Eg: glenohumeral arthritis, epicondylitis, comminuted fracture, muscle spasm.</td>
</tr>
<tr>
<td>Visceral pain</td>
<td></td>
<td>Eg: myocardial infarction, bowel impacting, AD,</td>
</tr>
<tr>
<td>Other Nociceptive pain</td>
<td></td>
<td>Eg: AD headache, migraine, surgical skin incision.</td>
</tr>
<tr>
<td>Neuropathic pain</td>
<td>As level SCI pain</td>
<td>Eg: spinal cord impression, nerve root compression, cauda equine compression</td>
</tr>
<tr>
<td>Below level SCI pain</td>
<td></td>
<td>Eg: spinal cord impression, nerve root compression, cauda equine compression</td>
</tr>
<tr>
<td>Other neuropathic pain</td>
<td></td>
<td>Eg: carpal tunnel syndrome, irritable bowel symptoms</td>
</tr>
<tr>
<td>Other Pain:</td>
<td></td>
<td>Eg: Trigeminal Neuralgia, CRPS Type 1</td>
</tr>
<tr>
<td>Unknown Pain:</td>
<td></td>
<td>Diabetic polyneurothy</td>
</tr>
</tbody>
</table>

Figure 4: International Spinal Cord Injury Pain Classification System
As described above, key pain features that assist identification of pain type are listed in both
the SCI Pain Assessment Tool and the SCI Pain Navigator. SCI Pain types can be defined
as follows, in accordance with the ISCIP Classification:

**Nociceptive Musculoskeletal Pain**

Nociceptive Musculoskeletal Pain is characterised by increased/decreased (or otherwise
changed) by movement or a change in position, tenderness of musculoskeletal structures to
palpation, skeletal pathology on imaging consistent with pain presentation, use of pain
descriptors such as “dull” or “aching”, response of pain to use of medications such as anti-
inflammatories or opioids.

**Nociceptive Visceral Pain**

Nociceptive Visceral Pain refers to pain located in the thorax, abdomen or pelvis arising from
visceral structures. Features may include a temporal relationship to food intake or visceral
functions, pain described as “cramping, dull or tender”, associated sweating or nausea and
abdominal tenderness on palpation, evidence of visceral pathology on imaging or testing.

*If there is pain in the thorax, abdomen or pelvis, but pain not related to visceral function, nor
indicated by physical examination/investigations, neuropathic pain may be indicated.*

**Other Nociceptive Pain**

Other nociceptive pain, includes pressure area pain or AD headache pain, but may also be
unrelated to SCI eg: migraine.

**At-level Neuropathic Pain**

At level neuropathic pain occurs in a segmental pattern anywhere within the dermatome of
the NLI or within three dermatomes below this level, arising from damage to the spinal cord
or the nerve roots. At level neuropathic pain is described when there are sensory deficits
within the pain distribution, allodynia or hyperalgesia within the pain distribution. Pain is
described as “hot-burning, tingling, pricking, pins and needles, sharp, shooting, squeezing,
painful cold and electric shock like.

**Below-level Neuropathic Pain**

Below-level neuropathic pain refers to pain that is located more than three dermatomes
below the level of the SCI, and otherwise is characterised by the features describing the at-
level neuropathic pain.

**Other Neuropathic Pain**

Other neuropathic pain refers to pain that is present above, at or below the neurological level
of injury, but is not directly pathologically related to the SCI eg: carpal tunnel syndrome
(CTS).

**Other or Unknown Pain**

Other pain is defined as pain without identifiable cause including nervous system damage.

Unknown pain is defined as pain that cannot be assigned to category with unknown
aetiology.
Felix et al (2007) suggests that in the SCI population, chronic pain is typically not one entity but often many types of pains, each with its own set of pain-generating and pain-maintaining mechanisms. Siddall and Middleton (2006) observe that toward a SCI Pain management algorithm, optimal relief of pain may be heavily reliant on accurate identification of the type of pain that is present. The SCI Pain Navigator provides information for the **Pain Management Plan** organised by **Pain Type** for:

- Assessment & Investigations
- Treatment, Referral and Resources

Each **Treatment** item is then divided further into:

- Medical treatment
- Physical treatment
- Psychological treatment

In this way, it is hoped that the SCI Pain Navigator provides a snapshot of the overall treatment plan, as well as the opportunity to explore discipline specific information in greater detail. The items selected from the assessment and classification and the selected treatment options of the SCI Pain Navigator, will populate a document – the Pain Management Plan - which may then be saved or printed out as a record of the session and to provide information for future appointments.

An example of how the SCI Pain Navigator presents information may be found in Figure 5, presenting a summary of the treatment options for Musculoskeletal pain, followed by Figure 6, describing physical approaches to treatment as well as links for further tools and resources that may assist the overall pain management plan. Research evidence underpins the recommended strategies, and collaboration with the Canadian SCIRE project and the associated Knowledge Mobilisation Network, may assist to link the current evidence to the “front-end” of the SCI Pain Navigator.

Treatment options are expanded in this way for each of the main pain types after SCI. For example, treatment approaches for neuropathic pain can be seen in summarised version in Figure 7, followed by a more details medical treatment guide in Figure 8, which can then be expanded further. Psychosocial and self-management treatment strategies are linked to each treatment page of the SCI Pain Navigator, emphasising their crucial role in developing a successful pain management plan.
### Musculoskeletal Pain: Treatment & Resources

<table>
<thead>
<tr>
<th>DIAGNOSIS</th>
<th>POSSIBLE TREATMENTS</th>
</tr>
</thead>
</table>
| **Inflammation**                               | - Paracetamol  
- Non steroidal anti-inflammatory drug (NB: Warning - gastric symptoms may be masked in people with high level SCI)  
- Opioid (NB: Warning - slowed bowel motility after SCI may increase constipating effects of opioids. Monitor bowel function using a bowel chart and modify bowel routine accordingly. If constipation is a problem, prior to commencing on opioids, perform ORT, have a taper-case plan upon commencement and plan for short term opioid therapy only to reduce risks)  
- Functional activity review, Exercise & Stretching to improve muscle balance and ensure optimal biomechanics of movement  
- Therapeutic techniques e.g. joint mobilisation, Acupuncture, TENS  
- Referral to Physiotherapist and/or Occupational Therapist or other health professional |
| **Abnormal posture/Seating**                   | - Review of functional mobility skills and transfer techniques  
- Equipment, wheelchair and seating review  
- Referral to Physiotherapist and/or Occupational Therapist |
| **Muscle spasms**                              | - Oral Baclofen (used alone or in combination with other antispasmodic medications)  
- Referral to Spinal Specialist for review  
- Focal Botulinum toxin injections  
- Intrathecal baclofen (referral to spinal or procedural pain specialist) |
| **Muscle tension**                             | - Stretching, relaxation techniques  
- Massage |
| **Deconditioning**                             | - Activity upgrading  
- Exercise program  
- Goal setting, problem solving |
| **Overdoing**                                  | - Activity pacing (fact sheet)  
- Referral to psychologist |
| **Fracture, joint instability, deformity, contractures, tendon rupture** | - Referral to Orthopaedic Surgeon**  
- Splinting or orthopaedic supports (Warning: monitor skin closely if using splints in areas of reduced or absent sensation)  
- If surgery is being considered, pre-planning for period of immobilisation with short term equipment loans and the implications of reduced independence. In self-care is essential. Consider the use of a pre-surgical checklist in your treatment planning. |
| **Pain self management strategies**            | - Goal-setting, problem-solving, activity pacing, relaxation and meditation techniques, distraction, desensitisation, cognitive behavioural therapy (CBT) for persistent pain including management of unhelpful thinking |

### Consumer Resources & Education
- Paracaud Armed for Life  
  www.paracaud.org.au  
- MSK Pain handout  
  www.sci.washington.edu/info/pamphlets/sci-pain_msicc.pdf  
- Preservation of UI Function – Guide for Consumers  
  www.pva.org

### Clinician Resources
- PVA UI Guide – Clinician  
  www.pva.org  
- SOS HQ – Pain, Spasm & Neurological Function & SOS HQ Musculoskeletal Function  
### PHYSICAL APPROACHES TO MANAGE PAIN

<table>
<thead>
<tr>
<th>Approach</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Assessing Neurological Level of Impairment</strong></td>
<td>The individual's neurological level of injury is defined as the most caudal dermatome with normal sensation to pin prick and light touch, or the myotome with normal motor function. It is important to understand what this neurological level means in relation to functional skills, movement patterns and exercise prescription. For details on how to assess NLI, it is recommended that you visit the International Standards E-Learning program: <a href="http://www.asia-spinalinjury.org/elearning/elearning.php">http://www.asia-spinalinjury.org/elearning/elearning.php</a>.</td>
</tr>
<tr>
<td><strong>Exercise - Stretching</strong></td>
<td>Muscle shortening can arise from maintained positioning of a muscle in a shortened position, overuse of a muscle group for a functional or sporting activity, an imbalance in the muscles innervated about a specific joint, or muscle spasticity. Maintaining optimal muscle lengths with a regular stretching routine is an important strategy to reduce pain that may arise from muscle shortening. For details of specific stretching exercises designed for individuals with spinal cord injury: <a href="http://www.physiotherapyexercises.com">www.physiotherapyexercises.com</a>. For details of neurological level of SCI and muscles at risk of shortening: <a href="http://www.elearnsci.org">www.elearnsci.org</a>.</td>
</tr>
<tr>
<td><strong>Exercise - Strengthening</strong></td>
<td>Incorporate resistance training as an integral part of a fitness program (that is) individualised and progressive, and of sufficient intensity to improve strength and muscular endurance. Strengthening exercise should provide stimulus to exercise all the major available muscle groups to pain free fatigue. (Preservation of UL function following spinal cord injury: A clinician's guide <a href="http://www.pva.org">www.pva.org</a>). Recent SCI Physical Activity Guidelines, based on evidence-based data have been published. These guidelines, as well as a comprehensive variety of practical tools for exercise training after SCI can be downloaded from: <a href="http://sclactioncanada.ca/guidelines/">http://sclactioncanada.ca/guidelines/</a>, <a href="http://sclactioncanada.ca/guidelines/toolkit">http://sclactioncanada.ca/guidelines/toolkit</a>. For detail of strengthening exercises that can be incorporated into a individualised exercise program for people with a spinal cord injury visit <a href="http://www.physiotherapyexercises.com">www.physiotherapyexercises.com</a>. For details about level of SCI, functional skills and muscles appropriate for strengthening with respect to NLI, visit: <a href="http://www.elearnsci.org">www.elearnsci.org</a>.</td>
</tr>
<tr>
<td><strong>Exercise - Fitness / Conditioning</strong></td>
<td>Maintaining physical fitness after SCI is important for pain management, maintaining cardiovascular health and reducing risk factors for secondary health conditions. Recent guidelines have been published regarding SCI Physical Activity Guidelines, derived from evidence based data: <a href="http://sclactioncanada.ca/guidelines/">http://sclactioncanada.ca/guidelines/</a>.</td>
</tr>
<tr>
<td><strong>Posture / Seating</strong></td>
<td>A correctly prescribed wheelchair and seating system will optimise function, correct and prevent postural and pressure injuries and help to meet a client’s community participation needs. The short and long term consequences of an incorrectly prescribed system can be profound, as are the safety issues associated with wheelchair use. It is equally important to consider how a client perceives their wheelchair, and the psychological issues of self- and societal perception of wheelchair use when working with an individual and setting goals. It is essential that the wheelchair is ergonomically suited to the persons needs, and for further information contact your local specialised seating clinic, occupational therapist or physiotherapist. Online spinal seating resources including training modules, video’s and downloadable tools and information, are also available at: <a href="http://www.scl.health.nsw.gov.au/networks/spinal-seating">http://www.scl.health.nsw.gov.au/networks/spinal-seating</a>.</td>
</tr>
<tr>
<td><strong>Activity Pacing and Activity Modification</strong></td>
<td>If musculoskeletal or neuropathic pain is exacerbated by overuse, muscle fatigue or a particular activity, it is important to thoroughly analyse the individual’s routine and implement activity modification and pacing strategies as appropriate.</td>
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</tbody>
</table>

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**Figure 6:** PHYSICAL APPROACHES TO MANAGE PAIN
<table>
<thead>
<tr>
<th>DIAGNOSIS</th>
<th>POSSIBLE TREATMENTS</th>
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</thead>
<tbody>
<tr>
<td>At level neuropathic pain and</td>
<td><strong>Medications</strong> (Stepwise protocol)</td>
</tr>
<tr>
<td>Below level neuropathic pain</td>
<td>- Anticonvulsant (e.g. pregabalin, gabapentin)</td>
</tr>
<tr>
<td></td>
<td>- Antidepressant (e.g. amitriptyline, nortriptyline, duloxetine)</td>
</tr>
<tr>
<td></td>
<td>- Weak opioid (e.g. tramadol) (opioid guidelines)</td>
</tr>
<tr>
<td></td>
<td>- Strong opioid</td>
</tr>
<tr>
<td><strong>Physical</strong></td>
<td><strong>Exercise/fitness program</strong></td>
</tr>
<tr>
<td><strong>Psychological</strong></td>
<td><strong>Addressing identified yellow flags</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Goal-setting, problem-solving</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Activity pacing</strong></td>
</tr>
<tr>
<td></td>
<td>- Attention management strategies (meditation, relaxation, distraction, desensitisation)</td>
</tr>
<tr>
<td></td>
<td>- Cognitive behavioural therapy for persistent pain including management of unhelpful thinking</td>
</tr>
<tr>
<td></td>
<td>- Self hypnosis</td>
</tr>
<tr>
<td><strong>Stimulation</strong></td>
<td><strong>TENS</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Acupuncture</strong></td>
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<tr>
<td></td>
<td><strong>Other - Spinal cord stimulation (see below under procedural interventions)</strong></td>
</tr>
<tr>
<td><strong>Surgery</strong></td>
<td><strong>Decompression of nerve root or spinal cord (orthopaedic or neurosurgical referral)</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Drainage / shunting of syrinx or arachnoid de-tethering with duraplasty (neurosurgical referral)</strong></td>
</tr>
<tr>
<td><strong>Procedural interventions</strong></td>
<td><strong>Intrathecal medication via implanted pump</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Spinal cord stimulation</strong></td>
</tr>
</tbody>
</table>
### First Line Medications for SCI Pain: Neuropathic

<table>
<thead>
<tr>
<th>Medication</th>
<th>Starting Dose &amp; Titration</th>
<th>Maintenance Dosage</th>
<th>Mechanism of Action</th>
<th>Side Effects</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1st line treatment:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Anticonvulsants</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gabapentin</td>
<td>100-300mg NOCTE increase by 100-300mg every 3 days (up to 1800-3600 mg/day)</td>
<td>300-1200mg TDS</td>
<td>Binds to presynaptic calcium channels in the dorsal horn, resulting in reduced release of excitatory neurotransmitters such as glutamate and substance P.</td>
<td>Drowsiness, dizziness, fatigue, nausea, sedation, oedema, vasodilatation, weight gain, ataxia, visual disturbance, amnesia, abnormal thinking, dry mouth, rash.</td>
<td>Be cautious with use in renal impairment and elderly. Reduce dose or increase interval in renal failure. Consider starting at 100mg/day in the elderly.</td>
</tr>
<tr>
<td>Pregabalin</td>
<td>50-75 mg BD increase by 75mg BD each 2 weeks to a maximum of 300mg BD</td>
<td>150-300mg BD</td>
<td>As above, but has linear pharmacokinetics and higher affinity for presynaptic calcium channel.</td>
<td>Dizziness, drowsiness, visual disturbance (diplopia, blurred vision), ataxia, dysarthria, lethargy, memory impairment, euphoria, tremor, weight gain, constipation, dry mouth, peripheral oedema, facial oedema.</td>
<td>Reduce dose in renal impairment. Consider starting at 25mg once or twice/day in the elderly.</td>
</tr>
</tbody>
</table>

| **1st line treatment:** |                                                                                         |                    |                                                                                     |                                                                            |                                                                            |
| **Tricyclic Antidepressants** |                                                                                     |                    |                                                                                     |                                                                            |                                                                            |
| Amitriptyline           | 10-25mg NOCTE increase by 10-25mg every 7 days.                                        | 25-100mg NOCTE     | Block the reuptake of noradrenaline and serotonin, block hyperalgesia induced by N-methyl-D-aspartate agonists. Block sodium channels. | Sedation, confusion, dry mouth, blurred vision, orthostatic hypotension, urinary retention, constipation, sedation. Can provoke cardiac dysrhythmias. | Contraindicated in individuals with cardiac conduction abnormalities. Caution when using in persons with coronary heart disease, orthostatic hypotension, prostatic hypertrophy, closed angle glaucoma, hyperthyroidism, epilepsy, hepatic impairment, elderly, use of other serotonergic drugs. Start at 10mg/day in the elderly. |
| Nortriptyline           | 10-25mg NOCTE increase by 10-25mg every 7 days.                                        | 25-100mg NOCTE     | TCAs are often used as adjunctive anti-neuropathic medication together with an anticonvulsant. |                                                                            |                                                                            |

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**Figure 8: FIRST LINE MEDICATION FOR NEUROPATHIC PAIN**
An essential component of a successful pain management plan is achieved via regular monitoring and re-assessment. The SCI Pain Navigator guides the clinician to re-assess the pain intensity and interference items as a minimum re-assessment item, although they are certainly not limited to only these items.

At the point of re-assessment, clinicians are prompted to consider the relative success of their chosen pain management strategies for their client, and the impact of these treatments on pain intensity and pain interference. They are asked to consider whether tertiary referral is required, or whether further treatments or strategies can be implemented.

If referral to tertiary pain services is required, links to services and referral forms will be available from the website and in order to optimise access, telehealth options are being explored in the establishment of a specialised SCI Pain Program at Greenwich Hospital. As an adjunct to the SCI Pain Navigator and the online resource development, a series of specialist pain clinics throughout NSW have been consulted to establish resources required by these services to optimise access for individuals with SCI. Thus, a SCI pain resource package and a copy of the SCI Pain Book (both currently in development) will be distributed to the tertiary pain services in NSW to assist with assessment, exercise prescription and goal setting for individuals with SCI presenting to tertiary pain centres for support.
5. EVALUATION

The SCI Pain Assessment Tool and the SCI Pain Navigator have undergone preliminary testing during a series of Focus Groups at the Lifetime Care & Support Authority offices in Parramatta and Sydney City, as well as a Webex focus group for rural clinicians unable to travel to the Sydney focus groups. In excess of fifty individuals registered to attend these focus groups including LTCSA Coordinators, LTCSA-approved Case Managers, medical, nursing, physiotherapy, social work and occupational therapy clinical staff - representative of the likely end users of the tool.

Focus group attendees were asked complete a short questionnaire at the beginning and end of the session, to rate their confidence in identifying red flags, yellow flags, pain classification and the ability to access resources for SCI pain;

- **Red Flags**
  
  Prior to training, only 34% attendees reported feeling confident to identify red flags associated with SCI pain, whereas after training, this figure increased to 84%.

- **Yellow Flags**
  
  Prior to training, only 17% of attendees reported being confident to identify yellow flags associated with SCI pain, whereas after training, this figure increased to 81%.

- **Accessing SCI Pain resources**
  
  Prior to training, 17% of participants reported being confident that they can access SCI pain resources, whereas after training, this figure rose to 84%.

- **SCI Pain Classification**
  
  Prior to training, 26% of attendees reported being confident to classify SCI pain types, whereas after training, this figure rose to 78%.

Additional evaluation of the SCI Pain Navigator will be carried out in conjunction with the assistance of Dr Janet Long, A/Prof James Middleton and Prof Phillip Siddall as part of the project “Implementation of a decision support tool and web-based resources for managing chronic pain after spinal cord injury”.
SUMMARY

The SCI Chronic Pain Project funded by the Lifetime Care and Support Authority and being run through the NSW Agency for Clinical Innovation is being conducted in response to identified resource gaps. A thorough review of the literature has provided a global perspective of the issues in managing SCI pain, and locally the needs of consumers and clinicians have been explored via a range of surveys, interviews and focus groups. From this Needs Analysis, it was shown that clinicians required access to a comprehensive resource that would facilitate a thorough assessment of individuals with SCI, identifying any areas requiring urgent medical attention. Resources would also guide the clinician to develop a comprehensive pain management plan informed by the best research evidence available.

The SCI Pain Navigator has been designed as an interactive Clinical Decision Support System, to be hosted on the SCI Pain Network Website as a tool to guide screening, assessment, classification, treatment planning and reassessment of SCI pain.

Evaluation will continue for the duration of the project. Web-based resources are currently in the design phase with Limelight Creative Media, and the drafts are being reviewed for comment by the SCI Pain Advisory Committee members.

6. FUTURE PLANNING

The development of the SCI Pain Navigator will link the current evidence base with practical tools and resources for health professionals working with individuals with persistent SCI pain. The SCI Pain Navigator will be assessed and evaluated during implementation in both primary care and tertiary centres over the coming months as part of the SCI Pain Project implementation study under the direction of A/Prof James Middleton.

Further reports to LTCSA will outline the ongoing resource development of the SCI Pain Project. These reports will outline the development of the online consumer resources as well providing details of the model SCI Pain Program at Greenwich Hospital Pain Clinic ie:

7. REFERENCES


8. APPENDICES

APPENDIX 1: Algorithm for SCI pain management


Figure 1  Assessment and treatment algorithm for the management of nociceptive pain following SCI
APPENDIX 1: Algorithm for SCI pain management


Figure 2  Assessment and treatment algorithm for the management of neuropathic pain following SCI
APPENDIX 2: The Spinal Cord Injury Pain Questionnaire

**Personal Details:**

Name:  
Contact Details:  

**Spinal Cord Injury Details:**

<table>
<thead>
<tr>
<th>Level of SCI:</th>
<th>Type of SCI:</th>
<th>Date of injury:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Complete</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Incomplete</td>
<td></td>
</tr>
<tr>
<td>SNSCI / AIS A</td>
<td>(if known)</td>
<td></td>
</tr>
<tr>
<td>SNSCI / AIS B</td>
<td>(if known)</td>
<td></td>
</tr>
<tr>
<td>SNSCI / AIS C</td>
<td>(if known)</td>
<td></td>
</tr>
<tr>
<td>SNSCI / AIS D</td>
<td>(if known)</td>
<td></td>
</tr>
</tbody>
</table>

**Health Screening Questions:**

In the table below, please tick all that apply to your current pain problem:

- [ ] This is a new pain (pain in a new location or pain has new characteristics)
- [ ] This is a flare up (or worsening) of an existing pain
- [ ] I have noticed a change in sensation (reduced/altered sensation where sensation was previously unaffected by SCI)
- [ ] I have noticed a loss of muscle strength or function
- [ ] I have a fever and/or chills
- [ ] I have noticed nausea, a lack of appetite and/or weight loss
- [ ] This pain causes me to have symptoms of Autonomic Dysreflexia
- [ ] My bladder function has recently changed (may include symptoms of bladder infection, bladder leakage, difficulty emptying)
- [ ] My bowel function has recently changed (may include constipation, bowel accidents, abdominal pain, bloating, rectal bleeding)
- [ ] I have a current area of skin breakdown
- [ ] This pain started after a recent fall or trauma
- [ ] I have noticed an increase in my muscle spasms
## Pain Details:

1. Have you had any pain during the last 7 days including today? *
   - Yes [ ]
   - No [ ]

2. In general, how much has pain interfered with your day-to-day activities in the last week? *
   - 0 (no interference)
   - 1
   - 2
   - 3
   - 4
   - 5
   - 6
   - 7
   - 8
   - 9
   - 10 (extreme interference)

3. In general, how much has pain interfered with your overall mood in the last week? *
   - 0 (no interference)
   - 1
   - 2
   - 3
   - 4
   - 5
   - 6
   - 7
   - 8
   - 9
   - 10 (extreme interference)

4. In general, how much has pain interfered with your ability to get a good night’s sleep? *
   - 0 (no interference)
   - 1
   - 2
   - 3
   - 4
   - 5
   - 6
   - 7
   - 8
   - 9
   - 10 (extreme interference)

5. How many different pain problems do you have? *
   - 0
   - 1
   - 2
   - 3
   - 4
   - 5 or more

For the following questions, answer in relation to your WORST pain problem.

6. Where is your worst pain located?

7. Average intensity of worst pain in the past week 0-10/

8. How long does the pain last?
   - Constant
   - Intermittent

9. Is the pain below your level of injury in an area of reduced sensation? **
   - Yes
   - No

10. What time of day is the pain most intense?*
    - Morning
    - Afternoon
    - Evening
    - Unpredictable

11. What words best describe your pain? ** (tick all that apply)
    - Aching
    - Shooting
    - Dull
    - Electric
    - Burning
    - Cramping
    - Sharp
    - Pins & Needles
    - Icy Cold
    - Squeezing

---

*Questions from the International Spinal Cord Injury Pain Basic Data Set (Widstrom-Noga et al 2014)
12. What makes the pain feel worse?

- Prolonged postures
- Transfers or Personal Care
- Wheelchair mobility
- Exercise or Sport
- Other

- Fatigue or Stress
- Constipation or bloating
- Bladder infection
- Unaffected by activity

13. What makes the pain feel better?

- 
- 
- 
- 

14. Are you using or receiving any treatment for your pain problem?

- Yes
- No

Details: __________________________

If you have more than one pain problem, download the additional pages of the questionnaire and repeat these questions for your 2nd and 3rd worst pain.

If using medications for pain relief, please state the dose and how often you use it, whether it is helpful and any side effects.

<table>
<thead>
<tr>
<th>Medication</th>
<th>Dose</th>
<th>Frequency</th>
<th>Helpful?</th>
<th>Side Effects</th>
</tr>
</thead>
<tbody>
<tr>
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</table>

Comments: ________________________________________________________
