

Psychosocial care of adults with spinal cord injuries guide

Recommendations

July 2023

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

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Title	Psychosocial care of adults with spinal cord injuries guide: Recommendations		
Replaces	First edition: June 2008; revised August 2013. Guide for health professionals on the psychosocial care of adults with spinal cord injury.		
Revised	July 2023. Complete revision and update of evidence. Spilt into three documents, see also Models of care and Background and methodology.		
Next review	2028		
Produced by	The ACI's Spinal Cord Injury Service Network. Trauma, Pain and Rehabilitation, PRISM (Preserving and Restoring Interventions in Surgery and Medicine)		
Preferred citation	NSW Agency for Clinical Innovation. Psychosocial care of adults with spinal cord injuries guide: Recommendations. Sydney: ACI; 2023		
TRIM ACI/D23/1818	SHPN (ACI) 230295	ISBN 978-1-76023-508-6	ACI_7060 [06/23]

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Summary

General principles for the psychosocial care of people with spinal cord injury

- Services for people with spinal cord injury (SCI) should be designed around person-centred care to be respectful of, and responsive to, personal preferences, needs and values to promote optimal psychosocial adjustment and resilience.
- The rehabilitation and treatment environments should promote a sense of support, safety and recovery.
- Staff should be sensitive to signs of distress, including neuropsychological symptoms (e.g., post-concussion symptoms) and signs of cognitive impairment.
- Staff should provide generous emotional and social support and use effective communication skills, including using the services of a registered interpreter when appropriate.
- Clients should be provided with timely and targeted information suitable for their level of cognitive functioning.
- Self-management and adjustment/resilience models should be promoted as the basis of psychosocial rehabilitation.
- Caregivers and significant others of people with SCI need to be routinely given support and information.

Principles for integrating psychosocial dynamics into acute and rehabilitation phases

- Person-centred care involves addressing psychosocial aspects of rehabilitation that should start when the person is admitted to the SCI rehabilitation unit.
- A member of the rehabilitation team should be allocated as the “key worker” to each person newly admitted to the SCI inpatient program.
- An initial psychosocial assessment, as well as a cognitive screen, should be conducted as soon as practicable following injury to inform and guide treatment planning.
- All people with SCI should receive a multidisciplinary rehabilitation program in which person-centred care and psychosocial care are core components based on an assessment of individual needs, beliefs and abilities.
- Services should actively involve the person with SCI in planning and decision-making, connecting the person’s past to the future in the adjustment process and making the rehabilitation program relevant to the outside community and society.

Recommendations for caring for people with SCI who have cognitive impairment

- Because people with SCI have an increased risk of cognitive impairment, awareness of cognitive impairment needs to be raised after admission to SCI rehabilitation. Staff should be aware of warning signs and common symptoms of cognitive impairment.
- It is important to standardise terminology of what constitutes mild, moderate and severe cognitive impairment in adults with SCI.
- SCI units should use validated neurocognitive screens to detect the presence of mild cognitive impairment in SCI.
- If a neurocognitive screen detects cognitive impairment, consideration should be given to referral for comprehensive testing, depending on the individual case.

- Person-centred care should be a particular focus when treating a person with SCI who also has cognitive impairment.
- The use of verbal, language and speech strategies that improve communication should be used where possible and tailored to the person's communication or understanding ability and health literacy.

Recommendations for psychosocial assessment in SCI units

- Everyone acquiring SCI should receive sensitive and timely psychosocial assessment at critical time points. The results of the psychosocial assessment should be collated and available to the treating team.
- The initial psychosocial assessment should be conducted early after admission to rehabilitation.
- If possible, a neurocognitive screen should be conducted within 10 days after admission to rehabilitation.
- An abridged psychosocial and cognitive assessment should be repeated close to discharge and six to 12 months after living in the community.
- People being transitioned from paediatric to adult SCI services should receive a comprehensive psychosocial needs assessment.
- Members of the treating team should be able to conduct brief assessments of common psychosocial problems so they can deliver mental health first aid and facilitate appropriate management.

Monitoring, follow-up and peer support

- Ongoing support for the self-management approach to SCI should be provided following discharge from rehabilitation.
- The progress of psychosocial adjustment and social reintegration should be routinely monitored in the community.
- Case management should be used for those presenting with complex psychosocial needs where the capacity for self-management is compromised.
- Ongoing psychosocial support services should be available to people with continuing or emerging psychosocial needs.
- Peer support provided by those with lived experience is a valuable resource for ongoing support.

Staffing considerations

- To ensure optimal rehabilitation, ongoing professional development should be provided to enhance and promote psychosocial skills, including awareness of cognitive impairment following SCI.
- An appropriate health professional staffing mix should be provided in order to deliver effective psychosocial rehabilitation.
- Staff will require appropriate orientation and ongoing professional development to sustain the acquisition and maintenance of the required skills.

Based on the principles of the above models, and where possible, best evidence, the following principles and recommendations are proposed for the psychosocial care of people with SCI. To ensure these recommendations can be successfully applied to the psychosocial care of SCI, staff will need to be adequately trained, prepared and resourced to undertake some of these roles.

Recommendations for the psychosocial care for people with SCI

General principles for the psychosocial care of people with SCI

There are a number of general principles regarding the way in which psychosocial care is provided by the whole of the treating team that provide the foundation for all other psychosocial interventions delivered.

Psychosocial services and needs that impact rehabilitation outcomes should be integrated into all SCI services

Throughout the lifespan of a client, psychosocial needs may arise at any point after injury. Therefore, people with SCI should be able to access appropriate services at all stages of life. It is desirable that services should actively plan for psychosocial needs when providing care to those with SCI.

Services for people with SCI should be designed around person-centred care in order to promote culturally safe and appropriate care and optimise psychosocial adjustment and resilience

Person-centred care (PCC) is about treating a person with SCI during their rehabilitation stay and after discharge into the community with dignity and respect and involving them in making decisions about their health. Models of adjustment also provide direction for promoting healthy self-management, for example:

- psychoeducation about what factors lead to positive rehabilitation outcomes
- teaching a range of self-management skills, like self-monitoring of important activities
- enhancing self-appraisal and re-appraisal processes, e.g., boosting self-efficacy.

This principle may be reflected both in the physical environment of in-patient services (such as providing access to areas for the practise of skills out of usual therapy hours) and in the rehabilitation process (such as promoting the client's active participation and decision-making in the treatment and discharge planning process). Participation in activities that promote wellbeing, such as adequate physical and social activity, should be actively promoted as part of SCI services.

Attempts should be made to create treatment environments that promote a sense of support, safety and healing

Due to the environmental constraints of the hospital setting, it is important to promote safe, supportive and healing surroundings for the person with SCI, as well as visiting family and friends. Efforts to consider the person's privacy and to promote opportunities to make meaningful and valued contributions to decisions made in their environment will lessen the effects of being in a demanding institutional clinical setting.

Members of the treating team should be sensitive and open to signs and symptoms of distress, as well as cognitive impairment

Providing adequate psychosocial care is predicated on the ability to detect signs and symptoms of distress. This requires a culture in which the concerns of the person with SCI and their family are at the centre of care. This culture generates a systemic awareness of what constitutes an appropriate response to the range of issues that may arise; for example, wanting to be isolated from everyone or suicidal ideation. It also enables the realisation that appropriate responses may well form an important contribution to the process of adjustment.

Members of the treating team should provide generous emotional and social support

Given the shock, distress and confusion prevalent in the early stages of the injury, the treating team should provide generous emotional and social support. This will assist in the development of the relationship

between the person with SCI and the rehabilitation team and enhance the ability of health staff to detect any unmet or pressing psychosocial needs.

Health professionals should use effective communication skills, including using the services of a registered interpreter when appropriate

Communication should be tailored or adapted to the person's communication and level of understanding and health literacy. Effective communication skills need to be used when interacting with the person with SCI and their family at the time of admission to the SCI unit, given the potential for elevated distress, confusion and disorientation.

This is also true throughout the rehabilitation phase. Effective communication is based on empathy and active listening. If the person with SCI and their family do not have English as their first language, or the individual is a user of sign language, it is essential that a registered interpreter be engaged.

Clients should be provided with timely and targeted information suitable to their cognitive function status

A person admitted with an acute SCI requires timely and targeted information about diagnosis and prognosis when it is deemed that they are ready. However, this needs to be done without overwhelming them. This is also crucial to their understanding of the processes involved in their rehabilitation. The person depends on accurate information to facilitate their active engagement in the discussion of treatment options.

Fluctuating clinical presentations, and the development of secondary complications, result in an on-going need for good quality information. Certainly, there is a need for information about diagnosis and prognosis to be repeated as necessary. Overcoming barriers to shared decision-making is important. There are a range of barriers and facilitators to effective shared decision-making. These may include the:

- age, gender, culture, attitudes, opinions, level of education and past experience of patients
- emotional readiness for partnering
- degree of trust and confidence in the healthcare system and clinicians
- communication skills of both parties.

Most common barriers are organisational structure/administrative supports (e.g., lack of decision trees for the condition or scenario) and lack of time to build relationships and trust and explore all the options, or the available evidence, to allow informed decision-making.

The following approaches have been found to augment shared decision-making:

- actively supporting people to be involved in decision-making
- emphasising options and problem solving
- developing care plans as a partnership between patients and professionals
- setting person-centred goals and following up on the extent to which these are achieved over time
- using decision aids rather than merely providing information
- providing opportunities to share and learn from peers with the same condition.

Self-management and adjustment/resilience models should be promoted as the basis of psychosocial rehabilitation

Following discharge from rehabilitation, clients are responsible for the ongoing management of their condition in association with their treating team and care providers. Explicit preparation for this role is essential, with due care given to co-morbidities that may impact upon their ability to undertake this

effectively. Self-management and adjustment models (discussed in the accompanying document, Psychosocial Care of Adults with Spinal Cord Injuries Guide: Models of Care) should form the framework upon which psychosocial rehabilitation is based.

Routine provision of support and information is necessary for caregivers and significant others of people with SCI

Carers and significant others of people with SCI experience an increased level of psychosocial challenges. This requires appropriate assessment and intervention. It is recommended that caregivers (carers) and family members of a person with an acute SCI be introduced to non-government organisations providing services such as:

- peer support
- advocacy
- accommodation programs
- specialist consultancy.

During inpatient admissions of the person with SCI, carers and family members should be provided with a key contact person on the team (such as the key worker) through whom to address questions and concerns.

Specialist information and support services may be required for parents of children with SCI, for example, in managing behaviour, managing the impact of the injury upon a sibling and emerging sexuality issues.

It is important to note that carers of a person with SCI are at increased risk of stress and mental health problems. They should be referred to relevant professionals for assessment and management if symptoms of psychological disorders are detected.

Principles for integrating psychosocial aspects into the acute and rehabilitation process

Psychosocial aspects of rehabilitation should start from admission to the unit

PCC involves psychosocial care. This should begin immediately after admission to a SCI unit, depending on the patient's medical condition and cognitive status. It is recommended that psychosocial care begin with an orientation to the psychosocial components of the rehabilitation program. If possible, the family should be included in an orientation process.

A “key worker” should be allocated to each person with an acute SCI who is admitted to the SCI inpatient program

To facilitate effective communication and coordination of rehabilitation, a health professional key worker should be designated and allocated to each new person with SCI admitted to the inpatient program. The key worker acts as the co-ordinator of the rehabilitation process for each individual client. They are the first point of contact for the client, their family or significant others.

The key worker will ensure that a psychosocial needs assessment is conducted by someone appropriately trained to do this and ensure that it is integrated into the multidisciplinary treatment plan. Where specific psychosocial co-morbidities are thought to be present (such as a psychiatric disorder) the key worker should be someone with skills in the management of such issues or at the very least, liaise with a colleague who has those skills.

An initial psychosocial assessment as well as a validated cognitive screen should be conducted as soon as practicable following injury

The purpose of the initial psychosocial and brief cognitive assessment is to ensure that the treating team is aware of psychosocial issues that may impact on the process of rehabilitation. The cognitive assessment should be done after the patient has settled into the rehabilitation phase. It should not be done if the person is unwell.

The assessment may be based on the client's history as obtained from others, such as family members and the general practitioner, regarding risk factors such as a previous history of psychiatric disorder. As soon as the individual is able to communicate, it should also include direct assessment.

All people with SCI should receive a multidisciplinary rehabilitation program in which PCC and psychosocial care are core components based upon an individual needs assessment

The psychosocial aspects of the multidisciplinary rehabilitation program should also include peer support components. Based upon the initial psychosocial assessment, this should be developed to cover all stages of the adjustment process, including inpatient rehabilitation, integration into the community and outpatient rehabilitation. It should contain information concerning the treatment, such as:

- presenting needs
- individual and family goals
- expectations about the specific goals of the treatment received
- any anticipated risks or barriers to successful outcome.

The Needs Assessment Checklist is an excellent tool for determining the patient's needs and is highly recommended.¹⁷⁶ The multidisciplinary rehabilitation program should be regularly reviewed and revised to reflect changes in an individual's condition or long-term goals.

The program should include the following components:

Be comprised of well-defined goals

Prompt and regular goal planning meetings that include the person with SCI and their clinical treating multidisciplinary team should occur. Goal setting should be collaborative involving the person with SCI, their family, the clinical/treating team, and peer support members.

Treatment goals should be meaningful to the person with SCI and linked to broader activity and participation goals. Treatment goals should comprise specific steps so that clients are aware of how each goal builds upon previous ones and towards the overall long-term goals. These goals should be well defined and objective, using say, the SMART goal setting format. Monitoring is required through regular goal planning meetings to track goal attainment, abandonment or identify barriers to goal attainment.

Be considerate of the concerns of family members by including a family conference as part of the planning process

A family conference should be held during the planning stages of the initial multidisciplinary rehabilitation program and repeated meetings should be held regularly throughout rehabilitation and shortly before discharge.

Include access to structured psychosocial treatment programs during the rehabilitation stage

Structured psychosocial treatment programs should be offered to all people with SCI during their rehabilitation stage, with the program varying according to their needs. (More detail can be found in the section, Recommendations for the provision of specific psychosocial interventions, page 15.)

Include access to specialised psychosocial care for those who require it due to the presence of significant psychosocial co-morbidities

Access to specialised treatment programs for co-morbidities such as traumatic brain injury (TBI), drug and alcohol abuse, mental health problems and chronic pain should be facilitated based upon the individual's needs assessment and the multidisciplinary treatment plan.

It is recommended that there is a collaborative relationship developed between the treating team, primary care and community services, and the relevant providers of specialised psychosocial care in order to ensure that the needs of the person with SCI are met appropriately. In some cases, there will be a need for formal coordinated case management. See Recommendations for the provision of specific psychosocial interventions on page 15 for additional detail.

Discharge planning should begin early in the inpatient program

To ensure the smooth transition into the community, discharge planning should begin early in the multidisciplinary rehabilitation program. This requires the input of all team members, peer support, vocational input, with significant input from the individual with SCI and family. This is particularly important where there are significant psychosocial co-morbidities that may impact access to appropriate services.

Vocational prospects should be actively addressed during rehabilitation as part of routine planning for community participation

During the rehabilitation phase, maintaining contact between the client and the employer is to be encouraged where return to pre-existing work is a possibility. If unable to undertake this directly, assistance should be provided in liaising with the employer. Emphasis should be placed on investigating vocational identity, level of education/transferable skills and employment prospects throughout the rehabilitation process. As well, planning for eventual return to work should be integrated into the treatment plan.

Healthcare providers should consider the financial constraints of patients and support their access to appropriate services, for example, patients over 65 years who require high-care needs and equipment. Psychosocial factors and specific strategies should be addressed to support Aboriginal patients in their SCI rehabilitation.

Recommendations for the care of people with cognitive impairment

Recommendations about the care of people with SCI who also have mild-moderate cognitive impairment were developed by a special multidisciplinary committee in 2020 and 2021. Consensus was primarily driven by strength and quality of evidence and clinical discretion by conducting a Delphi study.

Need to assess level of cognitive functioning in people with SCI due to increased risk of cognitive impairment

Current evidence suggests that a person with SCI has substantially increased risk of cognitive impairment. Therefore, it is important to assess cognitive function in people with SCI during rehabilitation.

Important to raise awareness of the occurrence of cognitive impairment following a SCI

It is important to raise the awareness of rehabilitation staff members of an increased likelihood of cognitive impairment in people with SCI who are admitted for SCI rehabilitation. This is because this period is when most intensive rehabilitation takes place, and the presence of cognitive impairment increases the risk of poor rehabilitation outcomes in the long-term.

There are numerous possible contributors/causes of cognitive impairment in people with SCI

While comorbid TBI is a common cause of cognitive impairment following a traumatic SCI, there are several other possible causes. They may include:

- older age
- decentralised cardiovascular function
- sleep apnoea
- psychological disorder
- polypharmacy.

Research is required to confirm possible additional factors like chronic pain, fatigue and neural inflammation that can contribute to impaired cognitive function in SCI.

It is important to standardise terminology for what constitutes mild, moderate and severe cognitive impairment in adults with SCI

Mild cognitive impairment can be defined as cognitive impairment (e.g., mild memory loss) greater than expected for an individual's age and education level but that does not interfere markedly with activities of daily life.

Moderate to severe cognitive impairment can be defined when there is evidence of significant cognitive decline from a previous level of performance greater than expected for the person's age in one or more cognitive domains, such as:

- memory
- attention
- perceptual-motor
- language
- social cognition
- executive function.

The rating of severity depends on the extent to which cognitive deficit/s interfere with independence and everyday functioning resulting in loss of independence, including substantial need for assistance in daily tasks, such as managing finances and taking medications. The cognitive decline should not be due to delirium.

Staff should be aware of common symptoms of cognitive impairment

These include:

- memory loss
- difficulty with solving life problems
- difficulties communicating
- trouble recognising familiar people and places
- problems with attention
- trouble exercising judgment, such as knowing what to do in an emergency
- difficulty planning and carrying out tasks.

There may also be associated emotional and adjustment problems, including elevated anxiety and depressive mood.

SCI units should use validated neurocognitive capacity screens

Valid neurocognitive screens can be important tools that can be used to detect the presence of mild-moderate cognitive impairment in SCI. However, there are no neurocognitive measures created specifically for SCI. Rehabilitation staff should receive training (such as from a neuropsychologist or clinical psychologist) in conducting cognitive screens, as well as in their interpretation.

If the results of a neurocognitive screen suggest cognitive impairment, consider referral for comprehensive neuropsychological testing depending on the individual case

If a person with SCI is assessed as having cognitive impairment with a valid neurocognitive screen, then it is strongly recommended that they be referred for comprehensive neuropsychological cognitive testing.

Depending on the mechanism of injury and irrespective of level of injury, evidence suggests individuals with SCI should be screened for evidence (e.g., PTA) of TBI when admitted to the emergency department (ED) and/or acute care to inpatient rehabilitation.

In cases where individuals with SCI are suspected to have sustained a TBI, the Abbreviated Westmead Post-Traumatic Amnesia Scale should be administered on admission to ED or in acute care, where possible.¹⁷⁷

Person-centred care should especially be the focus when treating a person with SCI who also has cognitive impairment

PCC involves an individual's values and preferences that are elicited and once expressed, guides all aspects of their healthcare, supporting their health and life goals. This is achieved through a dynamic relationship among those who are important to them, and all relevant providers.

PCC involves the SCI rehabilitation team engaging a person with SCI in a collaborative, flexible, encouraging and sensitive manner, and will most likely result in improved SCI perceptions/ participation in rehabilitation for those with cognitive impairment. Factors essential to PCC like trust in relationships, emotional intimacy, and participation encourage post-traumatic growth in people with a SCI.

The use of verbal, language and speech strategies that improve communication should be used where possible

The use of cognitive support strategies (i.e., environmental, verbal, language, speech, written) may improve communication between rehabilitation staff when interacting with people with SCI who also have cognitive impairment. Supportive and helpful language employing strengths-based approaches should be used when communicating with people who have mild to moderate cognitive impairment after SCI. Here are suggestions based on consensus.

- It is best to moderate speech, for example, don't talk too loudly or too softly, unless necessary.
- It is believed best to explain and re-explain who you are and your role, if required.
- It is believed best when introducing yourself for the first time, to consider having a family member or other familiar person present.
- It is believed important to support and reassure the person by acknowledging when they respond.
- It is believed best to keep your conversations short and as simple as possible, as long conversations/instructions may confuse and create difficulties for people with SCI who have cognitive impairment.
- It is believed best to avoid the phrase, "Don't you remember?"
- It is believed best to avoid the use of complex medical or health terms, as this may help enhance understanding and improve confidence to self-manage in people with cognitive impairment.
- It is believed important to present one question, instruction or statement at a time.
- It is believed best to provide gentle and optimistic assistance if the person with cognitive impairment is finding it difficult to find or say a word.
- It is believed best if the person with cognitive impairment hears you but does not understand you, to rephrase your statement in a more understandable manner. For example, ask, "Would you like a cup of tea?" rather than, "Would you like something to drink?"
- It is believed best that you ensure that you are clear in your own mind about what you are communicating or trying to say.
- If English is not the person's primary language, then it is believed best to communicate initially using some words from their native language such as hello, goodbye, how are you?
- It is believed best that you talk to the person with SCI in a place that is quiet and that does not have many distractions. Background distractions, such as a television or adjacent conversations, can compete for attention and impair communication.
- It is believed best to maintain appropriate eye contact when talking or when the person is talking to you. Eye contact (non-verbal communication) followed with an acknowledgement (verbal communication) are excellent ways to let the person know they are being heard.
- The health professional should present with a calm and reassuring demeanour when interacting with a person with SCI who has cognitive impairment.
- It is believed where appropriate that simple written instructions about strategies and solutions should be provided.
- It is believed that initiating conversation by asking friendly non-intrusive questions and showing interest in what the person is attempting to say or communicate will build relationships.
- Older people with SCI and cognitive impairment who have hearing or vision loss are at risk of their impairment being complicated and worsened.

- Make sure that the lighting is appropriate and adequate, not too bright or dark. Bright light can interfere with vision and understanding, while a dark room may increase confusion.
- It is believed advantageous to use gestures when appropriate, such as pointing to objects or demonstrating an action.
- It is believed helpful if the health professional draws pictures or writes things down for the person with cognitive impairment if they think this will help their understanding.
- It is believed that an open and friendly posture when talking to people with cognitive impairment (e.g., shoulders back, head up, maintain eye contact, and smile) will foster relationships rather than a defensive or non-interested posture (e.g., arms folded or on hips, head down or turned partially away, little eye contact, and neutral/stern/worried face).
- In order to improve communication, you can become a creative listener.
- It is believed best not to interrupt a person with SCI who has cognitive impairment when they are trying to communicate a thought or idea, as this may cause them to become confused or lose their train of thought. However, some people with impairment may be extremely verbose or tangential in their speech. In this case, conversations should be more structured. It is suggested to do so sensitively and gently, using clear and specific prompts for topic maintenance and redirection.
- People with SCI and cognitive impairment may exhibit short-term memory problems that affects their train of thought and ability to communicate. This could be a barrier.
- People with SCI and cognitive impairment may quickly forget what they understand in a conversation, and this could be barrier. To facilitate memory, a communication notebook/or notes on their phone (verbally recorded) could be used by staff to record important information for the client. Encourage the client to review this and show it to family members.
- People with SCI and cognitive impairment may require adjustments and/or accommodations to be made (e.g., additional time, writing things down to assist recall) to support them to participate fully in their treatment and the decisions made affecting their treatment.
- People with SCI and cognitive impairment may have communication challenges with resulting frustrations. This may mean an increased risk of negative mood and behaviours, and this could be a barrier to improved communication.

Recommendations for psychosocial assessment

Everyone acquiring SCI should receive sensitive and timely psychosocial assessment at critical time points

It is recommended that a systematic psychosocial assessment process be established that covers aspects of psychosocial function. This can be contributed to by all relevant members of the multidisciplinary team. This information is needed to develop appropriate goals and an effective treatment plan. In addition, the [Emotional Wellbeing Toolkit](#) with its standardised and validated brief clinical tools, can be used on a daily or weekly basis to determine psychological status.

A systematic psychosocial assessment could include the following components.

Pre-morbid details

This should include prior psychopathology and substance abuse. It is recommended that all inpatients with SCI receive a brief alcohol and drug screening assessment. All relevant staff should be trained to deliver this screening procedure. Details for this can be found in the [Emotional Wellbeing Toolkit](#).

Current mental health and psychological status

It is recommended that the following be assessed at admission: a mental health screen (e.g., the [Emotional Wellbeing Toolkit](#) could be used for this) that assesses post-traumatic stress, depressive mood, anxiety, anger and fatigue; and appraisals and perceptions (e.g., self-efficacy). If pain is present, a brief pain assessment should be conducted, such as pain intensity and interference, pain self-efficacy and pain catastrophising. These measures are important for determining protective factors related to resilience, as well as risk factors related to poor psychosocial adjustment.

Psychosocial assessment for those with a suspected TBI or with cognitive impairment

As discussed in the section Recommendations for the care of persons with SCI who have cognitive impairment, a high risk of cognitive impairment exists for those with SCI, who also have a suspected co-morbid TBI or other risk factors (e.g., older age). Therefore, a psychosocial assessment of risk factors associated with cognitive impairment/TBI should be conducted. This information should be integrated into treatment plans and needs.

A brief personality assessment

Personality issues can sometimes create barriers to effective rehabilitation. If required, a personality assessment may provide avenues for reducing such risks.

A structured interview to assess a broad range of social factors

Social factors to be assessed include the following: ethnic, cultural and spiritual factors; sexual concerns, vocational and educational status, social support and family networks, financial status, housing and living arrangements, leisure interests and expectations of rehabilitation for the individual with SCI and their family.

The results of the psychosocial assessment should be collated and available to the treating team

It is recommended that results of assessment be computer scored and data collected into a central patient file that provides comprehensive information on the needs of the person with SCI. This information should then be used to determine goals and the care plan.

The initial psychosocial assessment should be conducted within five days of admission to the SCI unit

An initial psychosocial assessment should be conducted within five days of admission to the spinal cord unit as part of the overall evaluation of the individual. It will be primarily based upon history available from informants and focus on aspects of the psychosocial history that may indicate strengths and protection factors (e.g., strong social support). It should also include risks of poor outcome, such as prior psychiatric history, history of a previous TBI or a co-morbid TBI.

An abridged assessment should be repeated just before discharge and after 12 months of living in the community

The initial assessment should be repeated just before discharge and 12 months after living in the community. Additional assessment of community participation and caregiver status should be included at these points.

People being transitioned from paediatric to adult SCI services should receive a comprehensive psychosocial needs assessment

Individuals with SCI being transferred from paediatric to adult services should receive a comprehensive psychosocial needs assessment during this period. Particular care should be taken to assess the need for further rehabilitative input in those areas that may not have been systematically addressed at the time of initial injury, such as sexuality.

Members of the treating team should be able to conduct brief assessments of common psychosocial problems in order to deliver mental health first aid and facilitate appropriate management

All staff should have a basic level of psychosocial assessment skills to screen for psychological distress, conduct brief and appropriate interventions, and make appropriate referral in between formal assessments. All staff should have the requisite skills to deliver mental health first aid (see Figure 1). In summary, it is to access risk of suicide or harm, listen non-judgmentally, give reassurance and information, encourage the person to get appropriate professional help and encourage self-help strategies.

Figure 1: Mental health first aid

Adapted from Kitchener and Jorm¹



Recommendations for the provision of specific psychosocial interventions

Given the extensive evidence that SCI presents a significant challenge to all those who experience it and that it is associated with increased risk of psychological disorders, it is considered important that everyone should participate in a form of psychosocial rehabilitation intervention following an acute SCI. The level of intervention is best matched to the level of need. Those people with higher risk of adverse psychosocial outcomes or who develop psychosocial problems, need to be offered more intensive and specialised interventions. Those with specific psychosocial co-morbidities will require specialised treatment. Further details of these can be found on page 16 in the section, Individuals with suspected severe psychological disorders may need to be referred to specialised assessment and treatment and in a timely fashion.

All people admitted for rehabilitation of a SCI should participate in an evidence-based psychosocial rehabilitation group or individual intervention

Everyone with SCI admitted for rehabilitation should participate in an evidence-based, structured psychosocial rehabilitation group program consisting of cognitive behaviour therapy (CBT) and related psychological components as part of their multi-disciplinary rehabilitation program. If the person does not wish to participate in a group format, they should be offered individual programs. Depending on the needs of the person with SCI, three different levels of intervention can be offered. These are:

Psychosocial Rehabilitation Intervention Level 1

All people attending rehabilitation, including those with no diagnosis of anxiety or depressive disorder and normal levels of negative psychological states, should receive a minimal psychoeducational and brief CBT intervention. The treatment should be designed to enhance feelings of self-efficacy, increase adaptive coping strategies, boost use of appropriate social skills and problem solving, introduce self-management and relapse prevention strategies, sexuality and couple counselling, vocational counselling and social communication and integration. The program could be delivered in a group or one-to-one format for six hours over a period of six or so weeks.

Psychosocial Rehabilitation Intervention Level 2

This level is for people with no diagnosis of anxiety, depressive or co-morbid disorder, but who show risk factors, such as elevated levels of negative psychological states, low self-efficacy and ineffective coping strategies. Those assessed in this category should receive the same program described in Level 1, plus additional individual structured CBT sessions designed specifically to counter known risk factors.

Psychosocial Rehabilitation Intervention Level 3

This level is for those assessed as having definite diagnosis of mental health disorder, such as depression, PTSD, or showing signs of suicidal ideation. It is recommended they receive a specialised structured CBT program. Inpatients assessed in this category should receive the same program described in Level 1 and 2, plus additional individual structured CBT sessions designed specifically to address the major psychological disorders. This intervention may need to be offered over a longer period of time (in the form of individual treatment). People with SCI in this category may need to receive combination therapy, that is, medication plus the CBT program. Referral for such a program may be necessary.

The effectiveness of psychosocial treatment provided should be assessed for each participant

It is recommended the effectiveness of the structured psychosocial treatment (individual or group format) be assessed at the termination of the CBT program for each participant using brief measures discussed on page 24 in the accompanying document, Psychosocial Care of Adults with Spinal Cord Injuries Guide:

Models of Care. If treatment has not resulted in demonstrable improvement, the person with SCI may need to be referred for specialised interventions.

People demonstrating risk factors for particular co-morbidities may need to be referred for specialised assessment and treatment

It is recommended that people with SCI and major secondary conditions may need to be referred for specialised treatment. For instance, for a person experiencing high levels of chronic pain, referral to a specialised pain management program is recommended (see Chronic pain, page 18). For people with a history of substance abuse, referral to a specialised substance abuse prevention program may be required (see Drug and alcohol disorders, page 17).

Individuals with suspected severe psychological disorders may need to be referred to specialised assessment and treatment and in a timely fashion

It is advised that an inpatient family conference be held before a referral is made to a specialised service for further assessment and treatment. Specialised assessment and treatment may be provided by health professionals integral to the SCI service. Or they can be provided by specialist services such as:

- drug and alcohol
- mental health
- trans-cultural mental health services.

Such external health services should be accessible to those with SCI in a timely fashion. Specialised care programs should be evidence-based where possible and should be fully accessible. Much of the evidence base for treatment of psychological and psychiatric disorders is applicable to people with SCI, although some modifications may be required in order to account for polypharmacy or co-morbidities, such as TBI.

Practitioners are encouraged to draw on the relevant evidence base in treatment planning. In some cases, joint case management between teams may be required (such as TBI and SCI, or psychiatric and SCI services). Examples of disorders that may require referral include:

Major depressive disorders

People with SCI who are diagnosed with severe types of depression (e.g., bipolar disorder, major depressive disorder) should first be screened for suicidal ideation, followed by specialised treatment. Specific guidelines regarding the care of those with SCI and mental health disorders are available from the Paralyzed Veterans of America.¹⁶ Treatment for the depressive disorders should follow guidelines recommended by the [Australian and New Zealand College of Psychiatry Clinical Practice Guidelines for the Treatment of Depression](#).

Anxiety disorders

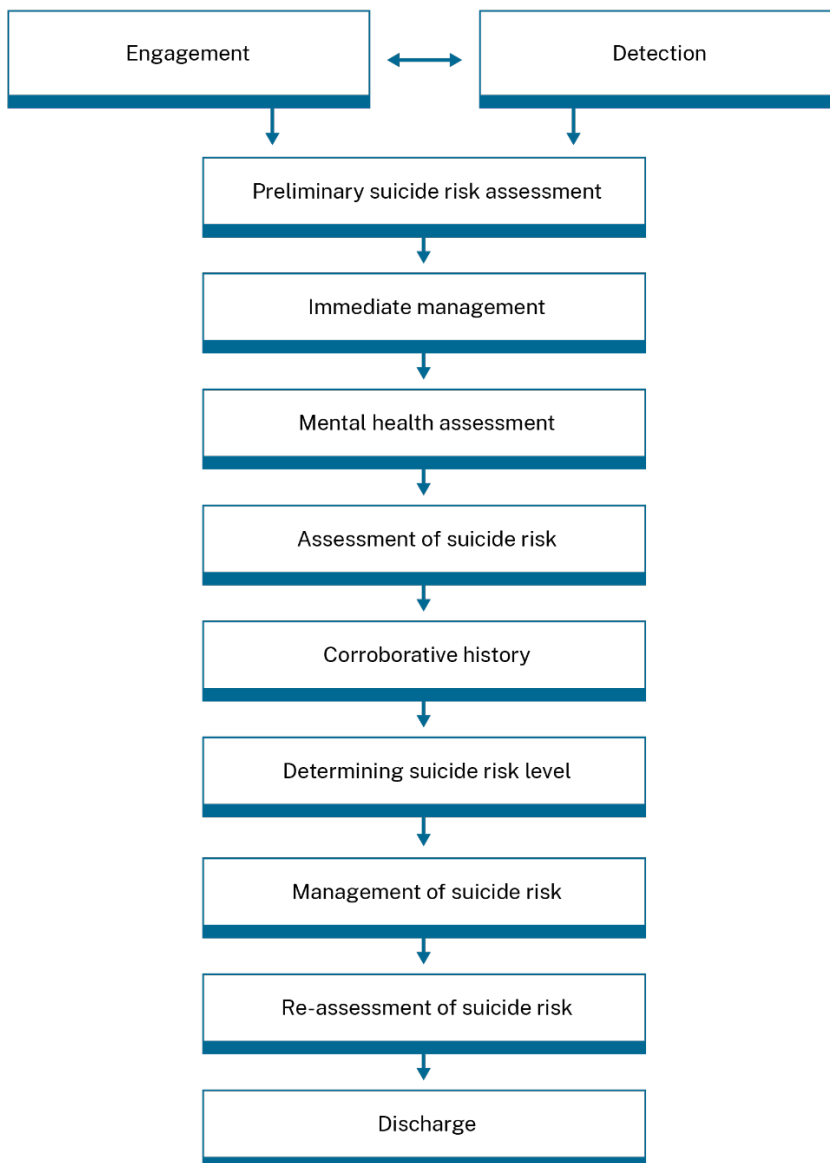
Post-trauma related anxiety disorders can be appropriately managed using the advice available regarding anxiety from sources such as the [Australian Centre for Posttraumatic Mental Health](#). Other anxiety disorders should be managed using guidelines available for the management of the specific condition diagnosed, such as generalised anxiety disorder.

Suicide

Risk of suicide should be routinely assessed and those believed to be at risk should be referred for specialist treatment. NSW Health has developed a framework for suicide risk assessment and management, supported by guidelines developed for various settings (See Figure 2, page 17). These guidelines are also available from the NSW Health website. The framework asserts that all health providers should be able to undertake a preliminary suicide risk assessment and create the most appropriate management plan, including referral to more specialised services. This framework is supported by training events available throughout NSW Health.

Figure 2: NSW Health Suicide Risk Assessment and Management Framework

(Adapted from the [Framework for Suicide Risk Assessment and Management for NSW Health](#)).



Drug and alcohol disorders

People with SCI who are diagnosed with a substance abuse problem should be referred for treatment that follows guidelines recommended by the [Commonwealth Department of Veteran Affairs and the National Drug and Alcohol Research Centre Guidelines for the Treatment of Alcohol Problems](#). There are a range of other guidelines on the management of drug and alcohol issues relevant to people with SCI, including psychosocial interventions. They are available from the [NSW Department of Health](#) website.

Traumatic brain injury

As discussed previously, people with SCI identified as having signs and symptoms of TBI (such as the presence and/or persistence of post traumatic amnesia) should be referred for neuropsychological assessment as soon as medically appropriate. [Guidance on the assessment and management of brain injury](#) is available from guidelines published by the [State Insurance Regulatory Authority](#). Further information on evidence-based treatment can be found on the [NeuroBITE](#) (formerly PsycBite) database.

Chronic pain

Presence of pain should be routinely assessed. All people with SCI who have persistent pain should be screened for suicidal ideation. Advice regarding the assessment and management of SCI-related pain is available.¹⁷⁸⁻¹⁸¹ Individuals reporting that pain is impacting their psychological wellbeing or physical functioning should be assessed by an appropriately trained professional.

In persistent or severe cases this should usually be in the context of a multidisciplinary pain assessment rather than by an individual practitioner. Psychosocial management strategies should be recommended as part of a comprehensive treatment plan rather than an alternative to other treatments such as analgesics. Clinicians should be encouraged to refer to a specialised CBT program to assist in training individuals in effective pain self-management strategies. Table 4 shows components recommended for a pain management program.¹⁸² Psychosocial self-management strategies should be explained as an approach aimed at reducing suffering associated with pain rather than as a curative treatment.

Table 1: Components recommended for a pain management program

(Adapted from Craig, Guest, Siddall and Middleton¹⁸²)

Components	Description
Introduction	Describing the components and goals of program, symptoms of pain, mood and anxiety discussed, the multi-disciplinary nature of treatment
Neuroscience education (integrated throughout the program)	Discuss neurophysiology of pain, models of pain to explain ascending and descending influences, pain sensitivity, causes of pain in the long-term
Goal setting and self-monitoring	Introduction to short- and long-term goals, self-monitoring of pain, mood, sleep and breath rate
Sleep management and diet	Healthy sleep guidelines and discuss the importance of a regular balanced diet
Activity pacing and benefits of physical activity	Concept of activity pacing introduced, paced physical activities planned, an exercise regime agreed on
Problem solving	Structured problem-solving exercises adapted to problems being experienced
Physical relaxation strategies	Education on respiration and stress, role of vagus nerve and breathing in reducing anxiety and pain, slow breathing, mindfulness/distraction strategies taught
Cognitive strategies to control unhelpful thinking	Evidence-based thinking and cognitive skills to manage fear of pain and catastrophising, thought monitoring and management, fear/avoidance cycles
Isometric and visualisation/imagery relaxation	Principles of isometric and visualisation/imagery relaxation taught
Pleasant life events schedules	Exploring activities client enjoys and wishes to engage in, schedules developed
Return to work	Problem solving related to return to work
Coping with flare-ups	Coping strategies already taught and problem solving to address flare-ups; medications used for flare-ups
Social and interpersonal skills	Social skills and assertive training and communication, exercises applied to client context, interpersonal relationships explored
Relapse prevention	Ongoing sessions devoted to progress and prevention of relapse (e.g. deteriorating mood and pain), review of medications ongoing

Monitoring, follow-up assessment and peer support

The extended period of time required to accommodate to the challenges of living with a SCI, and the continuing possibility of the development of significant psychosocial co-morbidities, means that it is imperative that the individual's progress is monitored and access to relevant services across the lifespan facilitated. As well, the individual may require support to continue to apply the self-management strategies necessary for the effective management of their condition that were developed during the rehabilitation process. Peer support is an important resource that is recommended to be used when suitable during rehabilitation.

Ongoing support for the self-management approach to SCI should be provided following discharge from rehabilitation

A psychosocial self-management program should be made available for use following discharge from rehabilitation. The program needs to be designed to promote self-care and mental health management. This should be based on evidence from programs such as the Expert Patient and Flinders Chronic Condition Self-Management programs. (See Table 2 in the accompanying Psychosocial Care of Adults with Spinal Cord Injuries: Models of Care). Careful attention should be given to ensuring that this is widely accessible, for example through use of internet or other technology. It is possible that the Spinal Outreach Services could manage or outsource such a program perhaps in combination with community organisations, such as [Spinal Cord Injuries Australia](#) or [Forward Ability Support](#) (formerly ParaQuad NSW).

The [Health Maintenance Tool](#) (HMT), developed by Royal Rehab and The University of Sydney with funding from icare NSW, can be a valuable resource for supporting the person with SCI in their self-management. The HMT is a consumer-friendly resource that aims to promote and support collaborative self-management of common health issues in people with SCI across five priority health issues: bladder, bowel, skin, pain and autonomic dysreflexia. A sixth module on mental health and wellbeing has recently been developed.

Progress of psychosocial rehabilitation should be routinely monitored level

It is recommended that monitoring of the individual's psychosocial status continue following completion of rehabilitation, at a minimum on discharge and after a period of six to 12 months.

Case management should be used for those presenting with complex psychosocial needs where the capacity for self-management is compromised

The management of those with SCI who also have co-morbidities and other complex psychosocial needs, can create a significant challenge for services. It is recommended that these individuals be provided with case management services to facilitate an integrated management plan. This may be required for varying lengths of time, depending on the variation in clinical presentation of the individual concerned, up to life-long case management in the most complex cases.

Ongoing psychosocial support services should be available to individuals with SCI for those with continuing or emerging psychosocial needs

People with chronic conditions can benefit greatly from support programs.¹⁴⁴ The SCI care plan should therefore provide access to structured, ongoing support and relapse prevention services through community referrals. These may include:

- community mental health programs
- driver's education and training
- health and other educational programs

- financial assistance services
- home health services
- home modification services
- independent living centres
- recreation programs
- sexuality and couple counselling
- SCI associations
- transportation services
- vocational rehabilitation services.

Peer support

is a valuable resource for people with a SCI during their rehabilitation period, and most importantly, following discharge into the community. Peer support officers can be a very important component of the SCI multidisciplinary team in its management and care of those who have an acute SCI. Peers with lived experience can provide a positive role model for people with a SCI. They can also provide non-clinical information and practical guidance. Peer and family support is available from lived experience staff at [Spinal Cord Injuries Australia](#), who also have an online health support service. Support is also available from [Forward Ability Support](#) (formerly ParaQuad NSW).

Staffing considerations

An appropriate staffing mix should be provided in order to deliver effective psychosocial rehabilitation

SCI rehabilitation treating teams will require adequate support from psychosocial specialists, such as liaison psychiatrists, social workers, clinical psychologists and neuropsychologists, in order to deliver appropriate psychosocial rehabilitation. (See Table 2, Recommended staffing for the management of SCI rehabilitation patients on page 22). Guidance is available from several sources regarding appropriate staffing levels, and national standards such as from the [Australasian Faculty of Rehabilitation Medicine](#).

Staff will require appropriate orientation and ongoing professional development to acquire and maintain the required skills

Staff should be provided with additional training in order to be adequately resourced and skilled to effectively implement psychosocial care, undertaking the recommended tasks and roles. In addition, support will be required in order to promote the continued use of the skills, such as access to supervision. Professional development for detecting, assessing and managing cognitive impairment should also be offered.

The skills required for members of the SCI rehabilitation treating team can be learnt through appropriate training, such as using the [SCI Emotional Wellbeing Toolkit eLearning Module](#) found on the ACI Website. The Emotional Wellbeing eLearning Modules (4 x 20 minutes) provide an excellent overview of adjustment following SCI, covering topics such as emotional difficulties, trauma, pain, psychosis, as well as trauma-informed care, ageing with SCI, sexuality and compassion focussed care and self-care.

Structured, employer-assisted education and support programs should be developed for staff in order to support the provision of psychosocial care. Examples of possible modules include:

- workshops concerning psychological and iatrogenic reactions in the acute stage of catastrophic injury (psychological distress, derealisation or depersonalisation, awareness of paralysed body parts, effects of medication on cognition and emotion)
- strategies for the management of patients who have delirium and cognitive impairment
- the effective management of difficult behaviours and coping styles including aggression management
- motivational interviewing and effective communication techniques.

The care of people with chronic conditions like SCI takes its toll on healthcare workers. Appropriate mechanisms of support for SCI staff should be developed to promote continued psychological wellbeing. This may include attendance at regular team debriefing sessions. Ongoing professional development is also available from the [Australian Psychological Society Rehabilitation Psychology of Injury, Chronic Illness and Pain Interest Group](#).

It is crucial that health professionals involved in SCI rehabilitation are familiar with factors influencing perceptions of psychosocial care as well as the barriers to its effective provision together as a team. Furthermore, a more collaborative interdisciplinary care model should be promoted to integrate psychosocial care into routine practice. This should include:

- an understanding of each disciplinary scope of practice
- establishing a process of responding or escalating patients' psychosocial distress during business hours and afterhours
- using relevant clinical assessment tools to address each patient's psychosocial adjustment.

Table 2: Recommended staffing for the management of SCI rehabilitation patients

Full time equivalents (FTE)	
Inpatient staff to patient ratios (for 10 patients with SCI)	
Social workers	1.2 FTE
Psychologists	0.5 FTE
Ambulatory rehabilitation services staff (for each 20 patients with SCI)	
Social workers	1.0 FTE
Psychologists	0.5 FTE

Adapted from the Australasian Faculty of Rehabilitation Medicine Standards 2005 page 7 and Victorian Allied Health in Rehabilitation Consultative Committee. Allied Health Resources, Version 10 July 2007. Accessed July 2008. Also see Australasian Faculty of Rehabilitation Medicine and The Royal Australasian College of Physicians (2012). Standards for the provision of inpatient adult rehabilitation medicine services in public and private hospitals 2011. Sydney: RACP. www.racp.edu.au

Conclusion

This guide has made recommendations concerning the psychosocial care of people who have sustained a SCI. Since its first publication in 2008, important psychosocial initiatives and strategies have begun to be introduced into the rehabilitation of people with SCI in NSW. With this revised version available in 2023, it is hoped that additional innovative and evidence-based changes will be made so that the psychosocial care of SCI is further improved and standardised.

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.