

# Psychosocial care of adults with spinal cord injuries guide

Models of care

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

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## Psychosocial aspects influencing adjustment following spinal cord injuries

This section, Psychosocial Care of Adults with Spinal Cord Injuries Guide: Models of Care, is one part of the overall guide that was developed for health professionals and practitioners. The guide's aim is to support clinicians to make judicious decisions for people with a spinal cord injury about their:

- assessment
- treatment
- referral
- living arrangements.

Although paediatric spinal cord injuries (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

The information collected 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.

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

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

<b>Level I</b>	Systematic review or meta-analysis of randomised controlled trials
<b>Level II</b>	At least one well-designed randomised controlled trial
<b>Level III-1</b>	Well-designed pseudo-randomised controlled trials
<b>Level III-2</b>	Comparative study with concurrent controls, such as controlled cohort or case-control studies with non-randomised controls
<b>Level III-3</b>	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
<b>Level IV</b>	Case series or before and after studies.

Evidence-based information gathered, enabled this list of models of care that can influence service design in SCI rehabilitation.

## Epidemiology (Level 111-2 evidence)

SCI is caused by damage to the nervous system and spinal cord as a result of bruising, compression or severance following a traumatic injury, or with degenerative changes of the spine, infection, vascular accident, or tumours in non-traumatic disease. SCI is not a common disorder, with variation reported across world regions for North America (40 per million), Western Europe (16 per million) and Australia (15 per million).<sup>20 21</sup> The worldwide prevalence of SCI (i.e., the number of people with SCI at any one time including from a traumatic and non-traumatic cause) has been reported to range between 236 to 1,298 cases per million people<sup>22</sup>, with the prevalence varying between regions and countries. In NSW in 2017-18, 344 people sustained a new acute SCI, and there were an estimated 5,500 people living with an existing SCI in NSW (690 per million population), based on hospital records from 2001-02 onwards.<sup>23</sup>

Typically, younger males aged 16-30 years are more vulnerable for sustaining a traumatic SCI given they have a higher risk of experiencing a road crash or sporting injury. However, in countries with ageing populations, there has been an increase in the rate of older people aged 65 years and older having a SCI due to a fall.<sup>8 24</sup> Males are more likely to sustain a traumatic SCI in a ratio of around 4:1 males to females. However, non-traumatic SCI disease due to vascular disorders, infectious conditions, spinal canal stenosis, disc herniation, myelopathy and cancer are more evenly distributed between genders.

Aging in the SCI population is also a factor that affects psychosocial care within SCI rehabilitation. With increased life expectancy following a SCI, there is an increase in medical and functional problems.<sup>25</sup> People with SCI who live into their older years with stable health and function experience natural physical deterioration that occurs with aging.<sup>26</sup> Those who live to an older age will more likely have higher quality of life, incomplete and/or lower-level injuries and have higher levels of independence and good health.<sup>27 28</sup>

In Australia the number of people living with a SCI was estimated to range between 11,000 to almost 20,000 persons in June 2011.<sup>29</sup> The number of people living with SCI (prevalence rate) is increasing due to improved survival rates, though mortality rates are higher for those with tetraplegia and with complete lesions, and mortality risks are highest in the first two to three months following the injury.<sup>8 30</sup>

## Nature of psychosocial outcomes

Psychosocial outcomes are rarely clearly defined or operationalised. For example, terms such as 'adjustment following SCI' or 'coping' are often used in discussions of psychosocial outcomes following SCI. But these terms can refer to somewhat different concepts at different times and when used by different authors.

'Adjustment' has been said to be 'the act of bringing something into conformity with external requirements' and 'harmony achieved by modification or alteration of a position'.<sup>31</sup> Based on definitions developed by Middleton and Craig (2008), adjustment following SCI could be defined as:

*'a person with SCI responding adaptively to their injury, that is, modifying their behaviour, thinking and personal circumstances in relation to the many factors associated with the injury and impairment, with a goal of achieving a satisfactory quality of life through resumption of desired social role'.<sup>32</sup>*

Equally, 'coping' could be considered to be a psychosocial outcome measure and is used variously to mean either a purposeful and effortful response to a challenge or a more passive and reflexive response. For the purposes of this guide, we define 'coping' as:

*'an effort expended by the person to solve challenges and difficulties experienced, with the goal of mastering or minimising their problems or conflicts'.<sup>32</sup>*

Therefore, a desirable psychosocial outcome following SCI would be to assist people with SCI to adjust and cope satisfactorily to their life challenges and problems. Recent trends place emphasis on improving self-management and building resilience.<sup>3 33</sup>

In addition to the systematic use of validated impairment and activity outcome measures (e.g., ISNCSCI level/motor and sensory score, AIS grade, SCIM score), it is important that appropriate psychosocial outcome measures are available to evaluate the progress and success of psychosocial aspects of SCI rehabilitation. Quality of life (QOL), for instance, which reflects the degree to which a person is satisfied with their life, can be measured by a health-related QOL measure called the SF-36. It covers various relevant domains, such as:

- physical functioning
- emotional functioning
- vitality
- mental health
- social functioning
- pain.

## Psychosocial outcomes following SCI

Research into the psychosocial outcomes for individuals with a SCI has been increasing over the past 15 years. Summaries have been provided in the following sections.

### Social and community participation (Level III evidence)

The pressures and daily demands associated with SCI place extraordinary strains on the family, in addition to the person with SCI.<sup>34-36</sup> Stable employment and financial pressures can be major problems, especially if the person with SCI is the primary income earner before the injury.<sup>37</sup> More than likely, given the global damage sustained in a SCI, substantial changes will be required in the family. For example, research has found that in comparison to a non-carer spouse, the carer spouse of a person with SCI will suffer high risks of frustration, stress, fatigue, health problems, isolation, guilt feelings, resentment and greater risks of depression.<sup>38 39</sup>

When the person with SCI leaves hospital to live in the community, they face many difficulties in adjusting to physical and social barriers, as well as vocational and financial challenges. It must be remembered that in addition to issues relating to community and social reintegration, people with SCI face increased risks of having secondary health complications, and consequently many may experience frequent hospitalisations.<sup>2</sup> Community reintegration may be made more difficult by medical problems, such as:

- spasticity and recurrent infections
- environmental barriers from reduced accessibility
- mobility and transportation restrictions due to their physical impairment.

For optimum adjustment, it is crucial that during hospitalisation individuals with SCI regain a degree of personal autonomy that allows them to participate socially in activities of their own choice within their community.<sup>4</sup> Regrettably after discharge from hospital, many people with SCI will be at risk of diminished personal autonomy with simultaneous decreased capacity for social participation.

While the majority of people with SCI still engage and participate in their communities to some extent,<sup>36 40</sup> a substantial number will experience significant difficulties with social participation that will impact negatively on their social support, social and family relationships and ultimately their mental health.<sup>4 41</sup> For example, research found a decline in social participation in a SCI sample over the long-term. This was due to difficulties with reduced independence, mobility and employment, even though economic self-sufficiency steadily improved over time.<sup>41</sup>

Returning to work or finding new employment is often challenging because of the complex interactions of physical impairment, personal (e.g., previous work, personality and preferences), vocational and environmental factors.<sup>42</sup> The process of seeking and gaining employment post-injury is interrelated with the effectiveness of adjustment to SCI.<sup>43</sup>

While employment will have a positive influence, many people with SCI will not be able to be consistently employed and this will increase risks of a lower quality of life.<sup>37 44</sup> Common barriers to employment have been found to be problems with:

- transportation
- poor health
- physical limitations
- lack of work experience
- education or training needs
- physical and/or architectural barriers
- discrimination by employers
- loss of social security benefits.<sup>44</sup>

Early interventions tailored to the person's interests and competencies, integrated with rehabilitation services, are important for the person's hope and vocational identity.<sup>45 46</sup> At an early stage, the relevant health professional should explore and address key influencing factors that may impact negatively on future decisions about employment after SCI.<sup>45</sup> These factors may include self-confidence, perceptions about work ability (job demands versus personal resources), health issues (such as pain, fatigue and medication side effects) and the presence of competing responsibilities.

### **Sexual adjustment (Level III evidence)**

Sexual adjustment is also a challenge following a SCI.<sup>47 48</sup> Research into sexual dysfunction following SCI has been neglected. Essentially, orgasm is often altered or impossible, and fertility severely impaired.<sup>49</sup> The extent of sexual dysfunction is influenced by:

- the level and severity of the neurologic lesion
- the presence of bladder and bowel problems
- pain
- spasticity
- difficulties with interpersonal and social relationships.<sup>50</sup>

In spite of these, many people with SCI report a satisfying sexual relationship following the injury, however, studies have found women with SCI may suffer decreased sexual satisfaction.<sup>51 52</sup> Furthermore, as with any major life event, marital relationships can be strained, with a high risk of separation following the injury and opportunities to find a partner limited.<sup>53</sup> There are additional challenges faced by carers of those with SCI acquired during childhood or adolescence, particularly in relation to the management of developmental factors, such as sexual maturity.

### **Emotional wellbeing and mental health**

Living with SCI will test a person's resources and resilience.<sup>3 4 34 54</sup> The majority of people who sustain a SCI will experience grief and sadness as a result of the impairment and loss. This is considered a normal reaction to such an injury.<sup>55</sup> Therefore, distinguishing between grief and depression is important and this requires careful diagnostic assessment because of the obvious difference this will make to management.<sup>55</sup>

### **Anxiety and post-traumatic stress (Level III-2 evidence)**

Elevated levels of anxiety following SCI is a risk for up to 30% of people with SCI.<sup>5 56-58</sup> Given the trauma and loss associated with the injury, it is not surprising that a person with SCI becomes anxious about their wellbeing and future. This is especially the case when secondary health conditions are present such as chronic pain.<sup>59</sup>

Anxiety levels have been found to steadily increase from the initial week after the injury up to just before discharge in up to 60% of a sample, with levels similar to clinically elevated anxiety levels in people with an anxiety disorder. After discharge, anxiety levels drop below the clinical cut off scores for anxiety disorder.<sup>60</sup> Higher levels of anxiety were found to correlate significantly with:

- depressive mood
- chronic pain
- poorer quality of social support.<sup>60</sup>

A minority of people with SCI, ranging from around 10% up to 40%, are at risk of developing post-traumatic stress disorder (PTSD).<sup>34 57 58 61</sup> Given that many people with SCI sustain their injury during a traumatic event (motor vehicle crash, fall or act of violence) it is understandable that disturbing and distressing memories related to their injury are common.



### Depression, suicide and chronic fatigue (Level III-2 evidence)

Adults with SCI have a high risk compared to the general population of experiencing elevated levels of depressive mood and negative psychological states, such as anxiety.<sup>5 13 34 56 60 40 62 63</sup> The catastrophic nature of SCI and the difficulties adjusting to its impairments were shown to result in a 20-40% chance of experiencing depression or elevated depressive mood in the rehabilitation phase and up to a 40% chance when living in the community.<sup>5 56 60 64 65</sup>

Fann and colleagues (2011) found the occurrence of possible major depression to be around 23% in people with SCI living in the community, with 29% of those receiving antidepressant medications (mostly serotonergic antidepressants) and 11% receiving psychotherapy of some type, in the previous three months.

Recent research found a spot prevalence of 51% of clinically elevated depressive mood in people with SCI living in the community.<sup>66</sup> A meta-analysis examining studies that estimated rates of depression following a SCI concluded that up to 26% of adults with SCI will have a depressive disorder depending on the time after the injury.<sup>63</sup> Research has also shown that unless the depression and distress are treated, levels will remain elevated for up to at least two years after the injury.<sup>67</sup>

The occurrence of psychological morbidity in adults with a SCI was determined in a prospective study that followed adults with SCI:

- from admission to rehabilitation after intensive care (that is, generally within four to six weeks of the injury)
- through four to eight months of inpatient rehabilitation to discharge (depending on level of lesion and complexity)
- after 12-months post-injury and when living in the community.<sup>34</sup>

The rate of any diagnosed mental disorder at admission to rehabilitation was up to 30%, about 25% at discharge and around 30% at the 12-month period. The most prominent mental disorders were depression, followed by alcohol dependence and abuse disorder, drug dependence and abuse disorder, suicidality, bipolar disorder, and generalised anxiety disorder. The occurrence of PTSD was low at around 4%.<sup>34</sup> There was a high rate of co-morbidity, with most common co-morbidity being depression with a substance use disorder, followed by depression with suicidality. These mental health disorder rates in SCI are much higher than Australian community estimates.<sup>34</sup>

Adults with a SCI also have elevated risk of suicide.<sup>14 68-70</sup> Evidence suggests the suicide rate can be up to five times higher than the general population depending on the country.<sup>68</sup> Risk factors for suicide include:

- being male
- having a schizoid, depressive or narcissistic personality
- abuse of alcohol or other drugs
- showing symptoms of significant depression.

Attempted suicide leading to SCI was determined to be just over 2% of the total SCI cases over the years from 1970 to 2000 in NSW. Suicide attempts leading to SCI have increased significantly over this time period,<sup>72</sup> with the frequency of suicide following SCI estimated to be around 8%.<sup>72</sup>

Chronic fatigue is related to poor life satisfaction,<sup>73 74</sup> and is a significant risk for those people with SCI who are depressed or who have chronic pain.<sup>9</sup> Research found the occurrence of chronic fatigue in adults with SCI to be around 56% when living in the community.<sup>66</sup> Fatigue is defined as excessive chronic tiredness involving feelings of exhaustion and negative emotions, such as anxiety and poor mood.<sup>75</sup>

Excessive daytime sleepiness (EDS) is also another related problem suffered by many with SCI, being a susceptibility to fall asleep during the day.<sup>76</sup> It is prevalent in individuals with tetraplegia and those with complete lesions, and sleep disorder (such as obstructive sleep apnoea), a condition that is also common in adults with SCI, increases EDS and vice versa.<sup>76 77</sup> Chronic fatigue is different to EDS and tiredness arising from daily physical and mental exertion by its chronic feelings of low mood and anxiety,<sup>75</sup> though daytime sleepiness and fatigue will obviously be related.<sup>76</sup> Major problems associated with fatigue can include:

- increased chance of making errors when performing tasks
- reduced motivation
- circadian rhythm and homeostatic disruption
- increased chances of negative mood states, such as anxiety and confusion
- negative thinking.<sup>66 74</sup>

Research has found that elevated negative mood states (e.g., depressive mood, anger, fatigue) are risk factors for poor rehabilitation outcomes in adults with SCI. Depression is predictive of more frequent and longer hospitalisations (e.g., more time in bed and fewer days spent outside the ward), increased medical complications, poorer self-care, higher medical expenses and greater difficulties with transportation.<sup>12 56 78</sup> People with SCI who report elevated chronic pain have been found to be more depressed and have higher levels of distress, that then negatively interferes with their daily living activities.<sup>9 79 80</sup> Chronic pain, such as neuropathic pain, is associated with increased depressive symptoms.<sup>9 79</sup> If depressed people with SCI are not treated they have higher risks of suicide, and it is likely that risks of suicide also increase if chronic pain is present and not treated successfully.<sup>79</sup>

### **Long-term positive psychological adjustment and resilience (Level III-2 evidence)**

Best evidence found that most people who sustain a SCI adjust well to the injury and demonstrate remarkable resilience with post-traumatic growth in response to the injury and associated impairment.<sup>3 5 36 81 82</sup> For example, a prospective study following adults with an acute SCI up to 12 months post-injury showed that around 60% were resilient.<sup>82</sup> Unfortunately, almost 15% were found to have persistently poor resilience over the 12 months, while a further 25% deteriorated in their resilience over the 12 months.<sup>82</sup> Factors like higher self-efficacy, stable positive mood and higher levels of social support were shown to be linked with stronger resilience.<sup>6</sup>

Other research found improved resilience was related to:

- fewer life problems
- adaptive thinking styles
- greater acceptance
- fighting spirit
- lower social dependence and disengagement.<sup>3</sup>

Employment, financial income, a low frequency of medical complications and having social opportunities were also found to be associated with improved resilience.<sup>83</sup> Many with SCI will suffer distress and despondency, as well as lower QOL following the injury.<sup>84</sup> However for most people, the distress diminishes after two years, with for instance, no differences found for 'fighting spirit' between able-bodied controls and a SCI sample two years after the injury.<sup>85 86</sup>

### **Quality of life (Level III-2 evidence)**

As might be expected, studies have shown that SCI negatively impacts QOL across a range of dimensions, such as physical functioning, social and emotional functioning, mental health, vitality and pain using a widely used self-reported instrument, such as the SF-36.<sup>60 84 87 88</sup> Additionally, factors such as neuropathic pain, pressure injuries, negative mood states, and chronic fatigue have been shown to decrease QOL,<sup>74 84 89</sup> along with factors such as spasticity, socioeconomic disadvantage and medical complications that have similarly been found to be associated with lower QOL.<sup>84 88</sup>

Caregivers of people with SCI are also at risk of having lowered QOL.<sup>90</sup> It is likely that psychological and social factors are equally important in determining QOL for people with SCI in the long term. However, it would be a mistake to conclude that an injury like SCI will result in low QOL just because of the onset of severe physical impairment.<sup>84</sup> For instance, robust self-efficacy was shown to be related to QOL similar to able-bodied norms. While poor self-efficacy was associated with substantially reduced QOL comparable to the effect of chronic pain on QOL.<sup>84</sup>

## Factors influencing psychosocial adjustment

There are many factors contributing to the process of adjustment following SCI.<sup>2,91</sup> These can be grouped into different areas, such as perceptions and attitudes, medical, physical, environmental, social and community factors. The impact of some of these on adjustment are discussed below.

### Perceptions of control, self-efficacy, feelings of helplessness, and coping (Level III-2 evidence)

Attributional processes and coping styles have been shown to be important predictors of psychological adjustment.<sup>2,6,60,92</sup> People with SCI who attribute their life outcomes more to chance and powerful others (e.g. poor self-efficacy/perceived helplessness) are more likely to experience higher levels of distress than those who rely more upon their own resources, while poor treatment outcomes have been found to be linked with helplessness beliefs.<sup>2</sup> Having helplessness or poor self-efficacy beliefs may also be associated with an increased likelihood of experiencing PTSD and general health problems.<sup>93</sup> Research has shown that people with SCI with poor self-efficacy had significantly elevated levels of depressive mood and anxiety in comparison to those with high levels of self-efficacy.<sup>94</sup> People with SCI who had poor self-efficacy were also found to have higher levels of chronic fatigue.<sup>66</sup>

A robust perception of control (the belief that one can influence life outcomes) has been found to be associated with positive coping strategies, such as fighting spirit and acceptance. It was also found to be related to greater wellbeing.<sup>95</sup> Conversely, Kennedy and colleagues reported that poor self-efficacy was associated with more dependent coping styles (e.g., relying on others) and this was found to be related to poorer wellbeing. There is a need to counter the development of perceptions of helplessness or poor self-efficacy in adults with an acute SCI, as this will have a negative impact on adjustment and resilience.<sup>2</sup>

Therefore, it is essential to foster a sense of personal control in the person with SCI during rehabilitation. Indeed, in a model called the SCI Adjustment Model or SCIAM, it has been argued that the “engine room” of the ability to adjust involves the dynamic influence of primary and secondary appraisal processes, such as self-efficacy, and other cognitive processes, such as catastrophising, perceived barriers to change, and self-esteem.<sup>2,96</sup> Modelling has also identified that the majority (around 60%) of adults with SCI have moderate to high levels of self-efficacy accompanied with low levels of depressive mood. As well, low self-efficacy was strongly linked to clinically elevated depressive mood. Low self-efficacy was also found to be related to higher severity of secondary conditions and negative appraisals.<sup>81</sup> Robust self-efficacy was also related to level of adequate social participation in the community. Further, self-efficacy was a strong predictor of resilience at discharge from rehabilitation and 12-months post-injury, while sociodemographic and injury factors did not contribute significantly to participation.<sup>4</sup>

### Cognitive impairment (Level III-2 evidence)

Traumatic SCI involves significant physical trauma, such as arising from a road accident or a fall, and, therefore, an elevated risk of sustaining a co-morbid traumatic brain injury (TBI) exists. A TBI often results in cognitive impairment.<sup>10,97-99</sup> Rates of a co-morbid TBI in SCI have been shown to range between 30-60%,<sup>10,100</sup> and the presence of a co-morbid TBI is usually based on assessment of post-traumatic amnesia (PTA) and the presence of a cerebral lesion on neuroimaging. Variability in dual diagnosis estimates largely depends upon differences in the screening processes and criteria used,<sup>101</sup> along with factors (e.g., critical care, intubation, alcohol/substance intoxication) potentially confounding or delaying a TBI diagnosis.<sup>102,103</sup>

A dual diagnosis of SCI and TBI will possibly negatively impact a person's progress in intensive SCI rehabilitation, as well as be associated with increased risk of difficulties with re-integration into the community following discharge from hospital.<sup>10,104</sup> Cognitive impairment related to a TBI in SCI included:

- reduced processing speed
- reduced comprehension

- memory
- problem-solving capacity.<sup>99</sup>

Given this risk, it is important to conduct early screening (e.g., in ambulance, emergency and/or intensive care) for a TBI.<sup>10 102 105</sup> This is especially true for TBI of mild severity (making up to 90% of all TBIs) that are more commonly missed due to the subtle/transient signs and symptoms.<sup>102</sup> Screening for TBI in adults with traumatic SCI should involve testing/screening their history for an altered level of consciousness and mental status. For example, loss of consciousness and/or post-injury confusion/disorientation and/or an impaired Glasgow Coma Scale (GCS) score and/or evidence of PTA and/or abnormalities on CT/MR brain imaging.<sup>101</sup> <sup>102</sup> Additional screening should focus on those observed to be having difficulties retaining information or problems with procedural learning/skill acquisition during rehabilitation. Formal neuropsychological evaluation should be recommended to inform rehabilitation delivery.<sup>10 105</sup> Further, a failure to detect the presence of less severe TBI such as a mild TBI, could lead to poorer uptake of functional independent living and self-management skills introduced and taught during the rehabilitation inpatient phase. This may potentially result in poor self-management outcomes, increased levels of dependence and reduced adjustment capacity.<sup>10 98 104</sup>

Surprisingly, cognitive impairment studies have commonly failed to assess for mental health disorder, such as an undiagnosed depression, that has also been linked with reduced cognitive performance.<sup>34 107</sup> It is also important to appreciate that traumatic SCI is associated with post-traumatic inflammation as a result of the repair process, and this can also result in neurodegeneration.<sup>108 109</sup>

However, TBI is only one known cause of cognitive impairment in people with SCI. This is because many people will have sustained their SCI due to non-traumatic causes or at an advanced age. Therefore, it is necessary to appreciate factors other than a TBI that can contribute to cognitive impairment following SCI.<sup>10 105 106</sup> Factors associated with cognitive impairment include:

- pre-injury learning difficulties
- prior head trauma (e.g., a pre-morbid sporting injury or assault)
- persistent fatigue affecting attention and thinking capacity
- the presence of a sleep disorder such as obstructive sleep apnoea
- the presence of chronic pain, elevated anxiety and depressive mood
- taking multiple medications such as narcotics and neuroleptics for pain, alcohol and substance abuse.
- older age.<sup>10 106</sup>

Surprisingly, cognitive impairment studies have commonly failed to assess for mental health disorder, such as an undiagnosed depression, which has also been linked with reduced cognitive performance.<sup>34 107</sup> It is also important to appreciate that traumatic SCI is associated with post-traumatic inflammation as a result of the repair process, and this can also result in neurodegeneration.<sup>108 109</sup>

## Medical factors

Medical and injury factors, such as level and completeness of injury have not been found to contribute strongly to adjustment following SCI.<sup>84</sup> However, secondary health complications can occur in people with SCI,<sup>110</sup> and are known to have a negative influence on adjustment. These are described below.

### Pain (Level II, III-2 evidence)

Chronic pain can be defined as any pain that:

- persists past the expected healing time following an injury
- persistent pain experienced for at least three months.<sup>111</sup>

This definition takes into account expected times for an injury to heal, and also allows for cases where there is persisting neurological damage,<sup>111</sup> as is likely in SCI. Pain is a major problem affecting a majority of people with SCI, with up to 50% reporting severe pain.<sup>9 112 113</sup> Chronic pain will have a serious negative impact on many aspects of life, including sleep, work and participation in daily living activities, as well as increasing functional disability beyond that which directly results from loss of motor control.<sup>114 115</sup>

Chronic pain is known to be a significant risk factor for suicide among general chronic pain patients, approximately double that of controls without chronic pain. Pain catastrophising, helplessness, hopelessness, fear avoidance and sleep-onset insomnia are among the factors that appear to be important in contributing to suicidality.<sup>116</sup> To date there have been no investigations specifically regarding the association between pain and suicidality following SCI. But clearly there is potential for persistent pain to be one of the factors that contributes to increased risk of suicide in people with SCI.

In randomised and non-randomised trials of people with SCI who also had high levels of chronic pain, cognitive behaviour therapy was found to improve wellbeing, with reductions in chronic pain, increases in participation and reductions in anxiety found.<sup>79 117</sup> Research in adults with SCI revealed that chronic pain is positively associated with fatigue and depressive mood, difficulties in coping, functional limitations, greater dependence on medications and negatively associated with resilience.<sup>9 118-120</sup> Further, chronic pain following a SCI is highly associated with reduced QOL and negative cognitive biases, like pain catastrophising.<sup>36 74 84 118 121</sup>

### **Weight gain (Level III-2 evidence)**

People with SCI are vulnerable to central and visceral obesity and the consequences that can occur as a result, such as diabetes, heart disease, cancer, pressure injuries, sleep disorder, gout and even depression, all of which will lead to reduced QOL.<sup>122</sup> A systematic review concluded that while greatest weight reduction in people with SCI was linked with bariatric surgery, it also found that a combination of physical exercise and diet therapy was successful. Pharmacologic treatment was not found to result in reduced weight.<sup>122</sup> A SCI also results in physiological changes that markedly reduces whole-body metabolism, resulting in neurogenic obesity via adipose tissue accumulation.<sup>123</sup> In addition, evidence of dietary inadequacies (e.g., fatty foods) with poor intake of fruits, vegetables, whole grains, fibre, seafood and plant protein, often occurs following SCI.<sup>124</sup>

### **Infections (Level III-2 evidence)**

People with SCI are vulnerable to secondary complications, such as urinary tract and respiratory tract infections and pressure injuries.<sup>125 126</sup> Psychosocial factors have been found to contribute to increased complication rates.<sup>53</sup> The risk of death in people with SCI is substantially higher from conditions such as septicaemia, postoperative wound infections, pneumonia, influenza, and urinary tract infections when compared to the general population.<sup>70 127 128</sup>

### **Sleep disturbance (Level III-2 evidence)**

Adults with SCI have increased risk of developing sleep disorder or disturbance,<sup>129 130</sup> with obstructive sleep apnoea estimated to range between 30-60% of adults with SCI, and those with cervical and complete injuries have even higher risks.<sup>77</sup> Sleep disturbance involves difficulties getting to sleep and/or interrupted sleep due to problems like obstructive sleep apnoea, pain and spasticity.<sup>77</sup> Excessive daytime sleepiness (EDS) is a related problem experienced after SCI, which involves a susceptibility to falling asleep during the day.<sup>76</sup> Sleep disorder and EDS are significant challenges that can disrupt function and lower ability to work. For example, research shows that reciprocal associations exist between sleep and chronic pain. In other words, chronic pain interferes with sleep quality, while poor sleep increases chronic pain.<sup>131</sup> It has been shown that EDS reduces top-down cortical resources (e.g., attention), resulting in diminished capacity to detect and modulate pain.<sup>132</sup>

### Coronary artery disease (Level III-2 evidence)

The risk of cardiovascular problems is elevated in people with SCI.<sup>133</sup> Research suggests that elevated depressive symptoms are a robust risk factor for coronary artery disease (CAD).<sup>134 135</sup> This increases the concerns about CAD risk factors, such as inactivity, being overweight and elevated negative psychological states (e.g., elevated depressive mood or negative states, such as helplessness and anger) may have on wellbeing after SCI. While it has been shown that CAD is a major problem in the SCI population,<sup>136</sup> more research is needed on the influence of psychosocial risk factors, such as elevated negative psychological states on CAD risks in SCI.

### Pre-morbidity factors (Level III-3 evidence)

Psychological status post-injury depends very much on the pre-morbid status of the person with SCI. We know, for instance, that rates of substance abuse are high in the SCI population before they are injured.<sup>137</sup> Evidence exists that screening for, and brief interventions regarding alcohol abuse among trauma patients reduces risk of further injury.<sup>138</sup> A pre-injury history of psychological treatment increases substantially the risk of mental disorders post-SCI.<sup>34</sup> Best evidence also suggests a minority of people with SCI are at risk of having a complex psychological profile due to pre-morbid factors.<sup>72</sup> Stanford and colleagues (2007) found that only 56 of 2,752 SCI admissions to a spinal ward during the period 1970-2000 were due to attempted suicide.<sup>72</sup> Psychiatric diagnoses of those who acquired a SCI through attempted suicide and were subsequently admitted to the spinal ward were often multiple, and included:

- personality disorder (48%)
- schizophrenia (28%)
- depression/mood disorder (43%)
- chronic alcohol abuse (18%).

Of those who attempted suicide before their injury, 8.5% actually committed suicide during the eight years following the SCI.<sup>72</sup>

### Environment factors (consensus)

Institutionalisation is an influential factor in determining outcomes.<sup>139</sup> Institutionalisation in a medical or hospital context refers to the negative influence on the patient of hospital “rules”, “controls” and “expectations”. Dehumanisation (the unintentional act of degrading people with SCI and asserting their “inferiority”) could result from the effect of institutionalisation. For instance, patients in SCI units were found to spend a considerable proportion of their time in the wards exhibiting solitary, disengaged and socially negative behaviours, with little difference found between the therapeutic day and the evening. This was interpreted to be in conflict with the ideals of an active rehabilitation program.<sup>139</sup> Access to supportive social networks to strengthen social participation is crucial as discussed in Social and community participation (Level III evidence) on page 7.

Design of medical facilities can serve to compound dependency by their very nature of being busy, clinical, and stressful environments. The physical setting of hospitals can deprive inpatients of the ability to control their environment where, for example, access to privacy and the opportunity to make individual choices are limited.<sup>140</sup> Hospitals have a role in facilitating patient access to the natural environment for psychological escape and positive distraction. Research in this area is gaining attention, with natural objects like plants being promoted as having intrinsic benefits that can positively affect human wellbeing.<sup>141 142</sup>

The acute care environment is also believed to influence adjustment outcomes, though research in this area is needed. Immediately following the injury, a person with a suspected SCI is usually admitted to an acute care facility where they are exposed to exhaustive and extensive medical procedures, that may include artificial ventilation. The person will experience sensory deprivation and a cocktail of medications, mixed with



separation from loved ones, pain, discomfort, interrupted sleep, bodily trauma, fatigue and potential confusion about the significance of their injury.

The person with SCI will be in a state of shock that may be a form of psychological protection. They may believe they will walk again, which can be interpreted as denial. Although it could also be viewed as a sign of hope or simply lack of familiarity with such injuries and their outcomes. However, if unrealistic optimism impedes progress with rehabilitation it may become counterproductive.<sup>143</sup> As well as the physical environment, the social environment in hospital treatment facilities is also important. Communication with health professionals is believed to influence adjustment following SCI (consensus) and effective communication has been shown to improve patient outcomes in other patient populations.<sup>144</sup>

## Efficacy of psychological treatment for SCI (Level II, III-2 evidence)

Best evidence from meta-analyses and clinical trials indicates that psychological/psychosocial based therapies (e.g., cognitive behaviour therapies or CBT) significantly improve the psychological status of adults with SCI, enhancing their wellbeing in the long-term.<sup>11 145</sup> Clinically controlled studies have demonstrated that CBT or coping effectiveness training (CET) are effective at improving mood and anxiety following a SCI though efficacy declines for many in the long-term.<sup>11 67 146-151</sup>

These programs involve structured treatment components designed to help people improve their coping styles, negative attitudes and thinking styles, as well as improve their self-management of stress and anxiety, sexuality, and social skills.<sup>11 145 146 151</sup> Other research (providing Level III evidence) has shown a combination of CBT and antidepressant medication over a six-month period to be effective at reducing depressive mood in SCI.<sup>56 150</sup> CBT is likely the most widely used psychological intervention. The efficacy of CBT for adult people with SCI has been investigated using meta-analysis or systematic review.<sup>11 145 152 153</sup> Dorstyn et al., (2011) identified 10 studies that met inclusion criteria involving 424 participants with SCI.<sup>11</sup> They concluded that CBT has a significant positive impact on short-term psychological outcomes such as mood and assertiveness following SCI.<sup>11</sup> However, benefits in the long-term up to two-years post injury were not sustained.<sup>11</sup>

Another systematic review of nine studies that met inclusion criteria, including two randomised controlled trials, six prospective controlled trials and one cohort study, concluded that CBT held promise for improving outcomes in depressive mood, anxiety, adjustment, and coping.<sup>145</sup> In a review study of the efficacy of CBT for adults with SCI, Post and Van Leeuwen (2012) concluded that while CBT or CET show promise, findings are limited by methodological weaknesses, such as lack of randomisation and small sample sizes.<sup>153</sup>

Craig and colleagues have consistently found that CBT offered in the SCI rehabilitation inpatient phase has shown promise for improving outcomes like depressive mood, anxiety, self-efficacy and resilience.<sup>6 67 147</sup> However, it is recognised that benefits found have been minimal when the CBT has been offered to everyone in the SCI unit, regardless of whether they have depressive mood, elevated anxiety or poor resilience.<sup>152</sup> In a secondary analysis of a controlled trial,<sup>152</sup> significant benefits accrued 12-months post-injury for those participants with SCI who were diagnosed with clinically elevated depressive mood and anxiety during inpatient rehabilitation. This was also found in an earlier controlled study.<sup>67</sup> Consequently, mental health resources should be strategically concentrated on those assessed with psychological morbidity, such as depressive mood, PTSD, anxiety disorder, substance dependence or suicidality, during their rehabilitation phase. The effectiveness of CBT offered when adults with SCI are in the community requires further study, as few if any such studies have been conducted.

Pain management for people with SCI is also an important area of consideration. The NSW Agency for Clinical Innovation has information about the most effective ways of managing SCI pain. A randomised controlled trial assessed the efficacy of a multidisciplinary CBT program for persons with SCI who also had chronic neuropathic pain.<sup>79</sup> The intervention consisted of psychoeducational, cognitive, and behavioural techniques. Outcome measures included pain intensity, pain-related disability and secondary outcomes such as mood and life satisfaction, with assessment taken at baseline and three and six months after baseline. This CBT and pain management program showed promising benefits, such as decreases in pain intensity,

pain-related disability, anxiety, and increases in participation in activities in the intervention group.<sup>79</sup> See Table 1 for the summary of level of evidence.

**Table 1: Summarising the level of evidence**

Headings	Evidence
<b>Epidemiology</b>	<b>Level III-2</b>
<b>Psychosocial outcomes following SCI</b>	
Social and community participation	Level III
Sexual adjustment	Level III
Emotional wellbeing and mental health	
<ul style="list-style-type: none"> <li>anxiety and post-traumatic stress</li> </ul>	Level III-2
<ul style="list-style-type: none"> <li>depression, suicide and chronic fatigue</li> </ul>	Level III-2
<ul style="list-style-type: none"> <li>long-term positive psychological adjustment and resilience</li> </ul>	Level III-2
<b>Quality of life</b>	<b>Level III-2</b>
<b>Factors influencing psychosocial adjustment</b>	
Perceptions of control, self-efficacy, feelings of helplessness and coping	Level III-2
Cognitive impairment	Level III-2
Medical factors	
<ul style="list-style-type: none"> <li>pain</li> </ul>	Level II, III-2
<ul style="list-style-type: none"> <li>weight gain</li> </ul>	Level III-2
<ul style="list-style-type: none"> <li>infections</li> </ul>	Level III-2
<ul style="list-style-type: none"> <li>sleep disturbance</li> </ul>	Level III-2
<ul style="list-style-type: none"> <li>coronary artery disease</li> </ul>	Level III-2
Pre-morbid factors	Level III-3
Environmental factors	Consensus
<b>Efficacy of psychological treatment for SCI</b>	<b>Level II, III-2</b>



## Overview of models of care

Models that explain how people adjust and cope with life challenges have the potential to contribute positively to service design in SCI rehabilitation. Equally, there are examples of services that have been designed based upon conceptualisations of how the adjustment process occurs, and which may help to optimise the management of the psychosocial aspects of rehabilitation. However, no one model can capture or explain the complex process involved in adjustment following SCI, with individual models contributing unique components to the psychosocial care of people with SCI.

Some of the early influential models have now been rejected in favour of more thorough explanations of the adjustment process. For instance, the biomedical model has contributed strongly to SCI rehabilitation services through its emphasis on physiological and biological factors, resulting in lowered risks of morbidity and mortality. However, the strict use of this model has resulted in the neglect of psychosocial aspects of rehabilitation, such as the responsibility of the patient to take an active role in treatment or rehabilitation choices. Furthermore, medical factors were shown to be poor contributors to adjustment following SCI.<sup>84</sup> A strict use of the biomedical model can also result in a view that the person with SCI is 'abnormal', thus needing to be normalised. Equally, one of the earliest psychological approaches to responses to SCI (collectively known as stage models) postulated that people with SCI needed to pass through a series of stages (i.e., denial, anger, bargaining, depression and acceptance) in order to adjust and cope adequately with the injury, based largely upon work on reactions to bereavement.<sup>31 154</sup> This approach has also been rejected as there is no reliable evidence to suggest that a person with SCI must, of necessity, pass through a series of stages before they can accept their loss.<sup>91 143</sup> For instance, no association has been found between age or time since injury and psychological status of people with SCI admitted to rehabilitation.<sup>155</sup> Similarly, linear models of adjustment cannot account for the unpredictability and complexity of adjusting to a severe problem like SCI, that is associated with ongoing fluctuations in status rather than any single event.<sup>2 143</sup>

Other models have made important contributions to our understanding. Detail about these is in the next section, Theoretical models influencing understanding of adjustment to SCI. It presents information about four models that have contributed to our understanding of adjustment. These are the:

- Stress Appraisal Model (Figure 1, 1984)
- Model of Human Occupation (Figure 2, 2000)
- Transtheoretical Readiness to Change Model (Figure 3, 1994)
- Social Disability Model (1997).

Each has its own limitations. Another model, called the cognitive-behavioural model, which had its beginnings in the 1960s, made a valuable contribution by emphasising the importance of both thinking style and behaviour in the adjustment process. For example, the negative effects of having a pessimistic view of the future or preferring to isolate or disengage (behavioural avoidance/disengagement) when adjusting to illness or injury. However, this model failed to highlight the importance of cultural, political, religious and social forces in the adjustment process.

Thus, it has become clear that a model is desirable that can account for a more continuous and cyclical process of adapting to the personal and societal problems arising from SCI. This model needs to consider variables both in the individual and family, as well as in the wider social, physical and political environment. For instance, adjusting to SCI can be viewed as a life-long process of adapting to:

- challenges that alter with environmental context and influences
- the condition (e.g., the development of secondary conditions, such as pain or depression)
- changing life roles (such as becoming a parent or unemployed).

For many people, it will involve periods of negative adjustment in response to the initial injury or new challenges (e.g., a cycle in which the person feels depressed as a result of constantly experiencing high levels of chronic pain). Negative periods of trying to adjust and cope are usually followed by positive attempts to adjust, which in turn, may be followed by a further period of difficulty.<sup>2 143</sup>

A cyclical approach to adjustment will involve an ongoing process of learning to adapt to difficult and challenging life circumstances.<sup>156</sup> Any model of adjustment must take account of this complexity. Furthermore, adjustment should not be viewed as the sole responsibility of the person with SCI. Rather, it should be seen as a process in which attempts are made to resolve life challenges. This is best viewed as a combined effort of the person with SCI in collaboration with family, friends, the rehabilitation team, society and community, the workplace, and so on. In addition, the model should also provide a rationale and guide for the scope of services used by practitioners involved in the care of people with SCI.

There is consensus that the biopsychosocial model is a comprehensive model that satisfies the majority of the criteria required to explain and aid the understanding of the process of adjustment.<sup>157</sup> This model integrates biological, psychological and social dimensions that operate in the evolution of physical and mental health and social outcomes and has been applied successfully to SCI care.<sup>158 159</sup> This model presupposes that people with SCI, in addition to the physical challenges, have experienced psychological and social changes requiring substantial adjustment. Therefore, rehabilitation must be a complex process that involves biological, psychological, and social intervention components.<sup>158</sup> There are advantages of this model.

- It is cross disciplinary.
- The emphasis is placed on contextual factors, such as social, cultural and political forces.
- The importance of biological and physiological factors in health outcomes, as well as psychological and social factors are emphasised.
- It minimises the dehumanisation of people receiving medical care by, for instance, encouraging an active rather than a passive role for the person receiving care and by using non-discriminative and optimistic language.

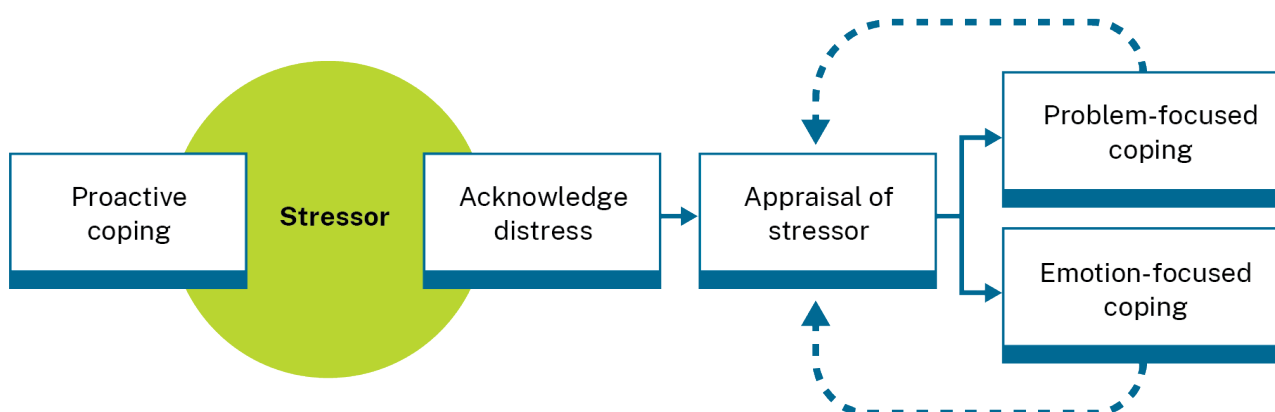
The recommendations presented in this guide have been influenced by the presuppositions of the biopsychosocial model. It is accepted that people with SCI should be given every chance to achieve mature adjustment and a satisfactory quality of life with full community reintegration and participation. Therefore, people with an acute SCI should receive a continuum of services from the onset of the injury, with support following throughout their life span. This will involve goals such as these.

1. Community and family acceptance
2. The maintenance of robust relationships
3. Access to supportive social networks and essential resources
4. Access to productive vocational and recreational activities
5. Being able to make independent choices
6. Access to resources that will help develop psychological resilience
7. Having satisfactory physical health.

## Theoretical models influencing understanding of adjustment to SCI

### Stress Appraisal Model

The Stress Appraisal Model of Lazarus and Folkman<sup>160</sup> (see Figure 1) suggested that adjustment and coping depend upon a person's stress and health status, which was believed to be a product of how people perceived their ability to cope with life stressors.<sup>160</sup> For example, if a person with SCI believes they are able to cope with current and/or future stressors, then this acts to reduce their level of stress, enhancing their ability to cope and adjust. Conversely, if this person believes they are unable to cope with their stressors, then this acts to increase their level of stress, reducing their ability to cope and adjust. The model also predicts that people will respond and react to stress in individual/particular ways. Some respond negatively and consequently suffer problems like depression, while others may cope well with their stressors, resulting in an improved life satisfaction.<sup>160</sup> Outcomes are also believed to be influenced by primary appraisal (e.g., evaluating threat) and secondary appraisal (e.g., evaluating personal coping resources and options). A distinction is also made between problem solving coping strategies (e.g., confronting and taking control in order to modify the stressor) and emotion-focused coping strategies (e.g., denial or wishful thinking).



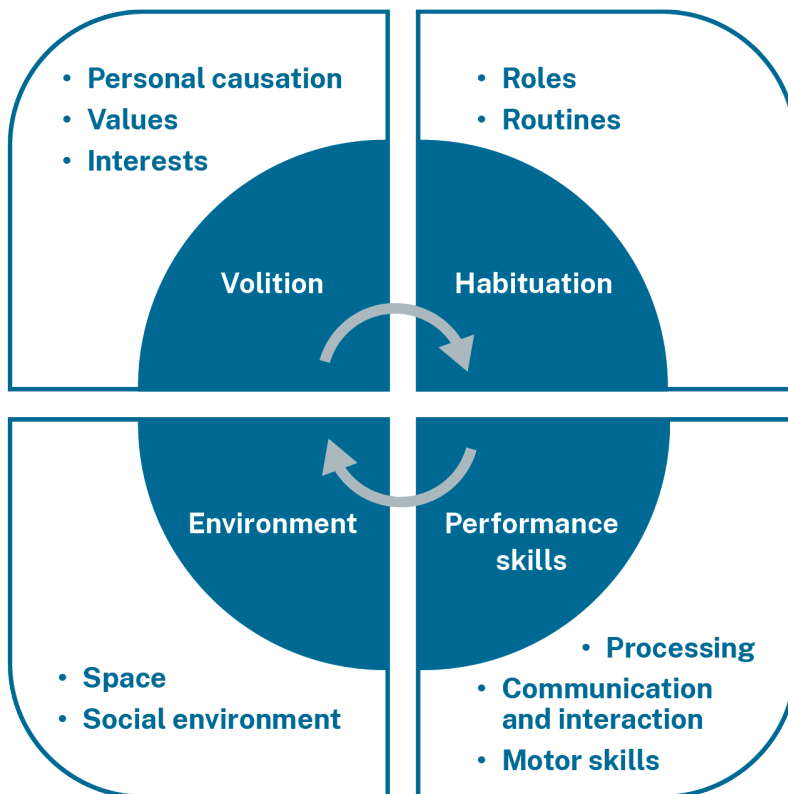
**Figure 1: Stress Appraisal Model**

### Model of Human Occupation

Kielhofner<sup>161</sup> developed the Model of Human Occupation (see Figure 2) that provides a conceptual model of practice for explaining aspects of healthy occupation and problems that arise in association with life transitions, including illness and disability.<sup>161</sup> Its concepts address:

- the motivation for occupation
- the routine patterning of occupational behaviour
- the nature of skilled performance
- the influence of environment on occupation.

The model stresses the importance of the person undergoing change, referring to their beliefs about how effective they are in acting on the world (a concept of self-efficacy), their values and their life pleasures. The model predicts therapy outcomes in terms of their beliefs, values and goals related to their capacity to perform. The person's behaviour will also be influenced by the social and physical environment. Assessment is seen as an important tool for enhancing outcomes.



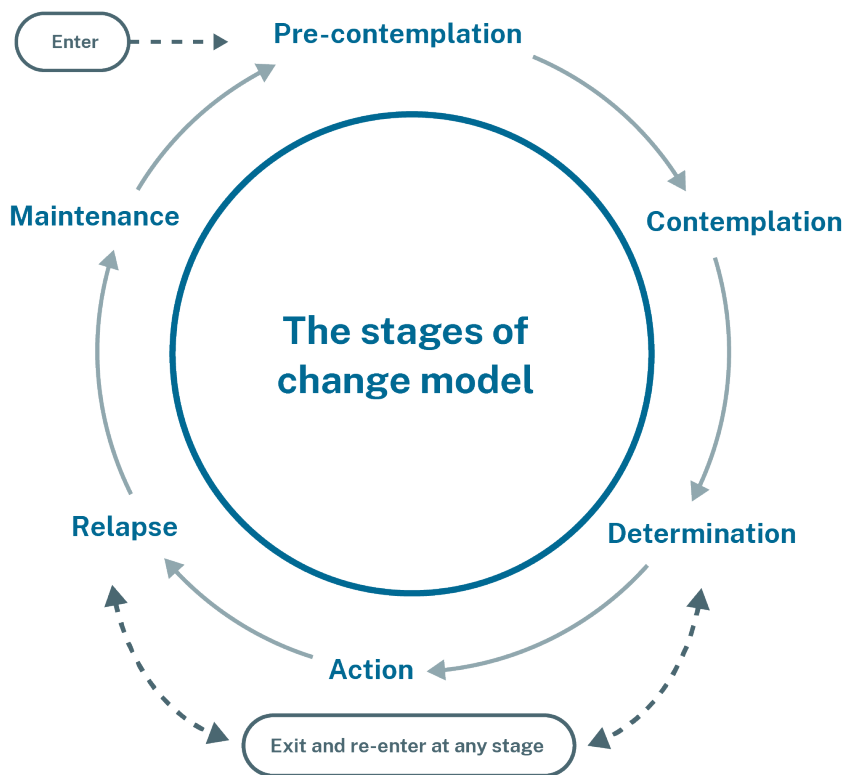
**Figure 2: Model of Human Occupation**

### Transtheoretical Readiness to Change Model

Prochaska and colleagues<sup>162</sup> in the Transtheoretical Readiness to Change Model (see Figure 3) suggested that the ability to change depended upon the relationship between stages of the change and decisional balance, that is, their psychological readiness to change.<sup>162</sup> Stages of change include:

- pre-contemplation (not ready to change and perhaps in denial)
- contemplation (thinking of changing but still needing mental commitment)
- preparation (ready to change and committed)
- action (making changes but now need to commit long-term)
- maintenance (continuing to maintain change).

Such a stage model of change has the potential of making a valuable contribution to the rehabilitation and community reintegration of people with SCI.



**Figure 3: Transtheoretical Readiness to Change Model**

### Social Disability Model

The Social Disability Model<sup>163</sup> emphasised the role of social and political forces in the adjustment process, reinforcing the importance of the person with SCI playing an active partner role in rehabilitation. It also stressed the importance of distinguishing between 'disability' and 'impairment', and that vocational, family and community forces need to play very active roles in the adjustment

## The Spinal Cord Injuries Adjustment Model

The SCI Adjustment Model (SCIAM) shown in Figure 4 was developed with contributions from the above theories/models to explain dynamics about how people cope with and adjust to SCI.<sup>35,143</sup> It attempts to clarify, and to some extent, it simplifies, how a complex non-linear process of adjustment can occur, and how ongoing life events and challenges may influence ongoing adjustment and resilience. For example, people may be more prepared to change at particular times after the SCI. Bombardier and Rimmele showed that shortly after the SCI, those abusing alcohol pre-injury were more likely to consider positive changes to their alcohol use.<sup>164</sup> They suggested there are specific times in rehabilitation that represent a window of opportunity to help the change process and to reduce problems like depression and alcohol abuse.<sup>164</sup>

SCIAM emphasises the appraisal and re-appraisal process involving dynamics such as self-efficacy, in the process of adjustment or maladjustment, and so aspects of the Stress Appraisal and Coping Model were integrated.<sup>2 35 143 160 165</sup> Also, aspects of the Health Belief Model such as “perceived barriers” and “perceived susceptibility” believed to contribute to health behaviours were integrated.<sup>166</sup> SCIAM contends that multiple factors contribute to the process of adjustment, and that this contribution occurs in an interactive non-linear and often reciprocal manner. The goal of SCIAM was to explain processes involved in adjustment that could then be better understood and then applied to improve rehabilitation outcomes.<sup>2 35 143</sup>

SCIAM reinforces that not only will pre-injury factors influence short, medium and long-term outcomes, but so will admission into a medical setting, such as institutionalisation resulting from an extended hospital stay involving emergency services, and the influence of intensive medical and rehabilitation care. It is accepted that during hospitalisation a person’s emotional and psychological condition will be dominated by feelings of:

- confusion
- shock
- pain
- numbness
- disbelief
- anger
- helplessness.

Such emotions will be aggravated by being separated from their family, friends, school and/or work. SCIAM predicts this will have major impacts on adjustment. Additionally, transitioning from the supportive multidisciplinary rehabilitation setting where the “patient” becomes dependent on hospital staff, procedures and resources, into the community can be distressing for some. In the community, they will often have to take on responsibility for their own care, and this can be overwhelming and challenging.<sup>10 118 152</sup> The reader is directed to explore the SCIAM model further.<sup>2 35 143</sup> Below is a summary of the main processes of adjustment.

### Main processes of adjustment as asserted by SCIAM

In SCIAM, factors called moderators are shown in Figure 4, including level of SCI, age, sex, pre-injury cognitive performance, personality, and so on. These have the potential to influence adjustment outcomes by strengthening or weakening adjustment and resilience. And of course, there will be multiple interactions occurring between these factors, including the influence of time post-injury. Figure 4 also shows factors called mediators. These include dynamic mechanisms that produce changes in adjustment (e.g., worsening mental health or lowered resilience). SCIAM asserts these mediators exert a strong dynamic and interactive influence. Common interactions between moderators will involve:

- biological/medical factors (e.g., medications, sex, age, level of injury, presence of a TBI),
- personal (e.g., personality traits, general self-efficacy, pre-morbid psychological status, and sexual desire/activity)

- social and community networks and resources (e.g., friend networks, family relationships, sexual relationships/problems, caregiver dynamics, financial security, employment, religious and cultural views, community access and mobility).

Moderators can also have an assumed positive influence (e.g., resilient personality, financially secure, caring family) or have a negative influence (e.g., severe chronic pain, cognitive impairment).

However, the “engine room” of SCIAM consists of the dynamic influence of mediators, including primary and secondary appraisal processes such as context related self-efficacy, cognitive distortions such as catastrophising, perceived barriers to change, and self-esteem.<sup>2 35 96</sup> This “engine room” is believed to influence coping strategies strongly. The success or failure of the coping strategy provides feedback to the “engine room”, and this results in secondary appraisal processing, leading to a continuation of the coping strategy, or an adoption of new coping strategies.

Appraisal-reappraisal will be influenced by modifying factors at any particular point in time. If, for example, negative/undesirable circumstances are perceived as outweighing positive/desirable circumstances and resources are perceived as low, the person will likely see the situation in a distressing light (e.g., I cannot do this) or irrationally (e.g., there is no point, no one cares). If the positive circumstances outweigh negative circumstances and perceived resources are viewed as adequate, the person will likely view the situation optimistically (e.g., maybe I can do this and self-manage).

Over time, SCIAM predicts that a person will adjust or will not adjust by this dynamic process. An illustration of this process includes the following:

- an unhelpful belief/appraisal will lead to a poor coping strategy
- leading to negative thinking/reappraisal and cognitive biases like catastrophising (e.g., the medications are useless, the pain is just too much, I can't handle it anymore; it is just too horrible).

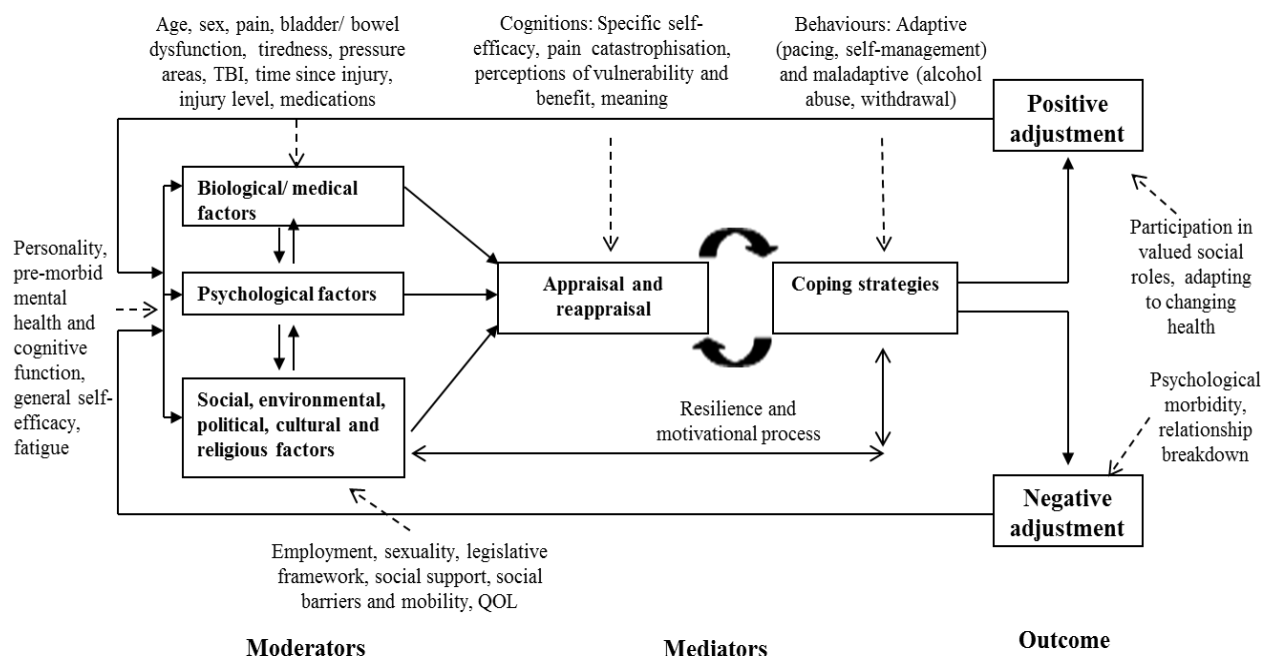
This may then lead to poor coping strategies (e.g., self-neglect or alcohol abuse) and poor outcomes (e.g., re-hospitalisation, depression, risk of suicide).

Conversely, positive reappraisal may lead to:

- adaptive coping strategies
- leading to helpful/realistic thoughts (e.g., the pain is severe but manageable; I can manage flare-ups; I've done this before, I can do it again)
- leading to adaptive outcomes (e.g., to maintain medication regime and adopt better self-management such as pacing, exercise and maintaining a balanced regular diet).

**Figure 4: Spinal Cord Injuries Adjustment Model**

It shows the relationship between moderators, mediators and medium- to long-term outcomes, and how people with SCI adapt and adjust over time to their injury.<sup>2 35</sup>



There is now significant research support for SCIAM.<sup>2 4 9 10 35 96 118 132 152 167</sup> In a meta-analysis, van Diemen and colleagues showed self-efficacy was negatively associated with depressive and anxiety symptoms after SCI.<sup>96</sup> They concluded that self-efficacy is a vital target in the rehabilitation of people living with SCI. Further, self-efficacy has been shown to predict positive adjustment 12-months after SCI.<sup>34</sup> Other research showed that less time since injury was associated with a small but significant increase in chronic pain, which in turn would increase depressive mood.<sup>9</sup> We theorised that chronic pain will have a cumulative impact on mood over time.

This hypothesis was supported by the high proportion of participants with chronic pain and high depressive mood. However, we also theorised that self-efficacy would have a mediating impact on the relationship between pain and mood. Results confirmed this relationship.<sup>9</sup> The mediating impact of self-efficacy on chronic pain and depressive mood outcomes was substantial. As hypothesised, the role of self-efficacy as a mediator in the relationship between chronic pain and depressive mood was clearly shown. The data suggests self-efficacy reduces the negative influence of chronic pain on mood in adults with SCI.

## Designing services to accommodate psychosocial aspects of adjustment

The core task of rehabilitation is to prepare the individual (and those close to them) to self-manage adaptively in the long term. The expanding knowledge about the psychosocial needs of individuals following SCI has been followed by attempts to factor this information into the design of rehabilitation services. This is now acknowledged by health service planners, for example the NSW Chronic Disease Strategy. The aspects of this approach relevant to the SCI population includes reducing the progression and complication of chronic illness, improving QOL and reducing avoidable hospital admissions or presentations for chronic illness. The NSW Chronic Disease Strategy is based upon principles relevant to SCI rehabilitation such as person-centred care, supporting active self-management and promoting integrated multidisciplinary care.

There are a number of different ways in which services can be designed with these issues in mind, and some of the notable attempts are described in the section Influential service design models on page 25. Key



characteristics of these models is the importance of engaging “patients” as active participants in their rehabilitation or management, with an explicit focus on using strategies to enhance self-efficacy and autonomy. Although few have specifically examined the outcomes of using these models in SCI populations, there is good evidence of their benefits in other populations with chronic conditions. One considered to be of particular relevance in providing an overall framework for our thinking about provision of services in these populations is the UK’s National Institute of Clinical Excellence Four-Tier Model (see Table 2).

It originated in cancer services, and explicitly delineates the different level of psychosocial input by those working in health and social care with varying levels of skill in the provision of such services. In order to implement services that integrate good practice in promoting psychosocial adjustment to SCI, the traditional staffing patterns of SCI units need consideration. Staff employed in roles that are currently well-represented in these services, such as physiotherapy and occupational therapy, may need to develop further skills required to implement strategies that do not currently form a core of pre-qualification training, such as teaching self-management skills. Other psychosocial disciplines, such as psychiatry, nursing, occupational therapy, psychology, neuropsychology or social work, may also need to be assisted to cover expanded roles.

As mentioned in the accompanying document, Psychosocial Care of Adults with Spinal Cord Injuries Guide: Background and Methodology (on page 4 in the section, Target audience and additional resources), the [Emotional Wellbeing Toolkit: A Clinician's Guide to working with Spinal Cord Injury](#) was developed to support rehabilitation clinicians to understand and manage psychosocial issues associated with acute and long-term SCI.<sup>168</sup> The toolkit covers areas relevant to adjustment following a SCI, including managing grief and loss, adjustment to SCI, and addressing common psychological and emotional issues experienced by those with a SCI. The toolkit highlights ways to distinguish between grief and depression and has a number of brief standardised tools to help clinicians assess issues such as mood, anxiety, pain, trauma, and substance use and psychosis. An action plan is provided in the toolkit that is quick and easy to implement, as well as providing a pathway for clinicians to follow. It also includes strategies for handling challenging behaviours. [The Emotional Wellbeing Toolkit eLearning Package](#) was launched in 2019 by the NSW State Spinal Cord Injury Service Psychosocial Strategy, and consists of four, 20-minute modules. They are:

- Module 1: Overview, purpose and use, the SCI Model of Adjustment, grief and loss
- Module 2: Common psychological presentations (mood, pain, psychosis, substance use)
- Module 3: Sexuality, ageing with SCI and TBI, post-traumatic amnesia, sexuality
- Module 4: Understanding distress and trauma using Trauma-informed Care Principals (TICP), compassion focused approaches and self-care, working with Aboriginal and Torres Straight Islanders, and other culturally and linguistically diverse clients.

In addition, the toolkit also has a purpose-built app available for phone (Android or iPhone/iPad) or tablet to assist with “just-in-time” evidence-based support to manage the many emotional challenges associated with SCI.

## Influential service design models

### Peer support (worldwide)

The concept of peer support began with the development of Alcoholics Anonymous (AA), operating on the principle that people who had experienced and overcome alcoholism would be more effective in assisting others who were trying to stop alcohol abuse. The peer concept has grown over the years in numerous settings and disciplines. Peer support programs can be offered on a one-to-one or a group basis, or a combination of both. Best evidence research into self-help and consumer initiatives has consistently shown that participation by consumers is associated with:

- reduced hospitalisation
- reduced use of other services

- increased knowledge, information and coping skills
- increased self-esteem and confidence
- an improved sense of wellbeing and of being in control
- stronger social networks and supports.<sup>169</sup>

For people with SCI, peer support programs exist in Australia (e.g., Spinal Cord Injuries Australia (SCIA) or its peer and family support program) and overseas. Bandura's Social learning Theory argues the importance of such social support for improving psychological status.<sup>170</sup>

### **Expert Patient Program (UK)**

The Expert Patients Program developed in the UK,<sup>171 172</sup> is a self-management program for people who are being treated for chronic illnesses and disorders and is based on the chronic disease self-management program developed at Stanford University.<sup>171</sup> Patients are trained to act as instructors to others with a chronic condition, with the aim of enhancing the participant's confidence and motivation to use their own skills and knowledge to gain effective self-control over their chronic illness in partnership with their healthcare providers. Typically, it involved groups of eight to 16 participants meeting for six structured sessions that deal with ways to manage the effects of their long-term condition. The emphasis is placed on the participants setting, practical and achievable goals and exploration of problem-solving strategies while enhancing decision-making skills throughout the six weeks. There is evidence demonstrating that this approach results in improved outcomes for people with chronic conditions such as asthma, arthritis, cardiovascular problems and depression.<sup>171 172</sup>

### **The Stoke Mandeville Model (UK)**



This model is based on a goal planning framework that uses an individual keyworker and systematic needs assessment process to identify and monitor progress towards goals during the SCI rehabilitation period.<sup>173</sup> The aim is to establish an optimal level of independence for each individual SCI person. Active patient involvement is central to this approach so that feelings of dependency are minimised, and the keyworker acts to ensure that the goal planning process enhances the confidence and skills of the person with SCI as they confront the challenges of rehabilitation. Aspects of this model (like goal planning) have been shown to be effective in enhancing rehabilitation outcomes in people with SCI.<sup>173 174</sup>

### **The Flinders Model of Chronic Condition Self-management (Australia)**

This model was developed by the Flinders Human Behaviour and Health Research Unit. It stresses the importance of the professional and patient working together in the process of care plans.<sup>175</sup> It includes the assessment of self-management behaviours, collaborative identification of problems and goal setting leading to the development of individualised care plans. The use of this model has resulted in improved outcomes in areas such as mental health, diabetes in rural Aboriginal populations, chronic lung disease and heart disease. The effectiveness of this self-management model applied to people with chronic conditions has been demonstrated.<sup>175</sup>

**Table 2: Four tier model of professional psychological assessment and support that can be applied to SCI rehabilitation**

Note: through all tiers, it is imperative that an emphasis is placed on self-management and social support.

	Level	Group	Assessment	Intervention
	1	All health and social care professionals	Recognition of psychological needs	Effective information giving, compassionate communication and general psychological support
	2	Health and social care professionals with additional expertise	Screening for psychological distress	Psychological techniques such as problem solving
	3	Trained and accredited professionals	Assessed for distress and diagnosis of some psychopathology	Counselling and specific psychological interventions, such as anxiety management and solution-focused therapy, delivered according to an explicit theoretical framework
	4	Mental health specialists	Diagnosis of psychopathology	Specialist psychological and psychiatric interventions such as psychotherapy, including cognitive behavioural therapy (CBT)

Taken from [Improving Supportive and Palliative Care for Adults with Cancer](#) March 2004, published by the UK National Health Service Institute for Clinical Excellence.

## 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: Background and Methodology.