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# Optimising support for informal carers of the long-term disabled to enhance resilience and sustainability

Briefing Document

September 2014

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**The National Trauma Institute (NTRI) Forum:** The NTRI Forum is a three-year project that aims to improve the care of brain, spinal cord or other major traumatic injuries. The NTRI Forum's model involves defining the major challenges through consultation with key stakeholders to understand the issues and complexities; gathering and summarising from publications and further consultation the information necessary to properly consider each challenge; convening stakeholder dialogues to connect this information with the people who can make change happen; and briefing the organisations and individuals who can effect change about their role in developed strategies. For more information visit [www.ntriforum.org.au](http://www.ntriforum.org.au)

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## Executive Summary

People with severe and chronic disabilities represent a significant proportion of the population who require assistance to live in their own home and be a part of the community. In addition to assistance from the paid carer workforce, this assistance is provided by family, relatives or friends who are not paid or formally trained in the provision of care and support. These informal carers assist with a variety of tasks including activities of daily living, emotional care and support and accessing medical care and ongoing therapy to optimise independence. There are 2.7 million people in Australia who provide informal (unpaid) care to a person with a disability or long-term health condition, of which 770,000 provide the majority of care and support to people with a severe disability. Given their substantial contribution to care provision and the physical, emotional and other impacts of providing care, it is important to understand the experience of informal carers and address their support needs. In recent years, studies have elucidated the substantial effects of providing care on the psychological, physical, social and other impacts of providing care to a person with a long-term disability. There are a range of interventions to mitigate these impacts, which are provided in Australia through a variety of national and local government and non-government entities with varying efficacy. Optimising carer resilience has direct benefits to carers, and additional benefits to the overall care support system by reducing dependence on paid care.

This NTRI Forum aims to investigate effective strategies for providing support (excluding skills-related education and training, i.e. manual handling and transfers) to informal carers that can help to optimise their resilience, and the sustainability of the long-term disabled.

An evidence review of literature identified 25 relevant reviews and primary studies and a further 16 ongoing primary studies. The overall results of reviews of carer support interventions were inconclusive, therefore firm conclusions regarding what works and doesn't work cannot be made. However, evidence was reported as 'good' for educational and psycho-educational interventions, counselling and psychosocial interventions and multicomponent interventions; Evidence for care co-ordination and family support interventions was described as 'promising'; Evidence for technology-based interventions was conflicting in the setting of Dementia, but more positive in the area of catastrophic injury; Evidence for respite care was described as 'not strong', and although benefits were reported, the importance of additional support strategies in conjunction with respite care was emphasised. Similarly, emerging positive evidence in favour of support groups was reported, however additional concurrent support strategies were recommended. Passive information dissemination alone was found to be ineffective. The review also outlined a range of factors to consider in interpreting this evidence and identified implications for practice and research.

Two questions were identified for deliberation in a Stakeholder Dialogue:

1. What challenges are currently faced by informal carers of people with a long-term disability, and how are these challenges being met?
2. How can knowledge of optimal strategies be applied locally to address these challenges over the lifetime of a person with a long-term disability?

An accompanying document Dialogue Summary, presents results of deliberation upon these questions.

## Background

### Demographics of Informal Care in Australia

In 2012, the Australian Survey of Disability, Ageing and Carers found that a total of 2.7 million people (12% of the Australian population) provided informal care to a person with a disability or long-term health condition, of which 770,000 (3.4%) were primary carers, that is, those that provide the majority of care and support to people with a severe disability<sup>1</sup>. The survey also found the majority of carers were female (comprising 56% overall, and 70% of primary carers); aged 55-64 years old; and were looking after a spouse.

However, the dynamics of informal care vary with the condition of the care recipient. For example, carers of people following traumatic brain injury, which disproportionately affects men aged 15-24,<sup>2</sup> are usually parents; carers of people following spinal cord injury are more equally distributed between spouses/defacto and parents<sup>3,4</sup>. In a study in New South Wales most people with traumatic brain injury (TBI) and spinal cord injury (SCI) were found to live with their family and receive either informal care or informal and formal care (67% for TBI and 82% for SCI)<sup>3</sup>.

For this reason, information and review evidence within this briefing document is presented at two levels:

1. Information pertaining to non-catastrophic injury, for example care recipients with conditions such as dementia
2. Information pertaining to catastrophic injury, defined as traumatic brain injury, spinal cord injury and stroke, which can all affect younger populations

Analysing information specific to catastrophic injury will enable examination of whether there are any carer support needs and interventions that are unique to this population.

### Understanding the experience and needs of informal carers

It is important to understand the experience of providing informal care and address informal carer needs for a range of reasons:

- Informal carers provide a critical, ongoing source of physical, emotional, practical and social support to those they care for, which is physically and emotionally demanding to the carers;
- Medical interventions, rehabilitation and ongoing support therapies are primarily directed at the person who has experienced injury or illness. Therefore, the needs of informal carers may be overlooked by health professionals or the interdisciplinary team;
- Informal carers are also less inclined to put their own needs ahead of the person they are providing care for, or they may not want others to know that they are providing care;
- Some carers may not even be considered 'carers' by family or friends if the person with the disabling condition is quite independent and self-sufficient and does not require physical care, however carers may require emotional support which is equally as important.

Although informal carers of people with long-term disabling conditions have been described as 'hidden' or 'invisible' carers,<sup>4,5</sup> over the last decade there is evidence of increased recognition and understanding of the important role that carers play, as reflected by literature

on carer burden and its effects on carer health and well-being.

### *Carer burden*

Carer burden has been defined as “the extent to which carers perceive that provision of care has had an adverse effect on their emotional, social, financial, physical and spiritual functioning<sup>6</sup>.” A recent review summarised the risk factors for carer burden, which include increased hours spent providing care, being female, low education, depression, living with the person with the disabling condition, social isolation and lack of choice in the carer role. This review also found carer burden has been attributed to the amount of hours/time that a carer provides, the number of tasks or duties that the carer performs and the person’s functional status (motor and cognitive)<sup>5</sup>. Furthermore, the review highlighted that “different thresholds exist for triggering carer burden”, for instance certain circumstances or duties may be stressful and burdensome for some carers but not others, i.e. financial deprivation, or need for heavy assistance with activities of daily living. Carers may also have to manage multiple roles at the same time including being a parent or spouse, having a paid job outside of the caring role, maintaining friendships and networks. Hence, care provision and carer burden need to be recognised as a highly individualised experience.

### *The effect of carer burden on health and well-being*

Numerous studies have examined the effect of carer burden on the health and well-being of carers:

- A large Australian 2007 survey-based study on carer health and wellbeing<sup>7</sup> found that carers had wellbeing rating equivalent to moderate depression; carers were more likely to experience chronic pain, have an injury, and have a medical or psychological condition, which decreased their wellbeing significantly; the average household income for carers was found to be lower than the general population, hence paying for resources (i.e. household essentials, food expenses, shopping) and having the income to cover expenses was severely compromised; and the greater the amount of time that carers put in to provide care, the greater their wellbeing decreased. In a sub-study<sup>8</sup>, Australian carers reported feeling that the government does not understand their needs and what realities they and their care recipient have to experience every day. They also felt “highly anxious” about their future and that of the person they were providing care.
- A survey conducted in 1998<sup>9</sup> found over 39% of primary carers had a disability. Carers also reported feeling a lack of satisfaction (67%), feeling tired due to a lack of sleep (34%), feeling anxiety or depression (31%) and experiencing a strain in the relationship with the person they provide care (22%)
- Carers who are employed outside of the provision of care report leaves of absence, have to manage interruptions if the person needing care contacts them and have difficulty in being productive resulting in difficulties in sustaining employment<sup>10</sup>. Being unemployed or having limited income can create distress for carers who may need to cover out-of-pocket costs for providing care. Leisure activities and social relationship may be reduced depending on the amount of care needing to be provided that can also lead to increased carer burden.

A number of other reports and studies have been published on understanding the needs of carers and identifying what services are currently available and being provided to them<sup>1, 7, 9, 11</sup>. This literature is predominantly based on people caring for those with dementia and cancer, including palliative care<sup>12</sup>. Although every carer has different needs at different points in time (dependent on the condition of the care recipient), there are similarities which have been identified across different groups of carers, including the emotional pressures of dealing with challenging behaviours, the future prospects of the person being cared for (particularly when the carer may not be around), financial and emotional costs ‘time out’ for themselves



and the need for practical assistance and greater confidence in their ability to perform everyday tasks<sup>13</sup>. Notwithstanding these similarities, it is important to consider that the person's disability may change with time, reflecting that the needs of carers are individualised and hence support interventions must be assessed in this way<sup>13</sup>.

*The experience and needs of informal carers of people with catastrophic injury*

Carers of people with catastrophic injuries have a difficult challenge to face - that the injury of the person they provide care to is sudden, acquired, complex, life-changing, emotionally traumatic, long-term, and puts them in a role that they are unprepared for<sup>4, 14, 15</sup>. There is limited evidence on the demographics of carers of people with catastrophic injury in Australia. However, a recent report found that in 2012-2013 there were 15,948 people with acquired brain injury and 39,140 people with neurological conditions (encompassing SCI) that utilised disability support services<sup>16</sup>. One study has been conducted in New South Wales utilising carers of 33 people with TBI and 28 people with SCI<sup>3</sup>. On average the total amount of time spent providing care was 59.66 and 59.37 hours per week for TBI and SCI, respectively.

Traumatic brain injury (TBI) results not only in physical impairment, but may also result in language deficits, sexual dysfunction, incontinence, poor memory and slowness in thinking, and impairment in emotional control.<sup>14</sup> This presents a complex range of challenges to informal carers of people following TBI that can result in carer stress and inability to cope. One of the most important challenges for carers to deal with is the loss or grief for the person they once knew and also the reality that the person will not achieve what they might have once been set out to do. Furthermore, if the carer is also looking after a child, they can experience losing contact with friends, resulting in social isolation, particularly if they are located remotely (Rees, 2011). A recent review<sup>14</sup> has found that studies of carers of people with TBI are mostly female and they experience increased stress, difficulties in adjustment to the new situation, depression and anxiety and this burden may even increase with time<sup>14</sup>. This burden increases with the ongoing demands of care and support, increased medication costs, the lack of community-based service supports, losses of transportation and losses of income. The review also found that cognitive, behavioural and emotional issues in people with TBI were high risk factors for causing anxiety and depression in their carers.

Following spinal cord injury (SCI), care and support needs vary depending on the type and level of injury. Some people with incomplete, lower level spinal injuries may be able to remain quite independent and do not require carer support. However, people with complete tetraplegia and complete paraplegia are generally not able to live independently and require carer support. A recent review<sup>17</sup> provides an insight into the dynamics of carers of people with SCI. One of the included studies reported that people with SCI received either informal (22%) or informal and formal care (16%), with an average of 11.5 hours of informal care provided each day. Most of the people with SCI who received informal care stated that it was primarily from their spouse/partner, with the second highest sub-group stating it was a parent. Another review<sup>4</sup> supports this finding, showing that 93% of carers of people with complete tetraplegia and 68% of carers of people with complete paraplegia were spouses<sup>18</sup>. A further review<sup>14</sup> found low level evidence that the carers of people with SCI were mostly female spouses. There was low level evidence that poor psychological well-being is associated with increased carer burden and that burden is also associated with the number of hours a carer provides. Increased burden was related to greater psychological support, economic needs, emotional needs, physical health, sleep, respite and information. Other studies have confirmed these findings<sup>4</sup>. The increased burden experienced by spousal carers of people with SCI has been found to decrease their social (community) participation<sup>4</sup>. Spouses were also found to have greater depression and not feel their needs met by their partner they provide care for. Some spouses cannot continue in the relationship, ultimately



leaving their spouse due to the increased burden.

### Interventions to Support Informal Carers

There are a number of interventions designed to support informal carers,<sup>12, 13, 19, 20</sup> Interventions covered by the evidence review contained in this briefing document were classified using an intervention framework derived from a recent Victorian Government Audit of Carer Support Programs<sup>19</sup>, which was iteratively developed according to further interventions identified through the evidence review process (Table 1):

**Table 1: Intervention Classification and Definitions used in Evidence Overview**

Intervention	Definition
Respite	“Provides support for the person receiving care, enabling short-term breaks for carers. Respite care can include overnight stays in residential facilities, day-care or outings, in-home care, community programs, camps or other flexible arrangements” (Victorian Auditor General 2012 p. 2)
Case management / Care co-ordination	“Provides assistance with coordinating and facilitating access to supports and services.” (Victorian Auditor General 2012 p. 2)
Pharmacological therapy	Use of prescription medication
Counselling / Support group	“Provides emotional and psychological support for carers in order to reduce stress and assist with coping strategies.” (Victorian Auditor General 2012 p. 2). Support group was considered group counselling unless otherwise defined.
Exercise program	Any physical exercise program developed for carers
Meditation / Relaxation	Meditation / Relaxation therapies, including Yoga
Singing group	[self-explanatory]
Financial support	“Provides assistance in the form of payments or brokerage funds for goods or services to assist carers to perform their care role.” (Victorian Auditor General 2012 p. 2)
Carer advocate/consultant	“Provides advocacy and peer support.” (Victorian Auditor General 2012 p. 2)
Information services	“Provide carers with access to information, such as: emergency services, carer support, domestic and nursing care, respite options and council services.” (Victorian Auditor General 2012 p. 2)
Education and training*	“Provides information and skills to assist carers to carry out their care role safely and effectively.” (Victorian Auditor General 2012 p. 2)
Discharge planning	Assessment and service provision provided prior to discharge of the person being cared for to the community
Online community / support / Telephone support	Provision of community discussion forums via online or telephone platforms
Clinical support / assessment / therapy (non-counselling)	Structured contact with a health professional to provide non-counselling services (for example a nurse, occupational therapist, physiotherapist or GP)
Volunteer ‘befriender’ support	Facilitated provision of a “befriender volunteer with the expectation that there would be weekly home visits by the befriender for at least six months” (Jones et al. 2012 p. 12)
Palliative Care	Provision of care to a person with a life-limiting illness towards the end of life.
Wheeled Seated Mobility	Provision of wheeled mobility devices to people with movement

Devices	limitations
Multifaceted	Any combination of the above interventions. Combinations were specified within description of reviews and primary studies

*\*(Note - this report will not focus on this intervention type, as this has been covered in a previous NTRI Forum: see <http://www.ntriforum.org.au/ntri-forums/ta-mh-following-tbi-in-the-community>)*

### Provision of Interventions to support Informal Carers

Various National (Australian) resources and services are available to Informal Carers, for example:

- National Respite for Carers Program (respite, support and counselling) - In 2012-13, 289 organisations were under the National Respite for Carers Program (108 of which are based in Victoria)<sup>21</sup>
- National Carers Counselling Program (NCCP) (information, education, support and counselling) provided by Carers Australia
- National Carer Payment (financial support)
- Carers Advisory Service (CAS)
- Commonwealth Respite and Care Link Centres
- Carer Information and Support Program
- Home and Community Care (HACC) services
- Support service directories
  - Commonwealth Respite and Carelink Centre, available to any carer (<http://www9.health.gov.au/ccsd/>)
  - ABI Services (<http://www.abis.org.au/>)
  - Spinal Hub, offering counselling services to carers of people with SCI (<http://www.spinalhub.com.au/support-equipment-funding/support-counselling>)

State-based resources and services mirror these national initiatives. For example, the Victorian State Government provides most of the programs listed above to an estimated 44,700 carers at an estimated cost of \$200.6 million/year.<sup>19</sup> For respite programs, the State of Victoria provides \$89.4 million/year. Services are provided by the Department of Human Services but are limited for carers of compensable clients (<http://www.dhs.vic.gov.au/for-individuals/disability/carer-and-family-support>). A recent review of Carer Support Programs undertaken by the Victorian Auditor General<sup>19</sup> found that:

- Although a range of carer supports such as counselling, respite and training are available, carers lacked awareness of their existence despite efforts to promote these, and there is also a lack of assessment and referral processes
- there was inconsistent use of standardised tools for assessing carer needs
- inequities in carer access to supports were identified
- a wide range in wait times to access carer supports was identified, making it difficult for carers to anticipate when supports will be available to them
- recognition of the carer role was variable, and low in the case of people caring for those with mental health issues
- inconsistent evaluation of carer support programs and ad-hoc use of carer-related outcome measurement tools

The report recommended “That the Department of Health and Department of Human Services:

- Identify and address gaps in the promotion of carer supports to improve carer awareness of services;
- Require consistent carer identification and needs assessment;
- Improve administration and monitoring of carer brokerage funds;
- Monitor and report on timeliness of access to carer supports;

- Develop outcome measures for carer supports and monitor outcomes.” [p. xi]

Other state-based organisations also provide services and support to carers, for example Carers Victoria (<http://www.carersvictoria.org.au/advice/services-supports/disability-chronic-illness>). There are also specialised services and resources available to carers of catastrophically injured clients. For example, in Victoria these include:

- Road Trauma Support Services Victoria that provide counseling and Support Victoria-wide by phone or in person for carers in the Barwon South Western and Gippsland areas (<http://www.rtssv.org.au/counselling-and-support>)
- The Bouverie Centre (F2F link-up) - <http://www.bouverie.org.au/help-for-families/family-to-family-f2f-link-up/>
- BrainLink - <http://www.brainlink.org.au/page/3/flexible-respite-opportunities>
- Arbias (Victoria and NSW) - <http://www.arbias.org.au/services/victoria.html>
- Action on Disability within Ethnic Communities (ADEC) - <http://www.adec.org.au/index.php/services>

In Victoria, people who experience catastrophic injury from a road accident are covered by the Victorian Transport Accident Commission (TAC), “a Victorian Government-owned organisation set up to pay for treatment and benefits for people injured in transport accidents, promote road safety and improve Victoria’s trauma system” [<http://www.tac.vic.gov.au/about-the-tac> Accessed Sep 16 2014]. Carer supports available through the TAC include respite care for up to 28 days per year, and over 28 days in exceptional circumstances such as clients requiring significant daily care and support [<http://www.tac.vic.gov.au/providers/fees-and-policies/policy/respice-services> Accessed Sep 16 2014]; and family counselling to support a relative of somebody who is severely injured (or dies) in a transport accident, to an annually indexed total value of approximately 15k [<http://www.tac.vic.gov.au/providers/fees-and-policies/policy/family-counselling> Accessed Sep 16 2014].

### **Impact of Support Interventions**

Two broad aims of carer support interventions are to optimise resilience and by doing this, contribute to the long-term sustainability of care at both a personal and system level.

#### *Resilience*

Resilience can be defined as “the process of negotiating, managing and adapting to significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate this capacity for adaptation and ‘bouncing back’ in the face of adversity. Across the life course, the experience of resilience will vary.”<sup>22</sup>

A carer can be described as resilient if the care they are providing is highly demanding and their perceived burden is low. The risk of increased burden and poor wellbeing in carers is heightened if the carer has low resilience (stress resistance). One study found that carers who had low resilience were found more likely to put the person with dementia into institutionalised care as they could not cope with the challenges imposed by providing care<sup>23</sup>. In another study, female carers of people with mental illness had higher resilience when they practiced positive cognitions, i.e. being optimistic about the future and believing in their self-worth<sup>24</sup>. A study of carers of people with Alzheimer’s disease identified two major themes for resilience including focusing on the positive aspects of caring (learning to be more tolerant, more meaningful relationships, keeping your loved one living with you, personal satisfaction and responsibility) and managing stress through support (enjoying hobbies, taking regular time out, exercise such as walking, participation in religious activities)<sup>25</sup>. There are a number of other factors which influence carer resilience including employment status, self-esteem, income, ethnicity, cognitive impairment, education, the age of the person with the long-term disability, gender, personal satisfaction, meaningful relationships, utilising formal supports to

help with carer duties, and duration of time providing care<sup>26</sup>.

### *Resilience in Catastrophic Injury*

A recent study of resilience in family members of people with TBI or spinal cord injury (SCI) has looked at the relationship of resilience, carer burden, affective state, carer strategies for coping<sup>27</sup>. The study found that in family members there is a positive association with positive affect and resilience scores. It found that family members with high resilience were better able to adapt to the adversity experienced by the person's injury. There was a weak negative association with the resilience score of family members and carer burden. There were no differences found between types of injury (TBI and SCI). Some learned examples of resilience from carers of people with a TBI include<sup>28</sup>:

- Finding contentment in whatever comes their way
- Remaining optimistic and positive
- Living life day by day
- Focusing on the future and on a particular interest of theirs which can include the person they are providing care to
- Celebrating time alone
- Ongoing professional consultation, not only when a crisis occurs
- Ongoing social support network.

### *Sustainability*

Provision of appropriate and effective informal carer support interventions can optimise the sustainability of long-term care in two ways. First, enhancing resilience in carers can help them to face and deal with significant challenges arising from their carer role and in doing so, enable carers to be able to continue for in that role over the long-term. Resilience can be measured by the use of scales, i.e. the Resilience Scale and the Carer Assessment of Managing Index (CAMI)<sup>22, 27</sup>. The measurement of carer resilience during their needs assessment may assist in providing more effective supports to ensure they can continue in their role. By understanding the factors which influence resilience, interventions can be better designed to effectively increase the carer's strengths and hence their sustainability in the caring role over the long-term. Expert opinion suggests that skills may also be taught to carers to enhance their resilience to be able to face the challenges associated with caring<sup>27</sup>.

Second, providing support to carers that enhances their resilience reduces economic pressure on paid carer support services. The provision of care comes at a cost to many individuals involved in the process – the person with a disabling long-term condition, the health care system, tax payers in the extended population, and quite importantly carers. In Australia, a survey conducted in 1998 revealed the average amount of hours that one in three primary carers provided was greater than 40 hours a week<sup>9</sup>. A more recent survey of carer health and wellbeing reported that 42% of the total number of carers stated in response to the average amount of hours spent caring was “almost all the time”. A report from Access Economics in 2010 has estimated that the total annual hours of informal care provided is an astonishing 1.32 billion, equivalent to 460 hours/year for one carer alone<sup>29</sup>. A recent review has reported that the economic value of providing informal care “dramatically surpasses” that provided by paid carers<sup>5</sup>. In Australia, the ‘replacement value’ of informal care was estimated at \$40.9 billion in 2010, \$10 billion greater than the same estimation conducted in 2005, indicating the increasing uptake of informal care by people with disabling conditions and increasing cost to the economy itself. The ‘replacement value’ is defined as “the resources needed to be diverted each year from the formal economy to replace the work done by informal carers, were their services no longer available”<sup>29</sup>. The opportunity cost or time for caring indicated by reduction in paid employment was estimated to be \$6.5 million or an estimated 129,900 carers without employment<sup>29</sup>. This loss of employment has a significant

impact on the Australian economy, with efficiency losses estimated to be around \$1.76 billion (in 2010) and impacts to the wider population with increased payment for income support for carers.

A 2012 study on the economic cost of care for adults with TBI and SCI in NSW has provided some key insights into how care is provided and the value associated with various aspects. The average annual cost of care as assessed by carer recall in the study was \$127,456 and \$98,078 for TBI and SCI, respectively<sup>3</sup>. Accounting for inflation after 10 years, the average cost was \$1,170,681 and \$900,847 for TBI and SCI, respectively. This cost will continue to increase with a greater number of people with disabling long-term conditions wanting to remain in their home and have care provided by the people they trust and feel at home with – their family or friends. With more effective rehabilitation and treatments available now, people with long-term conditions can live longer which means carers will have to provide care for a greater duration of time than once was provided.

### Legislative Context

Carers have been described as “de facto extensions of the health care system”<sup>30</sup>. In 2008 the National Carers Coalition made a submission<sup>31</sup> to the Australian Federal Government in an attempt to better recognise and support people providing informal care to family and friends in the community. The submission identified that the number of people requiring care indicated an escalating issue and the need for better strategy to plan both the compensation of informal caregivers and the provision of adequate funding for services to people with severe and chronic disability. The potential risk to the health of caregivers as a result of caregiving was also highlighted. Following on from this in 2010 the Australian Government asked the Productivity Commission to assess Disability Care and Support, resulting in an inquiry report<sup>11</sup>. The Department of Health and Department of Human Services are the principal bodies that develop policies, legislation and programs for support of carers. In 2012 the *Carers Recognition Act* was established that supports the needs of people in care relationships. It is composed of several principles which allow the carer to be respected as an individual, recognised for their contribution to the community, considered in the decision-making process and recognised for the impact that providing care and support has on their social wellbeing. Recognising the need for more optimal care and support systems, the Government has introduced the National Disability Insurance Scheme (NDIS) which commenced implementation in trial sites in 2013.<sup>32</sup> Several reviews have provided policy<sup>12, 20</sup> recommendations, including:

- More standardised eligibility criteria for carers to access programs, allowances and supports
- Ensure that new approaches to support strategies for carers align with the national programs at the system level including the National Respite for Carers program
- Better income support for carers who cannot maintain employment outside their caring role
- Improve awareness and access to support interventions for carers and work towards a national approach

### Summary

Two point seven million people in Australia provide informal (unpaid) care to a person with a disability or long-term health condition, of which 770,000 provide the majority of care and support to people with a severe disability. Given their substantial contribution to care provision and the physical, emotional and other impacts of providing care, it is important to understand the experience of informal caregivers and address their support needs. In recent years, studies have elucidated the substantial effects of providing care on the psychological, physical, social and other impacts of providing care to a person with a long-term disability. There are a range of interventions to mitigate these impacts, which are provided in Australia

through a variety of national and local government and non-government entities with varying efficacy. Optimising carer resilience has direct benefits to carers, and additional benefits to the overall care support system by reducing dependence on paid care. The 2012 Australian *Carers Recognition Act* highlights recognition of the important role of carers.



## Aims and Terms of Reference

People who experience severe injury or illness resulting in ongoing disability and live in the community have a range of physical, psychological and social needs following their discharge from inpatient hospital and rehabilitation care. These needs can be met through provision of paid carer support and / or informal carer support.

Informal carers undertake a range of activities including assistance with activities of daily living such as bathing, feeding, toileting and dressing; emotional care and support; assistance to access medical care and ongoing therapy to optimise independence; assistance to participate in the community through social activities and paid employment; transportation; administrative tasks related to care organisation; and general housework.

This NTRI Forum focuses on informal care, defined as provision of unpaid (informal) assistance to a relative, partner or friend who is aged or has a disability or long-term health condition<sup>7, 9, 10, 12</sup>.

### Aim of the Forum

This NTRI Forum aims to:

- Investigate effective strategies for providing support (excluding skills-related education and training, i.e. manual handling and transfers) to informal carers that can help to optimise their resilience, and the sustainability of the long-term disabled

### Terms of Reference

This NTRI Forum will address the following specific questions:

1. What can we learn from published literature about effective support strategies (excluding skills-related education and training, i.e. manual handling and transfers) for informal carers? *[Focus of this Briefing Document]*
2. What challenges are currently faced by informal carers of people with a long-term disability, and how are these challenges being met? *[Focus of Stakeholder Dialogue I, which will be presented in the accompanying Dialogue Summary for this NTRI Forum]*
3. How can knowledge of optimal strategies be applied locally to address these challenges over the lifetime of a person with a long-term disability? *[Focus of Stakeholder Dialogue II, which will be presented in the accompanying Dialogue Summary for this NTRI Forum]*

### Context of this NTRI Forum

NTRI Forum topics are identified through liaison with a broad range of neurotrauma research networks and organisations. All potential NTRI Forum topics are submitted to the Victorian Neurotrauma Advisory Council (VNAC) for approval. VNAC is an expert body representing



key stakeholders in the Victorian neurotrauma community including the Transport Accident Commission (TAC) and government, health and community services, researchers, and patient advocacy groups. Further information about VNAC can be found at: <http://www.ntri.org.au/research/vnac>

The topic for this NTRI Forum was identified through liaison with the TAC. This program is funded by the Transport Accident Commission (TAC) and Workcover through the Institute for Safety, Compensation and Rehabilitation Research (ISCRR). Online available outputs from this NTRI Forum could be utilised by researchers and other stakeholders to inform or develop projects in related areas. This NTRI Forum topic was approved by VNAC in February 2014.

### **Aims of the briefing document**

This briefing document is directed towards researchers, clinicians, service delivery and advocacy organisations and other stakeholders with experience and expertise in the provision of support to informal carers of people with long-term disability. The aims of the briefing document are to:

1. Provide an overview of Informal Care that describes carer demographics, the experiences and needs of informal carers, carer support interventions and their potential impact and Australian carer-support resources, services and legislation
2. Review literature regarding the effectiveness of carer support interventions
3. Present questions for deliberation at a Stakeholder Dialogue to inform development of local strategies to optimise support for carers in the community [*Outcomes of the Stakeholder Dialogue will be presented in the accompanying Dialogue Summary for this NTRI Forum*]

### **Background and Scope**

This briefing document was prepared to inform a structured stakeholder dialogue of which research evidence is one of many considerations. The dialogue aims to connect the information from the briefing document with the people who can make change happen, and energise and inspire the participants by bringing them together to address a common challenge. This use of collective problem solving can create outcomes that are not otherwise possible, because it transforms each individual's knowledge to a collective 'team knowledge' that can spark insights and generate action addressing the issue.

## Overview of evidence for support strategies for informal carers

A search was conducted to identify systematic reviews (SRs), primary studies (not included in the systematic reviews identified) and clinical trials (Appendix 1). A total of 2,876 citations were screened. The search resulted in the identification of 41 publications:

- One overview of reviews (n=57) and primary studies (n=56), including 1 review of Brain Injury, 2 Reviews and 1 Primary Study of Stroke / Brain Injury and 7 Reviews of Stroke (Appendix 2)
- Eleven reviews of primary studies of interventions to support of carers of non-catastrophically injured people (10 for carers of people with Dementia; 1 for carers of people with mixed Disability) (Appendix 3)
- One review of primary studies of interventions to support of carers of people with Traumatic Brain Injury (covering 16 studies; 7 RCTs across 13 papers; 4 non-RCTs across 6 papers and 5 case series) and 4 reviews encompassing primary studies of interventions to support of carers of people with Traumatic Brain Injury or Stroke (57 Stroke articles covering 51 studies; 10 TBI articles including 3 paediatric; 2 Dementia / Stroke) (Appendix 4)
- 8 completed primary studies of catastrophic injury not covered by identified reviews (3 Acquired Brain Injury; 1 Stroke; 2 Spinal Cord Injury; 1 Traumatic Brain Injury; 1 Disability) (Appendix 5)
- 16 ongoing primary studies, or studies with no published results (10 Dementia, 3 Stroke, 1 Chronic Illness, 1 Home Health Care, 1 Dependent Elderly) (Appendix 6)

Table 2 summarises results of literature reviews across identified interventions. Results are summarised according to findings of:

- The major review of Eagar et al. (2007)<sup>12</sup> commissioned by the Australian Government Department of Health and Ageing, which synthesised findings from 57 reviews and 56 primary studies of carer support interventions (further details Table 3)
- The eleven reviews pertaining to support of carers of people with Dementia (10) and Disability (1) (further details Table 4)
- The five reviews incorporating primary studies pertaining to support of carers of people with Traumatic Brain Injury or Stroke (further details Table 5)
- The eight primary studies of interventions not identified in the above reviews (further details Table 6).

Table 7 presents an overview of ongoing primary studies of support interventions for informal carers, including links to trial registration or information sites.

**Table 2: Summary of findings of identified reviews and primary studies regarding effectiveness of carer support strategies by intervention**

<b>Educational and psycho-educational interventions</b>	
<b>Source</b>	<b>Findings</b>
Review of Reviews and Primary studies <sup>12</sup>	“The overall evidence on educational and psycho-educational interventions is good, especially for carers of people with dementia, mental illness and disability.” <sup>20</sup> (p. 43) “Some of the studies...show promise for rural carers. About half of the papers on educational interventions have targeted carers of people with dementia, with most of the others targeting mental illness and disability.” (p. 65) <sup>12</sup> .
Systematic reviews of support interventions for informal carers: Non-Catastrophic Injury	Some evidence from one review to support carer coping strategy education. <sup>33</sup>
Systematic reviews of support interventions for informal carers: Catastrophic Injury / Stroke	Positive findings regarding psycho-education programs that incorporate problem-solving skills, caregiving and stress-coping for carers of people with stroke. <sup>34</sup>
Primary studies of support interventions for informal carers: Catastrophic Injury / Stroke	Conflicting effects of Problem Solving Training in 3 studies spanning carers of persons with Disability, <sup>35</sup> Traumatic Brain Injury <sup>36</sup> and Spinal Cord Injury <sup>37</sup> . Positive outcomes reported included decrease in dysfunctional coping style, beneficial effects on caregiver social <sup>37</sup> and physical functioning <sup>36, 37</sup> , improvements in problem-solving skills in caregivers <sup>12, 35, 36</sup> and decreases in depression in both caregivers, <sup>12, 36</sup> and care recipients <sup>12</sup> . However, no effects on caregiver depression were observed in the study by Elliott and Berry (2009) <sup>37</sup> , and Rivera et al. (2008) <sup>36</sup> found no effects on caregiver well-being, burden or constructive problem-solving styles.

**Respite care or day care**

Source	Findings
Review of Reviews and Primary studies <sup>12</sup>	Respite care was found to provide either small benefits or no measurable effects. The reviewers found “Other reviewers’ conclusions are consistent with ours: the evidence for the benefits of respite is not strong” (p. 40) <sup>20</sup> and concurred with previous findings that existing evidence does not allow firm conclusions about effectiveness and therefore, cannot inform current policy and practice. There was little or weak evidence regarding effectiveness of different types of respite care, dose effects, or effects for specific carer groups (for example spouses, parents, children, resident, non-resident, employed, young, old etc.). “The best evidence from well controlled trials has long suggested that in spite of the levels of satisfaction reported and apparently obvious practical benefits, few positive effects on carer wellbeing can be directly attributed to the use of respite services.” (pp. 59).
Systematic reviews of support interventions for informal carers: Non-Catastrophic Injury	The 1 review in which care recipients were predominantly children with disability found that while short breaks have positive impact on carers and children, they are not a panacea and other forms of support are required <sup>38</sup> .
Systematic reviews of support interventions for informal carers: Catastrophic Injury / Stroke	<i>[no results at the level of overall review findings]</i>
Primary studies of support interventions for informal carers: Catastrophic Injury / Stroke	Smeets et al. (2012) <sup>39</sup> found that despite a high appreciation of respite care, this is not sufficient for caregivers to attain a healthy level of well-being

**Information Giving**

Source	Findings
Review of Reviews and Primary studies <sup>12</sup>	The giving of written or verbal information alone was found to be ineffective.
Systematic reviews of support interventions for informal carers: Non-Catastrophic Injury	<i>[no results at the level of overall review findings]</i>
Systematic reviews of support interventions for informal carers: Catastrophic Injury / Stroke	<i>[no results at the level of overall review findings]</i>
Primary studies of support interventions for informal carers: Catastrophic Injury / Stroke	Rietdijk et al. (2012) <sup>40</sup> found an interactive skills-based program was more effective than provision of general information; Similarly, Boots et al. (2014) <sup>41</sup> found a combination of tailored information and interaction showed the most promise for improvement.

**Counselling and Psychosocial Interventions**

Source	Findings
Review of Reviews and Primary studies <sup>12</sup>	The overall evidence regarding counselling and psychosocial interventions was positive, although some studies reported no measurable effects. There was little or weak evidence on effectiveness of different types of counselling, dose effects, or effects for specific carer groups. However, some findings regarding care recipient conditions were made: “For dementia carers, theory based psychosocial treatments “with a coherent and explicit rationale” may be most effective...Results for carers of people with stroke or brain injury are mixed, but it appears that a carer’s ability to cope is enhanced by concrete approaches such as providing positive coping strategies and more information about stroke...Family therapy has clear benefits in schizophrenia... looking only at randomised controlled trials for chronic illness interventions involving family members, Martire, Lustig, Schulz, Miller, and Helgeson (2004) reported that the interventions had positive effects for carer burden, depression and anxiety...These reviewers suggested that improvements in family carer depressive symptoms and burden may have reduced the risk of carer mortality.” <sup>20</sup> (p. 41, 43)
Systematic reviews of support interventions for informal carers: Non-Catastrophic Injury	Good support for psychological interventions for dementia carers from six reviews <sup>33, 38, 42-45</sup> especially those based upon cognitive / cognitive-behavioural models <sup>42</sup> and those in which cognitive techniques such as reframing can be tailored to everyday carer problems <sup>45</sup> . One review focusing on subgroups <sup>44</sup> found most positive effects in female caregivers. Another review found a relationship between coping styles and anxiety and depression which suggests that psychological interventions should aim to modify dysfunctional coping styles <sup>46</sup> Some evidence from one review to support psychosocial intervention training for nurses and reminiscence therapy <sup>33</sup> Favourable findings regarding Nurse-led problem-solving counselling <sup>47</sup>
Systematic reviews of support interventions for informal carers: Catastrophic Injury / Stroke	<i>[no results at the level of overall review findings]</i>
Primary studies of support interventions for informal carers: Catastrophic Injury / Stroke	<i>[no results at the level of overall review findings]</i>

**Multicomponent interventions**

Source	Findings
Review of Reviews and Primary studies <sup>12</sup>	This review found there was good evidence regarding effectiveness of multicomponent interventions. “Interventions incorporating a variety of components— such as skills training, information and referral, respite, counselling, in-home environmental changes or care recipient treatments—have been widely tested with carers for frail aged people and/or those with dementia, stroke or brain injury...Sørensen and colleagues (2002) concluded that multicomponent interventions had significant positive effects on carer burden, wellbeing and knowledge. The most effective interventions appeared to be those that are comprehensive, intensive and tailored to carers’ needs” (pp. 41, 43) <sup>20</sup>
Systematic reviews of support interventions for informal carers: Non-Catastrophic Injury	<i>[no results at the level of overall review findings]</i>
Systematic reviews of support interventions for informal carers: Catastrophic Injury / Stroke	<i>[no results at the level of overall review findings]</i>
Primary studies of support interventions for informal carers: Catastrophic Injury / Stroke	Support for multifaceted programs, for example high satisfaction with a program combining Brain Injury education, skills training and psychological support <sup>48</sup> ; positive results from a program addressing areas of caregiving risk in Spinal Cord Injury which was found to be most effective in addressing health symptoms, depression and burden when administered to both caregiver and care recipient compared with caregiver only intervention and control (information-only) <sup>49</sup> ; and positive responses to a four-module education and support program for stroke caregivers, which also resulted in development of an ongoing social network amongst participants <sup>50</sup> .

**Care coordination**

Source	Findings
Review of Reviews and Primary studies <sup>12</sup>	“Although there have only been a small number of studies investigating case management and care coordination and their impact on the carer, the available evidence is promising.” (p. 43) <sup>20</sup> “Studies to date have reported positive outcomes for carers of people with dementia, frail aged and stroke.” (p. 58) <sup>12</sup>
Systematic reviews of support interventions for informal carers: Non-Catastrophic Injury	Favourable findings regarding case management <sup>47</sup>
Systematic reviews of support interventions for informal carers: Catastrophic Injury / Stroke	<i>[no results at the level of overall review findings]</i>
Primary studies of support interventions for informal carers: Catastrophic Injury / Stroke	<i>[no results at the level of overall review findings]</i>

**Family Support Interventions**

Source	Findings
Review of Reviews and Primary studies <sup>12</sup>	Overall the evidence was described as “promising, with four dementia studies and a randomised controlled trial in palliative care and bereavement, concluding that it is a well-supported intervention” (pp. iii – iv) <sup>12</sup> . There was little or weak evidence on effectiveness of different types of family support services, dose effects, or effects for specific carer groups. However, some findings regarding care recipient conditions were made: “Reviews of family support services for patients with a mental illness conclude that family support interventions are effective... The evidence is also good for carers of people with dementia, with four well designed studies finding that family support is effective” (p. 56, 67) <sup>12</sup> . Furthermore, the review found that “The effectiveness of this type of intervention depends on the skills of the provider, and may be affected by the complexity of the carer’s situation, and factors such as competing demands, health problems and past family relationships... Observation of the carer–care recipient dyad is essential in order to develop individualised approaches, and more work is required to be able to identify dyads suitable for this type of intervention before a crisis occurs” (pp. 42, 43) <sup>20</sup>
Systematic reviews of support interventions for informal carers: Non-Catastrophic Injury	<i>[no results at the level of overall review findings]</i>
Systematic reviews of support interventions for informal carers: Catastrophic Injury / Stroke	<i>[no results at the level of overall review findings]</i>



Primary studies of support interventions for informal carers: Catastrophic Injury / Stroke	Promising results from a pilot study of a program that connects families who have a family member with Acquired Brain Injury with the aid of a trained facilitator, with evaluation showing positive impacts for both families and facilitators <sup>51</sup>
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### Support groups

Source	Findings
Review of Reviews and Primary studies <sup>12</sup>	“The number of well-designed studies of mutual support groups is limited, so the evidence on support groups at this stage is not established but is emerging...Carers having something in common with each other is an obvious factor that contributes to mutual support and this is one area in which it appears that particular sub-groups of carers may benefit...support groups are valuable because they put primary carers in touch with each other and reduce the sense of isolation. They are, however, only part of the social support picture: carers also need some sort of practical intervention, such as a family conference arranged by the GP to ensure that the responsibility can be shared more fairly and they have back up when they need it...there is emerging evidence that support groups may be appropriate for carers of CALD backgrounds, carers of children with disabilities and carers of people with mental illness.” (pp. 56, 68 <sup>12</sup> ; p. 42 <sup>20</sup> )
Systematic reviews of support interventions for informal carers: Non-Catastrophic Injury	Group coping skills interventions alone and with behavioural activation significantly increase dysfunctional coping <sup>43</sup>
Systematic reviews of support interventions for informal carers: Catastrophic Injury / Stroke	<i>[no results at the level of overall review findings]</i>
Primary studies of support interventions for informal carers: Catastrophic Injury / Stroke	<i>[no results at the level of overall review findings]</i>

### Technology-based Interventions

Source	Findings
Review of Reviews and Primary studies <sup>12</sup>	<i>[no results at the level of overall review findings]</i>
Systematic reviews of support interventions for informal carers: Non-Catastrophic Injury	Conflicting conclusions regarding technology-based interventions for dementia carers, with one review of technology-based interventions <sup>52</sup> reporting insufficient evidence despite some positive findings; another review focusing on psychological interventions <sup>42</sup> concluding that multicomponent and technology-based interventions combining individual and group sessions are most effective; and another review finding that web-viewable videos and videos + weekly phone calls focusing on coping and behavioural management were effective in decreasing anxiety or depressive symptoms <sup>43</sup> .
Systematic reviews of support interventions for informal carers: Catastrophic Injury / Stroke	Generally positive findings regarding technology-based interventions from three reviews such as high satisfaction and good feasibility <sup>40</sup> , reduction in caregiver stress and improvement in well-being <sup>53</sup> and beneficial effects on caregiver confidence, stress, depression and self-efficacy <sup>41</sup> . However, the review by Boots et al. reported a lack of methodological quality in most of the included internet intervention studies <sup>41</sup> .
Primary studies of support interventions for informal carers: Catastrophic Injury / Stroke	<i>[no results at the level of overall review findings]</i>

### Meditation-based Interventions

Source	Findings
Review of Reviews and Primary studies <sup>12</sup>	<i>[no results at the level of overall review findings]</i>
Systematic reviews of support interventions for informal carers: Non-Catastrophic Injury	Meditation-based interventions appear to improve depression and burden in family dementia caregivers <sup>54</sup>
Systematic reviews of support interventions for informal carers: Catastrophic Injury / Stroke	<i>[no results at the level of overall review findings]</i>
Primary studies of support interventions for informal carers: Catastrophic Injury / Stroke	<i>[no results at the level of overall review findings]</i>

**Clinical support / assessment / therapy (non-counselling)**

Source	Findings
Review of Reviews and Primary studies <sup>12</sup>	<i>[no results at the level of overall review findings]</i>
Systematic reviews of support interventions for informal carers: Non-Catastrophic Injury	Favourable findings regarding in-home and telephone Occupational Therapist support <sup>47</sup>
Systematic reviews of support interventions for informal carers: Catastrophic Injury / Stroke	<i>[no results at the level of overall review findings]</i>
Primary studies of support interventions for informal carers: Catastrophic Injury / Stroke	<i>[no results at the level of overall review findings]</i>

## Summary of findings of identified reviews and primary studies regarding effectiveness of carer support strategies

### *Educational and psycho-educational interventions*

Overall there is good evidence for educational and psycho-educational interventions. In the setting of catastrophic injury / stroke, positive findings were reported for programs incorporating problem-solving skills, caregiving and stress-coping; however the effects of Problem Solving Training were variable.

### *Respite care or day care:*

Overall the evidence for the benefits of respite care was reported as 'not strong'. Both the overall evidence and evidence from catastrophic injury / stroke conclude that while respite care has benefits, other forms of support are also required to optimise caregiver welfare.

### *Information Giving:*

Overall, passive dissemination of information was found to be ineffective and this was reinforced by evidence from catastrophic injury / stroke, which emphasised the importance of an interactive component in conjunction with information-giving.

### *Counselling and Psychosocial Interventions:*

Overall the evidence was reported as positive. Although specifics of optimal type and dosage of counselling, and effects for specific carer groups are generally poorly understood, it appears that cognitive / cognitive-behavioural models are effective for carers of people with Dementia. In the setting of catastrophic injury / stroke, mixed results were reported, but concrete approaches including provision of positive coping strategies and information were identified as effective.

### *Multicomponent Interventions:*

Overall, good evidence was reported for multicomponent interventions – for example, those incorporating skills training, information and referral, respite, counselling, in-home environment changes or care recipient treatments. Positive findings from catastrophic injury / stroke were also reported in relation to multifaceted programs with a similar composition.

### *Care co-ordination:*

The volume of literature in this area was reported to be relatively low, but available evidence was described as promising, including in the area of stroke.

### *Family Support Interventions:*

Overall the evidence was described as 'promising', although as with counselling, understanding of intervention specifics, dosage and effects on specific carer groups is poor. In the setting of Acquired Brain Injury, a novel program of facilitated connection between families of people with ABI yielded promising results in a single primary study.

### *Support Groups:*

Overall the volume of literature was reported as low and although support groups were found to have beneficial effects, other concurrent strategies such as practical family and medical support were identified as important. One review of group coping skills found, contrary to their initial hypothesis, a significant increase in dysfunctional coping.

### *Technology-based Interventions:*

In reviews in the setting of non-catastrophic injury, conflicting conclusions regarding technology-based interventions for Dementia carers were identified, with more positive findings for interventions combining information with telephone support for coping and

behavioural management. Findings from catastrophic injury / stroke were generally positive, although study quality was reported as poor in one review. It is important to consider the content of technology-based interventions, rather than just the mode of delivery.

*Meditation-based Interventions:*

One review in the area of Dementia reported positive findings for depression and burden.

*Clinical support / assessment / therapy (non-counselling):*

One review of Dementia studies reported favourable findings for in-home and telephone Occupational Therapy support.

### **Summary of general findings**

In addition to the findings pertaining to specific intervention categories, there were a number of general findings reported in the identified literature:

- The overall results of reviews of carer support interventions were inconclusive. This was postulated to be due to insufficient sensitivity of outcome measures; lack of specificity of interventions; or inability to identify active ingredients of multidimensional interventions<sup>12</sup>
- Intervention effectiveness varies with family dynamics, implying that even if the needs of diverse carer groups are similar, different interventions may be required for each group to optimise effectiveness:
  - “There is also little evidence on what interventions are most effective for carers in different types of relationships with the care recipient - parents, spouses, children, friends, resident and non-resident carers. However, there is evidence to suggest that the same interventions achieve different outcomes for different carers. For example, Sörenson et al. (2002) found that spousal carers benefit less than adult children and that carers of people with dementia benefit less than other carers”<sup>12</sup> (p. 73). Van Mierlo et al. (2012) reinforced this finding: “relatively little research has been done into subgroups of...caregivers” and further stated that “more research is needed to better understand which psychosocial interventions are effective for specific subgroups of people with dementia” (p. 1)<sup>44</sup>
- One review reported insufficient description of costs to provide evidence of effectiveness / cost-effectiveness of caregiver support interventions in the setting of Dementia<sup>47</sup>
- One review reported evidence that culturally appropriate interventions are required to meet the health needs of Hispanic / Latino caregivers<sup>55</sup>. Although focused on a specific cultural population, this principle may apply to other cultural populations
- A review reporting beneficial effects for programs aiming to enhance caregiver capacity and health recommended that interventions integrate physical, mental, social and spiritual aspects of carer wellbeing<sup>56</sup>. This is consistent with the principles of multicomponent interventions
- The effectiveness of most interventions is only short-term, lasting approximately 7 months<sup>12, 57</sup>
- Characteristics of carers and the people they provide care to are not well reported<sup>12, 57</sup>
- Limited studies investigate the ‘fit’ between assessed carer needs and support intervention provided<sup>12, 57</sup>
- Type of evaluation applied to multicomponent support interventions are not suitable to assess what aspects are effective or not<sup>12, 57</sup>

### Issues to be considered in interpreting research evidence

Eager et al. (2007)<sup>12</sup> identified four key factors that influence interpretation of the effectiveness of carer interventions. These are described below with reference to the above evidence overview.

1. *Defining the intervention:* There is poor definition and description of interventions to support carers. For example, the location, planning and service intensity of respite services varies widely and similar issues apply to other carer interventions, including counselling, family support and psycho-education. This is reflected by the evidence overview, in which there is variation in the specifics of interventions within intervention categories. Furthermore, there is conceptual overlap in the intervention categories. For example, family support interventions may involve counselling, as with psycho-educational interventions; support groups may involve families. This highlights the difficulty of identifying the ‘active ingredients’ of interventions, and may explain why multicomponent interventions seem to have a positive impact.
2. *Specifying the target group:* Carers are not a homogenous group and carer needs are variable. Few studies examine the needs of carers receiving the intervention.
  - “There is little evidence that the needs of carers systematically vary based on the type of person they are caring for. For example, there is little evidence to suggest that the needs of carers of people with dementia are different to the needs of carers of people after stroke. In both cases, the specific needs of the care recipient and attributes such as challenging behaviours do have an impact on the carer. Interventions with carers of people with dementia have been the subject of the most research and, not surprisingly, the evidence is therefore strongest for this group.”<sup>12</sup> (p. iv)
  - Eager et al. (2007)<sup>12</sup> summarised the findings of 3 studies exploring the needs of carers of people with stroke and brain injury: “The key areas of carer need are similar to other care recipient groups...and use similar tools to describe the risks of burnout and burden such as the Caregiver Strain Index. Stroke and brain injury studies include the carer’s experience of severe and prolonged disability and managing issues such as mechanical ventilation<sup>58</sup>. Studies have investigated, for example, which carers of stroke patients living at home experience the highest levels of strain and are at risk of burn-out, and how support could be organised and when this support should be offered<sup>59</sup>. They have investigated differences in family stress levels related to the role of the injured person within the family and the severity of the injury (p. 595)<sup>60</sup>...The number of participants in studies of the needs of carers of people with brain injury and stroke is often limited, and the needs of this group of carers are more often captured in broader populations of carers. However descriptions of the carer experience are consistent with those in other technologically dependent populations, suggesting that consistent themes are inherent in the complex carer experience and are not isolated occurrences specific to a given patient population.”(p. 49)<sup>12</sup>
3. *Specifying the goal of the intervention:* The aim of carer support interventions varies. Outcomes measured include carer satisfaction; carer stress, burden, anxiety, depression, coping and physical health; satisfaction or self-esteem; and impact on and outcomes for care recipients. One way to address this was identified by Lawang et al. (2013) who recommended that “caregivers and other stakeholders should be involved in the development of any support intervention to ensure that they are relevant to the caregiving context and needs are better met” (p. 543)<sup>56</sup>. Such engagement would also elucidate appropriate outcome measures that capture carer

support intervention aims. Other reviews have also noted that outcomes of support interventions studies are not explicit, i.e. are they intended to be effective over the long or short term, or is the intention of the intervention study to be protective over the long-term<sup>12, 57</sup>

4. *Research bias and methodological issues:* Systematic Reviews of studies of carer interventions may be limited to Randomised Controlled Trials (RCTs), however there are other study designs that may be more feasible to evaluate carer support interventions. This means that the evidence at the review level appears less promising than the evidence at the primary study level.

The results of this evidence review should also be interpreted in the context that:

- The review focused primarily on synthesising findings from reviews. A more comprehensive review of primary studies may elucidate further information regarding effectiveness of interventions
- Quality appraisal of reviews and primary studies was not undertaken as part of this review. Reviews or primary studies with methodological limitations may be subject to bias, which could influence study findings
- The date range for the search was limited to 2007 - 2014. However, this limitation is partially offset by the inclusion of a major review from 2007 that was very comprehensive<sup>12</sup>
- This review has focused on effectiveness of interventions, rather than recommendations for future research. Readers wishing to obtain information on research implications are advised to access the review by Eager et al. (2007)<sup>12</sup>

### **Implications of the review for practice and research**

Although a number of broad intervention categories have good evidence of effectiveness, understanding the specifics of the interventions within these categories and therefore the 'active ingredients' that drive positive outcomes is challenging in this area. Developing a greater understanding of these specifics would enable a systematic approach to assessment, mapping of assessment findings to specific support needs and evaluation of effectiveness and sustainability. However, more research is required to facilitate this understanding:

"...the gaps in current knowledge provide the platform for the development of a future research agenda designed to provide answers to some critical questions:  
Which carers?  
Should receive what services?  
From whom?  
At what expected cost?  
With what expected effect?" (p. 74)<sup>12</sup>

The absence of definitive findings from the literature regarding specific interventions for specific carer groups reinforces the importance of engaging with caregivers to understand their support needs and identify the interventions that may address such needs. There are other factors that may also influence the carer experience that were not elucidated in the current review. For example, carer support, education and subsequent coping strategies and well-being may vary with in different health systems such as rehabilitation units compared to general hospitals.

The review findings strongly suggest that packages of interventions are more likely to be effective in supporting carers compared to discrete interventions such as respite care, support groups or information provision in isolation. It is also important to evaluate intervention effectiveness using outcome measures that are meaningful to both carers and



service providers. Given the importance of tailoring interventions to individual carer circumstances, individual case studies could add value to comparative research examining effectiveness of carer support strategies in larger populations. Several reviews<sup>12, 20, 57</sup> have identified further research recommendations:

- More research on preventive interventions rather than symptomatic support interventions
- Data on the assessment of carers needs to be optimised so outcomes can be measured more effectively
- A higher quality evidence base for research studies on support interventions with more explicit designs and goals tailored to the outcome measures
- There is little if any follow-up of the long-term effectiveness of support interventions
- No studies exist on assessing the effectiveness of support interventions for indigenous carers, particularly due to lack of access to services
- There is promise in low-cost long-distance technologies but needs further investigation
- Support interventions that are frequent and have educational inputs show potential

### Summary and Conclusions

An evidence review of literature regarding the effectiveness of carer support interventions identified 1 major overview of reviews and primary studies, 11 reviews of primary studies of interventions to support of carers of non-catastrophically injured people, 1 review of primary studies of interventions to support of carers of people with Traumatic Brain Injury, 4 reviews encompassing primary studies of interventions to support of carers of people with Traumatic Brain Injury or Stroke, 8 primary studies of catastrophic injury not covered by identified reviews and 16 ongoing primary studies.

The overall results of reviews of carer support interventions were inconclusive. This means that firm conclusions regarding what works and doesn't work cannot be made from the literature identified. Notwithstanding this, evidence was reported as 'good' for educational and psycho-educational interventions, counselling and psychosocial interventions and multicomponent interventions. 'Good' evidence was also reported, but with a low volume of evidence, for meditation-based interventions (1 review) and non-counselling clinical support (1 primary study). Evidence for care co-ordination and family support interventions was described as 'promising'. Evidence for technology-based interventions was conflicting in the setting of Dementia, but more positive in the area of catastrophic injury. Evidence for respite care was described as 'not strong', and although benefits were reported, the importance of additional support strategies in conjunction with respite care was emphasised. Similarly, emerging positive evidence in favour of support groups was reported, however additional concurrent support strategies were recommended. Passive information dissemination alone was found to be ineffective.

A number of factors need to be considered in interpreting this evidence other than the limited research volume as noted above. These include poor definition and description of interventions, variability within and conceptual overlap between intervention categories; the importance of specifying the target carer group and understanding their needs, which is not extensively undertaken within the identified literature; variability in the goals of the interventions and therefore, the outcomes measured; research bias and methodological issues; and the limitations of this evidence review.

The review identified a range of implications for practice and research, including:

- The need to enhance understanding of the 'active ingredients' that drive positive outcomes within broad interventions through a combination of comparative studies and individual case studies

- It is important to engage with caregivers to understand their support needs and identify the interventions that may address such needs
- Packages of interventions are more likely to be effective in supporting carers compared to discrete interventions such as respite care, support groups or information provision in isolation
- It is important to evaluate intervention effectiveness using outcome measures that are meaningful to both carers and service providers.

*“Although focusing on dementia carers, Kennet, Burgio, and Schulz (2000) summed up much of the literature when they concluded that anyone expecting to find a “silver bullet” solution to alleviating carer distress would be disappointed. “There is no single, easily implemented and consistently effective method for eliminating the stresses of caregiving” (p. 79)<sup>61</sup>.” (p. 40)<sup>20</sup>*

## Questions for Deliberation

1. What challenges are currently faced by informal carers of people with a long-term disability, and how are these challenges being met?
2. How can knowledge of optimal strategies be applied locally to address these challenges over the lifetime of a person with a long-term disability?

*An accompanying document, the Dialogue Summary, presents results of deliberation upon these questions from the Stakeholder Dialogue.*

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## Appendices

### Appendix 1: NTRI Forum search methods to identify support strategies for carers

#### Search methodology

- A comprehensive search of the following databases from January 2009 until August 2014 was undertaken: MEDLINE (search strategy below); The Cochrane Library; CINAHL Plus; PsycINFO and PsycBITE
- Google was also searched using the terms “support interventions or therapy” combined with “informal carers” with date restriction 2007 -2014. The first 100 results were screened
- Reference lists of included studies were also scanned to identify further relevant references
- A search of the clinical trials websites (*clinicaltrials.gov* and *anzctr.org.au*) using the words “carer support AND family caregiver NOT cancer”.

#### Inclusion/Exclusion Criteria

**Patient group:** Carers of people with a long-term disability, i.e. informal, family, unpaid (study can include interventions for carers and people with a disability but must be primarily directed at carers)

*Exclusion* – Carers of people with a mental health disorder, (i.e. schizophrenia, bipolar, depression, anxiety), cancer, palliative care, developmental disabilities, heart disease, kidney disease (studies of people primarily and also their carers)

**Intervention:** Support interventions or programs or strategies (i.e. National Carer Counselling Program, National Respite for Carers Program (NRCP), and Commonwealth Respite and Carelink Centre Services)

*Exclusion* – Skills-related education and training, i.e. written information or manual handling and transfers

**Phase of care:** Home, non-institutional setting

*Exclusion* - institutional settings including rehabilitation hospitals, nursing homes that have specialised infrastructure, and 24 hour multiple staffing facilities in which multiple residents are located

**Study type:** Systematic reviews, organisational reports, e.g. TAC, MAA, NZ ACC if available), and primary studies not included in systematic reviews

*Exclusion* – case studies, reviews (literature, historical)

**Date Range:** 2009 - Current

**Language:** English

**Example of search strategy (Medline) – not limited by patient sub-group**

1. caregivers/ or friends/ or spouses/ or parents/ or relatives/ or partners/ or family relations/ or intergenerational relations/
2. (carer\* or caregiv\* or care giv\* or care-giv\*).tw.
3. 1 or 2
4. counselling/ or social support/ or support groups/ or psychotherapy/ or respite care/ or family therapy/ or family health/
5. (support\* or counsel\* or therap\* or program\* or well being or well-being or psycho\* or social or coping or relaxation or respite or retreat or sleep or massage or yoga or meditation or listen\* or day care or daycare or mindfulness).tw.
6. 4 or 5
7. home nursing/ or community networks.mp. or patient care/ [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
8. (home nursing or non-professional care or non-professional nursing or informal care or communit\*).tw.
9. 7 or 8
10. 3 and 6 and 9
11. limit 10 to (english language and yr="2009 - 2014")

**Example of search strategy (Medline) – limited by patient sub-group to traumatic brain injury (TBI)**

1. caregivers/ or friends/ or spouses/ or parents/ or relatives/ or partners/ or family relations/ or intergenerational relations/
2. (carer\* or caregiv\* or care giv\* or care-giv\*).tw.
3. 1 or 2
4. counselling/ or social support/ or support groups/ or psychotherapy/ or respite care/ or family therapy/ or family health/
5. (support\* or counsel\* or therap\* or program\* or well being or well-being or psycho\* or social or coping or relaxation or respite or retreat or sleep or massage or yoga or meditation or listen\* or day care or daycare or mindfulness).tw.
6. 4 or 5
7. home nursing/ or community networks.mp. or patient care/ [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
8. (home nursing or non-professional care or non-professional nursing or informal care or communit\*).tw.
9. 7 or 8
10. 3 and 6 and 9
11. exp head injury/
12. exp Brain Injury/
13. exp Brain Edema/
14. exp Glasgow Coma Scale/
15. exp Glasgow Outcome Scale/
16. exp Unconsciousness/
17. exp Cerebrovascular accident/
18. ((head or crani\$ or cerebr\$ or capitis or brain\$ or forebrain\$ or skull\$ or hemispher\$ or intra-cran\$ or intracran\$ or inter-cran\$ or intercran\$) adj3 (injur\$ or trauma\$ or lesion\$ or damag\$ or wound\$ or destructi\$ or oedema\$ or edema\$ or fractur\$ or contusion\$ or concus\$ or commotion\$ or pressur\$)).ti,ab.
19. ((head or crani\$ or cerebr\$ or brain\$ or intra-cran\$ or intracran\$ or inter-cran\$ or intercran\$) adj3 (haematoma\$ or hematoma\$ or haemorrhag\$ or hemorrhag\$ or bleed\$ or pressur\$)).ti,ab.
20. (glasgow adj3 (scale\$ or score\$)).ti,ab.
21. "rancho los amigos scale".ti,ab.
22. ("diffuse axonal injury" or "diffuse axonal injuries").ti,ab.
23. "persistent vegetative state".ti,ab.

24. ((unconscious\$ or coma\$ or concus\$) adj3 (injur\$ or trauma\$ or damag\$ or wound\$ or fracture\$ or contusion\$ or haematoma\$ or hematoma\$ or haemorrhag\$ or hemorrhag\$ or bleed\$ or pressur\$)).ti.ab.
25. 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24
26. 10 AND 25
27. limit 26 to (english language and humans and yr="2009 -Current")

**Example of search strategy (Medline) – limited by patient sub-group to spinal cord injury (SCI)**

1. caregivers/ or friends/ or spouses/ or parents/ or relatives/ or partners/ or family relations/ or intergenerational relations/
2. (carer\* or caregiv\* or care giv\* or care-giv\*).tw.
3. 1 or 2
4. counselling/ or social support/ or support groups/ or psychotherapy/ or respite care/ or family therapy/ or family health/
5. (support\* or counsel\* or therap\* or program\* or well being or well-being or psycho\* or social or coping or relaxation or respite or retreat or sleep or massage or yoga or meditation or listen\* or day care or daycare or mindfulness).tw.
6. 4 or 5
7. home nursing/ or community networks.mp. or patient care/ [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
8. (home nursing or non-professional care or non-professional nursing or informal care or communit\*).tw.
9. 7 or 8
10. 3 and 6 and 9
11. exp Spinal Cord Injuries/
12. exp Spinal Cord Ischemia/
13. exp Central Cord Syndrome Central Cord Syndrome /
14. exp Spinal Injuries/
15. exp Back Injuries /
16. Paraplegia/
17. Quadriplegia/
18. (paraplegi\* or quadriplegi\* or tetraplegi\*).mp.
19. (myelopathy adj3 (traumatic or post-traumatic)).mp.
20. ((spine or spinal) adj3 (fracture\$ or wound\$ or trauma\$ or injur\$ or damag\$)).mp.
21. (spinal cord adj3 (contusion or laceration or transaction or trauma or ischemia)).mp.
22. ((cervical spine or cervical vertebrae or cervical vertebral or cervical spinal) adj3 (contusion or laceration or transaction or trauma or ischemia)).mp.
23. ((cervical spine or cervical vertebrae or cervical vertebral or cervical spinal) adj3 (fracture\$ or wound\$ or trauma\$ or injur\$ or damag\$)).mp.
24. ((lumbar spine or lumbar vertebrae or lumbar vertebral or lumbar spinal) adj3 (contusion or laceration or transaction or trauma or ischemia)).mp.
25. ((lumbar spine or lumbar vertebrae or lumbar vertebral or lumbar spinal) adj3 (fracture\$ or wound\$ or trauma\$ or injur\$ or damag\$)).mp.
26. ((thoracic spine or thoracic vertebrae or thoracic vertebral or thoracic spinal) adj3 (contusion or laceration or transaction or trauma or ischemia)).mp.
27. ((thoracic spine or thoracic vertebrae or thoracic vertebral or thoracic spinal) adj3 (fracture\$ or wound\$ or trauma\$ or injur\$ or damag\$)).mp.
28. (sacral adj3 (fracture\$ or wound\$ or trauma\$ or injur\$ or damag\$)).mp.
29. (sacral adj3 (contusion or laceration or transaction or trauma or ischemia)).mp.
30. OR/11-29
31. 10 AND 30
32. limit 31 to (english language and humans and yr="2009 -Current")

**Appendix 2: Overview of reviews of support interventions for informal carers<sup>12, 20</sup>**

<b>N (studies): [Type]</b>	<b>Conditions of care recipients (n reviews / n primary studies)</b>	<b>Interventions covered by review (n reviews / n primary studies)</b>
57 Reviews (53 SRs) / 56 Primary Studies	Dementia (18 reviews, 29 primary studies) Cancer / Palliative Care (9 / 4) Frail Aged (6 / 6) Psychiatric Disorders (5 / 6) Disabilities (0 / 9) Stroke (7 / 0) Multiple Disorders (5 / 1) Stroke / Brain Injury (2 / 1) Intellectual Disability + Challenging Behaviour (2 / 0) Brain Injury (1 / 0) Wheelchair user (1 / 0) Chronic Illness (1 / 0)	Multifaceted (27 / 8) Counselling / Support group (10 / 18) <ul style="list-style-type: none"> <li>• Counselling (6 / 4)</li> <li>• Family Support (4 / 6)</li> <li>• Support Groups (0 / 8)</li> </ul> Education and training (4 / 16) Respite (8 reviews, 7 primary studies) Case management (0 / 7) Palliative Care (6 / 0) Clinical support / assessment / therapy (non-counselling) (1 / 0) Wheeled Seated Mobility Devices (1 / 0)

### Appendix 3: Overview of systematic reviews of support interventions for informal carers: Non-Catastrophic Injury

Citation	N (studies): [Type]	Conditions of care recipients (n studies)	Interventions covered by review (n studies)	Review Findings
Hurley et al. 2014 <sup>54</sup>	8 [3 RCTs, 5 case series]	Dementia (8)	<b>Meditation / Relaxation:</b> Mantram repetition (2) Mindfulness-based (4) Yogic / Yoga and meditation (2)	“The results provide tentative evidence that meditation-based interventions do indeed improve levels of depression and burden in family dementia caregivers... longer-term follow-up results suggest that gains are not always maintained, indicating that interventions should consider whether caregivers may benefit from ‘booster’ sessions...future research should direct efforts to conduct larger scale, more rigorous studies” [pp. 281, 286]
Godwin et al. 2013 <sup>52</sup>	8 [representing 4 RCTs from 3 parent studies]	Dementia (8)	<b>Technology-driven (computer / web-based) interventions:</b> Counselling / Support Group* Information services* Education and training (1) Clinical support / assessment / therapy (non-counselling)* Online community / support / Telephone support * Multifaceted (any combination of the above*) (2)	“While all studies included an information and social-support component, the content and delivery differed across the studies...Of the studies that measured depression and anxiety, some demonstrated reductions in depression (n = 4) and anxiety (n = 2) for caregivers in the intervention group. Although each of these studies had some positive findings, there is currently insufficient evidence to support or refute technology-driven interventions for caregivers of PWD...Technology-driven interventions for caregivers of PWD continue to hold promise for the future of intervention research because of their convenience and variety of delivery formats...However, to date, too few RCTs of such interventions have been conducted to fully evaluate their merit.” [p. 221]
Elvish et al. 2013 <sup>42</sup>	20 [17 quantitative, 3 qualitative]	Dementia (20)	Counselling / Support Group (9)* Carer advocate/consultant* Information services* Education and training (5)* Multifaceted (any combination of the above) (5)	<ul style="list-style-type: none"> <li>“the results of this review suggest that interventions underpinned by cognitive / cognitive-behavioural models can produce meaningful change. Evidence also supports the use of interventions which aim to increase knowledge of dementia and address communication. It is more difficult to draw conclusions about the use of theoretical standpoints that are not primarily driven by cognitive-behavioural theory, not because of the quality of the studies, but because there are fewer of them</li> <li>Based on the findings of this review, it is suggested that multicomponent and technology-based interventions that are a combination of individual and group sessions are most effective. [pp. 2, 24 – 25]</li> </ul>
Van Mierlo et al. 2012 <sup>44</sup>	26 [reviews and primary studies]	Dementia (26)	Respite (1) Counselling / Support group (7)* Exercise program*	“Most positive effects were found in caregivers of people with a diagnosis of ‘dementia not otherwise specified’ and in the subgroup of female caregivers. Examples of outcomes were decreased depression and improved self-efficacy...This study gives a first overview of successful psychosocial

Citation	N (studies): [Type]	Conditions of care recipients (n studies)	Interventions covered by review (n studies)	Review Findings
			Information services* Education and training (5)* Online community / support / Telephone support (2) Clinical support / assessment / therapy (non-counselling) (1) Multifaceted (any combination of the above) (10)	interventions in subgroups of caregivers of people with dementia. It makes clear that until now, relatively little research has been done into subgroups of these caregivers. It also suggests that more research is needed to better understand which psychosocial interventions are effective for specific subgroups of people with dementia." [p. 1] □□
Hall & Skelton 2012 <sup>33</sup>	17 [5 reviews, 5 RCTs, 2 qualitative studies, 5 cohort studies]	Dementia	Respite (1) Case management (1) Counselling / Support group (8) Singing group (1) Information services* Education and training (3) Clinical support / assessment / therapy (non-counselling) (2)* Multifaceted (any combination of the above) (1)	"Of the 17 studies in this review, five were previous reviews, which investigated the impact of different types of interventions on the caregivers of people with dementia...The interventions that were identified as being effective in providing benefits to these caregivers were psychological interventions, such as caregiver coping strategy education Some interventions were found to be effective in improving caregiver outcomes, namely psychosocial intervention training for nurses Cognitive behavioural and reminiscence therapy can be effective in improving outcomes for caregivers of people with dementia, for example, level of burden, stress and strain, health and mood" [p. 283, 287]
Jones et al. 2012 <sup>47</sup>	12 [6 RCTs, 3 cohort studies, 2 Markov model based studies, 1 discrete event simulation]	Dementia	Respite (1)* Case management (1)* Pharmacological therapy (4 – all Donepezil) Counselling / Support group (2)* Online community / support / Telephone support* Clinical support / assessment / therapy (non-counselling) (1)* Volunteer 'befriender' support (1) Multifaceted (any combination of the above) (2)	"Of the trials included for full review, four recorded significant differences in outcome measures for caregivers as the result of an intervention: lower perceived burden [case management], higher sense of competence [in-home and telephone Occupational Therapist support], improved coping skills [nurse-led problem-solving counselling] and increased nursing knowledge [case management + nurse telephone support]" [p. 15] "At present few published studies report costs in enough detail to provide evidence of the effectiveness and cost-effectiveness of interventions for supporting caregivers." [p. 6]
Li et al.	8 RCTs	Dementia	Counselling / Support group (6)	"Two interventions significantly decreased depressive or anxiety symptoms

Citation	N (studies): [Type]	Conditions of care recipients (n studies)	Interventions covered by review (n studies)	Review Findings
2013 <sup>43</sup>	across 9 publications		Education and training (1)* Online community / support / Telephone support* Multifaceted (any combination of the above) (1)	[web-viewable videos, videos + weekly phone calls focusing on coping and behavioural management strategies]...Meta-analysis found that both group coping skills interventions alone...and with behavioral activation...significantly increased dysfunctional coping, while significantly reducing depressive symptoms. Positive coping (a mix of emotional and solution-focused strategies) increased...with group coping skills interventions and behavioral activation." [p. 204]
Li et al. 2012 <sup>46</sup>	35 (28 cross sectional, 7 longitudinal)	Dementia	N/A – Review did not focus on interventions, but the relationship between coping style and anxiety or depression	There is good evidence that using more dysfunctional, and less emotional support and acceptance-based coping styles are associated with more anxiety and depression crosssectionally, and there is preliminary evidence from longitudinal studies that they predict this morbidity. Our findings would support the development of psychological interventions for carers that aim to modify coping style.
Llanque et al. 2010 <sup>55</sup>	10 (7 from one trial, 2 pilot studies, 1 description of intervention)	Dementia	Case management* Counselling / Support group (2)* Information services* Education and training* Online community / support / Telephone support* (2) Multifaceted (any combination of the above) (6)	"In order to meet the health needs of this population, it is necessary that interventions be culturally appropriate. Values that the Hispanic/Latino culture endorses should be considered, such as religiosity, familism, and folk remedies. Bilingual, bicultural health care workers, and/or culturally compassionate health care workers who serve as liaisons to caregivers can enhance communication between caregivers and health care providers... an interactive and personal approach to intervention programs with Hispanic/Latino caregivers is crucial for success of interventions with these caregivers." [pp. 29 – 31]
Vernooij-Dassen et al. 2011 <sup>45</sup>	11 (RCT)	Dementia	Counselling / Support group (6)* Education and training (4)* Multifaceted (any combination of the above) (1)	"Cognitive reframing for family carers of people with dementia seems to reduce psychological morbidity and subjective stress but without altering appraisals of coping or burden...The impact of cognitive reframing might be higher when used alongside other interventions because this offers better opportunities to tailor cognitive reframing to actual everyday carer problems." [p. 2]
Robertson et al. 2011 <sup>38</sup>	60 (24 cross sectional, 19 qualitative, 8 quasi-experimental, 7 mixed)	<b>Various Disability (mainly paediatric):</b> Combination of disabilities (15); Not specified (11); Intellectual Disability	<b>Respite:</b> In home (7) Out of home (22) Combination (12) Not specified (19)	"...short breaks appear to have the potential to positively impact on not only the well-being of carers, but also the children receiving short breaks and their families as a whole. However, short breaks are not a panacea and policymakers should be cautious of placing undue emphasis on the provision of short breaks in the absence of other forms of support for disabled children and their families. In many cases, short breaks are simply allowing carers to

Citation	N (studies): [Type]	Conditions of care recipients (n studies)	Interventions covered by review (n studies)	Review Findings
	methods, 1 chart review, 1 systematic review)	(10); Learning / Severe Learning Difficulties (7); Autism (6); Complex medical needs / Chronic illnesses (4); Handicap (mod-sev) (3); Developmental / CP (3); Challenging behaviours (1)		engage in the basics required for human functioning such as sleep and social contact.

\*Intervention not covered individually in a discrete study but as part of a multifaceted package of interventions



**Appendix 4: Overview of systematic reviews of support interventions for informal carers: Reviews incorporating primary studies of catastrophic injury**

Citation	N (studies): [Type]	Conditions of care recipients (n studies)	Interventions covered by review (n studies)	Review Findings
Rietdijk et al. 2012 <sup>40</sup>	24 (7 RCTs across 13 papers, 4 non-RCTs across 6 papers, 5 case series)	TBI of any severity	<p><b>Telehealth Programs:</b></p> <p>Counselling / Support group*</p> <p>Information services*</p> <p>Education and training (5)*</p> <p>Online community / support / Telephone support*</p> <p>Clinical support / assessment / therapy (non-counselling)*</p> <p>Multifaceted (any combination of the above) (11)</p> <ul style="list-style-type: none"> <li>• Counselling + Education + Information (2)</li> <li>• Counselling + Education (6)</li> <li>• Counselling + Education + Clinical Support (1)</li> <li>• Information + Online Community + Clinical Support (1)</li> <li>• Information + Education (1)</li> </ul>	<p>“The results of several studies suggested an interactive skills-based program is more effective than providing caregivers with general information...few studies in this review provided information about program elements that contributed to effectiveness...Overall, caregivers reported a high satisfaction with telehealth interventions...” [p. 919]</p> <p>“Telehealth programs for family members of people with traumatic brain injury are feasible, with positive outcomes reported. Further research is needed to strengthen the evidence for the use of telehealth in comparison to face-to-face interventions, and to provide information to guide clinical decision-making.” [p. 913]</p>
Cheng et al. 2014 <sup>34</sup>	24 articles covering 18 studies (13 RCTs, 1 quasi-RCT, 4 cohort studies)	Stroke	<p>Counselling / Support group*</p> <p>Exercise program*</p> <p>Meditation / Relaxation*</p> <p>Information services*</p> <p>Education and training*</p> <p>Online community / support / Telephone support* (2)</p> <p>Multifaceted (any combination of the above) (16)</p>	<p>“Pooled analysis of two individual psycho-education programs showed a small effect on improving family functioning...Caregivers receiving psycho-education that aimed at equipping caregivers with the skills of problem-solving, caregiving, and stress-coping appeared to have a more positive influence on the caregivers’ psychosocial wellbeing and a reduced use of healthcare resources by stroke survivors...To support caregivers across the stroke trajectory, the core skills of problem-solving and stress-coping should be included in the psychosocial interventions.” [p. 30]</p>
Lawang et al. 2013 <sup>56</sup>	40 (6 English and 34 Thai: 5 RCTs, 8	Various [stroke (31); neurological patients (1); brain injury (6); mixed (2)]	<p>Case management (1)</p> <p>Counselling / Support group (10)*</p>	<p>“Most interventions sought to enhance caregiver capacity (28 studies), and almost half addressed caregiver health in some way (19). Seven studies had both goals.” [p. 537]</p>

Citation	N (studies): [Type]	Conditions of care recipients (n studies)	Interventions covered by review (n studies)	Review Findings
	observational , 5 action research, 22 case series)		Meditation / Relaxation* Education and training (21)* Discharge planning (2) Clinical support / assessment / therapy (non-counselling)* (1) Multifaceted (any combination of the above) (5)	Only 15 interventions were community-based. Despite variable research quality all studies showed benefits for caregivers, care recipients, and healthcare services. In developing countries without healthy caregivers physically disabled adults would not receive care... “...to improve the holistic health of caregivers and ensure they are able to maintain their role interventions should align with the four-domain definition of health that integrates physical, mental, social, and spiritual aspects of well-being... caregivers and other stakeholders should be involved in the development of any support intervention to ensure they are relevant to the caregiving context and needs are better met.” [pp. 534, 537, 543]
Hu et al. 2014 <sup>53</sup>	24 [16 RCTs, 8 open label studies]	Various [Dementia (6); Cancer (3); Traumatic Brain Injury (4 – 3 paediatric); Stroke (2); Anorexia Nervosa (2); Schizophrenia (2); Heart Transplantation (1); Frail Elderly (1); Hip Fracture (1); Infant / Toddler Sleep Problems (1); Fetal Alcohol Spectrum Disorders (1)]	<b>Internet-based interventions:</b> Counselling / Support Group (4) Information services* Education and training (6) Online community / support / Telephone support* Clinical support / assessment / therapy (non-counselling) (1) Multifaceted (any combination of the above*) (13)	“Internet-based interventions were mostly effective in reducing aspects of caregiver stress and improving their well-being. This systematic review of open-label studies and RCTs identified 24 such trials, with nine trials reporting positive benefits in the outcome measures, nine reporting partially positive outcomes, and six reporting no benefit of the internet-based intervention. With continued population acceptance of internet use, there are opportunities to use this platform to improve the lives of caregivers.” [p. 9]
Boots et al. 2014 <sup>41</sup>	12 [2 RCTs, 2 controlled trials, 5 case series, 1 survey, 1 qualitative]	Dementia (10) Dementia / Stroke (2)	<b>Internet-based interventions:</b> Counselling / Support Group * Information services* Education and training (1) Online community / support / Telephone support* Multifaceted (any combination of the above*) (11)	<ul style="list-style-type: none"> <li>• “The majority of Internet intervention studies for informal dementia caregivers lack methodological quality;</li> <li>• Internet interventions for informal dementia caregivers show beneficial effects on caregiver confidence, stress, depression, and self-efficacy;</li> <li>• Multicomponent Internet interventions combining tailored information with interaction among caregivers show the most promise for improvement.” [p. 343]</li> </ul>

\*Intervention not covered individually in a discrete study but as part of a multifaceted package of interventions

**Appendix 5: Overview of completed primary studies of support interventions for informal carers of people with catastrophic injury not covered by identified reviews**

Study (Country) Design n	Condition of care recipients	Intervention	Findings
Berry et al. 2012 <sup>35</sup> (USA) RCT 147	Disability	<b>Problem Solving Training (PST)</b> [identifying the problem; brainstorming solutions; critiquing the solutions; choosing and implementing a solution; evaluating the outcome]	Problem Solving Training (PST) “significantly improved the problem-solving skills of community-residing caregivers and also lessened their depressive symptoms. Care recipients in the PST group also had reductions in depression over time, and it appears that decreases in caregiver depression may account for this effect.” [p. 98]
Smeets et al. 2012 <sup>39</sup> (The Netherlands) Cohort 108	ABI	<b>Respite Care:</b> adult activity day care [nonresidential facility providing recreational activities with professional support, social stimulation, and general supervision]	“This study emphasizes the need for care for both caregivers and patients in the chronic phase after ABI. Although respite care is highly appreciated, it is not sufficient for caregivers to attain a healthy level of well-being. Results indicate that caregiver well-being might improve by targeting passive coping and mastery skills of caregivers and patients. Continuous support for both caregivers and patients is needed.” [p. 834]
Kreutzer et al, 2010 <sup>48</sup> (USA) Cohort 152 (76 pairs)	ABI	<b>The Brain Injury Family Intervention (BIFI):</b> “manualized, five session intervention designed specifically for persons with acquired brain injury and their caregivers...The BIFI provides education, skills training, and psychological support. The intervention also utilizes collaborative self-examination, a technique created by Virginia Commonwealth University (VCU) clinical researchers...to enhance self-evaluation, awareness, and communication” [p. 20]	High session helpfulness ratings for caregivers and patients. Between group comparisons (carers and patients) did not indicate differences for individual session helpfulness or goal attainment ratings. Qualitative analysis of BIFI topics were relevant and consistent with program goals.
Butera-Prinzi et al. 2010 <sup>51</sup> (Australia) Quan & Qual 46 (families)	ABI	<b>Family To Family Link Up Program (f2f Link Up):</b> This program aims to promote connections between families who have a family member with an Acquired Brain Injury. Link ups involve one or several sessions with members from two or more families. Link-Ups were conducted by ABI workers who were trained as facilitators	“Evaluation of the (pilot) program showed positive impacts for both families and facilitators and provided useful feedback on program implementation issues, benefits and constraints of the program. The opportunity to meet other families in brief, time-limited contacts with a trained facilitator is a useful and needed addition to a range of supports that might assist families caring for a member with an acquired brain injury.” [p. 31]
Mores et al.	Stroke	<b>The Family Informal Caregiver Stroke Self-management</b>	“the program offered hope, advocacy, sharing, and the sense of being

Study (Country) Design	Condition of care recipients	Intervention	Findings
2013 <sup>50</sup> (Canada) Cohort 11 family caregivers		<b>(FICSS) program</b> is “a four-module education and support series of facilitated small group discussions. Topics included: balancing changing roles, managing behavior changes, sexuality/intimacy, and community linkages. Each module was evaluated weekly and by focus group one month after the program.”	more informed about various topics including: coping skills, self-management, and how to access community service resources...The positive results indicate the short-term benefits of the program. However, due to the short duration of the program evaluation, only the immediate perceived impact of the program was investigated...One unintended consequence of the program was the development of an ongoing social network of several of the caregivers and stroke survivors after the program. The development of this new social support network is critically important, as there is often a loss of the previous support network after the stroke.” [p.24, 25]
Rivera et al. 2008 <sup>36</sup> (USA) RCT 67	TBI	<b>Problem solving training (PST)</b> - “In the PST group, contact between the caregiver and an interventionist was made monthly, with in-home problem-solving training sessions occurring at months 1, 4, 8, and 12. Telephone sessions were conducted once a month on the remaining 8 month.” It involved discussion of the principles of the problem solving model, followed by a card sort task of problems and then a discussion of the carer’s feelings of the experience and potential solutions.	“caregivers receiving problem-solving training reported significant decreases in depression, health complaints, and in dysfunctional problem solving styles over time. No effects were observed on caregiver well-being, burden, or constructive problem-solving styles.” [pg.931]
Schulz et al. 2009 <sup>49</sup> (USA) RCT 173	SCI	<b>Multifaceted</b> - “Caregiver and care recipient (individual with SCI) were randomly assigned to one of three conditions: a caregiver-only intervention condition; a dual-target intervention condition that targeted both the caregiver and the care recipient; or an information-only control condition in which the caregiver received standard printed information about caregiving, SCI, and aging typically available from social service and health agencies. Both intervention conditions involved the use of a computer-telephone technology system... The intervention targeted five known areas of caregiver risk: lack of knowledge about caregiving and caregiver burden, social support and integration, emotional well-being, communication, self-care and physical health. Because of the variability inherent in the caregiving	“At 12 months, caregivers in the dual-target condition had improved quality of life as measured by our multivariate outcome when compared to the control condition. Using the dyad as the unit of analysis, the dual-target condition was superior to both the control condition and the caregiver-only condition in our multivariate outcomes analysis. Dyads enrolled in the dual-target condition had significantly fewer health symptoms than control condition and caregiver-only condition participants and were less depressed when compared to participants in the caregiver only condition. In follow-up analyses we found that a higher proportion of caregivers in the dual-target condition had clinically significant improvements in depression, burden, and health symptoms when compared with the caregiver-only condition.”

Study (Country) Design n	Condition of care recipients	Intervention	Findings
		situation, the intervention allowed for some tailoring to meet the specific needs of the individual.”	
Elliott and Berry, 2009 <sup>37</sup> (USA) RCT 60	SCI	<b>Problem solving training (PST)</b> - “three face-to-face problem-solving training sessions (PST), educational materials, and telephone contacts as requested over the first year of caregiving.”	“Caregivers in the intervention group reported a significant decrease in dysfunctional problem-solving styles scores over time; there were no observable effects for PST on caregiver depression. There was also some indication that the intervention had beneficial effects on caregiver social and physical functioning.” [pg.406]

## Appendix 6: Overview of ongoing primary studies of support interventions for informal carers

Study (Country) Design N	Condition of care recipients	Intervention
Rosell-Murphy et al. 2014 <sup>62</sup> (Spain) RCT 282	Patients receiving home health care	<b>Multicomponent</b> - "1 individualized counselling session, 1 family session, and 4 educational group sessions conducted by participating Primary Health Care Team (PHCT) professionals; in addition to usual home health care visits, periodic telephone follow-up contact and unlimited telephone support" [p. 53]
Woodford et al. 2014 <sup>63</sup> (UK) RCT (Phase II)	Stroke	<b>CBT self-help</b> supported by mental health paraprofessionals
Engedal et al. 2011 (Norway) RCT 230	Dementia	A <b>multidimensional support program</b> (behavioural, i.e. psychotherapy, Lifestyle Counseling – "The family will receive individual consulting, teaching and problem solving in support groups." <a href="http://clinicaltrials.gov/show/NCT01287767">http://clinicaltrials.gov/show/NCT01287767</a>
Farran et al. 2007 (USA) RCT 240	Alzheimer's Disease and other related dementias	"The <b>Enhancing Physical Activity</b> treatment intervention focuses on two areas: increasing lifestyle physical activity and addressing well-established care-related concerns that are likely to interfere with increasing physical activity." <a href="http://clinicaltrials.gov/show/NCT00721383">http://clinicaltrials.gov/show/NCT00721383</a>
Massera et al. 2012 (Italy) RCT 900	Alzheimer's disease	<b>UP intervention</b> – "The following support will be provided by a case manager: At least 3 sessions of individual face-to-face counselling (housing arrangements, disease awareness, problem solving) consisting of an initial and two reinforcing sessions. Monthly follow-up telephone calls. Stress management training of the family caregiver and some practical items for management of patient care in the home. Information about services/aid/certification/subsidies offered by the National Health Service, by municipal social services and by local voluntary organizations. Information on health services, support connecting to GPs and health service units (medical specialists, hospital services) and social services (municipal offices and public offices of any capacity). Other: 3 preventive home visits by a nurse - home visits will occur at enrollment and after 6 and 12 months." <b>UP-TECH intervention</b> – "The following support will be provided by a case manager: At least 3 sessions of individual face-to-face counselling (housing arrangements, disease awareness, problem solving) consisting of an initial and two reinforcing sessions four and eight months after enrollment. Monthly follow-up telephone calls. Stress management training of the family caregiver and some practical items for

		<p>management of patient care in the home.</p> <p>Information about services/aid/certification/subsidies offered by the National Health Service, by municipal social services and by local voluntary organizations. Information on health services, support connecting to GPs and health service units (medical specialists, hospital services) and social services (municipal offices and public offices of any capacity).</p> <p>Other: Assistive Technologies - The technologies to be employed are devices already widely used and marketed, are simple to use and do not require high technical expertise for installation and maintenance. The devices will be assigned to subjects in the UP-TECH treatment group after an evaluation of the home, made by the case manager. Such technologies include e.g.: access facilitated telephone, timed drug dispenser, and housing adaptations such as anti-slip strips; home leaving sensors; sensors to detect night falls; Gas and water leak sensors, and automatic lights.</p> <p>Other: 3 preventive home visits by a nurse - The dyads will receive three home visits by a specifically trained nurse. Home visits will occur at enrollment and after 6 and 12 months.”</p> <p><a href="http://clinicaltrials.gov/show/NCT01700556">http://clinicaltrials.gov/show/NCT01700556</a></p>
Cheng et al. 2014 (China) RCT 128	Stroke	<p>“<b>Psychoeducational program</b> consisted of (1) two inpatient sessions of face-to-face education on stroke and its caregiving; (2) six biweekly problem-solving training via telephone contacts after the discharge of stroke survivors.”</p> <p><a href="http://clinicaltrials.gov/show/NCT02080910">http://clinicaltrials.gov/show/NCT02080910</a></p>
Dowling et al. 2013 (USA) RCT 196	Dementia	<p><b>Life Enhancing Activities</b> - “A six week intervention that consists of 5, 60-minute sessions followed by a 30 minute evaluation session conducted at week 6 and again at week 10. Follow-up assessments will be conducted at 1-month, 3-months, and 6-months post intervention.”</p> <p><a href="http://clinicaltrials.gov/show/NCT01825681">http://clinicaltrials.gov/show/NCT01825681</a></p>
O’Reilly et al. 2013 (Australia) RCT 20	Dementia	<p><b>TC-PCC Intervention (Respite)</b> – “A. Structured Person-Centred Communication (Respite Care Personal Profile; Pre-admission case conference between liaison nurse, care recipient and caregiver; up to daily call/email to care giver from liaison nurse to provide up to date feedback on care recipients status; exit interview from liaison nurse to give hand over to caregiver); and B. Person-Centred preparation for respite experience: prepare simple memory book to aid transition; familiar items bag; and carer comfort review to establish what support the caregiver needs.”</p> <p><a href="https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=365549">https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=365549</a></p>
Kangas et al. 2010 (Australia) RCT 30	Dementia-related conditions	<p><b>Behavioural and Acceptance Based Therapy (BABT)</b> – “The BABT intervention will be conducted by qualified psychologists in an individual face-to-face format and will consist of six consecutive weekly meetings, 1.5 hours each, plus two follow-up/booster sessions conducted at fortnightly intervals. Hence, the BABT program comprises a total of 8 sessions conducted over a 10 week period. The BABT components will be administered in a standardized format to all participants. In particular, the BABT program will comprise the following components: (1) education about the common reactions to caring for a partner (or</p>



		parent) with dementia; (2) acceptance and mindfulness based strategies to promote awareness and acceptance of internal sensations; (3) learning to deal with uncertainty; (4) behavioural/ experiential exercises to curtail avoidance reactions; and (5) re-evaluating and re-connecting with life-goals and values, as well as learning to engage/commit to pursuing valued activities.” <a href="https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?ACTRN=12611000575932">https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?ACTRN=12611000575932</a>
Moore et al. 2012 (Australia) RCT 546	Dependent (older people over 60 years of age)	“Six month <b>physical activity program</b> - An individualised home based strength, balance and walking programme (based on the Otago programme) for care recipient/carer dyads (that they can do together). It will be prescribed by the intervention physiotherapist for both the carer and the care recipient during a home visit within two weeks of baseline assessment. Although the functional levels are likely to vary, the intervention physiotherapist will aim to select several common exercises for the carer and care recipient with variation in elements to modify the specific difficulty of the exercise to the individual. In this way the carer/care recipient dyad will be able to have some common elements to share as they exercise together. Each participant will receive 4-8 exercises, to be performed at least five days each week at home (average duration around 20 minutes), and a walking program (where possible, the carer and care recipient will walk together). The intervention physiotherapist will perform a further four home visits over the 6-month duration of the exercise program, to review exercises, change exercises if indicated, and to encourage and support ongoing participation and adherence to the program.” <a href="https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=361974">https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=361974</a>
Castle et al. 2013 (Australia) RCT 200	Stroke	“The <b>self-management program</b> called ACCORD will utilise the Collaborative Therapy Framework delivered by a clinical care coordinator (CLT). ACCORD is composed of three core components adapted to suit the specific needs of the carer: a) The framework utilises a modular format. Each module encompasses a manualised discrete skill development intervention run over 12 weeks, one hour in duration, one on one, conducted by a trained health professional, involving: health promotion, interagency collaboration, accessible support care coordinator, information about stroke and resources, understanding stress, family and community support and caring relation to stroke...b) Self-efficacy, and c) Smooth integration from acute through to community care...The individualised Collaborative Therapy program (ACCORD) will involve 3-month, 6-month and 12-month follow-up and care coordination over a 4-year period.” <a href="https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=363132">https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=363132</a>
Lavretsky et al. 2012 (USA) RCT 40	Dementia	<b>Kirtan Kriya meditation</b> – “Meditation will be taught to 20 caregivers and supervised by Helen Lavretsky, M.D during their first visit. Meditation Kirtan Kriya will be performed for 12 minutes every day at the same time of the day for 8 weeks. Compliance will be monitored during visits and by daily diaries that will be reviewed at each visit.” <a href="http://clinicaltrials.gov/show/NCT01537679">http://clinicaltrials.gov/show/NCT01537679</a>
Teel et al. 2008 (USA) RCT	Alzheimer’s disease	<b>Self-Care TALK</b> – “The intervention includes creating a health-promoting, self-care education and support partnership between caregivers and nurses through the use of weekly telephone conversations” (6 sessions)

46		<a href="http://clinicaltrials.gov/show/NCT00646074">http://clinicaltrials.gov/show/NCT00646074</a>
Jordi Gol i Gurina Foundation 2013 (Spain) RCT 122	Chronically ill	<b>Problem-solving technique (lifestyle counselling)</b> <a href="http://clinicaltrials.gov/show/NCT01786083">http://clinicaltrials.gov/show/NCT01786083</a>
Williams et al. 2007 (USA) RCT 116	Alzheimer's disease or other dementia	<b>Video with exercises and telephone coaching</b> - Williams LifeSkills Family Caregiver Kit – Carers will view “10 modules of Williams LifeSkills Caregiver Video, do Workbook exercises for each module, and receive telephone coaching to enhance their ability to apply the skills taught in each module to caregiver situations.” <a href="http://clinicaltrials.gov/show/NCT00396825">http://clinicaltrials.gov/show/NCT00396825</a>
Steffen et al. 2002 (USA) RCT 74	Dementia	<b>“Multicomponent behavioral intervention</b> using 10-session video series (Steffen, et al., 2001) workbook (Steffen, et al., 2001), and weekly telephone coaching sessions.” <a href="http://clinicaltrials.gov/show/NCT00056316">http://clinicaltrials.gov/show/NCT00056316</a>



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