

Psychosocial care of adults with spinal cord injuries guide

Background and methodology

July 2023

The information in this document should not replace a clinician's professional judgement.

Agency for Clinical Innovation

1 Reserve Road St Leonards NSW
2065 Locked Bag 2030, St Leonards
NSW 1590

Phone: +61 2 9464 4666 | Email: aci-info@health.nsw.gov.au | Web: aci.health.nsw.gov.au

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Background and methodology to this guide

Purpose

This Psychosocial Care of Adults with Spinal Cord Injuries Guide was developed to assist health professionals and practitioners to make judicious decisions about assessment, treatment, referral and living arrangements for people with spinal cord injuries (SCI). Although paediatric SCI may be referred to in some instances, the main focus of the guide is for those involved with adult SCI services. It is intended that this guide enhance SCI rehabilitation practice and treatment. It will also serve to advocate for people with SCI by informing legislators, policy makers and other interested parties within the health care environment. The major goal was to develop practice guidelines that ensure people with SCI receive comprehensive and cost-effective psychosocial care that enhances their wellbeing and life goals.

The guide was written with the understanding that a variety of health professionals provide psychosocial care, including:

- nurses
- clinical psychologists
- psychiatrists
- physiotherapists
- rehabilitation counsellors
- rehabilitation medicine specialists
- neuropsychologists
- social workers
- occupational therapists

We hope that the information contained herein will be applicable to these professionals and assist them in providing the best possible rehabilitation programs for people with SCI. It is expected that its application will vary across different settings and in line with the practitioners' training in particular interventions. A revised version of the guide was completed in August 2013 and published in 2014. For this 2023 edition, up-to-date evidence concerning assessment, treatment and rehabilitation practice with addition of cognitive psychosocial guidelines, has been integrated into this document. It is also now complemented by other resources, such as the State Spinal Cord Injury Service (SSCIS) [Emotional Wellbeing Toolkit](#) and [eLearning Module](#).

Development of this guide

Process of developing this guide

Mental health can be challenged by difficult life events.¹ Arguably, people with SCI have to deal with one of the most devastating physical injuries. They face very significant mental health and personal challenges in the process of recovering and adjusting to the long-term impairments and life changes associated with their injury.²

Aside from the universal experience of adjusting to a physical injury, SCI is commonly associated with a range of secondary health conditions and challenges, including:

- traumatic brain injury (TBI)
- cognitive impairment
- frequent hospitalisations due to complications.

These complications range from infections or co-morbid psychiatric conditions, such as depression, chronic pain and chronic fatigue. People with SCI are also at risk of experiencing adverse social consequences, including high risk of separation from their partner, isolation and loneliness, substance abuse, social discrimination and unstable employment prospects. However, on an encouraging note, the majority of adult people with SCI adjust very well in the long-term.³⁻⁶

The rehabilitation of individuals following a SCI is a complex process, and defined by the World Health Organization (2004)⁷ as:

“... a proactive and goal-oriented activity to restore function and or maximise remaining function to bring about the highest possible level of independence, physically, **psychologically, socially** and economically.

“It involves combined and coordinated use of medical, nursing and allied health skills, along with social, educational and vocational services, to provide individual assessment, treatment, regular review, discharge planning and follow-up.

“Rehabilitation is concerned, not only with physical recovery, but also with **psychological and social recovery and reintegration (or integration) of the person into the community** [emphasis added by the authors].”

The physical rehabilitation of SCI has been subject to systematic study and refinement, resulting in:

- well-developed approaches to physical retraining and exercise
- developing new functional skills and/or use of compensatory strategies, assistive devices and equipment for independent living and self-management.

This has led to increased longevity, that is, reduced morbidity and mortality following a SCI.⁸ With the release of the first edition of this guide, psychosocial aspects of rehabilitation had been relatively neglected, resulting in psychosocial strategies being poorly developed. However, over the past 10 to 15 years since the first edition, there has been an encouraging increase in research in psychosocial aspects of rehabilitation and long-term outcomes, providing a growing evidence base for the rehabilitation of people with SCI.^{3 9-15}

Moreover, with increased life expectancy following a SCI,^{8 14} the issue of adverse psychosocial outcomes has become increasingly more important, resulting in an associated interest in how to improve these outcomes. Importantly, clinicians remain unsure and lack guidance about how, and when, to use interventions to enhance psychosocial outcomes following SCI. This is due to the lack of guidance on how to implement interventions that have been based on evidence.

The origins of this guide lie in the visit by Professor Paul Kennedy in 2005 as the inaugural recipient of NSW Ministry of Science and Medical Research Spinal Exchange Visiting Fellowship. His visit came at a time when psychosocial aspects of rehabilitation were becoming more visible in NSW. His visit provided a catalyst to discuss and review current practice and develop future plans. In his report, Dr Kennedy made these recommendations:

1. Develop enhanced models for psychological support during inpatient rehabilitation and community reintegration phases of management. This recommendation included the adoption of the UK's National Institute for Clinical Excellence Four-Tier Model, that makes explicit the different levels of care required for different types of presenting problems. See Table 2 in the Psychosocial Care of Adults with Spinal Cord Injuries Guide: Models of Care.
2. Develop new and enhanced service delivery models in inpatient, outreach and community-based services. This included developing the use of the Expert Patient model and the involvement of peers in the rehabilitation process See the Psychosocial Care of Adults with Spinal Cord Injuries Guide: Models of Care; Influential service design models, page 25.
3. Strategic development of psychological services for individuals with SCI and related conditions in NSW. This included examining workforce issues and provision of support and professional development opportunities for psychosocial specialists.

4. Expand current or establish new research collaborations in SCI and related conditions. This included developing improved international collaborations as well as developing a more local clinical research network in relation to psychosocial research.

A major purpose of this guide is to build on the work done since the visit of Professor Kennedy, to present latest research in this area, and to recommend strategies for the:

- delivery of rehabilitation services that promote optimal psychosocial adjustment
- management of psychosocial adjustment and co-morbid psychosocial disorders during the rehabilitation process
- management of those with cognitive impairment across the continuum of care
- management of psychosocial issues following rehabilitation.

Where possible, these recommendations will have an evidence base. Otherwise, the strategies presented will be based on consensus by a multidisciplinary panel of health professionals and experts in SCI rehabilitation.

Definition of psychosocial outcomes

Psychosocial outcomes can be defined as those outcomes that involve domains such as:

- resilience and quality of life
- psychological perceptions and status (e.g., personality, mood and anxiety states, pain catastrophising, coping styles, self-efficacy)
- social functioning (e.g., social networks, quality of relationships, sexual function)
- community participation (vocational and recreational status).

It is important to recognise that psychosocial outcomes will be influenced by multiple factors, especially cognitive function.

Objective and scope

This guide aims to provide direction for the appropriate provision of psychosocial care for people with SCI based upon existing research literature and applicable evidence-based practice guidelines. Where these were not available, the aim was to draw on the expertise of specialists in the area, e.g., the SCI Unit Medical Directors in the Sydney based SCI Units, relevant academics, clinical psychologists, neuropsychologists, social workers, occupational therapists, and clinical nurses.

Target audience and additional resources

The intended audience for this guide consists of the treating teams involved in the acute, rehabilitation and community care of people with SCI, as well as other specialised psychosocial care providers unfamiliar with the management of people with SCI.

More widely, the audience includes interested community organisations, including consumer groups such as Forward Ability Support (formerly ParaQuad NSW) and Spinal Cord Injuries Australia, as well as those involved in health planning and policy both within NSW and more broadly.

These resources are recommended in addition to this guide.

- The recent [Paralyzed Veterans of America Consortium for Spinal Cord Medicine's Clinical Practice Guidelines for Spinal Cord Medicine: Management of mental health disorders, substance use disorders, and suicide in adults with spinal cord injury: clinical practice guideline for healthcare providers](#).¹⁶

- The Agency for Clinical Innovation fact sheet previously published by the NSW State SCI Services [Psychological Adjustment after Spinal Cord Injury: Useful Strategies for Health Professionals](#),¹⁷ which remains a useful document alongside the guide.
- A journal paper summarising the 2014 guide for the reader's additional reference.¹⁸
- The [Emotional Wellbeing Toolkit: A Clinicians Guide to working with SCI](#) (NSW State Spinal Cord Injury Service Strategy for the Psychosocial Care of People with Spinal Cord Injury, 2016), developed as a SCI psychosocial screening and training package. The toolkit provides a description of how to distinguish between grief and depression and includes several brief standardised tools to help non-mental health clinicians assess mental health issues such as mood, anxiety, pain, trauma, substance use and psychoses. This toolkit was developed by clinical psychologist, Annalisa Dezarnaulds and social worker, Helen Tonkin.
- Spinal Cord Injury Emotional Wellbeing Toolkit [e-learning Course](#).

Process of developing this guide

In mid-2006, the NSW State SCI Services (SSCIS) formed the SSCIS Psychosocial Strategy Steering Group, chaired by Professor James Middleton. This group met frequently in order to develop a strategy for the provision of psychosocial care for people with SCI. The development of this guide was an important outcome of the strategy.

To assist in its development and gain a wide consensus, the steering group organised the NSW State Spinal Cord Injury Services Psychosocial Strategy Forum on 6 December 2006. This forum brought together service stakeholders in order to identify unmet needs and develop priorities for addressing them. The forum was structured by the phases of care experienced by people with SCI; that is, acute care, rehabilitation, community reintegration (referred to as transition) and community living.

The outcomes of the forum were analysed and synthesised by the steering group, and several priority areas were identified. These included:

- the need to standardise assessment
- the need for the identification of risk factors of poor psychosocial outcomes
- the need for the provision of education and support for providers of psychosocial care for people with SCI, and
- the need to improve psychosocial care by drawing on the experience of other relevant psychosocial service models (e.g., self-management models that use peer support).

The development and continued updating of this guide are arguably an effective way of addressing the goals of the guide, particularly in providing support for providers of psychosocial care.

The initial broad structure and content of the guide was agreed to by the steering group, after which Professor Ashley Craig and Dr Nicholson Perry produced a full draft. Members of the steering group edited drafts, with additional input from a wide range of participants provided through two specialised workshops held during the ANZSCoS conference in November 2007.

The guide was updated in 2013 and published in 2014. In 2021-22, guidelines for managing cognitive impairment in acute SCI were completed. Therefore, it became an opportune time to integrate these cognitive impairment guidelines into the psychosocial guide, as well as update the guide given the increased research in the area of psychosocial care following a SCI that has occurred since 2013-14.

Process and nature of evaluation of evidence conducted in 2021-22

The evidence was collected using two primary strategies:

1. A diverse range of health professionals involved in the medical and psychosocial care in specialist SCI services were asked to contribute their clinical expertise to review and update the 2014 guide, specific to the provision of psychosocial services to people with SCI.
2. New psychosocial guidelines for adults with SCI who have cognitive impairment have been added to this 2023 guide. Consensus for these cognitive impairment guidelines was determined by conducting a rigorous Delphi study with the provision of evidence-based statements. Professor Craig was the facilitator, and the experts were members of the advisory committee, many of whom are co-authors of this guide. Assessment involved agreement/disagreement of the suggested psychosocial strategies along with comments for the agreement/disagreement decision as well as comments for improving style or content. Consensus was reached in only two Delphi rounds.

Evidence regarding the specific and generic practice guidelines was gathered by conducting a series of reviews of the literature over a six months in 2021 (May to October) using primary search terms such as “*spinal cord injury*”, “*rehabilitation*”, “*adjustment*”, “*treatment*”. These primary terms were used in combination with secondary search terms such as “*depression*”, “*pain*”, “*cognitive impairment*”, “*social participation*”, and “*post-traumatic stress disorder (PTSD)*”. Search engines used included Medline, PsychInfo, and Google Scholar. Google Scholar was used to search for clinical practice guidelines in use by other relevant professionals in Australia and overseas. For the purpose of this guide, only those studies that reported objective psychosocial outcomes were included. Criteria that were applied to outcome measures included:

- objective measures that reflect how a person with SCI adapts, adjusts and copes with their injury
- measures that have demonstrated validity and an evidence base
- reliable measures that have face validity, that is, they have relevance to rehabilitation intervention goals
- measures that cover multiple domains that reflect useful products for consumers
- measures used with a range of disorders and injuries that would provide scope for comparisons.

The process of evaluating the evidence collected adhered to the [National Health and Medical Research Council \(NHMRC\) guidelines 2009](#).¹⁹

The following NHMRC criteria were used to rate the evidence of treatment effectiveness in descending order of strength.

Level I	Systematic review or meta-analysis of randomised controlled trials
Level II	At least one well-designed randomised controlled trial
Level III-1	Well-designed pseudo-randomised controlled trials
Level III-2	Comparative study with concurrent controls, such as controlled cohort or case-control studies with non-randomised controls
Level III-3	Comparative studies without concurrent controls, such as a historical control study or interrupted time series studies, or N of 1 single case experimental design studies
Level IV	Case series or before and after studies.

Where specific clinical practice guidelines adhering to the above NHMRC criteria were available for people with SCI (such as the *Clinical Practice Guidelines for Spinal Cord Medicine*, Bombardier et al., 2021¹⁶), or where generic guidelines that were appropriate for people with SCI were available, these have also helped to form the basis of the guide.

In the absence of any available clinical practice guidelines or research literature, recommendations were based on available literature and the results of wide-ranging consultation with experts associated with the field of SCI through the process described above. Only key references were cited in the guide and these were selected on their scientific merit. Therefore, the guide does not present the full range of possible studies conducted in the area.

The upgradation process of this edition of the guide adhered to guidance received from the NSW Agency for Clinical Innovation: Principles for Developing Clinical Guidance. Sydney: ACI; 2022.

Note: It is important to point out that there are very few studies qualifying for Level I or II evidence in psychosocial research following SCI. However, studies satisfying Level III evidence quality are numerous, providing a rich understanding of the issues. Furthermore, most findings were independently replicated, greatly strengthening conclusions.

Components of this guide

The guide focuses on these areas:

- Principles and recommendations concerning the psychosocial care for the treating team (including those health professionals providing acute, rehabilitation and primary care services), as well as for specialised psychosocial care by other providers.
- Models of care that can influence service design in SCI rehabilitation. It includes a brief review of psychosocial factors influencing adjustment following SCI and:
 - A brief review of the efficacy of psychological treatments
 - A brief review of cognitive impairment, co-occurring traumatic brain injury and SCI
- Background and methodology

To enable information to be easily accessed on mobile devices, the 2023 version has been divided into these documents:

- Psychosocial Care of Adults with Spinal Cord Injuries Guide: Recommendations
- Psychosocial Care of Adults with Spinal Cord Injuries Guide: Models of Care
- Psychosocial Care of Adults with Spinal Cord Injuries Guide: Background and Methodology.

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Edition third, 2023

Authors

Professor Ashley Craig, Professor of Rehabilitation Studies, John Walsh Centre for Rehabilitation Research, Northern Sydney Local Health District, and Kolling Institute, Faculty of Medicine and Health, The University of Sydney

Dr Mohit Arora, Senior Lecturer and Senior Research Fellow, John Walsh Centre for Rehabilitation Research, Northern Sydney Local Health District, and Kolling Institute, Faculty of Medicine and Health, The University of Sydney, NSW State Spinal Cord Injury Service, Agency for Clinical Innovation

Professor James Middleton, Clinical Director, NSW State Spinal Cord Injury Service, Agency for Clinical Innovation and Senior Staff Specialist, Spinal Outreach Service, Royal Rehab

Co-authors of third revision

Lynn Blecher, Prince of Wales Hospital	Catherine Ephraums, Royal Rehab
Ruyi Yao, Prince of Wales Hospital	Alison Hales, Royal Rehab
Annalisa Dezarnaulds, State Spinal Cord Injury Service	Jackson Singleton, Royal Rehab
Lisa Benad, Royal North Shore Hospital	Joe Hanna, Royal Rehab
Danielle Sandalic, Royal North Shore Hospital	Dr Yvonne Tran, Macquarie University
Wilhelmina Long, Royal North Shore Hospital	Dr Ilaria Pozzato, The University of Sydney

Spinal Cord Injury Unit Medical Director Approval

These guidelines were reviewed and approved by these Spinal Cord Injury Unit Directors:

Dr Sachin Shetty, Prince of Wales Hospital

Dr Jasbeer Kaur, Royal North Shore Hospital

Dr Gerard Weber, Royal Rehab.

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Previous editions

First edition, 2008

The guide was first written by Professor Ashley Craig and Dr Kathryn Nicholson Perry in conjunction with Professor James Middleton, Clinical Director, NSW State Spinal Cord Injury Service (SSCIS) and the SSCIS Psychosocial Strategy Steering Group.

The contributions of the following members of this group are acknowledged: James Middleton (Chair), David Andrews, Tullio Cittarelli, Ashley Craig, Michelina Pelosi, Kathryn Nicholson Perry, Neil MacKinnon, Anna Satharasinghe, Jackie Francis, Margaret Noonan, Kylie Wicks, Catherine Shorland, Tonina Harvey, Jill Steverson, Catherine Tulinski, Luisa Silva and Helen Oosthuizen.

Contributions to the project were also made by those attending the NSW State Spinal Cord Injury Services Psychosocial Strategy Forum on 6 December 2006, and by those attending related workshops at the 2007 Australian and New Zealand Spinal Cord Society (ANZSCoS) conference held in Sydney.

This project was supported by the NSW State Spinal Cord Injury Service, originally through the Greater Metropolitan Clinical Taskforce (GMCT), and the Motor Accident Authority, which is sincerely acknowledged and appreciated. Finally, grateful thanks to Professor Paul Kennedy for his inspiring visit in 2005 and generous support and encouragement with this work.

Second edition, 2014

Revised and updated in 2013-14 by Professor Ashley Craig, Northern Clinical School, The University of Sydney. The revision was funded by the NSW Agency for Clinical Innovation. For this Edition, the work by Selina Rowe, Manager, NSW Spinal Outreach Service, Royal Rehab, Ryde, and Frances Money Penny, ACI Network Manager, State Spinal Cord Injury Service, Chatswood, NSW, Australia, in coordinating and managing the project to review and update this fact sheet, one of a suite of 10 fact sheets, is acknowledged.

Summary of changes

Edition	Currency dates	Changes and other comments
First, 2008	Jun 2008 to Jul 2013	N/A
Second, 2014	Aug 2014 to Dec 2022	<ul style="list-style-type: none"> • Undertook new systematic literature search • Revision of the guide by updating latest research across all psychosocial aspects of SCI • Concept development of new and enhanced service delivery models in inpatient, outreach and community-based services. This included developing the use of the Expert Patient model and the involvement of peers in the rehabilitation process

<p>Third, 2023</p>	<p>Jan 2023 onwards</p>	<ul style="list-style-type: none"> • Undertook new systematic literature search • Revision of the guide by updating latest research across all psychosocial aspects of SCI • Inclusion of the SCI Adjustment Model (SCIAM) and Emotional Wellbeing Toolkit • Inclusion of two new sections for people with SCI with cognitive impairment: <ul style="list-style-type: none"> – See Psychosocial Care of Adults with Spinal Cord Injuries: Models of Care; page 11, Cognitive impairment (Level III-2 evidence) – See Psychosocial Care of Adults with Spinal Cord Injuries: Recommendations; page 12, Recommendations for the care of persons with SCI who have cognitive impairment • Inclusion of new sections on peer support: <ul style="list-style-type: none"> – See Psychosocial Care of Adults with Spinal Cord Injuries: Recommendations; page 22, Monitoring, follow-up assessment and peer support – See Psychosocial Care of Adults with Spinal Cord Injuries: Recommendations; page 23, Peer support • Involvement of a multidisciplinary team in updating the guidelines
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References

The references listed in this document can be found on the ACI web page, [Psychosocial care of adults with spinal cord injuries](#).

This 2023 update required the reordering of the original 2008 and 2014 versions. The text has been split into three shorter PDFs to enable information to be easily accessed on mobile devices. However, the references retain their original numbering, and the superscript matches the original chronological reference list numbering. The PDFs appear in this order of priority:

- Psychosocial Care of Adults with Spinal Cord Injuries Guide: Recommendations
- Psychosocial Care of Adults with Spinal Cord Injuries Guide: Models of Care
- Psychosocial Care of Adults with Spinal Cord Injuries Guide: Background and Methodology.