

# Care for the Carers

A Self-management Program for  
Carers of People with  
Vision Impairment



- A self-management program for carers and family members.
- Produced as part of the Vision Self-management in Practice Project, funded by the Commonwealth Department of Health and Ageing.

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# Acknowledgements

*Care for the Carers* is a self-management program for carers of adults living with vision impairment. *Care for the Carers* is one of the outcomes realised through the two year Vision Self-management in Practice Project, a collaboration between Curtin University of Technology and the Association for the Blind of Western Australia (ABWA). The goal of the project was to develop two new self-management programs for people with vision impairment, to develop related staff development workshops and to enhance the existing electronic database at the ABWA so that effectiveness of the programs can be monitored over time.

The *Care for the Carers* program grew out of a series of workshops for carers developed for ABWA by Susan Douglas and Lisa Viska. Based on the success of other self-management programs developed jointly by researchers at Curtin University and the ABWA, it was decided to further develop the workshops for carers into a self-management program, as part of the Vision Self-management in Practice Project. *Care for the Carers* was tested as a self-management program in early 2009 and further revised and refined based on feedback from facilitators and participants.

The project steering committee providing guidance included Margaret Crowley, Marina Re, Susan Douglas, Susie Sim, David Vosnacos, Margaret Johnson, Alice Turner, Anne Passmore and Sue Shapland. The steering committee was supported by Juanita Doorey, Vicki Drury and Crystal Simpson.

Susan Douglas provided the benefit of her extensive experience in working with people with a vision impairment and their family members and made a substantial contribution to the development and refinement of the program. Lisa Viska and Sharon Kellow facilitated the pilot of the self-management program and provided valuable input into the refinement of the program. The participants in the pilot program also provided constructive feedback enabling further development and improvement of the program.

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Tanya is Professor and Director of the Centre for Research into Disability and Society, School of Occupational Therapy at Curtin University of Technology in Perth, Western Australia. Prof. Packer has considerable experience in the development and testing of disease specific self-management interventions. In 2006 she developed the strategic directions document for a WA State-wide Self-management Initiative and in 2007 she served as an expert on the National Reference Group on self-management competencies and curriculum development for nursing, medicine and allied health. Tanya's Self-management Research Group supports a number of PhD and Honours students who are developing and testing self-management programs. All have been completed in conjunction with community agencies. In 2007/08 alone, her team has attracted close to \$800,000 for self-management research. The Vision Self-management in Practice Project, funded by the Commonwealth of Australia is one of these projects. In collaboration with the Association for the Blind of WA (ABWA) her team has developed the *Care for the Carers: A Self-management Program for Carers of People with Vision Impairment*.



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# **PART A**

## **Getting Started**

### **Information for Facilitators**



# Introduction

*Care for the Carers* is a self-management program for carers of people with a vision impairment.

The *Care for the Carers* manual includes all the materials necessary for a health professional to initiate and facilitate a six-session course for carers of people with a vision impairment. Step-by-step instructions for establishing the course and recruiting participants are also provided. The program is underpinned by the principles of self-management.

The *Care for the Carers* program grew out of a series of workshops for carers developed for ABWA by Susan Douglas and Lisa Viska. The *Care for the Carers* self-management program builds upon these workshops and embeds the principles of self-management in a structured program tailored for carers of people with vision loss. This protocol aims to provide people in a care giving role with the opportunity to gain more knowledge about their partner's or family member's vision loss, with practical strategies to assist their partner or family member to manage their vision loss and also with skills and strategies to enhance their self-care.

The *Care for the Carers* program comprised one component of the Vision Self-management in Practice Project, a collaborative project between the Centre for Research into Disability and Society of Curtin University and the Association for the Blind of Western Australia. The project aimed to develop and evaluate new self-management interventions, to provide health professionals with the knowledge and skills to facilitate self-management programs, and to develop organisational capacity to electronically record and monitor participant outcomes over time. The *Care for the Carers* component specifically aimed to empower people in a caring role, by providing them with information, strategies and skills, so as to increase their confidence in managing their caring role.

# How to use this manual

## Organisation of the Manual

The manual contains three parts, each of which is briefly described below:

### **Part A: Getting Started: Information for Facilitators**

This explains the purpose and rationale behind the program, the structure and organisation of the manual and instructions for its use. Included in this section is relevant information concerning self-management, psychoeducational groups and facilitation.

### **Part B: Caring, Vision Loss and Self-Management: A Review of the Literature**

A literature review is included which links appropriate contemporary evidence to practice. This section is provided for health professionals/group facilitators who have an interest in additional background information.

### **Part C: Planning and Delivering the *Care for the Carers* Program**

This section contains all the instructions and content needed to run Sessions 1-6. There are also instructions for planning and delivering the *Care for the Carers* program. For the convenience of the facilitator/s, the sessions are structured in the same way. Included in each session are the:

- Purpose and outline of the session (with suggested times for each component);
- List of required resources;
- Content for each session; and
- Information to support discussion.

The six sessions are run as weekly sessions over a six-week period.

## Use of fonts in the manual

Two different font styles are used throughout the manual, as demonstrated below:

1. *Facilitator Instructions:*    *Arial 12 pt Italic.*  
*Instructions for the facilitator/s to follow.*
2. Content of the sessions:    *Arial 12 pt Regular.*  
Content of the learning, discussion and practical sessions and additional information.

# Use of icons in the manual



This icon denotes a *Learning Session* where session content is introduced by the facilitator in an interactive style that encourages input and discussion by participants.



This icon denotes a *Discussion Activity* where participants discuss topics and issues. This may be in pairs, small groups or as a whole group.



This icon denotes a *Practise Activity* where participants learn and practise new skills.

# Use of Instructions in the Manual

Throughout the manual, active words are used to guide the facilitation of each session. The commonly used words and an explanation of their use are provided below.

## **Explain**

Verbally provide the information to the group.

## **Discuss**

Raise the discussion question/s with the group and invite group members to share their experiences, feelings, and points of view. Encourage the participants to provide as much information as possible.

Additional information to support the discussion questions is provided (for example *Use the following points as additional information*). Facilitators do not necessarily need to address all of the information. Discussion should be guided by the participants. This information may be appropriate to confirm, expand, support or challenge their discussion.

## **Brainstorm**

Raise the brainstorm topic with the group and ask the participants to input ideas. Use a whiteboard if appropriate.

# About the program

## Aims of the *Care for the Carers* Program

The overall aims of the *Care for the Carers* Program are:

1. To provide participants with knowledge about their partner's/family member's vision loss and with the skills to enable them to assist their partner/family member in managing their vision loss;
2. To provide information on resources, equipment and technology that are available for people with a vision impairment and their caregivers; and also,
3. To provide caregivers with the skills and resources to support and sustain them in their care giving role and to look after their own needs.

## Theoretical Underpinnings

### Introduction

Two theoretical models influenced the development of this program. Firstly, self-management principles provided a basic conceptual foundation. Secondly, the order of material presented and the structure of individual sessions were guided by an understanding of psychoeducational groups.

### Self-management principles

While self-management principles have primarily been incorporated into group programs for people with a chronic illness or disease, self-management principles have also been incorporated into interventions for other groups, including for carers. The following discussion of self-management principles and self-management support is framed from the perspective of carers.

Self-management is not, as the term may imply, getting people to manage their own health or living situation without any intervention or support from health or other relevant professionals. Rather it is a collaboration between the individual and healthcare professionals to achieve the desired health or quality of life outcomes. It enables the individual to take control of their own living situation through the implementation of strategies that help them to function effectively.

### Defining self-management

There is no universally accepted definition of self-management. Indeed some literature uses terms such as self care, self-management and empowerment interchangeably while other literature acknowledges differences between these three terms.

In the Expert Patient Program in the United Kingdom, self care is defined as the care taken by people concerning their own health and well-being. It includes care extended to family, friends and others within the community (Department of Health (UK), 2005). Self-management, on the other hand, relates to the tasks that an individual must accomplish to manage their living situation. These tasks include gaining confidence to deal with the management of a health condition or disability, role management, and managing emotions.

The Curtin University Self-management Research Group defines self-management and self-management support as follows:

‘Self-management is the client’s ability to manage their activities, relationships and treatments enabling them to participate in their chosen way of life. Self-management support is what the healthcare professional does to assist the client to manage their condition.’

Self-management can be both a process and an outcome. In the context of care giving, self-management as a process is used to describe the information, skills and strategies provided to people in care giving situations. Self-management as an outcome on the other hand suggests that people who are care givers have acquired the knowledge and skills to manage their care giving situations, the emotional aspects of their care giving role and the various roles they have within their family and the community. These behaviours are achieved both as a result of their life experience and from the skills and strategies they have gained through a self-management program.

Traditionally many people working in healthcare related fields have been taught that they are the experts and thus the drivers of care. Consequently the client’s (carer’s) role is a passive one and the healthcare worker ‘tells’ them what they should do or what is considered to be the best option. In this traditional model, successful interventions or outcomes have been measured by client compliance with either what they have been told to do or what they have been taught.

Self-management, on the other hand, recognises the individual as the key decision maker who is an expert in the circumstances of their own life. Self-management is based on self-identified concerns, problems and goals, providing individuals with potential strategies.

### **Defining self-management support**

In a care giving context, self-management support is essentially the support and encouragement provided by health professionals to people in a care giving role to assist them in taking the central role in managing their care giving role, to make informed decisions about management of the role and to make healthy behaviour choices. Thus, self-management support is about how to assist the person to change behaviours through knowledge, skills and self-efficacy. It is person-centred and person driven. Effective self-management support involves a collaborative approach where the healthcare worker is a facilitator and the person and their family manage the daily living situation. Using a collaborative approach ensures that the care giver, their families and the healthcare worker share information and work together towards common goals.

### **Self-management and self-management support in *Care for the Carers***

The *Care for the Carers* program operates on self-management principles by providing information, skills and strategies to assist the participants to feel more confident and in control of their daily lives and care giving situations. The program encourages participants to share and discuss their experiences. By doing so, group members provide additional ideas, strategies, and encouragement for others who have a similar problem or who are in a similar situation. Each participant is

responsible for choosing which strategies they would like to use, and what they feel is useful. Each person's experience of care giving is different and each participant knows what works best for them and can make their own decisions based on the information provided.

Self-efficacy is best described as the confidence an individual has to undertake or participate in an activity (Bandura, 1998). Low self-efficacy results in reluctance or avoidance to act while high self-efficacy is associated with willingness and success at undertaking new behaviours or activities. Self-efficacy is strengthened through four mechanisms: competence mastery (successfully completing an action or activity); vicarious modelling (seeing other people similar to you being successful); social persuasion (someone like you persuading you that you can be successful); and reinterpretation of emotional and physical reactions to experiences (Bandura, 1998).

Vicarious modelling, also known as observational learning, is the term used to describe learning that occurs through watching how others behave. Social persuasion occurs when people are told verbally that they possess the skills to master specific tasks. Personal responses are also significant in developing self-efficacy. Emotional and physical reactions as well as stress impact on a person's perception of their ability to manage situations. Both vicarious modelling and social persuasion are heightened if the person the individual is modelling or observing is perceived to be similar. In other words, other group members may have more influence than the health professional/facilitator delivering the program.

The format and structure of delivery of the *Care for the Carers* program was designed to ensure that all four mechanisms for change are maximised. Competence mastery is enhanced through practise of new techniques and skills, for example the Sighted Guide Technique. The group nature ensures ample opportunity to share with and learn from others in a similar situation enabling modelling and social persuasion to occur. Emotional and physical reactions to stress are also examined.

Facilitators are therefore presented with a structure and format that allows them to capitalise on known mechanisms for change. The role of the health professional in encouraging and supporting self-efficacy at each stage of the session is displayed in Figure 1.

<b>Session Activity</b>	<b>Most Likely Mechanism for Change</b>
Warm-up activity	Mastery /Modelling/Persuasion
Homework review	Modelling/Persuasion
Learning session	Modelling/Persuasion
Practise Activity Homework	Mastery

Figure 1: Mechanism for changing self-efficacy in each session



## Psychoeducational groups

As stated earlier, the development of the *Care for the Carers* program was based on an understanding of the principles of psychoeducational groups.

All psychoeducational groups progress through five stages during the lifespan of the group. The five stages of psychoeducational group development are: (1) preparation, (2) orientation and exploration, (3) dissatisfaction/resolution, (4) working/production, and (5) termination/ graduation (Ettin, Heiman, & Kopel, 1988). See Figure 2.

Session	Topic	Psychoeducational Stage
1	Overview of <i>Care for the Carers</i> , Introduction to Self- management and Understanding Vision Loss	Orientation and Exploration
2	Making the Most of Remaining Vision and Using Other Senses	Dissatisfaction / Resolution
3	Stepping Out: Orientation and Mobility	Working / Production
4	Taking Care of Ourselves	Working / Production
5	Exploring Emotional Issues	Working / Production
6	Resources for Caring – Now and in the Future	Termination / Graduation

Figure 2: Stages of group development across the *Care for the Carers* Program.

In the *Care for the Carers* program, the order of sessions recognises these psychoeducational stages. The preparation phase of group development involves recruiting participants who are similar enough to relate to each other, yet different enough to bring a wide variety of perspectives to the group (Ettin et al., 1988). Once the preparation phase is completed during a pre-group interview, each subsequent session in the *Care for the Carers* program is modelled along developmental lines.

For example, the first session (during the Orientation and Exploration Stage) provides an overview of the program, introduces self-management and also provides information on the causes of vision loss and specific eye conditions. The second session (Making the Most of Remaining Vision and Using Other Senses) introduces principles and strategies for maximising remaining vision and using other senses. During this Dissatisfaction Resolution Stage of the group, the healthcare professional/facilitator has to allay doubts and promote group cohesion (Ettin et al., 1988). Dissatisfaction and doubts are allayed by participants discussing approaches to managing common daily living tasks, with additional information being provided by the facilitator. This is a concrete way to build confidence and self-efficacy through vicarious modelling and social persuasion.

In addition to the overall structure of the program, each session reflects psychoeducational group theory. Each session begins with a review of homework and a warm-up activity. This is followed by presentation of new material and introduction of homework activities. A brief review concludes each session. The

phases of psychoeducational groups together with the role of the facilitator/health professional at each stage during the session are outlined in Figure 3.

<b>Activity</b>	<b>Stage of Psycho-educational Development</b>	<b>Facilitator Tools</b>	<b>Facilitator Hints</b>
Warm-up activity	<i>Orientation</i>	Create a safe working atmosphere. Establish focus of session.	Warm-ups are provided since they focus the group on the course and its content.
Homework review	<i>Dissatisfaction/Resolution</i>	Review negative and positive aspects of each member's experience.	Begin with difficulties to allow members to share common concerns and fears. End with successes to unite group.
Learning session, discussion and practise activities and homework assignment	<i>Working/Production</i>	Present new information through lectures, discussions, and activities. Encourage insight and feedback through discussion.	Participants tend to find discussion one of the most valuable learning tools, so having enough time for discussion is always important.
Conclusion	<i>Termination/Graduation</i>	Review new content. Clarify homework. Emphasise application of material to own life situation through homework.	Include time to discuss and begin homework during the session. Participants find it easier to complete throughout the week if started in class.

Figure 3: Stages of group development and the role of the facilitator

## Facilitation

*Care for the Carers* is designed to be run by two facilitators. Together they must have the skills to facilitate a group and have a good knowledge of the causes of vision loss and of eye conditions, of vision rehabilitation principles and of practical and psychological issues impacting on carers of people with vision loss. A combination of a social worker and a psychologist has proven successful. An occupational therapist would also be an appropriate facilitator. Please note that an orientation and mobility instructor is required for Session Three Stepping Out: Orientation and Mobility.

Facilitating groups is a process that is underpinned by theoretical frameworks. A facilitator empowers people to learn in an experiential group which is a group where learning 'takes place through an active and aware involvement of the whole person' (Heron, 1999, p. 1). In self-management programs it is essential that participants are supported to identify issues of importance and find solutions through a process of facilitation by a healthcare professional who has taken on a facilitation role. In self-management programs facilitation includes creating opportunities for competence mastery, vicarious modelling and social persuasion. Thus opportunities are continually focused on increasing participants' self-efficacy. In addition to understanding psychoeducational group process and mechanisms for improving self-efficacy, an understanding of readiness to change, adult education and motivational interviewing are helpful background and skills.

## Stages of change

Motivation is a vital element of change. Although motivation itself does not denote change, it is the part that gets people moving and leads to action (Keleher, MacDougall, & Murphy, 2007).

The Stages of Change Model evolved from the work of Prochaska and diClemente (1983) who originally developed the model when studying people who were quitting smoking. They identified that, as people struggled to cease smoking, they went through a number of phases. Initially they called this the Transtheoretical model as it was based on numerous psychosocial models. The key concept in the model is that there are stages of change or stages of motivational readiness - thus the term, the Stages of Change Model. This model can be used to determine motivational readiness in clients. Understanding the stages will assist in assessment of readiness. There are six stages in this model. Each is outlined below, along with characteristics observed during that stage. (Francis, Hoare, Chapman, & Mills, 2007; Keleher et al., 2007; McMurray, Johnson, Davis, & McDougall, 2002).

- 1. Pre-contemplation:** Not yet acknowledging that there is a problem behaviour that needs to be changed;
- 2. Contemplation:** Acknowledging that there is a problem but not yet ready or sure of wanting to make a change;
- 3. Preparation:** Getting ready to change;
- 4. Action:** Changing behaviour;
- 5. Maintenance:** Maintaining the behaviour change; and
- 6. Relapse:** Returning to older behaviours and abandoning the new changes (Prochaska & diClemente, 1983, p. 392).

## Adult learning principles

It is now widely accepted that adults learn in different ways to children. The seminal works of Knowles (1984) and Kolb (1975) have guided the understanding of adult learning and of different learning styles.

Adult learning principles use approaches to learning that are problem-based and collaborative rather than didactic, and also emphasise more equality between the teacher and learner.

The six principles of adult learning identified by Knowles (1984) are:

- Adults are motivated and self-directed;
- Adults bring life experiences and knowledge to learning experiences;
- Adults are goal orientated;
- Adults are relevancy orientated;
- Adults are practical; and
- Adult learners like to be respected.

Adult learning principles can help provide appropriate learning experiences for participants. However an understanding of adult learning alone is not sufficient. The structuring and delivery of programs and materials needs to include recognition of individual learning styles. Kolb (1975) suggests that effective learning involves four different skills — concrete experience, reflective observation, abstract conceptualisation, and active experimentation. Kolb's experiential learning theory suggests that a person can begin the learning experience from any of the four points but for effective learning to occur, all stages have to follow sequentially. Having an experience alone does not result in learning. Reflection on the experience is necessary for formation of new concepts that can be tested in similar situations at other times.

Kolb (1975) suggests that most people have overlapping learning styles but are stronger in one specific area. Kolb combined the learning modes to create four learning styles which represent a combination of two of the four learning styles – accommodators, divergers, convergers and assimilators. A brief description of learning styles follows:

### **Diverger** – Concrete experience and reflective observation

These learners prefer to watch rather than do and are able to look at concrete situations from different angles. They are usually sensitive and interested in people. They like learning situations that use ideas generation such as brainstorming and web searches.

### **Assimilator** – Active conceptualisation and reflective observation

For the assimilator ideas and concepts are more important than people. They like abstract ideas, problem solving, and conceptual frameworks and learn through analytical and conceptual exploration.

### **Converger** – Active conceptualisation and active experimentation

The converger likes technical tasks and likes finding solutions to practical problems. The converger enjoys learning through simulation and through applying knowledge to real world issues.

**Accommodator** – Concrete experience and active experimentation

The accommodator is a hands-on intuitive learner who does not learn well in structured lecture situations but prefers role playing and peer interaction.

## **Motivational interviewing**

Rollnick and Miller (1995, p. 325) define motivational interviewing (MI) as being a 'directive, client-centred counselling style for eliciting behaviour change by helping clients to explore and resolve ambivalence.' In other words the core focus of MI is to explore ambivalence with the client and to encourage the client to examine the reasons for their resistance to change. Thus MI can be used effectively with the Stages of Change Model.

There are four main principles involved in MI (Emmons & Rollnick, 2001; Miller, Zweben, diClemente, & Rychtarik, 1992; Rollnick & Miller, 1995). These are:

- 1. Express empathy** – being empathetic is critical in MI. Clients who feel understood and safe are more likely to be honest and share their feelings with the healthcare professional. Having a thorough understanding of a client's issues allows the healthcare professional to assess where support is needed and how that support can be provided.
- 2. Support self-efficacy** – the client's belief that they can make a change is an important contributor to motivation and success. The healthcare professional may help increase client self-efficacy by highlighting skills the client has and by identifying other goals the client has achieved.
- 3. Roll with resistance** – in MI rather than fighting client resistance to change the healthcare professional 'rolls with it'. In other words he/she uses client resistance to further explore why they think/feel that way. This generally decreases resistance and encourages clients to problem solve their own issues.
- 4. Develop discrepancy** – Motivation for change occurs when people perceive a discrepancy between where they are and where they want to be (Miller et al., 1992, p. 8).

## **Monitoring Program Effectiveness**

Evidence-based practice integrates the practitioner's expertise with the best available clinical evidence. Evidence can come from literature, research, clinical guidelines or other sources, with the main element being the need to demonstrate that the intervention or care being delivered is based in credible evidence.

Initially evidence is generated from research. This evidence is then rigorously reviewed and appraised. The next step in the process is to develop clinical guidelines that provide a guide to recommended practice as well as summarising the expected outcomes of the provided care. Clinical guidelines are considered from three perspectives — the evidence, the healthcare professional's experience and the client's wishes. Guidelines are then applied to practice and evaluated, which in turn produces more evidence.

## Evaluation of the *Care for the Carers* Program

The *Care for the Carers* program was tested by the ABWA in 2009 with one group of eleven participants. It was conducted as a six week program. Process evaluation and pre-test and post-test evaluations were carried out by researchers at the Centre for Research into Disability and Society at Curtin University of Technology.

The aims of the evaluation were two fold: firstly, to evaluate the content and delivery of the program from the perspective of participants. A second aim was to evaluate the outcomes of the program to determine if the program was associated with improvements in perceived quality of life, knowledge self efficacy in relation to vision loss and resilience.

The process evaluation consisted of a brief questionnaire which was completed by participants at the end of each session. Using ten point Likert scales it assessed participants' perceptions of the importance and relevance of the information in each session, the extent to which delivery of the information assisted their learning and overall satisfaction with the session.

The outcome evaluation consisted of pre test and post test questionnaires. The outcome measures included two items measuring quality of life (Graham and Longman 1987), the knowledge subscale of the Age Related Vision Loss Self Efficacy Scale, which was adapted for carers (Brody et al 1999; Girdler, 2006) and the Resilience Scale RS15 (Wilks 2008).

## Results of the evaluation

### Process evaluation

Participants' ratings of the relevance and importance of the information, delivery of information and overall satisfaction with the six week program are summarised in Figure 4. Participants rated each criterion highly, with the lowest mean score for an individual session being 7.8 (delivery of information) and the highest mean score for an individual session being 9.5 (overall satisfaction).

	<b>Relevance of information</b>	<b>Importance of information</b>	<b>Delivery of information</b>	<b>Overall satisfaction</b>
	Mean (Range)	Mean (Range)	Mean (Range)	Mean (Range)
Six week program (n = 8 – 11)	8.9 (8.6 – 9.1)	8.75 (8.1 – 9.1)	8.71 (7.8 – 9.3)	9 (8.3 – 9.5)

Figure 4: Process Evaluation Summary

### Outcome Evaluation

Knowledge self efficacy (ARVL Self-efficacy Scale) was significant at post-test ( $p = .012$ ) with participants' scores improving an average of 24%. There was a small percentage increase in participants' rating of quality of life and satisfaction with quality of life at post-test. However these were not significant at post-test which may reflect the very small sample size. Resilience scores showed a slight improvement at post-test, however these were not significant. Figure 5 contains the results of the comparison of pre-test and post-test outcomes.

Measure	Mean (SD)		Significance
	Pre-test	Post-test	
Quality of life items Rate QOL Satisfaction QOL (n = 8)	6.5 (1.773) 5.9 (1.458)	6.9 (1.126) 6.9 (1.458)	.257 .084
ARVL Self-efficacy - Knowledge Subscale (n = 8)	58.00 (20.06)	82.00 (7.33)	.012
Resilience Scale (RS15) (n = 7)	5.6 (.555)	5.8 (.368)	.138

Figure 5: Comparison of pre-test and post-test outcomes.





# **PART B**

## **Caring, Vision Loss and Self- Management**

### **A Review of the Literature**



# Caring, Vision Loss and Self-Management

## A Review of the Literature

If a person has a chronic condition, illness or disability clinical care is generally available to assist with acute and urgent issues (Wagner, Austin, & Korff, 1996). Outside of this care, the majority of responsibility falls on the person and their significant others to manage the condition on a daily basis (Cimarolli, 2006; Cimarolli, Reinhardt, & Horowitz, 2006; Delaney, 2004; Houts, Nezu, Nezu, & Bucher, 1996; Mack, Thompson, & Friedland, 2005; Wagner, Austin, & Korff, 1996). The unpaid care provided by family and friends is classified as informal care by the Australian Bureau of Statistics (Australian Bureau of Statistics, 2008; Delaney, 2004; Pearlin, Mullin, Semple, & Skaff, 1990). Informal carers are sometimes referred to as family carers. Paid carers are sometimes referred to as care workers or care aides. In this review, informal carers will be referred to as carers and paid carers will be referred to as such.

The Australian Bureau of Statistics (ABS) (2008) estimates there are 2.5 million Australians over the age of 15 (16% of the population) who provide informal care for another person. This figure is likely to be higher than recorded, as many people take on caring responsibilities without classifying themselves as carers (Delaney, 2004). One in five carers is a primary carer, that is the person who provides the majority of assistance (Australian Bureau of Statistics, 2008). Nearly half of primary carers care for partners, one quarter for their parent/s, about a quarter for a child with a disability, and a small number provide care for friends or other family members (Australian Bureau of Statistics, 2008). The majority of carers are women and most live with the care recipient (Mack, Thompson, & Friedland, 2005).

Caring may be an element of a relationship that occupies several hours a week, or the definition of a relationship in which care is provided full-time (Pearlin, Mullin, Semple, & Skaff, 1990). In 2003, the ABS (2008) found that approximately half of all carers spent at least forty hours per week caring. The level of care provided and the related stressors are dependent on many factors, including the:

- 1) Condition/illness or disability of the recipient (type, severity, duration) (McKeown, Porter-Armstrong, & Baxter, 2003; Wiles, 2003)
- 2) Amount of external assistance received from other family/friends, paid care workers, and other services;
- 3) Unique needs of the individuals in the caring relationship; and
- 4) The type of relationship between the carer and recipient.

Common conditions requiring care are dementia (Covinsky et al., 2003), multiple sclerosis (MS) (Finlayson & Cho, 2008; McKeown, Porter-Armstrong, & Baxter, 2003), heart conditions (Barnes et al., 2006), vision impairment (Strawbridge, Wallhagen, & Shema, 2007), and mental illnesses (Sorensen, Pinguart, & Duberstein, 2002). Caring demands may differ between these conditions but some are common to all. They often include assistance with transport (Finlayson & Cho, 2008; Finlayson, Garcia, & Preissner, 2008; Houts, Nezu, Nezu, & Bucher, 1996; Wiles, 2003), medication management (Houts, Nezu, Nezu, & Bucher, 1996), meal preparation, housework, mobility, dressing, transfers, feeding, bowel management, bladder management (Finlayson & Cho, 2008; Finlayson, Garcia, & Preissner, 2008; Wiles, 2003) falls prevention and community access (Wiles, 2003).

## **The significance of Carers**

Carers provide many benefits for individuals, communities and the government. In Australia in 2005, it was calculated that if carers were replaced by paid carers, it would have cost the government \$30.5 billion (Access Economics, 2005a). Despite these benefits, carers receive limited support, preparation, information or compensation to assume the tasks of health professionals from home (Elliott & Shewchuk, 2003). Without adequate support, carers can experience stress and poor health (Navaie-Waliser et al., 2002) and in turn neglect care of themselves (Houts, Nezu, Nezu, & Bucher, 1996; Navaie-Waliser et al., 2002; O'Connell, Bailey, & Walker, 2003). With reduced self-care, the health and safety of the care recipient is also compromised (Navaie-Waliser et al., 2002; O'Connell, Bailey, & Walker, 2003).

Due to medical advances, people are living longer (Australian Bureau of Statistics, 2005; Mack, Thompson, & Friedland, 2005; Pearlin, Mullin, Semple, & Skaff, 1990; Vitaliano, 1997) and the Australian population is ageing (Australian Bureau of Statistics, 2005; Pearlin, Mullin, Semple, & Skaff, 1990). Consequently in coming years more people will be living with chronic conditions and requiring care, with fewer carers available to assist (Mack, Thompson, & Friedland, 2005). The majority of carers will also be older in age and attempting to manage their own age-related conditions (Ekwall, Sivberg, & Hallberg, 2007; Mack, Thompson, & Friedland, 2005; Won, Fitts, Favaro, Olsen, & Phelan, 2008).

## **The experience of Caring**

Being in a care giving role can give meaning to a person's life (Moen, Robison, & Dempster-McClain, 1995) and strengthen their relationship with the care recipient (Australian Bureau of Statistics, 2008). However, this is not true for all carers. The ABS (2008) reported that carers experience an equal amount of positive and negative effects on their health and well-being. In 2003, the ABS found that 26% were satisfied in their caring role, and 34% reported that they lacked energy. Of primary carers, 64% reported no change in their physical and emotional well-being due to caring, however half of this group reported experiencing at least one negative affect e.g. feeling depressed.

Studies have been conducted into the predictors of positive experiences relating to carers. Positive experiences have been related to having a sharing and trusting relationship with the recipient (Barnes et al., 2006), having higher levels of perceived social support (McKeown, Porter-Armstrong, & Baxter, 2003), and better problem solving ability (Elliott & Shewchuk, 2003). For female carers especially, positive experiences are related to becoming a carer in the absence of other roles, having more traditional gender orientations of being a wife, mother and homemaker, becoming a carer between the ages of 50 and early 60s, and having higher education and better emotional health prior to taking on caring (Moen, Robison, & Dempster-McClain, 1995).

Predictors of negative caring experiences have also been identified. These include becoming a carer with insufficient skills, knowledge and resources to manage the recipient's condition and cope with the caring role (Houts, Nezu, Nezu, & Bucher, 1996). Experiences are dependent on the type and severity of the care recipient's condition, level of external support available, timing and length of caring, health of the carer, relationship to the care recipient, as well as the carer's age and gender. Covinsky et al. (2003) found that depression was more likely in carers of people with

dementia, with increased severity, increased hours of caring, and limited finances (Covinsky et al., 2003). Hirst (2005) and Schulz et al. (1997) found that the risk of carer distress increased with the intensity of care. Schulz et al. (1997) also found caring-related strain was associated with depressive symptoms, anxiety, less sleep, and less time for health and self-care activities. In other studies, carer strain was associated with becoming a carer in combination with many other roles (Moen, Robison, & Dempster-McClain, 1995), having lower income, education and more functional limitations (Schulz & Beach, 1999).

In a study by Navaie-Waliser et al. (2002) carers with poorer health were compared to carers in good health. Those with poorer health were more likely to be helping with bathing, dressing, transfers, financial management, telephone calls, and providing care for more than 20 hours per week. After health status of the recipient was controlled, carers with poor health were more likely to be providing higher intensity care, to have difficulty providing care, to be over the age of 65, married, with education of high school level or lower. It has also been found that short term caring is more likely to disrupt life patterns while longer term caring can become routine (Moen, Robison, & Dempster-McClain, 1995). However after eight years this was untrue for long-term caring as it tended to become strenuous (Moen, Robison, & Dempster-McClain, 1995). Barnes et al. (2006) found that reduced quality of life was associated with being a spousal carer, with two or more of their own health conditions and with existing symptoms of depression.

Increasing age has also been found to be a predictor of negative effects. After the age of 60, caring has negative implications for mastery, likely because women are worried about their own health and future ability to continue caring (Moen, Robison, & Dempster-McClain, 1995). Gender has also been found to be a predictor, with women more likely to experience negative effects as they take on the caring role in combination with work and home roles (Moen, Robison, & Dempster-McClain, 1995). The Australian Bureau of Statistics (2008) found females reported less satisfaction and more negative effects than men. However findings for gender differences are largely contradictory and have not been supported with rigorous research study designs.

The majority of studies reporting on these effects use self-report measures of health and well-being. These studies also focus on carers of different ages caring for people with different conditions, therefore effects may have been different had these factors been considered. Also, in most studies, the health and well-being of carers were measured at one point in time. Therefore any change in outcomes reported since commencing caring was often reported in hindsight. Additionally, many studies are based on American populations and therefore generalising results to Australian populations must be done with caution.

Overall the literature reports that carers experience high levels of distress when compared to controls or population norms. Negative experiences and effects are confounded by the fact that just over 30% of carers have a disability (Australian Bureau of Statistics, 2008), and many maintain part-time or full-time employment in addition to their caring role (Delaney, 2004; Mack, Thompson, & Friedland, 2005). Also, many are caring for people with chronic conditions that tend to worsen with age and therefore the demands on carers tend to increase over time. Depression, a common experience associated with caring, left untreated can lead to lost productivity, reduced quality of care, and earlier institutionalisation of the care

recipient (Gray, 2003). Importantly, the majority of carers are older adults (Mack, Thompson, & Friedland, 2005) or are approaching older adulthood (Australian Bureau of Statistics, 2008), and are therefore attempting to manage their own age-related impairments, chronic conditions and disabilities (McKeown, Porter-Armstrong, & Baxter, 2003; O'Connell, Bailey, & Walker, 2003). These factors increase the likelihood of the carer and care recipient requiring paid care, which places pressure back on the health care system (Gray, 2003).

## **Caring for a Person with Vision Impairment**

People with a vision impairment may also require some provision of care. Similar to people with other conditions, the majority of day-to-day care is provided at home by significant others, rather than by health professionals.

### **Vision Impairment: Definition and Incidence**

The term 'vision impairment' is inclusive of low vision and blindness (Resnikoff, Pascolini, Mariotti, & Pokharel, 2008; World Health Organisation, 2004). Based on the latest update by the International Statistical Classification of Diseases, considering best corrected vision in the better eye, blindness is defined as visual acuity less than 3/60 or a corresponding visual field loss to less than 10 degrees diameter, and low vision is visual acuity less than 6/18 but better than 3/60 or visual field loss to less than 20 degrees diameter (Resnikoff, Pascolini, Mariotti, & Pokharel, 2008; World Health Organization, 2004). Globally, vision impairment affected more than 161 million people in 2002 (Resnikoff, Pascolini, Mariotti, & Pokharel, 2008; World Health Organization, 2004). In Australia in 2004, vision impairment affected almost half a million people (Access Economics, 2004, 2005b; Taylor et al., 2005). The prevalence of vision impairment is expected to almost double in twenty years as the population ages (Resnikoff, Pascolini, Mariotti, & Pokharel, 2008; Taylor et al., 2005). In developed countries, age-related macular degeneration (AMD) is the leading cause of blindness (Access Economics, 2004; Resnikoff, Pascolini, Mariotti, & Pokharel, 2008; World Health Organization, 2004).

### **The Experience of Living with Vision Impairment**

Carers of people with vision impairment undertake many similar tasks to other carers. A number of activities are also unique. To understand the caring demands, it is important to understand the experience of living with a vision impairment. Loss of even a small amount of vision has implications. Depending on the eye condition, people may experience increased glare sensitivity, reduced ability to detect colour contrast (Watson, 2001), reduced clarity, and loss of central or peripheral fields. For some eye conditions, vision fluctuates and changes in vision are unpredictable (Watson, 2001). These impairments can result in familiar environments feeling unfamiliar, thus compromising safety and increasing the risk of falls and sometimes burns (Watson, 2001). Activity limitations related to living with vision impairment can include difficulty with mobility (walking, chair and bed transfers, outdoor access), medication management, meal preparation, social activities (Crews & Campbell, 2004), reading, writing, and recognising faces (Watson, 2001). People with vision loss can have difficulty interpreting non-verbal communication such as gestures, facial expressions and body language (Heine, Erber, Osborn, & Browning, 2002). Based on this experience, carers may provide assistance with rearranging the home environment (Watson, 2001), orientation and mobility in the home and community, falls prevention, transport, reading, medication management, and social contact.

Vision impairment is associated with many costs and co-morbidities, contributing to a compromised quality of life (Hassell, Lamoureux, & Keeffe, 2006; Soong, Lovie-Kitchin, & Brown, 2001; Vu, Keeffe, McCarty, & Taylor, 2005). Because people adapt to vision impairment in a network of family and friends (Travis et al., 2003), these costs and co-morbidities in turn affect family and/ or carers. In 2004, direct and indirect financial costs for every Australian with vision impairment over 40 years of age were \$10,482 (Access Economics, 2004). This figure is a result of increased health care utilisation, increased social dependence and social isolation (Access Economics, 2004; Jackson, 2006), lower rates of employment, greater emotional distress, earlier nursing home admissions (Access Economics, 2004), reduced mobility, longer hospitalisations and poorer nutrition than people without vision impairment (Jackson, 2006).

People with vision impairment also have double the risk of falls, four to eight times the risk of hip fractures (Ivers, Cumming, Mitchell, & Altebo, 1998), three times the risk of depression (Rovner & Ganguli, 1998), and more than double the pre-mature mortality of people without vision impairment (Access Economics, 2004). They may also have difficulty with non-verbal communication such as gestures, facial expressions and body language (Heine, Erber, Osborn, & Browning, 2002). Therefore conversations and interactions with others can be misinterpreted or responded to inappropriately. This can create difficulties between spouses, especially when discussing emotional issues (Sussman-Skalka, 2003). These associated effects can compromise social functioning, instrumental activities of daily living, life roles, leisure activities (Watson, 2001), social participation and physical and mental health (Access Economics, 2004).

### **Issues for Carers and Family Members**

There are many practical and emotional implications for carers and/ or partners and family of people with vision impairment (McCabe, Nason, Turco, Friedman, & Seddon, 2000; Sussman-Skalka, 2003; Watson, 2001). Some studies report on the issues of spouses without defining the spouses as carers. As the majority of carers are spouses (Australian Bureau of Statistics, 2008; Mack, Thompson, & Friedland, 2005), it is likely that the issues of spouses in these studies are related to caring tasks. Bernbaum, Albert, and Duckro (1993) reported that vision loss disrupts the spousal relationship and is associated with role ambiguity, separation and divorce. Strawbridge et al. (2007) investigated the impact of vision impairment on the health and well-being of spouses over a five year period. Compared to spouses of people without vision impairment, they had decreased physical functioning, mental health, well-being and marital quality. An interesting study of affect contagiousness was conducted by Goodman and Shippy (2002). They found that when an older adult with vision impairment is depressed, their spouse is also likely to be depressed.

Issues may also arise in relation to the amount of support and care to provide. Too much assistance can be interpreted by the recipient as overprotection, and insufficient assistance may be interpreted as lack of understanding (Cimarolli & Boerner, 2005). Carers themselves can feel isolated, frustrated, or ambivalent with respect to how, how much and when to assist (Sussman-Skalka, 2003). They may over or under estimate the capacity of the person due to lack of understanding of the eye condition, functional limitations and psychological impact (Cimarolli & Boerner, 2005). As there are many safety issues associated with vision impairment, overprotection is common (Cimarolli & Boerner, 2005). It has been stated that overprotection can lower the self-efficacy of the care recipient and increase burden

for the carer (Sussman-Skalka, 2003). However this evidence is anecdotal. Cimarolli et al. (2006) found that perceived overprotection was associated with lower levels of mastery and poorer adaptation to vision loss in older adults (Cimarolli, Reinhardt, & Horowitz, 2006), as well as higher distress (Cimarolli, 2006). A study by Horowitz et al. (2004) found that carers assessed the capacity of the person with vision loss in performing activities of daily living more negatively than the person themselves. An inappropriate level of support can exacerbate disability and impact on the well-being and functioning of the person with vision loss (Cimarolli & Boerner, 2005).

While there are implications for inappropriate levels of support, support for people with vision impairment is very important. Receiving practical and emotional support, or at least having the perception that the support is available, has been found to be important for adaptation to vision loss (Reinhardt, 1996; Reinhardt, Boerner, & Horowitz, 2006). In a study of 570 older adults with vision impairment, Reinhardt et al. (2006) found that perceived instrumental support was positively associated with adaptation to vision loss and actual physical and emotional support was important for adjustment (Reinhardt, Boerner, & Horowitz, 2006). In an earlier study by Reinhardt (2001) people who received affective support had less depression, more satisfaction and better adaptation to vision impairment than people who did not. However, carers must attempt to find this balance of perceived and actual support in different domains. If the family understands the functional implications of vision impairment, it is easier for them to understand the appropriate level of support, thereby improving outcomes for the individual with vision impairment (Watson, 2001).

### **Group Interventions for Carers of People with Chronic Conditions**

Australian governments have recognised carer strain and burden and sought to address this through the provision of programs and services including the Home and Community Care Program, the Community Aged Care Packages, the Veterans' Home Care Program, the Community Aids and Equipment Program, and Centrelink allowances. While these services reduce the amount of care required and / or provide financial assistance, they do not provide carers with the skills to cope with caring issues.

Group programs for carers have been implemented with the aims of increasing the ability of carers to provide quality care for themselves and the recipient (Houts, Nezu, Nezu, & Bucher, 1996). Many of these interventions are being delivered separately to interventions for recipients of care. It has been found that carers require different information, depth, and delivery to that typically provided to the recipient of care (Houts, Nezu, Nezu, & Bucher, 1996). They require education from health professionals about the care recipient's illness or condition, the causes and consequences, techniques for providing care, how and when to get help, strategies for preventing problems and overcoming barriers, problem solving skills, and adjustment to the caring role (Houts, Nezu, Nezu, & Bucher, 1996). Furthermore, carers require information and skills to find resources and to have confidence in their caring role.

The majority of the literature surrounding chronic conditions, illness and disability focuses on treatment of the person with the chronic condition or disability (Goodman & Shippy, 2002). Interestingly, many studies that focus on carers measure the care recipient rather than the carer outcomes. Meta-analyses, randomised controlled trials, and studies with comparison groups have evaluated and compared many interventions for carers of people with chronic conditions. Interventions have



included psychoeducational, supportive, psychotherapeutic, respite, behavioural and multi-component interventions. No single intervention is effective to influence all caring-related outcomes in all circumstances. For example, Sorensen, Pinquart, and Duberstein (2002) found in their meta-analysis that all aforementioned interventions were effective in alleviating depression and carer burden, and increase carer well-being, ability to provide care, satisfaction in caring, and knowledge of the recipients' symptoms for older adult carers of people with a range of conditions. Psychotherapeutic and psycho-educational interventions had the most consistent positive effects. Multi-component interventions were most effective in reducing carer burden and depression and improving well-being.

A meta-analysis of randomised studies was conducted by Martire et al. (2004). Psychosocial interventions for carers, or carers and recipients with chronic illness were evaluated and compared to usual medical care. Carer interventions were associated with positive effects in relation to reduced burden, depression, and anxiety. Effects were more pronounced for carers of people with conditions other than dementia. Including a spousal carer alone instead of another family member had a more positive impact on depression for recipients with chronic conditions.

It is important to note that people providing the highest levels of care, and unable to get respite, may be the people least likely to attend these programs. Therefore, the people who may be experiencing the most burden and negative health effects may be excluded from the results. Boise, Congleton, and Shannon (2005) and Hare and Newbrunner (2004) found that people who provided higher levels of care were more likely to withdraw from their carer programs. The interventions could be more effective for these carers, if accessibility to the interventions was improved through provision of respite services.

These studies have found benefits for psycho-educational interventions, but more consistent benefits for multi-component interventions. These interventions assist carers to deal with the range of emotions, feelings of burden, and provide support, opportunities to share concerns, education to enable the carer to reappraise their situation, and skills training for mastery and coping (Yee & Schulz, 2000). Interventions are difficult to compare due to different target populations and techniques. Significant results were found for some outcomes; however the limited rigor of many designs makes conclusions difficult outside of associations. The majority focus on female carers of older adults with chronic conditions or dementia. Carers of people with dementia face many difficult aspects of care, and it is thought that these interventions are less likely to produce positive effects than for other health conditions (Martire et al., 2004). Therefore, results from these studies may have been greater had the interventions been tailored for carers of other conditions. No one intervention has been found effective in all circumstances and few long-term results are reported. In summary, the efficacy of carer interventions is still developing (Martire et al., 2004).

### **Group Interventions for Carers of People with Vision Impairment**

Many similar interventions have been applied to assisting carers of people with vision impairment. Interventions that provide education on the eye condition and the functional and psychological impact of vision loss provide carers with an appropriate skill-base to provide care (Cimarolli & Boerner, 2005). Many programs enable carers to meet people in a similar situation, share feelings and experiences, discuss

solutions to caring problems, learn about resources, and receive assistance, comfort and support from people with a similar experience (Sussman-Skalka, 2003).

It is accepted practice in some organisations to include carers/ significant others in vision rehabilitation with the person with vision loss. Rees, Saw, Larizza, Lamoureux, and Keefe (2007) studied the opinions of 21 clients with vision impairment and 64 vision rehabilitation professionals from Australian private and public eye clinics. Both benefits and disadvantages were found for including significant others in vision rehabilitation. Over half of the clients said they would prefer to attend with a significant other. Reasons included company, sharing, and assistance with transport and mobility. Eighty-three percent of the professionals said clients should have the opportunity to bring a support person. Advantages to involvement were identified as practical and emotional support, assistance for remembering and implementing vision strategies at home, improving the significant others' understanding of vision loss, improving communication and ability to work together, and for significant others to meet people in a similar situation to themselves. Clients who did not want to involve significant others cited reasons as time constraints of their significant others or a preference to attend alone.

Health professionals stated including others may have a negative impact on group bonding, impair disclosure of issues, create privacy issues, create dependency on the significant other, and introduce the risk of significant others dominating the group. Logistical issues included time and resource constraints, and difficulty communicating with a larger group. It is important to consider that the reported benefits and disadvantages were anticipated, in that none of the participants in the study had been asked to attend an intervention and then provide feedback. However, the findings are still important even despite the methodological limitations and relatively small sample. While this study did not include the perspectives of significant others themselves, the findings suggest that clients (person with vision loss) should be given the choice to attend vision rehabilitation with a support person. However, in a group program setting, facilitators would need to anticipate and prepare for issues that could arise in relation to group bonding and other factors. In other studies, carers/ significant others of people with vision impairment have reported that they have insufficient understanding of the care recipient's eye condition and of how much assistance to provide (Sussman-Skalka, 2003). This study suggests that an integrative family approach could help overcome these issues.

Programs for carers of people with vision impairment are offered in combination with, or separate to, the care recipient. A program titled 'Program for Partners' has been evaluated in several studies in the United States, the first by Sussman-Skalka (2003). The aim of the program was to educate and support carers of older adults with vision impairment by assisting them to overcome stress, communicate caring issues, and understand the experience of their partners with vision loss. This in turn was designed to improve health outcomes and functioning of the care recipient. In the preliminary study by Sussman-Skalka (2003) the most effective methods to address the concerns of carers were investigated. Four models of support were tested and compared: a telephone group for carers and three face-to-face groups (for carers, for carers and partners with vision loss, and a self-directed group for carers). All groups had eight sessions, and all but the self-directed group were required to address the following topics: getting acquainted and sharing concerns; understanding partners' vision loss; exploring emotional issues; communication between partners; organising

the home for safety, accessibility and comfort; getting around safely; garnering support from family and friends; and managing and dealing with stress. Qualitative feedback was obtained from carers in each group. Benefits were found for all groups.

The telephone group was more accessible for carers in rural areas and/ or carers experiencing a chronic health condition. Carers in the telephone group received materials ahead of time, which was reported as beneficial and requested by all groups. Despite the self-directed group having no discussion guide, no additional topics to the other groups were addressed. It was concluded that the topics addressed in the other three groups were appropriate. Regardless of group, after attending the program many carers reported improved communication with their partners, increased feelings of closeness, more reciprocity in their relationship, improved ability to discuss stressful situations with their partner, greater understanding of vision services and their function, improved understanding of the visual function of their partners, and improved confidence about when and how to help their partner. These findings suggest that inclusion of carers in their partners' vision rehabilitation is beneficial, whether the group is designed for partners with vision loss and carers, or carers alone.

Cimarolli, Sussman-Skalka, and Goodman (2004) conducted a telephone evaluation of the 'Program for Partners.' Thirty-two carers aged 46-86 years participated in one of the four group models used by Sussman-Skalka (2003). After participating in the program, carers became more certain about how and when they could provide assistance, and how much to provide. There were statistically significant increases in carers' understanding of their partner's vision loss, their visual and functional capacity, as well as significant decreases in role captivity and the number of major issues reported. Additionally carers felt their ability to talk openly about stressful situations related to their partner's vision loss had improved. No impact was found on carers' levels of life satisfaction, depression, or relationship satisfaction. There may have been an impact long-term that was not detected post-test or these changes may have been outside the capacity of an educational support program.

The findings of these two studies indicate that carers of people with vision impairment can experience benefits from participating in carer-specific group programs delivered in several methods. Other studies have addressed carers of people with vision impairment (McCabe et al., 2000) however outcomes for the partner with vision impairment were investigated rather than those of the carer. More rigorous studies are required to address the effectiveness of interventions for carers themselves.

### **Self-Management Interventions for Carers**

The incidence of chronic conditions is increasing in Australia and worldwide (National Health Priority Action Council, 2006). To manage the impact of these conditions, Australian health policy is turning toward self-management interventions (Centre for Research into Disability and Society, 2006; Jordan & Osborne, 2007; National Health Priority Action Council, 2006; Walker, Swerissen, & Belfrage, 2003). Self-management involves an individual managing the treatment, symptoms, physical and psychological consequences of living with their condition while maintaining their quality of life (Barlow et al., 2002; Lorig, 2001; Lorig et al., 2000; Tousman, Zeitz, Bristol, & Taylor, 2006). In self-management groups, group problem solving is encouraged, clients work in partnership with health professionals, content is based

on the perceived needs of the clients (Lorig, 2003, 2001), and training is provided in behavioural and cognitive skills for coping (Lorig, 2001; Lorig et al., 2000; Tousman, Zeitz, Bristol, & Taylor, 2006).

Carers as well as the person with the chronic disease or illness are recognised as requiring assistance in chronic disease management (National Health Priority Action Council, 2006). The treatment of chronic conditions provided by the medical model of service delivery does not provide the person with the chronic disease or illness with resources to self-manage the condition (Wagner, Austin, & Korff, 1996). Self-management group interventions have been developed to address many consequences of living with vision impairment including emotional distress (depression and anxiety), lowered self-efficacy, reduced function, and decreased participation (Brody et al., 2002; Brody et al., 2005; Brody et al., 1999; Girdler, 2006). These interventions have been rigorously evaluated in three randomized controlled trials, two of which conducted follow-up evaluations (Brody et al., 2002; Brody, Roch-Levecq, Thomas, Kaplan, & Brown, 2005; Brody et al., 1999; Girdler, 2006).

### **Self-Management Interventions for Carers of People with Chronic Conditions**

Self-management interventions are beginning to be utilised to assist carers to manage their own health as well as the care they provide for their partner or family member. Some programs not identified as self-management programs are delivered according to self-management principles. An article by Finlayson et al. (2008) describes the first phases of developing an education program for carers of people with multiple sclerosis. While the authors do not define the program as self-management, it is grounded in self-efficacy theory, a central theory in self-management.

A 'Coping with Caregiving' Program (CWCP) developed in the United States for carers of people with dementia has also been underpinned by self-management principles (Gallagher-Thompson et al., 2003). The CWCP is a 10-week program and involves small group instruction and practise of cognitive and behavioural skills to cope with caring for a person with dementia. It is offered in both English and Spanish.

The 'Powerful Tools for Caregiving Program' (PTCP) is a standard curriculum developed in 1995 by Legacy Caregiver Services in Oregon, United States. It was designed to be a self-efficacy based education program for carers to improve emotional wellbeing, self-care behaviours, and self-efficacy for caring, and thereby maintain their own health. The PTCP was designed for carers of people with dementia, Parkinson's, stroke, and other long-term conditions (Won et al., 2008). It is a six week program with 2.5 hour sessions once per week. Carers receive a 300 page Caregiver Helpbook as a reference for the program. While the authors and researchers of the program do not define it as self-management, the curriculum and teaching techniques are modelled on the CDSMP and it is based strongly on self-efficacy theory. It also utilises self-management strategies of brain storming, role play and experiential learning (Won et al., 2008). The PTCP is disseminated throughout community settings in the US by Mather LifeWays, a not-for-profit organisation in Illinois. It is part of a large on-going study with evaluations by Boise et al. (2005), Kuhn, Fulton, and Edelman (2003) and Won et al. (2008).

Self-management interventions for carers are beginning to emerge in the published literature. None, as yet, have focused on carers of people with vision impairment.

The effectiveness of existing self-management programs for carers of people with a range of other conditions, and other types of programs for carers of people with vision impairment, may provide an indication of the benefits a self-management program could have for carers of people with vision loss.

### **Effectiveness of Self-Management Interventions for Carers**

Self-management interventions for carers are a relatively new area of study and studies into their effectiveness are limited. The PTCP and CWCP have published their evaluations, with three studies conducted into the PTCP (Boise, Congleton, & Shannon, 2005; Kuhn, Fulton, & Edelman, 2003; Won et al., 2008).

Gallagher-Thompson et al. (2003) conducted an evaluation of the CWCP Program. The program was compared to a community-based support group program. Pre-test and post-test evaluation was conducted with 213 female carers of people with dementia who were recruited from the community in one US region. The program was offered in English (122 Anglo carers) or Spanish (91 Latino carers). Regardless of the ethnic group targeted, the CWCP was associated with significant reductions in depressive symptoms, fewer negative social interactions, increased use of adaptive coping strategies and tendency to use fewer negative coping strategies compared to the support group program. The authors concluded the skill building approach offered by the CWCP was more beneficial than the provision of support alone. While dementia-specific, the program demonstrated benefits for mental health, coping, and social interaction for female carers.

Kuhn et al. (2003) evaluated the PTCP outcomes pre-test and post-test with 155 carers. The majority were female, adult children caring for their parents who had memory loss. Other participants were carers of spouses. After participating in the program, adult children showed statistically significant increases in self-efficacy, self-care, depression, vitality, exercise time, and decreased level of upset associated with the recipient's memory and behaviour problems. No increase was found in carers' attitudes toward taking care of their own health or the number of relaxation activities they engaged in. Spousal carers showed statistically significant improvements in self-efficacy, self-care, attitudes toward taking care of their health, the number of relaxation activities engaged in, and time spent exercising. Spousal carers showed no improvement in ability to make time for themselves, or in symptoms of depression or vitality. Kuhn et al. concluded that the PTCP was of benefit in many similar domains for both spouses and adult children providing care.

Boise et al. (2005) further evaluated outcomes from 33 classes of the PTCP. One-hundred and eighty-six carers of a person with Alzheimer's disease, heart disease, stroke, diabetes, Parkinson's, or cancer participated. Eighty-one percent of the sample reported that the care recipient also had some degree of memory loss. The majority of participants were female, adult children or spouses of the recipient, with an average age of 61 years (range 26-89 years). Pre-test and post-test outcome measures were administered and 69 participants continued with follow-up. The program was associated with statistically significant positive changes in emotional well-being, self-care behaviours, self-efficacy in caring, community service knowledge and utilisation. Most results were maintained at six-month follow-up.

Won et al. (2008) evaluated PTCP outcomes over 12 locations pre-test and post-test. One-hundred and eighteen carers participated, the majority of whom were female, older adults, caring for a person with dementia, heart disease or stroke. The PTCP

was associated with significant reductions in health risk behaviours and increased self-care and well-being, with the results being more marked for participants under the age of 65.

Results from these three studies indicate that the PTCP was associated with significant reductions in health risk behaviours, improved self-care and psychological well-being. Effectiveness was shown for carers of people with a range of health conditions, but primarily dementia or a form of memory loss. Separate analyses of outcomes between carers of people with different health conditions were not reported. Results of all three studies are not supported with rigorous designs.

While samples were relatively large, no control conditions were utilised to compare the findings. Participants in the studies were also convenience samples and the characteristics of these samples may have biased study outcomes. Results may also be attributable to factors other than the PTCP as activities outside of the program were not controlled. Generalising the results outside of American older female adults caring for people with memory loss (who were the majority of participants) must be done with caution.

There is some evidence that self-management programs can assist carers to develop confidence and skills to manage their own lives and the health of the care recipient. However randomised controlled trials are still required to confidently state the benefits of self-management for carers of people with a range of conditions, including vision impairment.

## **Summary**

The increasing need for carers combined with the economic benefits they provide to the community, highlight the importance of attending to the health and well being of carers (Ekwall, Sivberg, & Hallberg, 2007; McKeown, Porter-Armstrong, & Baxter, 2003; Navaie- Waliser et al., 2002; O'Connell, Bailey, & Walker, 2003; Vitaliano, 1997). In Australia, the health and well being of carers have become a concern of social and health policy (Australian Bureau of Statistics, 2008). Their contributions allow their partners, family members and others with disabilities, chronic conditions and age-related impairments to remain living in the community (Australian Bureau of Statistics, 2008).

Self-management interventions for carers are emerging, however there are as yet few published evaluations of these programs. None have targeted carers of people with vision loss thus far. Vision impairment is a condition of increasing incidence in Australia and worldwide. It has many impacts on the community and health care system (McCabe et al., 2000) as well as implications for individuals who experience vision loss and their significant others. There is a need for the development and testing of more self- management programs for carers of people with vision loss.

# **PART C**

## **Planning and Delivering the *Care for the Carers Program***





# Planning and Preparation

## Facilitators

*Care for the Carers* is designed to be run by two facilitators. Together they must have the skills to facilitate a group and have a good knowledge of the causes of vision loss and of eye conditions, vision rehabilitation principles and practical and psychological issues impacting on carers of people with vision loss. A combination of a social worker and a psychologist has proven successful. An occupational therapist would also be an appropriate facilitator. Please note that an orientation and mobility instructor is required for Session Three Stepping Out: Orientation and Mobility.

## Venue

A comfortable quiet room with chairs arranged in a semi circle or circle.

## Length of program and each session

A six-week program with each session being of 3 hours duration.

## Promotion of *Care for the Carers* Program

As with any program, consideration needs to be given as to where and how to promote the program to prospective participants. Some suggested ways to promote the program include:

- Within organisations providing vision rehabilitation services;
- To self help and other groups concerned with vision loss and related conditions;
- To healthcare professionals e.g. specialists, GPs, community nurses;
- To carer - related agencies/organisations;
- To community service providers eg local Home and Community Care agency.

## Pre-group Interview

The pre-group stage begins before the group itself meets. It provides an opportunity for the health professional facilitator and prospective participants to discuss the aims and logistics of the program and to clarify whether the program is suitable for and of interest to the carer. The interview may take place in person or over the telephone. During this stage the health professional/facilitator looks to establish a working relationship with each prospective participant and to build upon this during group sessions.

## **Purposes of the Pre-group Interview**

### **1. To interview applicants and assess their interest and suitability.**

The *Care for the Carers* Program is aimed at carers who:

- provide care and assistance for a partner, family member or friend who is blind or vision impaired;
- are aged 18 years or older;
- have sufficient hearing, cognition and English language skills to understand spoken English (unless interpreters can be arranged).

It is beneficial if group members are similar enough to be able to relate to each other, yet different enough to bring a wide variety of perspectives and life experiences to the program.

Ten to twelve members is the ideal size to generate this balance while allowing participation of all group members in discussions and activities.

### **2. To clarify the program goals and procedures.**

The health professional/facilitator explains the purpose and structure of the group and obtains a verbal commitment from each member.

### **3. To initiate a working relationship with each group member.**

The healthcare professional/facilitator learns about the uniqueness of each group member in order to accommodate individual differences during the course.

# Session One

## Understanding Vision Loss

### **Background information for group facilitators:**

#### **Stage of group development: Orientation and exploration.**

The early stages of any group are important for establishing trust and forming cohesion in the group. Participants are getting to know each other and understanding how the group works. They also need to establish spoken and unspoken rules, clarify their own personal goals and expectations, and the shared purpose of the group. Participants need to feel like the group is a safe place to learn and to share.

### **Purpose of Session One**

- 1. To provide group members with an overview of the program and to introduce self- management as a way to manage daily life.**

An overview of the program aims and content is provided and facilitators and participants introduce themselves to the group.

- 2. To provide an orientation to the facility.**

It is important that group members feel comfortable in the physical environment. A thorough orientation to the facility is provided.

- 3. To identify the role of group facilitators.**

The role of the facilitator/s is to provide a process for drawing out and building upon the knowledge and skills of participants.

- 4. To establish group culture and introduce group guidelines.**

Group guidelines are negotiated with participants. It is important that group members understand that the sharing of experiences is planned and critical to their learning.

- 5. To develop an understanding of the major causes of vision loss and of specific eye conditions.**

## Preparation for group facilitators

### 1. Eye conditions

It is important that the facilitators have a basic understanding of the structure of the eye and the major causes of vision loss, including those affecting older adults. If possible find out the eye conditions of partners / family members in the group so you can concentrate on these in the session.

### 2. Self management principles

Ensure you have a basic understanding of self management principles, and how these principles have been applied within the program.

### 3. Resources required for Session One

- ✓ Quiet room where chairs can be arranged in a semi circle
- ✓ A Participant Manual for each group member
- ✓ A folder for resources and hand outs
- ✓ Printed name tags
- ✓ Refreshments
- ✓ Diagram of vision loss statistics for your agency (or ABWA)
- ✓ A model of the eye or a large print diagram of the eye
- ✓ Simulation eye condition masks ('goggles')
- ✓ Examples of high/low contrast items
- ✓ A whiteboard / white board pens/eraser.

<b>Outline of Session One</b>	
<b>Introduction and warm up activity</b>	(30 minutes)
<b>Learning session:</b> Understanding vision loss Levels of vision and vision loss statistics The basic structure of the eye. Main causes of vision loss	(45 minutes)
<b>Break</b>	(15 minutes)
<b>Discussion activity:</b> Eye Conditions, symptoms and treatment	(60 minutes)
<b>Discussion activity:</b> Review learning	(20 minutes)
<b>Homework activity:</b> Review learning and locate additional information on eye condition	
<b>Summary of session</b>	(10 minutes)

# Introduction and Warm Up

## **Introduction of group facilitators and orientation to facility**

*Welcome participants and introduce yourself – for example name, work background. Refer participants to the ‘Orientation Checklist’ in their manuals and discuss each point.*

## **Introduction of participants**

*Choose one of the following as icebreakers:*

- a. Form a pair with someone you have not met before and talk with this person to find out their interests and hobbies, to share one little known fact about themselves and why they have decided to attend the group;
- b. Form a pair with someone you have not met before and talk with the other person to find out where they live, what hobbies and interests they enjoy and why they have decided to attend the group.

### ***For both:***

*Introduce the other person to the rest of the group, including why they have decided to attend the group.*

## **Aims of the course and introduction to self-management**

*Outline and discuss these aims, relating to participants’ own aims.*

1. To provide participants with information about their partner’s family member’s vision loss and with the skills to enable them to assist their partner/family member in managing their vision loss;
2. To provide information on resources, equipment and technology that are available for people with vision impairment and for their caregivers; and also,
3. To provide caregivers with skills and resources to support and sustain them in their care giving role and to look after their own needs.

*Introduce self-management using the following points, drawing on any previous experience of self- management amongst group members.*

The *Care for the Carers* program is underpinned by self -management principles;

- Self-management support works on providing people in a care giving situation with information, skills and strategies that may assist them in their care giving role;

- By learning new or additional information and skills, participants may select and use the strategies that best suit their individual circumstances;
- Participants also bring a wealth of experience and skills to the group which may be invaluable to others in a similar situation; sharing and problem solving together is an important part of the process;
- Health professionals/group facilitators can provide the information and the road maps but participants are in the driver's seat and are central in managing their own care giving role.

## **Overview of the course and session format**

*Provide an overview of the course and format of each session.*

The first three sessions focus on providing caregivers with practical information, skills and resources relating to their partner's/family member's vision loss and ways of managing their vision loss. The topics are:

- Session 1** Understanding vision loss
- Session 2** Making the most of remaining vision and other senses
- Session 3** Stepping out – orientation and mobility

The second group of three sessions focus on addressing the needs of carers themselves and providing skills and resources to support and sustain them in their care giving role. The topics are:

- Session 4** Taking care of ourselves
- Session 5** Exploring emotional issues
- Session 6** Resources for caring – now and in the future

Each session is 3 hours long and will usually consist of:

- A warm up activity
- A review of home work and an opportunity for information sharing
- A learning session
- Discussion and practise activities.

## **Group Guidelines**

*Discuss and include additional points identified by participants.*

### **1. You are responsible:**

Each person is responsible for his or her own learning, participation and growth.

### **2. Speak for yourself:**

It is important to speak about your *own* experiences and not to speak for others.

### **3. It's OK to pass:**

If something hits you as too personal, then just say 'I pass'. You don't have to participate if you are feeling uncomfortable.

### **4. All feelings are OK:**

It is human to have feelings. It's OK to feel sad, angry or happy or to cry and laugh. Don't say you're OK if you're not.

### **5. Accept and respect:**

Accept and respect that other people's views come from their own unique experiences.

### **6. Sharing is encouraged:**

Group members are encouraged to share their experiences and their thoughts. Participants are also encouraged to bring along resources and information to share with the group – there will be an opportunity to do this in each session.

### **7. It's confidential:**

Sharing and growing together is a privilege. Shared personal experiences should stay within the group.

### **8. Anything else?**



## Learning Session – Understanding Vision Loss

### **The term ‘blind’ – and some related terms**

*Ask participants to spend a few minutes reflecting on what the term ‘blind’ means to them, writing some points down in their manual. Explain that the group will revisit this at the end of the course (in session six).*

*Introduce and discuss the following terms.*

#### **Low vision**

A person is said to have low vision when their eyesight is limited or impaired and cannot be corrected by surgery, conventional glasses or contact lenses.

Low vision may result from injury, eye disease, a medical condition or a congenital birth defect. It may be experienced in a number of ways including loss of sharpness, distorted vision, loss of contrast, sensitivity to light or loss of visual field (Macular Degeneration Foundation, 2008, p. 2).

#### **Total blindness**

This refers to people who are unable to see light (Access Economics, 2004, p. 11).

#### **Legal blindness**

Legal blindness is a term applied by Centrelink and the Department of Veterans' Affairs for those with a permanent and significant loss of vision.

Legal blindness in Australia is defined as:

- Visual acuity reduced to less than 6 / 60 in the better eye with correction (that is, with the use of glasses or contact lenses) OR
- Visual field reduced to less than 10 degrees of arc from central fixation OR
- A combination of visual acuity and visual field resulting in the same degree of visual loss. (Access Economics, 2004, p. 11).

### **Vision loss in Australia**

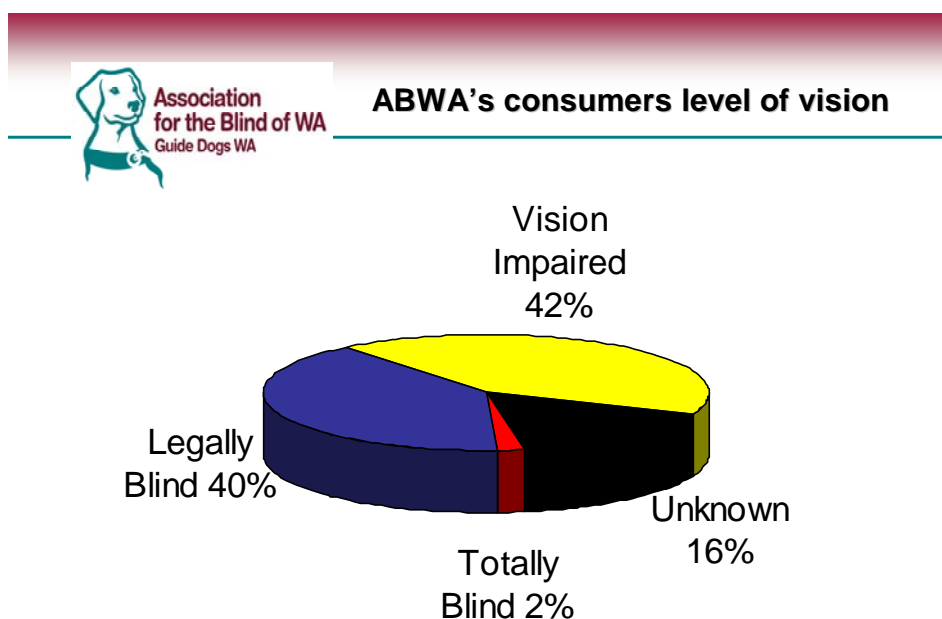
*Introduce these points and circulate the diagram for your agency if applicable (or ABWA statistics as below).*

According to a 2004 report by Access Economics:

- More than 480,000 Australians are visually impaired in both eyes;
- Over 50,000 of these people are blind (Access Economics, 2004, p. 5).



The statistics for the Association for the Blind of Western Australia consumers are shown in the chart below.



(ABWA, November 2004).

Is this what you would have expected? Does anything surprise you?

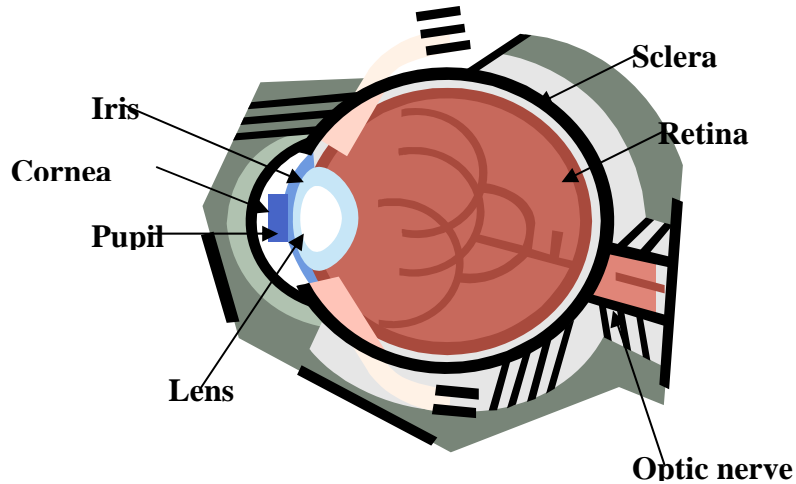
## How our eyes work

*Explain how the eye and the brain work together.*

The visual system is comprised of two basic parts – the Eye and the Brain.

- The eye works very much like a camera. The front of the eye, including the cornea, iris, pupil and lens, focuses the image onto the retina which lines the inside of the eye.
- The retina is sensitive to light and acts like the film in a camera. It captures images, sending them to the brain via the optic nerve, where they are interpreted.
- The brain interprets the image received from the eye. We use our eyes to look but we see with our brain. Both eyes work together gathering information, making it possible for one eye to lose vision without this being noticed. (Vision Eye Institute, 1999)

Explain the function of each part of the eye, using the eye model or diagram and the following information.



### ***The external eye***

**Cornea** – the clear window at the front of the eye which prevents germs and dust from entering the eye. Its curved shape helps to focus light rays.

**Sclera** – this is commonly referred to as the ‘white of the eye’. It is the tough, white outer coat of the eye.

**Iris** – is the coloured part of the eye which changes size to control the amount of light entering through the pupil.

**Pupil** – this is the opening (gap) at the centre of the iris. It acts like the aperture of a camera and regulates the amount of light getting into the eye by contracting and dilating, for example in dull light the pupil becomes larger to allow more light to enter, with the opposite in bright light.

## ***The internal eye***

**Lens** – sits behind the pupil and assists in focusing and concentrating light through the vitreous onto the retina.

*Explain that the link between the lens and cataracts will be covered later in the session.*

**Vitreous** – the eyeball is filled with a clear jelly-like substance called the vitreous which helps give the eyeball its shape.

**Retina** – is the lining inside the eye. It is like the film in a camera. This light sensitive tissue captures the image. The retina is a complex layer containing millions of light sensitive cells (photo receptors) called rods and cones. It converts these to messages, which it forwards to the brain. If the retina is damaged by disease, visual acuity and visual fields may be affected.

*Explain that diabetic retinopathy will be covered later in the session.*

**Macula** – this is the tiny area in the very centre of the retina. It is where most of our cone cells (the photo receptors which enable us to see fine detail and colour) are concentrated. The macula is important to see fine detail for near and distance vision.

*Explain that macular degeneration will be covered later in the session.*

**Optic nerve** – is the pathway that conveys messages from the eye, to the area of the brain that gives meaning to the things that we see.

*Explain that the link between the optic nerve and glaucoma will be covered later in session.*

(Centre for Eye Research Australia, 2004).

## How vision is measured

*Ask if anyone has observed their family member having their vision tested?*

*If yes, discuss what was measured and how, incorporating the information below.*

**Visual Acuity** = Assessing a person's ability to see detail.

- Visual acuity is a measure of a person's ability to see detail - both at a distance and nearby;
- Each eye has its own level of visual acuity;
- A Snellen Eye Chart is commonly used to measure distance visual acuity;
- The measure of distance visual acuity looks like, but isn't a fraction, eg 6/60. If a person is only able to read the top line of the Snellen Chart (with biggest letter), their visual acuity would be recorded as 6/60. This means that the person experiencing vision loss can see at a distance of 6 metres what a person with full vision can see at 60 metres.

**Visual Fields** = Assessing a person's ability to see using central and peripheral (side) vision.

- The field of vision is the area that can be seen whilst the eye is focused on a central point;
- Visual acuity and colour vision are best at the centre of the visual field;
- We rely on the peripheral (side) field of vision for seeing at night and in conditions of low light; and also for orientation and movement;
- Ophthalmologists and optometrists most frequently measure visual fields using computerised perimetry tools which, whilst measuring the field, monitor the ability of the person to maintain focus on a central point. The Humphrey Visual Field Analyser provides a map of the visual field and can be used to screen and monitor a number of eye and neurological conditions (MedicineNet, 2007).
- The Bjerrum field test involves the assessor moving a target of specific size to areas within a Bjerrum screen in order to assess the central 30 degrees of the visual field.

**Contrast sensitivity** = Assessing a person's ability to see details in low contrast. *Use an example of high / low contrast eg cutting an onion on a white plastic chopping board.*

- Contrast sensitivity measures the ability to see details at low levels of contrast; if a person can see details at very low contrast they have high contrast sensitivity, and vice versa.
- The Melbourne Edge Test involves the assessment of a person's ability to see lines or edges separating dark and light backgrounds, of reducing contrast, with variable orientation, on 20 circles, 2.5 mm (1 inch) in diameter. The paper test has now been replaced by an illuminated tool. (Grosvenor, 2006, p. 172).

## **Causes of vision loss**

*Introduce types of vision loss*

There are age related changes that occur as a result of the normal ageing process as well as eye pathology resulting in specific eye conditions.

### **The ageing process**

*Discuss what changes in vision people may experience as a normal part of the ageing process, using the following information.*

Some of the changes in the visual system as people age include:

- Reduced ability of the eye to adjust to abrupt changes in lighting;
- Difficulty in discerning slight variations in colour. eg the difference between black and blue;
- Difficulties with contrast eg light coloured objects are more difficult to see;
- Increased sensitivity to strong light and glare.

### **Eye conditions**

- Although age-related changes may contribute to some reduction in the ability to see, it is eye conditions which result in major losses in vision;
- Age-related Macular Degeneration (AMD); Glaucoma; Diabetic retinopathy and Cataracts are among the most common causes of acquired vision loss;
- Vision loss may also be due to congenital eye conditions, including: Retinitis pigmentosa; Albinism; Retinopathy or prematurity.

**TEA BREAK**



## Discussion Activity – Eye Conditions

*Ask participants to break into groups of three or four to discuss the following:*

1. What eye condition/s does your partner/family member have?
2. Share with others what you know about their eye condition – including cause, symptoms, treatment.
3. How does this eye condition affect their vision and day to day living?

*Ask participants to come back to the larger group and discuss the eye conditions.*

*Use the information on the following pages to support this discussion, focusing on the eye conditions that are relevant to the group.*

*Provide participants with an eye mask simulating the specific eye condition, as appropriate.*

### Macular Degeneration

#### What is macular degeneration?

- MD is the most common cause of vision loss among older adults, though it also affects younger people; it has often been referred to as Age-Related Macular Degeneration (AMD).
- The **macula** is the very centre of the retina and is responsible for central, detailed vision (*refer to model of eye.*)
- MD causes progressive loss of central vision, affecting a person's ability to recognise faces, to see fine detail, read and drive safely.
- The cause of MD remains unknown.

#### What are some of the common symptoms?

- A gradual decrease in the ability to see objects clearly.
- Distorted vision, whereby straight lines such as a fence, look wavy.
- Dark or empty spaces blocking the central field of vision (peripheral or side vision will usually remain quite normal).

### **Who is at risk of developing MD?**

- People over the age of 75.
- Smoking, sunlight, alcohol and certain medications can contribute to MD.

(Department of Health and Ageing, 2009).

### **Dry and Wet Macular Degeneration**

The two most common forms of MD are Dry (atrophic) and Wet (exudative).

#### **Dry MD**

- This is the most common form and is caused by the thinning of the macula, when tiny blood vessels are unable to nourish it adequately.
- Vision loss is usually gradual. Some cases of Dry MD will progress to Wet MD.

#### **Treatment:**

- There is no effective treatment for Dry MD at present.
- A diet including fresh fruit and vegetables to provide antioxidants and nutrients may slow the progression of Dry MD.

#### **Wet MD**

- Is caused by abnormal blood vessels growing and leaking into the retina and is characterised by a sudden loss of vision

#### **Treatment:**

- Treatment includes laser therapy to the retina. The laser seals the leaking blood vessels that eventually damage the macula.

(Macular Degeneration Foundation, 2007).

# Glaucoma

## What is glaucoma?

- Glaucoma is an eye condition that causes damage to the **optic nerve**, the fine nerves that connect the eye to the brain (*refer to model of the eye*).
- 'Normal' pressure in the eye occurs when the amount of fluid produced by the eye is balanced by the amount draining away. If the fluid cannot escape because the exit channels have become narrowed or blocked, the pressure in the eye rises and causes damage to the optic nerve.
- The damage often occurs slowly and the person may be unaware of any problem until the majority of nerve fibres have been destroyed and a significant amount of vision is lost.

## What are the symptoms of glaucoma?

- Often there are none and a person may lose significant peripheral (side) vision without being aware of it.

## Who is at risk of developing glaucoma?

People of all ages can develop glaucoma but it is more common in people who:

- Have a family history of glaucoma;
- Are aged 50 years or over.

## What treatment is available?

Once it has been diagnosed glaucoma can be treated, however, vision lost prior to treatment usually cannot be restored.

Treatment may include:

- Eye drop medication.
- Laser surgery and other surgery.

(Department of Health and Ageing, 2009).



## Diabetic Retinopathy

### What is diabetic retinopathy?

- Diabetic retinopathy is an eye disease caused by complications of diabetes.
- It occurs when the small blood vessels that nourish the **retina** (the light sensitive part of the eye) are damaged and may expand and leak fluid (*refer to model of the eye.*).

### What are the symptoms of diabetic retinopathy?

- In the early stages there may be a blurring of both central and peripheral (side) vision;
- As it progresses, there may be cloudiness and blind spots or floaters in the vision. In advanced stages, there may be additional distortion and blurred vision.

### Who is at risk of developing diabetic retinopathy?

- Not every one with diabetes goes on to develop retinopathy, but the chances of retinopathy increase after having diabetes for several years.
- Strict management of diabetes will delay the development.

### What treatment is available?

- Laser treatment and other procedures may be performed in some cases to decrease the risk of vision loss.  
(Department of Health and Ageing, 2009).

# Cataracts

## What is a cataract?

- A cataract is formed when the proteins that make up the **lens** are damaged or altered due to trauma, or more commonly, age; (*refer to model of the eye*).
- The lens changes from clear to cloudy in the same way that the proteins in an egg white change when cooked.
- Vision becomes poor giving the sense of looking through frosted glass.

## What are some of the symptoms of cataracts?

- Less ability to see contrast and problems with perception of depth.
- Need for more light and increased sensitivity to glare.
- Overall blurring.

## Who is at risk of developing cataracts?

- The most common cause of cataracts is advancing age.
- Specific causes of cataracts are uncertain, however exposure to sunlight, physical injury to the eye, infection or chemicals can cause cataracts.

## What treatment is available?

- Surgery is the only treatment for cataracts currently available and is effective and readily available;
- During surgery the clouded lens is removed and replaced with a plastic lens implant. This avoids the need to wear strong glasses or contact lenses.

(Department of Health and Ageing, 2009).

## Homonymous Hemianopia

### What is homonymous hemianopia?

- Homonymous Hemianopia is a condition that results from a stroke or injury to the brain; it is not a condition that affects the eye itself.
- Hemianopia relates to the brain's impaired ability to receive information transmitted through both eyes. It may be complete or partial.

### What symptoms are experienced?

- A person may experience difficulty seeing one side of the surrounding environment or will report that one side appears different from the other.
- With complete hemianopia the person can only see to one side when looking straight ahead. With partial hemianopia, objects appear differently in terms of clarity or brightness.
- Other effects include double vision, difficulty interpreting visual information and sometimes visual images may distort or disappear.
- Some hemianopias resolve naturally over time. The majority are permanent. Loss of half the visual field may affect a person's ability to manage many daily living skills and mobility;
- Vision rehabilitation services and training can assist someone to manage their condition.

(The Royal Society For The Blind, 2005).

## **Inherited or congenital conditions**

Congenital eye conditions (those present at birth) are either inherited or caused during pregnancy or birth by other means.

Some congenital eye conditions may cause total and irreversible blindness while others may be treatable or may leave some vision remaining.

Congenital conditions include:

### **Retinitis Pigmentosa (RP)**

- Refers to a group of inherited diseases that cause degeneration of the retina;
- People with RP often have tunnel vision and poor night vision;
- As the disease progresses central vision is lost;
- There is no treatment for RP and it usually presents itself during the teen years or in early adulthood.

### **Albinism**

- This condition is caused by a hereditary lack of pigment and leads to a sensitivity to bright light (photophobia) and severe vision impairment;

### **Retinopathy of prematurity**

- This is generally found in premature infants exposed to too much oxygen.
- It involves the abnormal development of blood vessels in the retina and can lead to retinal detachment and blindness.



## Discussion Activity

*Ask participants to pair up with one other person in the group, taking turns to discuss and record the key factors discussed today which are relevant to the person they provide care for.*

### Homework activity

*Discuss the home work assignment (below) and also encourage participants to bring information and resources that they would like to share with the group to the next session.*

During the course of the week, review and reflect upon what you have learnt today that is of significance to you and the person you care for. If it appears appropriate discuss this with your partner/family member.

You may also like to locate more information about their specific eye condition, using the list of sources provided in your manual. Bring anything you find to show others next week.

### Summary of session

*Discuss the main points covered in this session.*

- Some key terms relating to vision loss.
- Vision loss in Australia and statistics for your local agency if applicable (or ABWA).
- The basic structure of the eye and how our eyes work.
- How vision is measured.
- Main causes of vision loss, including age-related vision loss and specific eye conditions.
- Specific eye conditions, symptoms, treatment.



# Session Two

## Making the most of remaining vision and using other senses

### **Background information for group facilitators:**

#### **Stage of group development: Dissatisfaction/Resolution.**

By session two participants may be questioning their personal commitment to the group and the usefulness of the course. This stage is important in development and will later result in a greater commitment to the group. The facilitators need to recognise these feelings, work to allay fears and highlight the relevance of the course.

### **Purpose of Session Two**

- 1. To provide information about strategies for maximising remaining vision, and which may be of assistance to caregivers.**

The specific strategies covered include the four 'B's': Bigger, Brighter, Bolder, and Being Organised principles.

- 2. To identify ways in which other senses can be used by a person with vision loss to obtain information about their environment.**

This section may be particularly useful for caregivers who have a partner/family member with very limited or no vision.

- 3. To identify ways in which these principles and strategies can assist a person with vision loss and their care giver/s in managing daily living activities.**

This is achieved through discussion and homework activities.

## Preparation for facilitators

### Resources required for Session Two

- ✓ Whiteboard and whiteboard pens / eraser.
- ✓ A number of black felt tipped pens (various thicknesses).
- ✓ Some bold lined writing paper.
- ✓ Some ordinary lined writing paper.
- ✓ A number of blue / black fine tipped pens.
- ✓ Eye masks simulating eye conditions.
- ✓ Various types of magnifiers (for demonstration).
- ✓ Examples of various reading material, with a range of fonts.
- ✓ Examples of a large print personal diary, a large print calendar.
- ✓ Examples of desk lamps.
- ✓ Examples of Braille; tactile markings.
- ✓ A number of telephones with large numerals and telephone directories.

### Outline of Session Two

<b>Introduction and welcome</b>	(5 minutes)
<b>Review of homework / information sharing</b> Reflections on Session One and / or discussion with partner / family member about their eye condition. Locating more information about their specific eye condition.	(15 minutes)
<b>Warm up activity:</b> Writing a shopping list / letter	(15 minutes)
<b>Learning Session :</b> Making the most of remaining vision 'Bigger, Brighter, Bolder and Being Organised'	(30 minutes)
<b>Practise activity:</b> Using the telephone.	(20 minutes)
<b>Break</b>	(20 minutes)
<b>Learning Session:</b> Using other senses	(25 minutes)
<b>Discussion activity:</b> Managing daily living tasks	(30 minutes)
<b>Homework activity:</b> Reflect on the 'Bigger, Bolder, Brighter, Being Organised' strategies and / or using other senses.	(10 minutes)
<b>Summary of session</b>	(10 minutes)



# Introduction and Warm Up

*Welcome participants and introduce any new members. Discuss any questions arising from the first session.*

## **Review of homework and information sharing**

*Review and discuss the homework activity. What worked well? Were there any difficulties?*

Homework task from Session One:

“During the course of the week review and reflect upon what you have learnt today that is of significance to you and the person you care for. If it appears appropriate discuss this with your partner / family member who has a vision impairment.

You may also like to locate more information about their specific eye condition, using the list of sources provided in your manual.”

*Invite participants to share other information / resources that they have located.*

## **Warm up activity**

*Ask participants to form pairs and provide each pair with ordinary lined paper, ‘standard’ pens and simulation goggles or blindfolds.*

*Participants to take turns wearing the simulation goggles or blindfolds and writing a shopping list or letter, reading it back and signing the page.*

*Discuss:*

What is it like doing this task whilst wearing the simulation goggles or blindfolds?



## Learning Session – Maximising remaining vision

### Introduction

*Explain that this part of the session aims to provide some insight into the experience of living with low vision and that information relating to people living with very limited or no vision is provided later in the session.*

*Discuss the following questions, using the points below as additional information.*

What are the benefits for your partner / family member of making the most of the vision that they have?

What do you see as the benefits for you as a care giver?

- To enable the person with vision loss to be as independent as possible.
- To increase their self esteem, confidence and dignity as a consequence of being more independent.
- To minimise the dependence of the person upon others.
- To enable the care giver to maintain a sense of balance and independence in their own life.

How can a person with low vision make the most of their remaining vision?

- By modifying their environment according to their (and their carer's) unique circumstances.
- Through compensatory techniques and equipment for everyday tasks.

### **'Bigger, Brighter, Bolder, Being Organised'**

*Discuss examples of strategies that partners family members use to make the most of their vision eg magnifier, large print items. Write a list on the whiteboard.*

*Introduce the four B's principle, using examples provided by participants and the information below.*

- The 'Bigger, Brighter, Bolder, Being Organised' principle (the four B's) can assist a person who experiences vision loss to be more independent with daily living activities.

- The strategies that work best for each person are very individual and it is important that each person establishes what works best for them.
- It is helpful if carers, family members and people in the household are aware of these strategies.
- The Four B's can be applied to most activities of daily living.

*Demonstrate and circulate examples of each strategy.*

## **Making things Bigger!**

*Demonstration examples: magnifiers; a large print diary or calendar*

- This can be applied by enlarging, eg font size on a computer screen, telephone with large buttons, and by magnifying objects.

### **Magnification aids:**

- Magnifiers can help a person to see details they may otherwise miss.
- Different magnifiers may be needed for different tasks.
- As each person's vision loss is different, what works well for one person may not work as well for someone else.
- An optometrist should prescribe magnifiers. Optometrists and orthoptists can provide advice and training in their use.

### **Large print adaptations:**

- Examples include: Large print calendars; large print clocks and watches; large print diary; large print teledex.
- Large print items such as crossword books and playing cards can also help people to maintain leisure activities that they enjoy.

## **Making things Brighter!**

*Demonstration examples: types of desk lamps eg gooseneck style arm.*

- One of the best ways to make things brighter is to use more light.
- People with vision loss generally need double the amount of lighting, however the amount of light will depend on their eye condition and the arrangement or combination that best suits them.

There are two main ways to achieve adequate lighting:

➤ *General lighting:*

This is the general or overall level of light in an area; it is provided by light from windows, glass doors, skylight, and ceiling lights.

➤ *Task lighting:*

This is light that is directly focused on a concentrated area such as a desk or workbench; it is generally provided by lamps or by a torch.

## **Making things Bolder!**

*Demonstration examples: Black felt tipped pens in various thicknesses; bold lined writing paper.*

- Using contrast can be effective; many people with vision loss find that black on white provides a good contrast, eg plain dark tablecloth or mats and white crockery.
- Contrast can also help make areas safer, eg write strips or brightly coloured tape or paint on the edge of steps.
- Using a bold font style – for example for printed/reading material.

## **Being organised!**

*Brainstorm ways of being organised around the house and garden.*

Some practical ways include:

- Keeping things in the same place eg keys, money, medications.
- Decreasing the amount of clutter and getting rid of things that aren't used.
- Each person in the household, as well as visitors to the household, being aware of systems that are in place.



## Practise activity – Using the telephone

*Ask participant to form pairs and provide each pair with a telephone directory, telephones with large numerals and / or a tactile marking on the number 5, bold lined paper, felt tip pens and simulation goggles or blindfolds.*

*Ask participants to take turns wearing the goggles or blindfolds and look up a 'phone number, dial that 'phone number and speak with their partner.*

*Ask the pair to have a brief conversation and to make some notes.*

*Discuss as a group:*

How did you find this experience?

What was helpful? Did you have any difficulties? How could these be overcome?

## TEA BREAK



## Learning Session – Using other senses

*This section may be particularly relevant for caregivers whose partner/family member has very limited or no sight. You may wish to include a practical activity.*

*Discuss these questions, using the points below as additional information.*

What senses do we use in addition to sight to gather information about our environment? What are some examples?

How does your partner/family member use other senses to compensate for their vision loss?

### Hearing

- What is being heard and where the sound is coming from, eg listening for approaching traffic noise before crossing a street.

### Smell

- Sense of smell can provide a sense of pleasure, for example flowers in the garden, freshly brewed coffee.
- It can also provide protection, for example smelling leaking gas, burning toast.

### Taste

- Sense of taste is made up of four components – sweet, salty, bitter and sour.

### Touch

*Circulate examples of Braille and/or tactile markings on everyday objects.*

- Touch can be a very important sense for a person with vision loss;
- One of the best known uses of touch is reading Braille;
- Markings placed on objects that can be felt rather than seen are referred to as 'tactile marking'; for example to indicate on and off settings on stoves and washing machines.



## Discussion Activity – Managing daily living tasks

*For this activity, ask participants to break into smaller groups of three or four. Outline the discussion activity.*

1. Discuss within your group any challenges that you and your partner/family member may be having or may have experienced with daily activities – for example with mealtimes, making hot drinks, reading, writing, using the telephone, telling the time and date, handling money, shopping, gardening or leisure time.
2. Share ways of managing these difficulties, including strategies that you have found helpful. These could include using the four B's and other senses. One person may like to record these (*provide pen and paper*).

*Ask participants to come back into the larger group and share the difficulties and solutions they discussed. List these on the whiteboard.*

3. Share examples of difficulties / challenges and discuss strategies / solutions.

*The following information may help to support this discussion. Focus on the issues and strategies identified by participants.*



### Eating / mealtimes

#### Some difficulties

- Where things are located on the table.
- What food is on the plate and how it is arranged.
- Pushing food off the plate by accident.
- Knowing how much salt, pepper etc to put on.
- Holding conversations with others at the table.

#### Possible solutions

##### Brighter

- A lamp or additional stand light can provide task lighting if the table area is too dark.
- When eating out, if possible book or choose a table in good light.

### **Bolder**

- Having a contrast between floor covering and table and between table cloth/place mat and crockery is helpful.
- Light or white crockery ensures that most food will contrast with the background.
- Condiments should also contrast with the cloth or place mats.

### **Being organised**

- Having a set place at the table makes locating it easier; this may also help with conversations during mealtimes.
- Having a consistent location and position of cutlery, crockery and food items on the table.
- Use the clock technique to advise what is on the plate, eg meat at 6 o'clock, peas at 12 o'clock.

### **Touch**

- The tip of the fork can be used to determine differences in texture.
- Becoming aware of the weight of the food on the fork or spoon is helpful.
- Using a trailing technique to locate objects on the table reduces accidents.
- Salt and pepper can be sprinkled into the palm of the hand or over the back of the palm.



## **Making hot drinks**

### **Some difficulties**

- Missing the cup.
- Not knowing how much liquid is going in.
- Getting the right amount of milk.
- Risk of burning.

### **Possible solutions**

#### **Bigger**

- Large print labels can be placed on packets and/or canisters.

#### **Brighter**

- A lamp can provide task lighting if the area is too dark and glare from the window onto the draining board should be avoided.

#### **Bolder**

- A cup or mug with a white inside surface sitting on a dark surface increases accuracy for filling and decreases spills. Adding tea or coffee before milk ensures that the dark liquid contrasts with the white inside surface of the cup or mug.



## Hearing

- Liquid Level Indicators provide an audible buzz when the cup is filling or full. They are only suitable for people who have no difficulty getting the liquid into the cup.

## Other points

- Using a cordless kettle with elements hidden means there is no danger of the element overheating and no need to plug it in. Measuring the required cups of cold water into the kettle provides the correct amount of water and eliminates an unnecessarily heavy kettle;
- When pouring, the spout should rest against the cup to help guide the water flow;
- Using the microwave – pour cold water into a cup, heat for two minutes with a wooden pop-stick in the cup (to avoid surface tension problems).
- Milk – use a measure eg half a dark plastic egg cup or squeeze sauce Container.
- Sugar cubes provide an accurate measure.
- Thermal travel mugs with a cover or tray mobile can be used when moving a hot drink.



## Telling the time and date

### Some difficulties

- Not being able to see the hands of a clock.
- Not being able to see the date on calendars, diaries.

### Possible solutions

#### Bigger

- Large print clocks and watches.
- Large print calendars and diaries.

#### Hearing

- Talking clocks and watches.
- Talking calendars.

#### Touch

- Tactile clocks and watches (numbers marked by raised dots).



## Using the telephone

### Some difficulties

- Not being able to read the teledex or phone book
- Not being able to see the numerals on the keypad

### Possible solutions

#### Bigger

Large print stickers (numerals)

- These can be easily applied and trimmed to fit smaller keypads.
- Black on white background or white on black provides good contrast.

Large print telephone models

- These have high visibility numerals.
- They are available from most telephone retailers.

Large print teledex

- These are available from agencies for the vision impaired eg ABWA.

#### Touch

Tactile marking

- Most telephones already have a raised dot on the number 5; this can serve as a reference point to find the surrounding numbers.
- This can be made bigger using tactile marking.



## Reading

### Some difficulties with reading

- Reading correspondence including bills, books, newspapers and magazines.
- Reading labels on groceries and medication bottles or packets;
- Reading a computer screen.

### Possible solutions

#### Bigger

- Magnifier – at home and out shopping.
- Large print accounts can be requested from Telstra and Alinta Gas.
- Photocopy enlargement of text including crosswords and recipes.
- Large print labelling of household goods.
- Closed Circuit Television (CCTV) – reading equipment that consists of a stand-mounted or hand-held video camera which displays a magnified image on a video monitor, television screen or computer monitor.

#### Brighter

- Task lighting.

#### Hearing

- Talking books.
- Voice feedback software eg JAWS.
- Text readers – equipment that scans and then reads out the print.



## Writing

### Some difficulties with writing

- Not being able to see the lines or where to write.
- Keeping the writing straight.
- Not being able to read back what is being written.
- Signing in the correct spot.
- Filling in forms eg account ledgers, score cards, application forms, cheque books.
- Writing off the edge of the page.
- Writing over existing writing.

## Possible solutions

### Bigger

- Printing rather than cursive writing, using a broader wrist action generally creates bigger text.

### Bolder

- Using a bolder pen or felt pen (Artline 210) or broader nibbed felt pen as required.
- Writing on dark lined paper.
- Using a signature guide.

### Brighter

- Task lighting.

### Touch

- Braille users can apply Braille labels.
- Writing frames provide a tactile guide for hand writing.
- Touch typing allows a person with a vision impairment to access a computer. Talking Typer is a computer program which teaches the skill.

### Hearing

- Tapes can be used for correspondence, for recording 'phone numbers and even making shopping lists.

## Homework activity

During the week reflect upon the 'Bigger, Bolder, Brighter, Being Organised' strategies and the use of other senses, covered in today's session.

If and when it appears appropriate, discuss with your partner/family member any of the strategies you think may be most valuable. Discuss whether any of these could be useful in the home environment and if they are, how these could be introduced.

## Summary of session

*Discuss the main points covered in the session.*

- Strategies for maximising remaining vision - the four 'Bs' – 'Bigger, Bolder, Brighter' and 'Being organised';
- Using other senses – hearing, taste, smell and touch.
- How these strategies can be applied to a range of daily living tasks.

# **Session Three**

## **Stepping out – orientation and mobility**

### **Background information for group facilitators:**

#### **Stage of group development: Working / Production**

The group is moving into the more mature 'working' phase of the group. Group members are starting to feel a sense of belonging and the group is functioning as a cohesive unit. Members will be more open to sharing and learning from each other. Facilitators should capitalise on the 'work ethic' within the group.

### **Purpose of Session Three**

- 1. To identify aids and equipment to assist with orientation and mobility.**
- 2. To develop skills in the Sighted Guide Technique.**

## Preparation for group facilitators

An Orientation and Mobility instructor is required for this session.

### Resources required for Session Three

- ✓ Name tags
- ✓ Refreshments
- ✓ Video 'What do you do when you meet a person with vision impairment' (Guide Dogs NSW /ACT) if available.
- ✓ Television set and equipment to play video.
- ✓ Eye masks simulating eye conditions.
- ✓ Examples of identification cane, long cane and support cane.
- ✓ Monocular telescope and other low vision aids

### Outline of Session Three

<b>Introduction and welcome</b>	(5 minutes)
<b>Review of homework / information sharing</b> Reflections on the four B's and use of other senses.	(15 minutes)
<b>Warm up activity:</b> Guiding exercise	(20 minutes)
<b>Learning session:</b> Orientation & mobility aids and equipment	(45 minutes)
<b>Break</b>	(15 minutes)
<b>Learning session:</b> The Sighted Guide Technique	(20 minutes)
<b>Practise activity:</b> Sighted Guiding	(45 minutes)
<b>Homework activity:</b> Reflections on orientation and mobility, including the Sighted Guide Technique.	(5 minutes)
<b>Summary of session</b>	(10 minutes)

# Introduction and Warm Up

*Welcome participants and discuss any questions arising from the first session.*

## **Review of homework and information sharing**

*Review and discuss the homework activity - what worked well, were there any difficulties?*

Homework task from Session Two:

“During the week reflect upon the ‘Bigger, Bolder, Brighter, Being Organised’ strategies and the use of other senses, covered in today’s session.

If and when it appears appropriate, discuss with your partner/family member any of the strategies you think may be most valuable. Discuss whether any of these could be useful in the home environment and if they are, how these could be introduced.”

*Invite participants to share other information / resources that they have located.*

## **Warm up activity**

*Ask participants to form pairs and provide each pair with eye goggles.*

*Each person to take turns giving verbal instructions and assistance to the person wearing eye goggles to get out of their chair and to walk a short distance in the room.*

*Facilitators to closely supervise this activity.*

*Discuss:*

What was it like being the guide?

What was it like being the person who was guided?



## Learning Session – Mobility aids and equipment

### Introduction

*Introduce the Orientation & Mobility Instructor and explain their role, using the following information as required.*

- Orientation and Mobility Instructors train vision-impaired people to use their remaining eyesight and their other senses (sound, touch, smell and the sensation of body movement) to detect landmarks and reference points and work out where they are;
- They often provide instruction in the use of the long cane (which is discussed later in the session) and may also teach clients to use electronic travel devices together with the cane.

*Ask participants to form pairs and discuss the following;*

Does your partner's/family member's vision loss affect their mobility?

If it does, how? Is this more likely in some situations eg on uneven footpaths?

Do they use any mobility aids? Do you assist them with mobility?

### Mobility aids and equipment

*Explain that mobility aids and equipment can include:*

- Different types of canes – identification, long and support cane.
- Low vision aids, electronic devices, Guide dogs.
- The Sighted Guide Technique.

### Types of canes

*Demonstrate the following canes, encouraging input from participants whose partner / family member uses any of these canes.*

#### Identification Cane

- The identification cane (or ID) is primarily for identifying to others that the cane user is vision impaired;
- It is not an aid to mobility as such or a support cane, only an identification device.



### **Long Cane**

- The long cane is considered to be an extension of the index finger, and is said to 'probe the environment' in front, to be 'one step ahead' of its user;
- This helps the user to detect and avoid obstacles, hazards, ground level changes and stairs.

### **Support Cane**

- The support cane is used by people who are vision impaired but who also need some additional support for balance;
- It can provide stability when walking and checking the height of stairs.  
(Guide Dogs NSW/ACT, 2003)

### **Other mobility aids**

*Demonstrate these mobility aids, encouraging input from participants whose partner/family member uses any of these aids.*

#### **Low vision aids for distance**

- A monocular telescope (half a binocular), used with one eye, can help the user to read street signs and indicator boards in train and bus stations and at airports.
- It is small, portable and available in a range of magnification powers.

#### **Electronic aids**

- A number of electronic travel aids are available which provide audible and/or tactile feedback about the environment and are commonly used in conjunction with a long cane or a guide dog.
- One example is the 'Miniguide', a hand held sensor which helps someone to move around safely in a variety of environments.
- The user can scan both left and right when walking and it provide either vibration or an auditory beep when an object is detected.

(Guide Dogs NSW/ACT, 2003)

#### **Guide dogs**

- Guide Dogs are probably the most recognisable aid to mobility used by people with vision loss. Not every person with vision loss needs or is suitable for a Guide Dog.
- People who apply to have a dog are assessed for their suitability, ability to care for the dog, and ability to give the dog plenty of work and exercise.

# **TEA BREAK**



## Learning Session – The Sighted Guide Technique

*Ask if anyone is familiar with this technique and if so, draw on their experiences while introducing the following points.*

- The objective of guiding techniques is to enable a person who has low vision to move through an environment safely and efficiently with the assistance of a sighted person – the guide.
- Good verbal communication between the guide and the person being guided is an important starting point;
  - Always ask first if assistance is needed and what is needed;
  - Describe what you see around you – objects and where they are located; advise of any changes in layout of furniture etc.
  - Use precise, descriptive terms, for example, ‘The door is on your left’ rather than ‘The door is over there’;
  - Give accurate directions such as ‘to the right’ or ‘to the left’;
  - Look ahead and advise of upcoming obstacles – at the foot level, head height and to the side.

Some safety tips relating to orientation and mobility

- Keep doors closed or open against a wall; that is, not half open or half closed.
- Keep circulating areas clear of obstacles;
- Inform people with vision loss of any changes in layout eg furniture;
- If leaving someone alone, advise him/her you are leaving, and leave him/her in a comfortable place, perhaps in contact with a familiar object.

### Using the Sighted Guide Technique

- Walk at a comfortable pace; the person being guided is likely to indicate any discomfort by the way he / she grips the guide;
- The correct grip is important for comfort and safety;
- The correct stance is important for protection;

- Doorways – it is important to allow the person being guided to be in control of the door therefore they should be on the hinge side;
- Narrow spaces – advise the person that a narrow space is ahead and adjust the technique accordingly;
- Stairs – stop at the first step and tell the person you are guiding whether the steps go up or down. Stop when you reach the end of the stairs and tell the person you are at the top or bottom;
- Seating – place the person's hand on the back of the chair, tell him/her it's the back of the chair, and explain which way the chair is facing and where it is placed in relation to the rest of the room.



## Practise Activity – The Sighted Guide Technique

*Show video 'What do you do when you meet a person with vision impairment' (Guide Dogs NSW ACT) if available. Otherwise Orientation and Mobility Instructor to demonstrate.*

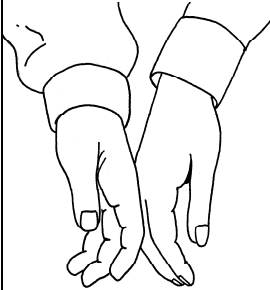
*Ask participants to form pairs and to practise the following techniques with each other as you describe and demonstrate each technique.*

- Making contact
- Grip
- Stance
- Opening doors
- Getting into a chair

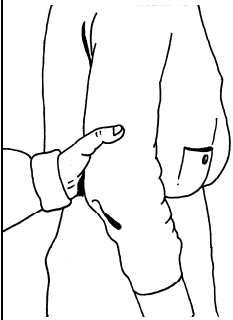
*Participants to practise the technique, taking turns to be the sighted guide and the person with a vision impairment (wearing the eye goggles or a blind fold).*

*It is recommended that the Sighted Guide Technique be first introduced in a controlled and familiar environment.*

The following information will help to support this activity.



**1. Making Contact** - Verbally communicate your intention to offer assistance. If the person is in a chair, allow him/her to get up unassisted. Touch the back of your hand against the back of his/her hand. This is the signal for the person to take your arm.



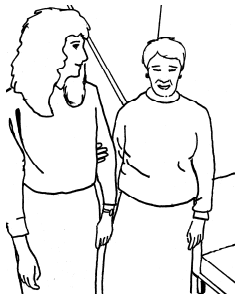
**2. Grip** - The person being guided takes hold of your arm just above your elbow - with his/her four fingers on the inside and the thumb on the outside of your arm. The grip should be firm but not tight enough to cause you discomfort.



**3. Stance** - Keep your arm relaxed. The arm of the person being guided is also relaxed, bent at about 90 degrees and held close to his/her side. The person being guided should stand beside you, about half a pace behind.



**4. Narrow Places** – For narrow aisles, doorways and other places where it is difficult to walk two abreast, make a definite move with your arm backwards and over to the centre of your back.



The person being guided responds by straightening out his/her arm and stepping directly behind you. Now you are in single file, one full pace apart. His/her arm must remain extended to prevent either of you from tripping over the other's feet. When you have passed through the narrow place, return your arm to its normal position (by your side). The person being guided responds by returning to the normal position.

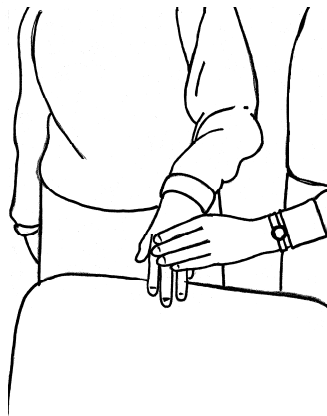
**5. Opening doors** – The person being guided must be on the hinge side of the door. As you are approaching the door, say to the person "We are coming to a door. It opens away from us and to the right."



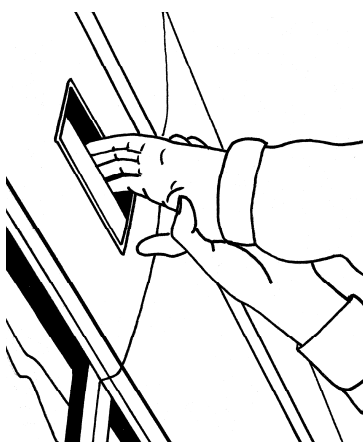
If the person is not on the hinge side, change sides. Take the doorknob in your left hand and open the door. Ask the person you are guiding to hold the door until you have both passed through then the person shuts the door. For doors opening towards you the procedure is the same. For doors opening to the left, the directions should be reversed.



**6. Stairs** – Tell the person you are guiding that you are approaching stairs and whether they are going up or down. Always approach stairs and curbs at right angles and stop as you reach them. If the person being guided is not on the handrail side, ask him/her to change sides if he/she wishes. As you step down remain one step ahead, and then proceed together in rhythm. Stop when you reach the end of the stairs. This indicates that you have reached the bottom (or top).



**7. Getting into a Chair** - Place the person's hand on the back or side of the chair. You may like to mention which way the chair is facing. From then on most people will manage by themselves.



**8. Getting into a car** - Place the person's hand on the door handle and indicate which way the car is facing.

When the door is opened, the free hand contacts the edge of the car roof and can then be brought down to contact the back of the car seat.

(Royal Guide Dogs for the Blind Associations of Australia, 1980).

## **Modifications to the grip**

- Frail elderly people or someone with balance problems may prefer to link arms with the guide;
- A child may be encouraged to grip the wrist of the guide;
- When there is substantial height difference the person experiencing vision loss may rest his/her hand on the guide's shoulder.

(Guide Dogs Victoria, 2005)

*Discuss, following the practise activity.*

1. How did this compare to the warm up activity?
2. Did anyone lose track of where they were?
3. Did it make it easier to know where you were if you were under blindfold on the way back? (The importance of knowing the area to help keep your orientation.)
4. How comfortable were you? (The importance of trust.)
5. How did you feel if the ground surfaces changed?
6. What did you notice the most? (Noises? Other senses?)
7. Do you think it will be useful for you and the person you care for?

## **Homework activity**

Reflect on orientation and mobility, including the Sighted Guide technique during the week. If it appears appropriate discuss this with the person you care for. Determine if he/she would like a referral to be made for an Orientation and Mobility Instructor to talk with him/her about the Sighted Guide Technique, with a view to providing training for you both.

## **Summary of session**

*Discuss the main points covered in the session.*

- Orientation and mobility aids and equipment;
- The Sighted Guide Technique.





# Session Four

## Taking Care of Ourselves

### **Background information for group facilitators:**

#### **Stage of group development: Working/Production**

The group is moving into the more mature 'working' phase of the group. Group members are starting to feel a sense of belonging and the group is functioning as a cohesive unit. Members will be more open to sharing and learning from each other. Facilitators should capitalise on the 'work ethic' within the group.

### **Purpose of Session Four**

This is the first of the second group of three sessions which focus on the health and wellbeing of the carer. This session aims:

**1. To identify strategies to enhance carers' self care, including stress management and relaxation techniques.**

This includes a discussion about how to look after physical health and well being and some strategies for doing this. Recognising signs of stress and strategies for managing stress, including relaxation techniques are also included.

**2. To identify support networks and community resources that may provide assistance to carers.**

**3. To develop and practise goal setting skills.**

This provides an opportunity for participants to identify any changes that they wish to make and to formulate a goal to achieve this.

## Preparation for facilitators

### Resources required for Session Four

- ✓ Name tags
- ✓ Refreshments
- ✓ Whiteboard and whiteboard pens
- ✓ Brochures – Commonwealth Carer Respite Centre, Commonwealth Carelink, Centrelink payments, local Carers' organisation; support groups for carers.
- ✓ Overhead projector

### Outline of Session Four

<b>Introduction and welcome</b>	(5 minutes)
<b>Review of homework and information sharing</b>	(15 minutes)
<b>Warm up activity:</b> Who is a 'carer'?	(10 minutes)
<b>Learning session:</b> Looking after our health and well being	(30 minutes)
<b>Practise activity:</b> Relaxation techniques	(20 minutes)
<b>Break</b>	(15 minutes)
<b>Learning session:</b> Getting the balance right	(30 minutes)
<b>Learning activity:</b> Setting personal goals	(20 minutes)
<b>Practise and homework activity:</b> Goal setting.	(25 minutes)
<b>Summary of session</b>	(10 minutes)

# Introduction and Warm Up

*Welcome participants and discuss any questions arising from the last session.*

## **Review of homework and information sharing**

*Review and discuss the homework activity - what worked well, were there any difficulties?*

Homework task from Session Three:

“Reflect on orientation and mobility, including the Sighted Guide Technique during the week.

If it appears appropriate discuss this with the person you care for. Determine if he/she would like a referral to be made for an Orientation and Mobility Instructor to talk with him/her about the Sighted Guide Technique, with a view to providing training for you both.”

*Invite participants to share other information / resources that they have located.*

## **Warm up activity**

*Ask participants to spend a few minutes reflecting on what the term ‘carer’ means to them, writing some points down in their manual. Explain that this will be revisited again in the last session.*

*Then discuss in pairs.*

Who is a ‘carer’? Do you see yourself as a carer?



## Learning Session – Looking after our health and wellbeing

### Introduction

*Discuss the first three questions as a group, encouraging participants to draw on their own experiences and current situation.*

*Divide the whiteboard into three columns and progressively list responses for questions 1 – 3.*

1. What helps keep us healthy? eg exercising, eating well.
2. What can get in the way of doing each of the things that keeps us healthy – as listed in Q1? eg Working long hours, care giving tasks, lack of motivation.
3. How can we overcome these obstacles – as identified in Q2? Think about what works for you. eg Joining a local walking group with a friend.

*Discuss in pairs:*

How well are you taking care of yourself at the moment?

On a scale of 1 – 10, where 1 is low and 10 is high, where would you rate yourself?

Are there any changes you would like to make, to take better care of yourself?

*The following information may assist this discussion:*

- A healthy balanced diet is vital to good long term health.
- Lack of nutrients can make us feel tired, run down and irritable.
- Try to eat plenty of fruit and vegies – the National ‘Go for 2 & 5’ campaign recommends two serves of fruit and five serves of vegetables every day. (Department of Health and Ageing, 2008).
- Lack of sleep can reduce our ability to do everyday tasks and to handle stress.
- If you’re having trouble sleeping, limit intake of caffeine (tea, coffee, chocolate) in the evening and try to do something relaxing before going to bed.
- Do physical activities that you enjoy, for example, gardening. Or walk with a friend or a neighbour if you find it a chore to walk on your own.

- If finding time for exercise is a problem, try to build it into your daily activity; for example do frequent short amounts of exercise instead of exercise that requires large blocks of time;
- Have a regular check up with your doctor.

## **Recognising stress**

*Discuss, using the following points as additional information.*

How do you know when you're under stress?

How does stress affect you?

- Stress is an everyday occurrence and we all experience varying amounts of stress in our day to day lives.
- Stress is our body's reaction to a threat or to danger – a stress response causes physical changes, for example in heart rate, blood pressure, breathing rate. Stress chemicals are released into our body. (McGeown, 2002).
- Stress can give us the drive to achieve – if a person lacks stress they can be under-stimulated and under-motivated – so a certain amount of stress can be beneficial.
- If a person experiences too much stress and over a long period of time they can experience chronic or excessive stress.
- Symptoms of excessive stress can include anxiety, tension, headaches.

Show chart on overhead projector and refer participants to their manuals.

## Some responses to excessive stress

Feelings	Thoughts	Behaviour
Anxious. Aggressive. Apathetic. Tired. Depressed. Frustrated. Irritable. Tense.	Difficulty in making decisions. Less able to solve problems. Forgetful. Poor concentration.	More accident prone. Over or under eating. Excessive smoking or use of alcohol. Restlessness.
Physical effects	Health effects	Work effects
Increases in heart rate and blood pressure. Dryness of mouth. Sweating. Dilation of pupils. Numbness. Butterflies in the stomach.	Chest and back pains. Dizziness. Diarrhoea. Frequent urination. Headaches / migraines. Nightmares. Insomnia. Skin complaints Ulcers.	Increased absenteeism. Higher accident rate. Poor communication. Less job satisfaction. Reduced productivity.

## Managing stress

*Discuss in pairs and then as a larger group, using the following points as additional information.*

Try to recall a recent situation that made you feel stressed or anxious. eg having medical tests; partner or family member being unwell.

How did you deal with the situation? What helped? What didn't?

What helps you relax on a day to day basis? eg gardening, doing crosswords.

- Stress management involves two key stages:
  - Awareness – identifying what is causing the stress and your own stress reaction;
  - Control – working towards managing your stress reaction.

(David et al, 1998).
- When we know that we're stressed, it is important that we make time to invoke a relaxation response.
- The circumstances causing the stress may not necessarily change, but a relaxation response gives the body a chance for the stress chemicals to dissipate and for the body to rebalance; eg heart rate, blood pressure, breathing rate goes down.
- There are many strategies that people use to manage stress eg exercise; listening to music; spending time with family and friends; sharing feelings with a trusted person; hobbies; yoga, meditation, relaxation exercises.

## Relaxation Exercises

*Introduce relaxation techniques using the following information. Encourage participants who are familiar with these techniques to share their experiences.*

- Relaxation exercises aim to reduce symptoms of stress. When a person relaxes physically, the impulses arising in the various nerves in the muscles change the signals that are sent to the brain. This change brings about a general feeling of calm and well being, both physically and mentally (Payne 2004).
- Regular use of relaxation exercises (for example by using a relaxation tape or CD) can help by substituting relaxation as a habitual response rather than tension or anxiety.
- The main types of relaxation techniques include: focused breathing, progressive muscle relaxation, tension breaking techniques and guided imagery.
- As with any new skill, regular practise of relaxation exercises is vital. The degree of success (relaxation) you attain will depend largely on the amount of effort you put into it.



## Practise Activity – Relaxation Exercises

*Choose the most appropriate exercises to practise (you may wish to use a relaxation CD).*

*Discuss which techniques participants prefer.*

### **1. Focused breathing** *Repeat this cycle 5 – 6 times.*

Settle comfortably in your chair and breathe normally for a few seconds.

You may wish to close your eyes.

Focus on your breathing.

Now breathe in through your nose for 2 – 3 seconds and hold for a few seconds.

Breathe out slowly over 5 seconds, and feel yourself relaxing as you do.

### **2. Tension breaking exercise**

Sit comfortably with your eyes closed.

Say these words in your own mind, directing each part of your body.

‘I now choose to relax completely’

‘My left arm is heavy and warm’

‘My right arm is heavy and warm’

Let the numbers 1 – 6 float in your mind:

1...2...3...4...5...6

Count to 6 as you breathe in and as you breathe out.

As you breathe in say ‘re...’ and as you breathe out say ‘..lax..’



### **3. Progressive muscle relaxation (PMR)**

The objective of PMR is to tense up a group of muscles so that they are as tightly contracted as possible and then hold them in a state of tension for a few seconds. You then relax the muscles to their previous state and consciously relax them again as much as you can. (Payne, 2004)

*Read the following or choose your own exercise.*

Sit comfortably with your eyes closed.

Raise your eyebrows as high as possible, feeling the tension build.

Hold that tension for a moment. Now relax your eyebrows, and feel the tension flow out.

Squeeze your eyes shut as tight as you can. Hold that tension.

Now relax your eyes. Feel the relief from the tension.

Clench your teeth together tightly. Let the tension build. Hold it.

Now release your jaw, letting it go loose.

Squeeze your whole face up into a knot and hold it there. Hold it. Let the tension build as you squeeze your eyes, mouth and nose together hard. And now relax.

Feel how relaxed your face feels.

### **4. Guided imagery relaxation**

*Introduce and explain guided imagery relaxation*

Settle comfortably in your chair. Close your eyes and focus on your breathing

Imagine yourself leaving the area where you live ... Leaving the daily hassles

Imagine yourself going across a valley and moving closer to a mountain range ...

You are going up a winding road ... Find a place to stop ... You find a path to walk up ... Start walking up the path...

Find a comfortable place to stop on the path ... At this place take some time to examine all the tension and stress in your life ... Look at them very carefully and after you have done this, put them down on the side of the path ...

Continue walking up the path until you come to the top of a hill... Look out over the hill ... What do you see? Find an inviting comfortable place and go there .... What is your special place like? Be aware of the sights, smells and sounds ...

Be aware of how you are feeling ... Get settled and gradually start to relax ... Experience feeling relaxed ... Pause for three to five minutes ... Look around at your special place once more ...

Remember this is your special place to relax, and you can come here anytime you want to ... Come back to the room and tell yourself that this imagery is something you have created, and you can use it whenever you want to feel released. When you are ready slowly open your eyes and return to the group (adapted from Davis et al, 1980).

## **TEA BREAK**



## Learning Session – Getting the balance right

### Managing roles

*Discuss in pairs, then as a larger group, using the information below to support this discussion.*

What are the main ways in which you assist or support your partner/family member?

Has the type of assistance or the amount of assistance that you provide changed over time or remained much the same?

How do you see the balance between your care giving role and other parts of your life?

Has this changed over time?

- For some people, becoming a care giver may happen gradually and over a long period of time, while for others it may happen suddenly and with little choice;
- This and other factors can influence how care givers adjust to their new role as well as to any changes in their relationship with the person they provide care for;
- Other roles and relationships can also change as a consequence of being a care giver eg as a grandmother or being a volunteer.
- To help sustain the care giving role, it is beneficial to maintain the other roles you have in your life eg as a volunteer or being a grandmother;
- It's also beneficial to maintain other activities and relationships that you enjoy – in other words, to maintain a sense of yourself and of balance in your life. (Commonwealth Carer Resource Centre, 2009)

### Getting support from others

*Ask participants to reflect on the questions in their manuals (Session Four) and write some brief notes.*

*Then discuss the following questions, using the information below to support this discussion.*

What did you learn about your supports?

When would you turn to someone you don't know; someone who isn't a family member or friend?

- Sources of support can include family members, friends, neighbours, community services, health professionals and others in a similar situation (peer support);
- Different people provide different kinds of support; for example we may prefer to go to some people for emotional support, while other people are very helpful with practical matters;
- It's vital to know our own limits and to recognise when we need some help.
- Carers may sometimes feel that they would like more support from family or friends but can feel reluctant or guilty to ask them; or they may feel that they should be able to 'cope'.
- It can be helpful to seek support from others who are in the same situation – from someone who understands how you feel or who has had similar experiences; this may be through informal contact with other carers or in a more formal group situation eg carer support group.

(Commonwealth Carer Resource Centre, 2009).

## **Community supports for carers**

*Discuss which community services participants use or are aware of.*

*Briefly review the following services as applicable, providing brochures for each.*

### **Respite services**

*Circulate brochures for Commonwealth Carer Respite and Commonwealth Carelink Centres.*

- Respite basically means taking a break from looking after someone;
- Respite services can be provided in a person's home or in a variety of settings outside of the home; eg with a support worker or through day centre programs;
- It might be for a few hours, a day or longer; it can also be arranged as a regular break eg weekly, fortnightly or as needed;
- There are eligibility criteria and individual assessments for respite services and also some costs/fees associated with different types of respite.

(Independent Living Centre, 2009).

## **Support Groups**

*Circulate information / brochures for local support groups for carers.*

- Support groups are an opportunity to meet with other carers who are in similar circumstances and to share common experiences;
- Many support groups welcome all carers while others focus on a specific condition or disability.

## **Financial support for carers**

### **Carer Payment**

- Carer Payments are provided by Centrelink to people who don't receive any other payment (pension);
- Although the person is not required to live with the person being cared for, they must provide constant care to a person in their own home.

### **Carer Allowance**

- The Carer Allowance is a supplementary payment available to parents or carers who provide daily care and attention for adults or children with a severe disability or medical condition;
- It is paid in addition to the Carer Payment or other income support payments such as the age pension.

(Centrelink, 2007)



## Learning Activity – Setting personal goals

### Introduction

*Introduce goal setting using these points.*

- Today's session has been focused on ways of looking after yourselves as caregivers.
- During the session you may have thought about some changes you would like to make to better look after yourself or to have a bit more time for you;
- Setting goals is one way of doing this – they can help us to make changes in our lives.

*Discuss, using the following points as additional information.*

Have you set goals in the past eg New Year's resolution?

Did you achieve them? What happened?

- Having a goal gives us something specific to work towards in a particular period of time.
- Goals should be focused on action and what needs to be done.
- Goals can be either short or long term; short term goals are changes that can happen within the next month; long term are changes that can happen within the next year (Packer et al 1995).
- When setting a goal it's important that the time frame for achieving it is realistic.
- Goals shouldn't rely on other people eg partner or family member changing their behaviour.
- Goals need to have a plan regarding what needs to be done to achieve them. For example,
  - What do I want to achieve?
  - How will I achieve it?
  - When will I achieve it?
  - What do I need to achieve it?
  - How will I know I have achieved it?
  - What could block my progress? How will I overcome this?

Ask participants to brainstorm as a group some examples of changes they would like to make. Write these on the whiteboard.

Select one and work through the following exercise as a group:

1. The change I want to make is:
2. My goal for the next two weeks is:
3. The steps I will take to achieve my goal are (what, when, where, how much, how often).
4. The things that could make it difficult to achieve my goal include:
5. My plan for overcoming these difficulties includes:
6. My confidence level for achieving the goal is (using the 'getting to 7' scale\*)
7. Review date

### **'Getting to 7'**

Use the scale below to estimate how likely it is that you will be able to accomplish the goal you have set and within the next two weeks.

My goal is:

1 2 3 4 5 6 7 8 9 10  
Not likely Very likely

If you selected a number below 7, try to revise your goal to make it more realistically fit what you think you can actually accomplish.

My revised goal is:

1 2 3 4 5 6 7 8 9 10  
Not likely Very likely

### **Selecting your own goal**

*Explain and discuss*

Spend a few minutes reflecting on any changes that you would like to make. This may be one of the changes you identified earlier in the session.

Select a goal that you could work on during the next two weeks eg to walk for exercise, or to practise some relaxation techniques.

Work through each of the steps above, including the 'getting to 7 scale'

## **Homework activity**

Put your plan into action during this week.

Write down what works well and what doesn't. Bring this along to discuss next week.

## **Summary of session**

*Discuss the main points covered in this session.*

- Some strategies for enhancing carers' health and well being.
- Recognising stress and developing stress management techniques, including relaxation exercises.
- Recognising changes in roles and the importance of support networks to provide support.
- Setting goals as a strategy for making changes in our lives.





# **Session Five**

## **Exploring Emotional Issues**

### **Background information for group facilitators:**

#### **Stage of group development: Working/Production**

The group is moving into the more mature 'working' phase of the group. Group members are starting to feel a sense of belonging and the group is functioning as a cohesive unit. Members will be more open to sharing and learning from each other. Facilitators should capitalise on the 'work ethic' within the group.

#### **Purpose of Session Five**

This session builds upon the issues covered in session four, including ways of managing stress and using support networks.

The session aims to:

- 1. Identify the importance of recognising and learning from our feelings.**
- 2. Provide participants with some strategies for dealing with negative feelings.**
- 3. Identify the ways that feelings can be conveyed through communication, including through non verbal communication, and;**
- 4. Provide participants with some strategies for communicating effectively.**

## Preparation for facilitators

Facilitators need to be aware of the variability amongst participants in relation to their awareness of emotional issues and their level of comfort in contributing to discussions. Some participants may feel more at ease if they can externalise issues ('..people might..') while others may feel comfortable referring to their own situation. (Finlayson, 2006)

Facilitators also need to be aware of and respond to any discomfort that people may experience. It would also be beneficial to remind participants of the importance of confidentiality within the group.

### Resources required for Session Five

- ✓ Name tags
- ✓ Refreshments
- ✓ Whiteboard, white board pens / white board eraser
- ✓ Overhead projector
- ✓ Copy of chart - 'What makes an impression.'
- ✓ Brochure on local counselling services for carers

### Outline of Session Five

<b>Introduction and welcome back</b>	(5 minutes)
<b>Review of home work and information sharing</b>	(15 minutes)
<b>Warm up activity:</b> Body language	(15 minutes)
<b>Learning session:</b> Taking care of emotional well being	(45 minutes)
<b>Break</b>	(20 minutes)
<b>Learning session:</b> Communicating effectively	(45 minutes)
<b>Practise activity:</b> Making a communication plan	(15 minutes)
<b>Homework activity:</b> Goal setting / communication	(10 minutes)
<b>Summary of session</b>	(10 minutes)

# Introduction and Warm up

*Welcome participants and discuss any questions arising from the last session.*

## **Review of homework and information sharing**

*Review and discuss the homework activity.*

How did you go? What worked well? Did you have any difficulties?

Homework task from Session Four:

“Select a goal that you could work on during the next two weeks eg to walk for exercise, or to practice some relaxation techniques.

Put your plan into action during this week.

Write down what works well and what doesn't. Bring this along to discuss next week.”

*Invite participants to share other information / resources that they have located.*

## **Warm up activity**

*Explain that non verbal communication will be covered in the second half of the session. Ask participants, sitting in their chairs, to 'say' with their feet and legs*

'I am nervous'

'My shoes are too tight'

'I'm treading in mud'

*Then ask participants to say with their shoulders or hands or head (without speaking)*

'I'm worried'

'I'm tired'

'I'm surprised'

'I'm bored'

*Discuss as a group*

How much or how little was communicated?

How easy or how difficult was it not to speak?



# Learning Session - Taking care of emotional well being

## Introduction

*Review key points from previous session*

- During last week's session we looked at some ways of taking care of ourselves – keeping ourselves healthy and managing our stress levels;
- We looked at goal setting and practised this during the week.
- We also looked at some of the ways that you assist and support your partner or family member.

*Ask participants to spend a few minutes reflecting on the following questions, making some notes in their manuals.*

Thinking back over the past week, what was something that you really enjoyed or found rewarding?

Did anything get you 'worked up' – a situation that you found difficult or stressful?

*Discuss in pairs*

What were some of the feelings you experienced, in both the positive situation and the more difficult situation?

How did you deal with the situation that got you 'worked up'? Did it help?

## Recognising feelings

*Introductory points*

- Our feelings are like signposts; they tell us when things are going well or not going so well; they provide important messages to listen to and to learn from.
- There are no 'right' or 'wrong' feelings in any situation; each of us reacts or responds in our own way.

(Commonwealth Carer Resource Centre, 2009).

*Ask participants to share examples of both positive and negative feelings that they experienced (without describing details of the situation.) Draw out similarities and differences, using the following points as appropriate.*

- Most of us experience a range of emotions every day, generated by different situations and events.
- The positive feelings we experience are important for maintaining our emotional well being; some situations or events can invoke negative feelings, which can persist and undermine our sense of emotional well being.
- We can feel frustrated if what we want to do or achieve is somehow being blocked or if we're trying to change a situation that may be out of our control to change.
- People in a care giving role can feel driven to take on more and more responsibilities and to feel that they shouldn't ask for help; this may cause them to feel overwhelmed and prevent them from making time for themselves or pursuing their own interests and hobbies.
- Feelings of grief and loss are a natural reaction to major changes and to painful losses in our lives. Some losses are less obvious to others and are not always acknowledged by others, but are very painful.

(Commonwealth Carer Resource Centre, 2009)

## **Dealing with difficult feelings**

### *Introductory points*

- Negative feelings can build up over time, particularly if we don't have healthy outlets for them.
- It's important to be able to recognise when negative feelings are building up and to develop strategies for dealing with these feelings.

(Finlayson, 2006).

*Discuss in small groups, then ask participants to share some examples. Write responses on the whiteboard.*

What might be some 'warning signs' that negative feelings are building up? What are your warning signs?

What are some healthy outlets when negative feelings start to build up? What is a good 'safety valve' for you?

*Refer to the list generated by participants, using the following points as additional information. Emphasise the importance of each person selecting the strategies that suit them.*

Recapping on some points from last week's session ~

- ✓ **Taking care of your physical health** - regular exercise can be a great safety valve for reducing tension and stress;
- ✓ **Knowing what helps you to relax** - and making some time for this; using relaxation techniques; deep breathing exercises.
- ✓ **Knowing who you can turn to** - for practical help or for emotional support.

Some other strategies to consider;

- ✓ **Know your limits and know how to say 'no'** – taking on too many responsibilities can result in a person feeling overwhelmed and experiencing 'burnout'.
- ✓ **Decide on the things that have to be done** - 'the essentials' – and look at whether there are other things that you could leave or ask someone else to help with;

Some questions to ask yourself;

What needs to be done (what is necessary to my lifestyle)?

What do I like to do? Which activities do I enjoy?

What do others expect me to do? What do I expect of myself?

What can I eliminate? What can I delegate? (Packer et al 1995).

- ✓ **Try to schedule some time for yourself every day** – some space in the day when you focus on yourself and something that you enjoy.
- ✓ **Journaling** – keep a daily journal or list of things you appreciate, and refer back to it (Finlayson, 2006). Some people also find it helpful to write down their thoughts and feelings in a free flowing spontaneous way.
- ✓ **Positive self talk/affirmations** – focus on the positive aspects of your situation and give yourself praise along the way (Finlayson, 2006).
- ✓ **'Circuit breakers'** – it can really help to give yourself some 'time out' to look at a situation more objectively and to choose how to respond in a more controlled way. For example removing yourself from the situation by going for a short walk and collecting your thoughts.
- ✓ **Ask for some help when you need it** – from family, friends, health professions and community services.
- ✓ **Talking to a trained counsellor** – there are specific counselling services for carers – telephone and face to face, as well as general counselling services. *Circulate relevant brochures relating to counselling services for carers.*

## TEA BREAK



## Learning Session – Communicating effectively

*Explain that this part of the session focuses on communication and the ways in which feelings can be conveyed through communication. It includes the role of non verbal communication and the implications this may have for someone who has a vision impairment.*

*Introduce and discuss these points*

- Communication plays a very important part in our lives and the ways in which we communicate (our communication style) can vary greatly from those of other people, including people we are close to.
- What we communicate and how we communicate affects the quality of our relationships – with family, friends, work colleagues, neighbours etc.
- Some aspects of communication are conscious and intended eg the words we use.
- We may not always be aware of other things we are communicating eg our feelings or mood.

### **What's involved in communication?**

*Discuss these questions*

How do we communicate?

What do we use when we communicate?

*Photocopy and show the following chart on an overhead projector (you may need to enlarge it).*



(Dragonbridge, 2005)

Discuss these questions, using the following points as additional information.

Does this surprise you? Do you agree with it?

- Non verbal communication can be as important as the words we use; non verbal messages can account for more than half of what is perceived and understood by others.
- This is an important consideration when communicating with someone who is vision impaired and who may miss some of these non verbal cues.
- Non verbal communication can also differ between cultures and can result in *miscommunication* and *misunderstanding* between people from different cultural backgrounds.

Non verbal communication is made via:

- Facial expressions – for example, smile, frown, raised eyebrows, yawn.
- Eye contact – for example making eye contact when speaking to someone.
- Voice tone and volume – for example shouting or speaking quietly and slowly.
- Posture – for example leaning forwards while speaking or sitting with arms and legs crossed.
- Gestures – for example, fidgeting with objects.
- Touch – for example touching someone lightly on the arm or slapping them on the back when speaking to them;
- Personal space – standing very close or at a distance while speaking with someone.



*Discuss in small groups and then share examples in the larger group.*

What could be some of the implications for someone who has limited or no sight?

What might be some of the implications for people they are close to, for example, family members and friends?

Can you think of any examples from your own situation? For example your partner or family member having difficulties picking up on non verbal cues in social situations?

How does your partner / family member, or both of you, work around these difficulties?

### **Some barriers to communicating effectively**

*Briefly review and discuss the following points.*

- Our ability to communicate can also vary according to time and circumstance: for example, in difficult times of loss, pain, stress and confusion we may not be able to communicate clearly what we need; we may be in emotional pain and/or lack confidence.
- In times of conflict our emotions can run high; it can be difficult to keep focused or to listen carefully. Communication breakdown can occur and finding a useful resolution becomes difficult.
- Sometimes we mask our true feelings – for example, do you ever hear yourself ‘I’m OK’ or ‘I’m fine’ when you’re feeling terrible, or you say ‘yes I’d be happy to do that’ when you really want to say ‘no’?
- Giving or receiving mixed messages can also inhibit effective communication – for example, when asked to help a person says ‘Sure, that’s fine’, stamps her feet as she walks off and slams the door.

### **Some tips for communicating effectively**

*Discuss, using the following points as additional information.*

What helps us to communicate effectively?      What helps you?

- Think about *what* you want to say – try to be clear and specific – don’t hope that the person will guess what you are trying to say or what you need.
- Think about *how* you want to say it – including being aware of non verbal communication and what *this* is saying.
- Use ‘I’ messages when expressing your feelings or point of view; for example ‘I feel upset about’ or ‘I see it differently’ rather than ‘You are being unfair’ or ‘You are wrong’; this enables you to express your feelings without making the other person defensive or blaming them;
- Take time to listen carefully – people often think they’re listening but are really thinking about what they’re going to say next when the other person stops talking.

## Making a communication plan

- We have probably all had situations where we've found it difficult to ask for something we need, for example for the neighbours to turn down their loud music or for a family member to help us with something.
- It can help to make a communication plan – think about the 'why, when, where and how' of what we want to communicate. This can help to make us feel prepared and to give us confidence to say what we want to say. It can also help to take the 'emotional heat' out of a situation.

Why do you want to communicate?

- For example to allow family, friends and others to understand your situation; or
- To increase your support - let others know how they can assist you.

When do you want to communicate?

- When you feel others will be receptive.
- When they have time.
- When you need it most.
- Not in response to an event (wait until you are calm).

Where do you want to communicate?

- Somewhere quiet.
- A place that is comfortable for all concerned.

How and what do you want to communicate?

- Explain how the current situation may be affecting you.
- Explain what you need to support you or to change the situation.  
(adapted from Packer et al 1995).



## Practise Activity – Making a communication plan

*Brainstorm examples of situations or events where communication difficulties may arise. Select one example and work through the following steps as a group.*

Why do you want to communicate?

When do you want to communicate?

Where do you want to communicate?

How and what do you want to communicate?

*Ask participants to choose a situation where they would like to improve communication and, before working through the steps (in their manuals), identify who was involved, what made the communication difficult and how they might handle it differently if this situation arises again.*

*Participants may prefer to work on this in pairs. Spend time with each participant and /or pair, making suggestions as required.*

### Homework activity

Continue working on last week's goal.

OR (if you have achieved your goal)

Try to be more aware of your feelings and the why, when, where and how you communicate in the coming week.

You might choose to use a journal to record and reflect on this.

### Summary of session

*Discuss the main points covered in the session.*

- The importance of recognising feelings and taking care of emotional wellbeing.
- Strategies for dealing with a build up of negative feelings.
- The link between our feelings and how we communicate – including non verbal communication.
- Some strategies for communicating effectively.



# **Session Six**

## **Resources for Caring – now and in the future**

### **Background information for group facilitators:**

#### **Stage of Group Development: Termination / Graduation.**

This is the final session of the course and participants may be feeling sad about this. It is important for the facilitators to focus on achievements during the course and how participants can continue to use the information in their everyday lives. Facilitators also need to channel the energy of the group towards future plans and transfer of learning.

#### **Purpose of Session Six**

- 1. To review services and resources that may assist with care giving.**
- 2. To develop some advocacy skills.**
- 3. To identify some long term goals.**
- 4. To review the course and how this may assist with future care giving; and**
- 5. To enable participants to participate in a ritual for closing the group.**

## Preparation for group facilitators

### Resources required for Session Six

- ✓ Name tags
- ✓ Refreshments for graduation celebration
- ✓ Certificates of completion
- ✓ White board and white board pens
- ✓ Overhead projector

### Outline of Session Six

<b>Welcome and introduction</b>	(5 minutes)
<b>Review of homework and information sharing</b>	(15 minutes)
<b>Warm up activity:</b> Review of terms 'blind' and 'carer'	(15 minutes)
<b>Learning session:</b> Community resources for current and future needs	(45 minutes)
<b>Break</b>	(15 minutes)
<b>Practise activity:</b> Setting long term goals	(20 minutes)
<b>Discussion activity:</b> Reviewing the course	(30 minutes)
<b>Graduation ceremony and celebration</b>	(30 minutes)

# Introduction and Warm up

*Welcome participants to this final session and discuss any questions arising from the previous session. Explain that this final session includes a review of the course.*

## **Review of homework and information sharing**

*Review and discuss the homework activity. What worked well? Were there any difficulties?*

Homework task from Session Five:

“Continue working on last week’s goal.

OR

Try to be more aware of your feelings and the why, when, where and how you communicate in the coming week. You might choose to use a journal to record and reflect on this.”

*Invite participants to share other information / resources that they have located.*

## **Warm up activity**

*Refer participants to their notes about the terms ‘blind’ and ‘carer’ in their manuals (in sessions one and four) and discuss the following questions. You may wish to have some definitions of these terms available.*

In the first week of the course you wrote down some points about what the word ‘blind’ means to you. Reflecting on what you wrote, would you change anything?

A couple of weeks ago (Session Four) you also reflected on the term ‘carer’ and whether you see yourself as a carer. Again reflecting on what you wrote, would you change anything?



## Learning Session – Community resources – now and in the future

### Introductory points

- There are a range of community based services that may be of assistance to you and your partner/family member, either now or at some time in the future.
- It's helpful to know what types of services are available and where to locate them, should you need to.
- Many community based services are provided by 'not for profit' organisations which receive government funding or subsidy; they usually charge a small fee for the service.
- Most community services have eligibility criteria and will assess each person's needs on an individual basis.

*Brainstorm the following, making a list on the whiteboard. Refer to any types of services not identified which may be relevant.*

What types of community services have you and your partner/family member used (or services that you are aware of)? What assistance do they provide?

- ❖ Transport services eg volunteer drivers, shopping buses.
- ❖ Home help services eg heavier tasks such as vacuuming, mopping floors.
- ❖ Home and garden maintenance eg pruning overgrown bushes.
- ❖ Respite services eg in home respite or day centre.
- ❖ Mobile meal services – subsidised and private services.
- ❖ Services, resources and support groups for carers.



## **Finding information on community services**

*Brainstorm the following, making a list on the whiteboard. Refer to any sources not identified which may be relevant.*

Where do you find information on services or where would you look if you needed to?

- ✓ Local council / local library;
- ✓ Commonwealth Carelink Centre;
- ✓ Commonwealth Carer Respite Centre;
- ✓ Local newspapers;
- ✓ Local organisations for carers

## **Some questions when contacting a service for the first time**

*Brainstorm the following*

When contacting a service for the first time, what do you want to find out? What questions do you usually ask?

Some questions to consider asking;

1. What services do you provide?
2. Do you have any brochures or written information that I/we could look at?
3. Who is eligible to receive the service? How do I know if I/we are eligible?
4. What days and hours are these services available?
5. Are there any costs to receive the service?
6. What do I/we need to do to start receiving the service? What happens next?
7. How long will it take for the service to actually start? Is there a waiting list?
8. Will the service be provided by the same person each time (if applicable)?
9. Will the person providing the service have experience in working with someone who is vision impaired?

(adapted from Finlayson 2006)

## Resolving problems with services

- Situations can arise where you experience a problem with a service you're receiving, for example the care worker often arrives very late or there is a frequent change of care worker.
- During this part of today's session we will look at how you can work to resolve problems should the need arise. Many of you will probably have experience of doing this, perhaps in other contexts.
- The agency itself may also have a complaints procedure for clients.

*Discuss (ask participants not to name the agency or any staff members involved)*

Has anyone had a situation where they've needed to contact a service because there were 'issues'?

How did you go about it? Were you happy with the outcome?

## Some steps for resolving problems

*Discuss the following steps, encouraging participants to share examples from their own experiences.*

### 1. Identifying initial obstacles

There can be obstacles that prevent us from taking action and advocating for ourselves. Some of these obstacles could include:

- A lack of information / knowledge.
- A lack of confidence.
- Concerns about being misunderstood.
- Reluctance to question service providers / health professionals.
- Concern about losing their support or even their service.

### 2. Some ways to overcome these obstacles

- ✓ Know as many facts as possible;
- ✓ Ask for clarification or for more information if you need it;
- ✓ Write down the results you want before starting;
- ✓ Don't get side tracked.

### **3. Make your own action plan**

*Write the following steps on the whiteboard and review as a group.*

*Brainstorm possible problems, select one for the following exercise and work through as a group.*

Some things to include:

1. What is the issue/problem?
2. What solution do I want?
3. Who can I get to support me? eg daughter.
4. Who am I going to contact in the agency?
5. How am I going to contact them?
6. What do I have in my favour? eg I have always got on well with the staff.
7. What do I have going against me? eg I don't want to put the staff off side.
8. What other information would be useful?

(adapted from CarersWA 2007)

## **TEA BREAK**



## Practise Activity – Setting longer term goals

### Introductory points

- A couple of weeks ago (in session four) we looked at goal setting, as a strategy for making changes in our lives;
- And over the past two weeks you've been working on a goal that you set for yourself;
- You may have also thought about other goals that you'd like to achieve, in the near future, longer term or both.

*Review steps used in Session Four.*

*Encourage participants to identify one goal that they would like to achieve either in the near future or in the longer term.*

*Circulate and assist participants as required.*

1. The change I want to make is:
2. My goal for the next [ insert time period ] is:
3. The steps I will take to achieve my goal are (what, when, where, how much, how often).
4. The things that could make it difficult to achieve my goal include:
5. My plan for overcoming these difficulties includes:
6. My confidence level for achieving the goal is (using the 'getting to 7' scale)
7. Review date

## 'Getting to 7'

Use the scale below to estimate how likely it is that you will be able to accomplish the goal you have set.

My goal is:

1 2 3 4 5 6 7 8 9 10  
Not likely Very likely

If you selected a number below 7, try to revise your goal to make it more realistically fit what you think you can actually accomplish.

My revised goal is:

1 2 3 4 5 6 7 8 9 10  
Not likely Very likely



## Discussion Activity – Course review

*Introduce the course review activity.*

Thank you very much for your participation during the course – your contributions have been very valuable and we hope that you have also gained from contributions made by other group members.

*Refer participants to their workbooks, ask them to spend a few minutes responding to these questions, then discuss as a group*

1. What are the most important things you have learned through the course?
2. Which sessions or topics did you find the most valuable?
3. Have you found the contributions/sharing of other people in the group helpful?
4. In what ways have you started to use the information included in the course?
5. Are you planning to use any of the information in the near future, and if so, how?
6. Were there topics that you felt were not relevant to your situation?
7. What would you change about the course?

(adapted from Finlayson 2006)

## Graduation Ceremony

*The last half hour is devoted to the graduation ceremony and celebration to mark the end of the course.*

*You may wish to provide participants with certificates.*

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