FAMILY CARERS AND THE PHYSICAL IMPACT OF CARING – INJURY AND PREVENTION

EXECUTIVE SUMMARY

Introduction

A family ‘carer’ is defined as someone who provides care and support for a family member, friend or neighbour who has a disability, is frail aged, or who has a chronic mental or physical illness.

Australian Bureau of Statistics (ABS) figures indicate that more than 10% of the population are carers providing daily support for family or friends with disabilities. In addition, 16% of all carers are primary carers who assume the main responsibility for meeting the basic daily needs of a person with disabilities. Western Australia has a number of government and community based organisations which provide services for people with disabilities and their carers.

The Independent Living Centre of WA (ILC) is a non-government, not-for-profit, community based information and advisory service for people with disabilities and the frail aged, their families and carers. The service enables people to get information on and trial a range of equipment, technologies and resources, and provides them with access to advice to enable greater independence, easier caring and improved quality of life.

In 2005 – 2006 the ILC, with the assistance of the Office for Seniors Interests and Volunteering (OSIV), conducted research examining the physical impact of caring on family carers through an extensive survey and a small scale manual handling training project.

This project was informed by previous work in this area – Carers Association of Australian 2000 National Survey of Carer Health and Wellbeing and the Northern Suburbs Stroke Support Group carer pilot project.

The full detailed results of both components of the research are documented as section A & B in the body of this report.

CARER SURVEY
In late 2005, a survey of Western Australian carers was conducted to:
(i) Measure the physical impact of caring on WA carers
(ii) Measure the training, information, equipment, and assistance already received by carers in injury prevention
(iii) Identify which carers are at higher risk of injury in WA and the need for training

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2 Adapted from WA Disability Services Commission website, www.dsc.wa.gov.au
3 The Office for Seniors Interests and Volunteering is a state government agency. In addition to focusing on seniors and volunteers, the agency includes a Carers’ Secretariat, which assists the Minister for Seniors to administer the Carers Recognition Act 2004 and provides support to the Carers Advisory Council.
A self-completion feedback questionnaire was designed by ILC and OSIV to meet the research objectives. The questionnaires were posted out to 6,000 of the 6,500 carers who were registered with Carers WA and there was a good response rate with 1,619 carers returning completed questionnaires.

**Profile of carers and care recipients**

The information obtained from carers about themselves showed that:
- 81% of all carers in the survey were female
- 88% were aged 40 years or more
- 71% were not employed
- 81% lived in metropolitan regions
- 63% were born in Australia.

Thus, the majority of carers completing the survey were females aged over 40 years, and particularly 40-59 years, who were born in Australia, were not employed, and lived within the metropolitan areas of Western Australia.

Respondents were also asked for details about the person or persons they were caring for, with the following results:
- The majority of carers were looking after a member of their immediate family - 44% cared for a spouse, 38% cared for a child, 18% cared for a parent
- 53% of carers were looking after a person or persons aged 60 years or more
- 23% were looking after a young person or persons up to the age of 18 years
- 61% were looking after a male.

**Physical impact of caring on carers**

In measuring the physical impact of caring on carers in Western Australia, the survey showed that for many carers providing care was demanding and had a significant impact on their health. For instance:

- **43% of carers said they had been physically hurt or injured as a result of providing care**
- 63% reported that caring had a medium to very large impact on their physical health
- 40% described their current health as only ‘fair’ to ‘poor’
- **Carers were much more likely to say they had a health condition now than before becoming a carer: 65% vs 31%**
- Carers reported a higher level of orthopaedic or spinal problems, cardiovascular problems and emotional or mental problems now than before becoming a carer.

The before-after differences for the main health conditions are illustrated in the next graph.
Most of the injuries sustained were back injuries which were generally caused by lifting, lowering or carrying, ie manual handling tasks. The nature of the injury was primarily a sprain or strain. This is consistent with research showing that most reported accidents involving manual handling tasks cause back injury⁴.

Many of the respondents reported heavy caring workloads in terms of the length of time they had been providing care for, how long they expected to do so into the future, the amount of time spent each day providing care, how constant the need for care was and in some cases how many people they were providing care for:

- 42% had been providing care for ten or more years
- 48% believed they would still be a carer for another ten years or more
- 47% said they provided care for six or more hours each day, which is a significant proportion of the carer’s day
- 87% of carers lived with the person they care for
- 13% were caring for more than one person

As expected the higher the demands on the carer, the more likely they were to be adversely affected by continuing to provide care.

The research also found that the demands of providing care impacted on carers’ ability to continue providing that care, in particular among those who were injured while caring:

- Of those carers who had been injured, 46% said their injury had recurred or been made worse by continuing to provide care
- 42% of carers who had been injured said they had to get extra assistance to continue providing the care.

⁴ Australian Safety and Compensation Council (ASCC) website, [www.nohsc.gov.au](http://www.nohsc.gov.au)
Training, information, equipment and assistance received by carers

In determining what training, information, equipment and/or assistance carers have had or were receiving

- Only 36% of carers said they had received information or training on injury avoidance or risk management
- 55% of carers had never received such information or training and 9% were unsure
- Among those who did receive training or information, 29% had acquired this knowledge through their own personal experience or training.

Those who did receive training or information got this from a variety of sources including health professionals, community or private organisations, hospitals and government agencies

In terms of the assistance they received to provide care:
- Only 11% got assistance on a regular basis,
- Almost half (47%) had assistance ‘sometimes’
- 40% said they never received assistance with caring

The results show that many carers do not receive any assistance with caring for the person or persons they looked after, and in the case of older carers they were more likely than younger cares to be getting no assistance with caring. As a group they receive information and/or training on avoiding injuries or risk management in an ad hoc way. There is no co-ordinated system of providing information or training in a manner that is timely, relevant and responsive to carers needs and there is no process whereby information and training is updated and reviewed as care needs change.

Identification of higher risk groups and need for training

The carers that were identified as having a higher risk of injury were those with heavy workloads and those who had already been injured while providing care. Carers with heavier workloads (56%) were more likely than those with lighter workloads (37%) to have been injured when providing care.

In identifying those most in need of training, they are the one in five (21%) carers who have sustained an injury while caring and have never had training or information on injury avoidance. They have a similar profile to the group most at risk of injury, ie were more likely than others to be female, younger, care for more hours during the day, have a current health condition, and be in fair to poor health.
MANUAL HANDLING TRAINING for FAMILY CARERS RESEARCH PROJECT

The Manual Handling Training for Family Carers Project ran concurrently with the Carers Survey and focused on developing a best practise model for delivering manual handling training to carers.

From August 2005 to June 2006, the project offered manual handling skills training to people who care for family members with impaired mobility. This was offered to carers who resided in the north metropolitan area of Perth and used a model of providing up to three training sessions that were delivered in the home. A total of 53 carers and their care recipients self referred to the project, with 29 families completing all three home visits. The senior occupational therapist who delivered the training conducted an evaluation to determine what carers needed in terms of manual handling training, whether such training reduced their risk of injury and what value, if any, there was in conducting this training in the carer’s own home.

Profile of carers and care recipients

- The average age of the carers and care recipients who participated was 59 years of age, with the predominant age group being 50 to 69 years.
- All of the carers were adults and 74% were female.
- One in ten care recipients were less than 18 years of age.
- Two thirds of carers were caring for their spouse, and one fifth cared for their child with a disability.
- The majority of carers had health problems, mostly back, neck and shoulder pain or injury – all of which could be related to or were exacerbated by providing care.
- The care recipients had a number of different and often multiple health conditions. Many of these conditions were neurological in nature or related to ageing.
- Many of the care recipients required assistance with their mobility, and most required the use of some type of equipment in their care.
- The majority of participants had used services to assist them in their daily lives, such as respite, home help and personal care.
- **The majority of carer participants (85%) had not had any previous manual handling training.**

Changes as a result of training

Of the 53 participants, 29 had three visits and 25 of these returned an evaluation questionnaire after the third visit. The evaluation results show that the carers have as a result of the training experienced a positive change in their caring behaviour and in their own health:

- **92% had made changes to how they cared for their family member,**
- **64% had noticed an improvement in their own physical condition,** and
- **80% had made other changes as a result of the training.**
Benefits of in-home training

An important aspect of the project was to determine the benefits of carers having the training delivered in their own home. The results show that this was overwhelmingly the case:

- **All carers who completed the training and the evaluation questionnaire agreed that it was beneficial to have the training in their own home.**

The primary reasons why carers liked the training delivered in their own homes was because they felt it was relevant to their particular situation, familiar, and they could use their own equipment and furniture.

Some carers felt the in-home training was useful because the trainer could point out hazards that they (the carers) couldn’t see. For some carers it was simply more convenient and practical – a few said they wouldn’t have done the course otherwise.

In addition all family members who assisted with the care were included in the training and the care recipient also had a heightened awareness of the physical demands and impacts being placed on the carer.

Satisfaction with training

The results as to how satisfied carers were with the training were again overwhelmingly positive:

- **88% of carers said they were ‘very satisfied’ with the training provided**
- **12% said they were ‘fairly satisfied’**.

No carer said they were neutral or dissatisfied with the training. The very positive results for overall satisfaction are consistent with other results showing that the carers had noticed positive changes to how they did their caring and to their own physical health as a result of the training.

Risk assessment

In determining whether or not the level of risk of injury to the carer was reduced as a result of the training, a risk assessment was conducted with all carers during the first visit and repeated at the third home visit with the 29 carers who had three sessions.

The trainer assessed and recorded the level of risk to the carer when they assisted the care recipient with daily activities such as getting in and out of bed and/or chairs, toileting and bathing, assisting with general mobility etc. A range of factors was considered including: the carer’s posture and movements during these activities, eg whether they were lifting, twisting or bending; how much assistance the care recipient required; and how frequently the activity was carried out each day.
Five different levels of risk were used; the higher the number, the greater the level of risk:

1 = Low risk  
2 = Low to medium risk  
3 = Medium risk  
4 = Medium to high risk  
5 = High risk.

The activities with the highest level of risk were getting a person off the floor, in and out of bed, in and out of chairs and the car. The activities with the lowest level of risk were drying or dressing someone and assisting them with general mobility around the house.

The risk assessment data was analysed to determine if there had been any change in levels of risk to carers from the first visit to the third visits. This data was only available for the 29 carers who had three visits. Their average scores are summarised in this section:

**Graph 3.3.2: Levels of risk at 1st and 3rd visits**

The graph shows that once the training had been completed, risk levels were assessed as being lower for all activities.
CONCLUSION, DISCUSSION AND RECOMMENDATIONS FROM SURVEY AND MANUAL HANDLING TRAINING PROJECT

The 2005 WA carers’ survey achieved its objectives of measuring the physical impact of caring on family carers and the training, information and support they had received in injury prevention. The survey also created a profile of carers in Western Australia and identified high risk groups who would benefit most from training in injury prevention.

The survey showed that WA carers experience a variety of problems including physical and mental ill health, injuries, heavy workloads, and a lack of support and training.

The reasons why many carers did not receive assistance, information and/or training were not explored in the survey, but are likely to be affected by the lack of acknowledgement of the high rates of carer injury, and the difficulties that carers have in determining the availability and access to training.

The Manual Handling Training Project for Family Carers demonstrated that training effected a positive change in carers’ manual handling behaviours. The results also pointed to the level of risk to carers being reduced as a result of doing the training, and the carers themselves who completed the evaluation believed this to be the case. It is clear that carers felt that having this training in the home environment was particularly beneficial, and for some this was the only option. A high proportion of participants had never received manual handling training and many had little follow up regarding equipment and training needs, although 87% were receiving community based services.

The findings also suggest that a range of factors need to be considered to effectively provide manual handling training to carers. In particular, a very flexible approach needs to be taken when conducting such training in terms of the number of visits - some carers will only require one or two visits whereas others will need more training. Scheduling of visits also needs to be flexible to accommodate carers’ issues such as time pressures, physical and emotional status and the changing needs of the care recipients.

**Discussion**

The reason for the high proportion of participants in both the survey and training project who had not received risk prevention training warrants further exploration. In WA the commonly recognised methods whereby carers can access manual handling/injury prevention training include:-

- Back care information sessions conducted by carer and disability groups
- GP or self referral to Allied health services (private / public Physiotherapist)
- State Health Chronic Disease programs;
- State Health Occupational Therapy home visiting service (equipment and access focus)
- Independent Living Centre of WA
When carers do access training it appears to be in an adhoc manner. There does not appear to be any clear ‘system’ for injury prevention training for carers and therefore the level of unmet need is hard to gauge.

The apparent lack of training and follow up may be due to a range of factors, including:-

- Limited follow up capacity within existing allied health system
- Limited access to Allied health expertise in the home setting
- Length of waiting time to receive a service; and
- Systemic issues related to accessing appropriate assistive equipment, and maintaining and reviewing equipment in the home

It is not clear how aware carers are of the training options available to them or whether they knew about these options but did not pursue them.

Factors that may contribute to level of uptake include:-

- There is no requirement for training to be provided to carers (unlike the conditions for paid support workers where employers have a duty of care to provide training).
- Pathways to access training are not transparent and known
- The eligibility criteria to receive training is not defined
- Carers own lack of awareness about the benefits of training
- Current method of delivery may not meet the needs of carers or be flexible enough to accommodate the stresses and complexity of many caring situations
- The number of recommendations to participate in training coming from a trusted professional (GP or Allied Health)
- Carers may not access training due to their high level of stress, fatigue and/or time constraints

Interestingly, the higher risk carer groups were more likely to have received information or training on injury avoidance and risk management, particularly those who had been injured. This may be due to them requiring contact with medical services because of their injury. However this suggests that the information or training was not effective in preventing injury; either by being delivered after an initial injury; not impressing sufficiently on the carer the value of training in maintaining their own health; or because the training was not sufficiently relevant to the individual caring situation, environment or the changing care needs of the care recipient.

Many carers suffer from health conditions which are both physical and mental, and many have been injured as a direct result of providing care. These injuries are often exacerbated by continuing to provide care with many carers describing their health as fair to poor and that caring had impacted negatively on their physical health.

These findings have significant ramifications for the health, community care and residential care sectors as increasing numbers of carers become less able to continue to provide care, and are more likely to begin to require assistance themselves.

It is clear that action needs to be taken to ensure that the maintenance of carer health be given a higher priority, and that injury prevention in particular becomes a
focus of health and disability policy developers, decision makers and service providers.

**Recommendations**

1. That policy makers, GP’s and community care service providers acknowledge in practical ways that they have a role in preventing and minimising injury to family carers.

2. That existing health programs should include initiatives that focus on injury prevention for carers and encourage active referrals from GP’s and other health professionals.

3. That the design and delivery of training in injury prevention to family carers be by means and in formats that can accommodate the diversity and changing nature of their caring situations.

4. That in the first instance carers at highest risk of injury should be targeted to receive training and assistance.

5. That in-home models of training delivery should be prioritised through both program design and funding.

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