Caring for carers

Evaluation of a support program for carers of people with dementia

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Foreword

Informal carers, usually family members and friends, are vital in the provision of community dementia care. Their activities contribute significantly to national wellbeing, not simply through the expenditure saved by governments but also by the quality of the caring that they give. As dementia rates rise and as community care continues to be prioritised, reliance on informal carers is expected to increase, with the Productivity Commission's 2011 report, *Caring for older Australians*, indicating that they are the major source of direct care for older adults and play an important role in coordinating formal care services. To say that informal caring is an emotionally complex and often stressful task is becoming a truism, and it is perhaps surprising that the support offered to spouses, children and friends is underdeveloped.

The Brotherhood of St Laurence has pioneered the use of a particular form of support, which was originally based on a behavioural therapy intervention, but developed through practice into a system of emotional and practical engagement. Changes were guided by the issues that carers and professional helpers identified. While the numbers in this initial evaluation are small, and one-to-one support was found to be one of the most beneficial aspects of the program, our findings suggest extension of the model would benefit all who are directly affected by dementia.

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Acknowledgements

Abbreviations

CACP   Community Care Aged Care Package

EACH   Extended Aged Care at Home package

EACH-D   Extended Aged Care (Dementia) package

HACC   Home and Community Care

NRCP   National Respite for Carers Program

Summary

Caring for Carers (C4C) was initiated by the Brotherhood of St Laurence in 2009 as a pilot program to assist people caring for someone with dementia in the community. It provided carers with training and follow-up support, delivered by project workers experienced in community dementia care. Over three phases it developed into a personalised program of training and ongoing support. Using action research methodology in a program logic format, the evaluation gathered evidence from stakeholders, which was fed back to enable continuous improvement in program design and delivery. At the end of the program, an overall assessment was made of its impact on carers' experiences and wellbeing.

Key points

- Carers reflected positively on the program and drew a range of benefits from the different components of training and support. They valued most highly the regular one-on-one contact with a trained professional in the home. Many felt that the program was of considerable and lasting benefit and some described the program as life-changing.

- Carers were provided with advice on how to manage difficult dementia-related behaviour. They were able to trial techniques to assist with daily activities such as showering, dressing and shopping. Through these techniques carers felt that they were better able to maintain their caring role. Advice on managing behaviours such as 'shadowing' and repetitive questioning was also of benefit.

- Carers valued the information provided by the project worker. Information and literature on dementia, dementia-related behaviours, diversional therapy techniques, advanced care planning, additional support services and residential care equipped the carers with the knowledge to make informed decisions, which they felt improved their ability to care. With this information and ongoing support, carers were able to better prepare for events such as a move into permanent residential care or to take up additional help as required.

- As a result of the program, carers increased their use of, or used for the first time, additional support services such as respite. These services further contributed towards carer and care recipient wellbeing.

- Sustained contact over 32 weeks established an important dialogue between the carer and project worker. This allowed daily concerns to be discussed and addressed collaboratively and in a timely manner. Many carers commented that this was an empowering experience.

- The ability to talk openly and in a familiar environment also provided emotional support and relieved some of the stresses of caring. Carers felt able to discuss issues with the project worker that they could not raise with family, friends or formal care / support workers. This provided carers with an important outlet for feelings of burden and stress.

- The dialogue between the carer and project worker was extended to include formal care workers. This made care managers and respite service staff aware of issues that were previously unknown, subsequently enhancing formal care plans and respite services.

- The action research methodology allowed shortcomings in program delivery to be addressed as they arose and changes to be made accordingly. Thus, by the third and final phase the program represented an effective, multi-component model of carer support, tailored to the individual needs of carers. C4C proved able to address the complex issues that shape the caring relationship, primarily for those caring for a partner with dementia.

Background

Informal carers, usually family members and friends, play a crucial role in the provision of community dementia care. As dementia rates rise, and as community care continues to be prioritised, reliance on these carers is expected to increase. Yet the primary carers of people with dementia experience high levels of stress and burden. This is caused by a complex combination of factors, but dementia-related behaviour is considered to be a prime cause of stress. At the same time, programs to support the needs of dementia carers are few in number and vary in design and efficacy. With this in mind, BSL set out to improve support for carers of people with dementia. It used the STAR-C program, a clinical and behaviour therapy approach trialled and tested in the US state of Oregon (Teri et al. 2005), as the basis for exploring and further developing effective means of carer support.

BSL began delivering the Phase One of the program in 2009. This included an 8-week training period, followed by 24 weeks of follow-up support. This structure was maintained in successive phases (Phase Two and Phase Three) of the program. The training and ongoing support was provided by project officers trained in diversional therapy and with extensive experience of community dementia care. Following feedback after the first phase, the program was adapted to better suit individual carers. This involved a shift away from the clinical and prescriptive STAR-C approach to one that allowed individual carers' needs and particular issues to be addressed as they arose. The focus on individual carers emerged as a major feature of the program.

All 25 carers involved were caring for a family member with moderate to severe dementia, and most had been caring for more than two years prior to commencing the Caring for Carers program. This had shaped their individual needs and required an adaptive and flexible approach by the project officers.

The research

The Caring for Carers program was developed and evaluated using an action research methodology in a program logic format. Stakeholder views and feedback were used to test, reflect on and evaluate program developments, allowing continuous improvements in program design to be made.

As the program developed so too did the evaluative methods. The move away from the prescriptive and clinical approach of Phase One was matched by changes and refinements in data collection techniques. The clinical and statistical methods for measuring carer wellbeing were discontinued after Phase One and are not included in this report; and a comprehensive, three-stage interview schedule was developed to track and documents carers' reflections throughout the entire program. Carers participating in Phase Two and Phase Three were interviewed on three occasions rather than once as was the case in Phase One: at the commencement of training, after the training stage and during the follow-up support period. This interview schedule enabled carers' attitudes towards and experiences of caring to be assessed over an extended period, the reasons behind use of additional services to be explained and care experiences to be compared in greater detail. Along with detailed carer backgrounds, this made it possible to appreciate the care history and relationship, the barriers to carer support and the impact of the program on carers' wellbeing. Analysis of carer satisfaction surveys provided additional evidence for the assessment of the program. Interviews with the project officers were conducted on a similar schedule.

A care manager focus group yielded valuable information on the interaction between the carers program and formal care delivery and revealed the benefits of improved communication between carers, project officers and care managers.

The reflective methodology and the ability to refine techniques for gathering information provided a firm basis for determining the program's outcomes and effects over its two and a half year timeframe.

Research findings

Overall, carers responded positively to Caring for Carers. Most reported that the program had helped them to better manage their caring role. They could identify components that they found useful, such as the practical advice or the behavioural therapy techniques. The one-to-one support was the most beneficial aspect of the program according to carers. This personalised approach allowed the particular needs of individual carers to become the focus of training and ongoing support. For instance, some were in more need of emotional and personal support, whereas others drew more benefits from the practical advice and solutions to various problems. In all cases the program was tailored according to carers' distinctive needs.

Some of the carers commented that the Caring for Carers program was transformative. For these carers, the program represented a major turning point in their lives, in spite of the continuing health challenges which their loved one faced. It greatly improved their wellbeing, enhanced their experience of additional support services such as respite and enabled them to better understand and manage the demands of the caring role.

Program developments

Over the program's three phases a number of changes were made. Both partner carers and adult-children carers were involved in the first phase. The differences that emerged between carer groups resulted in the program being directed solely towards partner carers in subsequent phases. The topics covered during the training stage were also adapted according to carer need. In Phases Two and Three more emphasis was given to the issues that carers raised themselves. This represented a shift away from the clinical and prescriptive approach to a person-centred focus which evolved to meet the diverse needs of individual carers. Carers commented positively on these developments.

Multi-component program

Other research evidence suggests that multi-component programs are the most effective way to enhance carer wellbeing (Gallagher-Thomson & Coon 2007). The Caring for Carers program evolved to support multiple methods and approaches to dementia care. These included behavioural and diversional therapy strategies, emotional support, practical advice and information. This allowed individual carers' needs to be taken into account and different issues to be addressed as they arose.

Information

Carers valued the information and literature provided by the project workers, reporting that it helped them understand dementia and dementia-related behaviour and improved their knowledge of the services available. Such knowledge also allowed carers to make better informed decisions, and many described this aspect of the program as empowering.

Emotional support

Carers found that the program provided them with emotional support that was not available elsewhere. Given the personal and social demands of caring, this emotional support was highly valued by most of the participants.

Other support services

A clear majority of carers increased their use of respite care as a result of the program. Given that respite is considered a vital service for carer wellbeing, this represents a significant outcome.

Communication and collaboration

The program facilitated a vital dialogue focused on carers' needs. Carers were able to discuss with a project worker issues that they did not feel comfortable discussing with family members, care managers or other service staff, enabling them to address problems that would have simply remained hidden or unspoken. Collaboration between the carer and project worker allowed carers to feel more in control and proved effective in enhancing problem-solving skills. All of the carers commented that this conversation in itself contributed to increased wellbeing.

Project workers initiated dialogue about carers' needs with care managers and this improved formal care plans. Collaboration between project workers, care managers and respite staff was also evident and helped to improve formal care services.

External factors

A number of factors external to the program, such as family and care history and the progression of dementia, had a bearing on program outcomes. However, the person-centred approach provided helped carers deal with these. For example, in a number of cases the program helped carers overcome previous negative experiences of care services. It also helped some to prepare emotionally and practically for the care recipient's transition into permanent residential care when this became necessary.

Conclusion

Over its three distinct phases and through the input and reflections of stakeholders—carers, project staff and formal care workers—the Caring for Carers program evolved into an effective and person-centred approach to dementia care. It also facilitated communication between carers and formal care workers, which helped to integrate the variety of services made available to carers and care recipients. The person-centred approach to dementia carer support developed throughout is the main reason for the program's positive effect on carer wellbeing, and places the BSL in a position to further expand this approach.

The research findings justify the action research method and the program logic, as a way to improve program design and delivery and as an effective tool for evaluation. This is reflected in the continuing improvements made to the program and the improvements in data collection. It shows also how stakeholders' views can be effectively integrated into program development and evaluation so as to address shortcomings and enhance outcomes.

The findings also support a number of suggestions which relate to extending and expanding the program, further integrating the program into current BSL community care services, intervening earlier to support carers, introducing formal carer support plans, selecting staff and assessing the cost benefits of the program.

1 Introduction

Caring for Carers (C4C) was initiated by the Brotherhood of St Laurence (BSL) in 2009 as a pilot program to assist those caring for people with dementia in the community. Staff involved in aged care services recognised a pressing need to better support, train and inform dementia carers. Drawing on extensive experience in the provision of aged care services and on a number of reputable dementia care models, BSL developed and began trialling C4C. The project was made possible by a private individual donation and later by grants from the Portland House Foundation and the Hector Waldron Pride Charitable Trust.

Designed as a community-based approach to dementia care, the program focused on training family carers to reduce the prevalence and effects of certain types of behaviours and other identified issues in those experiencing dementia. By improving their capacity to manage difficult dementia-related behaviour, it aimed to improve the quality of life and general wellbeing of carers. It was also felt that this would improve the quality of life for those experiencing dementia and allow them to remain in their homes for as long as possible.

The program was designed and delivered in a number of phases. This facilitated an action research logic, whereby feedback from carers and other stakeholders informed changes and continuous improvements to the program. At first the program focused heavily on equipping carers with behavioural therapy techniques to manage challenging dementia-related behaviours. While this remained an important component, a more personalised level of support was developed during later phases of the program. This was a direct result of the action research logic and a response to carer needs.

The program provided sustained training and support to assist carers in the caring role with the aim of decreasing feelings of stress and burden. It was felt that such an approach would encourage carers to access additional support services such as respite, thereby further supporting carers to maintain their caring role. The following evaluation assesses whether the program achieved its stated aims and, where appropriate, suggests ideas for improvement. Multiple methods are used to consider the outcomes alongside the specific goals of the program.

Context

Alzheimer's Australia and Deloitte Access Economics have estimated the current number of people with dementia in Australia is 280,000 with this figure projected to rise to 385,000 by 2020 and 943,000 by 2050 (Deloitte Access Economics 2011). In Victoria an estimated 68,397 people have dementia, with 98,000 expected by 2020 and 246,000 by 2050 (Deloitte Access Economics 2011). Dementia is likely to become the leading cause of disability for older adults by 2016 and thus one of the key challenges in the future provision of aged care services (Commonwealth of Australia 2012). The Commonwealth Department of Health and Ageing recently announced dementia as the ninth National Health Priority Area, and has pledged to increase dementia funding and research, and introduce additional dementia-care programs (Butler 2012; Commonwealth of Australia 2012).

Dementia is used to describe the symptoms associated with a large group of illnesses which are characterised by cognitive deficits (American Psychiatric Association 1994) and which affect a person's functioning (Alzheimer's Australia 2005). Memory loss or impairment is the most common symptom, and, as the most prominent and earliest to be displayed, is central to dementia diagnoses. Individuals may also experience, particularly in the advanced stages of dementia, a

deterioration of language skills, impaired motor abilities, difficulty recognising objects and people, and disturbances in executive functioning, which impair abstract thinking and the ability 'to plan, initiate, sequence, monitor, and stop complex behaviour' (American Psychiatric Association 1994). Alzheimer's disease is the most common form of dementia, followed by Vascular dementia and then by other forms of the condition. The accepted view is that the onset of dementia 'is gradual and involves continuing cognitive decline', which further impairs social and occupational functioning (American Psychiatric Association 1994). While declining cognitive function is a key feature of dementia, the degree of impairment and disability often depends on the social setting and available supports (American Psychiatric Association 1994); and social factors are considered crucial to explaining the experience of those with dementia and also their carers. Indeed, the social context of dementia, as manifested in social relationships, social support and social attitudes, is critical for the quality of life of those experiencing dementia (Kitwood 1997). Overall, this further reinforces the important role played by informal carers and the various demands placed on those caring for someone with dementia.

Informal care-givers are now more than ever recognised as playing a crucial role in the provision of community aged care.[1] According to the Productivity Commission's report, *Caring for older Australians,* informal carers are the major source of direct care for older adults, play an integral role in coordinating formal care services and are essential to the functioning of the aged care system (Productivity Commission 2011b). Their importance is likely to increase in future years; along with an ageing population and the growing prevalence of dementia, the preference for community care is growing and government initiatives actively promote community care over institutional care. The Australian Institute of Health and Welfare (AIHW 2007) estimated that, in 2003, 57 per cent of people with dementia were living at home. The latest estimates put the figure at about 60 per cent (Access Economics 2009). Overall growth in the number and availability of community care packages, especially for dementia care, further indicates the prevailing trend towards community and home care (Productivity Commission 2011a). However, the Productivity Commission anticipates a decline in the number of informal carers over coming decades, adding impetus to calls for increased carer support (Productivity Commission 2011b).

Carer stress and burden is now a well-established facet of the care-giving experience (Cummins et al. 2007; Edwards et al. 2008; House of Representatives Standing Committee on Family, Community, Housing and Youth 2009; Savage & Bailey 2004; Schofield et al. 1998). Moreover, evidence has revealed that those caring for people with dementia are vulnerable to increased stress and suffer a range of physical and psychological ill-effects (Bruce, Paley & Nichols et al. 2005; Schultz et al. 1995). Caring for someone with dementia is characterised as complex and dynamic. Each care relationship is different and some carers may be better equipped to deal with the stresses and strains of caring for a relative than others. Moreover, caring for someone with dementia is generally understood as more stressful than caring for someone with physical disabilities and other debilities (Brodaty et al. 2005). People with dementia often require constant supervision and round-the-clock care. Yet, as Braithwaite (1990) has revealed, it is not necessarily the physical demands made on carers that define the burden of care, but rather the 'psychological deficits of caring' and the 'crises of decline'—degeneration, unpredictability, time constraints, the care relationship and a lack of choice. Studies have tended to emphasise the negative consequences of this kind of caring,

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[1] An informal carer is defined in Commonwealth legislation as a person 'who provides personal care, support and assistance to another individual' who has a disability, medical condition, mental illness or is frail and aged (*Carer Recognition Act 2010*).

but a holistic understanding of dementia care may be warranted. Indeed, a more-rounded understanding of the care relationship is emerging (Orpin et al. 2012).

While behavioural characteristics are shown to correlate strongly with care-giver stress and burden (Chappell & Pelling 1996; Teri 1997), a range of personal and social factors affect the dynamics of informal dementia care. A strong sense of duty and obligation may underpin the care-giving relationship (Egdell 2012), particularly as the responsibility for care often falls to one individual—the *primary carer*—who is usually a family member, spouse or child. As is often observed, women are more likely to assume the responsibility of care than men. Age and relationship status can play a part, with older adults caring for their partners likely to express higher levels of satisfaction and wellbeing than younger carers looking after parents (McConaghy & Caltabiano 2005). Carers may also experience profound feelings of loss and grief, as the symptoms of dementia can undermine spousal and family relations; such loss and grief may also be unacknowledged or 'disenfranchised' and may add to feelings of isolation and stress (Bull 1998). This is particularly marked in carers looking after a partner with younger-onset dementia. Moreover, as Egdell (2012) suggests, caring for a loved one with dementia is often not a choice, but 'the result of complex social, moral, emotional and cultural issues' (p. 16). A history of tension or conflict in the relationship between carer and care recipient may be a further source of stress and burden (Braithwaite 1990). These factors present a raft of challenges in the design of effective carer support services.

Support services such as respite and day programs are considered vital for carer wellbeing and quality of life: they can provide carers with a much-needed break, decrease caregiving hours and 'moderate the time caregivers spend dealing with and managing behavior problems' (Brodaty et al. 2005; Gaugler et al. 2003). Respite services may also lead to a 'reappraisal of the caregiving situation' and thus work to ease the burden experienced by carers (McConaghy & Caltabiano 2005). Support services also tend to complement informal care arrangements and networks rather than supplant them (Chappell & Blandford 1991). Consequently, they allow care recipients to remain in the community for a longer period. Yet, studies indicate that carers of people with dementia are often reluctant to use support services (Phillipson & Jones 2011b; Brodaty et al. 2005). That these services remain underutilised has begun to attract significant scholarly attention. The reasons are many and range from a lack of perceived need or awareness (Brodaty et al. 2005), to beliefs about the suitability of particular support services (Phillipson & Jones 2011a). Cultural values have also been shown to influence the use of carer support services (Alzheimer's Australia 2008). Carers are also confronted with a complex and fragmented aged care service sector, which can at times prove confusing and frustrating. Systemic barriers have also been identified (Gallagher-Thompson et al. 2012). More often than not it is a combination of factors that hinder access to services such as respite. Addressing multiple factors which underlie the care relationship and affect the consequent reluctance to use support services is crucial.

Numerous initiatives have been introduced to assist carers and increase the uptake of carer support services. These programs differ considerably in both design and efficacy. Alzheimer's Australia and Carers Victoria offer carer support programs and courses, including support groups, and referral and advice services. A National Dementia Helpline has also been established through Alzheimer's Australia to provide professional support, information, advice and education resources to assist carers and those experiencing dementia. Other programs train carers in ways to better cope with dementia-related behaviour, which is recognised as the primary source of stress and burden. Programs such as these can equip carers with effective strategies for managing difficult behaviour and thus reduce their stress. Brodaty et al. (1993) also found that such training had the potential to delay entry into permanent and/or nursing home care and reduce mortality among the persons with

dementia. In an international review of dementia-carer interventions, Torti et al. (2004) concluded that programs that incorporate aspects of different intervention strategies are more likely to reduce care-giver burden and stress. The study also suggests that tailored programs which are individualised and person-centred, are more likely to produce positive outcomes for carers (Torti et al. 2004).

The 'person-centred' model (Kitwood 1997) which is increasingly influential in the Brotherhood's approach to the delivery of aged care services provided the practical and theoretical basis for C4C, in combination with a behavioural therapy program from the United States (Teri et al. 1997, 2005). The STAR-C program involved training community consultants to 'teach family caregivers a systematic behavioral approach for reducing mood and behavioral problems in persons with Alzheimer's disease' (Teri et al. 2005, p 802). In a randomised controlled trial it was found that involvement in the STAR-C program reduced self-reported depression and caregiver burden and the frequency and severity of behavioural problems associated with dementia (Teri et al. 2005). The program was adapted by BSL and underwent further development to meet the specific needs of individual carers. C4C came to represent a multi-component intervention and support program, combining skill training, information and ongoing support in the home.

At its inception the C4C program aimed to:

1   Reduce family carer stress, depression and burden of caring for a person with dementia in the community.
2   Assist carers to maintain their caring role.
3   Decrease behaviours associated with dementia symptoms.
4   Increase wellbeing and quality of life for carers and those experiencing dementia living in the community.
5   Increase uptake of respite and other relevant support services.
6   Increase paid carers' ability to relate to individuals experiencing dementia and provide interactive, engaging, valuable, quality respite.
7   Provide a model which can be replicated across other services both locally and nationally. (BSL 2011).

The program's central aim was to improve the wellbeing and quality of life of carers and those experiencing dementia. It was also hoped that improvements in carer wellbeing would flow on to improve dementia-specific services offered through Brotherhood Community Care.

Like the STAR-C program, C4C assigned trained project workers to deliver the program in the carers' home and involved a unique mix of training, information and support for carers. The training stage lasted eight weeks, with ongoing one-on-one support provided for a further 24 weeks. The program was delivered in three phases, with each phase involving a different cohort of carers. Over each phase improvements were made so that the program evolved from an experimental approach to a comprehensive and integrated model of carer support able to be offered to large numbers of carers. This evaluation tracks this development and assesses the outcomes phase by phase.

2 Methodology

The project was evaluated using a mix of qualitative and quantitative research methods, including surveys, interviews and a focus group. The following elements were used as a guide.

- Track the implementation and delivery of the project from the perspective of a range of stakeholders, including carers, care managers and project staff.

- Identify and measure the outcomes of the project for the various stakeholders.

- Identify and measure the impact of the project on the various stakeholders.

- Compare and contrast the project with similar carer support programs.

The evaluation paid specific attention to:

- the support and training offered by the C4C Project, including the experience of carers, clients and care managers

- the reflections of project staff and care consultants on the impact of the project on the lives of carers and clients.

Evaluation framework

A program logic format provided the evaluation framework, within which an action research cycle was used to ensure stakeholders reflect on action and provide timely feedback. This allowed improvements in design to be made at critical points in the program's delivery. The following evaluation provides a comprehensive review of the program across all three phases, using the previous methods of evaluation as guides. It tracks the various changes between phases and measures the outcomes of the entire C4C program.

Carers, project staff, care managers and BSL respite staff were consulted to ensure that the information collected was valid and reliable. Information gathering followed an action research cycle (see Figure 2.1), so stakeholders were consulted during the different stages of the project.

Figure 2.1   Action research cycle

Observation: The issue or problem is described and monitored, with useful data recorded and collated.

Reflection: Observations are interpreted and shared so that any issue or problem can be better understood.

Planning: Actions are proposed to address issues or problems identified at previous stages.

Action: The plan is implemented and the cycle starts again as outcomes are observed, recorded and shared.

This ensured that all stakeholders were engaged in testing and evaluating the success of the C4C Project. The structure of this report follows the program logic: each phase of the program is described, observed and reflected on to reveal the successive cycles of design and delivery.

Qualitative data

The central component of evaluation consisted of the in-depth interviews of carers involved in the program. This information yielded valuable insights into the specific needs of carers, informing the reflection, planning and action phases of the Program Logic. Moreover, such an approach affirmed that informal carers are crucial in the provision of dementia care and are best placed to identify the needs of care recipients. Carers were asked to comment on the efficacy of training, information and support provided, and were further prompted to think about changes which the program encouraged in their approach to care and specific dementia-related behaviours. This allowed some sense of carer wellbeing to be gained and responses to specific aspects of training to be assessed.

Carer responses were tracked at set times. In Phase One, carers were interviewed once, at the completion of the whole program. In Phase Two and Phase Three, three in-depth interviews were conducted with each carer—at the beginning of the training period (0–1 month), on the completion of training (3 months) and at the end of the program (6 months). Given the demands on carers' time, some flexibility was required with the interview schedule, and for various reasons not all carers completed three interviews. However, over a six-month period all carers were interviewed at critical points of the program.

Interaction between project officers and care managers also contributed to the action research cycle. A vital dialogue was established between staff of C4C and the formal care management systems, allowing both improvements in care plans and adjustments to the program to be made.

Quantitative data

Evaluative methods included:

- satisfaction surveys. These were conducted with Phase Two and Phase Three participants upon completion and used to gain overall impressions of the program.

- appraisal of additional care services used. Services such as respite and carer support groups accessed by carers reveal whether the program resulted in increased use of available services.

Focus groups

A focus group was conducted with care managers whose clients were involved in the program. This forum provided useful information on topics including the general need for carer support services, the efficacy of the program and its impact on carer wellbeing. The focus group also provided information on how the C4C project officers worked with care managers, its implications for formal care plans and some possible improvements to the program. In the absence of a control group, care managers were able to provide some insight into how carers involved in the program compared with those not part of C4C.

Rationale and assumptions

The C4C project was underpinned by a set of assumptions drawn from the STAR-C model and current research on dementia care. This evaluation tested these assumptions by correlating them with the C4C program's outcomes. They include:

- Provision of training and one-on-one support will reduce carers' feelings of isolation, stress and anxiety, and will enhance overall wellbeing.

- Provision of training/information/education on strategies of behaviour management will decrease carers' burden and assist them in their caring role.

- Participation in the program will enhance carer wellbeing, reduce stress and empower carers to make decisions regarding different care options.

- Participation in the program will enable the client to remain in the community.

- Participation of the carer in the program will lead to increased uptake of respite.

- The program will lead to the development of a model and strategies to enhance the respite experiences for carers and care recipients.

- Enhanced respite experiences will lead to increased use of respite options.

External factors

There are also likely to be unanticipated external factors that impinge on program effectiveness. This evaluation monitored these factors and analysed their impact. Indeed, how well the program deals with external factors and different circumstances is a key measure of its success.

Program logic format

The program logic which guided data collection and analysis in each phase of the C4C program was as follows:

1   Project context

2   Project priorities

3   Documentation of *inputs* to program including the implementation model, resources, knowledge and experience and time provided by stakeholders.

4   Documentation of *outputs* including program resources, activities and participation to determine whether the outputs are consistent with the program's objectives

5   Evaluation of *impact*

- What impact has the C4C program had on key stakeholders and participants? For instance, has it led to decreased feelings of isolation for family carers? Has it enhanced the wellbeing of participants? Has it led to increased uptake of respite care?

6   Evaluation of *outcomes* – short-term

- Were the participants satisfied with all elements of the program? Have the needs and aspirations of the participants been met?

- Were the carers satisfied with the program, particularly the training and support? Have their needs and aspirations been met?

7   Evaluation of *outcomes* – short to medium-term

- To what extent are the outcomes consistent with the specified objectives?

- How have participants benefited from the program? Who encountered difficulties and why?

8   Success factors

- What factors (including external factors) best explain the program's performance?

9   Analysis and evaluation of the *assumptions*, both tacit and explicit, which underpinned the program

10   Analysis of response to any *unanticipated external factors* that impinged on the program

- Are there any factors that limited the delivery of C4C and what strategies could be applied to address these?

- Are there any issues arising from the implementation of the program? Are there any unintended outcomes of the program?

- Are there any other significant unforseen outcomes of the program?

11   Identification of potential *outcomes* – medium to long-term

- Can we posit any longer term impacts/outcomes that could be reviewed twelve to eighteen months after the completion of the program?

The headings, with supporting statements or questions, were used to guide two distinct areas of inquiry: the impact of the C4C program on individual carers, and its overall effect on carers as a group (see Table 2.1).By applying the program logic phase by phase, it was possible to analyse C4C from both an individual carer and a program-wide perspective. In the first instance the above questions were used to guide the interpretation of data drawn primarily from the interviews with

individual carers. The program-wide evaluation process adopted the above headings and questions as a more structured framework for assessment. This involved evaluating the program at each phase and consolidating data from a range of qualitative and quantitative sources.

Table 2.1   Evaluation guide

		Individual carer	C4C program
1	**Context**	Defining and understanding the individual care relationship, which prompts the following questions: How long has the carer been caring? What factors of the care relationship are affecting carer wellbeing? Are there already supports in place? What else is needed?	General need for carer support program Carer burden is well established in the literature and in care practice. Accepted techniques for reducing carer burden include: • Person-centred care approach • STAR-C Program
2	**Priorities**	What does the carer want to gain from the program? What is needed to improve carer wellbeing and reduce carer burden?	What factors have been identified as affecting carer wellbeing? How can the program address these factors? What approach works best?
3	**Inputs**	**Training and one-on-one support stages** • Resources provided to carer • Techniques used or put in place to reduce the impact of dementia-related behaviour • Other activities and advice provided • Services put in place to support carer	**Implementation model** • Caregiving training manual • Resources available to carers • Techniques and activities for carers made available • Staff time, resources and levels of experience (Changes were tracked over the three phases)
4	**Outputs**	Did the carer complete the whole program? Were different activities and techniques trialled by the carer? What types of resources were provided to the carer? What other supports were provided?	How many carers completed the program? What different types of activities and techniques were provided to aid carers in their caring roles? What different types of resources were made available to carers?
5	**Impact**	Does the carer express feeling less stressed, burdened and isolated as a result of the training and follow-up support provided? Does the carer feel they are managing the care responsibility? Have they got more time to spend on themselves? Has the carer considered increasing their use of respite and other support services?	Overall, did carers reflect on the program positively? What were the satisfaction rates? Did the program influence formal care plans and design/delivery of respite and other support services?
6	**Outcomes – short-term**	Is the carer satisfied with the program? Do they feel more calm and in control? What techniques and activities did they use or are still using? Has use of respite and other support services been initiated? If used, what is their experience of different respite/support services?	What different outcomes can be observed, and in what ways do they reflect carer wellbeing? What techniques and activities for managing difficult dementia were put in place? Did this differ between phases of the program?

		Individual carer	C4C program
7	**Outcomes – short to medium-term**	Does the carer continue to feel that the program worked to meet their needs? Are they continuing to use respite and other support services, and what has been their overall experience of respite/support services? Was the experience different from before? Do carers feel able to make long-term plans regarding themselves and the person they are caring for?	Was the program able to meet the needs of different carers? Overall, did the use of respite and other support services increase? Were changes made to the various respite/support services provided through BSL?
8	**Success factors**	What best explains the program's performance for each carer? How were carers' needs best met?	What best explains the overall performance of the program? (e.g. program model; staffing; communication between project staff, care managers and other relevant care staff) How did the program change over the three phases?
9	**Assumptions**	Did the program confirm the various underpinning assumptions for the individual carer?	Did the program confirm the various underpinning assumptions for carers as a group?
10	**External factors**	What external factors influenced the carer's progression through program? How did the care relationship change over the course of the program? Did permanent care become an issue?	How did the program address various external factors? What common and distinctive external factors can be identified?
11	**Potential long-term outcomes and ideas for improvement**	Do carers require further support beyond the program? What ideas/opportunities are there for improvement	Are supports in place to support carers once the program has finished? What ideas/opportunities are there for improvement

Ethics

The evaluation project was approved by the BSL Human Research Ethics Committee. All research participants were presented with a plain language statement and consent form which outlined the research aims as well as their rights of withdrawal and/or access to the final report. In cases where the interview procedure was likely to distress participants an interview was not conducted.

3 Findings

Due to the action research model, the findings are reported successively for each stage.

Phase One (pilot phase)

The training stage of Phase One was conducted between August and October 2009 and the follow-up support stage lasted from October 2009 to March 2010.

Selection of carers

Participants for the pilot phase were selected from carers of individuals currently accessing a BSL Aged Care Package and/or attending Banksia (BSL) respite centre, and thought to be experiencing stress or burnout. This differed from the eligibility criteria of the STAR-C program, which was based on care recipients having 'three or more agitated or depressed behaviour problems reported by their caregivers, occurring three or more times during the past week' (Teri et al. 2005, p. 803). Instead the BSL designed more open criteria, a shift away from behaviours to perceived stress. Discussions between the Project Manager, BSL care managers and BSL day-respite staff defined any individual caring for someone with dementia and believed to be experiencing stress as a potential participant. The reason behind this decision was that 'carers can have a high degree of stress without ... the client being particularly behaviourally challenging ... [They] can have just one behaviour which is significant enough to cause carer stress'. The interviews conducted with carers in the pilot phase reinforced this rationale: carers spoke of 'feeling isolated', 'overwhelmed' and 'stressed out', and described difficulties 'coping' with their caring role. One carer who had been caring for her mother for many years stated: 'I have worn myself out as a carer'; another who had been caring for her husband for over three years, reflected that it was 'very hard to look after someone with dementia'. The carers were organised into two groups—partners and adult children (see Table 3.1).

Table 3.1   Phase One carers (Groups 1 & 2)

Group 1

Age group	Gender of carer	Caring for	Living arrangement	Package/service level at start of C4C	Time caring (approx.)
50–60 years	Female	Partner	Living together	CACP	2+ years
70–80 years	Male	Wife	Living together	CACP	2+ years
80–90 years	Female	Husband	Living together	EACH	3+ years
80–90 years	Female	Husband	Living together	EACH-D	7+ years

Group 2

Age group	Gender of carer	Caring for	Living arrangement	Package/service level at start of C4C	Time caring (approx.)
–	Female	Mother	Living together	BSL respite services	2+ years
–	Male	Mother	Living together	EACH	2+ years
–	Female	Mother	Living together	NRCP	2+ years

All the carers lived in the south-eastern region of Melbourne. Those in the first group had been caring for a husband/wife/partner with medium to severe dementia for more than two years. Caring for someone with medium to severe dementia and for an extended period was likely to produce high

levels of stress, and this is supported by current research (see, for example, McConaghy & Caltabiano 2005). Participants in the second group were adult children caring for a parent, and while generally caring for a shorter period were considered to be experiencing comparable levels of stress and burden.

Staff

Two project workers were selected to train and support carers during Phase One. Both were trained in diversional therapy and had significant experience in working with people with dementia in the community, including day programs and in-home respite. A two-week orientation program took the project workers through the weekly aims of the training stage. Their progress was monitored throughout the program.

One project worker was assigned to assist carers looking after a partner with dementia and the other was assigned to the adult children looking after a parent. Each group had distinctive needs.

Training

The project workers delivered training to carers according to a program manual, which was based almost entirely on the Caregiving Consultant Manual developed through the University of Washington School of Nursing (Teri et al. 2002) and consistent with the STAR-C model. It proposed a highly structured set of training protocols. Each session had a detailed list of aims, goals, activities and homework. The session titles were as follows:

1. Defining target behaviour problems
2. Observing the ABCs[2]
3. Problem solving and the ABCs
4. Enhancing communication skills
5. Increasing pleasant events
6. Managing negative thinking
7. Caregiving issues and management
8. Review and maintaining gains

Within this framework a small amount of time was allotted in the 'treatment' and 'intervention' protocols for 'building rapport' between the carer and the 'therapist' (Teri et al. 2002).

Observation

In general, carers in Phase One reflected positively on the training provided. Only one carer stated that the training was of little to no use. Some carers mentioned as useful specific tasks or lessons, such as the ABC approach to behaviour and keeping a behaviour diary. Some gained a better understanding of dementia-related behaviour:

> I became more aware of his situation, even though he couldn't speak for himself; I started to understand that the anger was mainly his frustration with himself, and that he couldn't express it.

In turn, this understanding had 'made me stop and think and yell less at him'. Similarly, another carer commented that she had 'learnt to stop and listen to Mum' and was 'more patient' as a result.

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[2] According to the manual, 'every behavior is part of a process (A-B-C) with an Activator at the beginning, a Behavior in the middle, and a Consequence at the end. The Activator triggers the Behavior and the events following the behaviour are its Consequences'. By presenting certain types of behaviours in this way carers are encouraged to attend to the activators and consequences in order to 'modify mood and behavior problems' (Teri at al. 2002).

Understanding and empathy could translate into an increased sense of wellbeing and accomplishment, as one carer stated:

> [I] started to feel better, felt more confident, was able to look after him better and deal with his dementia; started to understand how to communicate with him more ... [I] have learnt to laugh at things, got less nervous [and] started to change how I did things for him.

The majority of carers indicated that the training had helped them to cope with the demands of caring. By learning and applying different coping strategies, they reported being able to better manage the caring role and felt more relaxed and less stressed as a result.

Many carers commented on the practical advice provided by the trainers. Through the techniques suggested for dealing with her husband's repetitive questions, such as 'changing the subject ... or putting on some music', one carer was able 'to let go' of her frustrations. Another carer recalled that difficulties in showering her partner were overcome by being more creative. Suggesting to her husband 'How about we go out and have a coffee and doughnut' instead of saying, 'Let's have a shower', was a way to sidestep the difficulties that had become part of this activity.

The most memorable and valued aspect of the training was the one-to-one contact carers had with a trainer; the fact that training was conducted in the carer's home at a time convenient for the carer and care recipient was also considered important. Six out of the seven carers valued the opportunity to talk about problems and discuss day-to-day issues. For one carer 'having someone on a regular basis to review what was going on' made her realise that she wasn't 'the only person having ... problems'. Another carer was able to discuss difficult personal and 'sexual issues' that would not have been possible with anyone else, especially family members. She valued having 'someone to talk to who was not family'.

The training also made carers aware of additional support services. For example, one carer was not aware initially that extended respite care could be provided. In turn, most carers increased their use of such services, or considered using them in the future, as a result of C4C. One carer stated that 'No other option worked as well as ... respite care'; and another said that she was 'reliant on respite to get a real break'. Overall, five out of seven carers stated that they would recommend the C4C program to other carers.

As it happened, only the partner carers were involved in the follow-up support stage. This consisted of weekly or fortnightly phone calls to gauge how carers were coping and whether they needed further advice or support. The project worker was able to feed information back to care managers who could then adjust formal care plans to better meet current and future needs. Information was also passed on to BSL day-respite staff to inform the design and delivery of respite services. Throughout this process, carers continued to value the one-on-one contact that such support allowed.

Phase one summary

The completion of the pilot phase of the program provided the opportunity to reflect on what worked well and where improvements were needed.

Most importantly, carers were raising issues that were not adequately addressed in the clinical approach of the STAR-C Program and set out in the original Caregiving Consultant Manual. And, while many of the behavioural strategies were beneficial, many of the carers had difficulty implementing them according to the manual. Project staff decided to redevelop the training manual. The changes to the program manual reflected the changes in program emphasis:

- more time spent discussing and outlining the entire program and building rapport between the carer and trainer

- shift from behavioural therapies to issues of concern identified by the carer

- more focus on how carer is feeling in situations of poor communication with the person they are caring for

- additional information and resources to support the project officer

- information on palliative care and other issues relevant to more advanced stages of dementia

- practical support and activities, such as life histories and photo books, to promote wellbeing for carer and care recipient

- more emphasis on respite options.

Overall, this did not represent a radical departure from the original program—much of the STAR-C material was maintained, but with significant additions and modifications. This represented a subtle shift favouring one-on-one support in the home, and allowing a focus on the specific needs of individual carers. Elements of the behavioural approach that were deemed beneficial would remain but the content would be delivered as part of a comprehensive training program involving communication techniques, practical advice and activities, forward planning and emotional support. Importantly, the new training schedule acknowledged that a trusting relationship could take weeks to develop. According to the program manager, it was important for the project worker to develop the 'capacity to get to know the individual and build that strong trusting relationship'. Conducting the training stage in the carers' home was essential for building trust. In subsequent phases, follow-up support in the home could be provided as an option for carers, and this would be done through weekly or fortnightly visits by the project worker. An awareness of the carer's history and the dynamics of the care relationship were also deemed essential for addressing carer needs.

The STAR-C Program Training Manual had been designed to assist people caring for someone with a 'moderate range of cognitive impairment' (Teri et al. 2005). By contrast, the carers selected for the C4C program were caring for someone with more advanced dementia. Thus, there was a realisation that carers in the C4C would need appropriate information about palliative care, residential care and planning for life after caring. On reflection, one project worker thought that a lot of the information from the initial training manual and delivered during the training stage did not adequately cater for carers' current needs and came too late. Moreover, delaying admission into permanent care—a central aim of many intervention strategies (Brodaty & Gresham 1989; Brodaty et al. 1993; Torti et al. 2004)—might not have been an attractive or likely option for some C4C carers. In such cases a more appropriate focus would be on how to best prepare carers for such eventualities and equip them with the skills and supports to confidently make important decisions at crucial points in the care relationship. The main aim—to support care decision-making—came to the fore as a result of reflections on Phase One.

Several factors highlighted differences in the reception of the program for partner carers and adult-children carers. Firstly, the project workers approached their respective roles in different ways. As a result, the project worker responsible for partner carers mainly reported positive results, whereas the other project worker emphasised the difficulties adult-children carers had in completing the program, that it was too long, and that different carer profiles affected their reception of particular topics. However, the evidence collected from carers suggests that all carers received some benefit from their involvement in C4C. Secondly, all project staff acknowledged that adult-children caring

for parents with dementia faced issues not shared by spousal carers. The dynamics of family, work and social obligation are considered to be very different for children caring for their parents (see, for example, Egdell 2012). Factors such as time constraints, family and work commitments and a different type of obligation affected adult-children carers differently from spousal-carers. Finally, since the model of carer support in Phase One was experimental, its aims had not been refined for specific carer groups. Together, these factors explain what were assessed at the time to be different outcomes for each group of carers, such as the fact that no adult-children carers participated in the follow-up stage of the program.

The evaluation method was adapted to reflect the changes to the program. Carers involved in Phase One were interviewed months after the program had finished and the recall of details proved a problem. Instead of a single in-depth interview with carers, a schedule of three interviews was proposed for the carers recruited for Phase Two: at the start of the training stage, at the completion of training and during or at the end of the follow-up support period. The project worker(s) would also be interviewed at critical points during the program. This would yield information for the entire program and provide a longer perspective as carers could be tracked over six to eight months. It was thought that with the new interview schedule it would be possible to trace the multiple factors carers faced as they negotiated difficult decisions and situations; to assess where, if at all, the C4C program provided useful assistance; and to measure the short to medium-term outcomes with greater accuracy.

Table 3.2   Phase One evaluation summary

		Phase One (pilot phase)
1	**Context**	BSL staff considered carer wellbeing a growing and pertinent concern STAR-C Model identified as a workable approach to carer support
2	**Priorities**	Provide training and ongoing support to reduce carer stress and burden linked to difficult dementia behaviours; and assist carers to maintain their caring role. Increase uptake of respite and other support services.
3	**Inputs**	STAR-C Model Training stage (in home): 8 weeks. Follow-up support stage (weekly or fortnightly phone calls): 24 weeks Caregiving training manual based wholly on the STAR-C manual, which outlined techniques and activities for carers, including the ABC approach to behaviour 2 project workers: one working with partner carers, the other with adult-children carers Carers with considerable diversity of backgrounds, experience in caring and knowledge of dementia. (All were caring for someone in the advanced stages of dementia and had been caring for at least two years before the program commenced.) Resources provided to carers by project worker(s): BSL Aged Care Dementia Library, relevant literature and web resources.
4	**Outputs**	Four out of seven carers completed the program. All four were partner carers. Two of the three adult-children carers completed the training stage, but were not involved in the follow-up support stage. All carers were instructed in techniques and activities to manage difficult dementia behaviour and improve communication with care-receiver. Single interviews with carers at the completion of the program; interviews with project staff;
5	**Impact**	Five out of seven carers found the training useful. Six out of seven carers indicated that being able to talk about problems and discuss issues was of value. Four out of seven carers indicated that they were coping better as a result of the program. Five out of seven carers would recommend the training to others. There was insufficient data to conclude whether the pilot phase of the C4C program influenced formal care plans and/or other services provided through BSL although it was shown to improve communication between care managers, the project workers and carers.
6	**Outcomes – short-term**	Most carers (especially those caring for a partner) reported feeling less stressed and more relaxed as a result of the training and specific behavioural strategies, and found the person they were caring for to be calmer and more settled. However, it was the ability to discuss issues as they arose and talk about specific problems that carers found most beneficial. Most carers were already using respite services prior to commencing the program, and all indicated that respite care was essential for their quality of life. Use of respite services increased for at least three carers.
7	**Outcomes – short to medium-term**	The program met a variety of carer needs. These needs were met through practical advice, information about dementia, emotional support and assistance filling out forms.

		Phase One (pilot phase)
8	**Success factors**	One-to-one support in safe and comfortable environment (the home) was the primary factor leading to success.
		The opportunity to discuss issues as they arose was appreciated.
		The project worker responsible for partner carers experienced a more positive response to the training and support provided. This relates mainly to the different needs of partner carers when compared with adult-children carers, suggesting that the program is better suited to those caring for a partner with dementia. The project workers' approaches may have contributed to different outcomes for each group.
9	**Assumptions**	Evidence collected through the interviews with carers suggested that the support and training improved overall carer wellbeing by helping carers to cope better with the demands of caring. However at this point the model of carer support needed further improvement before it can be replicated
10	**External factors**	Family history and family relationships shaped care-giving.
		For many of the care recipients the progression towards permanent care was unavoidable. The best the program can do is to support carers during this difficult time.
11	**Potential long-term outcomes and ideas for improvement**	As the carers involved were caring for someone in the advanced stages of dementia, more attention to issues surrounding permanent care was foreseen.
		Limited information existed on programs available to support carers post-C4C
		Improvements suggested for subsequent phases included:
		• only including partner carers
		• developing a less clinical approach by adapting the language and techniques of the training manual to carer needs.
		• concentrating on issues that carers want addressed
		• spending more time building rapport between carer and project worker.

Phase Two

The Phase Two training stage was carried out during November and December 2010, with the follow-up support stage from January to June 2011.

Selection of carers

As in Phase One, participants were selected from carers of current BSL clients with dementia and thought to be experiencing stress. Care managers were considered to be in the best position to identify the carers in most need of extra support. Given the complicating factors faced by individuals caring for parents with dementia, only spousal/partner carers were selected (Table 3.3).

Table 3.3   Phase Two carers

Age group	Gender	Caring for	Living arrangement	Package/service level at start of C4C	Time caring (approx.)
80–90 years	Female	Husband	Living together	EACH-D	6+ years
80–90 years	Female	Husband	Living together	HACC (Gold Card)	3+ years
70–80 years	Male	Wife	Living together	–	3+ years
80–90 years	Male	Wife	Living together	EACH-D	3+ years
50–60 years	Female	Husband	Living together	EACH-D	10+ years
80–90 years	Female	Husband	Living together	EACH-D	5+ years

All six carers were caring for a partner with advanced dementia. Most care recipients were on EACH-D packages administered through BSL, a further indication of the level of dementia and the services already in place. All but one carer was aged over 70 years.

In addition, more information on the life history of carers and care recipients was collected, which illuminated important aspects of the care relationship. These details influenced how receptive carers were to the different elements of the program. They also enabled a more thorough assessment of the ability of C4C to meet carers' individual needs.

Staff

Phase Two of the program was delivered by only one project worker, who increased her project hours to take on responsibility for the training and follow-up support stages for a new cohort of six carers.

Training

The sessions in the new training structure used for Phase Two were as follows:

1   Introduction and familiarisation
2   Issues/problems (including ABC approach to manage difficulty dementia behaviours)
3   Activity kits and respite
4   Communication
     Forward planning
5   Forward planning (continued)
     Grief and loss
6   Pleasurable events
7   Physical and emotional impact of caregiving
     Introduction to support networks

8   Review – maintaining goals

The behavioural therapy approach remained part of the training but was less prominent. Instead, issues to do with respite, grief and loss, and forward planning were introduced. The new manual also contained specific activities, such as constructing life histories and photo albums, as options for carers. The language and terminology were changed to promote a more personalised approach towards carer support. For instance, the ABC approach to behavioural problems was delivered in a less formal way. The carer was still encouraged to understand what activated a difficult behaviour, the behaviour itself and its consequences, in order to reduce its prevalence or effect. This was often achieved by reflecting on the triggers of particular behaviours without specific mention of the ABCs. In addition, the project worker exercised some discretion and flexibility in addressing specific topics, to enable the needs of individual carers to become the focus of the training and follow-up sessions, and carers' issues to be addressed as they arose.

Observation

The interview schedule, consisting of three in-depth interviews with carers at critical points during the program, provided greater insight into the caring relationship. Many carers initially commented during the training stage that they were managing their caring responsibilities as best they could, and that the training offered them little that was new or helpful. One participant, who had been caring for her husband for over three years, stated that 'I don't think anyone can teach me or show me to do anything that I'm not doing'. Another carer commented, 'I just feel as if I'm doing the right thing ... regardless of how I feel about it ... because it's pretty hard ... very difficult'. Despite obvious difficulties, carers seemed to accept their role. The same carer said, 'I've taken everything as it's come along', while another said, 'I can cope and I can manage ... with what I'm doing'. This is understandable given that all had been caring for their partner for at least three years, and some for much longer. Yet, as care managers observed, 'putting on a brave face' could conceal issues that needed to be addressed. These staff felt that carers often downplayed the difficulties they were facing, and needed 'a space to talk about their own issues'. Conducting training and support in a safe and comfortable environment (the home) helped to create such a space.

It took some time, according to the project worker, for carers to open up, and this varied from carer to carer. Trust between the carer and the project worker was essential, nonetheless, to enable a much-needed dialogue on how carers were actually coping with their responsibilities. Such a dialogue allowed for those other factors, such as family, life experiences and previous employment, so integral to the care relationship, to be included in the training and follow-up support. Care managers, who were focused on ensuring services for the care-recipient, were not always aware of the issues that needed to be addressed to improve carer wellbeing. Through one-on-one training and support in the home environment, the project worker 'was able to pick up on a lot of things' that the care manager was unable to see and often had a clearer understanding of what the care situation was really like for the carer.

Validating carers' individual approaches to care was an important first step in building trust and helping carers to recognise that they might benefit from support. For one carer, the program was important in 'giving ... assurance and reinforcing' what he was already doing. Similarly, another commented that it was 'nice to have someone to back you up'.

The one-on-one support had further benefits. Carers could express their frustrations. Carers felt that very few people understood their situation—a common conclusion of most carers across all phases

of the program. For one woman, having 'someone to vent to about the week' was the most valuable part of the program. This was vital in making sense of events and provided some relief.

According to the project worker, many carers did not realise at the time that they were being supported. She was able to suggest to individual carers ways to better manage their role, which often required sensitivity. For one carer, who at first believed he had learnt nothing new from the program, the provision of picture cards and photo books stimulated conversation with his partner and the carer began to feel more relaxed. He continued to use the cards and books well after the training stage had finished.

For others the program encouraged them to approach the individual they were caring for in a more thoughtful manner. As one carer stated: 'As carers we just deal with each layer as it comes ... we don't have time to stop and think'. The ability to stop and think also created calm. Keeping calm helped one carer to reduce her stress, which she believed also helped to reduce her partner's stress. Another carer also saw the value in remaining calm, but admitted that this was often hard to do.

Over six months it became possible to track developments in the care relationship and gauge carers' responses to the training and support. For some the program marked a transformation in their approach to caring, as Sarah's story shows (see Box).

Transforming the care relationship: Sarah

Sarah, who had been caring for her husband for almost six years, displayed a remarkable change during the program. She had over 40 years of nursing experience, which provided the major frame of reference for her caring role. Despite showing clear signs of stress, she claimed in the first interview that she was coping. While prepared to trial the project worker's practical suggestions, she expressed a general hopelessness that they would have any effect. She had come to realise by the time she became involved in the C4C program that not much could be done to affect her husband's condition, though she stated that she had difficulty accepting the changes in him.

During the program, and in combination with medical advice and other support, she learnt to let go, and 'just go along with things'—not fight with or demand as much from her husband. She always valued the one-on-one contact with someone who understood her situation. There were deeper issues at play and she discussed these with the project worker. In the final interview, Sarah explained: 'I've never thought in my whole life of focusing on myself ... I've always been doing for others'.

While able to arrange a few hours' respite each week, she was initially very resistant to any form of respite that involved an extended time away from her husband. It was discovered by the project worker that prior negative experiences with respite and Sarah's own doubts and feelings of guilt were significant barriers to using such extended respite. She reached a point, however, when extended respite became necessary. This marked a transformation in her life. Communication between the project worker, care managers and BSL day-respite service staff provided further assistance. Taking into account her negative experiences and her husband's life history suitable respite services were arranged, which subsequently changed her views of respite. Sarah commented in the final interview that she no longer felt guilty about someone else looking after her husband. She had also realised that nursing a partner was totally different from nursing in a professional capacity, and admitted 'that one can get worn out' in such a role. This was a far cry from her initial claim to be coping with the multiple demands of caring.

One carer was at first reluctant to engage with the program and the project worker: 'In the beginning I wasn't happy about doing the course ... I was rebelling'. She admitted, however, that she was struggling to accept the changes in her husband and the demands of caring. Being able to talk frankly with the project worker was crucial for this carer. It 'forced' her to talk about the issues, allowing her to gradually accept her role and the changes that came with it. She also equated increasing awareness and acceptance with improved wellbeing. As a result of the program she found herself less angry, able to focus on what was really important and more able to speak out.

For other carers the changes brought about by C4C were not described as life-changing, but were still significant. A woman who had already been caring for her husband for six years reflected that the program had made her more relaxed and calmer. Likewise, a man caring for his wife had also learnt to be calmer as a result of the program. Both valued the support of the project worker and were confident that they could contact her if necessary.

A couple of carers reported that C4C was of little or no help; yet this was not matched by their other comments about the benefits of the program. For instance, another carer was struggling with serious family and social issues, and required services and supports that were beyond the scope of C4C. The program, nevertheless, gave her an opportunity to escape the daily demands of caring and the family problems she was dealing with and to chat with the project worker. She stated: 'I love it when she [project worker] does come. It's my little bit of time'. She valued respite for the same reasons, and was at the time of the interview about to use overnight respite for the first time. A male carer also claimed to have gained little that was useful from the training, but enjoyed talking with the project worker. Describing himself as a 'practical person', he said, 'I just do what's got to be done'. The strategies that he found useful added to what he was already doing. Having someone to talk issues over with was the main benefit for this carer. He appreciated the weekly contact, stating about the project worker: 'She's the only person that I have to openly talk to ... I don't have that opportunity with family. I don't have that opportunity with friends'. Thus, while some carers gained more from the program than others, C4C proved able to meet a variety of carer needs.

Most carers in Phase Two increased their use of respite and other support services as a result of the program. This often involved collaboration between the C4C project worker, relevant care managers and BSL day and respite service staff. Care managers reported that the project worker was able to identify where services were needed, and in many cases fast-track and integrate additional services, such as respite. For carers who were initially reluctant to use respite services the C4C program had a lasting effect of introducing a more positive experience of respite and encouraging further use.

Phase two summary

Overall Phase Two of the program was less 'technical' than the first Phase. Carers felt that they benefited from the one-to-one support provided by the project worker. Having the opportunity to discuss issues as they arose was the key to meeting individual carer needs. Other research suggests that dementia carers desire 'human contact ... empathy, understanding ...' (Cascioli et al. 2008, p. 22). Moreover, it became clear that the demands on the project workers fluctuated according to the different needs of carers. Program flexibility emerged as both a benefit and a challenge. Addressing carers' needs as they arose placed considerable pressure on the project worker. These demands were partially met through effective communication between the project worker, relevant care managers and BSL day-respite staff. The collaboration developed between areas within BSL Community Care Southern was beginning to have an impact, and was expected to increase in the third and final phase.

External factors were impinging on the program and influencing its outcomes. These factors ranged from carers' previous negative experiences of services and providers to a growing need for residential care. The program was judged by the project team and the project worker to be meeting these challenges. It was doing this in the following ways:

- through the focus on individual carer needs, revealing external factors affecting the care relationship and contributing to carer stress. This permitted the carer and project worker to address issues collaboratively.

- equipping carers with relevant skills and techniques to cope with external factors.

- linking carers with other services where necessary and collaborating with other BSL care staff to enhance service design and delivery.

These facets of the program would be enhanced in Phase Three.

Importantly, improvements in the evaluation techniques were also made. Through the Phase Two interviews, important factors affecting carer wellbeing were becoming evident and slight changes were made to the interview questions to explore these. Phase Three carers would be asked how long they had been caring and what precipitated their role as carers. This would produce a more detailed picture of the care relationship, allowing care situations to be compared. It also allowed the role of C4C to be better appreciated.

More significantly, it became evident during Phase Two that a three-way conversation had opened up between the project worker, care managers and BSL day-respite service staff, with carer needs as the focus. This would be further shown in a care manager focus group, to be conducted upon the completion of Phase Three, and through discussion with BSL day-respite service staff.

The program's aims were refined to reflect the preliminary findings from Phase One and Two. The goals were now to be:

1 Provide one-on-one training and support to assist carers in their caring role, and reduce carer stress and burden. This will be achieved by:

- flexible delivery of relevant training and discussion topics in the C4C training manual

- providing a safe and comfortable space for carers to discuss their caring role

- addressing current and future issues as raised by carers

- developing effective techniques to manage difficult dementia behaviour and generally improve communication between carer and care-receiver

- providing emotional and personal support

- providing those experiencing dementia with meaningful and fulfilling activities

- informing carers about relevant aspects of dementia

- providing information on different care options.

2 Communicate carers' needs to relevant BSL staff, such as care managers and day-respite staff, to enhance carer support services, improve formal care plans and formulate detailed carer support plans.

3 Increase uptake of respite and other relevant support services.

4 Provide a model which can be expanded across other services both locally and nationally.

Table 3.4   Phase Two evaluation summary

		Phase Two
1	**Context**	Carer wellbeing still considered a growing and pertinent concern C4C program model well developed
2	**Priorities**	Main goals and aims maintained, but less emphasis given to behavioural strategies; focus on supporting carers in a broader sense enhanced. Provide training and ongoing support to reduce carer stress and burden linked to difficult dementia behaviours. Assist carers to maintain their caring role by focusing on issues identified by them Increase uptake of respite and other support services Improve communication between care and care-receiver, project worker and care managers, and other relevant staff Provide a model that can be expanded or replicated
3	**Inputs**	C4C training manual adapted and further refined from STAR-C model to better suit the needs of different carers Training stage (in home): 8 weeks. Follow-up support stage (weekly or fortnightly phone calls with the option of home visits depending on carers' preference): 24 weeks One project worker working with partner carers. Carers with considerable diversity of backgrounds, experience in caring and knowledge of dementia. (All were caring for a partner in the advanced stages of dementia and had been caring for some time before the program commenced.) More resources, such as information on dementia and activities for carers and care recipients to do together, provided to assist the project worker.
4	**Outputs**	Five out of six carers in Phase Two completed the program. All carers were instructed in techniques and activities to manage difficult dementia behaviour and improve communication with care-receiver. Topics were delivered according to carer need. A wide range of resources, including books, DVDs, web material and games were provided to carers. Carers were interviewed three times; project staff were interviewed; background and satisfaction surveys were conducted
5	**Impact**	All who completed the program in Phase Two agreed strongly (on a four-point scale ranging from 'strongly disagree ' to 'strongly agree') that: • they had gained a better understanding of dementia as a result; • ideas developed during the project worker's visits helped them to make changes to daily life • talking about problems experienced reduced their effect • discussions about recent changes in habits and behaviours were helpful in their caring role • the printed information on dementia was helpful; • the program helped them to feel more confident as carers. They also all considered that they were coping better as carers and were feeling better about themselves as a result of C4C and found the weekly visits supportive. All except one carer found the program valuable or very valuable. All would recommend it to other carers. According to the project worker and relevant care managers, Phase Two influenced formal care plans and/or other BSL services. C4C prompted changes to be made to formal care services and in several cases this greatly enhanced carer experiences of respite and other services.

		Phase Two
6	**Outcomes – short term**	All carers in Phase Two were satisfied with the program.
		They valued most highly and consistently the one-to-one contact with someone who understood their situation. Most carers indicated that they had gained useful skills and practical advice which helped them to manage the caring role.
		Most carers reported feeling less stressed and found the person they were caring for to be more settled.
		Most were already using respite services prior to commencing the program, and all indicated that respite care was essential for their quality of life. Use of respite services increased for all of the carers involved in Phase Two, and many began using extended blocks of respite.
7	**Outcomes – short to medium-term**	The program met a variety of carer needs. These needs were met through practical advice, information about dementia, emotional support, assistance with filling out forms and information/advice on different care options.
		The program established a dialogue between the carer and project worker which was essential for carer wellbeing. This dialogue was extended to include care managers and other relevant BSL staff.
8	**Success factors**	One-to-one support in a safe and comfortable environment was the primary factor leading to success.
		Carers valued the opportunity to discuss issues as they came to light.
		The different training topics were delivered according to carer need.
		Communication between the project worker and other care staff allowed unresolved issues to be addressed.
		Dialogue between carers, project workers, care managers and other relevant staff emerged as an effective way to resolve various carer issues.
9	**Assumptions**	The evaluation confirmed the following underlying assumptions:
		• Support and training improved overall carer wellbeing.
		• Carers were able to better manage and maintain their caring role.
		• Carers also noticed that the wellbeing of care-receivers improved.
		• Respite and other services increased.
		• Improved service design and delivery to the benefit of carers and those they are caring for.
		• The model developed and delivered during Phase Two is able to be expanded to include more carers.
10	**External factors**	Through a concerted focus on carer needs, the current program was better able to address external factors such as the family history and family relations that shape care-giving.
		For many people with dementia, the progression towards permanent care was unavoidable. The program proved able to support carers during this difficult time. The training schedule included this topic, which was delivered when the carer is ready. C4C helped several carers to better prepare for and cope with decisions regarding permanent care.
11	**Potential long-term outcomes and ideas for improvement**	Program aims and goals could be realigned on the basis of evidence from Phase One and Phase Two
		It became evident that carers would benefit from continued support post-C4C.
		Attention to issues surrounding permanent care has been put in place.
		Improvements suggested for subsequent phases include enhancing the person-centred approach of BSL aged care and dementia services

Phase Three

Delivery of the program in Phase Three was staggered over 12 months. This meant that once the training stage for one group finished, the training for the next group commenced (see Table 3.5).

Table 3.5   Phase Three timetable

Phase 3	Training stage (8 weeks)	Follow-up support stage (24 weeks)
Group 1	April 2011 – May 2011	June 2011 – November 2011
Group 2	July 2011 – September 2011	October 2011 – March 2012
Group 3	December 2011 – January 2012	February 2012 – July 2012

Selection

A new cohort of participants was selected according to the same criteria as Phase Two. There was a significant increase in the number of participants, from six to twelve carers.

Table 3.6   Phase Three carers, Groups 1, 2 and 3

	Age group	Gender	Caring for	Living arrangement	Package/service level at start of C4C	Time caring (approx.)
Group 1	80–90 years	Female	Husband	Living together	EACH-D	2+ years
	80–90 years	Female	Husband	Living together	Accessing BSL respite services	5+ years
	70–80 years	Female	Husband	Living together	EACH-D	2+ years
	80–90 years	Female	Husband	Living together	CACP	2+ years
Group 2	70–80 years	Female	Husband	Living together	EACH-D	1+ years
	80–90 years	Male	Wife	Living together	EACH	3+years
	70–80 years	Female	Husband	Living together	EACH-D	2+ years
	70–80 years	Female	Husband	Living together	EACH-D	8+ years
Group 3	80–90 years	Male	Wife	Living together	CACP	5+ years
	50–60 years	Female	Husband	Living together	EACH-D	2+ years
	80–90 years	Male	Wife	Living together	EACH-D	3+ years
	50–60 years	Female	Mother (joint carers)	Living separately		

All carers except two were caring for a partner diagnosed with a medium to high level of dementia. The only exception was the husband/daughter carers who cared jointly for their wife/mother. Only three of the carers were male and all but one carer were receiving community care packages through BSL. One person was caring for a partner with younger-onset dementia.

One project worker was responsible for delivering Phase Three of C4C and had, through the two previous phases, developed extensive knowledge of the program. She had established an effective way to build rapport with carers; crucial again was conducting the training in the home with the option of providing follow-up support in the home also. The project worker had also developed important links with other stakeholders, such as care managers and BSL day-respite staff. (The links between BSL staff in related services are systematised through the TCM client system

database which stores information on care recipients, carers and other stakeholders, and allows it to be shared securely among relevant BSL staff).

Training

The training manual for Phase Three remained the same as for Phase Two but topics were delivered according to carer need rather than in a predetermined order. This flexible approach was enhanced as the following discussion reveals.

Observation

Carers of Phase Three were asked by the evaluation interviewer to reflect on what had changed for them since taking on the role of caring. This encouraged them to open up to the interviewer and provided crucial data on the care relationship and ways to improve and enhance carer wellbeing. Most revealed significant changes to their lives as a result of caring for their partner. Two different kinds of changes were clearly evident: first, changes in the partner as a result of dementia, and second, (usually expressed as a direct consequence of the first), changes to the lifestyle of the carer and partner. The nature of and subsequent responses to both types of change defined the particular care relationship. In some cases the carer had noticed slight changes in their partner's behaviour, memory and/or functioning, often many years before a diagnosis of dementia. In others the change had been sudden and dramatic, with a fall, stroke or a particular event, which in its turn precipitated a dementia diagnosis. The experiences of seeking help, assessment and services differed considerably among the carers. Most, however, considered their role as carers to have commenced well before an official diagnosis—and for some, well before their partners were put on a community aged care package. Nonetheless, carers all reflected that their time caring marked a major turning point in their lives and they drew on familial, social and work-related issues to describe the meaning of their new role. These factors, in turn, revealed both common and personal needs of carers, which the program had been designed to address.

Adapting to the changes brought about in their partners by dementia presented carers with a range of challenges. A carer looking after her husband with younger-onset dementia stated:

> We were fine until he got sick ... It's only been in the last two years that we don't have a relationship. He's just a man that lives in my house and he's certainly not the man I married; he's certainly not my husband and he's no longer my best friend.

She claimed further that 'I now feel like I have a fourth child'. Aside from a radically different relationship with her husband, this carer was also juggling parental and work responsibilities. Another carer's wife's dementia was slower to progress but just as challenging. 'We were like Darby and Joan', he stated. 'My main problems is to realise that [she] is child-like now, and I still treat her as the adult ... that I have always known ... I am having difficulties with that aspect of it'. All carers displayed some level of grief and/or loss when reflecting on the changes to their partners, which highlighted the difficulties associated with changing circumstances. The ability to adapt became crucial for carer wellbeing. As one carer said: 'I've got to adapt to it myself. It's hard'. With varying success, each carer was wrestling with this aspect of the care relationship at the commencement of training.

The changes in lifestyle precipitated by dementia and by the caring role were therefore equally challenging and revealing. 'We don't go out much' stated one carer, remembering how it used to be different: 'We'd go on trips … we'd go away, and that sort of thing ... we were in a couple of clubs, senior citizens clubs ... Well we have dropped out of that'. Another reflected: 'We used to go out a

lot ... we used to go every single year to Queensland for a holiday ... we used to look after our grandchildren ... we used to help our kids, and all of sudden all this stopped'. Carers drew on important aspects of their lives, such as caring for children/grandchildren, work and leisure, to express the extent of the changes. The majority of carers had little to time to spend on themselves, and all reported high levels of stress and burden.

All carers felt a strong obligation to provide what quickly became full-time care. Asked whether her caring was a natural thing to do, one woman replied:

> Well I do ... yes ... I think it's what I should be doing ... we got married to be together and we've been together for sixty years, so I'm certainly not going to give him up to a nursing home easily.

One man stated that 'Well we've been together sixty-odd years' and built a 'good life together' when asked what made him want to continue caring for his wife. Another carer also reflected on sixty years of marriage, stating that 'we have always done things together'. A third carer expressed the same sentiments: 'because we've always been together ... for sixty-four years ... so it's a long time. The sense of continuing obligation was crucial aspects to the care relationship.

Many of the carers involved in Phase Three considered themselves the best providers of care. 'I'm the doctor, I do it myself', stated one carer, 'I know how to deal with my husband'. This was important in defining their role, but could also increase the burden. One carer reflected that it was at first hard to accept help: 'We were just doing it ourselves'. This could prove a barrier to the use of extra services and thus contribute to carer burnout. In many cases, the C4C project worker helped carers to realise that they could benefit from additional help. They 'could open up' and let their 'guard down', according to care managers. Encouraging carers to feel more at ease accepting help was critical, as were suggestions on appropriate services and service providers.

Feelings of stress, strain, burden, loss and grief were common among all of the carers. These feelings were often intensified by limited knowledge about dementia and dementia care, particularly during the early stages of their caring role. One carer stated that 'we knew nothing' at first and she had felt ill-equipped to handle the early stages of her husband's dementia. Another carer felt alone and unsupported: 'You get the diagnosis and then you're left ... You never know where you're actually at'. This increased the carers' feelings of isolation and contributed to an inability to plan for future events. The project worker provided additional resources and information on dementia, which was highly valued by many. The literature on dementia made one carer 'realise what can happen in the future', while another carer whose first language was not English commented that the project worker helped her to understand relevant material on dementia, and provided translated information sheets when needed.

All carers were called upon to assist with feeding, dressing, bathing and other daily activities. They identified these activities as significant causes of stress. Many were providing round-the-clock care. The constant demand on carers' time was one of the most stressful aspects of caring, leaving them with very little time to spend on themselves. 'Sleep', as one carer observed, was 'the only spare time' she felt she had. Another carer stated:

> I have not been out I don't think for over two years or more to do any personal things for myself ... I just can't get out there ... I feel I've lost my own identity a lot.

A new structure for daily life was often required, and this too was a cause of stress. Slight adjustments suggested by the project worker could make a world of difference, however.

Many carers valued the practical suggestions. 'Alex', for instance, approached difficulties in a practical and considered way (see Box). He looked to the project worker to provide practical solutions. He stated further: 'As each circumstance arises I'm able to draw back on what was learnt'. What could appear to be minor adjustments in daily activities in fact made a profound difference: simply changing his wife's pyjamas from flannelette material to silk made it easier to help her in and out of bed. Another carer looked forward to the project worker's visit so that a particular issue could be discussed and hopefully resolved. If the project worker could not immediately find a solution, further information and appropriate supports were promptly sought.

Solving problems together: Alex

Alex had been caring for his wife of more than sixty years for over three years. He recalled a very different life prior to his wife's dementia. Work, home and lifestyle all had changed in a relatively short space of time. He admitted that prior to commencing the program he was really 'struggling' with the demands and challenges of caring. It was a 'completely different ball game' and he struggled to accept the changes affecting his wife.

He stated in the first interview that 'I am having difficulty realising that ... [she] is not the [person] she has always been' and that he 'had to be told' how to adjust and adapt. As a practical man, Alex desired to comprehend the intricacies of problems. On a number of occasions he brought up his experience as a marathon runner and the systematic way he approached the possibilities and limits of his own body. He applied a similar approach to his wife's problems and his capacity to cope with caring and to relax when necessary.

He valued the expertise of the project worker and together they would discuss the causes of problems, and attempt to remedy them. He reported that: 'Every aspect so far she's been able to help me because she's experienced in it'. He enjoyed learning new things and appreciated the resources the project worker provided. He also learnt to see things from a different point of view, and found that this was crucial for maintaining his caring role.

He looked forward to the project worker's visits and valued both the information and friendship gained from the program. Despite often feeling stressed Alex considered his caring role rewarding. He commented that he and his wife had 'been together for sixty years now ... through sickness and in health' and had 'had a good life together.' Referring to his wife as a loving and lovely lady, he said: 'She appreciates everything I do, and that makes it a lot easier ... that's the reward that I get ... we all want to feel that we are needed and wanted ...'

The project worker was able to implement techniques of diversional therapy to assist both carers and care-receivers. Providing a baby doll for one person made a remarkable difference, as did providing a fluffy toy dog for another, which the carer initially thought was pointless. In another instance the project worker initiated a life-history photo book, which the carer and care-receiver worked on together. Often carers and the project worker teamed up to find solutions to problems and make 'joint decisions'. This collaborative approach was also evident in the project worker's contact with care managers.

Aside from practical advice, C4C provided carers with an important avenue to express their feelings related to the responsibilities of caring. One carer valued the opportunity 'to be honest with

someone who understands the situation', while another reported that, with the project worker, 'All my worries are coming out, from my heart'. Indeed, most carers expressed similar sentiments. They also felt that the issues discussed with the project worker could not be discussed with family, friends or care managers. Many also felt a need for meaningful conversation, which was no longer possible with their partners. 'The worst thing of all', claimed one carer, 'is not being able to have a conversation'. Another carer described being 'starved of meaningful conversation'.

Thus C4C facilitated dialogue essential for carer wellbeing and problem-solving. It allowed carers to open up and discuss the feelings they experienced as a result of caring. No subject was off limits, and this provided a vital outlet for carers. Feelings of anger and frustration were just as prominent as those of grief, loss and love. According to care managers, the project worker was able to validate feelings of guilt and frustration. Moreover, barriers to carer support and respite could be overcome through information shared between the project worker, care managers and BSL day-respite service staff. The practical outcomes included improved formal care plans and additional support services, such as respite.

The project worker often acted as interface between carers and various support and care services. This was most marked in the project worker's communication and collaboration with relevant care managers. Carers appreciated how the project worker was able to link services together, and benefited from referrals to specialists such as physiotherapists. In the opinion of care managers, simplifying service delivery helped reduce carer stress. Moreover, as care managers noted, carers are required to deal with an aged care system that is 'tiresome and frustrating'; they have to repeat their story on countless occasions to various agencies and service staff. One woman found this particularly tiring, and found herself 'always filling out paperwork'. By working with other agencies and service providers in the interests of carers, the project worker was able to reduce the stress involved.

Overall, the project worker was able to validate different coping strategies. Some carers used humour and games to overcome obstacles, and the suggestions made by the project worker, such as the use of fake money and cheap jewellery, supported their approach. One man preferred to approach the demands of caring pragmatically. Together, he and the project worker sought logic in his wife's behaviour and developed practical solutions to numerous problems. Another carer's positive outlook and focus on her job and children was also reinforced through the person-centred approach of the project worker.

As the program progressed, C4C helped many carers to adapt in the face of increasing functional decline. One carer stated that her husband was getting worse day by day and that she was more stressed as a result. The project worker was helping her prepare for what the carer described as the worst outcome: permanent care. According to one care manager, the transition from community to residential or permanent care presents the carer with a unique set of demands, and the program was able to support carers during this difficult time. 'The disease is ravaging her brain', stated one husband, 'I can see her capacity to think properly decreasing'. This carer also had to start considering residential care for his wife. By the third and final interview, the majority of carers were considering other care options such as residential care. During the follow-up support period, the project worker was able to give carers information on different care options, which empowered them to make difficult decisions, as Joanne's story illustrates.

Facing tough decisions: Joanne

Joanne was a carer in her fifties and was looking after her husband who had younger-onset dementia. Five years previously her husband had begun to display a range of behaviours that were of concern. Initially she put the paranoia and the loss of personal and household items down to stress. But 'things never got better' and within a short time her husband had been diagnosed with dementia and was receiving a community care package with appropriate services. Everything changed: she lost her husband, best friend and father to the children.

Joanne described her experience as a carer as 'very tiring [and] very lonely'. She had no time to herself and the household was rarely calm. Her main concern was for her teenage children and she found it necessary to remain focused on them and their needs. She had initially stated that 'In my head I had always had a plan' not to put her husband into care, but during the program residential care became more likely. She described being torn about what to do and how to plan for this eventuality.

The project worker supported her through the process of finding a residential facility, and provided a non-judgemental, objective person to discuss issues and feelings with. 'I can tell her anything', Joanne said, 'the good, the bad and the ugly.' She didn't feel she could have the same discussions with the care manager, family or friends. While the project worker provided practical solutions to a range of problems, it was the opportunity 'to be more honest with someone who understands the situation' that was of greatest value and assisted her during a particularly difficult time.

The ability to plan and make critical decisions confidently helped to improve carer wellbeing. For many, the experience of C4C was 'life-changing', according to care managers. Typifying this outcome was the comment of one carer: 'I have learnt more courage ... I know I am not alone there ... I know that someone is out there thinking of me'.

Phase three summary

Overall, Phase Three proved the most successful incarnation of C4C, encompassing the refinement of the approaches trialled in previous stages. All of the carers expressed satisfaction with the program and felt that it had improved their wellbeing. They valued most highly one-on-one contact with the project workers in their homes. Significantly, the program gave carers options and choices that they had never dreamt of.

Table 3.7   Phase Three evaluation summary

		Phase Three
1	**Context**	Carer wellbeing remains a pertinent concern
		C4C program model well developed after two phases
		Project worker well versed and attuned to C4C program and carer needs
		Strong and growing support for program from care managers and BSL day-respite staff
2	**Priorities**	Provide one-on-one training and support to assist carers in their caring role, and reduce carer stress and burden. This will be achieved by: • the flexible delivery of relevant training and discussion topics as contained in the C4C training manual • providing a safe and comfortable space for carers to discuss their caring role • addressing current and future issues as raised and identified by carers • developing effective techniques to manage difficult dementia behaviour and generally improve communication between carer and care-receiver • providing emotional and personal support • providing those experiencing dementia with meaningful and fulfilling activities • informing carers on relevant aspects of dementia • providing information on different care options. Communicate carers' needs to relevant BSL staff such as care managers and day-respite staff, to enhance carer support services, improve formal care plans and formulate detailed carer support plans. Increase uptake of respite and other relevant support services. Provide a model which can be replicated across other services both locally and nationally.
3	**Inputs**	C4C training manual used as flexible guide and resource to address individual carers' needs Training stage (in home): 8 weeks. Follow-up support stage (weekly or fortnightly phone calls with the option of in home visits depending on carers' preference): 24 weeks: (Phased implementation with three groups – 12 carers in total) One project worker, working with partner carers. Carers with considerable diversity of backgrounds, experience in caring and knowledge of dementia. (All were caring for someone in the advanced stages of dementia and had been caring for at least two years before the program commenced.) More resources, such as information-sheets, literature and research provided to assist and support the project worker. More information on permanent care provided.
4	**Outputs**	All 12 carers completed the program. All carers were instructed in techniques and activities to help manage difficult dementia behaviour and improve communication with care-receiver. Topics were delivered according to carer need. A wide range of resources, including books, DVDs, web material and, games were provided to carers. Carers were interviewed three times; project staff were interviewed at critical points of program development; background and satisfaction surveys were conducted; a focus group of care managers was held.

		Phase Three
5	**Impact**	All carers who completed a satisfaction survey (9 out of a possible 12) agreed strongly (on a four-point scale ranging from 'strongly disagree' to 'strongly agree') that:
		• they had gained a better understanding of dementia as a result
		• discussions and ideas developed during the project worker's visits helped them to adapt and make changes to daily life
		• talking about problems experienced reduced their effect
		• discussions about recent changes in habits and behaviours were helpful in their caring role
		• the printed information on dementia was helpful
		• the program overall helped them to feel more confident as carers.
		They also all agreed that were coping better as carers and were feeling better about themselves as a result of the program; and all found the weekly visits supportive. All found the program valuable or very valuable and all would recommend it to other carers.
		Carers felt that the program helped them to adapt to the changes brought about by dementia.
		C4C provided carers with an outlet for feelings about the demands associated with the caring role
		According to the project worker and relevant care manager, Phase Three continued to impact formal care plans and/or other services provided through BSL. C4C initiated service delivery and efficiency in a number of areas, especially respite. In a number of cases this greatly enhanced carer experiences of respite and other services.
		Some care managers began to implement 'carer support plans'
6	**Outcomes – short term**	All carers in Phase Three were satisfied with program
		They valued most highly and consistently the one-to-one contact with someone who understood their situation and needs, and who was knowledgeable and experienced in the field of dementia care. Most had received useful practical advice and had gained useful skills to manage their caring role.
		Most carers reported feeling less stressed and found the person they were caring for to be calmer.
		Many carers believed care-receivers' wellbeing had improved.
		In general, carers felt that they could make decisions and better plan for future events
		Most carers were already using respite services prior to commencing the program, and all indicated that respite care was essential for their wellbeing. Use of respite services increased for most of the carers involved in Phase Three of the C4C program, and many began using extended blocks of respite.
		C4C helped to streamline care services and put necessary services in place.
7	**Outcomes – short to medium term**	The program met a variety of carer needs. These needs were met through practical advice, information on dementia and different care options, emotional support, and assistance with understanding and completing forms relating to care.
		The program established a dialogue between the carer and project worker which was essential for carer wellbeing. This dialogue was extended to include care managers and other relevant BSL staff.
		Carers became and felt more a part of the formal care relationship.

		Phase Three
8	**Success factors**	One-to-one support in a safe and comfortable environment was the primary factor leading to success. Carers continued to value the opportunity to discuss issues as they came to light. The training and follow-up support stages of the program validated different approaches to caring and different coping strategies. Training topics were delivered according to carer needs. Carers found solving problems and addressing issues collaboratively an effective approach to caring. Training and support components of the program were better integrated in Phase Three. Training, advice and support continued throughout the 32-week period rather than in discrete stages. This represented a highly 'person-centred' approach to dementia care. C4C program was effectively integrated with other BSL services and packaged care services and was proven to streamline access to particular services. The project worker acted as an interface between the carer and formal support structures.
9	**Assumptions**	The evaluation confirmed the following underlying assumptions: • Support and training improved overall carer wellbeing. • Carers were able to better manage and maintain their caring role. • Use of respite and other services increased. • Experience of respite was enhanced. • Many carers found the program empowering • The model is able to be expanded to more carers. (Replicating C4C in a different setting requires more research).
10	**External factors**	Through a concerted focus on carer needs, the current program was better able to address external factors, such as the family history and family relations that shape care-giving. For many people with dementia, the progression towards permanent care was unavoidable. Phase Three helped a number of carers to negotiate the difficult decision about permanent care, through the care focus of the program and the provision of information and emotional support.
11	**Potential long-term outcomes and ideas for improvements**	Programs available to support carers post C4C, such as carer support groups and other services provided through community packages, need to be considered. BSL needs to look at putting in place systems for sharing carer information with relevant staff. It is important that any process does not interfere with the current focus of the C4C program or the work of the project worker. The program could be expanded to involve more carers, and integrated more firmly with care plans through the application of carer support plans. Replicating C4C in other settings requires more research. (See Recommendations for further information).

Features such as the 'person-centred' approach, flexibility delivery and integration with other BSL services were refined during Phase Three. Moreover, the training and follow-up support stages of the program were better linked during Phase Three so that carers felt that they were being provided with 32 weeks of training, advice, support, information and companionship. In the end carers identified more strongly with the project worker than with the program as such. This reinforces the need for care to be taken in staff selection and training, but reveals the distinctive value of the program.

4 Conclusions

In a recent multinational review, Gallagher-Thompson et al. (2012) categorise five types of dementia-care intervention: individual and family counselling; psychoeducation; specialised skill training; multi-component training; and psychotherapy/cognitive behavioural therapy. C4C began as a specialised skill training program based on STAR-C, but evolved into a multi-component program combining skill training, behavioural therapy techniques, home visits and supports and the creation of structured carer support plans. The evidence suggests that multi-program interventions and approaches are the most effective way to address carer wellbeing and reduce the burden of caring (Gallagher-Thompson & Coon 2007; Torti et al. 2004). As such, C4C proved an effective program for reducing carer stress and burden, and through involvement in the program carers felt that they were more adept at coping with their caring responsibilities. An increased sense of wellbeing for carers was achieved in the following ways:

- One-on-one support in the home allowed carers to discuss and address particular issues and problems with the project worker. This proved an important outlet for feelings of burden, guilt and frustration, and also an effective way to address problems as they arose and in a collaborative fashion.

- Particular approaches— practical, behavioural, diversional and emotional—delivered during the training stage and tailored to different care situations were effective in reducing the impact and prevalence of difficult dementia-related behaviours and improved the communication between carer and care recipient. These approaches also enabled carers to address their own stress levels.

- Increased use of respite allowed carers to take much-needed and regular breaks from care.

- Information on dementia and different care options provided by the project worker empowered carers to make critical care decisions and better understand the process of dementia.

- Meaningful activities, such as photo-books and life history folders, for carers and care recipients helped to increase communication and wellbeing. While these were not applicable to all care situations, those carers who did use them reported positive results.

By making carers' needs the focus of the program, support was provided on a number of levels. At all times the support provided was tailored to the specific care situation.

Carers involved in the program unanimously supported this approach and appreciated the various options that C4C provided. They also felt that the program was attuned to their specific needs and they valued the emotional and practical support provided.

Additionally, and where appropriate, C4C provided a vital referral point to other services, such as counselling, respite and carer support groups. This assisted carers in navigating a complex care system and produced positive outcomes. This may be because multi-component programs better respond to the fragmented nature of the aged and community care systems, enabling carers to deal with multiple agencies, services and personnel. While this contention requires further testing, the program facilitated carers taking up additional support services such as respite and acted as a vital interface between the carer and the care system.

Thus, most of the initial goals and assumptions of the program were met. Where this was not the case, notably the assumption that participation in the program would enable clients to remain in the community indefinitely, adjustments were made to support the carer to cope with the transition to

residential care, which was usually unwelcome and unanticipated. As it happened many of the care recipients did transition from home and community care into residential, permanent care, during or shortly after their carers had completed the program. Where possible carers were supported by the project worker during this transition, and valued the support provided.

Carers themselves expressed their need for sustained support, with many believing that they would have benefited from an earlier intervention. Many more commented that they had been struggling with the demands of caring prior to commencing the program and that C4C was delivered at a critical moment in their lives. This in itself suggests that the demand for such programs will grow as we learn more about the burdens of care and the complex nature of the caring role.

All of the carers involved in the program valued the one-to-one contact with the project worker and the concerted focus on their needs. This 'person-centred' approach has become a mainstay of the Brotherhood's approach to community and aged care (see BSL 2009). It involves collaboration across numerous areas of the BSL, and also requires new levels of staff training. Clearly the C4C program is an important marker in this development, reflecting also the need for care providers to incorporate the needs of carers into the different types of services provided.

Overall, C4C emerged as a workable program of carer support able to be expanded to include more carers currently accessing BSL care services. It began largely as an experiment and evolved to become a highly effective and responsive program of training and support. This enabled improvements to be made in light of the evidence collected from stakeholders over three design and delivery phases. Phase Three marks the program's maturation and its successful integration with other BSL services.

As a program C4C was able to address the unique demands of caring for someone with dementia, particularly during the later stages. The person-centred, carer-focused approach proved adept at handling the dynamics of different care relationships and a wide variety of carer needs, particularly for spouse and partner carers.

Finally the program, along with this evaluation, confirms the action research method and the program logic as both a way to improve program design and delivery and a valuable evaluation tool. This is reflected in the continuous improvements made to the program in successive phases and the accompanying methods of observation and reflection. It shows also how stakeholders' views can be effectively integrated into program development and evaluation.

5 Suggestions for carer support services

The following suggestions are made as a result of the evidence presented in this evaluation, which will enhance carer support services generally and the C4C program in particular:

- Care staff should place more emphasis on listening to carers' experiences. In addition to providing practical and behavioural strategies, carer support services should link carers more closely to other relevant services. Developments could include introducing formal carer support care plans where appropriate.

- Carer support programs such as C4C should be developed and expanded to reach larger numbers of carers.

- Workers responsible for carer training and support should act as advocates for carers and carers' needs.

- Further support and resources should be directed to understanding and informing the community about the process of dementia and the role of caring for someone with dementia.

- Adequate support and information should be provided to carers negotiating care transitions, such as that between community care and residential care.

- Adequate and up-to-date training should be provided to care workers involved in delivering carer support services and programs.

- Care services and managers should look at additional ways to provide carer support services to carers at an earlier stage in the care journey

- The best ways of assisting different kinds of carers such as adult children should be explored.

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