Guidance

on the support needs of adults with spinal cord injury

icare™

Guidance on the support needs for adults with spinal cord injury

You may copy, distribute, display and otherwise freely deal with this work for any purpose, provided that you attribute the icare (Insurance & Care NSW) as the owner. However, you must obtain permission if your wish to (1) charge others for access to the work (other than at cost), (2) include the work in advertising or a product for sale, or (3) modify the work.

ISBN: 978-0-9953850-2-3

Suggested citation:

icare (Insurance and Care NSW) (2017), Guidance on the support needs for adults with spinal cord injury (3rd Ed). Lukersmith, Sue (ed), Sydney, Australia.

For further copies:

Download from icare www.icare.nsw.gov.au/treatment-and-care/what-we-do/guidelines-and-policies

or email enquiries.lifetimecare@icare.nsw.gov.au or wisupport@icare.nsw.gov.au

or phone 1300 738 586

The Guidance is to be reviewed in 2027.

Guidance on the support needs of adults with spinal cord injury

Members of the working party for the Guidance

Name	Position	Organisation / region
Andrew Dowling	Service user representative Tertiary student	Urban Sydney, NSW, Urban
Ann Thompson	Senior Occupational Therapist Care needs assessor	Royal Rehabilitation Hospital Spinal, Unit Urban
Anne Willey	Senior Occupational Therapist	NSW Spinal Outreach Service, Urban and regional
Barbara Merran	Attendant Care Industry Association (ACIA) representative	Attendant care provider Southern Cross Community Healthcare, NSW, Urban and regional
Bronwyn Nagle	Senior Occupational Therapist Care needs assessor	Work Right Consulting Regional and rural, NSW
Danielle Bennet	ACIA President	Attendant care provider All About Caring Urban and regional, NSW
Greg Dubois	Service user Tertiary student	Sydney, NSW Urban
Jacqueline Scott	Service Development and Review Officer Occupational therapy background	icare lifetime care, NSW
Jayme Langfield	Service user Farm owner/manager	Regional and rural, NSW
Jeff Tonge	Service Development and Review Officer Rehabilitation Counsellor background	icare lifetime care Attendant Care Unit, NSW
Krishna Nair	Senior coordinator Occupational therapy background	icare lifetime care, NSW
Lauren Alach	Senior Occupational Therapist Care needs assessor	Private Practice, Sydney Urban
Lisa Harvey	Physiotherapist and academic, PhD	John Walsh Centre for Rehabilitation Research, University of Sydney
Margot Lilley	Senior Occupational Therapist Care needs assessor	Occupational Therapy Australia (OTA)
Megan McDonald	Service Development and Review Officer Social worker background	icare lifetime care, NSW Workers Care
Suzanne Lulham	General Manager - Service Delivery	icare lifetime care, NSW
Tony Jones	Service user representative	Spinal Cord Injuries Australia, NSW Urban and rural
Tessa Irwin	Senior Occupational Therapist	Prince of Wales Hospital Spinal Unit, NSW Urban
Yvette Mair	Clinical Nurse Consultant	Royal North Shore Hospital Spinal Unit, NSW Urban
Alex Tapia-Fabres, Heather Cameron	Carer Support worker	Representatives of carers (Casual attendance at working party)
Sue Lukersmith	Researcher Guideline methodologist and Developer	Project lead, research, author & editor

Conflict of interest

icare lifetime care (Insurance and Care) funded the development of this guidance. An independent guideline methodologist and developer (Sue Lukersmith) was contracted as project lead to develop the methods, undertake the research, facilitate the working party and nominal group methods, write the draft and finalise the guidance. icare staff reviewed the draft and provided feedback for consideration along with other national and international peer reviewers.

Working party participants were required to declare any conflict of interest. Signed declarations were collected at the first working party meeting (refer to the separate *Technical report to the guidance on the support needs of adults with spinal cord injury* for the conflict of interest explanation and statement). The affiliation (as an employee) of icare staff involved in the working party was declared. There were no financial conflicts or competing institutional interests which could influence or compete with the consensus of the working party.

The working party members did not receive any remuneration from icare for their time. Some working party members were employed by organisations (e.g. government, consumer representative organisation) and so were paid by that organisation for their time. Working party members who were self-employed, icare lifetime care participants, professional association representative or carer representatives were not funded for their time. Some working party members were refunded travel expenses. No working party member declared any other private, financial or other professional interest that could be, or be perceived to be, a potential conflict in their role as a member of the working party.

icare is not a provider of support services and there is no cost to access the guidance which is freely available on the internet.

Acknowledgements

The working party members were involved in identifying appropriately qualified peer reviewers. icare and Sue wish to thank the nine people from Australia and internationally who kindly gave of their time and reviewed the guidance during its development. They are listed in Appendix 1.

Contents

Foreword	7
1. Executive summary	8
2. Background	9
3. Aim and scope of this guidance	10
4. Population and health condition	10
5. Intended users	10
6. Use of the guidance	11
7. Guidance development	12
8. Support workers and carers explained	12
8.1 Who is the carer	13
8.2 Who is a support worker	15
9. Choice and control for the person with spinal cord injury	16
9.1 Receiving assistance from support workers	16
10. Making decisions on the need for support	17
11. Assistive technology (equipment and products)	20
11.1 Disposable items lists	21
11.1.1 Disposable items for no motor function below C1-C3	21
11.1.2 Respiratory disposables for C1-C3 ventilator dependent	22
11.1.3 C4 to S5 skin, bowel and bladder management disposable items	23
12. Levels of support and assistive technology	24
12.1 No motor function below the level of spinal cord injury	26
12.1.1 Level of support: Cervical 1–3 (C1–C3) no motor function below	26
Assistive technology C1–3 - no motor function below	27
12.1.2 Level of support: Cervical 4 (C4) no motor function below	28
Assistive technology C4 - no motor function below	29
12.1.3 Level of support: Cervical 5 (C5) no motor function below	30
Assistive technology C5 - no motor function below	31
12.1.4 Level of support: Cervical 6 (C6) no motor function below	32
Assistive technology C6 - no motor function below	33

Contents

12.1.5 Level of support: Cervical 7–8 (C7–C8) no motor function below 34

Assistive technology C7–8 - no motor function below 35

12.1.6 Level of support: Thoracic 1–4 (T1–T4) no motor function below 36

Assistive technology T1–T4 - no motor function below 37

12.1.7 Level of support: Thoracic 5–9 (T5–T9) no motor function below 38

Assistive technology T5–T9 - no motor function below 39

12.1.8 Level of support: Thoracic 10 to lumbar 1 (T10–L1) no motor function below 40

Assistive technology T10–L1 - no motor function below 41

12.1.9 Level of support: Lumbar 2 to sacral 5 (L2–S5) no motor function below 42

Assistive technology L2–S5 - no motor function below 43

12.2 Some motor function below the level of spinal cord injury 44

12.2.1 Cervical level some motor function below 44

Level of support: Cervical spine some motor function below 45

Assistive technology: C1–C5 some motor function below - non–walker 51

Assistive technology: C6–C8 some motor function below - non–walker 51

Level of support: Cervical spine some motor function below - household walker 52

Assistive technology: C1–C5 some motor function below - household walker 58

Assistive technology: C6–C8 some motor function below - household walker 58

Level of support: Cervical spine some motor function below - community walker 59

Assistive technology: C1–C5 some motor function below - community walker 65

Assistive technology: C6–C8 some motor function below - community walker 65

12.2.2 Thoracic to sacral level some motor function below 66

Assistive technology: Thoracic to sacral some motor function below - non–walker 66

Level of support: Thoracic to sacral some motor function below - non–walker 67

Level of support: Thoracic to sacral some motor function below - household walker 68

Assistive technology: Thoracic to sacral some motor function below - household walker 69

Level of support: Thoracic to sacral some motor function below - community walker 70

Assistive technology: Thoracic to sacral some motor function below - community walker 71

Contents

13. Practical matters to consider	72
13.1 Benchmarks	72
13.2 Coordination of supports	72
13.3 Communicationa and relationships	72
13.4 Emergency preparation	73
13.5 Overnight assistance from a support worker	73
13.6 Support worker and service provider elements	74
13.7 Qualifications and training of support workers	75
13.8 Work health and safety	76
13.9 Self-management of support workers	76
14. Glossary	78
15. Abbreviations	81
16. Resources	82
Guidance on the support needs of adults with spinal cord injury and information for the person with spinal cord injury and their family	82
Assistive Technology Maintenance Checklist	83
World Health Organization Quality of Life - BREF	84
Modified Caregiver Strain Index	85
17. Appendices	87
Appendix 1. List of external peer reviewers	87
Appendix 2. Overview of the methods used to develop the guidance	88
References	89

Foreword

We all need assistance with our day-to-day activities and life roles whether it is at home, when studying or training, at work, or for social and community activities. All of us have support from other people whether they are paid or not paid. It might be your family or partner, a neighbour or friend who does something to support you regularly or just every now and then. It might be assistance with shopping or giving you a lift in their car. As well, we all have paid workers who support us in our lives. It might be the staff at child care, a home cleaner, gardener or taxi driver. Having the right sort of support, at the right time, is crucial as it enables all of us to get on with life and participate in our community.

A support worker is an individual who is paid to assist a person to perform daily tasks. Support workers are important people in the life of a person with spinal cord injury. Getting the right mix of when, where, how and what the support worker does is critical for the person with spinal cord injury, but also impacts other people in their lives such as families, carers and friends.

The person with spinal cord injury and their family and carers are the experts in their own lives and so must be involved in determining their needs and have opportunities for choice. The guidance promotes a 'whole of person' approach and highlights the need to understand the person, their context and progress, and match the need with the assistance. Sometimes there will need to be compromise because of practical matters but it is important to start from the point of choice and what is most appropriate. The guidance affirms that the person has the right to be, is and should be, central to decisions around support workers.

I commend the guidance to you and encourage its use. As a tool, it provides information and guidance which will benefit all those involved in making decisions about assistance from support workers, including the person with spinal cord injury.

Rosemary Kayess

Director, Human Rights and Disability Project,
Australian Human Rights Centre,
UNSW Law

1. Executive summary

There are many factors to consider when deciding on support needs. The *Guidance on the support needs of adults with spinal cord injury* is a best practice tool to assist with making decisions around why assistance from support workers is needed. A working party of experts representing service users, health professions, providers, service delivery, support workers and researchers, worked with a guideline developer over a 14 month period to develop the guidance. The guidance was developed using adapted guideline methodology in recognition of the complexity of the topic. The guidance draws on the knowledge from the limited research evidence available but also the rich first-hand practical and contextual knowledge of the working party experts.

In this guidance there is a decision-making framework and overview of the factors to consider, information and resources. For the different levels of spinal cord injury (no motor function below and some motor function below the level of injury), there are tables on estimates for the levels of support and lists of assistive technology. Other sections provide definitions; highlight practical matters to consider; screening tools; an information sheet for the person with a spinal cord injury and their family.

2. Background

The *Guidance on the support needs of adults with spinal cord injury* was developed by icare (Insurance & Care NSW). icare is a public financial corporation governed by an independent Board of Directors. icare supports the provision of treatment, rehabilitation and care services to the people of New South Wales (NSW), Australia. One of icare's roles is to support the long-term and lifelong needs (including support workers) of people who have sustained any of the following serious injuries: spinal cord injury, moderate to severe brain injury, multiple or specific unilateral amputations, serious burns, or blindness, whether the injury occurred through a motor vehicle crash or at work. This guidance was developed to assist with determining the support needs of participants in the schemes administered by icare.

This guidance is the third edition of a previous guideline. The previous editions were the *Guidelines for levels of attendant care for people who have spinal cord injury and can claim under the New South Wales Motor Accidents Scheme* released in 2002 and the *Guidelines for levels of attendant care for people with spinal cord injury* released in 2007. This revision aimed to retain what was still relevant and 'fit for purpose', update areas where information is based on research evidence, remove or add information, and use the knowledge from expert practitioners, participants and providers to inform the guidance.

In this document, the term support worker is used to refer to someone who is paid to assist a person with spinal cord injury. Alternative terms commonly used in the literature and practice are attendant care worker, disability worker, personal attendant, aged care worker, community worker, homecare worker, care worker, caregiver, formal caregiver, support provider (the person not service), or paid carer.

3. Aim and scope of this guidance

The aim of this guidance is to inform, guide and assist those involved in making decisions about the need for assistance from support workers for people with *traumatic* spinal cord injury. The guidance provides a decision-making framework based on different sources of knowledge (refer to Figure 1 in Section 10).

Although the physical impact of traumatic spinal cord injury has not significantly changed, assistive technology, services, transport options, and people's lifestyle and personal goals can and do change. Access to appropriate support is crucial to resuming life roles and community participation following severe injury [1-4]. In the past, the determination of support (care) needs for a person with spinal cord injury involved assessment by a health professional, mostly with a focus on body functioning and self-care activities. There was less attention to and understanding of the interaction and influence of personal factors, context, goals and progress on the need for care. Feedback from people with spinal cord injury, the literature and experience at icare have shown it is critical to engage the person with the injury in setting their goals and making decisions, including on their need for assistance from support services.

4. Population and health condition

This guidance was developed with a specific focus on adults with a traumatic spinal cord injury. The definition for adults in this guidance is 16 years and older. The guidance is not intended for use with people who have health conditions other than traumatic spinal cord injury. Co-morbid and secondary conditions (refer to the glossary for definitions) in the context of spinal cord injury are included in the decision-making framework (Figure 1 in Section 10). The guidance may be applicable to non-traumatic spinal cord injury as a consequence of a non-progressive disease process. Some aspects of the guidance (e.g. the decision making framework) may be generalised or adapted for other health conditions affecting the spinal column (e.g. spina bifida); however, other aspects cannot and are specific to spinal cord injury (e.g. assistive technology lists and level of support tables).

5. Intended users

The intended users for the guidance include: people with spinal cord injury and their families and carers; health and rehabilitation professionals (in particular, occupational therapists, physiotherapists, nurses and care needs assessors); service providers; support workers; and funders of support services.

6. Use of the guidance

The guidance is intended to inform and guide the user. The guidance does not replace the need for education, supervision or clinical judgment. The guidance is different from process or procedural guidelines, or guidelines which relate to policy or statutory obligations.

This guidance is to be used to develop an holistic understanding of the person with a spinal injury, through individual assessment and understanding of the person's abilities, goals, living situation and context, personal factors, and progress. Knowledge of all these elements should be considered and discussed with the person when determining the level of support and assistance they need to enable their activities and participation.

Recommendation

Decisions about the need for assistance from support workers for a person with traumatic spinal cord injury should consider knowledge and understanding of the:

- person – goals, body function and structure, activities and participation, and the stage post injury
- person's context – environmental, personal factors, attitudes, beliefs and social norms, supports (informal and formal)
- person's progress – towards their goals, their outcomes, barriers and facilitators in the person's context.

The user should refer to the decision-making framework to guide their practice (Figure 1 in Section 10). Understanding the person, their context and progress will enable best-practice decision-making about their need for support workers.

In the guidance, there are definitions, tools and resources to support the recommended approach and information needed for decision-making. Relevant online resources are provided in boxes throughout the text and Section 16 includes resource tools. However, the guidance does not provide the only, nor all possible, resources and tools that can be used to determine the need for support workers for a person with spinal cord injury.

7. Guidance development

Like a guideline, this document provides guidance and a decision support tool. However, it is not called a guideline. Guidelines usually provide multiple statements on what course of action or actions should be taken and each statement of recommended action is graded. The recommendation and grade are usually based on a single dimension of information, which is the best available clinical research evidence. Given the complexity of this guidance topic, it was not surprising to find that the systematic literature search identified limited clinical research on which to base recommendations. There is limited research on personal assistance generally [5] and spinal cord injury specifically. Although there is only one recommendation in this document (to consider the need to understand the person's context), the guidance includes a significant body of information to inform and guide the user. Rigorous methodology was used to develop the guidance. Refer to Appendix 2 for an overview of the methods and the separate *Technical report to the guidance on the support needs of adults with spinal cord injury* for details.

8. Support workers and carers explained

We all receive informal and formal supports (refer to the glossary for definitions), be it a family member preparing a meal (not paid) or the taxi driver providing transport (paid). Typically, a person with spinal cord injury receives support from a mixture of informal support persons and formal support from support workers [1, 6-9]. There are differences in the proportion of paid and unpaid support depending on the person's needs and their circumstances. Service users and the literature describe some of the factors which may influence the types of supports including:

- funding and household income [7, 10, 11]
- activities of daily living functioning [12]
- key life roles (e.g. work, parenting)
- family structure [10], living alone or with others
- personal factors such as aging, carer/service user outlook, perception of having control and self-efficacy, social supports and information [13-15]
- the accommodation (transition accommodation, in home, out of home, on holidays)
- access within and around the home
- geographic locale and availability of services locally (urban, regional and rural).

Depending on the person's circumstances and needs, there may be other factors that influence the mix of supports required or received.

8.1 Who is the carer

A carer is a person who provides unpaid support and assistance and is generally a family member, spouse or partner, or friend. A carer may also be referred to as an informal support or caregiver. Carers can be adults, young adults (18–25 years) and also children (under 18 years).

Carers play an important role in the lives of many people with a disability. The *NSW Carers (Recognition) Act 2010* enacts a charter which recognises the important role and valuable contribution of carers to the community and to the people they care for [16].

Caring can have a number of positive impacts for carers such as feeling more self-aware and appreciated, and enhanced family cohesiveness [18]. However, caring is also associated with poor health and wellbeing, financial stress and social isolation, especially when formal supports are inadequate. Carers should be given a choice about what care tasks they wish and do not wish to perform; this will differ according to the caring role. Some tasks are more appropriate and sustainable for carers to perform than others (e.g. assistance overnight). At other times, assistance from a support worker might make a significant difference to alleviate carer stress (e.g. by performing a household task).

Negative emotional, psychological and relationship outcomes for carers reported in the literature include greater stress and anxiety; dissatisfaction with life; and decreased choice, control and productivity [17]. Some of the physical outcomes described are fatigue, lack of sleep and ill health [1, 17-22].

Sometimes it can be difficult for a carer to recall exactly how much time they spend in the carer role and they may under-report the time [10], which potentially can add to their stress and fatigue. One study identified that carers can be resilient for the first 12 months [19] and another study suggested psychological distress can decrease over a two-year period as the carer adapts to the challenge of providing support to the person [20]. However, these studies also show that the burden and strain on carer's do not decrease over time. These studies, as well as expert practice and experiential knowledge, confirm the need for early screening and regular review of carer distress and strain (refer to Box 1 for a carer burden screening tool). The circumstances of each person, their family and carers are different. If distress and strain are detected early, strategies to assist the carer should be put in place and, where necessary, treatments commenced (refer to Box 2 for resources for carer support services).

Box 1 Resource - Screening for carer strain

The Modified Caregiver Strain Index (MCSI) is a reliable and valid tool to screen the carers of people with spinal cord injury for carer strain.

The tool, references and explanation can be downloaded from https://consultgeri.org/try-this/general-assessment/issue-14.pdf

OR printed or copied from the Resources section (Section 16) of this guidance.

The tool does not give a breakdown of scores equivalent to low, moderate or high caregiver strain. Professional judgment is needed to evaluate the level of caregiver strain by total score. The tool effectively identifies families who may benefit from more in-depth assessment and follow-up. The higher the score, the greater need for more in-depth assessment.

Note: The Modified Caregiver Strain Index is distributed in its entirety with permission from The Hartford Institute for Geriatric Nursing, New York University, College of Nursing.

8. Support workers and carers explained

A recent systematic review of 62 studies explored the burden on carers and the interventions available to support them [17]. There were few interventions described across the studies. However, there is emerging evidence [1, 17-19, 21, 22] that the following factors assist to improve wellbeing and reduce the burden for carers:

- problem-solving training
- good family functioning
- personal coping skills
- social support
- peer and co-worker support networks
- more paid or professional support
- family and carer training and preparation for treatment and discharge.

Other organisations and websites providing resources include the European Association Working for Carers (www.eurocarers.org/, Carers Canada (www.carerscanada.ca), Carers UK (www.carersuk.org), and Family Carers Ireland (familycarers.ie), among others.

Box 2 Carer support services

There are efforts from various organisations to support and sustain carers in their work.

Carers NSW has developed and facilitates programs and resources such as peer support; carer support groups; phone lines for information, support and counselling; fact sheets; education and training; and mentoring and support programs.

Refer to the Carers NSW website www.carersnsw.org.au/about-us and the wecare website www.carersnsw.org.au/services-and-support/programs-services/wecare

The Australian Government Department of Social Services has developed a **Carer Gateway** which provides information about services and supports available for carers via a website, phone service, service finder and Facebook page.

Refer to the Department of Social Services website www.carergateway.gov.au/

8.2 Who is a Support worker

This guidance uses the revised definitions of support worker and related terms provided by the Attendant Care Industry Association (ACIA) Australia (www.acia.net.au); refer to ACIA Guideline 002 – *Provision of paid support services and nursing in the community* [23]). The definition of support worker is provided below.

The support worker is a paid person within the group of formal (paid) supports (refer to the glossary for definitions) that a person with spinal cord injury may have. A service provider is an organisation or a person who is funded for the delivery of supports and services to the user. The support worker should have access to training, support and advice from the service provider line manager or team leader (or arranged by the person with spinal cord injury if they are self-managing their funds).

Definition of support worker

An individual (paid) to assist or supervise a person to perform tasks of daily living to support and maintain general wellbeing and enable meaningful involvement in social, family and community activities in the person's home and community (ACIA Guideline 002 [23]).

The types of assistance, support or services provided by support workers in a person's home or community include (but are not limited to) (ACIA Guideline 002 [23]):

- personal care or support (e.g. assistance to shower)
- housework or domestic assistance
- transport assistance
- community access
- social support
- nursing services
- clinical supports
- gardening and home maintenance
- palliative care
- respite care.

In this guidance and specifically in the level of support tables in Section 12 (which are based on body functioning), the potential need for support in different health domains is described. The term support worker is used rather than specific terms (e.g. gardener, domestic assistant). Many support workers complete a range of tasks.

9. Choice and control for the person with spinal cord injury

For any person, active involvement in life means having the opportunity to exercise choice, being involved in making decisions about yourself (with the support needed), and accepting the associated responsibilities. Participation and engagement in life and making choices around supports is of itself beneficial to enhance a person's self-awareness, self-identity and adjustment to changed life circumstances. While the person needs information to assist with making decisions and informed choices, they are the expert about themselves and their situation, and should be viewed as such. The *Guidance on the support needs of adults with spinal cord injury and information for the person with spinal cord injury and their family* (refer to the information sheet in Section 16 – Resources) provides a brief outline of this guidance.

Choices might be everyday choices (like what to have for breakfast, showering in the morning rather than evening), lifestyle choices (like whether to go out and see a movie) or pervasive choices (like where to live). The person should also be able to exercise their choice around the provision of assistance from the service provider and support workers, including personal preferences (e.g. gender of carer). The right to choose also means that sometimes a person may elect not to have a support worker or assistance with a specific task. Each of us has the right to take risks and make what others may consider to be an unwise decision. Sometimes there are other factors (such as living in regional or remote areas, service availability, access to services, or the service provider not being able to accommodate all of the person's preferences) which influence opportunities for choice.

Box 3 Resources - icare attendant care providers

icare participants can choose from a list of quality approved service providers who provide support workers in their area.

www.icare.nsw.gov.au/injured-or-ill-people/motor-accident-injuries/attendant-care/find-an-attendant-care-provider

9.1 Receiving assistance from support workers

Box 4 Resources - Information for people with spinal cord injury on living with support workers

Living with attendant care for people with brain injury and spinal cord injury provides information on what it's like having attendant care (support workers) and how to get attendant care right. There are examples and video clips of people describing their experience of having attendant care in Australia.

www.living-with-attendant-care.info/index.html

There are numerous other resources on the experience of living with, using and managing support workers.[1]

[1]DeGraf, A.H. Caregivers and personal assistants: How to find, hire and manage the people who help you (or your loved one!). 3rd edition. 2002, Saratoga Access Publications: Fort Collins, CO.

Rodriguez Banister, K. The personal care attendant guide: The art of finding, keeping, or being one. 2007, Demos Medical Publishing: New York, NY.

Websites with multiple resources, for example, http://sci.washington.edu/info/forums/reports/caregivers-resources.asp#guides

10. Making decisions on the need for support

There are many factors to consider when deciding on the person with spinal cord injury's need for support (bearing in mind support workers are only one type of support). The key considerations include:

Why assistance is needed

- understanding the person
- understanding the person's context
- understanding the person's progress

Matching the need for assistance with the supports such as

- the type of formal and informal supports that exist within the home and community
- whether additional assistive technology is required or would assist
- who, how and when assistance is needed

Consideration of practical matters including

- criteria for funding
- 'when, how and who' will ensure that all the informal and formal supports (including support workers) are integrated and coordinated
- each person's circumstances related to the criteria for funding.

This guidance provides a decision-making framework which gives an overview of the factors to consider when deciding why assistance is needed (refer to Figure 1). Following the framework ensures that the barriers and facilitators in the person's immediate context are considered before matching the need for assistance with the supports. The framework does not provide prompts for considering the practical matters (many of which are discussed later in this guidance). It is crucial to consider the person's performance in their own environment (or familiar environment, e.g. their workplace), rather than their capacity in a standardised test or hospital situation (refer to the glossary for the definitions of capacity and performance).

The decision-making framework is not a linear or stepwise process; it is multi-dimensional. It uses interactive scaffolding to apply best-practice reasoning, and prompts those involved in determining a person's need for support to adopt a person-centred approach and use different sources of knowledge. The sources of knowledge are categorised as:

1. **Narrative:** The person's own descriptions, preferences and point of view; this is so that the individual context can be understood and considered and may include knowledge from the person's family and carers
2. **Evidence:** Current best research evidence, scientific knowledge or established facts, including objective measures of change in individual performance
3. **General reasoning:** Knowledge derived from professional experience; this may include a professional's experience of other patients/clients/participants in similar circumstances
4. **A shared view:** Knowledge derived from thinking and reasoning when the person's immediate and broader circumstances are considered, including feedback from the person's family, carers and range of service providers
5. **Pragmatic reasoning:** Knowledge of practical issues and contextual factors, and whether these influence the ability to achieve the desired outcome.

(Refer to the My Plan *Planning facilitator's manual* [24].)

10. Making decisions on the need for support

There are tools in Sections 9–13 and resources in Section 16 of this guidance to assist in determining the need for support for a person with spinal injury. The guidance and tools are based around two divisions of spinal cord injury (elsewhere typically referred to as complete and incomplete). How spinal cord injury is classified may change. For the purposes of this guidance, the motor level and movement functions are critical to how much support is needed. Thus the following terms are used:

- no motor function below the level
- some motor function below the level.

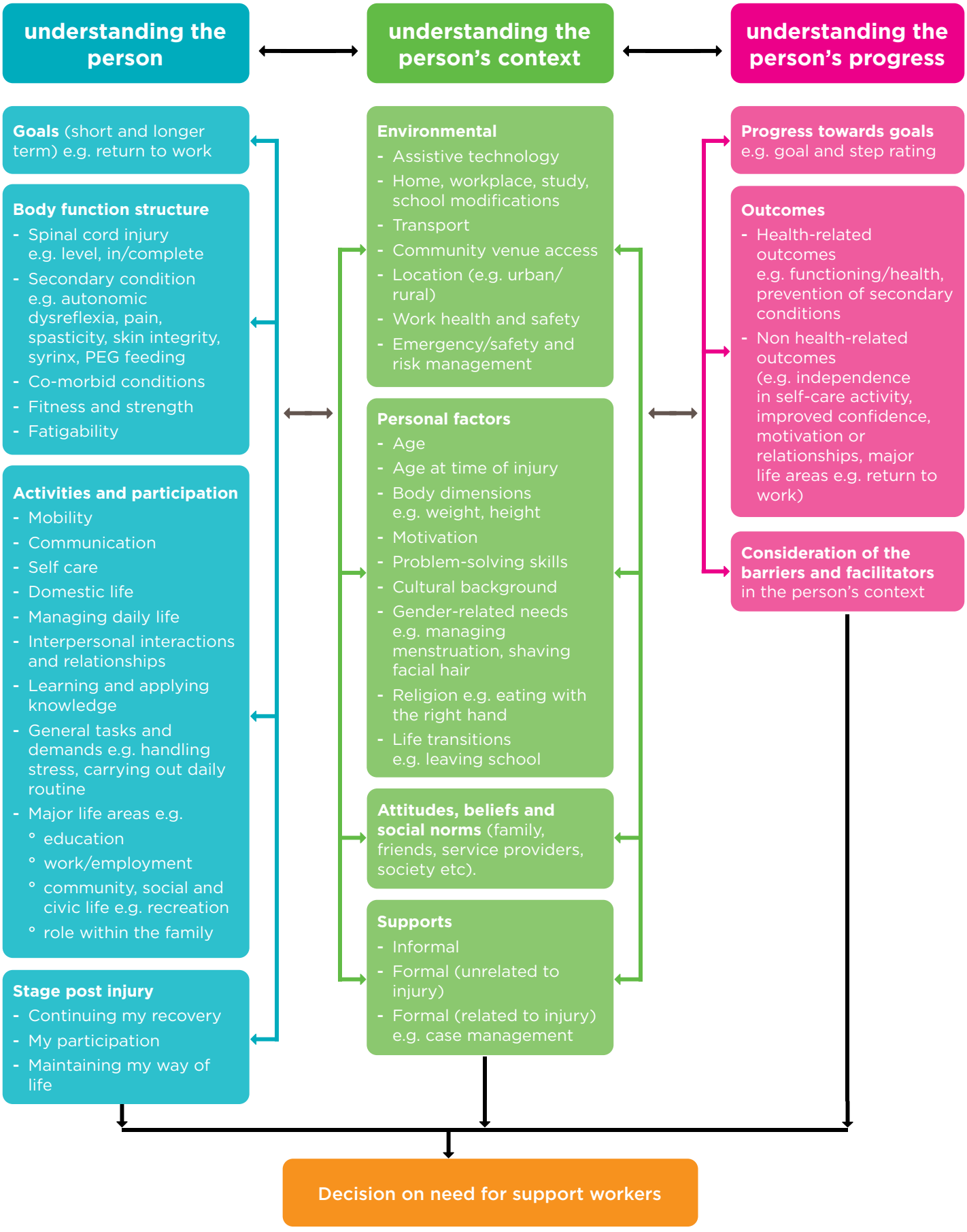
The motor levels referred to in this guidance are based on the American Spinal Injury Association (ASIA) scale. (Instructions for administration and the scoring form are available from http://asia-spinalinjury.org/wp-content/uploads/2016/02/International_Stds_Diagram_Worksheet.pdf). For the purposes of labelling in the tables provided in this guidance, only the motor level is used, not sensory impairment.

The guidance does not recommend specific assessment tools. Assessment tools for specific areas such as spasticity, upper limb or hand functioning, or range of motion should be considered by the practitioner. In the resources section of the guidance (Section 16), there is a carer screening tool (Modified Caregiver Strain Index) and a self-rating questionnaire to measure the person's quality of life (the World Health Organization Quality of Life – BREF version).

In the decision-making framework (Figure 1), boxes in the middle column 'Understanding the person's context' prompt consideration of the contextual factors within the biopsychosocial perspective of health that are defined in the International Classification of Functioning, Disability and Health (ICF) [25]. The environmental and personal factors listed in the boxes influence the person's activities and participation either as barriers or facilitators. It is critical that these are considered for each individual and their family and carer when deciding on the need for support. Some examples are provided below:

- location (urban, regional or rural) and transport
    - availability of wheelchair accessible public transport in the person's local area (e.g. buses, trains) or any public transport (e.g. limited in regional areas and often no public transport in rural areas).
- motivation, perceived control in life, positive self-image and coping style which influence the person's personal resources and may influence the need for support [26, 27]
- attitudes (of family, carers and person themselves) and cultural background which may influence choices around supports
- age as well as the person's age at the time of injury [28, 29]
- major life transitions, e.g. birth of a child.

figure 1 decision-making framework for a person with spinal cord injury and their need for support workers



11. Assistive technology (equipment and products)

Assistive technology refers to 'Any piece of equipment, or product, whether it is acquired commercially, modified or customized, that is used to increase, maintain or improve the functional abilities of individuals with disabilities' [30]. It includes equipment such as disposable continence products, medications, eating aids, walking and mobility aids, orthoses, wheelchairs, ocular devices, information and communication technology, mobile phones and environmental controls.

The assistive technology lists provided in the guidance are indicative of the assistive technology that should be considered and may be required. They are not intended to be comprehensive and should be taken as a guide only. Even at the same level of spinal cord injury, each individual's context, capacity and performance will vary. The situation can change for the individual over time (e.g. development of a secondary condition) and periodically other assistive technologies may be needed.

Assistive technology requests should be based on comprehensive assessment and substantiation of need and shared decisions with the user. Assistive technology should be trialled in the context where it will be used (e.g. home environment) with adequate training provided to any person using the assistive technology. Additional costs may be involved in the set-up and maintenance of the assistive technology and training in its use. Assistive technology should be maintained and/or replaced according to the manufacturer's specifications and prescribing therapist's recommendations.

Refer to the Assistive Technology Maintenance Checklist in the resources section of the guidance

In this section there are lists of disposable items for people at each level of injury (for no motor function and some motor function below the level of injury). In Section 12 (Levels of support and assistive technology), after each level of support table there are lists of non-disposable assistive technology for people with injury at each level (refer to Section 12.1 for those with no motor function below and Section 12.2 for those with some motor function below).

11.1 Disposable items lists

11.1.1 Disposable items for no motor function below C1–C3

- Antimicrobial filters suitable for use with ventilator as ordered
- Heat moisture exchange (e.g. humidivent)
- Tracheostomy care suction catheters 12 Fr/30.5cm length
- Re-usable blue swivel connectors
- 15mm x 22mm connectors
- Nebuliser with T piece mouthpiece and connecting bush
- Tracheostomy tubes (identical to current tube type and size prescribed as well as one size smaller as well as one size larger and one size smaller) – check exact type (i.e. LPC, cuffless, fenestrated/non-fenestrated).
- Blue flex tubing lengths
- Disposable Foley adaptors
- 50mL syringes
- Large dressing packs
- 10mL ampoules normal saline
- Xylocaine pre-loaded syringes
- Sterile pipe cleaners
- Cotton and velcro tracheostomy tapes
- Normal saline sterile sachets
- Sterile and non-sterile gloves
- Incontinence sheets
- Plastic disposable aprons
- Alcohol wipes
- Disinfectant handwash lotion
- Disposable Yanker sucker
- Sterile lubricating gel tubes
- Female urinary catheters (for use during bowel care – gender is irrelevant)
- Gauze squares
- 10mL ampoules hydrogen peroxide
- Sterile H2O nebulisers
- Urinary catheters (identical to current catheter size being used as well as one size larger and one size smaller)
- Quick drain catheter tube taps
- Urinary drainage 750mL long tube leg bags
- Catheter leg straps 45cm
- Night bottle
- Urinalysis dipsticks
- Micropore tape (2.5cm / 1 inch)
- Keyhole drain sponges

11.1.2 Respiratory disposables for C1–C3 ventilator dependent

- Antimicrobial filters suitable for use with ventilator as ordered
- Heat moisture exchange (e.g. humidivent)
- Closed tracheostomy care suction catheters 12FG/14FG 30.5cm length, and/or Y-suction catheters in appropriate size
- Disposable ventilator circuits
- Humidifier chamber
- Disposable resuscitation bag (e.g. ambi-bag)
- Re-usable blue swivel connectors
- 15mm x 22mm connectors
- Tracheostomy nebuliser kit with appropriate connectors
- Tracheostomy tubes (identical to current tube type and size prescribed as well as one size smaller)
- Spare inner tracheostomy cannula
- Blue flex tubing lengths
- Large dressing packs
- 10mL and 50mL ampoules normal saline
- 10mL syringe
- Sterile lubricating gel
- Hydrogen peroxide ampoules
- Sterile and non-sterile gloves
- Inner cannula cleaning brush
- Cotton and velcro tracheostomy tapes
- Suction tubing
- Dressing as required for around tracheostomy, e.g. split gauze, Allevyn
- Passy Muir/speaking valve
- Associated consumables for Cough Assist

11.1.3 C4 to S5 skin, bowel and bladder management disposable items

(These items may be required for people with either no motor function below the level of injury OR some motor function below the level of injury.)

The disposable item list is a general guide only. The person's needs should be assessed by an incontinence advisor and their personal preferences also considered. The list details all possible assistive technology that may be required for the level of motor functioning, but not all assistive technology is always required.

Bladder management equipment

Catheter – Foley type – Indwelling or suprapubic catheter

- Silicone catheter – male length
- Silicone catheter – female length

Catheter accessories

- Re-usable catheter thigh strap
- Catheter procedure pack (sterile) containing: tray, swabs, sterile gloves, lubricating gel, sterile water ampoules, saline sachet, drape and sterile towel
- 10mL syringe
- Sterile xylocaine gel
- Toomey syringe (catheter tip)
- Sterile kidney dish
- Bottle sterile saline
- Split gauze/drain sponge
- Alcohol wipes
- Catheter valve (flip flow)
- Specimen jar

Catheters for intermittent catheterisation*

- Single use nelaton type (double or single wrapped), male or female length
- Single use nelaton type pre-lubricated, male or female length
- Single use hydrophilic catheter, male or female length
- Single use pre-lubricated catheter sets with collection bag, in male or female lengths
- Re-usable intermittent catheter sets (e.g. Cliny)

*All intermittent catheter brands and types should be prescribed by a continence advisor, considering client preference for product choice.

Intermittent catheterisation accessories

- Clothing hook
- Splint
- Mirror
- Extension tubing
- Sterile lubricant
- Glycerine
- Baby wipes
- Plastic bags
- Hand sanitiser

External urodome (condom) drainage

- Latex one piece – self-adhesive
- Latex two piece
- Silicone one piece – self-adhesive
- Silicone two piece
- Non-lubricated condom

External drainage accessories

- Double-sided tape
- Single-sided foam tape
- Condom connector
- Adhesive – wipes/brush on/dab on
- Adhesive removal wipes

Drainage bags/bottles

- PVC leg bag – long tube
- PVC leg bag – short tube
- PVC leg bag – adjustable tube
- Night bottle
- Night bag

Drainage bag accessories

- Leg straps or catheter anchoring device
- Night bottle connector/tubing
- Night bag holder/stand
- Leg bag holder
- Rubber/silicone tubing
- Urosol detergent
- Milton liquid

Continence pads

- Disposable pads
- Washable pads
- Washable pants
- Disposable bed pads (e.g. Blueys)
- Male continence slips
- Mattress protector

Sundry items

- Portable urinal
- Xylocaine gel
- Uro-tainer Suby G
- Uro-tainer sodium chloride

Bowel management equipment

- Microlax micro enema
- Bisalax micro enema
- Fleet enema
- Glycerine suppository
- Durolax suppository
- Lubricant gel tube (water-based)
- Latex or hypoallergenic non-sterile gloves
- Female length nelaton catheter (soft)
- 10mL syringe
- Disposable bed pads (e.g. Blueys)
- Trans-anal irrigation system
- Anal plugs
- Wipes/disposable towels
- Rectal tube

Skin care equipment

Wound management (all appropriate to the size of wound)

- Basic dressing packs
- Variety of appropriate dressings (e.g. hydrocolloid, foam, hydrogel, alginate, film, non-adherent)
- Gauze swabs
- Combined dressing
- Saline sachets
- Retention tape
- Barrier wipes
- Crepe bandage
- Tubi-grip

Miscellaneous items

- Antibacterial handwash
- Antibacterial hand gel
- Disposable wash cloths
- Disposable apron
- Eye protection
- Air freshener spray

12. Levels of support and assistive technology

The following charts provide information to consider when determining the need for support workers for people with spinal injury. The tables provide information on the possible need for support and estimated hours per week for support worker(s) by level of spinal injury. The tables are based on **body functioning only,** either:

- No motor function below the level, or
- Some motor function below the level

(Refer to Section 12.2 for further explanation of the term some motor function below.)

The level of support tables include a brief description of the motor control and body functioning applicable to each level of injury.

The description and key for estimating the need for support code is provided in each table. The key describes a scale of support needs for activities and participation from 0 = no assistance (the person completes the task) to +++ = needs full support (the person completes 25% or less of the task). The list of activities and participation in each table is based on the biopsychosocial domains of functioning articulated in the ICF [25].

Assistive technology lists

Following the level of support table for each level of spinal cord injury, there is a list of assistive technology relevant to the level of injury. In general, the assistive technology list for each level of spinal cord injury, whether with no motor function below or some motor function below, is a guide only and is not inclusive of all the assistive technology/ products a person may require.

Level of support tables

The level of support tables provide an estimate of need and care hours based on the level of the person's injury. (This corresponds to 'Understanding the person' and specifically the 'Body function structure' box – spinal cord injury level – in the decision-making framework [Figure 1, Section 10]).

The need for support and estimated care hours are based on the person's performance in their home or familiar environment (i.e. not assessed capacity in a standard environment) on **one domain of health ONLY – body functioning.**

Estimations of the level of support assume that the person with spinal cord injury:

- has all the appropriate assistive technology they require and it is used
- is living at home
- lives alone (with no informal support or carer)
- if living in an apartment requires the lesser hours of 0.5 hours per week home maintenance
- lives in a home that is accessible or has been appropriately modified
- where appropriate has access to a modified vehicle.

The tables are a **starting point only** and do not consider other contextual factors that critically influence the individual's need for assistance and the estimated hours, e.g. secondary or co-morbid conditions, activities and participation, stage post injury, personal factors, environmental factors or facilitators, informal supports, access barriers (including geographic location), or progress towards their goals.

All contextual information relevant to the participant, as outlined in the decision-making framework (Figure 1), should be considered in addition to the information provided in the level of support tables.

12.1 No motor function below the level of spinal cord injury

12.1.1 Level of support: Cervical 1–3 (C1–C3) no motor function below[1]

Brief description of motor control and body functioning

- total paralysis of trunk and lower extremities
- no elbow, wrist or finger movement
- limited active head and neck movement
- respiratory muscle function impaired and respiratory capacity and endurance compromised – often requires ventilator support, assistance to clear secretions and intermittent suction, oxygen and humidification
- autonomic dysfunction

Key to estimating support needs

0 = no assistance	person completes the task
X = standby assistance	person completes task with monitoring, supervision
+ = needs some/set-up support	person completes more than 75% of the task
++ = needs moderate support	person completes approximately 25–75% of the task
+++ = needs full support	person completes 25% or less of the task

activity/participation	need for support	comment (e.g. capacity/performance, context)	estimated hours (per week) (depends on personal circumstances)
Transfers and moving around			196 (28 hours per day)*
transfers and bed mobility	+++	1–2 assistants depending on individual factors e.g. weight of person, spasms	
moving around home	x	• possible ability to manoeuvre power wheelchair with accessible controls and portable ventilator • needs full support for manual wheelchair	
moving around the community-wheelchair	+		
moving around the community-transport	+++	• wheel-in vehicle required • 2 assistants – the second support worker is required to drive, if the person is ventilated	
Self-care			
showering/washing self	+++	1–2 assistants depending on individual factors e.g. bathing/showering, bladder/bowel management, transfers, skin integrity	
grooming/caring for body	+++		
eating and drinking	+++		
toileting (bowel)	+++		
toileting (bladder)	+++		
dressing (upper)	+++		
dressing (lower)	+++		
overnight care	+++		
health needs (includes preventative health)	+++	• medical appointments • exercise • intermittent suction may be required • medication management • nursing – regular checks, catheter change	
Domestic life			5–21*
meal preparation	+++	routine domestic tasks can be attended to by support workers	
light housework	+++		
heavy housework	+++		
shopping	+++	shopping with the person	
communication and household management - set-up for devices e.g. computers, banking/life administration tasks, correspondence (mail)	+	possible use of assistive technology with accessible controls requiring set-up	
maintaining home and garden	+++	the lower range of hours expected for a person living in an apartment, although may require hours for minor home maintenance	0.5–2
Participation in major areas of life			need for support depends on the individual, and contextual (environmental and personal) factors
education (informal at home or other setting, school, tertiary, vocational)			
work and employment (includes non-remunerative work)			
caring for others e.g. parenting			
recreation, leisure, community life e.g. social ceremonies			
religious or spiritual practices e.g. attending church			

* Domestic assistance is included in 196 hours

[1] In this guidance on support, we begin with an estimate of the need for support based on body functioning. This table refers to a person whose C3 and above motor nerves are intact with no motor function below this. A range of other factors also need to be considered to establish the need for support workers (refer to Figure 1).

Assistive technology C1-3 - no motor function below

The list for C1–C3 when the person requires ventilator support is a guide only and is not inclusive of all the assistive technology/products a person may require. Other assistive technology or products may be recommended depending on individual circumstances, personal choice and independence. All assistive technology recommendations should be developed through best-practice reasoning and person-centred assessment.

- Motorised, height-adjustable bed, with appropriate controls and equipment as prescribed including: relevant controls, bolsters, footboard, trendelenburg, head and foot raise, knee break, side/grab rails, linked to environmental control unit; partner bed to be supplied where appropriate
- High-care pressure relief mattress, full air replacement with pump
- Twenty-four hour drinking system accessible from bed and wheelchair
- Mattress overlay for emergency use/when travelling
- Power tilt-in-space wheelchair with features as prescribed: head/chin/breath control, postural support devices, power recline and leg raise if required; may include attendant control system
- Replacement battery charger
- Tyre compressor/pump
- Pressure relief wheelchair cushions (2) and covers (2)
- Back-up manual or power wheelchair as prescribed
- Powered ceiling hoist, and portable electric hoist, hoist charger and batteries (2)
- Hoist slings (2 sets)
- Shower commode chair with prescribed features or shower trolley
- Portable shower hose as required
- Over-bed table, height adjustable
- Portable lightweight ramps
- Slide sheets
- Vehicle modifications for attendant-operated wheelchair accessible vehicle with safety (e.g. head and postural support, automatic tie downs) and prescribed features (e.g. air-conditioning)
- Independently activated environmental control systems accessible from wheelchair and bed, to include: door opener and intercom, call buzzer/ intercom, monitoring system, 'back-to-base' monitored personal alarm, temperature control (reverse cycle air-conditioning at a minimum in the bedroom and living area, fan, heater, blinds), lights, bed, TV/music
- Communication and information assistive technology devices including hardware and software with hands-free access features such as mouth stick, speaker phone, voice activation; devices may include computer/tablet/mobile phone and telephone landline
- Adjustable desk
- Exercise equipment as prescribed
- Splints as prescribed
- Ventilators as prescribed (2)
- Back-up /power source for all powered devices for use when power fails
- Ventilator breathing circuits (3) (specific to ordered ventilator)
- Air Viva resuscitator (2)
- Mains operated suction unit for use in the home
- Evacuation equipment
- Portable suction unit, battery operated
- Breathing circuits as indicated for use with oxygen and air cylinder (2)
- Cough Assist, BiPAP and/or CPAP machine
- Blood pressure monitor
- Thermometer
- Medical grade sheepskin sliding mat, boots and backrest
- Abdominal binders as indicated
- Anti-embolic or compression stockings and gloves

Additional assistive technology may be needed for other activities and participation in life roles depending on the person's individual preferences and lifestyle choices, for example, pre-injury activities, parenting role, work, recreation and leisure activities. This may include items such as a sports or recreational wheelchair, adapted sports equipment, club or other memberships, etc. Trial and possible hire of assistive technology should be considered.

12.1.2 Level of support: Cervical 4 (C4) no motor function below[1]

Brief description of motor control and body functioning

- total paralysis of trunk and lower extremities
- no elbow, wrist or finger movement
- can move head and neck with minimal shoulder movement
- respiratory muscle function impaired and respiratory capacity and endurance compromised
- autonomic dysfunction

Key to estimating support needs

0 = no assistance	person completes the task
X = standby assistance	person completes task with monitoring, supervision
+ = needs some/set-up support	person completes more than 75% of the task
++ = needs moderate support	person completes approximately 25–75% of the task
+++ = needs full support	person completes 25% or less of the task

activity/participation	need for support	comment (e.g. capacity/performance, context)	estimated hours (per week) (depends on personal circumstances)
Transfers and moving around			49–91 (plus 56 hours inactive sleepover)*
transfers and bed mobility	+++	1–2 assistants depending on individual factors e.g. weight of person, spasms	
moving around home	x	• ability to manoeuvre power wheelchair with accessible controls • needs full support for manual wheelchair	
moving around the community-wheelchair	+		
moving around the community-transport	+++	• wheel-in vehicle required • 1–2 assistants – the second support worker is required to drive: if the person is ventilated. If a taxi is used, only 1 support worker is required	
Self-care			
showering/washing self	+++	1–2 assistants depending on individual factors e.g. for bowel management, transfers, skin integrity	
grooming/caring for body	+++		
eating and drinking	+++		
toileting (bowel)	+++		
toileting (bladder)	+++		
dressing (upper)	+++		
dressing (lower)	+++		
overnight care	+++		
health needs (includes preventative health)	+++	• medical appointments • exercise • medication management • nursing – regular checks, catheter change	
Domestic life			18–21 0.5–2
meal preparation	+++	routine domestic tasks can be attended to by support workers	
light housework	+++		
heavy housework	+++		
shopping	+++	shopping with the person	
communication and household management - set-up for devices e.g. computers, banking/life administration tasks, correspondence (mail)	+	possible use of assistive technology with accessible controls requiring set-up	
maintaining home and garden	+++	the lower range of hours expected for a person living in an apartment, although may require hours for minor home maintenance	
Participation in major areas of life			need for support depends on the individual, and contextual (environmental and personal) factors
education (informal at home or other setting, school, tertiary, vocational)			
work and employment (includes non-remunerative work)			
caring for others e.g. parenting			
recreation, leisure, community life e.g. social ceremonies			
religious or spiritual practices e.g. attending church			

*If 24–hour care is provided, additional supports will not be required overnight.

[1] In this guidance on support, we begin with an estimate of the need for support based on body functioning. This table refers to a person whose C4 and above motor nerves are intact with no motor function below this. A range of other factors also need to be considered to establish the need for support workers (refer to Figure 1).

Assistive technology C4 - no motor function below

The list for C4 is a guide only and is not inclusive of all the assistive technology/products a person may require. Other assistive technology or products may be recommended depending on individual circumstances, personal choice and independence. All assistive technology recommendations should be developed through best-practice reasoning and person-centred assessment.

- Motorised, height-adjustable bed, with appropriate controls and equipment as prescribed including: relevant controls, bolsters, footboard, trendelenburg, head and foot raise, knee break, side/grab rails, linked to environmental control unit; partner bed to be supplied where appropriate
- High-care pressure relief mattress, full air replacement with pump
- Twenty-four hour drinking system accessible from bed and wheelchair
- Mattress overlay for emergency use/when travelling
- Power tilt-in-space wheelchair with features as prescribed: head/chin/breath control, postural support devices, power recline and leg raise if required; may include attendant control system
- Replacement battery charger
- Tyre compressor/pump
- Pressure relief wheelchair cushions (2) and covers (2)
- Manual wheelchair with appropriate features as prescribed
- Mobile arm supports
- Powered ceiling hoist, and portable electric hoist, hoist charger and batteries (2)
- Hoist slings (2 sets)
- Shower commode chair with prescribed features
- Portable shower hose as required
- Over-bed table, height adjustable
- Portable lightweight ramps
- Transfer board
- Vehicle modifications for attendant-operated wheelchair accessible vehicle with safety (e.g. head and postural support, automatic tie downs) and prescribed features (e.g. air-conditioning)
- Independently activated environmental control systems accessible from wheelchair and bed, to include: door opener and intercom, call buzzer/ intercom, monitoring system, 'back-to-base' monitored personal alarm, temperature control (reverse cycle air-conditioning at a minimum in the bedroom and living area, fan, heater, blinds), lights, bed, TV/music
- Communication and information assistive technology devices including hardware and software with hands-free access features such as mouth stick, speaker phone, voice activation; devices may include computer/tablet/mobile phone and telephone landline
- Adjustable desk
- Exercise equipment as prescribed
- Adaptive devices as needed for personal use, page turning, writing, etc.
- Splints as prescribed
- Back-up battery/power source for all powered devices for use when power fails
- Medical grade sheepskin sliding mat, boots and backrest
- Long-handled skin-inspection mirror
- Cough Assist, BiPAP and/or CPAP machine
- Blood pressure monitor
- Thermometer
- Abdominal binders as indicated
- Anti-embolic or compression stockings and gloves
- Slide sheets

Additional assistive technology may be needed for other activities and participation in life roles depending on the person's individual preferences and lifestyle choices, for example, pre-injury activities, parenting role, work, recreation and leisure activities. This may include items such as a sports or recreational wheelchair, adapted sports equipment, club or other memberships, etc. Trial and possible hire of assistive technology should be considered.

12.1.3 Level of support: Cervical 5 (C5) no motor function below[1]

Brief description of motor control and body functioning

- total paralysis of trunk and lower extremities
- limited movement in elbow and forearm
- no wrist or finger movement
- can move head and neck with moderate shoulder control
- respiratory muscle function impaired and respiratory capacity and endurance compromised
- autonomic dysfunction

Key to estimating support needs

0 = no assistance	person completes the task
X = standby assistance	person completes task with monitoring, supervision
+ = needs some/set-up support	person completes more than 75% of the task
++ = needs moderate support	person completes approximately 25–75% of the task
+++ = needs full support	person completes 25% or less of the task

activity/participation	need for support	comment (e.g. capacity/performance, context)	estimated hours (per week) (depends on personal circumstances)
Transfers and moving around			42–49 (plus 56 hours inactive sleepover)*
transfers and bed mobility	+++	1–2 assistants depending on individual factors e.g. weight of person, spasms	
moving around home	0	ability to manoeuvre power wheelchair with accessible controls although needs full support for manual wheelchair	
moving around the community-wheelchair	+		
moving around the community-transport	+	• may be able to drive with appropriately modified vehicle • may need assistance with transfer, loading wheelchair, clamping (++) • may need assistance with public transport (++)	
Self-care			
showering/washing self	++		
grooming/caring for body	++		
eating and drinking	+		
toileting (bowel)	+++		
toileting (bladder)	+++		
dressing (upper)	+++		
dressing (lower)	+++		
overnight care	+++		
health needs (includes preventative health)	++	• independent with arranging medical appointments, medication management • may need assistance with exercise, nursing – regular checks, catheter change	
Domestic life			18–21 0.5–2
meal preparation	+++	routine domestic tasks can be attended to by support workers	
light housework	+++		
heavy housework	+++		
shopping	+++	shopping with the person	
communication and household management - set-up for devices e.g. computers, banking/life administration tasks, correspondence (mail)	x	possible use of assistive technology with accessible controls requiring set-up (+)	
maintaining home and garden	+++	the lower range of hours expected for a person living in an apartment, although may require hours for minor home maintenance	
Participation in major areas of life			need for support depends on the individual, and contextual (environmental and personal) factors
education (informal at home or other setting, school, tertiary, vocational)			
work and employment (includes non-remunerative work)			
caring for others e.g. parenting			
recreation, leisure, community life e.g. social ceremonies			
religious or spiritual practices e.g. attending church			

*If 24 hour care is provided, additional supports will not be required overnight.

[1] In this guidance on support, we begin with an estimate of the need for support based on body functioning. This table refers to a person whose C5 and above motor nerves are intact with no motor function below this. A range of other factors also need to be considered to establish the need for support workers (refer to Figure 1).

Assistive technology C5 - no motor function below

Assistive technology C5 – no motor function below

The list for C5 is a guide only and is not inclusive of all the assistive technology/products a person may require. Other assistive technology or products may be recommended depending on individual circumstances, personal choice and independence. All assistive technology recommendations should be developed through best-practice reasoning and person-centred assessment.

- Motorised, height-adjustable bed, with appropriate controls and equipment as prescribed possibly including: relevant controls, bolsters, footboard, trendelenburg, head and foot raise, knee break, side/grab rails, linked to an environmental control unit; partner bed to be supplied where appropriate
- Appropriate high-care pressure relief mattress
- Twenty-four hour drinking system accessible from bed and wheelchair
- Mattress overlay for emergency use/when travelling
- Power wheelchair with features as prescribed: tilt-in-space, power recline, leg raise, adapted controls for arm drive, postural support devices, arm supports
- Replacement battery charger
- Tyre compressor/pump
- Back-up battery/power source for all powered devices for use when power fails
- Pressure relief wheelchair cushions (2) and covers (2)
- Manual wheelchair with appropriate features as prescribed: push rim adaptations/capstan rims; could include power assist functions
- Powered ceiling hoist, and portable electric hoist, hoist charger and batteries (2)
- Hoist slings (2 sets)
- Mobile arm supports if prescribed
- Push mitts, and replacements
- Shower commode chair with prescribed features
- Portable shower hose as required
- Over-bed table, height adjustable
- Portable lightweight ramps
- Transfer board
- Medical grade sheepskin sliding mat, boots and backrest
- Vehicle modifications for attendant-operated wheelchair accessible vehicle with safety (e.g. head and postural support, automatic tie downs) and prescribed features (e.g. air-conditioning), or appropriate adaptations to a self-drive vehicle including wheelchair hoist to access car
- Driving pressure relief cushion if transferring from wheelchair into vehicle seat
- Independently activated environmental control systems accessible from wheelchair and bed, to include: door opener and intercom, call buzzer/ intercom, monitoring system, ‘back-to-base’ monitored personal alarm, temperature control (reverse cycle air-conditioning at a minimum in the bedroom and living area, fan, heater, blinds), lights, bed, TV/music
- Communication and information assistive technology devices including hardware and software with hands-free access features such as mouth stick, speaker phone, voice activation; devices may include computer/tablet/mobile phone and telephone landline
- Adjustable desk
- Adaptive devices as needed for personal care (e.g. feeding, grooming, showering, dressing) and domestic tasks (e.g. page turning, writing), and clothing adaptations
- Long-handled skin-inspection mirror
- Exercise equipment as prescribed
- Splints as prescribed
- Cough Assist, BiPAP and/or CPAP machine
- Blood pressure monitor
- Thermometer
- Abdominal binders as required
- Anti-embolic or compression stockings and gloves
- Slide sheets

Additional assistive technology may be needed for other activities and participation in life roles depending on the person’s individual preferences and lifestyle choices, for example, pre-injury activities, parenting role, work, recreation and leisure activities. This may include items such as a sports or recreational wheelchair, adapted sports equipment, club or other memberships, etc. Trial and possible hire of assistive technology should be considered.

12.1.4 Level of support: Cervical 6 (C6) no motor function below[1]

Brief description of motor control and body functioning

- total paralysis of trunk and lower extremities
- minimal movement in elbow, forearm and wrist
- can move head and neck with moderate shoulder control
- respiratory muscle function impaired and respiratory capacity and endurance compromised
- autonomic dysfunction

Key to estimating support needs

0 = no assistance	person completes the task
X = standby assistance	person completes task with monitoring, supervision
+ = needs some/set-up support	person completes more than 75% of the task
++ = needs moderate support	person completes approximately 25–75% of the task
+++ = needs full support	person completes 25% or less of the task

activity/participation	need for support	comment (e.g. capacity/performance, context)	estimated hours (per week) (depends on personal circumstances)
Transfers and moving around			28–35
transfers and bed mobility	++	may be independent from wheelchair to bed, bed to commode needs full assistance with floor to chair transfer	
moving around home	0		
moving around the community-wheelchair	+	independent using power wheelchair or power assist Support with manual wheelchair on uneven surfaces/curbs	
moving around the community-transport	+	• independent driving with appropriately modified vehicle • may need assistance with transfer, loading wheelchair, clamping (+) • may need assistance with public transport (+)	
Self-care			
showering/washing self	+		
grooming/caring for body	+		
eating and drinking	+		
toileting (bowel)	+++		
toileting (bladder)	+++		
dressing (upper)	++		
dressing (lower)	+++		
overnight care	+++		
health needs (includes preventative health)	++	• independent with arranging medical appointments, medication management • may need assistance with exercise, nursing – regular checks, catheter change	
Domestic life			18–21
meal preparation	+++	assistance for complex meal preparation	
light housework	+++		
heavy housework	+++		
shopping	+++	shopping with the person	
communication and household management - set-up for devices e.g. computers, banking/life administration tasks, correspondence (mail)	x	possible use of assistive technology with accessible controls requiring set-up (+)	
maintaining home and garden	+++	the lower range of hours expected for a person living in an apartment, although may require hours for minor home maintenance	0.5–2
Participation in major areas of life			need for support depends on the individual, and contextual (environmental and personal) factors
education (informal at home or other setting, school, tertiary, vocational)			
work and employment (includes non-remunerative work)			
caring for others e.g. parenting			
recreation, leisure, community life e.g. social ceremonies			
religious or spiritual practices e.g. attending church			

[1] In this guidance on support, we begin with an estimate of the need for support based on body functioning. This table refers to a person whose C6 and above motor nerves are intact with no motor function below this. A range of other factors also need to be considered to establish the need for support workers (refer to Figure 1).

Assistive technology C6 - no motor function below

The list for C6 is a guide only and is not inclusive of all the assistive technology/products a person may require. Other assistive technology or products may be recommended depending on individual circumstances, personal choice and independence. All assistive technology recommendations should be developed through best-practice reasoning and person-centred assessment.

- Motorised, height-adjustable bed, with appropriate controls and equipment as prescribed possibly including: relevant controls, bolsters, footboard, trendelenburg, head and foot raise, knee break, side/grab rails, linked to an environmental control unit; partner bed to be supplied where appropriate
- Appropriate high-care pressure relief mattress
- Twenty-four hour drinking system accessible from bed and wheelchair
- Mattress overlay for emergency use/when travelling
- Power wheelchair with features as prescribed: tilt-in-space, power recline, leg raise, adapted controls for arm drive, postural support devices, arm supports
- Replacement battery charger
- Tyre compressor/pump
- Back-up battery/power source for all powered devices for use when power fails
- Pressure relief wheelchair cushions (2) and covers (2)
- Manual wheelchair with appropriate features as prescribed: push rim adaptations/capstan rims; could include power assist functions
- Powered ceiling hoist, and portable electric hoist, hoist charger and batteries (2)
- Hoist slings (2 sets)
- Mobile arm supports
- Push mitts, and replacements
- Shower commode chair with prescribed features
- Portable shower hose as required
- Over-bed table, height adjustable
- Portable lightweight ramps
- Transfer board
- Medical grade sheepskin sliding mat, boots and backrest
- Vehicle modifications for attendant-operated wheelchair accessible vehicle with safety (e.g. head and postural support, automatic tie downs) and prescribed features (e.g. air-conditioning), or appropriate adaptations to a self-drive vehicle including wheelchair hoist to access car
- Driving pressure relief cushion if transferring from wheelchair into vehicle seat
- Independently activated environmental control systems accessible from wheelchair and bed, to include: door opener and intercom, call buzzer/ intercom, monitoring system, 'back-to-base' monitored personal alarm, temperature control (reverse cycle air-conditioning at a minimum in the bedroom and living area, fan, heater, blinds), lights, bed, TV/music
- Communication and information assistive technology devices including hardware and software with hands-free access features such as mouth stick, speaker phone, voice activation; devices may include computer/tablet/mobile phone and telephone landline
- Adjustable desk
- Adaptive devices as needed for personal care (e.g. feeding, grooming, showering, dressing) and domestic tasks (e.g. page turning, writing), and clothing adaptations
- Long-handled skin-inspection mirror
- Exercise equipment as prescribed
- Splints as prescribed
- Non-invasive ventilator if sleep apnoea diagnosed
- Blood pressure monitor
- Abdominal binders
- Anti-embolic or compression stockings
- Oedema gloves
- Slide sheets

Additional assistive technology may be needed for other activities and participation in life roles depending on the person's individual preferences and lifestyle choices, for example, pre-injury activities, parenting role, work, recreation and leisure activities. This may include items such as a sports or recreational wheelchair, adapted sports equipment, club or other memberships, etc. Trial and possible hire of assistive technology should be considered.

12.1.5 Level of support: Cervical 7–8 (C7–C8) no motor function below[1]

Brief description of motor control and body functioning

- total paralysis of trunk and lower extremities
- full elbow movement
- moderate arm, wrist and finger control – a person with injury C7 has movement in thumbs and gross grip
- can move head and neck with good shoulder control
- respiratory muscle function impaired and respiratory capacity and endurance compromised
- autonomic dysfunction

Key to estimating support needs

0 = no assistance	person completes the task
X = standby assistance	person completes task with monitoring, supervision
+ = needs some/set-up support	person completes more than 75% of the task
++ = needs moderate support	person completes approximately 25–75% of the task
+++ = needs full support	person completes 25% or less of the task

activity/participation	need for support	comment (e.g. capacity/performance, context)	estimated hours (per week) (depends on personal circumstances)
Transfers and moving around			14–21
transfers and bed mobility	0	• may need assistance with uneven transfers (+) • may need assistance with floor to chair transfer (++)	
moving around home	0		
moving around the community-wheelchair	+	• independent using power wheelchair or power assist • needs assistance with manual wheelchair on uneven surfaces/curbs	
moving around the community-transport	0	• independent driving with appropriately modified vehicle • may need assistance with transfer, loading wheelchair, clamping (+) • may need assistance public transport (+)	
Self-care			
showering/washing self	0		
grooming/caring for body	0		
eating and drinking	0		
toileting (bowel)	++	may be independent	
toileting (bladder)	++	may be independent	
dressing (upper)	0		
dressing (lower)	++		
health needs (includes preventative health)	+	• independent with arranging medical appointments, medication management • may need assistance with exercise • may need assistance with nursing – regular checks, catheter change (++)	
Domestic life			7–21
meal preparation	0	assistance for complex meal preparation (+)	
light housework	+		
heavy housework	+++		
shopping	++	shopping with the person	
communication and household management - set-up for devices e.g. computers, banking/life administration tasks, correspondence (mail)	0		
maintaining home and garden	+++	the lower range of hours expected for a person living in an apartment, although may require hours for minor home maintenance	0.5–2
Participation in major areas of life			need for support depends on the individual, and contextual (environmental and personal) factors
education (informal at home or other setting, school, tertiary, vocational)			
work and employment (includes non-remunerative work)			
caring for others e.g. parenting			
recreation, leisure, community life e.g. social ceremonies			
religious or spiritual practices e.g. attending church			

[1] In this guidance on support, we begin with an estimate of the need for support based on body functioning. This table refers to a person whose C7 or C8 and above motor nerves are intact with no motor function below this. A range of other factors also need to be considered to establish the need for support workers (refer to Figure 1).

Assistive technology C7-C8 - no motor function below

The list for C7–C8 is a guide only and is not inclusive of all the assistive technology/products a person may require. Other assistive technology or products may be recommended depending on individual circumstances, personal choice and independence. All assistive technology recommendations should be developed through best-practice reasoning and person-centred assessment.

- Motorised, height-adjustable bed, with appropriate controls and equipment as prescribed, or an ensemble bed with additional bed equipment as prescribed, for example, attached or removable bed rails or rope ladder
- Appropriate pressure relief mattress
- Power wheelchair for outdoor use with features as prescribed, or manual wheelchair with prescribed features, for example, power assist
- Replacement battery charger
- Tyre compressor/pump
- Pressure relief wheelchair cushions (2) and covers (2)
- Push mitts, and replacements
- Powered hoists (ceiling and/or mobile) and slings (2 sets)
- Shower commode or tub transfer bench as prescribed
- Portable shower hose as required
- Long-handled skin-inspection mirror
- Over-bed table, height adjustable
- Portable lightweight ramps
- Transfer board
- Adaptive devices as needed for personal care (e.g. feeding, grooming, showering, dressing) and domestic tasks (e.g. writing, cooking), and clothing adaptations
- Sheepskin boots
- Vehicle modifications for attendant-operated wheelchair accessible vehicle with safety (e.g. head and postural support, automatic tie downs) and prescribed features (e.g. air-conditioning), or appropriate adaptations to a self-drive vehicle including wheelchair hoist to access car
- Driving pressure relief cushion if transferring from wheelchair into vehicle seat
- Environmental control unit for home system if indicated
- Reverse cycle air-conditioning, covering living area and bedroom at a minimum
- Push mitts, and replacements
- Adjustable desk
- Exercise equipment as prescribed
- Splints as prescribed
- Accessible computer hardware and software
- Communication and information devices including accessible home telephone/landline, intercom, personal alarm system that can be accessed independently, as prescribed
- Abdominal binders as indicated
- Anti-embolic or compression stockings
- Non-invasive ventilator if sleep apnoea diagnosed

Additional assistive technology may be needed for other activities and participation in life roles depending on the person's individual preferences and lifestyle choices, for example, pre-injury activities, parenting role, work, recreation and leisure activities. This may include items such as a sports or recreational wheelchair, adapted sports equipment, club or other memberships, etc. Trial and possible hire of assistive technology should be considered.

12.1.6 Level of support: Thoracic 1–4 (T1–T4) no motor function below[1]

Brief description of motor control and body functioning

- total paralysis of trunk and lower extremities
- limited upper trunk stability with impaired sitting balance
- good shoulder, elbow, forearm control: however, a person with injury at T1–T2 level may not have fine hand control
- respiratory muscle function impaired and respiratory capacity and endurance compromised
- autonomic dysfunction

Key to estimating support needs

0 = no assistance	person completes the task
X = standby assistance	person completes task with monitoring, supervision
+ = needs some/set-up support	person completes more than 75% of the task
++ = needs moderate support	person completes approximately 25–75% of the task
+++ = needs full support	person completes 25% or less of the task

activity/participation	need for support	comment (e.g. capacity/performance, context)	estimated hours (per week) (depends on personal circumstances)
Transfers and moving around			0–14
transfers and bed mobility	0	may need assistance with uneven transfers e.g. floor to chair transfer (+)	
moving around home	0		
moving around the community-wheelchair	0	• independent using power wheelchair or power assist • need assistance with manual wheelchair on uneven surfaces/curbs	
moving around the community-transport	0	• independent driving with appropriately modified vehicle • may need assistance with transfer, loading wheelchair, clamping (+) • may need assistance with public transport (+)	
Self-care			
showering/washing self	0		
grooming/caring for body	0		
eating and drinking	0		
toileting (bowel)	+	may be independent	
toileting (bladder)	+	may be independent	
dressing (upper)	0		
dressing (lower)	+	may need assistance	
health needs (includes preventative health)	0	• independent with medical appointments, medication management • may need assistance with exercise (+) • nursing – regular checks, catheter change (+)	
Domestic life			5–14
meal preparation	0		
light housework	0		
heavy housework	+++		
shopping	++	shopping with the person	
communication and household management - set-up for devices e.g. computers, banking/life administration tasks, correspondence (mail)	0		
maintaining home and garden	+++	the lower range of hours expected for a person living in an apartment, although may require hours for minor home maintenance	0.5–2
Participation in major areas of life			need for support depends on the individual, and contextual (environmental and personal) factors
education (informal at home or other setting, school, tertiary, vocational)			
work and employment (includes non-remunerative work)			
caring for others e.g. parenting			
recreation, leisure, community life e.g. social ceremonies			
religious or spiritual practices e.g. attending church			

[1] In this guidance on support, we begin with an estimate of the need for support based on body functioning. This table refers to a person whose T1 (or any level to T4) and above motor nerves are intact with no motor function below this. A range of other factors also need to be considered to establish the need for support workers (refer to Figure 1).

Assistive technology T1-T4 - no motor function below

The list for T1–T4 is a guide only and is not inclusive of all the assistive technology/products a person may require. Other assistive technology or products may be recommended depending on individual circumstances, personal choice and independence. All assistive technology recommendations should be developed through best-practice reasoning and person-centred assessment.

- Motorised, height-adjustable bed, with appropriate controls and equipment as prescribed, or an ensemble bed with additional bed equipment as prescribed, for example, attached or removable bed rails, bed positioning aids
- Pressure relief mattress or standard mattress as required
- Two wheelchairs (manual, power or power assist) as prescribed
- Push mitts, and replacements
- Pressure relief wheelchair cushions (2) and covers (2)
- Powered hoist (ceiling or mobile) and slings (2 sets)
- Shower commode or shower chair or bath seat as prescribed
- Portable shower hose as required
- Long-handled skin-inspection mirror
- Adaptive devices as needed for personal care (e.g. dressing, grooming, showering) and domestic tasks, cooking, cleaning, laundry etc.
- Over-bed table, height adjustable
- Portable lightweight ramps
- Transfer board
- Appropriate adaptations to a self-drive vehicle including wheelchair hoist; may require assistive transfer device
- Driving pressure relief cushion
- Reverse cycle air-conditioning, covering living area and bedroom at a minimum
- Adjustable desk
- Exercise equipment as prescribed
- Splints as prescribed
- Communication and information devices including accessible home telephone/landline, ‘back-to-base’ personal alarm system
- Abdominal binders
- Sheepskin boots
- Anti-embolic or compression stockings
- Non-invasive ventilator if sleep apnoea diagnosed

Additional assistive technology may be needed for other activities and participation in life roles depending on the person’s individual preferences and lifestyle choices, for example, pre-injury activities, parenting role, work, recreation and leisure activities. This may include items such as a sports or recreational wheelchair, adapted sports equipment, club or other memberships, etc. Trial and possible hire of assistive technology should be considered.

12.1.7 Level of support: Thoracic 5–9 (T5–T9) no motor function below[1]

Brief description of motor control and body functioning

- total paralysis of trunk and lower extremities
- moderate upper trunk stability with moderately impaired sitting balance
- full control of upper limbs
- compromised respiratory capacity and endurance
- autonomic dysfunction (people with spinal cord injury at T6 level and above)

Key to estimating support needs

0 = no assistance	person completes the task
X = standby assistance	person completes task with monitoring, supervision
+ = needs some/set-up support	person completes more than 75% of the task
++ = needs moderate support	person completes approximately 25–75% of the task
+++ = needs full support	person completes 25% or less of the task

activity/participation	need for support	comment (e.g. capacity/performance, context)	estimated hours (per week) (depends on personal circumstances)
Transfers and moving around			0–10
transfers and bed mobility	0	may need assistance with uneven transfers e.g. floor to chair transfer (+)	
moving around home	0		
moving around the community-wheelchair	0	may use power wheelchair or power assist for long distances	
moving around the community-transport	0	• independent driving with appropriately modified vehicle • may need assistance with transfer, loading wheelchair, clamping (+)	
Self-care			
showering/washing self	0		
grooming/caring for body	0		
eating and drinking	0		
toileting (bowel)	+	depends on level of injury	
toileting (bladder)	+	depends on level of injury	
dressing (upper)	0		
dressing (lower)	+		
health needs (includes preventative health)	+	• independent with medical appointments, medication management • may need assistance with exercise (+) • nursing – regular checks, catheter change (+)	
Domestic life			5–10
meal preparation	0		
light housework	0		
heavy housework	+++		
shopping	++	shopping with the person	
communication and household management - set-up for devices e.g. computers, banking/life administration tasks, correspondence (mail)	0		
maintaining home and garden	+++	the lower range of hours expected for a person living in an apartment, although may require hours for minor home maintenance	0.5–2
Participation in major areas of life			need for support depends on the individual, and contextual (environmental and personal) factors
education (informal at home or other setting, school, tertiary, vocational)			
work and employment (includes non-remunerative work)			
caring for others e.g. parenting			
recreation, leisure, community life e.g. social ceremonies			
religious or spiritual practices e.g. attending church			

[1] In this guidance on support, we begin with an estimate of the need for support based on body functioning. This table refers to a person whose T5 (or any level to T9) and above motor nerves are intact with no motor function below this. A range of other factors also need to be considered to establish the need for support workers (refer to Figure 1).

Assistive technology T5-T9 - no motor function below

The list for T5–T9 is a guide only and is not inclusive of all the assistive technology/products a person may require. Other assistive technology or products may be recommended depending on individual circumstances, personal choice and independence. All assistive technology recommendations should be developed through best-practice reasoning and person-centred assessment.

- Motorised, height-adjustable bed, with appropriate controls and equipment as prescribed, or an ensemble bed with additional bed equipment as prescribed, for example, attached or removable bed rails, bed positioning aids
- Pressure relief mattress or standard mattress as required
- Two wheelchairs (manual, power or power assist) as prescribed
- Push mitts, and replacements
- Pressure relief wheelchair cushions (2) and covers (2)
- Powered hoist (ceiling or mobile) and slings (2 sets)
- Shower commode or shower chair or bath seat as prescribed
- Portable shower hose as required
- Adaptive devices as needed for personal care (e.g. dressing, grooming, showering) and domestic tasks, cooking, cleaning, laundry etc.
- Long-handled skin-inspection mirror
- Over-bed table, height adjustable
- Portable lightweight ramps
- Transfer board
- Appropriate adaptations to a self-drive vehicle including wheelchair hoist; may require assistive transfer device
- Driving pressure relief cushion
- Reverse cycle air-conditioning, covering living area and bedroom, if clinically indicated
- Adjustable desk
- Exercise equipment as prescribed
- Splints as prescribed
- Communication and information devices including accessible home telephone/landline, ‘back-to-base’ personal alarm system
- Abdominal binders as required
- Sheepskin boots
- Anti-embolic or compression stockings as prescribed
- Non-invasive ventilator if sleep apnoea diagnosed

Additional assistive technology may be needed for other activities and participation in life roles depending on the person’s individual preferences and lifestyle choices, for example, pre-injury activities, parenting role, work, recreation and leisure activities. This may include items such as a sports or recreational wheelchair, adapted sports equipment, club or other memberships, etc. Trial and possible hire of assistive technology should be considered.

12.1.8 Level of support: Thoracic 10 to lumbar 1 (T10–L1) no motor function below[1]

Brief description of motor control and body functioning

- partial paralysis of lower trunk
- total paralysis of lower extremities
- minimally impaired sitting balance
- full control of upper limbs
- minimal compromise to respiratory capacity and endurance

Key to estimating support needs

0 = no assistance	person completes the task
X = standby assistance	person completes task with monitoring, supervision
+ = needs some/set-up support	person completes more than 75% of the task
++ = needs moderate support	person completes approximately 25–75% of the task
+++ = needs full support	person completes 25% or less of the task

activity/participation	need for support	comment (e.g. capacity/performance, context)	estimated hours (per week) (depends on personal circumstances)
Transfers and moving around			0–7
transfers and bed mobility	0	may need assistance with floor to chair transfer (+)	
moving around home	0		
moving around the community-wheelchair	0	may use power wheelchair or power assist for long distances	
moving around the community-transport	0	independent driving with appropriately modified vehicle	
Self-care			
showering/washing self	0		
grooming/caring for body	0		
eating and drinking	0		
toileting (bowel)	0	may need assistance (+)	
toileting (bladder)	0	may need assistance (+)	
dressing (upper)	0		
dressing (lower)	0		
health needs (includes preventative health)	+	• independent with medical appointments, medication management • may need assistance with exercise • nursing – regular checks, catheter change (+)	
Domestic life			3–10
meal preparation	0		
light housework	0		
heavy housework	+++		
shopping	+		
communication and household management - set-up for devices e.g. computers, banking/life administration tasks, correspondence (mail)	0		
maintaining home and garden	+++	the lower range of hours expected for a person living in an apartment, although may require hours for minor home maintenance	0.5–2
Participation in major areas of life			need for support depends on the individual, and contextual (environmental and personal) factors
education (informal at home or other setting, school, tertiary, vocational)			
work and employment (includes non-remunerative work)			
caring for others e.g. parenting			
recreation, leisure, community life e.g. social ceremonies			
religious or spiritual practices e.g. attending church			

[1] In this guidance on support, we begin with an estimate of the need for support based on body functioning. This table refers to a person whose T10 (or any level through to L1) and above motor nerves are intact with no motor function below this. A range of other factors also need to be considered to establish the need for support workers (refer to Figure 1).

Assistive technology T10-L1 - no motor function below

The list for T10–L1 is a guide only and is not inclusive of all the assistive technology/products a person may require. Other assistive technology or products may be recommended depending on individual circumstances, personal choice and independence. All assistive technology recommendations should be developed through best-practice reasoning and person-centred assessment.

- Motorised, height-adjustable bed, with appropriate controls and equipment as prescribed, or an ensemble bed with additional bed equipment as prescribed
- Pressure relief mattress or standard mattress as required
- Two wheelchairs (manual, power or power assist) as prescribed
- Push mitts, and replacements
- Pressure relief wheelchair cushions (2) and covers (2)
- Powered hoist (ceiling or mobile) and slings (2 sets)
- Shower commode or shower chair or bath seat as prescribed
- Portable shower hose as required
- Adaptive devices as needed for personal care (e.g. dressing, grooming, showering) and domestic tasks, cooking, cleaning, laundry etc.
- Long-handled skin-inspection mirror
- Over-bed table, height adjustable
- Portable lightweight ramps
- Transfer board
- Appropriate adaptations to a self-drive vehicle including wheelchair hoist; may require assistive transfer device
- Driving pressure relief cushion
- Adjustable desk
- Exercise equipment as prescribed
- Communication and information devices including accessible home telephone/landline, ‘back-to-base’ personal alarm system
- Abdominal binders as required
- Anti-embolic or compression stockings as prescribed
- Non-invasive ventilator if sleep apnoea diagnosed

Additional assistive technology may be needed for other activities and participation in life roles depending on the person’s individual preferences and lifestyle choices, for example, pre-injury activities, parenting role, work, recreation and leisure activities. This may include items such as a sports or recreational wheelchair, adapted sports equipment, club or other memberships, etc. Trial and possible hire of assistive technology should be considered.

12.1.9 Level of support: Lumbar 2 to sacral 5 (L2-S5) no motor function below[1]

Brief description of motor control and body functioning

- good trunk stability
- moderate to good control of the lower extremities: variable hip, knee, ankle control and foot movement, may use option of knee-ankle-foot orthoses
- may be independent in standing, require moderate assistance to independent in walking
- full control of upper limbs

Key to estimating support needs

0 = no assistance	person completes the task
X = standby assistance	person completes task with monitoring, supervision
+ = needs some/set-up support	person completes more than 75% of the task
++ = needs moderate support	person completes approximately 25–75% of the task
+++ = needs full support	person completes 25% or less of the task

activity/participation	need for support	comment (e.g. capacity/performance, context)	estimated hours (per week) (depends on personal circumstances)
Transfers and moving around			0–7
transfers and bed mobility	0	may require support with floor to chair transfer (+)	
moving around home	0		
moving around the community-wheelchair	0	may use wheelchair and power assist for long distances	
moving around the community-transport	0	independent driving with appropriately modified vehicle	
Self-care			
showering/washing self	0		
grooming/caring for body	0		
eating and drinking	0		
toileting (bowel)	0	may need assistance (+)	
toileting (bladder)	0	may need assistance (+)	
dressing (upper)	0		
dressing (lower)	0		
health needs (includes preventative health)	0	• independent with medical appointments, medication management, exercise • nursing – regular checks, catheter change (+)	
Domestic life			3–10
meal preparation	0	assistance for complex meal preparation (+)	
light housework	0		
heavy housework	+++		
shopping	0	major shopping (+)	
communication and household management - set-up for devices e.g. computers, banking/life administration tasks, correspondence (mail)	0		
maintaining home and garden	+++	the lower range of hours expected for a person living in an apartment, although may require hours for minor home maintenance	0.5–2
Participation in major areas of life			need for support depends on the individual, and contextual (environmental and personal) factors
education (informal at home or other setting, school, tertiary, vocational)			
work and employment (includes non-remunerative work)			
caring for others e.g. parenting			
recreation, leisure, community life e.g. social ceremonies			
religious or spiritual practices e.g. attending church			

[1] In this guidance on support, we begin with an estimate of the need for support based on body functioning. This table refers to a person whose L2 (or any level to S5) and above motor nerves are intact with no motor function below this. A range of other factors also need to be considered to establish the need for support workers (refer to Figure 1).

Assistive technology L2-S5 - no motor function below

The list for L2–S5 is a guide only and is not inclusive of all the assistive technology/products a person may require. Other assistive technology or products may be recommended depending on individual circumstances, personal choice and independence. All assistive technology recommendations should be developed through best-practice reasoning and person-centred assessment.

- Motorised, height-adjustable bed, with appropriate controls and equipment as prescribed, or an ensemble bed with additional bed equipment as prescribed
- Pressure relief mattress or standard mattress as required
- Two wheelchairs (manual, power or power assist) as prescribed
- Push mitts, and replacements
- Pressure relief wheelchair cushions (2) and covers (2)
- Hoist if required
- Shower commode or shower chair or bath seat as prescribed
- Portable shower hose as required
- Adaptive devices as needed for personal care (e.g. dressing, grooming, showering) and domestic tasks, cooking, cleaning, laundry etc.
- Long-handled skin-inspection mirror
- Over-bed table, height adjustable
- Portable lightweight ramps
- Transfer board
- Appropriate adaptations to a self-drive vehicle including wheelchair hoist; may require assistive transfer device
- Driving pressure relief cushion
- Adjustable desk
- Exercise equipment as prescribed
- Communication and information devices including accessible home telephone/landline, ‘back-to-base’ personal alarm system
- Abdominal binders as required
- Anti-embolic or compression stockings as prescribed
- Non-invasive ventilator if sleep apnoea diagnosed, as required
- Walking aids and orthotic devices as prescribed

Additional assistive technology may be needed for other activities and participation in life roles depending on the person’s individual preferences and lifestyle choices, for example, pre-injury activities, parenting role, work, recreation and leisure activities. This may include items such as a sports or recreational wheelchair, adapted sports equipment, club or other memberships, etc. Trial and possible hire of assistive technology should be considered.

12.2 Some motor function below the level of spinal cord injury

Definitions and descriptors

For the purposes of this guidance two descriptors of spinal cord injury with some motor function below were used. The description of ambulation and upper limb motor functioning are critical to determining the need for support.

i. **Ambulation**

A modification to the Hoffer Scale [31] was used for categorising ambulation. The definitions of ambulation used in the guidance for 'non-walker', 'household walker' and 'community walker' are detailed in the box below.

Definitions of terms for ambulation

Non-walker

Non-walker refers to a person who is not walking and always uses a wheelchair. This category includes a person who may be able to transfer in standing with assistance. It also includes a person who walks in therapy, but does not perform functional walking.

Household walker

Household walker refers to a person who can only walk indoors, usually with a walking aid. A household walker is able to get in and out of a chair and bed with little, if any, assistance. They may use a wheelchair for some indoor activities at home, work or school, and in the community.

Community walker

Community walker refers to a person who walks indoors and outdoors for most of their activities and may need crutches or braces, or both. They may use a wheelchair for long distances.

ii. **Upper limb**

The descriptor for upper limb functioning includes two grades of shoulder function and three grades of hand function. The definitions are provided below.

Definitions of upper limb function

Shoulder function

None to poor shoulder function (e.g. shrug shoulders)

Good to full shoulder function (e.g. raising arm to shoulder or above head)

Hand function

None to poor hand function (e.g. may have tenodesis grip)

Some to good hand function (e.g. may have active grasp/release, may not have fine hand movement)

Very good to full hand function (e.g. strong grip and good dexterity)

12.2.1 Cervical spine some motor function below

Level of support: C1–C5 some motor function below – requires ventilator support, non-walker, none or poor upper limb function

People whose injury is in this category who require ventilator support would generally require the same level of support and assistive technology as those with no motor function below C1–C5 level. Refer to the relevant level of support tables and assistive technology lists for C1–C5 no motor function below in Section 12.1 and disposable items lists in Section 11.1.

Level of support: Cervical spine some motor function below non-walker[1]

Brief description of motor control and body functioning

The need for support is the same as cervical 4 (C4) no motor function below and not ventilator dependent[2].

- total paralysis to limited control of trunk and lower extremities
- may have impaired head and neck control
- respiratory muscle function may be impaired and respiratory capacity and endurance compromised.
- may have autonomic dysfunction

Shoulder function	None – poor	✓	Hand fuction	None – poor	✓
	Good – full			Some – good	
				Very good – full	

Key to estimating support needs

0 = no assistance	person completes the task
X = standby assistance	person completes task with monitoring, supervision
+ = needs some/set-up support	person completes more than 75% of the task
++ = needs moderate support	person completes approximately 25–75% of the task
+++ = needs full support	person completes 25% or less of the task

activity/participation	need for support	comment (e.g. capacity/performance, context)	estimated hours (per week) (depends on personal circumstances)
Transfers and moving around			42–91 (lower range where the level of injury is lower) If sleepover is required - additional 56 hours per week
transfers and bed mobility	+++	1–2 assistants depending on individual factors e.g. motor control, weight of person, spasms	
moving around home	x	• ability to manoeuvre power wheelchair with accessible controls • needs full support for manual wheelchair (+++)	
moving around the community-wheelchair	++		
moving around the community-transport	+++	• wheel-in vehicle required	
Self-care			
showering/washing self	+++	1–2 assistants depending on individual factors e.g. bathing/showering, bladder/bowel management, transfers, skin integrity	
grooming/caring for body	+++		
eating and drinking	+++		
toileting (bowel)	+++		
toileting (bladder)	+++		
dressing (upper)	+++		
dressing (lower)	+++		
overnight care	+++		
health needs (includes preventative health)	+++	• medical appointments • exercise • medication management • nursing – regular checks, catheter change	
Domestic life			18–21 0.5–2
meal preparation	+++	routine domestic tasks can be attended to by support workers	
light housework	+++		
heavy housework	+++		
shopping	+++	shopping with the person	
communication and household management - set-up for devices e.g. computers, banking/life administration tasks, correspondence (mail)	+	possible use of assistive technology with accessible controls requiring set-up	
maintaining home and garden	+++	the lower range of hours expected for a person living in an apartment, although may require hours for minor home maintenance	
Participation in major areas of life			need for support depends on the individual, contextual (environmental and personal) factors
education (informal at home or other setting, school, tertiary, vocational)			
work and employment (includes non-remunerative work)			
caring for others e.g. parenting			
recreation, leisure, community life e.g. social ceremonies			
religious or spiritual practices e.g. attending church			

[1] In this guidance on support, we begin with an estimate of the need for support based on body functioning. This table refers to a person whose cervical spinal cord is intact above the level of the injury, with some motor function below this. A range of other factors also need to be considered to establish the need for support workers (refer to Figure 1). [2] Additional support needs should be considered for a person who is ventilator dependent.

Level of support: Cervical spine some motor function below non-walker[1]

Brief description of motor control and body functioning

- total paralysis to limited control of trunk and lower extremities
- may have impaired head and neck control
- respiratory muscle function may be impaired and respiratory capacity and endurance compromised – not ventilator dependent[2]
- may have autonomic dysfunction

Shoulder function	None – poor	✓	Hand fuction	None – poor	
	Good – full			Some – good	✓
				Very good – full	

Key to estimating support needs

0 = no assistance	person completes the task
X = standby assistance	person completes task with monitoring, supervision
+ = needs some/set-up support	person completes more than 75% of the task
++ = needs moderate support	person completes approximately 25–75% of the task
+++ = needs full support	person completes 25% or less of the task

activity/participation	need for support	comment (e.g. capacity/performance, context)	estimated hours (per week) (depends on personal circumstances)
Transfers and moving around			21–49 If sleepover is required- additional 56 hours per week
transfers and bed mobility	+++	• level of assistance depends on individual factors (+++) • needs assistance with floor to chair transfer (+++)	
moving around home	x	• ability to manoeuvre power wheelchair with accessible controls • needs assistance for manual wheelchair (+++)	
moving around the community-wheelchair	++		
moving around the community-transport	++	varies: • may be able to drive with appropriately modified vehicle • assistance needed with transfer, loading wheelchair, clamping (+++) • may need assistance with public transport (++)	
Self-care			
showering/washing self	++	depending on individual factors e.g. bathing/showering, bladder/bowel management, transfers, skin integrity	
grooming/caring for body	++		
eating and drinking	++		
toileting (bowel)	+++		
toileting (bladder)	++		
dressing (upper)	++		
dressing (lower)	+++		
health needs (includes preventative health)	++	• medical appointments • exercise • intermittent suction may be required • nursing – regular checks, catheter change	
Domestic life			16–18 0.5–2
meal preparation	++	routine domestic tasks can be attended to by support workers	
light housework	++		
heavy housework	+++		
shopping	++	shopping with the person	
communication and household management - set-up for devices e.g. computers, banking/life administration tasks, correspondence (mail)	0	• use of assistive technology with accessible controls requiring set-up • may need set-up assistance (+)	
maintaining home and garden	+++	the lower range of hours expected for a person living in an apartment, although may require hours for minor home maintenance	
Participation in major areas of life			need for support depends on the individual, and contextual (environmental and personal) factors
education (informal at home or other setting, school, tertiary, vocational)			
work and employment (includes non-remunerative work)			
caring for others e.g. parenting			
recreation, leisure, community life e.g. social ceremonies			
religious or spiritual practices e.g. attending church			

[1] In this guidance on support, we begin with an estimate of the need for support based on body functioning. This table refers to a person whose cervical spinal cord is intact above the level of the injury, with some motor function below this. A range of other factors also need to be considered to establish the need for support workers (refer to Figure 1). [2] Additional support needs should be considered for a person who is ventilator dependent.

Level of support: Cervical spine some motor function below non-walker[1]

Brief description of motor control and body functioning

- total paralysis to limited control of trunk and lower extremities
- may have impaired head and neck control
- respiratory muscle function may be impaired and respiratory capacity and endurance compromised – not ventilator dependent[2]
- may have autonomic dysfunction

Shoulder function	None – poor	✓	Hand fuction	None – poor	
	Good – full			Some – good	
				Very good – full	✓

Key to estimating support needs

0 = no assistance	person completes the task
X = standby assistance	person completes task with monitoring, supervision
+ = needs some/set-up support	person completes more than 75% of the task
++ = needs moderate support	person completes approximately 25–75% of the task
+++ = needs full support	person completes 25% or less of the task

activity/participation	need for support	comment (e.g. capacity/performance, context)	estimated hours (per week) (depends on personal circumstances)
Transfers and moving around			14–28
transfers and bed mobility	+++	• may be independent • needs assistance with floor to chair transfer (+++)	
moving around home	0	• independent with power wheelchair (and if required portable ventilator) • needs assistance for manual wheelchair (++)	
moving around the community-wheelchair	0		
moving around the community-transport	+	varies: • may be able to drive with appropriately modified vehicle • may need assistance with transfer, loading wheelchair, clamping (+) • may need assistance with public transport (+)	
Self-care			
showering/washing self	++	depending on individual factors e.g. bathing/showering, bladder/bowel management, transfers, skin integrity	
grooming/caring for body	++		
eating and drinking	++		
toileting (bowel)	+++		
toileting (bladder)	++		
dressing (upper)	++		
dressing (lower)	+++		
health needs (includes preventative health)	+	• medical appointments • exercise • intermittent suction may be required • nursing – regular checks, catheter change	
Domestic life			16–18 0.5–2
meal preparation	++	routine domestic tasks can be attended to by support workers	
light housework	++		
heavy housework	+++		
shopping	++	shopping with the person	
communication and household management - set-up for devices e.g. computers, banking/life administration tasks, correspondence (mail)	0	• use of assistive technology with accessible controls requiring set-up • may need set-up assistance (+)	
maintaining home and garden	+++	the lower range of hours expected for a person living in an apartment, although may require hours for minor home maintenance	
Participation in major areas of life			need for support depends on the individual, and contextual (environmental and personal) factors
education (informal at home or other setting, school, tertiary, vocational)			
work and employment (includes non-remunerative work)			
caring for others e.g. parenting			
recreation, leisure, community life e.g. social ceremonies			
religious or spiritual practices e.g. attending church			

[1] In this guidance on support, we begin with an estimate of the need for support based on body functioning. This table refers to a person whose cervical spinal cord is intact above the level of the injury, with some motor function below this. A range of other factors also need to be considered to establish the need for support workers (refer to Figure 1). [2] Additional support needs should be considered for a person who is ventilator dependent.

Level of support: Cervical spine some motor function below non-walker[1]

Brief description of motor control and body functioning

- total paralysis to limited control of trunk and lower extremities
- may have impaired head and neck control
- respiratory muscle function may be impaired and respiratory capacity and endurance compromised – not ventilator dependent[2]
- may have autonomic dysfunction

Shoulder function	None – poor		Hand fuction	None – poor	✓
	Good – full	✓		Some – good	
				Very good – full	

Key to estimating support needs

0 = no assistance	person completes the task
X = standby assistance	person completes task with monitoring, supervision
+ = needs some/set-up support	person completes more than 75% of the task
++ = needs moderate support	person completes approximately 25–75% of the task
+++ = needs full support	person completes 25% or less of the task

activity/participation	need for support	comment (e.g. capacity/performance, context)	estimated hours (per week) (depaends on personal circumstances)
Transfers and moving around			42–49 (lower range where the level of injury is lower) If inactive sleepover is required- additional 56 hours per week
transfers and bed mobility	+++	1–2 assistants depending on individual factors e.g. motor control, weight of person, spasms	
moving around home	x	• ability to manoeuvre power wheelchair with accessible controls and portable ventilator • needs assistance for manual wheelchair (++)	
moving around the community-wheelchair	+		
moving around the community-transport	++	• may be able to drive with appropriately modified vehicle • may need assistance with transfer, loading wheelchair, clamping (++) • may need assistance with public transport (++)	
Self-care			
showering/washing self	++	need for assistance depends on individual factors e.g. bathing/ showering, bladder/bowel management, transfers, skin integrity	
grooming/caring for body	++		
eating and drinking	+		
toileting (bowel)	+++		
toileting (bladder)	+++		
dressing (upper)	+++		
dressing (lower)	+++		
health needs (includes preventative health)	++	• may be independent with medical appointments and medication management • needs assistance with exercise, nursing –regular checks, catheter change	
Domestic life			18–21 0.5–2
meal preparation	+++	routine domestic tasks can be attended to by support workers	
light housework	+++		
heavy housework	+++		
shopping	+++	shopping with the person	
communication and household management - set-up for devices e.g. computers, banking/life administration tasks, correspondence (mail)	x	possible use of assistive technology with accessible controls requiring set-up	
maintaining home and garden	+++	the lower range of hours expected for a person living in an apartment, although may require hours for minor home maintenance	
Participation in major areas of life			need for support depends on the individual, and contextual (environmental and personal) factors
education (informal at home or other setting, school, tertiary, vocational)			
work and employment (includes non-remunerative work)			
caring for others e.g. parenting			
recreation, leisure, community life e.g. social ceremonies			
religious or spiritual practices e.g. attending church			

[1] In this guidance on support, we begin with an estimate of the need for support based on body functioning. This table refers to a person whose cervical spinal cord is intact above the level of the injury, with some motor function below this. A range of other factors also need to be considered to establish the need for support workers (refer to Figure 1). [2] Additional support needs should be considered for a person who is ventilator dependent.

Level of support: Cervical spine some motor function below non-walker[1]

Brief description of motor control and body functioning

- total paralysis to limited control of trunk and lower extremities
- may have impaired head and neck control
- respiratory muscle function may be impaired and respiratory capacity and endurance compromised – not ventilator dependent[2]
- may have autonomic dysfunction

Shoulder function	None – poor		Hand fuction	None – poor	
	Good – full	✔		Some – good	✔
				Very good – full	

Key to estimating support needs

0 = no assistance	person completes the task
X = standby assistance	person completes task with monitoring, supervision
+ = needs some/set-up support	person completes more than 75% of the task
++ = needs moderate support	person completes approximately 25–75% of the task
+++ = needs full support	person completes 25% or less of the task

activity/participation	need for support	comment (e.g. capacity/performance, context)	estimated hours (per week) (depends on personal circumstances)
Transfers and moving around			14–21 (lower range where the level of injury is lower)
transfers and bed mobility	0	• may require support with uneven transfers (+) • may need assistance with floor to chair transfer (++)	
moving around home	0	• independent using power wheelchair or power assist • needs assistance with manual wheelchair on uneven surfaces/curbs	
moving around the community-wheelchair	+		
moving around the community-transport	0	• independent driving with appropriately modified vehicle • may need assistance with transfer, loading wheelchair, clamping (+)	
Self-care			
showering/washing self	0		
grooming/caring for body	0		
eating and drinking	0		
toileting (bowel)	++	may be independent	
toileting (bladder)	++	may be independent	
dressing (upper)	0		
dressing (lower)	++		
health needs (includes preventative health)	++	• independent with arranging medical appointments, medication management • may need assistance with exercise • nursing – regular checks, catheter change (++)	
Domestic life			7–21 0.5–2
meal preparation	++	assistance for complex meal preparation	
light housework	+		
heavy housework	+++		
shopping	++	shopping with the person	
communication and household management - set-up for devices e.g. computers, banking/life administration tasks, correspondence (mail)	0	• use of assistive technology with accessible controls requiring set-up • may need set-up assistance (+)	
maintaining home and garden	+++	the lower range of hours expected for a person living in an apartment, although may require hours for minor home maintenance	
Participation in major areas of life			need for support depends on the individual, and contextual (environmental and personal) factors
education (informal at home or other setting, school, tertiary, vocational)			
work and employment (includes non-remunerative work)			
caring for others e.g. parenting			
recreation, leisure, community life e.g. social ceremonies			
religious or spiritual practices e.g. attending church			

[1] In this guidance on support, we begin with an estimate of the need for support based on body functioning. This table refers to a person whose cervical spinal cord is intact above the level of the injury, with some motor function below this. A range of other factors also need to be considered to establish the need for support workers (refer to Figure 1). [2] Additional support needs should be considered for a person who is ventilator dependent.

Level of support: Cervical spine some motor function below non-walker[1]

Brief description of motor control and body functioning

- total paralysis to limited control of trunk and lower extremities
- may have impaired head and neck control
- respiratory muscle function impaired and respiratory capacity and endurance compromised – not ventilator dependent[2]
- may have autonomic dysfunction

Shoulder function	None – poor		Hand fuction	None – poor	
	Good – full	✓		Some – good	
				Very good – full	✓

Key to estimating support needs

0 = no assistance	person completes the task
X = standby assistance	person completes task with monitoring, supervision
+ = needs some/set-up support	person completes more than 75% of the task
++ = needs moderate support	person completes approximately 25–75% of the task
+++ = needs full support	person completes 25% or less of the task

activity/participation	need for support	comment (e.g. capacity/performance, context)	estimated hours (per week) (depends on personal circumstances)
Transfers and moving around			14–21
transfers and bed mobility	0	• may need assistance with uneven transfers (+) • may need support with floor to chair transfer (+)	
moving around home	0	independent using power and manual wheelchair	
moving around the community-wheelchair	+	• independent using power wheelchair or power assist • may need assistance with manual wheelchair on uneven surfaces/ curbs (+)	
moving around the community-transport	0	varies: • independent driving with appropriately modified vehicle • may need assistance with transfer, loading wheelchair, clamping (+) • may need assistance with public transport (+)	
Self-care			
showering/washing self	0		
grooming/caring for body	0		
eating and drinking	0		
toileting (bowel)	++	may be independent	
toileting (bladder)	++	may be independent	
dressing (upper)	0		
dressing (lower)	++		
health needs (includes preventative health)	+	• independent with arranging medical appointments, medication management • may need assistance with exercise • nursing – regular checks, catheter change	
Domestic life			3–21
meal preparation	++	assistance for complex meal preparation	
light housework	+		
heavy housework	+++		
shopping	++	shopping with the person	
communication and household management - set-up for devices e.g. computers, banking/life administration tasks, correspondence (mail)	0	possible use of assistive technology with accessible controls requiring set-up	
maintaining home and garden	+++	the lower range of hours expected for a person living in an apartment, although may require hours for minor home maintenance	0.5–2
Participation in major areas of life			need for support depends on the individual, and contextual (environmental and personal) factors
education (informal at home or other setting, school, tertiary, vocational)			
work and employment (includes non-remunerative work)			
caring for others e.g. parenting			
recreation, leisure, community life e.g. social ceremonies			
religious or spiritual practices e.g. attending church			

[1] In this guidance on support, we begin with an estimate of the need for support based on body functioning. This table refers to a person whose cervical spinal cord is intact above the level of the injury, with some motor function below this. A range of other factors also need to be considered to establish the need for support workers (refer to Figure 1). [2] Additional support needs should be considered for a person who is ventilator dependent.

Assistive technology: C1-C5 some motor function below – non–walker

DOES NOT REQUIRE VENTILATOR SUPPORT

None to poor upper limb function

People whose injury is in this category would generally require the same assistive technology as those with no motor function below C1–C5 level. For example, C4 some motor function below, poor upper limb function and a non-walker would correspond to C4 level with no motor function below. Refer to the relevant assistive technology lists for no motor function below injury in Section 12.1.

Some to good upper limb function

People whose injury is in this category would generally require the same assistive technology as those with injury at the same level but with no motor function below. For example, C4 some motor function below and a non-walker would correspond to C4 level with no motor function below. Refer to the relevant assistive technology lists for no motor function below injury in Section 12.1.

Additional or different features of assistive technology may be required, such as:

- mobile arm supports
- adaptive technology accessories and equipment
- assistive devices for toileting (e.g. bidet attachment)
- adaptive clothing
- hoist as indicated
- appropriately modified vehicle.

Assistive technology: C6–C8 some motor function below – non–walker

None to poor upper limb function

None or poor upper limb function would generally not apply to injuries at this level with some motor function below unless there are other injuries or co-morbidities. People with injuries at C6–C8 would be expected to have some, good or full upper limb function.

Some to good upper limb function

People whose injury is in this category would generally require the same assistive technology as those with injury at the same level but with no motor function below. For example, C6 some motor function below, some to good upper limb function and a non-walker would correspond to C6 level with no motor function below. Refer to the relevant assistive technology lists for no motor function below injury in Section 12.1.

Very good to full upper limb function

People whose injury is in this category would generally require the same assistive technology as those with no motor function below C7–C8 level. Refer to the relevant assistive technology lists for no motor function below injury in Section 12.1.

Level of support: Cervical spine some motor function below household walker[1]

Brief description of motor control and body functioning

- limited control of trunk and moderate control of lower extremities
- respiratory muscle function may be impaired and respiratory capacity and endurance compromised
- may have autonomic dysfunction

Shoulder function	None – poor	✔	Hand fuction	None – poor	✔
	Good – full			Some – good	
				Very good – full	

Key to estimating support needs

0 = no assistance	person completes the task
X = standby assistance	person completes task with monitoring, supervision
+ = needs some/set-up support	person completes more than 75% of the task
++ = needs moderate support	person completes approximately 25–75% of the task
+++ = needs full support	person completes 25% or less of the task

activity/participation	need for support	comment (e.g. capacity/performance, context)	estimated hours (per week) (depends on personal circumstances)
Transfers and moving around			35–91 If the person is at risk of falls, inactive sleepover may be required (an additional 56 hours) or alternative safety strategy may be required.
transfers and bed mobility	++	may need assistance with floor to chair transfer (+) depending on individual factors e.g. motor control, weight of person, spasms	
moving around home	x	• possible ability to manoeuvre power wheelchair with accessible controls • needs full assistance for manual wheelchair (+++)	
moving around the community-wheelchair	+		
moving around the community-transport	++	varies: • may be able to drive with appropriately modified vehicle • may need assistance with transfer, loading wheelchair, clamping (++) • may need assistance with public transport (++)	
Self-care			
showering/washing self	+++	depending on individual factors e.g. bathing/showering, bladder/bowel management, transfers, skin integrity	
grooming/caring for body	+++		
eating and drinking	+++		
toileting (bowel)	+++		
toileting (bladder)	+++		
dressing (upper)	+++		
dressing (lower)	+++		
health needs (includes preventative health)	+++	• medical appointments • exercise • medication management • nursing – regular checks, catheter change	
Domestic life			7–14 0.5–2
meal preparation	+++	routine domestic tasks can be attended to by support workers	
light housework	+++		
heavy housework	+++		
shopping	+++	shopping with the person	
communication and household management - set-up for devices e.g. computers, banking/life administration tasks, correspondence (mail)	+	possible use of assistive technology with accessible controls requiring set-up	
maintaining home and garden	+++	the lower range of hours expected for a person living in an apartment, although may require hours for minor home maintenance	
Participation in major areas of life			need for support depends on the individual, and contextual (environmental and personal) factors
education (informal at home or other setting, school, tertiary, vocational)			
work and employment (includes non-remunerative work)			
caring for others e.g. parenting			
recreation, leisure, community life e.g. social ceremonies			
religious or spiritual practices e.g. attending church			

[1] In this guidance on support, we begin with an estimate of the need for support based on body functioning. This table refers to a person whose cervical spinal cord is intact above the level of the injury, with some motor function below this. A range of other factors also need to be considered to establish the need for support workers (refer to Figure 1).

Level of support: Cervical spine some motor function below household walker[1]

Brief description of motor control and body functioning

- some control of trunk and moderate control of lower extremities
- respiratory muscle function impaired and respiratory capacity and endurance compromised
- may have autonomic dysfunction

Shoulder function	None – poor	✓	Hand fuction	None – poor	
	Good – full			Some – good	✓
				Very good – full	

Key to estimating support needs

0 = no assistance	person completes the task
X = standby assistance	person completes task with monitoring, supervision
+ = needs some/set-up support	person completes more than 75% of the task
++ = needs moderate support	person completes approximately 25–75% of the task
+++ = needs full support	person completes 25% or less of the task

activity/participation	need for support	comment (e.g. capacity/performance, context)	estimated hours (per week) (depends on personal circumstances)
Transfers and moving around			21–49
transfers and bed mobility	++	may need assistance with floor to chair transfer depending on individual factors e.g. motor control, weight of person, spasms (+)	
moving around home	x		
moving around the community-wheelchair	+	• independent using power wheelchair or power assist • needs assistance with manual wheelchair on uneven surfaces/curbs (++)	
moving around the community-transport	++	varies: • may be able to drive with appropriately modified vehicle • may need assistance with transfer, loading wheelchair, clamping (++) • may need assistance with public transport (+)	
Self-care			
showering/washing self	+++		
grooming/caring for body	++		
eating and drinking	++		
toileting (bowel)	+++		
toileting (bladder)	++		
dressing (upper)	++		
dressing (lower)	+++		
health needs (includes preventative health)	+	• independent with arranging medical appointments, medication management • may need assistance with exercise • nursing – regular checks, catheter change	
Domestic life			16–18 0.5–2
meal preparation	++	assistance for complex meal preparation	
light housework	++		
heavy housework	+++		
shopping	++	shopping with the person	
communication and household management - set-up for devices e.g. computers, banking/life administration tasks, correspondence (mail)	0	possible use of assistive technology with accessible controls requiring set-up	
maintaining home and garden	+++	the lower range of hours expected for a person living in an apartment, although may require hours for minor home maintenance	
Participation in major areas of life			need for support depends on the individual, and contextual (environmental and personal) factors
education (informal at home or other setting, school, tertiary, vocational)			
work and employment (includes non-remunerative work)			
caring for others e.g. parenting			
recreation, leisure, community life e.g. social ceremonies			
religious or spiritual practices e.g. attending church			

[1] In this guidance on support, we begin with an estimate of the need for support based on body functioning. This table refers to a person where the cervical spinal cord is intact above the level of the injury, with some motor function below this. A range of other factors also need to be considered to establish the need for support workers (refer to Figure 1).

Level of support: Cervical spine some motor function below household walker[1]

Brief description of motor control and body functioning

- limited to full control of trunk and lower extremities
- minimal compromise of respiratory muscle function
- may have autonomic dysfunction

Shoulder function	None – poor	✓	Hand fuction	None – poor	
	Good – full			Some – good	
				Very good – full	✓

Key to estimating support needs

0 = no assistance	person completes the task
X = standby assistance	person completes task with monitoring, supervision
+ = needs some/set-up support	person completes more than 75% of the task
++ = needs moderate support	person completes approximately 25–75% of the task
+++ = needs full support	person completes 25% or less of the task

activity/participation	need for support	comment (e.g. capacity/performance, context)	estimated hours (per week) (depends on personal circumstances)
Transfers and moving around			14–28
transfers and bed mobility	+	may need assistance with floor to chair transfers (+)	
moving around home	x		
moving around the community-wheelchair	0	• independent using power wheelchair or power assist • needs assistance with manual wheelchair on uneven surfaces/curbs (++)	
moving around the community-transport	+	varies: • may be able to drive with appropriately modified vehicle • may need assistance with transfer, loading wheelchair, clamping (++) • may need assistance with public transport (+)	
Self-care			
showering/washing self	++	depending on individual factors e.g. bathing/showering, bladder/bowel management, transfers, skin integrity	
grooming/caring for body	++		
eating and drinking	++		
toileting (bowel)	+++		
toileting (bladder)	++		
dressing (upper)	++		
dressing (lower)	++		
health needs (includes preventative health)	+	• medical appointments • exercise • nursing – regular checks, catheter change	
Domestic life			16–18 0.5–2
meal preparation	++	routine domestic tasks can be attended to by support workers	
light housework	++		
heavy housework	+++		
shopping	++		
communication and household management - set-up for devices e.g. computers, banking/life administration tasks, correspondence (mail)	0	possible use of assistive technology with accessible controls requiring set-up	
maintaining home and garden	+++	the lower range of hours expected for a person living in an apartment, although may require hours for minor home maintenance	
Participation in major areas of life			need for support depends on the individual, and contextual (environmental and personal) factors
education (informal at home or other setting, school, tertiary, vocational)			
work and employment (includes non-remunerative work)			
caring for others e.g. parenting			
recreation, leisure, community life e.g. social ceremonies			
religious or spiritual practices e.g. attending church			

[1] In this guidance on support, we begin with an estimate of the need for support based on body functioning. This table refers to a person where the cervical spinal cord is intact above the level of the injury, with some motor function below this. A range of other factors also need to be considered to establish the need for support workers (refer to Figure 1).

Level of support: Cervical spine some motor function below household walker[1]

Brief description of motor control and body functioning

- some control of trunk and moderate control of lower extremities
- respiratory muscle function impaired and respiratory capacity and endurance compromised
- may have autonomic dysfunction

Shoulder function	None – poor		Hand fuction	None – poor	✓
	Good – full	✓		Some – good	
				Very good – full	

Key to estimating support needs

0 = no assistance	person completes the task
X = standby assistance	person completes task with monitoring, supervision
+ = needs some/set-up support	person completes more than 75% of the task
++ = needs moderate support	person completes approximately 25–75% of the task
+++ = needs full support	person completes 25% or less of the task

activity/participation	need for support	comment (e.g. capacity/performance, context)	estimated hours (per week) (depends on personal circumstances)
Transfers and moving around			21–49
transfers and bed mobility	+	• may only need supervision (x) • may need assistance with floor to chair transfer (++)	
moving around home	x		
moving around the community-wheelchair	+	• independent using power wheelchair or power assist • needs assistance with manual wheelchair on uneven surfaces/curbs (++)	
moving around the community-transport	++	• may be able to drive with appropriately modified vehicle • may need assistance with transfer, loading wheelchair, clamping (+) • may need assistance with public transport (+)	
Self-care			
showering/washing self	++		
grooming/caring for body	++		
eating and drinking	+		
toileting (bowel)	+++		
toileting (bladder)	+++		
dressing (upper)	+++		
dressing (lower)	+++		
health needs (includes preventative health)	++	• independent with arranging medical appointments, medication management • may need assistance with exercise • nursing – regular checks, catheter change	
Domestic life			18–21 0.5–2
meal preparation	+++	assistance for complex meal preparation	
light housework	+++		
heavy housework	+++		
shopping	+++	shopping with the person	
communication and household management - set-up for devices e.g. computers, banking/life administration tasks, correspondence (mail)	x	possible use of assistive technology with accessible controls requiring set-up	
maintaining home and garden	+++	the lower range of hours expected for a person living in an apartment, although may require hours for minor home maintenance	
Participation in major areas of life			need for support depends on the individual, and contextual (environmental and personal) factors
education (informal at home or other setting, school, tertiary, vocational)			
work and employment (includes non-remunerative work)			
caring for others e.g. parenting			
recreation, leisure, community life e.g. social ceremonies			
religious or spiritual practices e.g. attending church			

[1] In this guidance on support, we begin with an estimate of the need for support based on body functioning. This table refers to a person where the cervical spinal cord is intact above the level of the injury, with some motor function below this. A range of other factors also need to be considered to establish the need for support workers (refer to Figure 1).

Level of support: Cervical spine some motor function below household walker[1]

Brief description of motor control and body functioning

- some control of trunk and moderate control of lower extremities
- respiratory muscle function impaired and respiratory capacity and endurance compromised
- may have autonomic dysfunction

Shoulder function	None – poor		Hand fuction	None – poor	
	Good – full	✔		Some – good	✔
				Very good – full	

Key to estimating support needs

0 = no assistance	person completes the task
X = standby assistance	person completes task with monitoring, supervision
+ = needs some/set-up support	person completes more than 75% of the task
++ = needs moderate support	person completes approximately 25–75% of the task
+++ = needs full support	person completes 25% or less of the task

activity/participation	need for support	comment (e.g. capacity/performance, context)	estimated hours (per week) (depends on personal circumstances)
Transfers and moving around			7–21
transfers and bed mobility	+	needs assistance with floor to chair transfer (+)	
moving around home	x		
moving around the community-wheelchair	0	• independent using power wheelchair or power assist • may need assistance with manual wheelchair on uneven surfaces/curbs (+)	
moving around the community-transport	0	• independent driving with appropriately modified vehicle	
Self-care			
showering/washing self	0		
grooming/caring for body	0		
eating and drinking	0		
toileting (bowel)	++		
toileting (bladder)	+		
dressing (upper)	0		
dressing (lower)	+		
health needs (includes preventative health)	+	• independent with arranging medical appointments, medication management • may need assistance with exercise • nursing – regular checks, catheter change	
Domestic life			7–14 0.5–2
meal preparation	+	assistance for complex meal preparation	
light housework	+		
heavy housework	+++		
shopping	++	shopping with the person	
communication and household management - set-up for devices e.g. computers, banking/life administration tasks, correspondence (mail)	0	possible use of assistive technology with accessible controls requiring set-up	
maintaining home and garden	+++	the lower range of hours expected for a person living in an apartment, although may require hours for minor home maintenance	
Participation in major areas of life			need for support depends on the individual, and contextual (environmental and personal) factors
education (informal at home or other setting, school, tertiary, vocational)			
work and employment (includes non-remunerative work)			
caring for others e.g. parenting			
recreation, leisure, community life e.g. social ceremonies			
religious or spiritual practices e.g. attending church			

[1] In this guidance on support, we begin with an estimate of the need for support based on body functioning. This table refers to a person where the cervical spinal cord is intact above the level of the injury, with some motor function below this. A range of other factors also need to be considered to establish the need for support workers (refer to Figure 1).

Level of support: Cervical spine some motor function below household walker[1]

Brief description of motor control and body functioning

- some control of trunk and moderate control of lower extremities
- limited compromise of respiratory function
- may have autonomic dysfunction

Shoulder function	None – poor		Hand fuction	None – poor	
	Good – full	✔		Some – good	
				Very good – full	✔

Key to estimating support needs

0 = no assistance	person completes the task
X = standby assistance	person completes task with monitoring, supervision
+ = needs some/set-up support	person completes more than 75% of the task
++ = needs moderate support	person completes approximately 25–75% of the task
+++ = needs full support	person completes 25% or less of the task

activity/participation	need for support	comment (e.g. capacity/performance, context)	estimated hours (per week) (depends on personal circumstances)
Transfers and moving around			7–14
transfers and bed mobility	+	needs assistance with floor to chair transfer (+)	
moving around home	x		
moving around the community-wheelchair	0	• independent using power wheelchair or power assist • may need assistance with manual wheelchair on uneven surfaces/curbs (+)	
moving around the community-transport	0	• independent driving with appropriately modified vehicle	
Self-care			
showering/washing self	0		
grooming/caring for body	0		
eating and drinking	0		
toileting (bowel)	+		
toileting (bladder)	+		
dressing (upper)	0		
dressing (lower)	0		
health needs (includes preventative health)	0	• independent with arranging medical appointments, medication management • may need assistance with exercise (+) • nursing – regular checks, catheter change (+)	
Domestic life			7–14 0.5–2
meal preparation	0	assistance for complex meal preparation	
light housework	+		
heavy housework	+++		
shopping	++	may need assistance with loading and unloading	
communication and household management - set-up for devices e.g. computers, banking/life administration tasks, correspondence (mail)	0	possible use of assistive technology with accessible controls requiring set-up	
maintaining home and garden	+++	the lower range of hours expected for a person living in an apartment, although may require hours for minor home maintenance	
Participation in major areas of life			need for support depends on the individual, and contextual (environmental and personal) factors
education (informal at home or other setting, school, tertiary, vocational)			
work and employment (includes non-remunerative work)			
caring for others e.g. parenting			
recreation, leisure, community life e.g. social ceremonies			
religious or spiritual practices e.g. attending church			

[1] In this guidance on support, we begin with an estimate of the need for support based on body functioning. This table refers to a person where the cervical spinal cord is intact above the level of the injury, with some motor function below this. A range of other factors also need to be considered to establish the need for support workers (refer to Figure 1).

Assistive technology: C1–C5 some motor function below – household walker

None or poor upper limb function

People whose injury is in this category would generally require the same assistive technology as those with injury at the same level but with no motor function below. For example, C4 some motor function below, poor upper limb function and a household walker would correspond to C4 level with no motor function below. Refer to the relevant assistive technology lists for no motor function below injury in Section 12.1.

Additional or different features of assistive technology may be required, such as:

- environmental control system or technology as prescribed
- periodic use of a wheelchair
- mobility aids and orthotic devices for home and community
- a standing hoist
- assist-a-lift reclining chair
- mobile arm supports
- assistive devices for toileting (e.g. bidet attachment)
- adaptive clothing.

Some to good upper limb function

People whose injury is in this category would generally require the same assistive technology as those with injury at the same level but with no motor function below. For example, C4 some motor function below, some to good upper limb function and a household walker would correspond to C4 level with no motor function below. Refer to the relevant assistive technology lists for no motor function below injury in Section 12.1.

Additional or different features of assistive technology may be required, such as:

- may not require the highest level of pressure relieving devices (e.g. pressure mattresses, cushion or motorised height-adjustable bed)
- periodic use of a wheelchair or for long distances
- power assist for manual wheelchair
- walking aids and orthotic devices
- mobility and walking aids around home
- hoist
- assist-a-lift reclining chair and/or feature on wheelchair
- mobile arm supports
- assistive devices for toileting (e.g. bidet attachment)
- adaptive clothing
- accessible computer hardware and software
- appropriately modified vehicle.

Assistive technology: C6–C8 some motor function below – household walker

Some upper limb function

People whose injury is in this category would generally require the same assistive technology as those with injury at the same level but with no motor function below. For example, C6 some motor function below, some upper limb function and a household walker would correspond to C6 level with no motor function below. Refer to the relevant assistive technology lists for no motor function below injury in Section 12.1.

Additional or different features of assistive technology may be required, such as:

- may not require the highest level of pressure relieving devices (e.g. pressure mattresses, cushion or motorised height-adjustable bed)
- walking aids and orthotic devices
- assist-a-lift recliner chair and/or feature on wheelchair
- mobile arm supports
- adaptive clothing.

Good upper limb function

People whose injury is in this category would generally require the same assistive technology as those with injury at the same level but with no motor function below. For example, C7 some motor function below, good upper limb function and a household walker would correspond to C7 level with no motor function below. Refer to the relevant assistive technology lists for no motor function below injury in Section 12.1.

Additional or different features of assistive technology may be required, such as:

- may not require the highest level of pressure relieving devices (e.g. pressure mattresses, cushion or motorised height-adjustable bed).

Very good to full upper limb function

People whose injury is in this category would generally require the same assistive technology as those with no motor function below C7–C8 level. Refer to the relevant assistive technology lists for no motor function below injury in Section 12.1.

Additional or different features of assistive technology may be required, such as:

- may not require the highest level of pressure relieving devices (e.g. pressure mattresses, cushion or motorised height-adjustable bed).

Level of support: Cervical spine some motor function below community walker[1]

Brief description of motor control and body functioning

- good to full control of trunk and lower extremities
- may have impaired respiratory muscle function and compromised respiratory capacity and endurance
- may have autonomic dysfunction

Shoulder function	None – poor	✓	Hand fuction	None – poor	✓
	Good – full			Some – good	
				Very good – full	

Key to estimating support needs

0 = no assistance	person completes the task
X = standby assistance	person completes task with monitoring, supervision
+ = needs some/set-up support	person completes more than 75% of the task
++ = needs moderate support	person completes approximately 25–75% of the task
+++ = needs full support	person completes 25% or less of the task

activity/participation	need for support	comment (e.g. capacity/performance, context)	estimated hours (per week) (depends on personal circumstances)
Transfers and moving around			21–91
transfers and bed mobility	+	may need assistance with floor to chair transfer depending on individual factors e.g. motor control, weight of person, spasms (++)	
moving around home	0	• possible ability to manoeuvre power wheelchair with accessible controls • needs full support for manual wheelchair (+++)	
moving around the community-wheelchair	+		
moving around the community-transport	++	varies: • may be able to drive with appropriately modified vehicle • may need assistance with transfer, loading wheelchair, clamping (++) • may need assistance public transport (+)	
Self-care			
showering/washing self	+++	depending on individual factors e.g. bathing/showering, bladder/bowel management, transfers, skin integrity	
grooming/caring for body	+++		
eating and drinking	+++		
toileting (bowel)	+++		
toileting (bladder)	+++		
dressing (upper)	+++		
dressing (lower)	+++		
health needs (includes preventative health)	+++	• medical appointments • exercise • medication management • nursing – regular checks, catheter change	
Domestic life			18–21 0.5–2
meal preparation	+++	routine domestic tasks can be attended to by support workers	
light housework	+++		
heavy housework	+++		
shopping	+++	shopping with the person	
communication and household management - set-up for devices e.g. computers, banking/life administration tasks, correspondence (mail)	+	possible use of assistive technology with accessible controls requiring set-up	
maintaining home and garden	+++	the lower range of hours expected for a person living in an apartment, although may require hours for minor home maintenance	
Participation in major areas of life			need for support depends on the individual, and contextual (environmental and personal) factors
education (informal at home or other setting, school, tertiary, vocational)			
work and employment (includes non-remunerative work)			
caring for others e.g. parenting			
recreation, leisure, community life e.g. social ceremonies			
religious or spiritual practices e.g. attending church			

[1] In this guidance on support, we begin with an estimate of the need for support based on body functioning. This table refers to a person whose cervical spinal cord is intact above the level of the injury, with some motor function below this. A range of other factors also need to be considered to establish the need for support workers (refer to Figure 1).

Level of support: Cervical spine some motor function below community walker[1]

Brief description of motor control and body functioning

- good to full control of trunk and lower extremities
- may have impaired respiratory muscle function, compromised respiratory capacity and endurance
- may have autonomic dysfunction

Shoulder function	None – poor	✔	Hand fuction	None – poor	
	Good – full			Some – good	✔
				Very good – full	

Key to estimating support needs

0 = no assistance	person completes the task
X = standby assistance	person completes task with monitoring, supervision
+ = needs some/set-up support	person completes more than 75% of the task
++ = needs moderate support	person completes approximately 25–75% of the task
+++ = needs full support	person completes 25% or less of the task

activity/participation	need for support	comment (e.g. capacity/performance, context)	estimated hours (per week) (depends on personal circumstances)
Transfers and moving around			14–35
transfers and bed mobility	x	may need assistance with floor to chair transfer depending on individual factors e.g. motor control, weight of person, spasms (+)	
moving around home	0		
moving around the community-wheelchair	+	• independent using power wheelchair or power assist • needs assistance with manual wheelchair on uneven surfaces/curbs (++)	
moving around the community-transport	+	varies: • may be able to drive with appropriately modified vehicle • may need assistance with transfer, loading wheelchair, clamping (+) • may need assistance public transport (+)	
Self-care			
showering/washing self	+++	may require assistance with set-up	
grooming/caring for body	++		
eating and drinking	++		
toileting (bowel)	+++		
toileting (bladder)	++		
dressing (upper)	++		
dressing (lower)	+++		
health needs (includes preventative health)	+	• independent with arranging medical appointments, medication management • may need assistance with exercise • nursing – regular checks, catheter change	
Domestic life			16–18 0.5–2
meal preparation	++	assistance for complex meal preparation	
light housework	++		
heavy housework	+++		
shopping	++	shopping with the person	
communication and household management - set-up for devices e.g. computers, banking/life administration tasks, correspondence (mail)	0	possible use of assistive technology with accessible controls requiring set-up	
maintaining home and garden	+++	the lower range of hours expected for a person living in an apartment, although may require hours for minor home maintenance	
Participation in major areas of life			need for support depends on the individual, and contextual (environmental and personal) factors
education (informal at home or other setting, school, tertiary, vocational)			
work and employment (includes non-remunerative work)			
caring for others e.g. parenting			
recreation, leisure, community life e.g. social ceremonies			
religious or spiritual practices e.g. attending church			

[1] In this guidance on support, we begin with an estimate of the need for support based on body functioning. This table refers to a person whose cervical spinal cord is intact above the level of the injury, with some motor function below this. A range of other factors also need to be considered to establish the need for support workers (refer to Figure 1).

Level of support: Cervical spine some motor function below community walker[1]

Brief description of motor control and body functioning

- good to full control of trunk and lower extremities
- may have impaired respiratory muscle function, compromised respiratory capacity and endurance
- may have autonomic dysfunction

Shoulder function	None – poor	✓	Hand fuction	None – poor	
	Good – full			Some – good	
				Very good – full	✓

Key to estimating support needs

0 = no assistance	person completes the task
X = standby assistance	person completes task with monitoring, supervision
+ = needs some/set-up support	person completes more than 75% of the task
++ = needs moderate support	person completes approximately 25–75% of the task
+++ = needs full support	person completes 25% or less of the task

activity/participation	need for support	comment (e.g. capacity/performance, context)	estimated hours (per week) (depends on personal circumstances)
Transfers and moving around			14–21
transfers and bed mobility	x	may need assistance with floor to chair transfer depending on individual factors e.g. motor control, weight of person, spasms (+)	
moving around home	0		
moving around the community-wheelchair	0	• independent using power wheelchair or power assist • needs assistance with manual wheelchair on uneven surfaces/curbs (+)	
moving around the community-transport	+	varies: • may be able to drive with appropriately modified vehicle • may need assistance with transfer, loading wheelchair, clamping (+) • may need assistance with public transport (+)	
Self-care			
showering/washing self	++	may need assistance with set-up	
grooming/caring for body	++		
eating and drinking	+		
toileting (bowel)	++		
toileting (bladder)	+		
dressing (upper)	++		
dressing (lower)	++		
health needs (includes preventative health)	0	• independent with arranging medical appointments, medication management • may need assistance with exercise • nursing – regular checks, catheter change	
Domestic life			16–18 0.5–2
meal preparation	++	assistance for complex meal preparation	
light housework	++		
heavy housework	+++		
shopping	+	shopping with the person	
communication and household management - set-up for devices e.g. computers, banking/life administration tasks, correspondence (mail)	0	possible use of assistive technology with accessible controls requiring set-up	
maintaining home and garden	+++	the lower range of hours expected for a person living in an apartment, although may require hours for minor home maintenance	
Participation in major areas of life			need for support depends on the individual, and contextual (environmental and personal) factors
education (informal at home or other setting, school, tertiary, vocational)			
work and employment (includes non-remunerative work)			
caring for others e.g. parenting			
recreation, leisure, community life e.g. social ceremonies			
religious or spiritual practices e.g. attending church			

[1] In this guidance on support, we begin with an estimate of the need for support based on body functioning. This table refers to a person whose cervical spinal cord is intact above the level of the injury, with some motor function below this. A range of other factors also need to be considered to establish the need for support workers (refer to Figure 1).

Level of support: Cervical spine some motor function below community walker[1]

Brief description of motor control and body functioning

- good to full control of trunk and lower extremities
- may have impaired respiratory muscle function and compromised respiratory capacity and endurance
- may have autonomic dysfunction

Shoulder function	None – poor		Hand fuction	None – poor	✓
	Good – full	✓		Some – good	
				Very good – full	

Key to estimating support needs

0 = no assistance	person completes the task
X = standby assistance	person completes task with monitoring, supervision
+ = needs some/set-up support	person completes more than 75% of the task
++ = needs moderate support	person completes approximately 25–75% of the task
+++ = needs full support	person completes 25% or less of the task

activity/participation	need for support	comment (e.g. capacity/performance, context)	estimated hours (per week) (depends on personal circumstances)
Transfers and moving around			14–49
transfers and bed mobility	0	may need assistance with floor to chair transfer (+)	
moving around home	0	• independent using power wheelchair or power assist • assistance with manual wheelchair on uneven surfaces/curbs (++)	
moving around the community-wheelchair	+		
moving around the community-transport	+	varies: • may be able to drive with appropriately modified vehicle • may need assistance with transfer, loading wheelchair, clamping (++) • may need assistance with public transport (++)	
Self-care			
showering/washing self	++		
grooming/caring for body	++		
eating and drinking	+		
toileting (bowel)	+++		
toileting (bladder)	+++		
dressing (upper)	+++		
dressing (lower)	+++		
health needs (includes preventative health)	+++	• independent with arranging medical appointments, medication management • may need assistance with exercise • nursing – regular checks, catheter change	
Domestic life			16–18 0.5–2
meal preparation	+++		
light housework	++		
heavy housework	+++		
shopping	+++	• shopping with the person • assistance with loading and unloading	
communication and household management - set-up for devices e.g. computers, banking/life administration tasks, correspondence (mail)	0	possible use of assistive technology with accessible controls requiring set-up.	
maintaining home and garden	+++	the lower range of hours expected for a person living in an apartment, although may require hours for minor home maintenance	
Participation in major areas of life			need for support depends on the individual, and contextual (environmental and personal) factors
education (informal at home or other setting, school, tertiary, vocational)			
work and employment (includes non-remunerative work)			
caring for others e.g. parenting			
recreation, leisure, community life e.g. social ceremonies			
religious or spiritual practices e.g. attending church			

[1] In this guidance on support, we begin with an estimate of the need for support based on body functioning. This table refers to a person whose cervical spinal cord is intact above the level of the injury, with some motor function below this. A range of other factors also need to be considered to establish the need for support workers (refer to Figure 1).

Level of support: Cervical spine some motor function below community walker[1]

Brief description of motor control and body functioning

- good to full control of trunk and lower extremities
- may have impaired respiratory muscle function, compromised respiratory capacity and endurance
- may have autonomic dysfunction

Shoulder function	None – poor		Hand fuction	None – poor	
	Good – full	✔		Some – good	✔
				Very good – full	

Key to estimating support needs

0 = no assistance	person completes the task
X = standby assistance	person completes task with monitoring, supervision
+ = needs some/set-up support	person completes more than 75% of the task
++ = needs moderate support	person completes approximately 25–75% of the task
+++ = needs full support	person completes 25% or less of the task

activity/participation	need for support	comment (e.g. capacity/performance, context)	estimated hours (per week) (depends on personal circumstances)
Transfers and moving around			0–21
transfers and bed mobility	0	may need assistance with floor to chair transfer (+)	
moving around home	0		
moving around the community-wheelchair	0	• independent using power wheelchair or power assist • needs assistance with manual wheelchair on uneven surfaces/curbs (+)	
moving around the community-transport	+	varies: • may be able to drive with appropriately modified vehicle • may need assistance with transfer, loading wheelchair, clamping (+)	
Self-care			
showering/washing self	0	may be independent with all self-care	
grooming/caring for body	0		
eating and drinking	0		
toileting (bowel)	++		
toileting (bladder)	+		
dressing (upper)	0		
dressing (lower)	+		
health needs (includes preventative health)	0	• independent with arranging medical appointments, medication management • may need assistance with exercise (+) • nursing – regular checks, catheter change	
Domestic life			5–10 0.5–2
meal preparation	+	assistance for complex meal preparation	
light housework	0		
heavy housework	++		
shopping	+	assistance with loading and unloading	
communication and household management - set-up for devices e.g. computers, banking/life administration tasks, correspondence (mail)	0	possible use of assistive technology with accessible controls requiring set-up (+)	
maintaining home and garden	+++	the lower range of hours expected for a person living in an apartment, although may require hours for minor home maintenance	
Participation in major areas of life			need for support depends on the individual, and contextual (environmental and personal) factors
education (informal at home or other setting, school, tertiary, vocational)			
work and employment (includes non-remunerative work)			
caring for others e.g. parenting			
recreation, leisure, community life e.g. social ceremonies			
religious or spiritual practices e.g. attending church			

[1] In this guidance on support, we begin with an estimate of the need for support based on body functioning. This table refers to a person whose cervical spinal cord is intact above the level of the injury, with some motor function below this. A range of other factors also need to be considered to establish the need for support workers (refer to Figure 1).

Level of support: Cervical spine some motor function below community walker[1]

Brief description of motor control and body functioning

- good to full control of trunk and lower extremities
- may have impaired respiratory muscle function and compromised respiratory capacity and endurance
- may have autonomic dysfunction

Shoulder function	None – poor		Hand fuction	None – poor	
	Good – full	✔		Some – good	
				Very good – full	✔

Key to estimating support needs

0 = no assistance	person completes the task
X = standby assistance	person completes task with monitoring, supervision
+ = needs some/set-up support	person completes more than 75% of the task
++ = needs moderate support	person completes approximately 25–75% of the task
+++ = needs full support	person completes 25% or less of the task

activity/participation	need for support	comment (e.g. capacity/performance, context)	estimated hours (per week) (depends on personal circumstances)
Transfers and moving around			0–7
transfers and bed mobility	0	may need assistance with floor to chair transfer (+)	
moving around home	0		
moving around the community-wheelchair	0	independent using power wheelchair or power assist	
moving around the community-transport	0	varies: • independent driving with appropriately modified vehicle • may need assistance with transfer, loading wheelchair, clamping (+)	
Self-care			
showering/washing self	0	may be independent with all self-care	
grooming/caring for body	0		
eating and drinking	0		
toileting (bowel)	+		
toileting (bladder)	+		
dressing (upper)	0		
dressing (lower)	0		
health needs (includes preventative health)	0	• independent with medical appointments, medication management • may need assistance with exercise • nursing – regular checks, catheter change (+)	
Domestic life			3–7 0.5–2
meal preparation	0		
light housework	0		
heavy housework	++		
shopping	+		
communication and household management - set-up for devices e.g. computers, banking/life administration tasks, correspondence (mail)	0		
maintaining home and garden	++	the lower range of hours expected for a person living in an apartment, although may require hours for minor home maintenance	
Participation in major areas of life			need for support depends on the individual, and contextual (environmental and personal) factors
education (informal at home or other setting, school, tertiary, vocational)			
work and employment (includes non-remunerative work)			
caring for others e.g. parenting			
recreation, leisure, community life e.g. social ceremonies			
religious or spiritual practices e.g. attending church			

[1] In this guidance on support, we begin with an estimate of the need for support based on body functioning. This table refers to a person whose cervical spinal cord is intact above the level of the injury, with some motor function below this. A range of other factors also need to be considered to establish the need for support workers (refer to Figure 1).

Assistive technology: C1–C5 some motor function below – community walker

None to poor upper limb function

People whose injury is in this category would generally require the same assistive technology as those with injury at the same level but with no motor function below. For example, C4 some motor function below, poor upper limb function and a community walker would correspond to C4 level with no motor function below. Refer to the relevant assistive technology lists for no function below injury in Section 12.1.

Additional or different features of assistive technology may be required, such as:

- may not require the highest level of pressure relieving devices (e.g. pressure mattresses, cushion or motorised height-adjustable bed)
- environmental control system or technology as prescribed
- periodic use of a wheelchair for long distances
- power assist for manual wheelchair
- mobility aids and orthotic devices for home and community
- a standing hoist
- assist-a-lift reclining chair
- mobile arm supports
- assistive devices for toileting (e.g. bidet attachment).

Some to good upper limb function

People whose injury is in this category would generally require the same assistive technology as those with injury at the same level but with no motor function below. For example, C4 some motor function below, some upper limb function and a community walker would correspond to C4 level with no motor function below. Refer to the relevant assistive technology lists for no motor function below injury in Section 12.1.

Additional or different features of assistive technology may be required, such as:

- may not require the highest level of pressure relieving devices (e.g. pressure mattresses, cushion or motorised height-adjustable bed)
- walking aids and orthotic devices
- periodic use of a wheelchair or for long distances
- assist-a-lift reclining chair
- mobile arm supports
- assistive devices for toileting (e.g. bidet attachment)
- adaptive clothing
- accessible computer hardware and software
- appropriately modified vehicle.

Assistive technology: C6–C8 some motor function below – community walker

Some upper limb function

People whose injury is in this category would generally require the same assistive technology as those with injury at the same level but with no motor function below. For example, C6 some motor function below, some upper limb function and a community walker would correspond to C6 level with no motor function below. Refer to the relevant assistive technology lists for no motor function below injury in Section 12.1.

Additional or different features of assistive technology may be required, such as:

- may not require the highest level of pressure relieving devices (e.g. pressure mattresses, cushion or motorised height-adjustable bed)
- walking aids and orthotic devices
- assist-a-lift recliner chair and/or feature on wheelchair
- wheelchair for long distances
- mobile arm supports
- adaptive clothing.

Good upper limb function

People whose injury is in this category would generally require the same assistive technology as those with injury at the same level but with no motor function below. For example, C7some motor function below, good upper limb function and a community walker would correspond to C7 level with no motor function below. Refer to the relevant assistive technology lists for no motor function below injury in Section 12.1.

There may be additional or different features of the assistive technology required such as:

- may not require the highest level of pressure relieving devices (e.g. pressure mattresses, cushion or motorised height-adjustable bed)
- wheelchair for longer distances.

Very good to full upper limb function

People whose injury is in this category would generally require the same assistive technology as those with no motor function below C7–C8 level. Refer to the relevant assistive technology lists for no motor function below injury in Section 12.1.

Additional or different features of assistive technology may be required, such as:

- may not require the highest level of pressure relieving devices (e.g. pressure mattresses, cushion or motorised height-adjustable bed)
- walking aids and orthotic devices
- wheelchair for longer distances.

12.2.2 Thoracic to sacral spine some motor function below

Level of support: Thoracic to sacral some motor function below – non-walker

A person with paraplegia but with some motor function below the level of the injury and who is a non-walker would require the same level of support and assistive technology as for injury at the same level but with no motor function below. For example, T9 some motor function below and a non-walker would correspond to T9 level with no motor function below. Refer to the relevant assistive technology lists for no motor function below injury in Section 12.1.

Level of support: Thoracic to sacral spine some motor function below non–walker[1]

Brief description of motor control and body functioning

- total paralysis to some control of trunk and lower extremities
- full control of upper limbs. If the person has a T1 injury – use the chart for Cervical non–walker (good shoulder and good hand function).
- limited compromise of respiratory function

Shoulder function	None – poor		Hand fuction	None – poor	
	Good – full	✓		Some – good	
				Very good – full	✓

Key to estimating support needs

0 = no assistance	person completes the task
X = standby assistance	person completes task with monitoring, supervision
+ = needs some/set-up support	person completes more than 75% of the task
++ = needs moderate support	person completes approximately 25–75% of the task
+++ = needs full support	person completes 25% or less of the task

activity/participation	need for support	comment (e.g. capacity/performance, context)	estimated hours (per week) (depends on personal circumstances)
Transfers and moving around			Level of care for a person is the same as per the person with no motor function below the same level. Refer to the chart for the appropriate level.
transfers and bed mobility	x	may need assistance support with floor to chair transfer (+)	
moving around home	0	• independent using power wheelchair or power assist • needs assistance with manual wheelchair on uneven surfaces/curbs (+)	
moving around the community-wheelchair	0		
moving around the community-transport	0	• independent driving with appropriately modified vehicle • may need assistance with transfer, loading wheelchair, clamping (+) • may need assistance with public transport (+)	
Self-care			
showering/washing self	+		
grooming/caring for body	0		
eating and drinking	0		
toileting (bowel)	++	may need assistance	
toileting (bladder)	+	may need assistance	
dressing (upper)	0		
dressing (lower)	+	may need assistance	
health needs (includes preventative health)	+	• independent with medical appointments, medication management • may need assistance with exercise (+) • nursing – regular checks, catheter change (+)	
Domestic life			Level of care is the same as for a person with no motor function below the same level. Refer to the chart for the appropriate level. 0.5–2
meal preparation	0		
light housework	0		
heavy housework	+++		
shopping	++	shopping with the person	
communication and household management - set-up for devices e.g. computers, banking/life administration tasks, correspondence (mail)	0		
maintaining home and garden	+++	the lower range of hours expected for a person living in an apartment, although may require hours for minor home maintenance	
Participation in major areas of life			need for support depends on the individual, and contextual (environmental and personal) factors
education (informal at home or other setting, school, tertiary, vocational)			
work and employment (includes non-remunerative work)			
caring for others e.g. parenting			
recreation, leisure, community life e.g. social ceremonies			
religious or spiritual practices e.g. attending church			

[1] In this guidance on support, we begin with an estimate of the need for support based on body functioning. This table refers to a person whose T1 (or any level through to S5) and above motor nerves are intact with some motor function below this. A range of other factors also need to be considered to establish the need for support workers (refer to Figure 1).

Level of support: Thoracic to sacral spine some motor function below household walker[1]

Brief description of motor control and body functioning

- some control of trunk and moderate control of lower extremities
- a person with injury at T1-T2 may not have fine hand control
- minimal compromise of respiratory function

Shoulder function	None – poor		Hand fuction	None – poor	
	Good – full	✓		Some – good	
				Very good – full	✓

Key to estimating support needs

0 = no assistance	person completes the task
X = standby assistance	person completes task with monitoring, supervision
+ = needs some/set-up support	person completes more than 75% of the task
++ = needs moderate support	person completes approximately 25–75% of the task
+++ = needs full support	person completes 25% or less of the task

activity/participation	need for support	comment (e.g. capacity/performance, context)	estimated hours (per week) (depends on personal circumstances)
Transfers and moving around			0–7
transfers and bed mobility	0	may need assistance with floor to chair transfer (+)	
moving around home	x	• independent using power wheelchair or power assist • needs assistance with manual wheelchair on uneven surfaces/curbs (+)	
moving around the community-wheelchair	0		
moving around the community-transport	0	• independent driving with appropriately modified vehicle • may need assistance with transfer, loading wheelchair, clamping (+) • may need assistance with public transport (+)	
Self-care			
showering/washing self	0		
grooming/caring for body	0		
eating and drinking	0		
toileting (bowel)	x	may need assistance (+)	
toileting (bladder)	0	may need assistance (+)	
dressing (upper)	0		
dressing (lower)	0	may need assistance	
health needs (includes preventative health)	0	• independent with medical appointments, medication management • may need assistance with exercise (+) • nursing – regular checks, catheter change (+)	
Domestic life			7–14
meal preparation	0		
light housework	0		
heavy housework	+++		
shopping	++	shopping with the person	
communication and household management - set-up for devices e.g. computers, banking/life administration tasks, correspondence (mail)	0		
maintaining home and garden	++	the lower range of hours expected for a person living in an apartment, although may require hours for minor home maintenance	0.5–2
Participation in major areas of life			need for support depends on the individual, and contextual (environmental and personal) factors
education (informal at home or other setting, school, tertiary, vocational)			
work and employment (includes non-remunerative work)			
caring for others e.g. parenting			
recreation, leisure, community life e.g. social ceremonies			
religious or spiritual practices e.g. attending church			

[1] In this guidance on support, we begin with an estimate of the need for support based on body functioning. This table refers to a person whose T1 (or any level through to S5) and above motor nerves are intact with some motor function below this. A range of other factors also need to be considered to establish the need for support workers (refer to Figure 1).

Assistive technology: Thoracic to sacral some motor function below household walker

People whose injury is in this category would generally require the same assistive technology as those with injury at the same level but with no motor function below. Refer to the relevant assistive technology lists for no motor function below injury in Section 12.1.

Additional or different features of assistive technology may be required, such as:

- may not require the highest level of pressure relieving devices (e.g. pressure mattresses, cushion or motorised height-adjustable bed)
- walking aids and orthotic devices
- wheelchair for longer distances
- standing hoist if indicated
- assist-a-lift reclining chair.

Level of support: Thoracic to sacral spine with some motor function below community walker[1]

Brief description of motor control and body functioning

- good to full control of trunk and lower extremities
- may have impaired respiratory muscle function and compromised respiratory capacity and endurance
- may have autonomic dysfunction

Shoulder function	None – poor		Hand fuction	None – poor	
	Good – full	✔		Some – good	
				Very good – full	✔

Key to estimating support needs

0 = no assistance	person completes the task
X = standby assistance	person completes task with monitoring, supervision
+ = needs some/set-up support	person completes more than 75% of the task
++ = needs moderate support	person completes approximately 25–75% of the task
+++ = needs full support	person completes 25% or less of the task

activity/participation	need for support	comment (e.g. capacity/performance, context)	estimated hours (per week) (depends on personal circumstances)
Transfers and moving around			0–7
transfers and bed mobility	0		
moving around home	0		
moving around the community-wheelchair	0	independent using power wheelchair, power assist or manual wheelchair	
moving around the community-transport	0	• independent driving with appropriately modified vehicle • may need assistance with transfer, loading wheelchair, clamping (+)	
Self-care			
showering/washing self	0		
grooming/caring for body	0		
eating and drinking	0		
toileting (bowel)	+	may need assistance (+)	
toileting (bladder)	0	may need assistance (+)	
dressing (upper)	0		
dressing (lower)	0	may need assistance	
health needs (includes preventative health)	0	• independent with medical appointments, medication management • may need assistance with exercise (+) • nursing – regular checks, catheter change (+)	
Domestic life			3–7
meal preparation	0		
light housework	0		
heavy housework	++		
shopping	+		
communication and household management - set-up for devices e.g. computers, banking/life administration tasks, correspondence (mail)	0		
maintaining home and garden	++	the lower range of hours expected for a person living in an apartment, although may require hours for minor home maintenance	0.5-2
Participation in major areas of life			need for support depends on the individual, and contextual (environmental and personal) factors
education (informal at home or other setting, school, tertiary, vocational)			
work and employment (includes non-remunerative work)			
caring for others e.g. parenting			
recreation, leisure, community life e.g. social ceremonies			
religious or spiritual practices e.g. attending church			

[1] In this guidance on support, we begin with an estimate of the need for support based on body functioning. This table refers to a person whose T1 (or any level through to S5) and above motor nerves are intact with some motor function below this. A range of other factors also need to be considered to establish the need for support workers (refer to Figure 1).

Assistive technology: Thoracic to sacral some motor function below community walker

People whose injury is in this category would generally require the same assistive technology as those with injury at the same level but with no motor function below. Refer to the relevant assistive technology lists for no motor function below injury in Section 12.1.

Aadditional or different features of assistive technology may be required, such as:

- may not require the highest level of pressure relieving devices (e.g. pressure mattresses, cushion or motorised height-adjustable bed)
- walking aids and orthotic devices
- wheelchair for longer distances
- standing hoist if indicated
- assist-a-lift reclining chair.

13. Practical matters to consider

Those involved with support workers should consider practical matters and elements of best practice when determining, receiving, managing and monitoring assistance provided by support workers. The practical matters and best practice discussed below are: those mentioned in the 2nd edition of this guidance (and considered to be very useful by users responding to a survey about the guidance); issues that experts and service users raised during working party discussions; and other matters identified during the development of the guidance. The matters discussed are not in any order of priority, and are intended to highlight some common real-world issues rather than comprehensively cover every aspect of determining the need for and providing support workers.

13.1 Benchmarks

Those involved in providing support workers, and the support workers themselves, should aim to achieve the following best practice benchmarks.

1. The person with the spinal cord injury is involved in the planning, delivery and monitoring of the assistance from support workers.
2. The tasks assist and enable the person to increase and/or maintain their independence and achieve their goals.
3. Services are integrated, aligned and communication appropriately maintained between parties, for example, personal and domestic services, case management, other providers (e.g. exercise programs).
4. Support workers:
    - are culturally aware and sensitive
    - maintain professional boundaries with the person and the family and carer
    - work appropriately with the family and carer.
5. Support workers and their employing organisations meet industry and professional standards and competencies.

13.2 Coordination of supports

The World Health Organization (WHO) defines care coordination as 'a proactive approach in bringing care professionals and providers together around the needs of service users to ensure that people receive integrated and person-focused care across various settings' [32]. Coordination to ensure that informal and formal supports work properly and well together is critical for all those involved and particularly the person with spinal cord injury. Coordinated formal and informal supports that meet the service user's needs, so that they achieve their goals, are likely to be more cost-effective.

Initial and ongoing service coordination and communication may be the responsibility of the service provider, case manager, planning facilitator, care coordinator (or one of a team of support workers), a family member or carer, the service user themselves or a combination of these. The need for coordination of formal supports may reduce over time once the routine of life and participation is established. It is important to identify and review who is coordinating supports and how.

13.3 Communication and relationships

Mutual expectations of each of the parties involved should be discussed and agreed on. Rather than assuming this has been done, someone needs to ensure that expectations have been discussed, agreed on and some matters included in a service agreement signed by the relevant parties. Responsibilities for clarifying expectations will vary depending on who is involved.

Expectations and matters that need to be clarified include:

- **Communication** – the day-to-day practical matters of communication; what, when and how day-to-day issues are communicated
- **Practical issues concerning employment** – for example, minimum hours per shift
- **Tasks for the support worker** – for example, expected time frames to complete tasks; responsibilities; negotiating the support worker completing a combination of tasks (e.g. domestic and personal care)
- **Unfilled shifts** – plans for situations where a support worker is not available, or unable to commence or complete the shift, for example, if support worker is sick, or has transport difficulties (e.g. traffic congestion)
- **Complaints** – the procedure for making and

handling of complaints to, and from, all those involved in the provision of support workers.

There also needs to be clarity around more personal issues such as mutual respect (between the support worker and the person with spinal cord injury), consent, personal boundaries, and roles within the household.

13.4 Emergency preparation

It is important that there are plans and strategies in place to manage different emergency situations. Emergencies can range from natural disasters (e.g. storm, bushfire) to personal emergencies (e.g. fires in the home, personal safety at home or in the community). An emergency may involve anything from the support worker suddenly becoming ill and unable to work (see above), to a breakdown of a power wheelchair when away from home, to a flood blocking access.

Solutions and management strategies must be established for common emergency situations. These may include ensuring that the person and their support workers have phone numbers for after-hours support worker service providers, a support worker relief agency, and emergency mechanic or road service familiar with power wheelchairs; and emergency numbers for fire brigade, police and ambulance services. It is also important to inform the fire brigade and other emergency services of very limited mobility issues or limitations in emergency access so that if an emergency situation does arise, they are better prepared.

There are resources and tools available to assist with preparing for emergencies and developing a plan. The person with spinal cord injury, their family, carer and providers (including the planning facilitator/case manager, support worker and service provider) all have responsibilities to ensure that there is an emergency plan and strategies in place. There is also a role for initiating and contributing to the development of a disability inclusive disaster plan in the local community. The 'I'm Okay' website (http://imokay.org.au/action-steps) provides useful information and resources and outlines the following steps to prepare for an emergency:

- Know yourself and your community
- Make a plan
- Assemble an emergency kit
- Review and maintain the plan.

Refer to Box 5 for links to information and resources to guide emergency preparation (for both personal emergencies and natural disasters).

Box 5 Resources - Emergency preparation

At home and your community

I'm OK – http://imokay.org.au (Physical Disability Council of NSW, NRMA Insurance)

Disability inclusive (natural) disaster preparedness

http://sydney.edu.au/health-sciences/cdrp/projects/disasterdisab.shtml (University of Sydney – Centre for Disability Research and Policy)

http://www.redcross.org.au/prepare.aspx

(Australian Red Cross)

Risk management toolkit

http://managingrisk.living-with-attendant-care.info/

13.5 Overnight assistance from a support worker

It is important to differentiate the person's need for assistance overnight and consider the parameters of employing a support worker overnight.

Overnight needs of the person with spinal cord injury.

The need for assistance overnight differs with each person with spinal cord injury and their circumstances. Determining if a support worker is needed overnight should start with identifying the risks, followed by working out solutions and putting systems in place to safeguard against these (e.g. emergency call systems, pressure care equipment). Furthermore, a support worker should be provided on the basis of what does happen, not what may happen or 'in case of an emergency'. There are

circumstances when there are no alternative options to overnight assistance.

There may be a need for a support worker at specific periods or in the longer term because of:

- physical conditions such as:
  - autonomic dysreflexia caused by an uncontrollable irritant (e.g. irritated bowel)
  - treatment-resistant sleep apnoea
  - unstable medical conditions (e.g. a cough, need for suction, bronchitis, issues around menstruation or bowel function)
- requirement for re-positioning (e.g. chronic pain)
- personal factors or psychological condition (e.g. sleep walking, falls, anxiety)
- periods of exceptional circumstances (e.g. illness so that the person needs a drink, medication or PEG feed).

Employing a support worker overnight

In Australia, when a support worker is employed to sleep overnight (by a service provider or the person themselves) at the premises of the person with spinal cord injury, they must be provided with a separate room with a bed and the use of facilities (e.g. bathroom). There are also other requirements under the employment award. The span for a sleepover must be a continuous period of eight hours and there must be active work immediately before and/or immediately after the sleepover period so that the support worker is paid for four hours of work for at least one of these periods. If the support worker is required to attend to the person with spinal cord injury during the sleepover period, the support worker must be paid for the period of time they have worked (with a minimum of one hour). For more detail, refer to the Social, Community, Homecare and Disability Services Industry Award (2010), in particular section 25.7 (https://www.fwc.gov.au/documents/documents/modern_awards/award/ma000100/default.htm)

13.6 Support worker and service provider elements

Medication administration

Determining the need for support should also consider administration of medication. This should be discussed with the person, their family and carer. The risks, skill and competency required to assist the person to administer their medication should be determined and made clear to the people involved.

A support worker should have completed competency training on administration of medication. A support worker should not fill a box medication compliance aid with the prescribed tablets, but may administer oral medication from the pharmacy or manufacturer-labelled medication container or a blister pack (refer to the glossary for the definitions of relevant terms: medication, blister pack, box medication compliance aid). Box 6 provides the link to the ACIA guidelines for support workers administering medication.

Box 6 Administering medication guidelines

The ACIA guidelines *Administration of oral medication in the community by support workers (ACIA 004) and Administration of non oral and non injectable medication in the community by support workers* (ACIA 005) provide guidelines on best practice for medication administration by support workers in Australia (www.acia.net.au/education/acia-education-and-training-2).

Service provider accreditation, standards and approved providers

The person with spinal cord injury needs to be involved in decisions around which service provider is engaged. For those people and families who have never needed assistance from a support worker before, identifying the appropriate service provider can be a daunting task. There are two benchmarks for selecting service providers that a user should

consider when selecting a service provider:

- **Provider certification** – In Australia (and other countries), there is a national quality management standard for the provision of support worker services. Service providers can undergo a quality assessment of their service and be certified under an accreditation scheme. Refer to the Attendant Care Industry Standard (ACIS) (www.acia.net.au/getting-certified).
- **Approved provider** – Some (but not all) support worker funding organisations elect to screen service providers and develop a list of accredited service providers that they consider meet additional criteria such as
  - the required pool of skilled support workers to meet the assistance needs of the particular group of service users that they fund (e.g. spinal cord injury, traumatic brain injury)
  - agreed set fees structures
  - geographic location and other criteria such as support worker training, worker health and safety policies, etc.

Other factors that may be considered are rural and remote services, availability of live-in staff, or recruitment approach (e.g. service user involved with interviews and selection).

icare has developed a list of approved attendant care service providers for people with serious injuries in NSW. There is an online portal which enables the service user and their family and carer to identify approved service providers that have support workers in their area and enables the selection of their preferred provider. Refer to the attendant care provider portal at www.icare.nsw.gov.au/treatment-and-care/services-and-support/attendant-care-and-domestic-services/find-an-attendant-care-provider .

Retaining support workers

Retaining support workers is an issue reported both by service users and in the limited literature available [33-35]. The factors influencing how long a support worker remains in the job are many and varied. Turnover of support workers is disruptive for all parties involved, but particularly affects the service user and their family and carer. Although there is no specific guidance on retaining support workers to assist service users and providers, it is important that the parties involved attempt to identify the barriers, facilitators and patterns to retaining support workers in their context.

13.7 Qualifications and training of support workers

Matching the skills and competencies of support workers to the needs of the person with spinal cord injury is critical. Different skills are needed for different tasks. For example, providing personal care requires different skills to domestic tasks. Training of support workers should also include training on safety and interpersonal relationships, not just the relevant physical skills.

Beyond generic skills training, there is a need for additional orientation and (usually) onsite training related to the specific person receiving the support. At times, there may be a need for additional training when there are changes in the person's circumstances (e.g. a pressure area has developed, a fracture occurred, a suprapubic catheter was inserted) or changes in the roles within the home (e.g. carer no longer able to perform the task). The person with spinal cord injury should be involved in training the support worker.

Typically the service provider is responsible for developing and providing training for the support worker. On occasions, additional support worker hours may be required to enable the training specific to the person with spinal cord injury.

Box 7 Competency framework for service providers

The Capability Framework for Service Providers identifies the essential knowledge and skills required by the support worker to work effectively in their role. It enables the service provider to assess the induction and ongoing training of each support worker they employ.

The framework consists of five sections: orientation; provide personal care; maintain a safe environment; establish and maintain appropriate interpersonal relationships; provide complex support relating to catastrophic clinical matters.

The Capability Framework can be downloaded from www.acia.net.au/education/acia-education-and-training.

The framework can also be used by people who employ their own support workers.

13.8 Work health and safety

Working in someone's home is a unique work environment. The responsibility to take all reasonably practicable steps to ensure the support worker's health and safety lies with the person or business or organisation undertaking (including the funder) and employing the support worker. If the service user employs the support worker directly, it is their responsibility (see Section 13.9). The steps to ensure work health and safety involve eliminating or minimising the risk of injury to the support worker (and the service user) after having considered matters such as the likelihood and severity of the risk and the means to control it. Usually the maintenance of the workplace is the responsibility of all parties involved, and this also applies when the workplace is someone's home. In practice, all parties involved (i.e. the service provider, support worker and service user) are responsible and should work in partnership to maintain safe premises. This includes the property or business owner if away from the home (e.g. hotel).

For information and services refer to:

- Safe Work Australia (www.safeworkaustralia.gov.au/industry_business/heatlh-care-and-social-assistance)
- SafeWork NSW (www.safework.nsw.gov.au/health-and-safety)
- your local authority on work health and safety.

Training and work health and safety practices not only protect the support worker, but also the safety of the person with spinal cord injury (e.g. during person-related manual lifting where there are tasks involved such as personal care, transfers). The principles of health and safety practice should be reviewed and incorporated across all environments where assistance is provided, as well as when there is a change in the environment. For example, whether the support worker is involved in providing assistance in the home, or out of the home when on holidays or in transitional accommodation, or in work or study/education environments, potential risks should be considered. Expectations around responsibilities for work health and safety training of any new support worker or for assistance in different environments need to be clarified and included in service agreements.

Some of the topics for training in work health and safety include (but are not limited to):

- identifying risks and risk management in the home (refer to www.acia.net.au/safetymds.nsw)
- infection control and the use of personal protective equipment
- person- and assistive technology-related manual lifting
    - use of assistive technology (e.g. hoists, transfer board, slide sheet)
    - determining whether a one- or two-person lift is required (refer to the report at www.sprc.unsw.edu.au/media/SPRCFile/Report5_13_TwoCareWorkers_Final_for_web_June_2013.pdf)
- slips, trips and falls
- medication management
- food handling and safety
- managing difficult behaviours (where appropriate)
- prevention of workplace bullying
- first aid
- emergency plans and procedures.

There are a number of websites which provide information, resources and strategies for work health and safety training. Some of these are:

- Disability Safe project funded by the (Disability) Industry Development Fund
- http://idfnsw.org.au/work-health-and-safety-whs
- SafeWork NSW
- www.safework.nsw.gov.au/health-and-safety/manage-workplace-safety
- Workplace Health and Safety Queensland – Guide to working safely in people's homes www.worksafe.qld.gov.au/__data/assets/pdf_file/0018/82503/community-working-safely-in-peoples-homes.pdf

13.9 Self-management of support workers

Some funding programs are flexible and offer the option for the person with spinal cord injury to manage their own supports. Refer to Box 4 above for information about living with support workers, and Box 8 below on managing and employing support workers.

If self-management is possible and chosen, it enables the person to have more control over how the services are organised, who provides the supports and when they occur.

There are various levels of self-management:

- purchase of supports from providers
- engaging and training support workers but using an agency to manage employer responsibilities such as insurances and tax
- comprehensively managing support workers as an employer with all the associated responsibilities.

Usually there is an assessment of the person's circumstances and skills in order to ensure that self-management would not place the person at an unacceptable level of risk and that they are able to manage the associated tasks and responsibilities. The assessment must be completed before self-management can begin. It is possible to undertake training and skill development to enable a person to self-manage support workers. Refer to Box 8 for links to the icare self-management portal.

Box 8 Resources

Managing and employing support workers

icare lifetime care undertook a pilot study and subsequently developed a program by which icare lifetime care participants may self-manage their funds and support workers. For details refer to www.icare.nsw.gov.au/treatment-and-care/services-and-support/managing-your--supports

Resources and information on health and safety and self-management of support workers are available from www.acia.net.au/safetymds.nsw.

14. Glossary

Ability

A basic trait; what a person brings to their performance of a new task [25].

Activity

The execution of a task or action by an individual [25].

Assistive technology

Any item, piece of equipment, or product, whether it is acquired commercially, modified or customised, that is used to increase, maintain or improve the functional abilities of individuals with disabilities [30].

Blister pack

A sealed oral medication pack prepared by a pharmacist (also referred to by one brand name as Webster pack) (ACIA Guideline 004 [23]).

Box medication compliance aid

A box with slots that can be filled with oral medication, divided into days and times (also referred to by one brand name as Dossett box) (ACIA Guideline 004 [23]).

Capacity

An individual's ability to execute a task or an action; the highest probable level of functioning that a person may reach in a given domain at a given moment. Assessing the full ability of the individual needs a 'standardised' environment to neutralise the varying impact of different environments on the ability of the individual. This standardised environment may be (a) an actual environment commonly used for capacity assessment in test settings, or b) in cases where this is not possible, an assumed environment which can be thought to have a uniform impact [25].

Carer

A person that provides supports to a person with a disability at no cost (generally family or friend) (ACIA Guideline 002 [23]).

Co-morbid conditions

An additional condition independent of and unrelated to the primary condition. The detection and treatment of co-morbid conditions are often not well managed for people with disabilities and can later have an adverse effect on their health; for example, people with intellectual impairments and mental health problems commonly experience 'diagnostic overshadowing'. Examples of co-morbid conditions for a person with an intellectual impairment may include cancer or hypertension [30].

Context

The overall surroundings (of the person with spinal cord injury), their circumstances, environment, background and settings, which can all influence the person's functioning [25].

Environmental factors

The physical, social and attitudinal environment in which people live and conduct their lives. Environmental factors include [25]:

- equipment and technology
- setting (individual home, group home, place of employment, school, community)
- support and relationships
- social, family and professional's attitudes and norms
- building and architectural characteristics
- terrain
- services, systems and structures (e.g. legal systems, social policies, health systems)
- climate.

Formal supports

A task or work done by someone for another as a job or duty or task (paid). The support is usually organised or structured. Government, non-profit organisations and the for-profit sector usually provide the services. The person employed to perform the task is referred to as a support worker or attendant care worker, personal care assistant, domestic assistant, maintenance assistant or care worker [24].

General healthcare needs

People with disabilities require health services for general healthcare needs like the rest of the population, including health promotion, preventive care (immunisation, general health screening), treatment of acute and chronic illness, and appropriate referral for more specialised needs where required. These needs should all be meet through primary healthcare in addition to secondary and tertiary as relevant. Access to primary healthcare is particularly important for those who experience a thinner or narrower margin of health to achieve their highest attainable standard of health and functioning [30].

Informal supports

Resources (goods, services or a person who performs a task or work) that are inbuilt in the person's environment and enhance quality and security of life. Informal supports support the person when there is a need and may be reciprocated with different goods, services or tasks (unpaid). Informal supports are often provided by those in the person's network including family members, friends (family or friend might be referred to as a carer) or members of a community (unpaid). The support is typically 'ordinary' and less formal and may be ad hoc [24].

Medication

Any substance which is supplied by a pharmacist or doctor, or dispensed by a pharmacist on the prescription of a doctor, or supplied directly by the doctor and which has a label attached to it. The term also includes any over-the-counter medication or natural therapy products. Oral medication (taken by mouth) includes tablets whether crushed or whole, and liquids (ACIA Guideline 004 [23]).

Participation

Involvement of an individual in a life situation [25].

Performance

What an individual does in his or her current environment. The gap between capacity and performance reflects the difference between the impacts of current and uniform environments, and thus provides a useful guide as to what can be done to the environment of the individual to improve performance [25].

Personal factors

Personal factors include [25]:

- gender and age
- coping style
- social background and cultural context (which can influence values, roles, social support, sense of personal space, etc.)
- education, profession and work skills
- past and current experiences
- overall behaviour pattern
- character
- other factors that influence how disability is perceived and experienced by the individual.

Primary health condition (e.g. spinal cord injury)

The possible starting point for impairment, an activity limitation, or participation restriction. Examples of primary health conditions include depression, arthritis, chronic obstructive pulmonary disease, ischaemic heart disease, cerebral palsy, bipolar disorder, glaucoma, cerebrovascular disease and Down syndrome. A primary health condition can lead to a wide range of impairments, including mobility, sensory, mental and communication impairments [30].

Secondary conditions

An additional condition that presupposes the existence of a primary condition. It is distinguished from other health conditions by the lapse in time from the acquisition of the primary condition to the occurrence of the secondary condition. Examples include pressure ulcers, urinary tract infections and depression. Secondary conditions can reduce functioning, lower the quality of life, increase healthcare costs and lead to premature mortality. Many such conditions are preventable and can be anticipated from primary health conditions [30].

Service provider

An organisation or a person who provides supports and services to people.

Service user

A person (and their family or carer) who receive assistance from a support worker.

Skill

The level of proficiency with which someone performs a task [36].

Spinal cord injury

(the guidance was developed for traumatic spinal cord injury)

Damage to the neural tissues as a result of trauma or a non-progressive disease process, resulting in temporary or permanent sensory deficit, motor deficit or bladder/bowel dysfunction. Non-progressive diseases include transverse myelitis, compression by infective process, canal stenosis, haemorrhage or vascular occlusion. Spinal cord injury does not include progressive conditions such as demyelination, genetic disorders, degenerative conditions of the spinal cord or compression by metastatic lesions [3].

Support worker

An individual who assists or supervises a person to perform tasks of daily living to support and maintain their general wellbeing and enable meaningful involvement in social, family and community activities in the person's home and community. The support worker is a paid person who has access to education, support and advice from the service provider line manager or team leader. A support worker may also be known as an attendant care worker, disability worker, aged care worker, community worker, homecare worker, care worker or paid carer (ACIA Guideline 002 [23]). This definition encompasses the definition of 'Personal care, care of the worker, domestic assistant' as defined in the *Workplace Injury Management and Workers Compensation Act 1998* [37]

15. Abbreviations

ACIA	Attendant Care Industry Association Australia
icare	icare (Insurance & Care NSW)
ICF	International Classification of Functioning, Disability and Health
NSW	New South Wales

16. Resources

Information for the person with spinal cord injury and their family about the *Guidance on the support needs of adults with spinal cord injury*

What is the guidance?

This guidance is a tool with information to assist you, your family and other people involved in making decisions. There is useful information to consider as a starting point such as tables describing support for each level of spinal cord injury, assistive technology options, practical information like preparing for an emergency and overnight assistance.

Making decisions about your support needs?

There are many factors to take into account when deciding on your need for assistance from support workers. For example, why assistance is needed, whether the supports match your needs and practical matters all need to be considered.

How much assistance from a support worker do people in my situation usually have?

There is no standard level of support. It's not just about the level of the spinal cord injury nor who lives with you and how they assist you. Each person has different life activities, goals, home and local communities which can affect their need for support.

What is a support worker?

A support worker is someone who is paid by a funding organisation like icare (Insurance & Care NSW), to assist you with daily tasks and enables you to be involved in social, family and community activities. Usually support workers are employed by an organisation (called a service provider) to work with you, but you are involved in decisions about when, how and who assists you. Some funding organisations offer different levels of self-management which allows you to have more control and responsibility over how the services are organised.

What do I need to consider when I engage a support worker for the first time?

Having a support worker involved with you for the first time can be overwhelming. Think about questions that you can ask the service provider and other people involved such as:

- Are support workers available in my area or will they have to travel long distances? (Long distances can be a problem e.g. in an emergency or if there is traffic congestion and you need their assistance to get to work on time). What sort of assistance can a support worker provide for me? Who coordinates the support workers?
- Is there someone I can contact on a weekend if I unexpectedly need to make changes about my supports?
- Is there a service agreement?
- What is the policy on training support workers to meet my specific needs?
- What if I have a complaint?

Download the **Guidance on the support needs of adults with spinal cord injury** from the website www.icare.nsw.gov.au/treatment-and-care/what-we-do/guidelines-and-policies

Maintenance of assistive technology can include servicing by a technician, part replacement, cleaning or lubrication of parts, replacing, or testing/checking it is working order.

Planning and information

i. List the assistive technology used that will require maintenance.

Examples of such assistive technology: motorised bed; air mattress; mattress pump; wheelchair (manual and powered); any powered device such as ventilators, powered ceiling or mobile hoist; hoist to access a vehicle; reverse cycle air-conditioning; environmental control units; back-up battery packs; tyre compressor; non-invasive ventilator; and mains powered evacuation or portable suction equipment.

ii. Obtain information about the:

- possibility of a service agreement with the supplier of assistive technology requiring maintenance (e.g. wheelchair, hoist, environmental control unit)
- cost of repairs, routine maintenance and service and who will pay for this
- whole-of-life costs of the assistive technology, frequency of use and approximate replacement cycle
- known or perceived breakdown rates (gained through the rehabilitation team or the person's experience)
- impact of the environment on the need for routine maintenance and service requirements (e.g. salt air, dusty environment, floor surface).

iii. Develop a plan which establishes:

- recommended periods, frequency and routine for service, routine maintenance and repairs needed for each piece of assistive technology
- who will be responsible for arranging and performing the maintenance
- time frames for access to repairs (e.g. emergency and regular service turnaround times)
- availability of a local repairer for service and repairs, such as a local bicycle repairer, automotive electrician (for power wheelchairs), NRMA road service for wheelchair service and repairs, including after-hours (e.g. on weekends) emergency repair options.
- contingency plans for adverse events, such as breakdown, power failure or technology failure of essential assistive technology such as power wheelchairs, hoists, mattresses and beds. Consider contingency plans for these occasions at home but also if the assistive technology is used outside the home, in the street or at other places (e.g. work place, holiday accommodation), or if the breakdown occurs out of hours. Contingency plans should be documented.

Practical tasks

Ensure that tools are available and that the person, a family member or support worker knows how to use them. Ensure that daily, weekly or fortnightly routine maintenance tasks are completed.

Plan for provision of:

- a back-up of essential assistive technology where possible (e.g. second wheelchair when primary wheelchair is being repaired or serviced, travel/emergency pressure care mattress)
- written guides (from manufacturer, service technician or specifically developed for support workers and family) or weblinks on recommended maintenance tasks and frequency
- annual training for support workers on routine maintenance tasks such as cleaning and part lubrication (to accommodate turnover in staff)
- spare parts (what and how many) to be kept or carried for some of the equipment (e.g. spare tyres)
- an emergency repair kit where possible (e.g. basic tools such as allen keys, screwdriver)

Download the **Guidance on the support needs of adults with spinal cord injury** from the website www.icare.nsw.gov.au/treatment-and-care/what-we-do/guidelines-and-policies

World Health Organization Quality of Life – BREF

The World Health Organization Quality of Life Bref (WHOQoL) is included as one of the modules in the My Planning toolkit. Refer to this link for the module A7 and the self-rating quality of life scale and the WHOQoL score calculator.

www.icare.nsw.gov.au/treatment-and-care/information-for-service-and-healthcare-providers/planning-with-an-injured-person

general assessment series

try this:®

Best Practices in Nursing Care to Older Adults

From The Hartford Institute for Geriatric Nursing, New York University, College of Nursing

Issue Number 14, Revised 2007

Series Editor: Marie Boltz, PhD, GNP-BC
Series Co-Editor: Sherry A. Greenberg, MSN, GNP-BC
New York University College of Nursing

The Modified Caregiver Strain Index (CSI)

By M. Terry Sullivan, RN, MSW, MSN, CMC, Connecticut Community Care, Inc.

WHY: Informal supporters provide the majority of long-term care to chronically disabled older adults. Caregiving has been recognized as an activity with perceived benefits and burdens. Caregivers may be prone to depression, grief, fatigue, and changes in social relationships. They may also experience physical health problems. Perceived caregiver burden has been associated with premature institutionalization and patient reports of unmet needs. Screening tools are useful to identify families who would benefit from a more comprehensive assessment of the caregiving experience.

BEST TOOL: The Modified Caregiver Strain Index (CSI) is a tool that can be used to quickly screen for caregiver strain with long-term family caregivers. It is a 13-question tool that measures strain related to care provision. There is at least one item for each of the following major domains: Employment, Financial, Physical, Social, and Time. This instrument can be used to assess individuals of any age who have assumed the role of caregiver for an older adult. The Modified Caregiver Strain Index is a version of the Caregiver Strain Index developed in 1983. The tool was modified and developed in 2003 with a sample of 158 family caregivers providing assistance to adults aged 53 and older living in a community-based setting (Travis, et al, 2002; Thornton & Travis, 2003). Scoring is 2 points for each 'yes', and 1 point for each 'sometimes' response. The higher the score, the higher the level of caregiver strain.

VALIDITY AND RELIABILITY: Internal reliability coefficient is slightly higher (=.90) than the coefficient originally reported for the CSI in 1983 (=.86). Two-week retest data for one-third of the caregiving sample (n=53) were available and resulted in a test-retest reliability coefficient of .88.

STRENGTHS AND LIMITATIONS: The Modified CSI is a brief, easily administered, self-administered instrument. Long-term family caregivers were not comfortable with the dichotomous choice on the CSI and the modified instrument provides the ability to choose a middle category response best suited to some situations. The Modified CSI clarifies and updates some of the items on the original instrument. The tool is limited by lack of a corresponding subjective rating of caregiving impact. There is no breakdown of score regarding low, moderate or high caregiver strain, so professional judgment is needed to evaluate by total score the level of caregiver strain. The tool effectively identifies families who may benefit from more in-depth assessment and follow-up.

FOLLOW-UP: The higher the score on the Modified CSI, the greater the need for more in-depth assessment to facilitate appropriate intervention. Additional items and further efforts to develop and test a set of subscales could enhance the applicability of the instrument for research and practice. The patient's cognitive status and problematic behaviors should be assessed, as well as the caregiver's perception of role overload or deprivation in key relationships, goals or activities. Family conflict, work role-caregiving conflict, and caregiver social support are also important variables in the overall caregiving experience. Additional work with highly strained long-term caregivers who are receiving little or no formal services is indicated.

MORE ON THE TOPIC:

Best practice information on care of older adults: www.ConsultGeriRN.org.
Gerritsen, P., & Van Der Ende, P. (1994). The development of a care-giving burden scale. *Age and Ageing*, *23*(6), 483-491.
Novak, M., & Guest, C. (1989). Application of a multidimensional caregiver burden inventory. *The Gerontologist*, *29*(6), 798-803.
Parks, S.,M.D., & Novielli, K., M.D. (2000). A practical guide for caring for caregivers. *American Family Physician*, *62*, 2613-20, 2621-2.
Pearlin, L., Mullan, J., Semple, S. & Skaff, M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, *30*(5), 583-594.
Robinson, B. (1983). Validation of a Caregiver Strain Index. *Journal of Gerontology*, *38*(3), 344-348.
Thornton, M., & Travis, S.S. (2003). Analysis of the reliability of the Modified Caregiver Strain Index. The Journal of Gerontology, *Series B, Psychological Sciences and Social Sciences*, *58B*(2), S127-132.
Travis, S., Bernard, M., McAuley, W., Thornton, M., Kole, T. (2002). Development of the family caregiver medication administration hassles scale. *The Gerontologist*, *43*(3), 360-368.
Tsai, P., & Jirovec, M.M. (2005). The relationships between depression and other outcomes of chronic illness caregiving. *BioMed Central Nursing*, *4*(1), 3.

Permission is hereby granted to reproduce, post, download, and/or distribute, this material *in its entirety only* for not-for-profit educational purposes only, provided that The Hartford Institute for Geriatric Nursing, New York University, College of Nursing is cited as the source. This material may be downloaded and/or distributed in electronic format, including PDA format. Available on the internet at **www.hartfordign.org** and/or **www.ConsultGeriRN.org**. E-mail notification of usage to: **hartford.ign@nyu.edu**.

Modified Caregiver Strain Index

Directions: Here is a list of things that other caregivers have found to be difficult. Please put a checkmark in the columns that apply to you. We have included some examples that are common caregiver experiences to help you think about each item. Your situation may be slightly different, but the item could still apply.

	Yes, On a Regular Basis=2	Yes, Sometimes =1	No=0
My sleep is disturbed (For example: the person I care for is in and out of bed or wanders around at night)			
Caregiving is inconvenient (For example: helping takes so much time or it's a long drive over to help)			
Caregiving is a physical strain (For example: lifting in or out of a chair; effort or concentration is required)			
Caregiving is confining (For example: helping restricts free time or I cannot go visiting)			
There have been family adjustments (For example: helping has disrupted my routine; there is no privacy)			
There have been changes in personal plans (For example: I had to turn down a job; I could not go on vacation)			
There have been other demands on my time (For example: other family members need me)			
There have been emotional adjustments (For example: severe arguments about caregiving)			
Some behavior is upsetting (For example: incontinence; the person cared for has trouble remembering things; or the person I care for accuses people of taking things)			
It is upsetting to find the person I care for has changed so much from his/her former self (For example: he/she is a different person than he/she used to be)			
There have been work adjustments (For example: I have to take time off for caregiving duties)			
Caregiving is a financial strain			
I feel completely overwhelmed (For example: I worry about the person I care for; I have concerns about how I will manage)			

[Sum responses for "Yes, on a regular basis" (2 pts each) and "yes, sometimes" (1 pt each)]

Total Score =

Thornton, M., & Travis, S.S. (2003). Analysis of the reliability of the Modified Caregiver Strain Index. *The Journal of Gerontology, Series B, Psychological Sciences and Social Sciences*, *58*(2), p. S129. Copyright © The Gerontological Society of America. Reproduced by permission of the publisher.

try this: general assessment series
Best Practices in Nursing Care to Older Adults

A series provided by The Hartford Institute for Geriatric Nursing, New York University, College of Nursing

EMAIL hartford.ign@nyu.edu HARTFORD INSTITUTE WEBSITE www.hartfordign.org
CLINICAL NURSING WEBSITE www.ConsultGeriRN.org

17. Appendices

Appendix 1. List of external peer reviewers

Name	Position	Organisation/Affiliations
Angela Ryan	Regional Occupational Therapist	ParaQuad NSW, Australia
Gemma McDonald	Occupational Therapist	LifeAccess, NSW, Australia
Julie Bundz	Spinal Outreach Team	Queensland Spinal Cord Injuries Service, Division of Rehabilitation, Princess Alexandra Hospital, Metropolitan South Health, Queensland, Australia
Karin Roth	Clinical Nurse Practitioner Leading Nurse Expert	Swiss Paraplegic Centre, Nottwil, Switzerland
Kylie Jones	Regional Clinical Service Manager	ParaQuad NSW, Australia
Kylie Pershouse	Spinal Outreach Team	Queensland Spinal Cord Injuries Service, Division of Rehabilitation, Princess Alexandra Hospital, Metropolitan South Health, Queensland, Australia
Sarah Judd-Lam	Senior Policy and Development Officer	Carers NSW, Australia
Sharon Mortensen	Clinical Nurse	Queensland Spinal Cord Injuries Service, Transitional Rehabilitation Program, Queensland, Australia
Veronika Vrbska	Senior Occupational Therapist	International Spinal Cord Society (ISCOS) Occupational Therapy Special Interest Group Royal National Orthopaedic Hospital, London Spinal Cord Injury Centre, United Kingdom

Additional reviewers from icare lifetime care:

Kylie Downes Senior Development and Review, Attendant care programme
Robyn Gleeson Senior Development and Review, Self-management programme

Appendix 2. Overview of the methods used to develop the guidance

Refer to Sections 2–7 for the background and overview of the guidance.

The revised guidance was developed in seven key steps using mixed methods. For detailed information on the methods for each step and the results, refer to the separate document '*Technical report to the guidance on the support needs of adults with spinal cord injury*' (2017).

An overview of the steps is outlined below.

1. A systematic literature search on multiple databases of peer-reviewed published and grey literature using key word searches (2006–2010).
2. A survey of stakeholders to gain feedback on what they found useful (or not useful) in the 2007 edition of the guidance, as well as other topics and information they would see as relevant to include in the revised edition (n=71 respondents). The survey was disseminated in May 2016 and remained open until October 2016.
3. Analysis of the use of support workers by icare lifetime care participants with spinal cord injury, per year since the injury (total cost and average hourly rate). The data was extracted in June 2016.
4. Identification of different but valid sources of information other than the research literature to underpin the structure and concepts in the guidance, including:
    - international trends in spinal cord injury (e.g. changes to the terms used for describing the neurological level of injury)
    - international frameworks for holistic concepts of health and functioning (biopsychosocial model of functioning, disability and health of the World Health Organization International Classification of Functioning, Disability and Health (ICF) [25])
    - logic model research (including its uses and commentary in the literature) to support the development of the decision-making framework
    - key concepts for decision-making (e.g. pragmatic reasoning)
    - support worker industry information (e.g. standards).
5. Working party of experts. There were seven group meetings of 4 hours each involving 20 participants over 8 months (June 2016 – February 2017). The experts included health practitioners, care needs assessors, service provider and provider association representatives, service users, disabled person's organisation representatives, carer and support worker representatives, specialist spinal cord injury researchers, policy makers, and funders of services. The working party group meetings were conducted using nominal group techniques. This involves a structured approach through facilitated face-to-face discussion with all participants encouraged to contribute. In the group, responses and ideas related to questions or problems posed to the group are discussed and openly clarified. Different ideas and iterations are discussed to develop consensus. The technique relies on the expert practice and experiential knowledge of key areas of concern (e.g. levels of support, factors that influence the need for support and decisions, assistive technology). The level of support tables and assistive technology lists for this edition started with those in the 2nd edition of the guidance [38]. The expert working party further refined the modified Hoffer definitions of shoulder and hand function from the 2nd edition and established the global definitions through group discussion. Both the level of support tables and assistive technology lists underwent a lengthy and detailed process of revision within the working party including restructure, discussion and critique, further revisions and then finally agreement reached by the practice and experience experts of the working party.
6. Stakeholder feedback. Participant representatives were asked for feedback via three regional icare lifetime care participant reference groups held in March 2017.
7. Peer review of the draft guidance. The working party experts, and national and international reviewers were asked to appraise and critique the draft guidance in July 2017. The draft document was revised and the feedback considered and incorporated into the final document.

Reference

1. Boucher, N., W.C. Miller, and E.M. Smith, *Housing and attendant services: Cornerstones of community reintegration after* SCI. 2015, Spinal Cord Injury Rehabilitation Evidence (SCIRE): Vancouver.
2. Carr, J.J. and M.B. Kendall, *Community participation for individuals with spinal cord injury living in Queensland, Australia*. Spinal Cord, 2016. 55(2): p. 192-197.
3. World Health Organization (WHO) and The International Spinal Cord Society (ISCOS), *International perspectives on spinal cord injury*. 2013, WHO: Geneva.
4. Noreau, L., et al., *Spinal cord injury community survey: A national, comprehensive study to portray the lives of Canadians with spinal cord injury*. Topics in Spinal Cord Injury Rehabilitation, 2014. 20(4): p. 249-264.
5. Mayo-Wilson, E., P. Montgomery, and J.A. Dennis, *Personal assistance for adults (19–64) with physical impairments*. Cochrane Database of Systematic Reviews, 2008. (Issue 3): Art. No.: CD006856.
6. Robinson-Whelen, S. and D.H. Rintala, *Informal care providers for veterans with SCI: Who are they and how are they doing?* Journal of Rehabilitation Research and Development, 2003. 40(6): p. 511-516.
7. Rutherford Owen, T. and I. Marini, *Attendant care and spinal cord injury: Usage patterns and perspectives for those with life care plans*. Journal of Life Care Planning, 2012. 10(4): p. 33-44.
8. Barclay, L., R. McDonald, and L. Primrose, *Social and community participation following spinal cord injury: A critical review*. International Journal of Rehabilitation Research, 2015. 38(1): p. 1-19.
9. Young, A.E., et al., *Services provided following compensable work-related tetraplegia*. Spinal Cord 2004. 42(4): p. 248-260.
10. Lannin, N., et al., *The economic cost of attendant care for adults with traumatic brain injury and spinal cord injury in NSW (Report to the Motor Accidents Authority of NSW). 2012*, The University of Sydney, Rehabilitation Studies Unit: Sydney.
11. Walker, E.A., et al., *Racial-ethnic variations in paid and unpaid caregiving: Findings among persons with traumatic spinal cord injury*. Disability and Health Journal, 2015. 8(4): p. 527-534.
12. Weitzenkamp, D.A., G. Whiteneck, and D.P. Lammertse, *Predictors of personal care assistance for people with spinal cord injury*. Archives of Physical Medicine and Rehabilitation, 2002. 83(10): p. 1399-1405.
13. Munce, S., et al., *Perceived facilitators and barriers to self-management in individuals with traumatic spinal cord injury: A qualitative descriptive study*. BMC Neurology, 2014. 14: p. 48.
14. Craig, A., et al., *Adjustment following chronic spinal cord injury: Determining factors that contribute to social participation*. British Journal of Health Psychology, 2015. 20(4) p. 807-823.
15. van Loo, M.A., et al., *Care needs of persons with long-term spinal cord injury living at home in the Netherlands*. Spinal Cord, 2010. 48(5): p. 423-428.
16. New South Wales Government, *Carers (Recognition) Act 2010.* 2010, NSW Government: Sydney.
17. Baker, A., et al., *Caregiver outcomes and interventions: A systematic scoping review of the traumatic brain injury and spinal cord injury literature*. Clinical Rehabilitation, 2017. 31(1): p. 45-60.
18. Charlifue, S.B., et al., *Family caregivers of individuals with spinal cord injury: Exploring the stresses and benefits*. Spinal Cord, 2016. 54(9): p. 732-736.
19. Elliott, T.R., et al., *Resilience in the initial year of caregiving for a family member with a traumatic spinal cord injury*. Journal of Consulting and Clinical Psychology, 2014. 82(6): p. 1072-1086.

20. Middleton, J.W., et al., *Psychological distress, quality of life, and burden in caregivers during community reintegration after spinal cord injury*. Archives of Physical Medicine and Rehabilitation, 2014. 95(7): p. 1312-1319.

21. Post, M.W.M., *Burden of support for partners of persons with spinal cord injuries*. Spinal Cord, 2005. 43(5): p. 311-319.

22. Boschen, K.A., J. Gargaro, and M.I. Tonack, *Community integration and quality of life comparisons among spinal cord injured, provider support and comparative samples*. Topics in Spinal Cord Injury Rehabilitation, 2005. 10(4): p. 116-134.

23. Attendant Care Industry Association (Australia). *ACIA guidelines.* 2016; Available from: http://www.acia.net.au/education/acia-education-and-training-2/.

24. Lifetime Care Authority. *My Plan Planning facilitator's manual*. 2015; Available from: https://www.icare.nsw.gov.au/treatment-and-care/information-for-service-and-healthcare-providers/planning-with-an-injured-person

25. World Health Organization (WHO), *International classification of functioning, disability and health (ICF)*. 2001, WHO: Geneva.

26. Martz, E. and H. Livneh, *Coping with spinal cord injuries: Wholeness is a state of mind, in Coping with chronic illness and disability: Theoretical, empirical and clinical aspects*, E. Martz and H. Livneh, Editors. 2007, Springer: Portland, OR. P.363-388

27. Moos, R.H. and C.J. Holahan, *Adaptive tasks and methods of coping with illness and disability, in Coping with chronic illness and disability: Theoretical, empirical and clinical aspects*, E. Martz and H. Livneh, Editors. 2007, Springer: Portland, OR. P. 107-128

28. Putzke, J.D., et al., *Age and spinal cord injury: An emphasis on outcomes among the elderly*. Journal of Spinal Cord Medicine, 2003. 26(1): p. 37-44.

29. Liem, N.R., et al., *Aging with a spinal cord injury: Factors associated with the need for more help with activities of daily living*. Archives of Physical Medicine and Rehabilitation, 2004. 85(10): p. 1567-1577.

30. World Health Organization (WHO) and World Bank, *World report on disability*. 2011, WHO: Geneva.

31. Hoffer, M., et al., *Functional ambulation in patients with myelomeningocele*. Journal of Bone and Joint Surgery, 1973. 55(1): p. 137-148.

32. World Health Organization (WHO), *People-centred and integrated health services: An overview of the evidence*. 2015, WHO: Geneva.

33. Bushnik, T., J. Wright, and D.L. Burdsall, *Personal attendant turnover: Association with level of injury, burden of care, and psychological outcome*. Topics in Spinal Cord Injury Rehabilitation, 2007. 12(3): p. 66-78.

34. Butler, S.S. and N. Rowan, *Supporting home care aides*. Home Healthcare Nurse, 2013. 31(10): p. 546-552.

35. Butler, S.S., et al., *Determinants of longer job tenure among home care aides: What makes some stay on the job while others leave*. Journal of Applied Gernontology, 2014. 33(2): p. 164-188.

36. EnableNSW and Lifetime Care & Support Authority (LTCSA), *Guidelines for the prescription of a seated wheelchair or mobility scooter for people with a traumatic brain injury or spinal cord injury*. 2011, EnableNSW and LTCSA: Sydney.

37. WorkCover, *WorkCover guidelines for the provision of domestic assistance*. 2004, NSW Government: Sydney.

38. Lifetime Care & Support Authority (LTSCA) and Motor Accidents Authority of NSW (MAA), *Guidelines for levels of attendant care for people with spinal cord injury*. 2007, MAA and LTCSA: Sydney.