Chronic Pain & Spinal Cord Injury (SCI) Project
Report 4: Development of The SCI Pain Online Toolkit
Report 4: The following report summarises the process of developing the SCI Pain Toolkit – a series of online resources developed 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.
Acknowledgements

The extensive support from the SCI Chronic Pain Project Management Team including Jenni Johnson, Prof. Philip Siddall, A/Prof James Middleton, A/Prof Kathryn Nicholson Perry, Frances Monypenny and members of the SCI Pain Project Advisory Committee representatives of the spinal injury units, community health services and consumer advocacy/non-government organisations in NSW are acknowledged for their expertise and valuable assistance in the development of this online resource package.
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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. The project also involves the development of resources and tools to support the clinicians who work with individuals with SCI pain and the development of a specialist SCI pain service for consultation and referral (Appendix 1).

This report forms the fourth 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 and/or participation in an online survey.
- **Report 3 – Development of the SCIPAIN NAVIGATOR** – an online clinical decision support tool designed to assist health professionals to navigate the often complex clinical picture of chronic SCI pain.
- **Report 4 – Development of the SCI Pain Consumer Resources** – a series of online educational resources for consumers and clinicians
- **Report 5 – Development of the SCI Pain Clinic**

![Figure 1: Reports detailing progression of resource development](image)
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). Of the 70% of people with SCI who experience pain, 30% experience severe symptoms, over 50% of people experience neuropathic pain (Bonica et al 1991) and 83% of people in employment report that SCI pain affects their ability to work (Rose et al 1988).

Spinal cord injury increases the risk of developing a number or secondary health complications. Burkell et al (2006) found that some of the most commonly experienced secondary complications were pain (87%), spasms (80.7%) & shoulder pain (74.4%). Health maintenance approaches are often predicated on a medical model, which requires timely interaction with the healthcare system to access outpatient specialist care (Potter et al 2004). However, access to specialist medical and allied health services can be limited by availability of resources in the outpatient/ambulatory care area, as well as by issues such as geographic location, transport and further complicated by the challenges of finding SCI – proficient health professionals and resources in the primary care setting. Up to 87% of clinicians confident with managing other secondary health conditions experienced by people with spinal cord injury express the need for further education about pain-management techniques (Norrbrink et al 2012). This was consistent with our findings in the local needs analysis survey, where 81.13% of clinician’s reported being under-resourced to manage SCI pain, despite often a high level of expertise in spinal cord injury rehabilitation practice.

Clinicians and consumers expressed limited knowledge of non-pharmacological methods of pain management for chronic SCI-related pain and to date, published treatment algorithms have focused primarily on medication management of SCI-related chronic pain, although research demonstrates that non-pharmacological strategies may have a favorable pain management effect (Heutink et al 2011). The discrepancy between treatment approaches and patient expectations has been described as significant and there is benefit from clinicians and peers having the opportunity of hearing the patient’s voice to share the techniques and strategies that are most helpful in managing SCI-related pain (Norrbrink et al 2012). Studies identify that some individuals with SCI-related pain have learned effective coping strategies on their own, such as physical activity, massage, stretching, exercise, relaxation and distraction (Henwood 2004), and the benefit of accessing a pain management service promoting active self-management techniques has been examined in individuals with chronic pain after SCI (Norrbrink et al 2006, Nicholson Perry et al 2010). Access to specialist pain management services in NSW may be restricted often due to lack of SCI-appropriate
assessment tools and difficulty tailoring treatment resources to SCI-related pain. The resource gaps and obstacles to accessing services have been explored during the diagnostic phase of the project, and the resource package presented here aim to address this identified need.

3. **Method**

The Consumer and Clinician Needs Analysis identified areas of need for resource development to support people in the community with spinal cord injury who experience chronic pain. Consumer survey respondents identified the following priority areas:

- Access to an educational resource regarding pain after spinal cord injury, including the following key topic areas:
  - Mechanisms causing pain after SCI
  - Effects and side-effects of pain medications for SCI pain
  - Non-pharmacological strategies for pain management after SCI
  - Effect of SCI on the body including effects of ageing and pain
  - Education regarding SCI & pain red flags and when to seek medical attention
- The survey also highlights the need for the following areas of education:
  - Peer support and education
  - Family, Carer & workplace education and training
  - Education and training for the primary healthcare team
  - Building of healthcare resources specific to SCI pain management
- The results of the survey suggest the need to develop an online resource in line with the majority of individuals (74%) indicating a preference for this mode of delivery of health information. However, the provision of information as downloadable flyers is also available due to 25-50% of individuals requesting this type of resource.

Self-directed care is an important aspect of health maintenance, particularly for those living with chronic conditions (Lorid et al 2001). After SCI, providing information that supports an understanding of the condition and the ability to identify effective self-management strategies is crucial (Burkell et al 2006). Burkell (2006) observes that individuals with SCI actively seek to access health care information long after discharge from acute care. Access to high quality and evidence informed health information is important for the well-being of people living in the community after spinal cord injury. Information should be delivered in a flexible format, when and where it is needed & accommodating for changing needs over time to truly support self-management. In line with the principles of adult learning, information must be considered intrinsically important and presented at a time that is meaningful to the individuals for the information to be retained (Potter et al 2004). Individuals with SCI also indicate that
they want to access pain information on an “as – needed” basis rather than at a specific time during their rehabilitation (Wolfe et al 2002). This factor makes it difficult from a clinician perspective to plan and deliver timely and accurate information at an inpatient or outpatient level. The Chronic Pain & SCI Project has developed a package or toolkit of resources including an online consumer resource with written, film and audio learning opportunities, and an online clinician resource that can also be accessed by consumers, encouraging evidence informed and consumer driven pain management plans. Additional resources have been developed by the SCI Pain working group with resources such as the SCI Pain Book, the SCI Pain workbook and the SCI Pain Clinic at Greenwich Hospital, to assist promotion of a supported self-management approach.

4. **Results**

The website can be view at: [www.aci.health.nsw.gov.au/chronic-pain/spinal-cord-injury-pain](http://www.aci.health.nsw.gov.au/chronic-pain/spinal-cord-injury-pain) & the following key topic areas are addressed:

- Introduction to Spinal Cord Injury & Chronic Pain
- Understanding pain after SCI
- Getting help from your health care team
- SCI Pain, Physical Activity & Exercise
- Pain: Lifestyle and Nutrition
- SCI Pain and Medications
- SCI Pain thoughts and feelings
- Pain and Sleep

These topics cover the key domains as identified by both consumers and specialist clinicians. The resources include five new SCI-specific films featuring three consumers of different age, gender, type of pain, level of spinal cord injury and time since injury. The opportunity to represent further diversity in the consumer group was achieved by additional quotes, stories and photographs of individuals throughout the written resources that can be downloaded from the website. Specialist clinicians A/Prof James Middleton, Prof Philip Siddall and A/Prof Kathryn Nicholson Perry also feature in the video resources and information regarding pain types, understanding the mechanisms of pain and strategies to support effective pain management are explored. Three additional topics are linked from the ACI Pain Management Network website covering the topics of nutrition, sleep and getting help from your healthcare team – although these three films are duplicated from the “for
everyone” section of the website, the information in these films remain relevant to SCI and the recommended links and downloadable text resources contain information specific to SCI. The health professionals’ resource – The SCI Pain Navigator is also linked from this main menu page, encouraging consumers to view the Navigator and promote its use with their healthcare team, and also encouraging health professionals to explore the online consumer resource. The site map may be viewed in Appendix 2 outlining the extent of the online resources

Figure 2: SCI Pain Online Toolkit
The resources are geared to empower the individual by increasing consumer knowledge of pain and pain management techniques and it is hoped that providing this information may allow patients to more easily self-advocate and ultimately result in improved patient care.

Website Accessibility

Information accessibility is optimised with audio and visual representation of key messages, video of consumers providing information about their pain and pain management strategies, written transcript of all films, animated graphics to explain complicated neurophysiology in a simple and meaningful way, and visual access options such as plain text, font size/style change and high contrast options, all easily accessed from the home page as shown in Figure 3.

Figure 3: Accessibility options

The website is optimised for various devices including PC/laptop computer, tablet computer and smartphone. Additionally, a package of information has been distributed to Tier 2 & 3 pain clinics around NSW, the Rural Spinal Cord Injury Services Coordinators, and the Spinal Injury Units and SCI Non-Government Organisations for reference. All resource packs contain a copy of all films from the website on a USB plus a hardcopy and a soft copy of the downloadable resources from the website, to assist in areas where internet access is limited. The SCI Pain Book is also being distributed to participating NSW public libraries (N=70) and the Tier 2 & 3 Pain Clinics (N=19) to further extend resources.

There has been an identified gap between treatment recommendations and treatments studied in trials, and those preferred by individuals with SCI and pain (Norrbrink et al 2012) and transparent information with education about research processes is an important part of encouraging evidence – informed consumer choice.
Individuals with SCI express a desire to learn more about treatment options and reliable alternative sources for obtaining information on their pain and pain management (Norrbrink et al. 2012). To support an evidence-informed consumer self-management approach, various tools are embedded into the website. Practical tools such as the Spinal Cord Injury Pain Questionnaire and the Health Plan are linked to each of the webpages, as well as a drop-down list of relevant links and a downloadable document summarising the chapter content.

Figure 4: Pain Questionnaire, Health Plan, Resources & Links

The Spinal Cord Injury Pain Questionnaire: SCI-PQ

Communication about pain between clients, case managers, clinicians in primary care and specialist services is often hindered by difficulties defining and classifying SCI pain types. There are a number of different common pain types after SCI, and accurate classification is an important early step in achieving a successful pain management outcome. Two recent
publications in SCI pain research – the International Spinal cord Injury Pain Classification and the International Spinal Cord Injury Pain Basic Data Set - must be considered, and the tools and resources should aim to be compatible with these two important works.

International consensus for SCI-related pain classification has been achieved (Bryce et al 2012) as detailed in Figure 5 - the International Spinal Cord Injury Pain Classification System (ISCIPC).

<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></td>
<td>Visceral pain</td>
<td>Eg: myocardial infarction, bowel impacting, AD,</td>
</tr>
<tr>
<td></td>
<td>Other Nociceptive pain</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></td>
<td>Below level SCI pain</td>
<td>Eg: spinal cord impression, nerve root compression, cauda equine compression</td>
</tr>
<tr>
<td></td>
<td>Other neuropathic pain</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, Diabetic polyneuropathy</td>
</tr>
<tr>
<td>Unknown Pain:</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Figure 5: International Spinal Cord Injury Pain Classification System (ISCIPC)

The first level of classification into pain types (Tier 1) is the essential link between assessment and treatment phases in the SCI Pain Navigator and indeed classification can be seen as a cornerstone of successful pain management. However, the classification table as a stand-alone tool requires significant assumed knowledge to accurately identify the key features of the pain and further skill to progress through the classification tiers.
The International Spinal Cord Injury Pain Basic Data Set - ISCIPBDS (Widerstrom-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 documenting pain classification but does not provide diagnostic guidance to the clinician to establish a classification and a degree of SCI specialisation is assumed, Figure 6.

Figure 6: International SCI Pain Basic Data Set (ISCIPBDS)
It is imperative that any assessment tools recommended as part of this project are compatible with these two essential developments in SCI pain research, but also demonstrates 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 Philip Siddall to amalgamate elements of the ISCPBDS and the ISCIPC to form a practical clinical SCI Pain Assessment Tool (Appendix 3). 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 has been refined and modified after consumer feedback and from recent consumer focus group feedback, appears acceptable as a consumer self-report tool.

As can be seen in Figure 7, 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.

**Figure 7: The SCI Pain Questionnaire**
The SCI Pain Questionnaire also prompts the individual to report their pain with respect to intensity on a scale of zero to ten and rate interference with activity, sleep and mood which are all recommended assessment items of the ISCI PBDS. Individuals are also asked to report on aggravating and easing factors, pain description, and their level of injury and location of pain – all key factors to enable classification in accordance with the ISCI PC. The assessment tool provides a series of prompt questions to establish a clinical picture, however this tool is not design to restrict assessment, and clinicians may 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. Patients can complete the questionnaire independently/self-report to use as a communication tool with their health care team and in this way, ensure health professionals are given the information they need in a timely fashion which may assist in pain management planning.

Essential questions to be included in the pain subjective assessment include:

- **Level of SCI**
- **Where** is the pain located?
- Is this **above or below** the level of the spinal cord injury?
- **When** did the pain start?
- Has the pain **changed**?
- What is the **intensity** of the pain? (0 – 10 / 10)
- What **words best describe** the pain? (chosen from list of descriptors)
- What activities **aggravate** the pain? (chosen from list of descriptors)
- What things **ease** the pain? (chosen from list of descriptors)
- What are the **temporal features** of the pain? (how does it change over a day)
- How does pain interfere with activity (0 – 10 / 10)
- How does pain interfere with mood (0 – 10 / 10)
- How does pain interfere with sleep (0 – 10 / 10)

**SCI Pain Management Plan – My Health Plan**

In addition to the SCI Pain Questionnaire, another document is linked to every page of the consumer website - the SCI Pain Management Plan – titled My Health Plan. This document encourages users to view the educational videos and then begin goal setting and
establishing a structured pain management plan to best suit their individual needs. For full details of the pain management plan document, please refer to Appendix 4.

Structured planning is an essential element of a successful pain management program, and individuals are encouraged to identify issues for each domain and plan actions or strategies to address these concerns. With a structured staged follow up, progress visits in primary care are encouraged, as is referral to allied health practitioners if required for a holistic and goal focused approach to management.

![Pain Management Network](image)

**Figure 8: My Pain Management Plan / My Health Plan**

This goal setting document is designed to support self-management and increase client engagement with the pain management strategy, optimising the opportunity to embrace change and develop active coping techniques.

To support learning from the online resource, downloadable material will be available for each topic area, including written summaries of the educational film and in many cases a worksheet or tool to encourage more active learning and application of the principles to the individual’s particular situation.


An example is also located in Figure 9.
Figure 9: Sample of downloadable summary information & tools
Strategies for Promotion and Distribution of the online SCI Pain Toolkit

The SCI Pain Toolkit resources are freely available on the NSW ACI Website:


The website was launched at the Spinal Cord Injury Network – Connections 2014 forum at Randwick Racecourse Oct 13th 2014. An official Press Release from NSW Agency for Clinical Innovation was distributed at that time to Chief Executives of all Local Health Districts, and to each Medicare Local in NSW, as well as the NSW Lifetime Care and Support Authority. Each LHD or Medicare Local have been encouraged to promote the resources as they wish and examples of articles and promotional material generated for local area health districts and Medicare Locals are attached in Appendix 5.


Correspondence was forwarded to the Chief Executives and the Communications Officers at Spinal Cord Injuries Australia and Paraquad NSW, as well as members of the SCI Pain Advisory Committee. The resource has been actively promoted through SCIA membership lists as well as the website and social media http://scia.org.au/news/681-help-to-manage-chronic-sci-pain . The NSW Lifetime Care and Support Authority has supported the project throughout, actively involving staff and participants during the Needs Analysis phase, through to testing, training and advertising the online toolkit. Promotion of materials included articles in LTCSA E-News, Momentum and Shine newsletters, Focus Groups with Co-ordinators and Case Managers, nurses and allied health therapists and online webinar training sessions.

Additional promotion of the resource includes postcards in the conference satchels at the Australian and New Zealand Spinal Cord Society 2014 conference in Auckland, New Zealand November 2014 and presentation of a poster at the conference detailing the pilot SCI Pain Clinic at Greenwich Hospital. An information booth was arranged at the Pain Interest Group Nursing Issues (PIGNI) – Neuropathic Pain education day in October 2014, and there was additional opportunity for promotion of the website resource during The SCI Pain Book launch 13th November 2014 at Greenwich Hospital. Pain consumer advocacy organisations have encouraged members to visit the SCI Pain website resource – with e-news articles for Pain Australia, Chronic Pain Australia & the Australian Pain Management Association.

Organisations and resources such as Spinal Hub, a Victorian initiative have been linked from the SCI Pan Toolkit as helpful and high quality resources, and in turn publicity about the NSW ACI resource is achieved through reciprocal publicity online and in social media https://www.facebook.com/AQASpinalSupport/posts/777197432344087

There has been international interest in the website, including a recent article written for SCI BC Consumer Magazine – The Spin http://sci-bc.ca/stories/spin-magazine/ as well as discussion in New Zealand, UK, Canada and USA.

Since the launch of the SCI Pain Toolkit on Oct 13th 2014, there has been 17 225 hits on the SCI Pain website, and this is likely to increase as training and education initiatives further promote specific online resource material. Preliminary evaluation has been undertaken, collating feedback from the Australian College of Remote and Rural Medicine workshop, Clinician Focus Groups through LTCSA, presentation of resources to the staff at the
Tamworth Integrated Pain Service, and Consumer Focus Group and education session at Tamworth Spinal Cord Injuries Australia branch. Future training, evaluation and promotion will take place in early 2015, with education sessions to be planned for Royal North Shore Hospital, Royal Rehab, Spinal Outreach Service, Hunter Spinal Cord Injury Service, Prince of Wales Hospital, Rural Spinal Cord Injury Service and Tier 2 & 3 Pain Clinics in NSW. Formal evaluation of the health professional tools – The SCI Pain Navigator - will also take place in collaboration with A/Prof James Middleton’s knowledge translation project, with sites including GP clinics, specialist centres and Medicare Locals, as well as collaboration with a Canadian research team.

Since the launch of the SCI Pain Toolkit on October 13th 2014

SCI pain resource pages have had 17,225 views

Focus Groups held in collaboration with Spinal Cord Injuries Australia (SCIA) Hunter New England branch, with 35 attendee’s including individuals with SCI, their family and caregivers, demonstrate excellent engagement and a high level of user satisfaction. A Webinar organised through LTCSA with private physiotherapists, case managers and occupational therapists attending also yielded positive feedback.

Future consumer user acceptability testing & evaluation is planned for the Hunter area in collaboration with Hunter Spinal Cord Injury Service & Paraquad NSW in early 2015 during the project extension period, with additional online training via webinar also to be arranged. Training sessions with the Tier 2 and 3 pain clinics and also further consumer sessions in collaboration with NSW SSCIS, LTCSA, Paraquad NSW and SCIA are to be explored further in early 2015 to provide extensive dissemination of resources and also to optimise the evaluation of the projects resource material.

Opportunities to develop an online/e-learning module for the SCI Pain Navigator clinician tool and for the consumer website are future considerations to safeguard sustainability and use of project resources into the future.
CONSUMER & CLINICIAN FEEDBACK

“The web site which I have just looked at is fantastic. The most comprehensive web site that I have seen on chronic pain in spinal cord injuries. Please pass on my congratulations to the team.”

Liz

“Thank you again for such a wonderful day. We have had nothing but great responses. Keep us in mind when you have another concern that needs to be put out there as we are very interested.”

Glenda

“I have been reading your book and it’s amazing. There is so much of it I can relate to – so much!”

Joe

“The web videos I have watched so far have a really great way to explain complex pain - it is refreshing to hear it explained simply and to hear the consumer’s perspective. I think the colour scheme is eye catching without being too distracting. I like the website layout. The electronic feedback form is super nifty! It is great that LTCSA and ACI have funded the development and roll out of this resource and I hope they continue to.”

Viv
5. **Summary**

The SCI Chronic Pain Project funded by the NSW 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 survey’s, interviews and focus groups. From this needs analysis, it was shown that a resource was required to educate both clinicians and people in pain regarding the causes of pain, pain types, and pain management techniques. Innovative strategies are needed to address the information needs and preferences of individuals who live with SCI-related pain, and the diverse range of clinicians who work with them towards their goals. Information is required for to support people with SCI, their family and carers how to manage pain after SCI, and to equip them with skills to successfully manage chronic pain in the long term.

In response to the needs analysis, an online resource has been developed utilising film and written resources, assessment forms and communication tools to improve the scope for individuals with SCI-related pain to successfully manage their symptoms in the community. Additionally, the online resource – including both the consumer pages and the SCI Pain Navigator - provides health professionals with resources required to make evidence-informed decisions and develop a more comprehensive pain management plan.

Over the final three months of the project Dec 2014 – March 2015, further training and evaluation will take place, regarding use of the consumer web-pages, tools, resources, and use of the health professionals clinical decision support tool. User feedback from both health professionals and individuals with SCI-related pain will be examined and fed-back to the SCI Pain Advisory Committee and the Lifetime Care and Support Authority to guide further implementation efforts and to optimise sustainability of the resource.

The development of the pilot SCI Pain Clinic at Greenwich Hospital will be examined in Report 5 – the final report in the series.
6. References (Biography)


7. Appendices

Appendix 1: Chronic Pain and SCI Project Planning
Appendix 3: The Spinal Cord Injury Pain Questionnaire

The Spinal Cord Injury Pain Questionnaire

**Personal Details:**

Name:

Contact Details:

**Spinal Cord Injury (SCI) Details:**

<table>
<thead>
<tr>
<th>Level of SCI:</th>
<th>Date of SCI:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complete</td>
<td>1/1/2023</td>
</tr>
<tr>
<td>Incomplete</td>
<td>1/1/2023</td>
</tr>
</tbody>
</table>

Type of SCI:

- □ Complete
- □ Incomplete

AIS # (if known):

- □ A
- □ B
- □ C
- □ D

American Spinal Cord Injury Association Impairment Scale (AIS) describes the sensory & motor level of SCI according to the International Standards for the Neurological Classification of Spinal Cord Injury.

**Health Screening Questions:**

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

- □ This is a new pain (pain in a new location or pain that has new characteristics)
- □ This is a significant flare up (or worsening) of an existing pain
- □ There has been a recent change in my level of sensation
- □ There has been a recent decrease in my muscle strength or function
- □ I have had 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
- □ I have noticed a recent change in my bladder function (may include symptoms of bladder infection, bladder leakage, difficulty emptying)
- □ I have noticed a recent change in my bowel function (may include constipation, bowel accidents, abdominal pain, bloating, rectal bleeding)
- □ I have a current area of skin breakdown
- □ I have had a recent fall or trauma
- □ There has been an increase in my muscle spasms

Discuss ticked items with your Doctor or Health Professional as soon as possible.

NSW Lifetime Care & Support Authority  www.aci.health.nsw.gov.au/chronic-pain

ACI

Page 22/36
<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Have you had any pain during the last 7 days including today?</td>
<td>□ Yes</td>
<td>□ No</td>
</tr>
<tr>
<td>2. In general, how much has pain interfered with your day-to-day activities in the last week?</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>(where 0 = no interference and 10 = extreme interference)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. In general, how much has pain interfered with your overall mood in the last week?</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>(where 0 = no interference and 10 = extreme interference)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. In general, how much has pain interfered with your ability to get a good night’s sleep?</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>(where 0 = no interference and 10 = extreme interference)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Average pain intensity in the past week?</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>(where 0 = no pain and 10 = pain so bad you can imagine)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. How many different pain problems do you have?**</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
</tbody>
</table>

For your worst pain, provide the following details:

6. Where is the pain located?

7. Is the pain above or below your level of SCI? **
   □ Above   □ Below

8. Is the pain in a region of reduced sensation? **
   □ Yes   □ No

9. When did the pain start? (Date of onset*)
   ______ / _____ / ______

10. Was there an event that triggered the pain?
    □ Yes   □ No
    Details: ____________________________

11. What words best describe your pain? **
    (check all that apply)
    □ Aching   □ Burning
    □ Dull   □ Icy cold
    □ Cramping   □ Electric shocks
    □ Tender   □ Pins & Needles
    □ Squeezing   □ Tingling
    □ Sharp   □ Other: ________

12. How does pain change over the course of the day?


**Questions to help identify SCI Pain Type – International Spinal Cord Injury Pain Classification (Bryce et al 2012)
13. What makes the pain feel worse? **
- Personal care
- Mobility - transfers
- Mobility – wheelchair
- Mobility – walking
- Exercise/recreational sport
- Spasm
- Other: __________________
- Fatigue
- Stress
- Anxiety
- Constipation
- Bloating
- Bladder infection
- Other: __________________

14. What makes the pain feel better? **
- Rest
- Position/posture change
- Activity Pacing
- Exercise
- Medications
- Distraction

15. What medications do you use for pain?

<table>
<thead>
<tr>
<th>Medication</th>
<th>Dose</th>
<th>Frequency</th>
<th>Helpful?</th>
<th>Side Effects</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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<td></td>
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<td></td>
<td>□ Y □ N</td>
<td></td>
</tr>
</tbody>
</table>

16. Are you using or receiving any treatments for your pain problem? □ Y □ N

17. Treatment Details:


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

Appendix 4: My Pain Management Plan

## My Pain Management Plan

**Name:**

**Date:**

### What is important to me?


### Goal: (If my pain management improves I want to achieve this within the next 6 months?)


### How can I start working on this today?


### Who can help me stay on track?


### How will I monitor my progress?


### When will I review my progress?


---

### My Issues

<table>
<thead>
<tr>
<th>Understanding Pain</th>
<th>My Actions</th>
</tr>
</thead>
<tbody>
<tr>
<td>eg: Why do I feel pain where I have no sensation?</td>
<td>eg: I will watch &quot;Understanding Pain after SCI&quot; 3 times online</td>
</tr>
<tr>
<td>Building my health team</td>
<td></td>
</tr>
<tr>
<td>eg: My healthcare team doesn’t understand SCI pain</td>
<td>eg: I will show my healthcare team the SCI Pain Investigator</td>
</tr>
<tr>
<td>Physical Activity &amp; Exercise</td>
<td></td>
</tr>
<tr>
<td>eg: I am not sure what exercise options are best for me</td>
<td>eg: I will talk to my physiotherapist about setting up an exercise program</td>
</tr>
<tr>
<td>Lifestyle &amp; Nutrition</td>
<td></td>
</tr>
<tr>
<td>eg: I eat too many processed foods</td>
<td>eg: I will add more fruit, nuts, and vegetables to my diet</td>
</tr>
<tr>
<td>Medications</td>
<td></td>
</tr>
<tr>
<td>eg: I am worried about side effects of medication</td>
<td>eg: I will discuss medications with my GP or pain doctor</td>
</tr>
<tr>
<td>Thoughts &amp; Feelings</td>
<td></td>
</tr>
<tr>
<td>eg: I feel that nothing can help improve my pain</td>
<td>eg: I will watch the sci pain management film online to help develop a plan</td>
</tr>
<tr>
<td>Pain &amp; Sleep</td>
<td></td>
</tr>
<tr>
<td>eg: I am unable to get to sleep at night</td>
<td>eg: I will try relaxation practices 15 mins before bed</td>
</tr>
<tr>
<td>flare up management</td>
<td></td>
</tr>
<tr>
<td>eg: I don’t know what to do when my pain flares</td>
<td>eg: I will make a “flare up plan” of 3 options to try when I get a flare up</td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
<tr>
<td>eg: I am not able to find recreation options that interest me</td>
<td>eg: I will visit <a href="http://www.Add2Us.org">www.Add2Us.org</a> and other links from the website for ideas</td>
</tr>
</tbody>
</table>
Appendix 5: Distribution and Promotion of the SCI Pain Toolkit

New resources for people with pain after spinal cord injury

October 28, 2014 • admin

After spinal cord injury, 70% of individuals experience chronic or persistent pain which impacts upon activity levels, mood, sleep, and quality of life. A recent survey found that 91% of individuals with SCI pain consult their General Practitioners for assistance with pain, and 80% of health care professionals working with people with SCI feel that they are inadequately resourced to manage SCI pain.

In response to this, a series of resources have been developed through a partnership between the Agency for Clinical Innovation (ACI) Pain Management Network and the NSW State Spinal Cord Injury Service with support from the Lifetime Care and Support Authority (LTCSA).

These ground-breaking new resources for people with spinal cord injuries and the health professionals who care for them, were launched on 13th October 2014 at the Spinal Cord Injury Network Connections 2014 Forum for spinal cord injury research.

Dr Nigel Lyons, ACI Chief Executive explained that improving access to the latest scientific information on chronic pain management is an important focus.

“Chronic pain is pain which persists for more than three months or beyond the usual time for tissue healing. It is real and not imagined and unfortunately is a common experience for up to 70% of people after a spinal cord injury,” said Dr Lyons.

“With funding provided by the LTCSA, we have worked with pain and spinal cord injury experts to design new online resources that provide a better understanding of this type of pain and developed practical tools and resources that help people with a spinal cord injury to better manage pain,” Dr Lyons said.


- A series of videos that include personal stories about successful strategies used by people with spinal cord injuries to manage chronic pain
- A clinician decision support tool based on the latest scientific evidence – The SCI Pain Navigator. This tool guides healthcare professionals through the complexity of chronic pain in spinal cord injury to support the development of a pain management plan
- Complementary resources for consumers, so that patients and healthcare professionals can work in partnership to produce pain management plans.

The Local News

The Spinal Cord Injury Pain Book will be launched by six time Paralympian and gold medallist, Liesl Tesch AM during Spinal Cord Injury Awareness week on November 13.

This first of its kind, the book provides vital support for the two out of three people with spinal cord injury who experience chronic pain. For many of these people, dealing with pain is the most difficult consequence of their injury and yet, until now, this serious issue has been largely invisible.

Ms Tesch, a sailing gold medallist at the London Paralympics, says of the book: ‘It is great to be able to have a conversation about another of the invisible challenges of our disability, in the form of the detailed information within this book.’

The Spinal Cord Injury Pain Book’s unique contribution is to present the latest research on how pain works, while addressing the specific pain challenges for people living with a spinal cord injury – all in an easy read format with more than a dozen illustrations.

Written by some of Australia’s most experienced spinal cord injury pain experts—Philip Siddall, Rebecca McCabe, and Robin Murray (with Kathryn Nicholson Perry and Lyndall Katto)—it also includes the personal stories of people living with spinal cord injury pain.

The book is available from Amazon and Hammond Care Media:

Help to manage chronic SCI pain

The ACI Pain Management Network has created the online toolkit to help improve the quality of life for people living with spinal cord injury who experience chronic pain. SCIA members and clients shared their experiences of pain and how they cope to assist the ACI Pain Management Network in creating this toolkit, which includes:

- Videos about successful strategies used by people with spinal cord injury to manage chronic pain
- A ‘Navigator’ decision support tool to guide healthcare professionals through the complexity of chronic pain in spinal cord injury to support the development of a pain management plan
- Complementary resources for consumers, patients and healthcare professionals to work in partnership and produce pain management plans.

The toolkit helps people manage pain through topics like physical activity, exercise, lifestyle, nutrition, medications and sleep.

Associate Professor James Middleton, Director and Chair of the ACI State Spinal Cord Injury Service, led the toolkit’s development with a number of experts in the field. He stressed the importance of self-management for people with SCI who experience chronic pain.

“The most effective pain management is to arm the person with spinal cord injury and pain with a range of skills and self-management strategies to build into daily life and routines,” said Associate Professor Middleton.

The toolkit is available online by clicking here or you can borrow The Spinal Cord Injury Pain Book via the SCIA library.
Toolkit Empowers Chronic Pain Sufferers

‘Connections 2014’ hosted by the Spinal Cord Injury Network will mark the launch of an online toolkit for people with chronic pain and spinal cord injury, on 13th October at the Royal Randwick Racecourse in Sydney.

With funding from the Lifetime Care and Support Authority of NSW, the ACI Pain Management Network created the online toolkit to help improve the quality of life for the 60% of people living with spinal cord injury who experience chronic pain.

Chronic pain affects around 3.2 million Australians and costs more than $34 billion to the Australian economy.

The online toolkit will be an easily accessible collection of resources, which include:

- Videos about successful strategies used by people with spinal cord injury to manage chronic pain
- A ‘Navigator’ decision support tool to guide healthcare professionals through the complexity of chronic pain in spinal cord injury to support the development of a pain management plan
- Complementary resources for consumers, patients and healthcare professionals to work in partnership and produce pain management plans.

Associate Professor James Middleton, Director and Chair of the ACI State Spinal Cord Injury Service, led the toolkit’s development with a number of experts in the field. He stressed the importance of self-management in people with chronic pain and spinal cord injury.

“We know the best evidence for the most effective pain management is to arm the person with spinal cord injury and pain with a range of skills and self-management strategies to build into daily life and routines,” said Associate Professor Middleton.

HammondCare will also be launching ‘The Spinal Cord Injury Pain Book’ written by Professor Phil Siddall, Rebecca McCabe, Dr Robin Murray, Associate Professor Kathryn Nicholson-Perry, and Lyndall Katte, at Connections 2014.

Connections 2014 will bring together researchers, clinicians, decision-makers and the community in a single interactive forum to discuss spinal cord injury research.
Tools for Pain

A new, valuable online resource for managing SCI neuropathic pain recently launched in Australia, and people around the world can benefit.

Apparently, they take pain seriously Down Under, judging by a government-funded, comprehensive online chronic pain toolkit for people with SCI launched in October.

The toolkit was created by the New South Wales Agency for Clinical Innovation (NSW AClI) Pain Network, with funding provided by the New South Wales government. It is intended for both people dealing with chronic pain and SCI, and for health care professionals.

The toolkit’s development began with an extensive consumer and clinician consultation process to determine what it should include.

“Many people get mixed advice or none that applies to SCI, and this project will help ensure people with chronic pain and SCI are able to access the right advice and treatment in a timely manner,” says Jena Johnson, Manager of the Pain Network. “The Spinal Cord Injury and Chronic Pain Project has found long wait lists and lack of a standardized approach are key issues for people with SCI and chronic pain in New South Wales, and has highlighted the need for a pain management service specific to SCI.”

Johnson explains that a survey of health professionals found that over 60 percent of clinicians were under-resourced to manage chronic pain after SCI, that individuals with SCI were often not able to access multidisciplinary pain clinics throughout NSW and that, often, the only pain management tools offered to people with SCI were medications.

“We know from research that medications alone are not the answer, and that a combination of education, physical and psychological strategies, and the option of additional good medication management, is likely to achieve the best results,” explains Johnson. “The new online resources are designed to help facilitate better pain management in both primary and tertiary care, with the client taking an active role in their care.”

The finished product offers a wealth of resources, including SCI pain strategies and plans, pain assessment forms, handy hints, useful links, an interactive clinical pathway for SCI pain management called the SCI Pain Navigator, and videos based on the latest evidence in pain management, which are delivered by experts in the field.

Video topics include understanding SCI and pain, getting help from health teams, pain and physical activity, pain lifestyle and nutrition, pain and thoughts, pain and sleep, pain and the role of medications, and how strategies can be implemented in daily routines of people with chronic pain and SCI. The videos are professionally produced and polished.

“The website videos specific to SCI feature prominent clinicians led by Professor James Middleton, Director/Chief of the State Spinal Cord Injury Service, and individuals sharing their own personal experiences of pain after SCI,” says Johnson. “Hearing the consumer voice is so important.”

The SCI Pain Navigator, a clinical decision support tool based on the latest scientific evidence in the field, alone makes the entire kit worthy of pointing out to members of your own health care teams here in BC.

“The SCI Pain Navigator guides clinicians through a series of phases including screening for pain, assessment of pain intensity and interference, pain types, screening for yellow flags or psychological considerations, and screening for SCI red flags or physiological considerations of major concern,” says Johnson. “Clinicians are guided through any additional assessment or investigations that may be required, and suggested treatment strategies are provided with a holistic medical, physical and psychological approach.”

In particular, says Johnson, the red flags screening pages are critically important, as they provide a physician with fast and easy access to important SCI-specific health information. “This is particularly important for individuals with SCI who present with an increase or change in their neuropathic pain that may be an indication of something occurring in their body in an area where their sensation is reduced or absent,” she says.

While the SCI Pain Navigator is a clinician tool, one of the primary goals of the entire toolkit is to give people with SCI a powerful resource at their fingertips so that they can play an integral role in their own pain treatment.

“We know the best evidence for the most effective pain management is to arm the person who has a spinal cord injury and pain with a range of skills and self-management strategies to build into daily life and routines,” says Middleton.