

# Rural Spinal Cord Injury Project

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# PSYCHOLOGICAL ADJUSTMENT

## after Spinal Cord Injury



Useful Strategies for  
Health Professionals

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## INTRODUCTION

Spinal cord injury (SCI) is a devastating event with far - reaching **physical, social** and **psychological** effects. While literature on the psychological impact following the sudden onset of SCI is limited, it does document the presence of a severe **emotional reaction**, which threatens both psychological integration and security. Insufficient attention has been paid in the past to the **importance of psychological adjustment following SCI**. Often the success of rehabilitation tends to be measured only in physical and functional terms. The literature tends to concentrate on the acute phase in hospital, without longitudinal follow-up to study long-term psychological sequelae and adjustment to SCI.

### SUMMARY

- **Frequently, there is a severe emotional reaction following SCI that threatens both psychological integration and security, requiring attention to the long-term psychological adjustment of individuals following SCI.**
- **Successful rehabilitation involves reintegration into the community and adjustment to a very different lifestyle with the re-establishment of satisfying relationships, roles, and opportunities to express one's own identify.**
- **Experiencing a SCI poses a huge challenge and requires one to tap into strengths and to discover new ways of doing things, not only physically but emotionally.**
- **Each person is unique with his or her own individual personality characteristics and coping style.**

## MEETING THE PERSON WITH A SCI FOR THE FIRST TIME

**First contact** may be made with the individual soon after a SCI or in the early days of hospitalisation. This phase marks the **beginning** of the healing process. Experiences can be **frightening** for the person, highlighting the **importance** of this first meeting.

**Psychological adjustment** is influenced by **how** people are treated during the **rehabilitation phase**. Working with people in this early phase should initially be **slow, limited to relationship building** and **gathering information**. It is important to provide reassurance, delivered at the level people are able to accept.

### SUMMARY

- **Emotional recovery is dependent on structure and normality, which should be put in place as soon as possible.**
- **The daily routine set by the hospital helps to establish some structure.**
- **A sense of normality is created by interaction with the various health professionals.**
- **It is essential that support is provided from the beginning and the individual is treated with respect as they begin to rebuild their lives, remembering that the rehabilitation process is both physically and emotionally intrusive.**

## PERSONALITY AND SCI

Spinal cord injury can happen to anyone, although young, active males are over-represented. Research suggests that there is a relationship between **personality** and **aspects of adjustment** after SCI, with optimism, humour, self-efficacy and practical, solution-focussed coping strategies predicting good outcome. Pre-injury education level has also been noted to play a role in long-term adjustment.

Younger people have been found to be more accepting of their injury regardless of duration. They tend to be more flexible and open to new directions and experiences, having a greater ability to adapt to new situations. Other research has found a positive correlation between increasing age and risk of depression.

**Personality, behavioural** and **cognitive** changes may be apparent for those individuals who have also sustained a Traumatic Brain Injury (TBI). Up to 50% of people with SCI have evidence of some cognitive impairment on neuropsychological testing. Sometimes personality changes can be extreme and may also manifest in behavioural changes. Changes in personality, emotional state and behaviour may include: poor impulsive control, disinhibition, mood swings, aggression, depression, agitation, reduced insight, and poor self-monitoring. Changes in cognitive function may include deficits in memory, problem solving and organising, decision making, concentration, initiation and abstract reasoning.

### SUMMARY

- **SCI can affect anyone.**
- **There is a relationship between personality and aspects of adjustment.**
- **Younger people tend to be more accepting of SCI.**
- **There is a greater risk of depression for older people with SCI.**
- **40%-50% of people with SCI present with varying degrees and patterns of cognitive impairment due to TBI, which may manifest in personality, behavioural and cognitive changes.**

## PSYCHOLOGICAL SEQUELAE OF SCI/ADJUSTMENT AND COPING

There is nothing predictable about the psychological sequelae of SCI. The response is individual and is mediated by both pre-morbid individual characteristics and external factors. For most people, SCI induces a severe emotional reaction, which may not be evident initially. A psychological diagnosis warranting intervention from a clinical psychologist and/or psychiatrist occurs in only 40% of the SCI population. The majority of people do not have disabling emotional, behavioural or cognitive symptoms following SCI. Characteristics such as humour, optimism, a sense of self-efficacy and a practical, problem-solving approach to difficulties have been identified as common to this latter group. The earlier these symptoms are treated, the greater the likelihood of full emotional recovery.

Spinal cord injury produces a **variety of emotional reactions**, including:

- Sadness & crying
- Despair & guilt
- Fear of losing control
- Disbelief & panic
- Helplessness & inadequacy
- Disorganisation
- Confusion
- Resentment & bargaining
- Loss of interests
- Fatigue & lethargy
- Loneliness & isolation
- Withdrawal

### **Changes that accompany SCI**

- Lack of privacy
- Loss of independence
- Changes to role/lifestyle
- Uncertainty regarding the future
- Sense of helplessness
- Separation from family and friends
- Inability to control basic bodily functions
- Changes in physical health and functional ability
- Changes in body image

### **Other Factors that affect psychological adjustment**

- Pain
- Medication
- Isolation
- Boredom
- Medical complications and body image
- Cognitive problems/TBI
- Family/ Friends/Social supports

**Pre-injury personality** characteristics such as self-concept, self-efficacy, locus of control and coping styles are considered to be as crucial in determining adjustment to SCI as the **external factors** of social support, socio-economic status and financial status.

The **level and extent of injury or functional impairment** have **NOT** been found to predict adaptation to disability. People with tetraplegia have been found to be just as capable as those with paraplegia of achieving healthy adjustment.

## **PSYCHOLOGICAL COMPLICATIONS AND MANAGEMENT**

A **psychiatric diagnosis** can be made in about **40%** of people with a recent-onset spinal cord injury. The most common psychiatric diagnoses are: substance abuse disorders, conditions attributable to delirium or brain injury, adjustment disorders (see Appendix A) and depressive disorders.

**Post-Traumatic Stress Reaction** is frequent in persons following a major life stress. Symptoms fall into physical, cognitive and emotional domains (see Appendix B). If not appropriately treated, the symptoms may develop into **Post-Traumatic Stress Disorder** (see Appendix C).

## DEPRESSION VERSUS GRIEVING REACTION

There is frequent mention of individuals suffering from “depression” in rehabilitation units. This may have been used loosely to describe people “having a bad day” or to describe Major Depression (see Appendix D). Clinical impressions have tended to over-estimate psychological disturbance with a consistent bias of staff to over-estimate depressed mood relative to the person’s self-report. Findings suggest that those who are least depressed function best during rehabilitation and later after discharge.

### SUMMARY

- **Major depression is not a normal and necessary or essential part of the process of adjustment to SCI, but indicates that the person is distressed and not coping.**
- **The presence of depression is not related to level or degree of injury, contrary to popular opinion.**
- **The grieving reaction may appear similar to depression, but unlike depression will dissipate over time as the individual learns to live with his or her disability.**
- **Mourning or grieving may also present with physical complaints, preoccupation with a former self-image, feelings of guilt, feelings of anger and irritability, and behavioural changes.**
- **The important distinction between mourning and depression is that people who are experiencing a grief reaction will be focused on the lost body part and the accompanying secondary emotional reactions. For example, the individual with SCI would bemoan the altered quality of life without independence and limbs. In reactive depression, the focus is self-critical, with feelings of worthlessness, hopelessness, helplessness and withdrawal from others.**

## PREDICTORS OF PSYCHOLOGICAL VULNERABILITY

### PREDICTORS FOR POST-INJURY PSYCHIATRIC MORBIDITY INCLUDE:

- **A history of psychiatric disorder (including substance abuse)**
- **Family history of psychiatric disorder**
- **A history of impulsiveness (which is over-represented in SCI populations)**
- **A history of family fragmentation**
- **Lack, and especially recent loss, of an intimate relationship**

In contrast, the level and severity of the spinal cord injury and the extent of related injuries are either only weakly correlated with psychiatric disturbance or not at all. The only injury-related variable consistently associated with **depression** is the presence of **persistent neuropathic pain**.

## SUICIDE

**Suicide** is the extreme behavioural response to SCI. Death from suicide has been found to approximately **five times as often** in the SCI population as in the general population. There has been an alarming increase in suicides amongst this group over the last 20 years. It is most likely to occur within **5-6 years post injury** and is responsible for 6-10 % of all SCI deaths. **Passive** suicide is thought to account for additional deaths related to self-neglect, leading to recurrent pressure areas, urinary tract infections and pneumonia.

Suicidal ideation is common, and should be **taken seriously**. Never assume that because a person has a disability they cannot commit suicide. A **referral** to an experienced mental health clinician should be made for an assessment and management if suicidal thoughts are expressed.

### RISK FACTORS FOR SUICIDE

- **Depression**
- **Anger & aggression**
- **Alcohol and other drug abuse throughout hospitalisation**
- **Pre-morbid psychiatric illness**
- **Past suicide attempts**
- **Family disintegration**
- **Male gender**
- **Chronic pain**
- **Multiple medical problems**
- **Isolation**
- **Schizophrenia**
- **Expressions of hopelessness**

### RECOMMENDED MANAGEMENT

- **If an individual expresses suicidal ideation, ensure the person's immediate safety.**
- **Obtain an urgent psychiatric consultation if the person's immediate safety is at risk.**
- **Determine the appropriate setting of care.**
- **Treat underlying problems such as depression, substance abuse, pain, etc.**
- **Involve family and friends where possible.**
- **Regular observation of the person is important.**
- **Active listening by staff.**
- **Encourage expression of feelings and encourage active coping.**
- **Help with maintenance of hygiene, nutrition, bowel and bladder programs while the person is in a depressed state.**

## APPENDIX A

### ACUTE STRESS REACTION

An **Acute Stress Reaction** is a transient condition that develops in response to a traumatic event. This diagnosis is appropriate only for symptoms that occur within 1 month of the extreme stressor and resolves within a 4 week period (DSM-IV which differs from ICD-10). If symptoms persist for more than 1 month then a diagnosis of Post-Traumatic Stress Disorder may be made.

**SYMPTOMS** may include a varying mixture of:

- **Appearing dazed or distracted**
- **Reduced levels of consciousness**
- **Agitation or overactivity**
- **Withdrawal**
- **Anxiety symptoms (eg. sweating, increased heart rate, flushing)**
- **Narrowing of attention**
- **Disorientation**
- **Depression**
- **Amnesia**

Management strategies will always vary from one individual to the next depending on the individual's particular problem. However, the management of an acute stress reaction generally involves the following:

### RECOMMENDED MANAGEMENT

- **Recognise the symptoms and organise a prompt referral to an experienced mental health clinician, such as a clinical psychologist or psychiatrist to determine the severity of the symptoms. Persistent symptoms may require more specialized treatment and a revised diagnosis of Post-Traumatic Stress Disorder and/or Depression.**
- **Let people know that these are commonly experienced after a traumatic and life threatening event, and a normal reaction to such a stressful situation.**
- **Encourage the person to talk about what they are experiencing with family and friends. Discussion may help reduce any negative appraisals of his/her reaction during the experience.**
- **Time. Reassure the person that the acute stress reaction is likely to pass in a short period of time.**
- **Social support will be critical for helping the individual cope after a trauma has occurred. It may be necessary to identify potential sources of support and facilitate support from others (eg. partners, family, friends, work colleagues, peer support).**

## APPENDIX B

### POST- TRAUMATIC STRESS DISORDER

**Post-Traumatic Stress Disorder (PTSD)** is characterized by the development of a long lasting anxiety response following a traumatic or catastrophic event. Typically, the individual experiences or witnesses a traumatic event such as actual or threatened death, serious injury to oneself or another person or a threat to the personal integrity of oneself or others. The response involves helplessness, intense fear or horror.

PTSD is often undiagnosed due to failure to appreciate symptoms especially, emotional numbness, a physical/ medical focus, lack of direct questioning by clinician and person trying to avoid/deny feelings.

**PTSD usually develops within 3-6 months of the traumatic event (although sometimes later) and involves:**

- **Images, dreams, or flashbacks of the traumatic event**
- **Avoidance of cues which act as reminders of the traumatic event**
- **Amnesia about important aspects of the traumatic event**
- **Depressed or irritable mood**
- **Social withdrawal**
- **Concentration and memory difficulties**
- **Nightmares are disturbed sleep**
- **Being easily startled**

### DIFFERENTIAL DIAGNOSIS

PTSD is distinguished from an Acute Stress Disorder by the time frame in which symptoms are experienced. In an Adjustment Disorder the stressor need not be as severe as in PTSD and individuals do not tend to relive the unpleasant experience/s as they do in PTSD. Depression may co-occur with PTSD.

### RECOMMENDED MANAGEMENT

- **Recognise symptoms and organise a prompt referral to an experienced mental health clinician, such as a clinical psychologist or psychiatrist to determine the severity of the symptoms. PTSD is difficult to treat.**
- **Effective treatment involves helping the person to systematically confront experiences, memories and situations associated with the traumatic event, which requires considerable skill.**

## APPENDIX C

### ADJUSTMENT DISORDER

**Adjustment Disorders** are characterized by a short period of distress and emotional disturbance following the occurrence of a significant life change or stressor. Examples of some such life stressors are: bereavement, divorce, chronic illness, or threat of illness, a natural disaster and retirement to name a few. The stressor may affect the individual, an entire family, or an entire community.

The symptoms must develop within 3 months after the onset of the stressor(s). The clinical significance of the reaction is indicated either by marked distress, or by significant impairment in social or occupational functioning.

An adjustment disorder must resolve within 6 months of the termination of the stressor. However, the symptoms may persist for a prolonged period (ie. longer than 6 months if they occur in response to a persistent stressor such as chronic illness).

**Adjustment disorders increase the risk of attempted and completed suicides** and may complicate the course of illness in individuals who have a general medical condition (eg. decrease compliance with the recommended medical regime or increased length of hospital stay).

#### **COMMON SYMPTOMS OF ADJUSTMENT DISORDER include:**

- **Depressed mood**
- **Anxiety or worry**
- **Feeling unable to cope with life at present or plan ahead**
- **Insomnia**
- **Stress-related physical symptoms (headaches, abdominal distress, chest pain, and palpitations)**
- **Interference with social functioning or performance of daily activities**

There needs to be strong evidence that the disorder would not have developed in the absence of this stressor or life change. A diagnosis depends on the content and severity of symptoms and on an individual's personality and history.

## RECOMMENDED MANAGEMENT

- Offer a supportive and confiding relationship
- Encourage control of negative thoughts
- Assist and encourage problem-solving
- Encourage involvement in positive activities
- Promote health maintenance
- Provide controlled exposure to reminders of loss

## APPENDIX D

### MAJOR DEPRESSIVE EPISODES

Depression is a mood state characterised by significantly lowered mood and a loss of interest or pleasure in activities that are normally enjoyable. While depressed mood occurs to everyone at sometime it can be distinguished from a major depressive episode by its severity, persistence, duration and the presence of specific symptoms.

### COMMON EMOTIONAL, BEHAVIOURAL, AND PHYSICAL SYMPTOMS OF MAJOR DEPRESSION are:

- Markedly depressed mood
- Loss of interest or enjoyment
- Reduced self-esteem and self-confidence
- Feelings of guilt and worthlessness
- Bleak and pessimistic views of the future
- Ideas or acts of self-harm or suicide
- Disturbed sleep
- Disturbed appetite
- Decreased libido
- Reduced energy leading to fatigue and diminished activity
- Reduced concentration

### WHO IS AT RISK OF DEVELOPING DEPRESSION?

A personal or family history of depressive illness increases the risk of developing depression during a grief reaction. Premenstrual tension/ hormonal factors for women can also effect ones mood and depressive state.

## RECOMMENDED MANAGEMENT

- **Referral to an experienced general practitioner, clinical psychologist or psychiatrist for assessment.**
- **Individually planned management program.**
- **Appropriate first-line treatments include a structured psychotherapy such as cognitive-behavioural therapy (CBT) or interpersonal therapy (IPT), and/or trial of antidepressant medication.**
- **Address issues of stigma, bias against people with mental health issues in rehabilitation settings.**

## CONTACTING MENTAL HEALTH PROFESSIONALS

Access to Clinical Psychologists and Psychiatrists is often limited requiring the G.P to take a critical role in dealing with mental health issues and Community Mental Health Teams.

- For people living within the community, GP's are required to refer individuals to psychiatrists for a psychiatric consultation.
- A psychological consultation requested by can be made by contacting the Clinical Psychologist directly. Most rehabilitation units have a consultation-liaison psychiatry service that can be contacted by the rehabilitation consultant or registrar.
- A referral is not required for a consultation by a Clinical Psychologist. Private Clinical Psychologists can be accessed through the Yellow pages for your area or by contacting the Australian Psychological Society.
- In the case of an emergency, the Community Mental Health Team is available to conduct psychiatric assessments and, will provide a management plan and follow-up if necessary.

If you are unsure of the availability of psychiatrists or clinical psychologists in your region, check with your Area Health Service.

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## RURAL SPINAL CORD INJURY PROJECT

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This document was published as a fact sheet for the Rural Spinal Cord Injury Project (RSCIP), a pilot healthcare program for people with spinal cord injuries (SCI) conducted within New South Wales. It is not a stand alone resource but part of a series of eight fact sheets produced by specialists to fulfil the educational components of the project.

All recommendations are for spinal patients as a group. Individual therapeutic decisions must be made by combining the recommendations with clinical judgement, including a detailed knowledge of the individual patient's unique risks and medical history, as well as the resources available. This document is published as a guide only and does not take the place of advice from your regular health professional and /or medical practitioner.

