



ACI NSW Agency
for Clinical
Innovation

Guide for Health Professionals on the Psychosocial Care of Adults with Spinal Cord Injury



Authors:

Ashley Craig

Rehabilitation Studies Unit, Sydney Medical School–Northern, The University of Sydney

Kathryn Nicholson Perry

Clinical and Health Psychology, University of Western Sydney

Reviewed and updated in 2013 by Professor Ashley Craig

Sydney Medical School–Northern, The University of Sydney

AGENCY FOR CLINICAL INNOVATION

Level 4, Sage Building

67 Albert Avenue

Chatswood NSW 2067

PO Box 699

Chatswood NSW 2057

T +61 2 9464 4666 | F +61 2 9464 4728

E info@aci.health.nsw.gov.au | www.aci.health.nsw.gov.au

Produced by: ACI State Spinal Cord Injury Service

SHPN: (ACI) 140010

ISBN: 978-1-74187-956-8

Further copies of this publication can be obtained from the Agency for Clinical Innovation website at: www.aci.health.nsw.gov.au

Disclaimer: Content within this publication was accurate at the time of publication.

This work is copyright. It may be reproduced in whole or part for study or training purposes subject to the inclusion of an acknowledgment of the source. It may not be reproduced for commercial usage or sale. Reproduction for purposes other than those indicated above, requires written permission from the Agency for Clinical Innovation.

Published Feb 2014.

Next Review 2027.

© State of New South Wales (Agency for Clinical Innovation)

ACKNOWLEDGEMENTS

First edition, 2008

The Guide was written by Professor Ashley Craig¹ and Dr Kathryn Nicholson Perry² in association with Associate Professor James Middleton, Director, NSW State SCI Services (NSW SSCIS) and the NSW SSCIS Psychosocial Strategy Steering Group. The contributions of the following members of this group are acknowledged: James Middleton (Chair), David Andrews, Tullio Cittarelli, Ashley Craig, Michelina Pelosi, Kathryn Nicholson Perry, Neil MacKinnon, Anna Satharasinghe, Jackie Francis, Margaret Noonan, Kylie Wicks, Catherine Shorland, Tonina Harvey, Jill Steverson, Catherine Tulinski, Luisa Silva and Helen Oosthuizen. Contributions to the project were also made by those attending the NSW State Spinal Cord Injury Services Psychosocial Strategy Forum on 6th December 2006, and by those attending related workshops at the 2007 ANZSCOS conference in Sydney.

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

Second edition, 2014

Revised and updated in 2013 by Professor Ashley Craig, Sydney Medical School–Northern, The University of Sydney. The revision was funded by the NSW Agency for Clinical Innovation.

How to use the Guide

The Guide aims to provide direction and support to relevant health professionals who are involved in the rehabilitation of people with SCI, either in specialist SCI settings or in other general or specialist health, social service or non-governmental organisations. The Guide does not act as a substitute for the knowledge and skill of individual practitioners, and it is therefore advised that it be used in conjunction with the clinician's judgment within the context of the client-practitioner relationship. In accord with the self-management and resilience model approaches to SCI care, it is desirable that whenever possible, decisions about treatment and ongoing care should be made collaboratively with the individual, their family, carers and other professionals involved in their care.

The work by Selina Rowe, Manager, NSW Spinal Outreach Service, Royal Rehab, Ryde, and Frances Monypenny, ACI Network Manager, State Spinal Cord Injury Service, Chatswood, NSW, Australia, in coordinating and managing the project to review and update this fact sheet, one of a suite of 10 fact sheets, is acknowledged.

¹ Rehabilitation Studies Unit, Sydney Medical School–Northern, The University of Sydney

² Clinical and Health Psychology, University of Western Sydney

FOREWORD

It was my pleasure to be awarded the inaugural NSW Office for Science and Medical Research Spinal Exchange Program Fellowship in 2005, during which I participated in a series of activities with the objective of facilitating communication on techniques, treatment and therapies that would improve the psychosocial rehabilitation and quality of life for people with SCI and related conditions. The NSW State Spinal Cord Injury Service has continued this work by convening a Psychosocial Strategy Steering Group to oversee the development and implementation of a comprehensive strategy for the psychosocial care of people affected by SCI, and this Guide is one of the projects that they have undertaken.

This is a comprehensive, well researched and service-focused Guide for all health professionals working with people with spinal cord injuries. The authors have reviewed and integrated clinical needs with best practice models and provided a wealth of informed, relevant and professional guidance. It is critical that the recommendations are addressed to ensure that people with spinal cord injuries in New South Wales have access to twenty-first century healthcare model systems.

Paul Kennedy DPhil (2008)

Professor of Clinical Psychology and Academic Director Oxford Doctoral Course in Clinical Psychology University of Oxford and Trust Head of Clinical Psychology, Stoke Mandeville Hospital, England, UK

'Knowing is not enough, we must apply. Willing is not enough, we must do.'

Goethe

TABLE OF CONTENTS

ACKNOWLEDGEMENTS	1
FOREWORD	2
1. EXECUTIVE SUMMARY	6
1.1 Purpose	6
1.1.1 Details	6
2. INTRODUCTION	8
2.1 Background to this Guide.....	8
2.1.1 Need for the Guide.....	8
2.1.2 Definition of psychosocial outcomes.....	9
2.1.3 Objective and scope	9
2.1.4 Target audience.....	9
2.1.5 Structure of the Guide.....	9
3. METHOD	10
3.1 Process of developing the Guide	10
4. UNDERSTANDING THE PSYCHOSOCIAL ASPECTS OF SCI.....	12
4.1 Epidemiology.....	12
4.2 The nature of psychosocial outcomes.....	12
4.3 The nature of psychosocial outcomes.....	13
4.3.1 Social function and community participation	13
4.3.2 Emotional Well-being and Mental Health	13
4.3.3 Quality of life	14
4.4 Factors influencing psychosocial adjustment.....	15
4.4.1 Perceptions of control, self-efficacy, feelings of helplessness and coping.....	15
4.4.2 Medical factors.....	15
4.4.3 Pre-morbid factors	16
4.4.4 Environmental factors	16
5. MODELS OF CARE	18
5.1 Designing services to accommodate psychosocial aspects of adjustment	19

6. RECOMMENDATIONS FOR THE PSYCHOSOCIAL CARE OF PEOPLE WITH SCI.....	23
6.1 General principles for the psychosocial care of people with SCI	23
6.1.1 Psychosocial factors that impact on rehabilitation outcomes should be integrated into all SCI services provision, and clients should have access to psychosocial support services throughout the lifespan.....	23
6.1.2 Services for people with SCI should be designed to promote psychosocial adjustment	23
6.1.3 Attempts should be made to create treatment environments that promote a sense of support and healing	23
6.1.4 Members of the treating team should be sensitive and open to signs and symptoms of distress	23
6.1.5 Members of the treating team should provide generous emotional and social support.....	23
6.1.6 Health professionals should use effective communication skills, including using the services of an interpreter when appropriate.....	24
6.1.7 Clients should be provided with timely and targeted information	24
6.1.8 Self-management models should be promoted as the basis of psychosocial rehabilitation	24
6.1.9 Routine provision of support and information is necessary for caregivers and significant others of those with SCI	24
6.2 Principles for integrating psychosocial aspects into the acute and rehabilitation process.....	24
6.2.1 Psychosocial rehabilitation should commence at the point of admission to the unit.....	24
6.2.2 A key worker should be allocated to each new SCI person admitted to the SCI inpatient program.....	24
6.2.3 An initial psychosocial assessment should be conducted as soon as practicable following injury	25
6.2.4 All SCI patients should receive a multidisciplinary rehabilitation program in which psychosocial care is a core component based upon an individual needs assessment.....	25
6.3 Recommendations concerning psychosocial assessment	26
6.3.1 Everyone acquiring SCI should receive sensitive and timely psychosocial assessment at critical time points	26
6.3.2 The results of the psychosocial assessment should be collated and available to the treating team	26
6.3.3 The initial psychosocial assessment should be conducted within five days of admission	26
6.3.4 An abridged assessment should be repeated just before discharge and 12 months after living in the community.....	27
6.3.5 People being transitioned from paediatric to adult SCI services should receive a comprehensive psychosocial needs assessment	27
6.3.6 Members of the treating team should be able to conduct brief assessments of common psychosocial problems in order to deliver mental health first aid and facilitate appropriate management.	27
6.4 Recommendations for the provision of specific psychosocial interventions	27
6.4.1 All individuals admitted for rehabilitation of an SCI should participate in an evidence-based psychosocial rehabilitation group intervention	28
6.4.2 The effectiveness of the psychosocial treatments provided should be assessed for each participant	28
6.4.3 Those demonstrating risk factors for particular psychosocial co-morbidities may need to be referred for specialised assessment and treatment.....	28
6.4.4 In certain cases, individuals with suspected severe psychological disorders may need referral to specialized assessment and treatment	28

6.5	Monitoring and follow-up Assessment.....	31
6.5.1	Ongoing support for the self-management approach to SCI should be provided following discharge from rehabilitation.....	31
6.5.2	The progress of psychosocial rehabilitation should be routinely monitored	31
6.5.3	Case management should be used for those presenting with complex psychosocial needs where the capacity for self-management is compromised.....	31
6.5.4	Ongoing psychosocial support services should be available to individuals with SCI for those with continuing or emerging psychosocial needs.....	31
6.6	Staffing considerations Assessment.....	31
6.6.1	Ongoing professional development to support the skills identified should be provided routinely.	31
6.6.2	An appropriate staffing mix should be provided in order to deliver effective psychosocial rehabilitation	31
6.6.3	Staff will require appropriate orientation and ongoing professional development to sustain the acquisition and maintenance of the required skills.....	32
7.	CONCLUSION.....	33
8.	SHORT QUIZ.....	34
9.	REFERENCES.....	35

1. EXECUTIVE SUMMARY

1.1 Purpose

This Guide for Health Professionals on the Psychosocial Care for People with Spinal Cord Injury (SCI), hereafter referred to as the Guide, was developed to assist health professionals and practitioners to make appropriate decisions about assessment, treatment, referral and living arrangements for people with SCI. Although paediatric SCI may be referred to in some instances, the main focus of the Guide is for those involved with adult SCI services. It is intended that this Guide enhance SCI rehabilitation practice and treatment as well as serving 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 ensures people with SCI receive comprehensive and cost effective psychosocial care that suits and enhances their wellbeing and life goals.

The Guide was written with the understanding that a variety of health professionals provide psychosocial care, including medical practitioners, nurses, psychologists, psychiatrists, social workers, physiotherapists, occupational therapists and rehabilitation counsellors. We hope that the information contained herein will be applicable to these professionals and assist them in providing the best possible rehabilitation programs for people with SCI. It is expected that its application will vary across various settings and in line with the practitioners' training in particular interventions. A revised version of the Guide was completed in December 2013, and latest best evidence concerning assessment, treatment and rehabilitation practice has been integrated into the document.

The Guide has four sections:

- The first provides background.
- The second provides details concerning the psychosocial aspects of SCI.
- The third presents select models of care that can influence SCI rehabilitation.
- The fourth presents principles and key recommendations for the psychosocial care provided by the rehabilitation team and other specialised carers.

1.1.1 Details

General principles for the psychosocial care of people with SCI

- Psychosocial factors that impact on rehabilitation outcomes should be integrated into all SCI services provision and clients should have access to psychosocial support services throughout the lifespan.
- Services for people with SCI should be designed to promote psychosocial adjustment and resilience.
- The rehabilitation and treatment environments should promote a sense of support and healing.
- Members of the treating team should be sensitive and receptive to signs and symptoms of distress.
- Members of the treating team should provide generous emotional and social support.
- Health professionals should use effective communication skills, including using the services of an interpreter when appropriate.
- Clients should be provided with timely and targeted information.
- Self-management and resilience models should be promoted as the basis of psychosocial rehabilitation.
- Routine provision of support and information is necessary for caregivers and significant others of those with SCI.

Principles for integrating psychosocial dynamics into the acute and rehabilitation process

- Psychosocial aspects of rehabilitation should commence at the point of admission to the unit.
- A key worker should be allocated to each new SCI person admitted to the SCI inpatient program.
- An initial psychosocial assessment should be conducted as soon as practicable following injury.
- All SCI patients should receive a multidisciplinary rehabilitation program in which psychosocial care is a core component based upon an individual needs assessment.

Recommendations concerning psychosocial assessment

- Everyone acquiring SCI should receive sensitive and timely psychosocial assessment at critical time points.
- The results of the psychosocial assessment should be collated and available to the treating team.
- The initial psychosocial assessment should be conducted within five days of admission.
- An abridged assessment should be repeated close to discharge and 6 to 12 months after living in the community.
- People being transitioned from paediatric to adult SCI services should receive a comprehensive psychosocial needs assessment.
- Members of the treating team should be able to conduct brief assessments of common psychosocial problems in order to deliver mental health first aid and facilitate appropriate management.

Recommendations for the provision of specific psychosocial interventions

- All individuals admitted for rehabilitation of a SCI should participate in an evidence-based psychosocial rehabilitation intervention.
- The effectiveness of the psychosocial treatments provided should be assessed for each participant.
- Those demonstrating risk factors for particular psychosocial co-morbidities should be referred for specialized assessment and treatment.
- Individuals with suspected psychological disorders should receive specialised assessment and treatment.
- All individuals with SCI should be able to access specialised evidence-based psychosocial care in a timely fashion.

Monitoring and follow-up

- Ongoing support for the self-management approach to SCI should be provided following discharge from rehabilitation.
- The progress of psychosocial rehabilitation should be routinely monitored.
- Case management should be used for those presenting with complex psychosocial needs where the capacity for self-management is compromised.
- Ongoing psychosocial support services should be available to individuals with SCI for those with continuing or emerging psychosocial needs.

Staffing considerations

- Professional development should be provided routinely to enhance and promote the psychosocial skills required to ensure optimal rehabilitation..
- An appropriate health professional staffing mix should be provided in order to deliver effective psychosocial rehabilitation.

2. INTRODUCTION

2.1 Background to this Guide

2.1.1 Need for the Guide

Arguably, people with spinal cord injury (SCI) have to deal with one of the most devastating physical injuries and they face very significant challenges in the process of recovering and adjusting to the long-term impairments associated with their injury.^{65,74}

Aside from the universal experience of adjusting to the physical injury, SCI is commonly associated with a range of secondary conditions and challenges, including traumatic brain injury (TBI), hospitalisation, co-morbid psychiatric conditions such as depression, chronic pain and chronic fatigue. People with SCI are also at risk of experiencing adverse social consequences, including high risk of divorce and loneliness, substance abuse, social discrimination and unstable employment prospects. However, on an encouraging note, the majority of adult people with SCI adjust very well in the long-term.^{8,24}

The rehabilitation of individuals following a SCI is a complex process, and defined by the World Health Organisation, 2004¹¹⁷ as:

*'a proactive and goal-oriented activity to restore function and or maximise remaining function to bring about the highest possible level of independence, physically, **psychologically, socially** and economically. It involves combined and coordinated use of medical, nursing and allied health skills, along with social, educational and vocational services, to provide individual assessment, treatment, regular review, discharge planning and follow-up. Rehabilitation is concerned, not only with physical recovery, but also with **psychological and social recovery and reintegration (or integration) of the person into the community**' (emphasis added by the authors).*

The physical rehabilitation of SCI has been subject to systematic study and refinement, resulting in highly developed approaches whose application has resulted in increased longevity, that is, reduced morbidity and

mortality as a result of sustaining a SCI.⁷⁵ With the release of the first edition of this Guide, psychosocial aspects of rehabilitation had been relatively neglected, resulting in psychosocial strategies being less developed. However, over the past five years since the first edition of this Guide, there has been an encouraging increase in research in psychosocial aspects of rehabilitation, providing a growing evidence base for the rehabilitation of people with SCI.^{8,25,36,48,66}

However, with increased life expectancy following a SCI, the issue of adverse psychosocial outcomes has become more apparent, resulting in a concomitant interest in how to improve these outcomes. Importantly, clinicians are still unsure and lack guidance about how and when to use interventions to enhance psychosocial outcome following SCI due largely to the lack of accessible guidance on the implementation of interventions for which there is an evidence base.

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

1. Develop enhanced models for psychological support during inpatient rehabilitation and community reintegration phases of management. This recommendation included the adoption of the UK's National Institute for Clinical Excellence Four-Tier Model, which makes explicit the different levels of care required for different types of presenting problems (see **Figure 5.3**);
2. Develop new and enhanced service delivery models in inpatient, outreach and community-based services. This included developing the use of the Expert Patient model and the involvement of peers in the rehabilitation process (see **Figure 5.2**);
3. Strategic development of psychological services for individuals with SCI and related conditions in

NSW. This included examining workforce issues and provision of support and professional development opportunities for psychosocial specialists; and

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

A major purpose of this Guide is to build on the work done during Professor Kennedy's visit by recommending strategies for:

- delivery of rehabilitation services that promote optimal psychosocial adjustment
- the management of psychosocial adjustment and co-morbid psychosocial disorders during the rehabilitation process
- the management of psychosocial issues following rehabilitation.

Where possible, these recommendations will have an evidence base. Otherwise, strategies will be selected on a consensus basis.

2.1.2 Definition of psychosocial outcomes

Psychosocial outcomes can be defined as those outcomes that involve domains such as wellbeing and quality of life, psychological perceptions and status (e.g. personality, mood states, pain catastrophisation, coping styles, self-efficacy), social functioning (e.g. social networks, quality of relationships, sexual function) and community participation (vocational and recreational status).

2.1.3 Objective and scope

This Guide aims to provide direction for the appropriate provision of psychosocial care for people with SCI based upon existing research literature and applicable evidence-based clinical practice guidelines. Where these are not available, the aim is to draw on the expertise of specialists in the area to direct health professionals attention to factors requiring consideration.

2.1.4 Target audience

The intended audience for this Guide consists of the treating teams involved in the acute, rehabilitation and community care of people with SCI, as well as other specialised psychosocial care providers unfamiliar with the management of people with SCI. More widely it also includes interested community organisations including consumer groups such as ParaQuad NSW and Spinal Cord Injuries Australia; and those involved in health planning and policy both within NSW and more broadly.

2.1.5 Structure of the Guide

The Guide is organized into four sections:

- Introduction and Background
- A brief review of the issues involved in the psychosocial care of people with SCI
- A description of models of care that can influence service design in SCI rehabilitation
- Principles and recommendations concerning the psychosocial care for the treating team (including those health professionals providing acute, rehabilitation and primary care services), as well as for the specialised psychosocial care by other providers.

The information booklet previously published by the NSW SSCIS Rural Spinal Cord Injury Project entitled 'Psychological Adjustment after Spinal Cord Injury: Useful Strategies for Health Professionals'³⁴ remains a useful document alongside the Guide. For a discussion of the wider application of psychology to the process of rehabilitation, the reader is also directed to an Australian Psychological Society Position Paper titled "Psychology and Rehabilitation in the Health Sector: Its Role and Contribution".⁴ To assist consumers and health professionals, we have also created a complementary Psychosocial Resources and Information Directory for People with SCI.

The Directory is available at <http://www.aci.health.nsw.gov.au/networks/spinal-cord-injury/resources>

3. METHOD

3.1 Process of developing the Guide

In mid 2006, the NSW State SCI Services (NSW SSCIS) formed the NSW SSCIS Psychosocial Strategy Steering Group, chaired by Associate Professor James Middleton. Since its formation, this group has met frequently in order to develop a strategy for the provision of psychosocial care for people affected by SCI. The development of this Guide is an important outcome of the strategy.

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

The outcomes of the Forum were analysed and synthesised by the Steering Group, and a number of priority areas were identified. These included:

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

The writing of this Guide was agreed upon as a way of addressing some of these priority areas, particularly in providing support for providers of psychosocial care. The broad structure and content of the Guide was agreed by the Steering Group, after which a full draft was produced by Professor Craig and Dr Nicholson Perry. Drafts were edited by members of the Steering Group,

with additional input from a wide range of participants provided through two specialised workshops held during the ANZSCOS conference in November 2007.

The evidence upon which this Guide is based was collected through two main of strategies: A diverse range of health professionals involved in psychosocial care in specialist SCI services were asked to contribute examples of guidance specific to the provision of psychosocial services to people with SCI, other potentially relevant information (such as services for people with traumatic brain injury), or research reports relating to psychosocial care of people with SCI.

Evidence regarding the specific and generic clinical practice guidelines was accumulated by conducting a systematic review of the literature using keywords such as spinal cord injury, adjustment, treatment, depression, and PTSD. Search engines used included Medline, PsychInfo, and Google Scholar. Google was used to search for clinical practice guidelines in use by other relevant professionals in Australia and overseas. For the purpose of this Guide, only those studies that reported objective psychosocial outcomes were selected for inclusion. Outcome measures criteria that were applied included:

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

The process of evaluating the evidence collected adhered to the National Health & Medical Research Council (NHMRC) guidelines. Therefore, the following NHMRC criteria were used to rate the evidence of treatment effectiveness in descending order of strength:

- Level I Systematic review of all randomised controlled trials
- Level II At least one well-designed randomised **controlled trial**
- Level III-1 ... Well designed pseudo-randomised trials
- Level III-2 ... Controlled cohort or case-control studies **with concurrent controls (non randomised)**
- Level III-3 ... Comparative studies with an historical control
- Level IV Case series or before and after studies.

An example of the above process follows. Best evidence shows that people with SCI have raised levels of depressive mood and negative psychological states such as anxiety.^{18,24,43,63,66,77,88,93} People with SCI also have significantly lowered quality of life.⁷⁶ The implication of these findings is that it is crucial that people with SCI receive psychosocial treatments shown to be effective in reducing psychological morbidity and improving quality of life. There is published evidence from randomised and non-randomised psychological interventions providing Level I and II evidence for the efficacy of CBT in reducing psychological morbidity after SCI.³⁶ Results of a recent systematic review⁷³ and meta-analysis³⁶ provide evidence that – randomised and non-randomised clinical controlled studies have demonstrated that cognitive behaviour therapy (CBT) is effective at reducing depressive mood and lowering anxiety in SCI in the long-term.^{21,22,23,36,39,40,55,58} CBT programs typically 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.^{23,36,58,73} Other Level III evidence research has shown a combination of CBT and antidepressant medication over a six month period to be effective at reducing depressive mood in SCI.⁵⁵

Where specific clinical practice guidelines adhering to the above NHMRC criteria were available for people with SCI, or where generic guidelines that were appropriate for people with SCI were available, these have formed the basis of the Guide. In the absence of any available clinical practice guidelines or research literature, recommendations were based on available literature and the results of wide-ranging consultation with experts associated with the field of SCI through the process described above.

Only key references have been cited in the Guide and these were selected on their scientific merit. Therefore the Guide does not present the full range of possible studies conducted in the area. During the 2013 revision all references were reviewed for currency and updated were necessary.

4. UNDERSTANDING THE PSYCHOSOCIAL ASPECTS OF SCI

4.1 Epidemiology

While SCI is a potentially devastating injury, with wide implications for the individual and those around them, it is relatively rare. The incidence (or risk) of SCI (due to trauma) in Australia has been reported to be steady at around 15 persons per million over the period 1986-1997.⁹¹ However, the risk in those 15 years and over is higher at 20 per million, and the risk is higher again for males aged 15-24 years at around 40 per million.⁹¹ Worldwide prevalence (the number who have SCI at any one time) has been estimated to range between 223 to 755 per million people.¹¹⁸ Only a very small minority of injuries are acquired among those under 16 years of age.

The population of people with SCI in Australia has been estimated to be around 10,000 persons in 2007.⁹⁰ 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 2 to 3 months following the injury.^{75,104} The average age of the SCI population is therefore increasing due to improved survival rates and increased life expectancy following injury.¹⁰⁴ Traumatic injuries such as motor vehicle accidents, falls and sport related injuries are the most common causes of SCI.^{91,28} It has been reported that 73% of people admitted to a SCI unit sustain a SCI from a traumatic cause, while 26% result from a non-trauma cause such as cancer or ischaemia.²⁸

4.2 The nature of psychosocial outcomes

The domains included within the general range of psychosocial outcomes have been briefly outlined in **Section 2.1.2**. However, these are frequently not 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 refer to somewhat different concepts at different times and when used by different authors. 'Adjustment'

has been defined by Treischmann (p.3) as "the act of bringing something into conformity with external requirements' and 'harmony achieved by modification or alteration of a position."¹⁰⁹ Based on definitions developed by Middleton and Craig⁷⁴, this suggests that adjustment following SCI could be defined as:

'a SCI person 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'

Equally 'coping' could also 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 these purposes we will 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'

A desirable psychosocial outcome following SCI therefore, would be to assist people with SCI adjust and cope satisfactorily to their life challenges and problems. Recent trends place emphasis on improved self-management and resilience.^{8,16}

In addition to the systematic use of validated medical and physical outcome measures (e.g. ASIA levels), it is important that appropriate psychosocial outcome measures are available to evaluate the 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, which covers various relevant domains such as physical functioning, emotional functioning, vitality, mental health, social functioning and pain.

4.3 The nature of psychosocial outcomes

There is a great deal known about psychosocial outcomes in individuals following an SCI, and this is summarised in the sections below.

4.3.1 Social function and community participation

The severe pressures and daily demands associated with a SCI place extraordinary strains on the family of the SCI person.^{61,88} Stable employment and financial pressures can be major problems especially if the SCI person was the primary income earner prior to the injury.⁷⁹ 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 SCI person will suffer high risks of frustration, stress, fatigue, health problems, isolation, guilt feelings, resentment and greater risks of depression.^{37,113} Sexual adjustment is also a challenge following a SCI. While many people with SCI report a satisfying sexual relationship following the injury, studies have found women with SCI may suffer decreased sexual satisfaction.^{44,100} 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.¹⁹ 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.

When the person with SCI moves to 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 surrounding community and social reintegration, people with SCI potentially face secondary complications⁵² and consequently many may experience frequent hospitalisation.¹⁹ Community barriers may be made more difficult by medical problems such as spasticity and infection, and access/ mobility is demanding due to their physical impairment. Additionally, financial concerns, home modification issues and transportation difficulties all combine to make community reintegration a challenge.⁵²

While employment will have a positive influence, many people with SCI are not able to be consistently employed and this may well increase risks of an unsatisfactory quality

of life.^{70,79} Return to work has been found to be higher in persons injured at a younger age, who had less severe injuries and higher functional independence.⁷⁰ 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 and loss of social security benefits.⁷⁰

4.3.2 Emotional Well-being and Mental Health

4.3.2.1 Anxiety and post traumatic stress disorder

Abnormal levels of anxiety following an SCI is a risk for up to 30% of people with SCI.^{18,19,43,65,77} Given the trauma and loss associated with the injury, it is not surprising that a person with SCI becomes anxious about their well being and future. This is especially the case when secondary conditions are present such as chronic pain.¹¹⁰ Anxiety levels have been found to steadily increase from the initial week after the injury up to 48 weeks after (just before discharge), to clinically elevated anxiety levels seen in people with an anxiety disorder, after which anxiety levels drop below the clinical cut off score for clinical disorder.⁶³ Higher levels of anxiety were found to correlate significantly with depressive mood, chronic pain^{20,63} and poorer quality of social support.⁶³ A minority of people with SCI, ranging from around 10% up to 40%, are at risk of developing post traumatic stress disorder (PTSD).^{59,77} Given that many people with SCI sustain their injury during a traumatic event such as a motor vehicle crash, a fall or act of violence, it is understandable that disturbing and distressing memories related to their injury are prevalent. Best evidence at Levels I and II has found that psychological/ psychosocial based therapies (eg. cognitive behaviour therapies) reduce significantly the level of anxiety of the person with SCI and enhance their wellbeing in the long-term.^{36,73}

4.3.2.2 Depression, suicide and chronic fatigue

The devastating nature of SCI and the difficulties adjusting to its impairments have been shown to result in a 20 to 40% chance of experiencing depression or elevated depressive mood in the rehabilitation phase and up to 40% chance when living in the community.^{18,24,38,43,54,63} Fann and colleagues⁴³ found the chances 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 past 3 months. Recent research found a spot prevalence of 51% of clinically elevated depressive mood in people with SCI living in the community.²⁶ Research has also shown that unless the depression and distress are treated, levels will remain elevated up to at least two years after the injury.²¹ Best evidence at Levels I and II has found that psychological/ psychosocial based therapies (eg. cognitive behaviour therapies) improve significantly the mood of the person with SCI and enhance their wellbeing in the long-term.^{36,73}

Chronic fatigue is related to poor QOL^{5,116} and has been found to be a significant risk for those people with SCI who are depressed or who have chronic pain.²⁵ Recent research estimates the spot prevalence of chronic fatigue in people with SCI to be around 56% when living in the community.²⁶ Research has also found that elevated negative mood states (eg. depressive mood, anger, fatigue) are obvious risk factors for poor outcomes in people with SCI. For instance, depression is predictive of longer and more frequent hospitalisations (with more time in bed and fewer days spent outside the ward), increased medical complications, decreased self-care, higher medical expenses and more difficulties with transportation.^{43,48,107} People with SCI who report elevated chronic pain have been found to be more depressed and have higher levels of distress, which then negatively interferes with their daily living activities.^{25,51,95} Chronic pain (eg. neuropathic) is related to depressive symptomatology^{20,25,51} and if people with SCI who are depressed are not treated, they have higher risks of suicide, and more than likely risks of suicide increase if chronic pain is present and not treated successfully.⁵¹ Best evidence suggests the suicide rate can be up to five times higher than the general population depending on the country.³⁵ Risk factors for suicide have been found to be: (i) male, (ii) having a schizoid, depressive or narcissistic personality, (iii) abuse alcohol or other drugs, and (iv) show symptoms of the development of

significant depression.⁵³ Attempted suicide leading to SCI was determined to be just over 2% of the total SCI cases over the years 1970 to 2000 in NSW, Australia, and suicide attempts leading to SCI have increased significantly over this time period.¹⁰³ Stanford and colleagues¹⁰³ found the frequency of suicide following the SCI was high (estimated to be 8%).

4.3.2.3 Long-term positive psychological adjustment and resilience

Best evidence suggests that the majority of people who suffer SCI adjust well to the injury and show astounding resilience to the severe associated impairment.^{8,18,24,61} Factors found to be associated with resilience included fewer QOL problems, adaptive thinking styles, greater acceptance and fighting spirit, and less coping through social reliance and behavioral disengagement.⁸ People with SCI have been shown to cope effectively with their injury, loss and impairment and 'getting on' with life. Satisfaction with life after SCI has been found to be associated with factors such as employment, financial income, a low frequency of medical complications and having social opportunities.¹¹² People with SCI will obviously suffer transient distress and despondency, as well as lower quality of life (QOL) following the injury.⁷⁶ 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.¹⁸

4.3.3 Quality of life

As might be expected, studies have shown that SCI negatively impacts quality of life (QOL) across a range of dimensions such as physical functioning, social and emotional functioning, mental health, vitality and pain using a widely used instrument such as the SF-36^{47,49,63,76} Additionally, factors such as neuropathic pain, negative mood states, and chronic fatigue have been shown to decrease QOL,^{76,116} while factors such as spasticity, socioeconomic disadvantage and medical complications have also been found to be associated with lower QOL.^{49,76} Caregivers of people with SCI are also at risk of having lowered QOL.¹¹¹ It is likely that psychological and social factors are equally important in determining QOL for SCI persons in the long-term. It would be a major mistake to believe that an injury like SCI will result in low QOL just because of the onset of severe physical impairment.⁷⁶ For instance, poor self-efficacy was associated with substantially reduced QOL comparable to the effect on QOL of chronic pain.⁷⁶

4.4 Factors influencing psychosocial adjustment

There are many factors contributing to the process of adjustment following SCI.⁸⁸ These can be grouped into areas such as medical/ physical, individual/ psychological, environmental, social and community factors. Many of these are discussed briefly below and their impact on adjustment and coping assessed. It is important that objective outcome measures be employed to assess these factors during and after rehabilitation.

4.4.1 Perceptions of control, self-efficacy, feelings of helplessness and coping

Attributional processes and coping styles have been shown to be important predictors of psychological adjustment.⁶² People with SCI who attribute their life outcomes more to chance and powerful others (helplessness or poor self-efficacy) are more likely to suffer 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.²¹ Having helplessness or poor self-efficacy beliefs may also be associated with an increased likelihood of experiencing PTSD and general health problems.¹¹ Recent research has 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,²⁷ and people with SCI who had poor self-efficacy were found to have higher levels of chronic fatigue.²⁶ 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 which was also found to be related to greater well-being.⁶² 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 well-being. There is a need to counter the development of perceptions of helplessness or external control in SCI patients, as this is known to have a negative impact on adjustment and resilience.¹⁶ It is essential therefore to foster a sense of personal control in the SCI person during rehabilitation.

4.4.2 Medical factors

As stated above, medical factors such as level of injury

and completeness of injury have not been found to contribute strongly to measures of adjustment, such as depressive mood or quality of life.⁷⁶ However, secondary medical complications can occur in people with SCI⁶⁵ and are known to have a negative influence on adjustment. These include:

4.4.2.1 Pain

Pain is a major problem possibly affecting up to 90% of people with SCI,²⁵ with up to 50% reporting severe pain.^{25,98} 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 results directly from loss of motor control.^{87,114} In a prospective study of SCI persons followed up to two years after their injury, Craig and colleagues²⁰ found that pain was an important predictor of depressive mood. Evidence is beginning to highlight the importance of catastrophic patterns of thinking about pain as a risk factor for pain-related disability and distress in this population.¹⁰⁸ Chronic pain is well-known as a significant risk factor for suicide among general chronic pain patients, approximately double that of controls without chronic pain, with pain catastrophising, helplessness, hopelessness, avoidance and sleep-onset insomnia being among the factors that appear to be important in contributing to suicidality.¹⁰⁶ Although to date there have been no investigations specifically regarding the association between pain and suicidality following SCI, clearly there is potential for persistent pain to be one of the factors that contribute to increased risk of suicide in people with SCI. In a 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.^{51,86}

4.4.2.2 Traumatic brain injury (TBI)

Co-morbid traumatic brain injury (TBI) ranges from 25 to 50% of SCI cases.^{15,31} Cognitive impairment and/or behavioural disturbance resulting from an associated TBI is known to have a substantial negative impact upon function and independence in a person with SCI.¹⁰² This may include problems with learning/retaining new information, sequencing and mastering skills (e.g. self-care activities); initiating self-care behaviours (e.g. intermittent self-catheterisation); safety risks due to impulsivity/poor judgement (e.g. transfers, wheelchair skills, crossing road); or difficulty problem solving in

novel situations (e.g. blocked catheter, autonomic dysreflexia, pressure area issues). Co-morbidity of TBI with drug and alcohol abuse in people with SCI is arguably of particular concern given the potential of alcohol overuse to add to neurological complications.

4.4.2.3 Infections

People with SCI are vulnerable to secondary complications such as urinary tract and respiratory tract infections and pressure ulcers.^{30,52} Psychosocial factors have been found to contribute to increased complication rates.¹⁹ The risk of death in people with SCI is substantially higher from conditions such as septicaemia, pneumonia and influenza, diseases of the urinary system when compared to the general population.¹⁰¹

4.4.2.4 Sleep disturbance

A common complaint among people with SCI is difficulty in sleeping⁴¹ and this is particularly so among those experiencing pain.¹¹⁴ In comparison to the able-bodied population, individuals with SCI have higher risk of sleep disorders, greater difficulty falling asleep, have more frequent awakenings, are more often prescribed sleeping pills and snored more and for a longer duration.^{41,115}

4.4.2.5 Coronary artery disease

The risk of cardiovascular problems is elevated in people with SCI.⁹⁶ Research suggests that elevated depressive symptoms are a robust risk factor for coronary artery disease (CAD).³² Therefore, another concern is the effect that CAD risk factors such as inactivity, being overweight and elevated negative psychological states (e.g. elevated depressive mood or states such as helplessness and anger) may have. While it has been shown that CAD is a major problem in the SCI population,⁹² little is known about the influence of psychosocial risk factors such as elevated negative psychological states on CAD risks in SCI.

4.4.3 Pre-morbid factors

Psychological status post-injury is idiosyncratic and depends very much on the SCI person's pre-morbid status. We know, for instance, that rates of substance abuse are high in the SCI population before they are injured⁵⁰ and evidence exists that screening for and brief interventions regarding alcohol abuse among trauma patients reduces risk of further injury.⁴⁶ Best evidence also suggests a minority of SCI persons are at risk of having a complex psychological profile due to pre-morbid factors.¹⁰³ Stanford and colleagues¹⁰³ found that 56 of 2,752 SCI admissions to a spinal ward during the period 1970-2000 were due to attempted suicide. Psychiatric diagnoses of those who acquired an 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%) or chronic alcohol abuse (18%). Of those who attempted suicide before their injury 8.5% actually committed suicide during the eight years following the SCI.¹⁰³

4.4.4 Environmental factors

Institutionalisation is known to be an influential factor in determining outcomes.⁶⁰ 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 SCI people and asserting their 'inferiority') could result from the effect of institutionalisation. For instance, patients in SCI units have been 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.⁶⁰

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.⁶ 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.⁶⁸

The acute 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, which may include artificial ventilation for a period of time. The person will experience sensory deprivation and a cocktail of medications, mixed with pain, discomfort, lost sleep, bodily trauma, fatigue and potential confusion about the significance of their injury. Many will have experienced head trauma, for instance, 22% of motor vehicle related injuries were reported to have head injury or loss of consciousness²⁸ and so may be confused and amnesic.⁸⁸

The person with SCI will be in a state of shock which may be a form of psychological protection. They may believe they will walk again, which can be interpreted as denial, though 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 progressive rehabilitation it may become counterproductive.⁷⁴ It is worth noting that very few patients admitted to a SCI unit with a neurological deficit are discharged with no neurological deficit. In 2004-2005 in Australia, only 2% of all cases admitted (N=381) had no neurological deficit on discharge.²⁸

As well as the physical environment, the social environment in 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.⁸¹ An excellent source that outlines and describes strategies for improving communication can be found in a text on counselling written by Richard Nelson-Jones.⁸³

The next section will review important models, both those explaining people's responses to health challenges and those developed to guide the design of services, which provide important concepts and principles to guide the psychosocial care of people affected by SCI.

5. MODELS OF CARE

Models constructed to 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 which have been designed, often based upon particular conceptualisations of how the adjustment process occurs, that 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. Individual models will contribute 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. A strict use of the biomedical model can also result in a view that the SCI person is 'abnormal', 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 in order to adjust and cope adequately with the injury, based largely upon work on reactions to bereavement.^{67,109} 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.^{74,88} For instance, no association has been found between age or time since injury and psychological status of people with SCI admitted to rehabilitation⁹ and linear models of adjustment cannot account for the unpredictability and complexity of adjusting to a severe problem like SCI which is associated with ongoing fluctuations in state rather than a single event.⁷⁴

In the wake of stage models, other models have made important contributions to our understanding. **Figure 5.1** presents information about four models that have contributed to our understanding of adjustment. Each has its own limitations. Another model, called the cognitive-

behavioural model, made a valuable contribution by emphasising the importance of both of thinking style and behaviour in the adjustment process, for example the negative effects of having a catastrophic outlook of the future or preferring to disengage (behavioural avoidance) when adjusting to illness or injury. However, this model failed to highlight the importance of cultural, political and social forces in the adjustment process.

Thus it has become clear that a model is required that can account for a more continuous and cyclical process of adapting to the personal and societal problems arising from SCI, taking into account variables both in the individual and in the wider social, physical and political environment. For instance, adjusting to SCI can be viewed as a life-long process of adjusting to challenges that alter with the environment, the condition (e.g. the development of additional consequences, such as pain) and with changing life roles (such as becoming a parent). For many people it will involve periods of negative adjustment in response to the initial injury or new challenges (e.g. a negative cycle in which the person feels depressed as a result of constantly experiencing high levels of chronic pain, leading to higher pain levels, resulting in more severe depression). 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.⁷⁴ A cyclical approach to adjustment will involve an ongoing process of learning to adapt to difficult and challenging life circumstances.⁵⁶ 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, and this is 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 SCI people.

There is consensus that the biopsychosocial model is a comprehensive model that satisfies the majority of the criteria required to explain and aid the process of adjustment. This model integrates biological, psychological and social dimensions that operate in

the evolution of physical and mental health outcomes and have been applied successfully to SCI care.^{2,72} 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.² The advantages of the model include:

- it is cross disciplinary
- emphasis is placed on contextual factors such as social, cultural and political forces
- the importance of molecular and physiological factors in health outcomes as well as psychological and social factors is 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 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, SCI people should receive a continuum of services from the onset of SCI, with support following throughout their life span. This will involve goals such as:

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 psychologically resilience
7. having satisfactory physical health.

5.1 Designing services to accommodate psycho-social aspects of adjustment

The core task of rehabilitation is to prepare the individual and those close to them to be able to 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 increasingly being explicitly acknowledged by health service planners, for example the NSW Chronic Disease Strategy. The aspects of this approach relevant to the SCI population include aiming to reduce 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 a number of principles relevant to SCI population such as person centred care, promoting an active self-management approach 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 **Figure 5.2**. Some of the key characteristics of these models have included the attempt to engage “patients” as active participants in their rehabilitation or management, with an explicit focus on using strategies to enhance self-efficacy/ perceptions of control. 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 **Figure 5.3**), which originated in cancer services and which 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 which integrate good practice in promoting psychosocial adjustment to SCI, the traditional staffing patterns of SCI units may need to be adjusted. Staff employed in roles that are currently well-represented in these services, such as physiotherapy and occupational therapy, may need to further develop some 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, psychology, neuropsychology or social work, may also need to be assisted to cover expanded roles. Advice regarding appropriate psychosocial staffing of rehabilitation units is available from a number of sources, and details are available in **Table 6.1**.

Figure 5.1 Theoretical models influencing our understanding of adjustment to SCI

Stress Appraisal Model	Model of Human Occupation
<p>The Stress Appraisal Model of Lazarus and Folkman⁶⁹ 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. For example, if a SCI person believes they are able to cope with current and/or future stressors, then this acts to reduce their level of stress, acting to enhance the ability to cope and adjust. Conversely, if a SCI person believes they are unable to cope with their stressors, then this acts to increase their level of stress, acting to reduce 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.⁶⁹ Outcomes are also believed to be influenced by primary appraisal (evaluating threat) and secondary appraisal (evaluating personal coping resources and options), and a distinction is made between problem solving coping strategies (e.g. confronting and taking control in order to modify the stressor) and emotion-focussed coping strategies (e.g. denial or wishful thinking).</p>	<p>Kielhofner⁶⁴ developed the Model of Human Occupation (MOHO) which 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. Its concepts address: (i) the motivation for occupation, (ii) the routine patterning of occupational behaviour, (iii) the nature of skilled performance, and (iv) 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.</p>
Transtheoretical Readiness to Change Model	Social Disability Model
<p>Prochaska and colleagues⁹⁴ in the Readiness to Change Model 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. Stages of change include (i) pre-contemplation (not ready to change and perhaps in denial); (ii) contemplation (thinking of changing but still needing mental commitment); (iii) preparation (ready to change and committed); (iv) action (making changes but now need to commit long-term), and (v) 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.</p>	<p>The Social Disability Model⁹⁷ 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 process.</p>

Figure 5.2 Influential service design models

Peer Support (Worldwide)	Expert Patient Programme (UK)
<p>The concept of peer support began with the development of Alcoholics Anonymous (AA), operating on the principle that persons 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 well-being and of being in control, and stronger social networks and supports.¹³ For people with SCI, peer support programs exist both in Australia and overseas.</p>	<p>The Expert Patients Programme³³ (EPP) developed in the UK, is a self-management program for people who are being treated for chronic illnesses and disorders, and is based upon the chronic disease self-management program developed at Stanford University.⁷¹ Patients are trained to act as instructors to others with chronic condition, with the aim of enhancing the participants' confidence and motivation to use their own skills and knowledge to gain effective self-control over their chronic illness in partnership with their health care providers. Typically it involved groups of 8 to 16 participants meet for six structured sessions that deal with ways to manage the effects of their long-term condition. The emphasis is placed on participants setting practical, achievable goals and then exploring problem solving strategies and enhancing decision making skills throughout the six weeks. There is evidence that demonstrates this approach results in improved outcomes for people with chronic conditions such as asthma, arthritis, cardiovascular problems and depression.^{33,71}</p>
The Stoke Mandeville Model (UK)	The 'Flinders Model' of Chronic Condition Self-Management (Australia)
<p>This model is based upon 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.⁵⁷ The aim is to establish optimal 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. This model has been shown to be effective in enhancing rehabilitation outcomes in SCI people.⁵⁷</p>	<p>This model was developed by the Flinders Human Behaviour and Health Research Unit and stresses the importance of both health professional and patient working together in the process of care plans.⁴⁵ 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.⁴⁵</p>

Figure 5.3 4-Tier Model of Psychological Support*

The model encompasses the range of psychological skills and expertise on which patients may draw and represents the diversity of psychological skills covered by different professional disciplines. The function of each level of provision is as follows.

Recommended model of professional psychological assessment and 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 psychological 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	Specialists psychological and psychiatry 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 <http://www.nice.org.uk/nicemedia/live/10893/28816/28816.pdf> (Accessed Nov 2013)

6. RECOMMENDATIONS FOR THE PSYCHOSOCIAL CARE OF PEOPLE WITH SCI

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

6.1 General principles for the psychosocial care of people with SCI

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

6.1.1 Psychosocial factors that impact on rehabilitation outcomes should be integrated into all SCI services provision, and clients should have access to psychosocial support services throughout the lifespan

Throughout the lifespan, psychosocial needs may arise at any point after injury, and therefore people with SCI should be able to access appropriate services at all stages of life. Services should actively plan for the impacts of psychosocial factors when providing care to those with SCI.

6.1.2 Services for people with SCI should be designed to promote psychosocial adjustment

This can be done by promoting skills and attributes required for self-management, such as self-monitoring (logging important activities) and positive self-appraisal (e.g. self-efficacy). This principle may be reflected both in the physical environment of in-patient services (such as providing access to areas for the practise of skills out of usual therapy hours) and in the rehabilitation process (such as promoting the client's active participation and

decision-making in the treatment and discharge planning process). Participation in activities that promote well-being, such as adequate physical and social activity, should be actively promoted as part of SCI services.

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

Due to the environmental constraints of the hospital setting, attempts should be made to promote supportive and healing surroundings for the patient with SCI, visiting family and friends. Efforts to consider patients' privacy and to promote opportunities to make meaningful and valued contributions to decisions made in their environment will lessen the effects of the being in a stressful clinical setting.

6.1.4 Members of the treating team should be sensitive and open to signs and symptoms of distress

Provision of adequate psychosocial care is predicated on the ability to detect signs and symptoms of distress. This requires a culture in which the concerns of the patient and their family are at the centre of care, and there is a systemic awareness of what constitutes an appropriate response to the range of issues that may arise (e.g. such as suicidal ideation), with the realisation that appropriate responses may well form an important contribution to the process of adjustment.

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

Given the shock, distress and confusion prevalent in the early stages of the injury, the treating team should provide generous emotional and social support. This will assist in the development of the relationship between the client and the treatment team, and so enhance the ability of staff to detect any unmet or pressing psychosocial needs.

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

Effective communication skills need to be used when interacting with the person with SCI and their family at the time of admission to the SCI ward, given the potential for elevated distress, confusion and disorientation as well as throughout rehabilitation. Effective communication is based upon empathy and active listening. If the person with SCI and family do not have English as their first language, or the individual is a user of a form of sign language, it is essential that an interpreter be engaged.

6.1.7 Clients should be provided with timely and targeted information

People admitted to services following the acquisition of a SCI require timely and targeted information about diagnosis and prognosis, as well as the processes of rehabilitation. Clients are dependent upon accurate information to facilitate their active engagement in the discussion of treatment options. Fluctuating clinical presentations, and the development of secondary complications, result in an on-going need for good quality information.

6.1.8 Self-management models should be promoted as the basis of psychosocial rehabilitation

Following discharge from rehabilitation, clients are responsible for the on-going management of their condition in association with their treating team and care providers. Explicit preparation for this role is essential, with due care given to co-morbidities which may impact upon their ability to undertake this effectively. Self-management models discussed in Chapter 5 should form the framework upon which psychosocial rehabilitation is based.

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

Carers and significant others of those with SCI experience an increased level of psychosocial impairment, and this requires appropriate assessment and intervention. It is recommended that carers and family of SCI inpatients be introduced to non government organisations providing

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

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

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

6.2 Principles for integrating psychosocial aspects into the acute and rehabilitation process

6.2.1 Psychosocial rehabilitation should commence at the point of admission to the unit

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

6.2.2 A key worker should be allocated to each new SCI person admitted to the SCI inpatient program

To facilitate effective communication and coordination of rehabilitation, a health professional key worker should be designated and allocated to each new SCI person admitted to the inpatient program. The key worker acts as the co-ordinator of the rehabilitation process for each individual client and as the first point of contact for the client and their family or significant others. The key worker will ensure that a psychosocial needs assessment is conducted and that it is integrated into the multidisciplinary treatment plan. Where specific psychosocial co-morbidities are thought to be present

(such as psychiatric disorder) the key worker should be someone with skills in the management of such issues.

6.2.3 An initial psychosocial assessment should be conducted as soon as practicable following injury

The purpose of the initial psychosocial assessment is to ensure that the treating team is aware of psychosocial issues that may impact upon the process of rehabilitation. The assessment may be based upon the client's history as obtained from others, such as family members and the general practitioner, regarding risk factors such as a previous history of psychiatric disorder. As soon as the individual is able to communicate it should also include direct assessment.

6.2.4 All SCI patients should receive a multidisciplinary rehabilitation program in which psychosocial care is a core component based upon an individual needs assessment

The psychosocial aspects of the multidisciplinary rehabilitation program, based upon the initial psychosocial assessment, should be developed to cover all stages of the adjustment process, including inpatient rehabilitation, integration into the community and outpatient rehabilitation. It should contain information concerning the treatment such as presenting needs, individual and family goals and expectations about the specific goals of the treatment received, and any anticipated risks or barriers to successful outcome. The multidisciplinary rehabilitation program should be regularly reviewed and revised to reflect changes in an individual's condition or long-term goals. The multidisciplinary rehabilitation program should:

6.2.4.1 Be comprised of well-defined goals

Treatment plan goals should comprise specific steps so that clients are aware of how each sub-goal will build upon the previous ones and towards the overall goal.

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

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

6.2.4.3 Include access to a structured psychosocial treatment programs during the rehabilitation stage

Structured psychosocial treatment programs should be offered to all SCI people during their rehabilitation stage, with the program varying according to their needs. Further details are provided in **Section 6.4**.

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

Access to specialised treatment programs for co-morbidities such as TBI, drug and alcohol, mental health and pain should be facilitated based upon the individual's needs assessment and the multidisciplinary treatment plan. Further details are provided in **Section 4.4**. It is recommended that there is a collaborative relationship developed between the treating team, primary care and community services, and the relevant providers of specialised psychosocial care in order to ensure that the SCI person's needs are met appropriately. In some cases, there will be a need for formal coordinated case management.

6.2.4.5 Discharge planning should begin early in the inpatient program

In order to ensure the smooth transition to the community, discharge planning should begin early in the multidisciplinary rehabilitation program. This requires the input of all team members, as well as the individual with SCI and family, particularly where there are significant psychosocial co-morbidities which may impact upon access to appropriate services.

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

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

6.3 Recommendations concerning psychosocial assessment

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

It is recommended that a comprehensive and systematic psychosocial assessment process be established that explicitly covers all aspects of psychosocial function. This should be contributed to by all relevant members of the multidisciplinary team. This information is needed to develop appropriate goals and an effective treatment plan. The comprehensive and systematic psychosocial assessment should include the following components:

6.3.1.1 Pre-morbid details

This should include any occurrence of prior psychopathology and substance abuse. It is recommended that all SCI inpatients receive a brief alcohol and drug screening assessment, and that all relevant staff be trained to deliver this screening procedure.

6.3.1.2 Current mental health and psychological status

It is recommended that the following be assessed: a structured or semi-structured mental health interview (conducted by Psychiatry); psychological questionnaires assessing post-traumatic reaction and negative psychological states such as depressive mood, anxiety, anger, fatigue and confusion; appraisals and perceptions (eg. self-efficacy); psychological responses to physical consequences of SCI, such as pain; and quality of life. These psychological measures are important for predicting protective factors related to resilience as well as risk factors related to poor psychosocial adjustment.

6.3.1.3 Cognitive status screening assessment

Given the high rates of TBI in those with SCI, a screening assessment of risk factors associated with TBI should be conducted on all those admitted with SCI. Where a significant risk of TBI is identified, a full neuropsychological assessment should be conducted as soon as possible in order to allow for management of the TBI to be integrated into treatment plans.

6.3.1.4 A brief personality assessment

Personality issues can sometimes create barriers to effective rehabilitation. Personality assessment may provide avenues for reducing such risks.

6.3.1.5 A structured interview to assess a broad range of social factors

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

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

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

6.3.3 The initial psychosocial assessment should be conducted within five days of admission

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

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

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

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

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

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

All staff should have a basic level of psychosocial assessment skills to screen for psychological distress, conduct brief and appropriate interventions, and make appropriate referral in between formal assessments. All staff should have the necessary skills required to delivery mental health first aid (see **Figure 6.1**).

Figure 6.1 Mental health first aid

Cited from Kitchener & Jorm (2002) page 3



6.4 Recommendations for the provision of specific psychosocial interventions

Given the extensive evidence that SCI presents a significant challenge to all those who experience it and that it increases the risk of developing psychological disorders, it is considered that everyone should participate in a form of psychosocial rehabilitation intervention following SCI. The level of intervention should be matched to the level of need, with those with higher risk of adverse psychosocial outcome or who develop psychosocial problems being offered more intensive and specialised interventions. Those with specific psychosocial co-morbidities will require specialised treatment, and further details of these can be found in **Section 6.4.4**.

6.4.1 All individuals admitted for rehabilitation of a SCI should participate in an evidence-based psychosocial rehabilitation group intervention

All individuals with SCI admitted for rehabilitation should participate in an evidence-based, structured psychosocial rehabilitation group program consisting of cognitive behavioural treatment (CBT) and related psychological components as part of their multi-disciplinary rehabilitation program. Depending on the needs of the person with SCI, three different levels of intervention should be offered. These are:

6.4.1.1 Psychosocial Rehabilitation Intervention Level 1

All those attending rehabilitation, including those with no diagnosis of anxiety or depressive disorder and normal levels of negative psychological states, should receive a minimal CBT intervention. The treatment should be designed to enhance feelings of self-efficacy and self-mastery, increase adaptive coping strategies, boost use of appropriate social skills and problem solving, introduce self-management and relapse prevention strategies, sexuality and couple counselling, vocational counselling and social communication and integration. The program could be delivered in a group or one to one format for 6 hours over a period of 6 or so weeks.

6.4.1.2 Psychosocial Rehabilitation Intervention Level 2

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

6.4.1.3 Psychosocial Rehabilitation Intervention Level 3

This level is for those assessed as having definite diagnosis of mental health disorder, such as depression, PTSD, or showing signs of suicidal ideation. They should receive a specialised structured CBT program. Inpatients assessed in this category should receive the same

program described in Level 1 and 2, plus additional individual structured CBT sessions designed specifically to address the severe psychological conditions. This intervention may need to be offered over a longer period of time (in the form of individual treatment). SCI persons in this category may need to receive combination therapy, that is, medication plus the CBT program. Referral for such a program may be necessary (see **Section 6.4.4**)

6.4.2 The effectiveness of the psychosocial treatments provided should be assessed for each participant

It is recommended the effectiveness of the structured psychosocial treatment be assessed at the termination of the CBT program for each participant. If treatment has not resulted in demonstrable improvement, the person with SCI may need to be referred to specialised interventions (see **Section 6.4.4**).

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

It is recommended that SCI with major secondary conditions may need to be referred for specialised treatment. For instance, for persons with high levels of chronic pain, referral to a specialised pain management program is recommended (see **Section 6.4.4.6**). People with a history of substance abuse, referral to a specialised substance abuse prevention program may be required (see **Section 6.4.4.4**).

6.4.4 In certain cases, individuals with suspected severe psychological disorders may need referral to specialized assessment and treatment

An inpatient family conference is advised to be held before referral to specialized assessment and treatment. Specialised assessment and treatment may be provided by health professionals integral to the SCI service, or by specialist services such as drug and alcohol, mental health or trans-cultural mental health services. Such external health services should be accessible to those with SCI. Specialised care programs should be evidence-based where possible and should be fully accessible. Much of the evidence base for treatment of psychological and psychiatric disorders is applicable to people with SCI, although some modifications may be

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

6.4.4.1 Major depressive disorders

SCI persons diagnosed with severe types of depression (bipolar disorder, major depressive disorder, dysthymia and so on) should first be screened for suicidal ideation, followed by specialised treatment. Specific guidelines regarding the care of those with SCI and depression are available from the Paralyzed Veterans of America. Treatment for the depressive disorders should follow clinical guidelines recommended by the Australian and New Zealand College of Psychiatry clinical practice guidelines for the treatment of depression.

6.4.4.2 Anxiety Disorders

Post-trauma related anxiety disorders can be appropriately managed using the advice available regarding anxiety following a motor accident and more general traumas from the NSW Motor Accident Authority and the Australian Centre for Posttraumatic Mental Health. Other anxiety disorders should be managed using guidelines available for the management of the specific condition diagnosed, such as Generalised Anxiety Disorder.

6.4.4.3 Suicide

Risk of suicide should be routinely assessed and those believed to be at risk should be referred for specialist treatment. NSW Ministry of Health has developed a framework for suicide risk assessment and management, supported by sets of guidelines developed for various settings (see **Figure 6.2**). These are available from the NSW Ministry of Health website (http://www0.health.nsw.gov.au/pubs/2005/suicide_risk.html) (Accessed November 2013). The framework asserts that all health providers should be able to undertake a preliminary suicide risk assessment and make arrangements for the most appropriate management plan including referral to more specialised services. This framework is supported by training events available throughout NSW Ministry of Health.

6.4.4.4 Drug and alcohol disorders

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

6.4.4.5 Traumatic brain injury

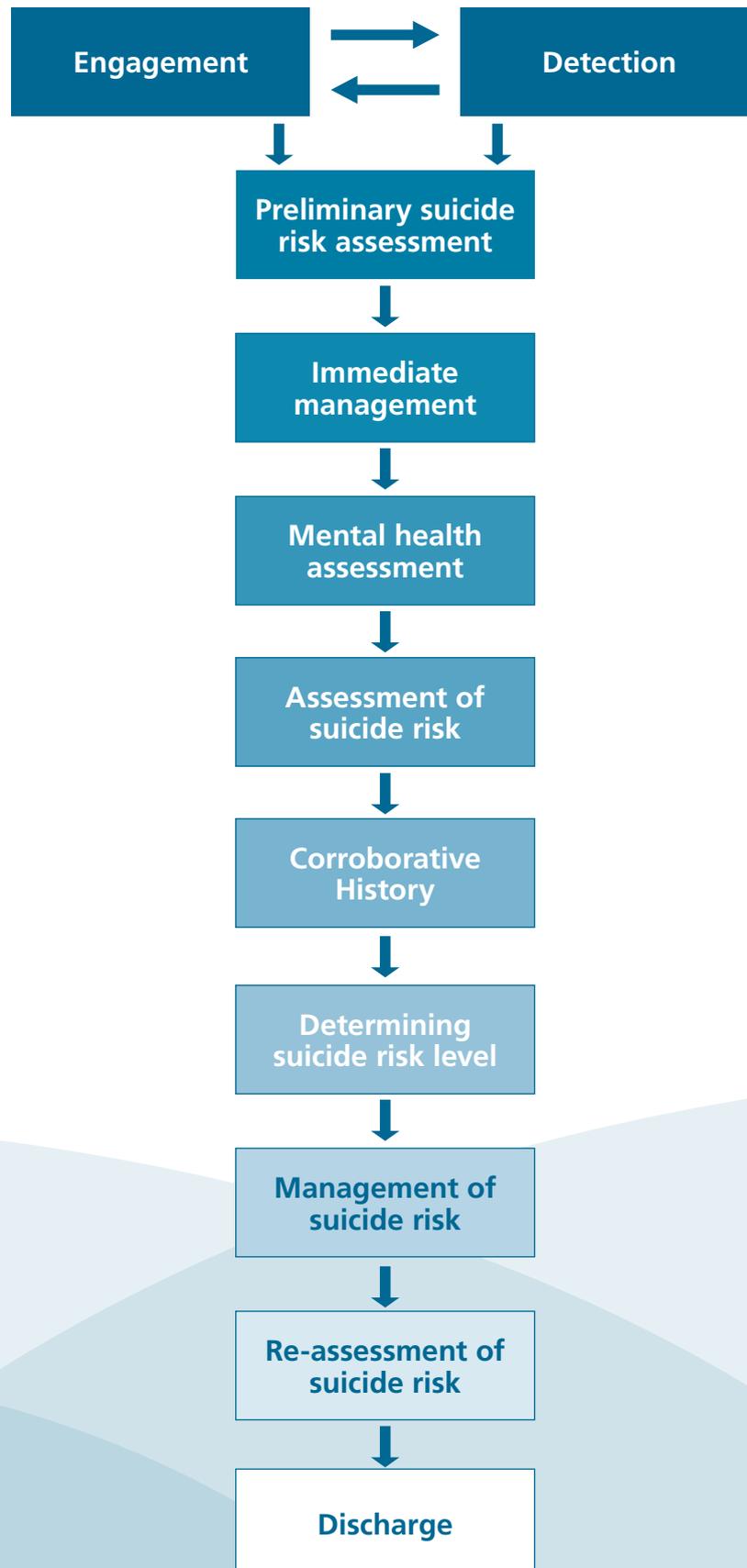
SCI persons identified as having risk factors for a traumatic brain injury (such as prolonged Post Traumatic Amnesia) should be referred for neuropsychological assessment as soon as medically appropriate. Guidance on the assessment and management of brain injury is available from guidelines published by the Motor Accident Authority⁷⁸ and further information on evidence-based treatment can be found on the PsycBite database (www.psycbite.com) (Accessed November 2013).

6.4.4.6 Chronic pain

Presence of pain should be routinely assessed and all patients with SCI who also have persistent pain should be screened for suicidal ideation. Advice regarding the assessment and management of SCI-related pain is available.^{85,99} Individuals reporting that pain is impacting upon psychological well-being or physical functioning should be assessed by an appropriately trained professional. In persistent or severe cases this should usually be in the context of a multi-disciplinary pain assessment rather than an individual practitioner. Psychosocial management strategies should be recommended as part of a comprehensive treatment plan rather than an alternative to other treatments such as analgesics. Clinicians should be encouraged to refer to a specialised CBT program to assist in training individuals in effective self-management strategies. Psychosocial self-management strategies should be explained as an approach aimed at reducing suffering associated with pain rather than as a curative treatment.

Figure 6.2 NSW Health Suicide Risk Assessment and Management Framework

Taken from Framework for Suicide Risk Assessment and Management for NSW Health page 5. (available at http://www0.health.nsw.gov.au/pubs/2005/suicide_risk.html) (Accessed Jan 2014)



6.5 Monitoring and follow-up Assessment

The extended period of time required to accommodate to the challenges of living with a SCI, and the continuing possibility of the development of significant psychosocial co-morbidities, means that it is imperative that the individual's progress is monitored and access to relevant services facilitated. In addition, the individual may require support to continue to apply the self-management strategies necessary for the effective management of their condition that were developed during the rehabilitation process.

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

A specialised psychosocial self-management program should be developed for use following discharge from rehabilitation, designed to promote self care and mental health management. This should be based upon evidence from programs such as the Chronic Disease Self Management Program (CDSMP)⁷¹, Expert Patient Programme (EEP)³³ and Flinders Model of Chronic Condition Self Management⁴⁵. Careful attention should be given to ensuring that this is widely accessible, for example through use of internet or other technology.

6.5.2 The progress of psychosocial rehabilitation should be routinely monitored

It is recommended that monitoring of the individual's psychosocial status continue following completion of rehabilitation, at a minimum on discharge and after a period of 6 to 12 months.

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

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

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

People with chronic disorders can benefit greatly from support programs.⁸¹ The SCI care plan should therefore provide access to structured, ongoing support and relapse prevention services through community referrals which may include: community mental health programs; driver's education and training; health and other educational programs; financial assistance services; home health services; home modification services; independent living centres; recreation programs; sexuality and couple counselling; SCI associations; transportation services and vocational rehabilitation services.

6.6 Staffing considerations Assessment

6.6.1 Ongoing professional development to support the skills identified should be provided routinely.

The skills required for members of the treating team in implementing psychosocial care effectively can be learned through appropriate training. In addition, support will be required in order to promote the continued use of the skills, such as access to supervision.

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

Treating teams will require adequate support from psychosocial specialists, such as psychiatrists, social workers, psychologists and neuropsychologists, in order to deliver appropriate psychosocial rehabilitation. Guidance is available from a number of sources regarding appropriate staffing levels, and national standards such as from the Australasian Faculty of Rehabilitation Medicine.

6.6.3 Staff will require appropriate orientation and ongoing professional development to sustain the acquisition and maintenance of the required skills

Staff should be provided with additional training in order to be adequately resourced and skilled to undertake the recommended tasks and roles. Structured, employer-assisted education and support programs should be developed for staff in order to support the provision of psychosocial care. Examples of possible modules include workshops concerning psychological and

iatrogenic reactions in the acute stage of catastrophic injury (psychological distress, derealisation or depersonalisation, awareness of paralysed body parts, effects of medication on cognition and emotion); the effective management of difficult behaviours and coping styles including aggression management; and motivational interviewing and effective communication techniques. The care of people with chronic conditions like SCI takes its toll on health care workers. Appropriate mechanisms of support for SCI staff should be developed to promote continued psychological well-being. This may include attendance at regular team debriefing sessions.

Table 6.1 Recommended staffing for the management of SCI rehabilitation patients

Inpatient Staff to Patient Ratios (for 10 Spinal Cord Injured Patients)	Full time equivalents (FTE)
Social workers	1.2 FTE
Psychologists	0.5 FTE
Ambulatory Rehabilitation Services Staff (for each 10 Spinal Cord Injured Patients)	
Social workers	0.4 FTE
Psychologists	0.5 FTE

*adapted from the Australasian Faculty of Rehabilitation Medicine Standards³ page 7 and Victorian Allied Health in Rehabilitation Consultative Committee. Allied Health Resources, Version 10 July 2007. Accessed July 2008.

See also: Australasian Faculty of Rehabilitation Medicine and The Royal Australasian College of Physicians (2012). Standards for the provision of inpatient adult rehabilitation medicine services in public and private hospitals 2011. Sydney: RACP. www.racp.edu.au (Accessed January 2014).

7. CONCLUSION

This Guide has made recommendations concerning the psychosocial care of people who have sustained a SCI. Since its first publication in 2008, important psychosocial initiatives and strategies have begun to be introduced into the rehabilitation of people with SCI in NSW. With the revised version, it is hoped that additional innovative and evidence based changes will be made so that the psychosocial care of SCI is further improved and standardised. As a part of this process, the NSW SSCIS produced a directory containing sources of information and support for people with SCI, as well as for health professionals working with them. This is available from the NSW SSCIS website: <http://www.aci.health.nsw.gov.au/networks/spinal-cord-injury/resources> (Accessed January 2014).

8. SHORT QUIZ

1. Which of the following is not a spinal cord injury priority area identified by the Psychosocial Steering Group:
 - a. the need for improved medication regimens
 - b. the need to standardize assessment
 - c. the need for the identification of risk factors of poor psychosocial outcomes
 - d. the need to improve psychosocial care
2. Evidence for psychosocial clinical guidelines was accumulated mostly by:
 - a. conducting randomised clinical trials
 - b. conducting focus groups
 - c. conducting systematic reviews of the literature
 - d. conducting expert groups that led to consensus
3. Depressive mood is a risk for what percentage of adults with SCI living in the community:
 - a. Almost all people with SCI are at risk of developing depressive mood
 - b. 20 to 40% of people with SCI are at risk of developing depressive mood
 - c. 10-20% of people with SCI are at risk of developing depressive mood
 - d. None of the above
4. Evidence suggests the majority of people with SCI:
 - a. are at risk of suicide or at least, self-harm behaviour
 - b. will never return to work at all
 - c. become seriously fatigued and anxious
 - d. adjust well to the injury and show resilience to the associated impairment
5. Which of the following is not a common secondary condition for adults with SCI:
 - a. chronic pain
 - b. sleep disturbance
 - c. urinary and respiratory infections
 - d. cancer of the stomach
6. The most appropriate model of care for people with SCI is:
 - a. the biomedical model
 - b. the cognitive-behavioural model
 - c. the biopsychosocial model
 - d. an integration of the biopsychosocial and cognitive models

Answers: 1: a, 2: c, 3: b, 4: d, 5: d, 6: c

9. REFERENCE

1. Alexander, C. J., Sipski, M. L., & Findley, T. W. (1993). Sexual activities, desire, and satisfaction in males pre- and post-spinal cord injury. *Archives Sexual Behavior, 22*, 217-228
2. American Association of Spinal Cord Injury Psychologists and Social Workers (AASCIPSW) (1995). *Standards for psychologists and social workers in SCI rehabilitation (2nd Edition)*. AASCIPSW.
3. Australasian Faculty of Rehabilitation Medicine (2005) *Standards 2005: Adult Rehabilitation Medicine Services in Public and Private Hospitals*. Sydney: Australasian Faculty of Rehabilitation Medicine.
4. Australian Psychological Society Working Group of the Directorate of Professional Issues (2006) *Psychology and Rehabilitation in the Health Sector: Its Role and Contribution*. Melbourne: APS.
5. Barat, M., Dehail, P., & de Seze, M. (2006). Fatigue after spinal cord injury. *Annales de Réadaptation et de Médecine Physique, 49*, 365–369.
6. Barnes, M., & Marcus, C. C. (1999). *Healing Gardens: Therapeutic Benefits and Design Recommendations*. New York: John Wiley & Sons, Inc.
7. Biering-Sorensen, F., & Sonksen, J. (2001). Sexual function in spinal cord lesioned men. *Spinal Cord, 39*, 455-70.
8. Bonanno, G. A., Kennedy, P., Galatzer-Levy, I. R., Lude, P., & Elfström, M. L. (2012). Trajectories of Resilience, Depression, and Anxiety Following Spinal Cord Injury. *Rehabilitation Psychology, 57*, 236–247.
9. Buckelew, S. P., Frank, R. G., Elliott, T. R., Chaney, J., & Hewett, J. (1991). Adjustment to spinal cord injury: stage theory revisited. *Paraplegia, 29*, 125-130.
10. Bunker, S. J., et al., (2003). Stress and coronary heart disease: psychosocial risk factors. *Medical Journal of Australia, 178*, 272-276.
11. Chung, M. C., Preveza, E., Papandreou, K., & Prevezas, N. (2006). The relationship between post-traumatic stress disorder following spinal cord injury and locus of control. *Journal of Affective Disorders, 93*, 229-232.
12. Consortium for Spinal Cord Medicine (1998) *Depression following Spinal Cord Injury: A clinical practice guideline for primary care physicians*. Washington DC: Paralyzed Veterans of America.
13. Consumer Involvement Work Group (2006). *Report of the Consumer Involvement Work Group*. http://pathprogram.samhsa.gov/pdf/ConsumerWorkgroupReport_706.pdf (Accessed November 2013).
14. Corden, A. (2000). Smoothing the path from incapacity benefits to work: Introducing incentives and reducing disincentives within UK social security arrangements. *The Year 2000. International Research Conference on Social Security*. Helsinki, 25-27 September 2000. <http://www.issa.int/pdf/helsinki2000/topic2/2corden.pdf> (Accessed November 2013).
15. Cotter, I. (2008). Cognitive impairment following SCI: Implications for rehabilitation (p.175-195). In A. Craig and Y. Tran (Eds.). *Psychological dynamics associated with spinal cord injury rehabilitation: New directions and best evidence*. New York: Nova Science Publishers.
16. Craig, A. (2012). Resilience in people with physical disabilities (Ch. 26). In P. Kennedy (Ed.). *The Oxford Handbook of Rehabilitation Psychology*. New York: Oxford University Press, 474-491.
17. Craig, A. R., Hancock, K., & Chang, E. (1994a). The influence of spinal cord injury on coping styles and self-perceptions two years after the event. *Australian and New Zealand Journal of Psychiatry, 28*, 307-312.
18. Craig, A. R., Hancock, K. M., & Dickson, H. G. (1994). A longitudinal investigation into anxiety and depression in the first 2 years following a spinal cord injury. *Paraplegia, 32*, 675-679.

19. Craig, A., Hancock, K., & Dickson, H. (1999). Improving the long-term adjustment of spinal cord injured persons. *Spinal Cord*, 37, 345-350.
20. Craig, A. R., Hancock, K. M., & Dickson, H. G. (1994). Spinal cord injury: A search for determinants of depression two years after the event. *British Journal of Clinical Psychology*, 33, 221-230
21. Craig, A. R., Hancock, K. M., Chang, E., & Dickson, H. G., (1998). Immunizing against depression and anxiety following spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, 79, 375-377.
22. Craig, A., Hancock, K., Chang, E., & Dickson, H. (1998). The effectiveness of group psychological intervention in enhancing perceptions of control following spinal cord injury. *Australian New Zealand Journal of Psychiatry*, 32, 112-118.
23. Craig, A. R., Hancock, K., Dickson, H., & Chang, E. (1997). Long-term psychological outcomes in spinal cord injured persons: Results of a controlled trial using cognitive behaviour therapy. *Archives of Physical Medicine and Rehabilitation*, 78, 33-38.
24. Craig, A., Tran, Y., & Middleton, J. (2009). Psychological morbidity and spinal cord injury: a systematic review. *Spinal Cord*, 47, 108-114.
25. Craig, A., Tran, Y., Siddall, P., Wijesuriya, N., Lovas, L., Bartrop, R., & Middleton, J. (2013). Developing a model of associations between chronic pain, depressive mood, chronic fatigue and self-efficacy in people with spinal cord injury. *The Journal of Pain*, 14, 911-920. DOI: 10.1016/j.jpain.2013.03.002
26. Craig, A., Tran, Y., Wijesuriya, N., & Middleton, J. (2012). Fatigue and tiredness in people with spinal cord injury. *Journal of Psychosomatic Research*, 73, 205-210.
27. Craig, A., Wijesuriya, N., & Tran, Y. (2013). The influence of self-efficacy on mood states in people with spinal cord injury. *ISRN Rehabilitation*, vol. 2013, 1-6.
28. Cripps, R. A. (2006). *Spinal cord injury, 2004-2005*. Canberra: Australian Institute of Health and Welfare.
29. Cushman, L. A., & Dijkers, M. P. (1990). Depressed mood in spinal cord injured patients: Staff perceptions and patient realities. *Archives of Physical Medicine and Rehabilitation*, 71, 191-196.
30. Darouiche, R. O. (2010). Infection and spinal cord injury (p. 263-269). In Vernon W. Lin (Ed.) *Spinal cord medicine. Principles and practice*. New York: Demos medical Publishing.
31. Davidoff, G. N., Roth, E. J., & Richards, J. S. (1992). Cognitive deficits in spinal cord injury: Epidemiology and outcome. *Archives of Physical Medicine and Rehabilitation*, 73, 275-284.
32. Davidson, K. W., Rieckmann, N., & Rapp, M. A. (2005). Definitions and distinctions among depressive syndromes and symptoms: Implications for a better understanding of the depression-cardiovascular disease association. *Psychosomatic Medicine*, 67, Supplement 1:S6-S9.
33. Department of Health (2001). *The expert patient: A new approach to chronic disease management for the 21st Century*. http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyandGuidance/DH_4006801 (Accessed Jan 2014).
34. Dezarnaulds, A., & Ilchef, R. (2013). *Psychological adjustment after spinal cord injury. Useful strategies for health professionals (Second Edition)*. Sydney: Motor Accidents Authority.
35. DeVivo, M. J., Black, K. J., Richards, S. & Stover, S. L. (1991). Suicide following spinal cord injury. *Paraplegia*, 29, 620-627.
36. Dorstyn, D., Mathias, J., & Denson, L. (2010). Efficacy of cognitive behavior therapy for the management of psychological outcomes following spinal cord injury. A meta-analysis *Journal of Health Psychology*, 20, 1-18.
37. Dreer, L. E., Elliott, T. R., Shewchuk, R., Berry, J. W., & Rivera, P. (2007). Family caregivers of persons with spinal cord injury: Predicting caregivers at risk for probable depression. *Rehabilitation Psychology*, 52, 351-357.
38. Dryden, D. M., Duncan Saunders, L., Rowe, B. H., May, L. A., Yiannakoulis, N., Svenson, L. W., et al., (2005). Depression following Traumatic Spinal Cord Injury. *Neuroepidemiology*, 25, 55-61.
39. Duchnick, J. J., Letsch, E. A., & Curtiss, G. (2009). Coping effectiveness training during acute rehabilitation of spinal cord injury/dysfunction: A randomized clinical trial. *Rehabilitation Psychology*, 54, 123-132.

40. Elliott, T. R., & Kennedy, P. (2004). Treatment of depression following spinal cord injury: An evidence-based review. *Rehabilitation Psychology*, 49, 134-139.
41. Epstein, L. J., & Brown, R. (2010). Sleep disorders in spinal cord injury (p.230-240). In Vernon W. Lin (Ed.) *Spinal cord medicine. Principles and practice*. New York: Demos Medical Publishing.
42. Ernst, F. A. (1987). Contrasting perceptions of distress by research personnel and their spinal cord injured subjects. *American Journal of Physical Medicine*, 66, 12-15.
43. Fann, R., Bombardier, C. H., Richards, J. S, Tate, D. G., Wilson, C. S., & Temkin, N. (2011). Depression after spinal cord injury: Comorbidities, mental Health service use, and adequacy of treatment. *Archives Physical Medicine Rehabilitation*, 92, 352-360.
44. Fisher, T. L., Laud, P. W., Byfield, M. G., Brown, T. T., Matthew J., Hayat, M. J., & Fiedler, I. J. (2002). Sexual health after Spinal Cord Injury: A longitudinal study. *Archives of Physical Medicine and Rehabilitation*, 83, 1043-1051.
45. Flinders Human Behaviour & Health Research Unit (2006). The 'Flinders Model' of Chronic Condition Self-Management Information Paper. Adelaide: Flinders University
46. Gentilello, L. M., Rivara, F. P., Donovan, D. M., Jurkovich, G. J., Daranciang, E., Dunn, C. W., Villaveces, A., Copass, M., & Ries, R.R. (1999). Alcohol interventions in a trauma center as a means of reducing the risk of injury recurrence. *Annals of Surgery*, 230, 473-80.
47. Gething, L., Fethney, J., Jonas, A., Moss, N., Croft, T., Ashenden, C., & Cahill, L. (2002). Life after injury: Quality of life issues for people with traumatically-acquired brain injury. Report. Sydney: Research Centre for Adaptation in Health and Illness, USyd. <http://trove.nla.gov.au/people/1309351?c=people> (Accessed Nov 2013).
48. Geyh, S., Nick, E., Stirnimann, D., Ehrat, S., Müller, R., & Michel, F. (2012). Biopsychosocial outcomes in individuals with and without spinal cord injury: a Swiss comparative study. *Spinal Cord*, 50, 614-622.
49. Haran, M. J., Lee, B. B., King, M. T., Marial, O., & Stockler, M. R. (2005). Health status rated with the Medical Outcomes Study 36-Item Short-Form Health Survey after spinal cord injury. *Archives Physical Medicine Rehabilitation*, 86, 2290-2295.
50. Heinemann, A. W., Doll, M. D., Armstrong, K. J., Schnoll, S., & Yarkony, G. M. (1991). Substance use and receipt of treatment by persons with long-term spinal cord injuries. *Archives of Physical Medicine and Rehabilitation*, 72, 482-487.
51. Heutink, M., Post, M. W. M., Bongers-Janssen, H. M. H., Dijkstra, C. A., Snoek, G. J., Spijkerman, D. C. M., & Lindeman, E. (2012). The CONECISI trial: Results of a randomized controlled trial of a multidisciplinary cognitive behavioral program for coping with chronic neuropathic pain after spinal cord injury. *Pain*, 153, 120–128.
52. Johnson, R. L., Gerhart, K. A., McCray, J., Menconi, J. C., & Whiteneck, G. G. (1998). Secondary conditions following spinal cord injury in a population-based sample. *Spinal Cord*, 36, 45-50.
53. Judd, F. K., & Brown, D. J. (1992). Suicide following acute traumatic spinal cord injury. *Paraplegia*, 30, 173-177.
54. Judd, F. K., Stone, J., Webber, J., Brown, D. & Burrows, J. D. (1989). Depression following spinal cord injury: A prospective in-patient study. *British Journal of Psychiatry*, 154, 668-671.
55. Kemp, B. J., Kahan, J. S., Krause, J. S., Adkins, R. H., & Nava, G. (2003). Treatment of major depression in individuals with spinal cord injury. *The Journal of Spinal Cord Medicine*, 27, 22-28.
56. Kendall, E., & Buys, N. (1998). An integrated model of psychosocial adjustment following acquired disability. *Journal of Rehabilitation*, 64, 16-21.
57. Kennedy, P. (2006). Keyworker training. Goal planning and the needs assessment checklist (NAC). National Spinal Injuries Centre, Stoke Mandeville Hospital.
58. Kennedy, P., Duff, J., Evans, M. & Beedie, A. (2003). Coping effectiveness training reduces depression and anxiety following traumatic spinal cord injuries. *British Journal of Clinical Psychology*, 42, 41-52.
59. Kennedy, P., & Evans, M. J. (2001). Evaluation of post traumatic distress in the first 6 months following SCI. *Spinal Cord*, 39, 381-386.
60. Kennedy, P., Fisher, K., & Pearson, E. (1988). Ecological evaluation of a rehabilitative environment for spinal cord injured people: Behavioural mapping and feedback. *British Journal of Clinical Psychology*, 27, 239-246.

61. Kennedy, P., Lude, P., & Taylor, N. (2006). Quality of life, social participation, appraisals and coping post spinal cord injury: a review of four community samples. *Spinal Cord*, 44, 95-105.
62. Kennedy, P., Marsh, N., Lowe, R., Grey, N., Short, E., & Rogers, B. (2000). A longitudinal analysis of psychological impact and coping strategies following spinal cord injury. *British Journal of Health Psychology*, 5, 157-172.
63. Kennedy, P., & Rogers, B. (2000). Anxiety and depression after spinal cord injury: A longitudinal analysis. *Archives of Physical Medicine and Rehabilitation*, 81, 932-937.
64. Kielhofner, G. (2002). *A Model of Human Occupation: Theory and Application*. New York: Lippincott Williams & Wilkins (3rd edition).
65. Krause, J. S. (2007). Self-reported problems after spinal cord injury: Implications for rehabilitation practice. *Topics in Spinal Cord Injury Rehabilitation*, 12, 35-44.
66. Krueger, H., Noonan, V. K., Williams, D., Trenaman, L. M., & Rivers, C. S. (2013). The influence of depression on physical complications in spinal cord injury: behavioral mechanisms and health-care implications. *Spinal Cord*, 51, 260-266.
67. Kubler-Ross, E. (1969). *On death and dying*. New York: MacMillon.
68. Kuo, F. E. (2002) Horticulture, Well-Being and Mental Health: From Intuitions to Evidence in Relf, D. (Ed.) *Proceedings of the XXVI International Horticultural Congress, Toronto, Canada 11-17 August, 2002: Expanding Roles for Horticulture in Improving Human Well-Being and Life Quality* . Leiden: ISHS, 27-34.
69. Lazarus, R., & Folkman, S. (1984). *Stress appraisal and coping*. New York: Springer.
70. Lidal, I. B., Huynh, T. K., & Biering-Sorensen, F. (2007). Return to work following spinal cord injury: a review. *Disability and Rehabilitation*, 29, 1341-1375.
71. Lorig K R, Mazonson P D & Holman H R (1993). Evidence suggesting that health education for self-management in patients with chronic arthritis has sustained health benefits while reducing health care costs. *Arthritis and Rheumatism*, 36, 439-46.
72. Matthew, K. M., Ravichandran, G., May, K., & Morsley, K. (2001). The biopsychosocial model and spinal cord injury. *Spinal Cord*, 39, 644-649.
73. Mehta, S., Aubut, J-A. L., Legassic, M., Orenczuk, S., Hansen, K. T., Hitzig, S. L., & Teasell, R. W. (2011). An evidence-based review of the effectiveness of cognitive behavioral therapy for psychosocial issues post-spinal cord injury. *Rehabilitation Psychology*, 56, 15-25.
74. Middleton, J., & Craig, A. (2008). Psychological challenges in treating persons with spinal cord injury. In A. Craig and Y. Tran (Eds.). *Psychological dynamics associated with spinal cord injury rehabilitation: New directions and best evidence*. New York: Nova Science Publishers.
75. Middleton, J. W., Dayton, A., Walsh, J., Rutkowski, S. B., Leong, G., & Duong, S. (2012). Life expectancy after spinal cord injury: a 50-year study. *Spinal Cord*, 50, 803-811.
76. Middleton, J., Tran, Y., & Craig, A. (2007). Relationship between quality of life and self-efficacy in persons with spinal cord injuries. *Archives of Physical Medicine and Rehabilitation*, 88, 1643-1648.
77. Migliorini, C., Tonge, B., & Taleporos, G. (2008). Spinal cord injury and mental health. *Australian and New Zealand Journal of Psychiatry*, 42, 309-314.
78. Motor Accident Authority (2006). *Neuropsychological assessment of adults with moderate to extremely severe traumatic brain injury. Guidelines for the NSW CTP scheme 2006*. Sydney: Motor Accident Authority. Available from the MAA website at www.maa.nsw.gov.au (Accessed November 2013).
79. Murphy, G. C., & A. E. Young. (2008). Vocational achievement following traumatic spinal cord injury. In A. Craig and Y. Tran (Eds.). *Psychological dynamics associated with spinal cord injury rehabilitation: New directions and best evidence*. New York: Nova Science Publishers.
80. Murphy, G. C., Young, A. E., Brown, D. J., & King, N. J. (2003). Explaining labor force status following spinal cord injury: The contribution of psychological variables. *Journal of Rehabilitation Medicine*, 35, 276-283.
81. National Breast Cancer Centre and the National Cancer Control Initiative (2003). *Clinical practice guidelines for the psychosocial care of adults with cancer*. National Breast Cancer Centre, Camperdown, NSW.

82. National Health Service, Department of Health Publication(2001). The expert patient: A new approach to chronic disease management for the 21st Century. http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyandGuidance/DH_4006801 (Accessed Nov 2013).
83. Nelson-Jones, R. (2005). Practical counseling and helping skills. Text and exercises for the lifeskills counseling model (5th Edition). London: Sage Publications Ltd.
84. NSW Health (2005) Framework for Suicide Risk Assessment and Management for NSW Health. Sydney: NSW Health. Available from http://www0.health.nsw.gov.au/pubs/2005/suicide_risk.html (Accessed Nov 2013).
85. Nicholson Perry, K., Middleton, J., Siddall, P., & Nicholas, M. (2008) The problem of pain and its management in A. Craig and Y. Tran (Eds.). Psychological dynamics associated with spinal cord injury rehabilitation: New directions and best evidence. New York: Nova Science Publishers.
86. Nicholson Perry, K., Nicholas, M., & Middleton, J. (2010). Comparison of a pain management program with usual care in a pain management center for people with spinal cord injury-related chronic pain. *The Clinical Journal of Pain*, 26, 206-216.
87. Norrbrink Budh, C., Hultling, C., & Lundeberg, T. (2005). Quality of sleep in individuals with spinal cord injury: a comparison between patients with and without pain. *Spinal Cord*, 43, 85-95.
88. North, N. T. (1999). The psychological effects of spinal cord injury: a review. *Spinal Cord*, 37, 671-679.
89. NSW State Spinal Cord Injury Service (2006). Psychosocial forum report. Sydney: NSW SSCIS.
90. O'Connor, P. J. (2005). Prevalence of spinal cord injury in Australia. *Spinal Cord*, 43, 42-46.
91. O'Connor, P. J. (2006). Trends in spinal cord injury. *Accident Analysis and Prevention*, 38, 71-77.
92. Phillips, W. T., Kiratli, B. J., Sarkarati, M., Weraarchakul, G., Myers, J., Franklin, B. A., et al., (1998). Effect of spinal cord injury on the heart and cardiovascular fitness. *Current Problems Cardiology*, 23, 641-716.
93. Pollard, C., & Kennedy, P. (2007). A longitudinal analysis of emotional impact, coping strategies and post-traumatic psychological growth following spinal cord injury: A 10-year review. *British Journal of Health Psychology*, 12, 347-362.
94. Prochaska, J. O., Velicer, W. F., Rossi, J. S., Goldstein, M. G., Marcus, B. H., Rakowski, W., et al., (1994). Stages of change and decisional balance for 12 problem behaviours. *Health Psychology*, 13, 39-46.
95. Richards, J. S., Meredith, R. L., Nepomuceno, C., Fine, P. R., & Bennett, G. (1980). Psycho-social aspects of chronic pain in spinal cord injury. *Pain*, 8, 355-366.
96. Sabharwal, S. (2010). Cardiovascular dysfunction in spinal cord disorders (p.241-255). In Vernon W. Lin (Ed.) *Spinal cord medicine. Principles and practice*. New York: Demos Medical Publishing.
97. Shakespeare, T., & Watson, N. (1997). Defending the Social Model. *Disability & Society*, 12, 293-300.
98. Siddall, P. J., & Loeser, J. D. (2001). Pain following spinal cord injury. *Spinal Cord*, 39, 63-73.
99. Siddall, P. J. & J. W. Middleton (2006). A proposed algorithm for the management of pain following spinal cord injury. *Spinal Cord* 44: 67-77.
100. Sipski, M. L., & Alexander, C. J. (1993). Sexual activities, response and satisfaction in women pre and post spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, 74, 1025-1029.
101. Soden, R. J., Walsh, J., Middleton, J. W., Craven, M. L., Rutkowski, S. B., & Yeo, J. D. (2000). Causes of death after spinal cord injury. *Spinal Cord*, 38, 604-610.
102. Sommer, J. L., & Witkiewicz, P. M. (2004). The therapeutic challenges of dual diagnosis: Traumatic brain injury/spinal cord injury. *Brain Injury*, 18, 1297-1308.
103. Stanford, R. E., Soden, R., Bartrop, R., Mikk, M., & Taylor, T. K. F. (2007). Spinal cord and related injuries after attempted suicide: psychiatric diagnosis and long-term follow-up. *Spinal Cord*, 45, 437-443.
104. Strauss, D. J., DeVivo, M. J., Paculdo, D. R., & Shavelle, R. M. (2006). Trends in life expectancy after spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, 87, 1079-1085

105. TAFE NSW Western Sydney Institute. (2005). SpinalWorks: The coordination of vocational education and training programs for people with recent spinal cord injury. Sydney: TAFE. <http://www.voced.edu.au/content/ngv20478> (Accessed November 2013).
106. Tang, N. K. Y. & C. Crane (2006). Suicidality in chronic pain: a review of the prevalence, risk factors and psychological links. *Psychological Medicine*, 36, 575-86.
107. Tate, D., Forchheimer, M., Maynard, F., & Dijkers, M. (1994). Predicting depression and psychological distress in persons with spinal cord injury based on indicators of handicap. *Archives of Physical Medicine and Rehabilitation*, 73, 175-183.
108. Turner, J. A., Jensen, M. P., Warms, C. A., & Cardenas, D. D. (2002). Catastrophizing is associated with pain intensity, psychological distress, and pain-related disability among individuals with chronic pain after spinal cord injury. *Pain*, 98, 127-134.
109. Trieschmann, R. B. (1982). *Spinal cord injuries. Psychological, social and vocational adjustment*. New York: Pergamon Press.
110. Ullrich, P. M., Smith, B. M., Poggensee, L., Evans, C. T., Stroupe, K. T., Weaver, F. M., & Burns, S. P. (2013). Pain and post-traumatic stress disorder symptoms during inpatient rehabilitation among operation enduring freedom/ operation Iraqi freedom veterans with spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, 94, 80-85.
111. Unalan, H., Gencosmanoglu, B., Akgun, K., Karamehmetoglu, S., Tuna, H., Ones, K., et al., (2001). Quality of life of primary caregivers of spinal cord injury survivors living in the community: controlled study with the short form-36 questionnaire. *Spinal Cord*, 39, 318-322.
112. Vogel, L. C., Klass, S. J., Lubicky, J. P., & Anderson, C. J. (1998). Long-term outcomes and life satisfaction of adults who had pediatric spinal cord injuries. *Archives of Physical Medicine and Rehabilitation*, 79, 1496-1503.
113. Weitzenkamp, D. A., Gerhart, K. A., Charlifue, S. W., Whiteneck, G. G., & Savic, G. (1997). Spouses of spinal cord injury survivors: the added impact of caregiving. *Archives Physical Medicine Rehabilitation*, 78, 822-827.
114. Widerstrom-Noga, E. G., Duncan, R., Felipe-Cuervo, E., & Turk, D. (2002). Assessment of the impact of pain and impairments associated with spinal cord injuries. *Archives of Physical Medicine and Rehabilitation*, 83, 395-404.
115. Widerström-Noga, E.G., Felipe-Cuervo, E., & Yeziarski, R.P. (2001). Chronic pain after spinal injury: interference with sleep and daily activities. *Archives Physical Medicine and Rehabilitation*, 82, 1571-1577.
116. Wijesuriya, N., Tran, Y., Middleton, J., & Craig, A. (2012). The impact of fatigue on the health related quality of life in persons with spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, 93, 319-324.
117. World Health Organisation (2004) *A glossary of terms for community health care and services for older personnel*. World Health Organisation Centre for Development, Ageing and Health Technical Report, Vol 5. Geneva: World Health Organisation.
118. Wyndaele, M., & Wyndaele, J. J. (2006). Incidence, prevalence and epidemiology of spinal cord injury: what learns a worldwide literature survey? *Spinal Cord*, 44, 523-508.

