FINAL EVALUATION REPORT

MOBILE RESPITE TEAM
BEGA VALLEY, SOUTHERN NSW

Samantha Abbato and Associates
January 2014
ACKNOWLEDGEMENTS

I would like to sincerely thank the clients of the Bega Valley Mobile Respite Team (MRT) service who welcomed us into their homes, gave of their time and generously shared, and in many cases “re-lived” their experiences in the telling of their stories with an openness and honesty that enabled an in-depth insight into their journey with dementia and the impact of the MRT on their lives. The participation of carers, people with dementia they are caring for and other family members was very much appreciated.

I would also like to thank the local Bega Valley stakeholders who participated in surveys or interviews. Finally I would like to acknowledge the assistance and generosity of the MRT workers and staff of the Alzheimer’s Australia Bega Valley for their openness to this evaluation and their assistance in recruiting evaluation participants, transporting us to homes around the Bega Valley and introducing us to their clients.
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**ABBREVIATIONS**

<table>
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<th>Abbreviation</th>
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<tr>
<td>AC-QoL</td>
<td>Adult Carer Quality of Life Questionnaire</td>
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<tr>
<td>DoHA</td>
<td>Department of Health and Ageing</td>
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<tr>
<td>GDP</td>
<td>Gross domestic product</td>
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<td>GP</td>
<td>General Practitioner</td>
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<td>MRT</td>
<td>Mobile Respite team</td>
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<td>NRCP</td>
<td>National Respite for Carer’s Program</td>
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<td>PWD</td>
<td>Person with dementia</td>
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<tr>
<td>QoL</td>
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<td>QoL- AD</td>
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<td>RAC</td>
<td>Residential aged care</td>
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EXECUTIVE SUMMARY

Alzheimer’s Australia NSW Mobile Respite Team service covering the Bega Valley Shire has been operating for more than ten years. It is currently funded by the Department of Health and Ageing (DoHA) under the National Respite for Carers Program (NRCP) until June 30 2014. The Mobile Respite Team service was externally evaluated from January to December 2013 to illicit the model on which it is based, compare the model to best practice for dementia carer support nationally and internationally, and assess the program’s effectiveness and potential application to contribute to aged care improvement in Australia.

Evaluation Methodology

A mixed methods evaluation approach (combined qualitative and quantitative methods) was used. The quantitative component included a pre and post survey administered to carers and the person with dementia (PWD) at commencement of the service and at the eighth visit of the mobile respite team (MRT) (n=7 participant pairs) and a satisfaction survey administered at exit from the MRT service for those already receiving MRT service at the commencement of the evaluation (n=10). In addition, an online satisfaction survey was administered to stakeholders (n=9).

The qualitative element included in-depth face-to-face interviews with carers, PWD and MRT staff, in-depth phone interviews with family members and service providers and document analysis including analysis of client case notes and client database. A total of ten client sets participated in in-depth interviews- including ten carers, four PWD and two family members. The qualitative methods were combined to develop case-studies presented as a multiple case report to describe the program model and provide evidence for the causal links of the MRT service in increasing the capacity of carers to continue in their role and increased time of PWD living in the community.

MRT model

MRT is a multi-component intervention that includes six main components to help caregivers of persons with dementia. It includes:

1. Psychosocial intervention
2. General support for the carer
3. Carer/Care recipient (PWD) relationship support
4. Respite
5. Individualised support and intervention for the care recipient (PWD) with a focus on re-enablement and meaning attribution.

In addition, the MRT intervention includes an additional component to the majority of psychosocial interventions for caregivers reviewed in the literature:

6. Supporting the carer and PWD through the transition into residential aged care.

The features of the MRT model include:

1. Multi-component intervention with five model components
2. Flexibility in dosage enabling change in frequency and duration of service based on changing needs
3. Increasing use of local community services and understanding of local contexts
4. Involving active participation of the caregiver
5. Involving PWD in the program as well as the carer
6. Involving the family of the carer and PWD where appropriate
Inclusion of both group and individual settings allowing both adaption to specific needs and increase in social support, including peer support.

Focus on enabling clients and increasing “sense of control”.

These eight features of the MRT model have been shown in the literature to be associated with: delayed institutionalisation, decrease in caregiver burden and depression, increase in caregiver subjective wellbeing, increased satisfaction with caring, increased ability and knowledge, increased social support and decreased morbidity and mortality of the carer.

**MRT Impact**

The qualitative interviews with MRT clients, family members, staff and service providers combined with review of the literature showed that the major impacts of the MRT service included:

1. Appropriate support, education and guidance incorporating social contexts and specific to the situation, needs and changing circumstances of clients and their families, delivered through a multi-component intervention reduces caregiver burden and increases time in community.

2. Supporting existing social networks and social support and replacement of lost social networks and social support including emotional and instrumental support contributing to better health, increased life satisfaction and decreased risk of burden in the carer.

3. Guiding clients in “navigating” the medical, aged care, legal, social and other systems required by their situation providing increased support and decreased stress.

4. Providing carers and care recipients and their families with support, guidance and a “sense of control” through the whole dementia journey, including the transition to residential care resulting in a more positive experience and decreased stress.

The quantitative analysis comparing carer and PWD quality of life (QoL) prior to receiving MRT service and at the completion of the eighth visit showed no significant overall increase in QoL of either carers or PWD.

However, median carer QoL overall remained in the mid-range QoL level as assessed through the Adult Carer (AC)-QoL instrument. One of the eight carer QoL subscales showing a significant improvement after the eighth MRT visit compared to first was their “Ability to Care” (p<0.05 based on Wilcoxon Signed Ranks test). Five of the seven carers completing the AC-QoL survey showed improved ability to take care of the needs of the person they are caring for including managing situations and making the PWD life better with the median score shifting from medium to high quality of life in this aspect.

The qualitative data provides evidence that the rapid progression of dementia experienced by MRT clients over a short period of time continues to work against positive impact the MRT service may have on the QoL of both carers and PWD as measured using QoL surveys.

**Client and stakeholder satisfaction**

Clients and stakeholders of MRT alike communicated extremely high levels of satisfaction with MRT service and staff.

All stakeholders demonstrated they clearly understood the goals and objectives of MRT.

All stakeholders were able to provide concrete examples of how MRT has helped carers and PWD in the region.

The only suggestion for improvement offered by stakeholders and clients alike was to increase the hours of the service from three days a week to at least five days a week.
**BACKGROUND AND INTRODUCTION**

Dementia is the single greatest cause of disability in older Australians (65+) (Australian Institute of Health and Welfare 2012). An estimated 1.2 million Australians are caring for someone with dementia (Alzheimer’s Australia 2-11) and family caregivers bear the main responsibility for people with dementia living at home.

Interventions that delay residential aged care placement by preventing overburdening of family caregivers are of considerable importance to society (Mittelman, Haley et al. 2006). Multi-component interventions shown to be effective include: those that increase the use of community care (including respite services and support), counselling, cognitive-behavioural therapy, interventions for care recipients, and psycho-educational programs (Pinquart and Sorensen 2006).

Not only is it of importance to individuals, family and society to provide support to caregivers in the community to increase the time people with dementia can live at home, it is also crucial to support a proactive approach to the transition of people with dementia (PWD) into residential aged care to minimise the negative outcomes associated with this transition (Alzheimer’s Australia NSW 2012).

Alzheimer’s Australia NSW Mobile Respite Team service covering the Bega Valley Shire has been operating for more than ten years. It is currently funded by the Department of Health and Ageing (DoHA) under the National Respite for Carers Program (NRCP) until June 30 2014. It operates on an innovative model that has evolved to provide support, respite, links to community services and a transition to residential aged care for PWD where appropriate. The service includes two support workers employed three days a week working as a team, one with a focus on working with the carer to provide education and support and the other simultaneously working with the care recipient (PWD)\(^1\).

In 2012-2013 financial year, the MRT provided service to 32 carer/PWD pairs and exited 19 sets of clients. Of the 19 client pairs exiting the service in 2012-2013, the duration of MRT service was 10.5 months (Range from 2 to 28 months). The frequency of MRT home visits varies depending on need and the average length of contact time for client visits is 2 hours, 15 minutes.

The MRT service and the model it is based on has until now never been documented or evaluated.

The Australian Government has recently embarked on a ten-year process to reform the aged care system. This reform aims to build an integrated system of supports that offer more choice and control to older people has a greater emphasis on restorative and preventative care and on addressing the needs of the ageing population. It includes a focus on tackling dementia and increased support for carers (Aged Care Reform Implementation Council 2013).

The Mobile Respite Team service was externally evaluated from January to December 2013 to illicit the model on which it is based, compare the model to best practice for dementia carer support nationally and internationally, assess the program’s effectiveness and potential application to contribute to aged care improvement in Australia.

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\(^1\) Care recipient and Person with dementia (PWD) are terms that are used interchangeably throughout this report.
EVALUATION METHODOLOGY

Overall evaluation design

The focus of the evaluation was on program effectiveness including eliciting the program model and assessment of whether the program model was effective and the program objectives met, satisfaction of clients and stakeholders and program sustainability and capacity building.

A program map was developed in consultation with Mobile Respite Team staff and this guided the evaluation. The project map is shown in Figure 1.

The evaluation was carried out between January and December 2013.

Methodology

A mixed methods evaluation approach (combined qualitative and quantitative methods) was used. The quantitative component included a pre and post survey administered to carers and the person with dementia (PWD) at commencement of the service and at the eighth visit of the mobile respite team (MRT) and a satisfaction survey administered at exit from the MRT service from March to November 2013. In addition, an online satisfaction survey was administered to stakeholders in February 2013. The qualitative element included the development of case studies based on in-depth face-to-face interviews with carers, PWD and MRT staff, in-depth phone interviews with family members and service providers, document analysis including analysis of client case notes and analysis of the MRT client database.

Pre and post client surveys

After consent to participate in the evaluation was obtained, the Adult Carer Quality of Life Questionnaire (AC-QoL) (Elwick, Joseph et al. 2010) and the Quality of Life- Alzheimer’s Disease (QoL- AD) (Logsdon, Gibbons et al. 1999, Logsdon, Gibbons et al. 2002) instrument was administered by MRT staff to all carers at entry into the MRT service from April 2013 (pre-survey) and again at the eighth visit by MRT (post survey). In addition, the QoL-AD was administered by MRT staff to PWD at entry into the service and at the eighth visit. Additional questions measuring change of knowledge of dementia, abilities in dealing with dementia as a carer and access to in-community services and support were included in the pre and post (eighth visit) carer’s survey.

A total of seven carer and PWD pairs completed a survey at entry into the MRT service and again at the eighth visit.

The carer and PWD survey instruments are included in Appendix 1 and 2.

Survey responses were entered onto an EXCEL spreadsheet by MRT staff. A sample of the data was checked for errors. The data was exported to IBM SPSS and analysed for changes in pre and post responses overall and on subscales of QoL using the non-parametric Wilcoxon Signed ranks test.

Client satisfaction surveys

MRT client satisfaction surveys were administered to carers exiting the MRT service who were already receiving MRT service at the commencement of the evaluation between March and November 2013.

The survey included questions about perceived increase in access to community support, knowledge of dementia and increased ability to care in addition to satisfaction with the service.

Ten carers completed a satisfaction survey.
The survey instrument is included in Appendix 3

**Stakeholder surveys**

An online satisfaction survey was administered to 14 MRT stakeholders from ten organisations nominated by MRT staff. Nine of the 14 stakeholders completed an online survey and they represented 7 of the 10 organisations. A copy of the online stakeholder survey is included in Appendix 4. The survey responses were exported and analysed in Microsoft Excel. A request was made in the survey for participation in a 30 minute phone interview to glean their perspective on specific client experiences of the MRT service for triangulation of client experiences based on client interviews, discussion with MRT team and review of MRT case notes.

**In-depth interviews**

In-depth face-to-face interviews were conducted with carers and PWD. Phone interviews were conducted with stakeholders. This interview data was additionally supported through face-to-face interviews with MRT workers and document analysis.

**Face-to-face interviews with carers and PWD**

Participants at various stages of involvement in the MRT service, representing different types of carer-PWD relationships (e.g. parent/adult child, husband/wife), different genders, different types of broader family situations (e.g. second marriages as well as first, supportive and unsupportive families) were selected to represent a diverse range of client types. Information sheets and consent forms were developed by the evaluator and administered to potential interview participants by MRT staff and a day, time and place (either at participants home or Alzheimer’s Australia NSW Bega office) was negotiated with clients prior to interviews. Interviews were conducted in early June 2013 by the external evaluator. The interview team (interviewer and note-taker) were introduced to participants by the MRT staff and once a level of rapport was established, the MRT staff occupied either the carer or PWD with an activity in another part of the house where the interview could not be heard or through an activity outside the house negotiated with the carer or PWD such as a walk or drive.

In-depth interviews with carers were of around 90 minutes duration and interviews with PWD lasted for approximately 30 minutes. The majority of interviews were conducted face-to-face and some interviews were conducted over the phone. The interviewer and note-taker alternated roles for each interview so that immediately after interviewing one client, the interviewer would take on the note-taker role for the next client.

A semi-structured interview schedule was used to guide interviews with carers and PWD. The interview schedules were used to ensure topic areas were covered but that the overall style of the interview was conversational.

The carer interview schedule included questions on: 1. Initial contact with MRT, why they needed it, how they knew of it and what made them start with the service, 2. What sorts of things they learnt about dementia from the MRT, 3. What difference MRT made to their relationship with the person they are caring for including management of behaviours, 4. What difference MRT made to their relationship with other family members, 5. Access to community support, respite services and other service providers, 6. Changes in quality of life and 7. Suggested improvements for MRT.

The PWD interview guide included broad open-ended questions on: 1. Good things about the service, 2. How the service has helped them, 3. What difference the service has made to their life, 4. How different their life would be without the service. A third party approach was used to
elicit more information from PWD as suggested by the literature (Allan 2000, Aggarwal, Vaas et al. 2003). For example, PWD were asked “What would you say about (MRT workers names) and what they did for you, if a friend asked you ‘How they helped?’ If a friend’s name was known through the interview with carer, the specific name of the friend was used in this sentence. Other specific prompts based on what the activities the MRT workers and PWD had recently done together as part of the service were used where possible. Photos of the MRT workers were used to remind PWD of the subject of the interview and shown to the PWD when they appeared to forget the topic of the interview.

To increase the validity of the qualitative data triangulation of: interviewer, perspective and data source were used (Patton 1987, Davidson 2005). All interviews involved an interviewer and a note-taker and each interview was discussed by the interviewer/note-taker team following the interview to increase the validity of interpretation and avoid bias of one person working alone (through triangulation of interviewer). To further increase validity, triangulation of perspective was used by interviewing the MRT workers and stakeholders about each client participating in an interview. Furthermore triangulation of data source was used by comparing interview notes with MRT case notes and quantitative data from the MRT client database and pre and post surveys.

A total of ten client sets participated in in-depth interviews this included ten carers of PWD, four PWD and two family members (both daughters) living interstate but closely involved with the carer and PWD and in regular contact with MRT. All interviews with carers and PWD were conducted face-to-face in the home or at the Alzheimer’s Australia NSW office. The two interviews with family members were conducted over the phone. The carers comprised of: 3 wives of PWD, 5 husbands of PWD and 2 daughters of PWD. Five of the PWD were placed in residential care and one PWD was unwell and as a result they did not participate in a face-to-face interview.

Saturation was reached in the interviewing where no new information was forthcoming from later interviews supporting the rigour of the qualitative case-study component of the evaluation (Lincoln and Guba 1985, Patton 1990).

**Phone interviews with stakeholders**

Stakeholders involved in the client cases interviewed were invited to participate in a phone interview to elicit the stakeholder perspective on the client cases participating in a face-to-face interview with a focus on assistance that MRT provided. Six stakeholders were interviewed. The average duration of interview was 30 minutes and the interview followed a semi-structured question guide for each of the clients they were familiar with. Questions included: (1) Most important things MRT did to assist client, (2) How the client journey would be different without MRT and (3) Whether the client could get this assistance from another source. In addition, questions were asked about each of the major themes of the MRT model arising from the in-depth interviews with carers, PWD and family members.

**Data analysis**

The survey responses were exported and analysed in IBM SPSS.

Qualitative thematic and content analysis was used to analyse the in-depth interviews and quantitative and qualitative data were combined to develop four case studies which are presented as a multiple case report (Yin 2014).
Figure 1: Program map of MRT

**INPUTS**
- Funding: DoHA- until 30 June 2014 (National Respite for Carers Program) $203,508 annually (including GST)
- Staff: 1 carer support worker (CSW), 1 respite specialist worker (RSW) 22.8 hours week each
- Alzheimer's Australia NSW, South East NSW Advisory Committee
- Consumer consultation meetings (Twice yearly)
- Referrals from other service providers

**ACTIVITIES**
- Promotion of service through local networks, meetings, flyers to medical services (for receipt of referrals)
- Assessment of referrals for eligibility
- In home identification of needs* of carer & PWD and appropriate interventions
- Respite activities provided for PWD by RSW, including diversional therapy & arranging day respite activities
- Short-term+ support provided to carer and PWD including: - access to support groups - assistance in planning for respite & residential care - Accessing community services & advocacy - Support & referrals for family issues
- Education provided to carer on - Understanding dementia - Services available - Working with difficult behaviours

**OUTPUTS**
- Number of referrals to MRT received
- Number of referrals accepted as clients
- Number of carer/PWD couples receiving assessment and needs identification
- Number of home-visits for each carer/PWD couple and overall
- Number of carer/PWD couples exiting the MRT program
- Duration of service received (calendar time and hours of service)
- Number of carers and PWD transitioning to appropriate in-community respite
- Number of referrals out to respite services
- Number of referrals out to non-respite services

**OUTCOMES 1**
- Increased access to community based support services and other relevant service providers
- Increased awareness of and access to respite services in the community
- Increased understanding of dementia for carer
- Improved behaviour management strategies, problem solving and relationships skills of carer
- Improvement in carers ability to manage broader family relationships impacted by the situation of PWD
- Increased in-community social support for carer and PWD
- Increase in perceived social support by carer and PWD
- Improved Quality of life for carer and PWD including increase in meaning, control and feeling of safety

**OUTCOMES 2**
- Increased capacity of carer to continue in the carer role
- Increased time living in home environment for PWD (delayed nursing home placement)
- Reduced stigma around dementia in the family and broader community

* Needs assessment covers the following 6 areas: Education, support, physical, emotional, social, spiritual
+ Support is delivered over around 8-10 visits over a time period between 2 to 3 months. After exiting, clients can re-enter service if they require it at a later stage.
**CASE STUDIES USED THROUGH THE REPORT**

Case studies were developed out of the qualitative content and thematic analysis of the in-depth interviews with MRT clients, staff and stakeholders, case notes and quantitative data on MRT clients. Each case study is a blend of one to two sets of MRT clients and the four case studies represent typical clients gleaned from the qualitative interviews.

The case studies are introduced at the beginning and their experiences are used as examples to illustrate the components of the MRT program model and as evidence of the effectiveness of the MRT service in the sections that follow.

Fictitious names are used for clients and locations to protect the confidentiality of the MRT clients interviewed. Quotes provided are actual quotes from participants.

**Case study 1: George and Joan**

George and Joan had been married for 53 years and are both in their early seventies when they first come into contact with the MRT. They have a daughter and a son both living interstate with families of their own. Both George and Joan had both began to notice some problems with Joan’s memory and although their GP told them it was just that “she was getting older”, they saw an advertisement in the local paper about an information session about Alzheimer’s run by Alzheimer’s Australia NSW offered locally. They attended and after talking to the facilitator arranged an appointment with a geriatrician and Joan received a diagnosis of early Alzheimer’s based on an assessment and scan. The facilitator followed up with the couple who confirmed a positive diagnosis and they were referred to the MRT service. The MRT service commenced home visits soon after referral for three months. Service was recommenced several times over a period of four years as the couple needed support through many behavioural and communication issues resulting from the disease’s progression. One of the major issues for this couple was the change in their roles in their relationship with George having to take on more responsibility and the major role in running the household. Stakeholders observed a likely breakdown within the home, the relationship and George’s health had it not been for the continued support of the MRT.

Four years after the first visit, MRT assisted Joan’s transition to RAC. Both George and Joan regularly attended the monthly MRT social groups including the carers support group and Coffee and Chat social group from the beginning of the MRT service. George continues to attend the carers support group six months after Joan was placed in RAC. He has recently assisted taking a new carer participant to the social group at the request of MRT. Over the four years a total of 80 MRT contact hours were spent with each of George and Joan as well as 42 hours of indirect (non-face-to-face) time.

**Case study 2: Sandra and Tom**

Sandra and Tom had been married for 50 years and were both in their mid-seventies when Sandra approached Alzheimer’s Australia NSW Bega office because of Sandra and her daughter’s concern with Tom’s behaviour over the last several years. The couple have a supportive family, three children and several grandchildren, one daughter in the area and the remaining daughter and son, interstate. The couple were referred to a geriatrician seeking a diagnosis and Tom was diagnosed with vascular dementia. They were supported by MRT as soon as the diagnosis was received. They received home visits at varying regularity over 13 months until Tom was placed into RAC. Sandra attended the monthly carers support group and both Sandra and Tom attended the combined social Coffee and Chat session for carer’s
and PWD. Sandra continues to attend the carers support group several months after Tom’s placement. Over the 13 months of service MRT spent a total of 64 direct contact hours with each of Sandra and Tom and 26 hours of indirect work.

Case study 3: Nancy and Bill

Nancy and Bill have been married for 20 years and are both in their mid-sixties. This is a second marriage for both and they both have grown children with families from their first marriages but not from their marriage together. Nancy has a brother, a daughter and a son who live interstate. They are supportive but only visit occasionally. Bill had three sons. One son died three years ago, one who has children visits only rarely and without the children and his son with diagnosed schizophrenia visits regularly. This son is upset by his father’s diagnosis and they have spent several nights drinking together in Nancy and Bill’s home as a way of coping. As a result of Bill’s deteriorating condition they have recently had to move from a large farm property into town and are in the process of trying to sell the farm. Bill had not been a particularly violent man in the past but as a result of the dementia had started acting violently towards Nancy and this was having a major impact on their relationship with Nancy considering leaving him as she was struggling to cope both emotionally and physically.

The couple were referred to MRT by the NSW Health Dementia Behaviour Advisory Management Service. They received home visits from MRT at varying regularity depending on changing need for 12 months which ended when Bill was placed into RAC. Both Nancy and Bill were continually encouraged to attend the MRT social groups but declined. Over the 12 months MRT spent a total of 44 direct contact hours with the couple and 30 hours of non-face-to-face work for the couple.

Case study 4: Susan and Jean

Susan is 81 year old Jean’s only daughter and her carer. Jean’s husband died five years ago and according to Susan, Jean’s memory and functioning took a sharp fall in the period following her husband’s death and from several surgical procedures in the past couple of years. Susan has no children and although she has her own home, she spends most of her time caring for Jean in Jean’s home. Susan and Jean were referred to MRT during a visit to their geriatrician. They have had regular home visits over four months and have been encouraged to participate in the monthly social group activities but as Susan still works, it is difficult for her to find time to attend. Susan and Jean have only been receiving assistance from MRT for just over two months and MRT have so far spent 8 hours of direct time with them and 9 hours of non-face-to-face time.
WHAT IS THE MODEL OF MRT?

MRT is a multi-component intervention that includes six main components to help caregivers of persons with dementia as shown in Figure 2. It includes: (1) Psychosocial intervention, (2) General support for carer, (3) Carer/Care recipient relationship support (4) Respite and (5) Individualised support and intervention for the care recipient, i.e. person with dementia. In addition, the MRT intervention includes an additional component to the majority of psychosocial interventions for caregivers reviewed in the literature. The MRT model includes: (6) Supporting the carer and PWD through the transition into residential aged care.

The features of the MRT model are highlighted in the section that follows on “Impact of the MRT service”. As Figure 2 shows, these eight features have been shown in the literature to be associated with: delayed institutionalisation, decrease in caregiver burden and depression, increase in caregiver subjective wellbeing, increased satisfaction with caring, increased ability and knowledge, increased social support and decreased morbidity and mortality of the carer.

Each of the five components of the model is briefly described below with examples provided from the four case studies.

(1) Psychoeducational intervention: The MRT workers provide educational information about dementia and caregiving-related issues from the beginning of their work with clients. This educational support involves an active participation of caregivers in applying skills learned one-on-one with the MRT worker. In addition, MRT provide strategies for both the caregiver and care-recipient to apply to their relationship with each other and broader family relationships. Through subsequent home visits they are guided by the workers in the application of these strategies. The case studies showed and the stakeholders interviewed emphasised that the education is tailored to the specific carer and PWD taking into account the context in which they live and that the regular contact assists in the development of their relationship with the clients and successful delivery of education. Furthermore, additional strategies are provided in the group format through the monthly support group held for carers. This allows carers to share strategies and experiences within a safe environment. PWD separately participate in a monthly activities group which provides them with support and enjoyable activities.

Example- Case study 1: George and Joan: Joan was increasingly having difficulties in completing household tasks and communicating and George was increasingly frustrated by this because for all their married life Joan had always done the cooking, cleaning and management of household finances. This was causing continued conflict in the couple. The MRT provided information about dementia explaining how the disease progressed and that these changes are the disease and not the person. The workers gave George and Joan strategies including “a time out” technique for when they became frustrated or agitated. The couple implemented these strategies between visits and reported that because of this they were getting along better.

George learnt additional strategies through the Carer’s Catch-up (carer support group). As he says that at the group, participants are asked to make suggestions to help the feelings of the person they are caring for. He says, “I understand more and the feelings. If she is not feeling good, give her a hug.”

Example- Case study 2: Sandra and Tom: When Sandra first started getting support she didn’t know what dementia was. MRT explained it to her and explained how dementia impacts on
personality and behaviour. They provided her with strategies including “going with the flow” rather than getting angry or confrontational in reaction to frustrating behaviour including accepting tea made with cold water and the alternative meal when Tom insisted he ordered the meal that she did when dining out. Sandra reported that because of this guidance on how to react from MRT, she lost the anger she had.

(2) General support for carer: General support provided includes; information about and referral to other agencies, providing access to community support, assistance with navigating the system and provision of emotional support and facilitation of new social networks. A major part of this work is assisting carers to navigate systems required including the medical, aged care, legal and government support systems.

Example- Case study 1: George and Joan: As Joan was no longer able to complete paperwork, MRT assisted George in completing forms, writing letters and getting in touch with doctors. Because George did not know how to cook, they provided him with information about Meals on Wheels and with some sample meals from the service for him to try. They also contacted services to assist with teaching George to cook. Social activities Joan was participating in were becoming too difficult for her. MRT discussed with Joan alternative activities including the social support group for people with mild to moderate dementia which she started attending.

Example- Case study 3: Nancy and Bill: As a result of dementia-related behaviour changes, Bill had started acting violently towards Nancy a few weeks after they had started receiving support from MRT. Bill had an appointment with a neurologist but was planning to attend this appointment alone. Nancy expressed her concern to MRT that the neurologist would only have Bill’s part of the story and no information about the violence at home and impact it was having on her. MRT suggested that she write a letter to the neurologist and make sure that he received this letter prior to the appointment with Bill. Nancy said that she wouldn’t have known it was appropriate to do this but that it changed the course of their lives as the neurologist then discussed residential care with Bill and without the additional knowledge would not have done so.

(3) Carer/Care recipient relationship support: In addition to working with the carer to assist them with strategies to apply to their relationship with the PWD and a re-enablement approach for PWD, MRT work with the carer and care recipient together to provide support for their relationship where this is appropriate. The sound working partnership between the two members of the MRT team provides a positive relationship example for this component of the MRT work.

Example- Case study 1: George and Joan: During a home visit requested by George at a Carer’s Catch up session, the MRT staff arrived at their home to find both George and Joan visibly depressed. The MRT staff met with George and Joan together to identify their main concerns and they elicited anger and frustration from both. George was frustrated in large part because of a lack of meaningful activities together with Joan and individually. Joan was frustrated by her increasing inability to express her emotions due to the progression of Alzheimer’s. MRT then put in place strategies both for working with George and Joan together and individually to increase the harmony in their relationship through the initiation of meaningful activities for the couple and one-on-one sessions with George to increase his understanding of Joan’s situation.
(4) **Respite:** Through the home visits respite is provided to the carer as one of the two workers spend time with the PWD. In addition, MRT provide information about local respite available and assistance in applying for financial assistance for respite. Different respite options are discussed concurrently by one worker with both the carer and PWD and then together as a group. They explain the importance of respite for self-care and the relationship. In many cases there is reluctance for carers to seek respite both as a result of lack of knowledge about what is available to them, and feelings of guilt and abandonment of the PWD. MRT workers ease the guilt of the carers and support both the carer and PWD in accessing respite, which in many cases provides a buffer for the relationship crisis many of the clients find themselves in when they access MRT.

*Example- Case study 1:* Until contact with MRT, George had not had any respite from his carer’s role. MRT assisted Bill in filling out Centrelink paperwork to receive financial carers allowance entitlements and for financial assistance for respite and informed him of respite services available in the region and arranged for Joan to be transported to regular once a week respite. He said he wouldn’t have done this on his own and that this respite “relieves” him for the day and enables him to continue to play social bowls.

*Example- Case Study 3:* MRT took Bill independently of Nancy to both a dementia specific day centre and an overnight respite facilities and activities to have a look and get a feel for what it would be like. The MRT worker helped him understand the importance of respite for his relationship with Nancy. With MRT encouragement, he accepted respite and reported enjoying many of the social activities that were involved while on respite.

(5) **Individualised support and intervention for the care recipient:** MRT work with the person with dementia includes assisting them in improving their competence at tasks through a re-enablement approach by encouraging them to continue activities that matter the most to them and introducing them to additional meaningful activities to assist and support memory and facilitate an increase in self-confidence and self-esteem.

*Example- Case study 3:* The MRT worker introduced Bill to memory enhancing activities on an IPAD and showed him how to send emails. He was referred to day respite which involved regular group memory activities and games which he reported enjoying a great deal. Bill was an intelligent man and importantly the MRT workers explained to him what was going on with the progression of dementia and at the same time encouraged him both to keep up current interests and take up new ones.

*Example-Case study 4:* The MRT worker introduced Jean to memory enhancing activities on an IPAD and encouraged her to continue the activities she had already engaged in prior to MRT.

(6) **Support of transition into RAC:** Most interventions to help caregivers of people with dementia reviewed in the literature do not include supporting the transition into RAC. It is noted that assistance with RAC placement is in contradiction to prolonging time in the community. The reality is that the majority of PWD will progress to a point where they can no longer be cared for at home and that preparing the carer for this eventuality and assisting them through the transition decreases the stress of the transition for both the carer, PWD and other family members and contributes to a more positive experience of one of the most stressful life events clients will experience. MRT incorporates this reality and a plan for this transition early in their service to clients.
Case study 1: MRT first assisted Joan’s placement into RAC care a couple of years prior to the placement by building up trust between MRT workers and both the carer and PWD and assisting them with organising respite care at a facility that was later able to offer a permanent placement. Both Joan and George participated in choosing a facility and were shown the facility and introduced to staff before respite and almost a year before eventual placement. They were supported both instrumentally and emotionally on the day of placement and in the early weeks following RAC placement.
Figure 2: Operational model of the MRT service

**Model Components**

**Psychoeducational Intervention**
- Providing information and strategies
- Skills development
- Guiding clients in applying knowledge/strategies
- Advice and assistance with family relationships

**General Support for Carer**
- Opportunity to share feelings and concerns as individuals
- Support groups for sharing feelings and concerns
- Referral to other services
- Assistance in navigating the system
- Emotional support
- New social networks

**Carer/Care Recipient Relationship Support**
- Relationship work- together and individually

**Respite**
- Regular respite through MRT for carer
- Arrangement of external respite

**Individualised Support for PWD**
- Re-enabling through individual work
- Group work to increase social connection
- Activities to assist in memory, self-esteem
- Activities to increase meaning
- Referral to other services for support and activities

**Support of Transition into RAC**
- Reinforce major attributes to smooth transition
- Emotional and instrumental support

**Model Features**

- Multicomponent intervention
- 6 model components

- Flexibility in dosage
- Change in frequency and duration for need
- Longer where necessary

- Increases use of local and other services through incorporating specific contexts, knowledge of region including services, understanding of social context

- Involves “active participation” of caregiver

- Involves PWD in the program as well as carer

- Involves the family of the carer and PWD

- Includes both group and individual settings
  - Individual- Adapt to specific needs
  - Group- Increase social support

- Focus on enabling clients
  - (both carer and PWD)
  - Increasing “sense of control”

**Associated Outcomes Evidenced in Literature**

- Delay or prevention of institutionalisation

- Decrease in caregiver burden and depression, increase in caregiver subjective wellbeing, satisfaction with caring, ability and knowledge

- Increased social support for carer and PWD

- Decreased morbidity and mortality
WHAT IS THE IMPACT OF MRT?

What is the impact of MRT on people with dementia, their carer's and families?

The qualitative interviews with MRT clients, family members, staff and service providers combined with the analysis of the QoL surveys and review of the literature showed that the major impacts of the MRT service included:

1. Appropriate support, education and guidance incorporating social contexts and specific to the situation, needs and changing circumstances of clients and their families delivered through a multi-component intervention facilitating a “sense of control” for both carers and care recipients, improving carer’s ability to care, reducing caregiver burden and increasing time in community;
2. Supporting existing social networks and social support and replacement of lost social networks and social support including emotional and instrumental support;
3. Guiding clients in “navigating” the medical, legal, social and other systems required by their situation;
4. Providing carers with support, guidance and a “sense of control” through the transition to residential care.

(1) Appropriate support, education and guidance and “sense of control” and “meaning” increases ability to care, reduces burden and delays RAC placement

The qualitative data shows that the MRT model of home visits involving two staff members over a period of time and increasing the frequency of visits when required, one working with the person with dementia and the other with the carer, is an optimal model for providing flexible support, education and guidance to people with dementia (PWD), their carer’s and families. The literature supports the effectiveness of this approach.

Evidence from studies show that working with the caregiver and the PWD simultaneously produces a significant improvement in caregiver burden, depression, subjective well-being, perceived caregiver satisfaction, ability and knowledge, and in some cases care-recipient symptoms (Brodaty, Green et al. 2003, Schulz and Martire 2004, Pinquart and Sorensen 2006). In addition, interventions combining several strategies such as education and skills development of carer, individualised support and intervention for the care recipient, respite and general support such as MRT generate larger effects than narrowly focussed interventions and have been shown to be significantly related to delayed institutionalisation(Brodaty, Green et al. 2003, Schulz and Martire 2004, Pinquart and Sorensen 2006). Furthermore, higher intensity interventions with more frequency and longer duration have been shown to have a greater positive impact on the carer than comparable interventions of lower intensity(Kennet, Burglo et al. 2000, Schulz and Martire 2004). Longer interventions have been shown to result in lasting changes in the lives of caregivers resulting in a greater likelihood of delayed institutionalisation (Brodaty, Green et al. 2003, Pinquart and Sorensen 2006).

Support and guidance to increase ability to care

The in-depth interviews show that, prior to the MRT service, carers are overwhelmed by the impact of dementia on their spouse or parent and the ramifications it has had on their relationships not only with the PWD but on their other relationships with family, friends and community. They are not accessing support they need, they know little about the disease and its impact and likely trajectory and do not feel prepared or in a state of mind to
make the large life-decisions they need to make for themselves and the person they are caring for. As Sandra (Case study 2) describes the situation before MRT support:

“I knew I had to do something. I was grasping at straws, at the end of my tether. It (MRT) was a straw. I am glad I grabbed it because it turned out to be a lifeline."

George (Case study 1) says:

“I think it is pretty good really...I’d be lost without it. I was surprised. I knew nothing about (dementia) until we got referred to (MRT).”

Through the MRT model, MRT workers are able to assist in relationship building between the carer and PWD through educating, supporting and guiding both individuals separately as well as other family members and then with the carer and PWD together taking into consideration the family and broader social context in which they are living. Both the carer’s and PWD see the MRT workers as close friends or “like family” and trust is rapidly established in the relationships with MRT workers. As one PWD says:

“It is almost like having an extra friend, except she’s my advisor also”

A carer says:

“We are one big happy family (with MRT), that is how I see it anyway...Like a brother talking to a sister.”

George’s daughter says: “(MRT) won (mum and dad’s) trust. They were quietly in the background but they were always there and that is what (mum and dad) needed through this experience. As mum and dad floundered more, they leaned on (MRT) more.”

Sandra (Case study 2) says:

“They are part of the journey with you and they become friends because they are not pushing you away because of the dementia.”

Almost all the carers interviewed said that they did not know what they would do without MRT support as they could not talk about the disease and how to understand and deal with it day-to-day because their social networks had diminished and many family members were in denial of the diagnosis. The MRT becomes a major, and in many cases the only, source of emotional and instrumental social support in the carer’s life. This need of the carer of PWD for these types of social support has been highlighted in the literature (Haley, Brown et al. 1987, Monahan and Hooker 1995, Lilly, Richards et al. 2003).

Clients talk about how through the home visits and working closely both with the carer and PWD, the MRT can see what the issues are and give the carer practical assistance with their relationship with the PWD. For example, most carers talked about the importance of MRT increasing their understanding that specific behaviours in the PWD is the disease and not the person themselves and gave them strategies to deal with specific behaviours. In addition, carers talk about how MRT provide them education and guidance in applying behavioural strategies to their situation. It has been shown that structured interventions requiring more active participation of the caregiver such as MRT are more effective than less structured interventions and education in a classroom format (Pinquart and Sorensen 2006). It has been shown that information provision increases caregiver knowledge but that it is only when caregiver education involves active participation of the caregivers that the interventions have a significant effect on caregiver burden, depression, subjective wellbeing and symptoms of dementia in the care recipient (Pinquart and Sorensen 2006).
The quantitative analysis of the QoL surveys (n=7) showed that the MRT service significantly improved carer’s “ability to care”\(^2\) over the first eight visits or approximately six months (p<0.05 based on Wilcoxon Signed Ranks test).

In many examples illustrated through the case studies, the MRT service is shown to alleviate caregiver burden through reducing relationship dysfunction, potential violence and crisis resulting from people not having support and specific education about the dementia. Carers and other family members remarked on the immediate response to their concerns. They said that knowing they can call and talk to one of the MRT workers immediately or that they would be called back the same day was comforting to them because of the need for emotional and practical support for difficult behaviours. As Sandra (Case study 2) says:

“He (husband with dementia) would make cold cups of tea. Without (MRT) I wouldn’t have been able to go with the flow. ‘Cause I was with (MRT) I lost the anger. I would say “thanks, that’s nice.”

Nancy (Case study 3) says: “I said I didn’t want to get to the hate and resentment stage. This was my aim. (MRT) helped me a lot to keep the openness between Bill and I. It made a difference. It gave me the strength to look at the relationship from a different point of view. It made me see that dementia acts on their personality in a way to make them angry and resentful…They gave me strategies based on their experience. Sometimes what they told me was effective and sometimes I got into defensive mode and it didn’t work.”

Some carers and family members interviewed noted that the limited availability of MRT and the Alzheimer’s NSW office, three days a week (Tuesday to Thursday) having been an issue when needing to talk to someone they trusted when facing a crisis resulting from a behaviour of PVD at home. As George (Case study 1) said, “I am comfortable talking to someone else in the office…I know who I am ringing…I don’t want to talk to someone in Melbourne or Timbucktoo!”

Nancy (case study 3) explains the situation when her husband was physically violent on a Friday: “I tried the Dementia Hotline but that finishes at 5. I tried Lifeline… that wasn’t very helpful. Lifeline said to go to a GP as soon as possible. I waited until Tuesday and came straight to see (MRT workers)”.

**Appropriate education and support tailored to the situation of the client**

A critical aspect of the education MRT provide carers is that it is specific to their social context and what they are capable of taking on board at the time. A common issue that arose in the in-depth interviews was carers’ concern about information overload and the emotional burden of having too much information at once about dementia and their situation. Typical comments by carers include that of Susan (Case study 4) who said: “They have been wonderful at feeding information to me” and of George (Case study 1)“ They were good because they did not bombard us with information…just ease us into it”. Carers appeared to be appreciative of learning about dementia and the implications gradually and not having to deal with difficult information all at once. Most are busy coping with the present stage of the illness and are often not ready to find out about the details of their longer term prospects.

\(^2\) Ability to care subscale (AC-QoL instrument) measures the extent to which the carer is able to provide care for the person they care for, how they cope with the caring role, and how they feel about their competency to care) (Elwick, Joseph et al. 2010).
The results of the carer surveys administered at beginning of the service and at the eighth visit (an average of 6 months later) support this approach. For example, the average (median) rating of their knowledge of dementia was “Average” (2.0) at both points of time. However, in contrast the survey at exit shows that all 10 carers surveys either agree (n=4) or strongly agree (n=6) that they have a better understanding of dementia and how it affects the brain as a result of the MRT service.

**Fostering a “sense of control” for carers and care recipients**

Carers note that the MRT provide guidance and reassurance and importantly do not tell them what to do so that carers feel in control of their decisions and relationships. As George’s daughter (*Case Study 1*) says, “They (MRT) were not pushy. They were positive. They would suggest things.” This aspect of the MRT model that ensures carers, care recipients and other family members feel control over their own situation whilst at the same time being supported emotionally and practically is consistent with the social epidemiological literature that shows that the sense of control over one’s life circumstances as well as having emotional and practical support contributes to positive health outcomes (Syme 1990, Lachman, Ziff et al. 1994, Berkman and Glass 2000).

**Optimising remaining abilities and sense of meaning and connection in PWD**

Alongside encouraging a “sense of control” in PWD, MRT also provided tailored one-on-one re-enablement approach of support and guidance to improve the competence of the PWD and optimise their remaining abilities and assist them in involvement in meaningful activities. Interventions that include optimising remaining abilities are recommended in the literature and are shown to have a positive effect on caregiver outcomes as well as on the PWD(Kasl-Godley and Gatz 2000, Pinquart and Sorensen 2006). In the interviews with clients with dementia, this aspect of the MRT appeared to have a significant positive impact on them. For example, Jean (*Case study 4*) who did not appear to remember much about MRT in the interview suddenly became animated when asked about a computer activity she did on an I-PAD recently with the MRT worker and said:

“I think that is a marvellous idea. I liked it. It is something I can do…We sat in the corner over there and (The MRT worker) shook it this way and that, you know… I think that is wonderful. (The MRT worker) said “there is no reason you can’t use it” and I told her “Well if you think so, I’ll be right!”

People with dementia want to be involved in meaningful activities and the activities that matter most to people are those that are intrinsically meaningful in the context of past experience and everyday life (Phinney, Chaudhury et al. 2007, Vernooij-Dassen 2007). Activities that provide a sense of connection and belonging making people feel that they still belong in the world and activities that support autonomy are critical (Phinney, Chaudhury et al. 2007). In providing individualised support to PWD, MRT work with the PWD to provide individualised, meaningful support by learning what is meaningful for the client in terms of their interests and activities. This assists them in associating meaning in their changing life.

For example, Bill (case study 3) had a long interest in his family history in farming and also poetry. The MRT worker brought and discussed poetry books that Bill was interested in to home visits and assisted him in using family history software and internet sites on an I-Pad both at home, respite and eventually at RAC.
(2) Supporting and replacing lost social networks and social support

There is now a vast amount of literature that shows the link between social networks and social support to mortality, morbidity and disability (Berkman and Glass 2000). House and others stated in an article in Science in 1988, “Social relationships, or the lack thereof, constitute a major risk factor for health-rivaling the effect of well-established health risk factors such as cigarette smoking, blood pressure, blood lipids, obesity and physical inactivity” (House, Landis et al. 1988). A recent meta-analysis showed a 50% increased likelihood of survival for participants with stronger social relationships (Holt-Lunstead, Smith et al. 2010). Higher levels of social networks and perceived social support in carers of people with dementia have been shown to be associated with better health, increased life satisfaction and decreased risk of burden in the carer (Haley, Levine et al. 1987, Vitaliano, Russo et al. 1991, Monahan and Hooker 1995).

The in-depth interviews show that the onset of dementia is associated with a decrease in social networks and social support and increase in social isolation of both the person with dementia and the carer. This is supported by the literature (Brodaty and Hadzi-Pavlovic 1990, Lilly, Richards et al. 2003). For example, Lilly and others reported that some caregivers and care recipients experience “shrinkage” in the circle of friends, “being dropped” by friends, being misunderstood by friends and having friends “wear out and get tired of hearing it”. For the carer, the loss of support includes the loss of social and emotional support from the person they are now caring for and decrease in contact with family and friends. Sandra (Case study 2) describes this decrease in social networks:

“When you have a partner with Alzheimer’s it is like a leper’s bell. People just fade away…”

George (Case study 1) who considers himself an introvert without many friends to begin with says:

“Most people don’t want to know about it (the dementia). Friends stopped coming…I can’t imagine what it would be like if I’d been completely on my own…Especially for me, I don’t have many friends.”

The MRT workers themselves provide a relationship of emotional and instrumental support to both the carer and PWD. This is consistent with the primary source of support for elderly being shown to be a confident who provides both emotional and instrumental support who is usually either a relative (other than spouse or children) or close friend (Seeman and Berkman 1988). It is an even more critical confidant relationship given the stigma associated with dementia and the reluctance of people to discuss the situation even with those they are close to. As Sandra (Case study 2) who has a close family says:

“(MRT) has taught me to open up and let it out because you don’t feel comfortable doing this even with your own family.”

Susan (Case study 4) says:

“I have no siblings. This is why it is good having (MRT) so I can talk to them. I don’t beat around the bush and I can talk to them…I haven’t needed to call them yet but I know I can and that they will call me back.”

Through the regular social groups for carers and PWD provided as part of MRT, new social networks and avenues of emotional support are made available to clients. The qualitative data from the in-depth interviews provide evidence that these avenues of support are
critical and have a large impact on the quality of life of both the carer and PWD. Sandra (Case study 2) explains:

“It seems to feel relaxed because they are going through the same as you. Compared to other people outside that have no idea of the pressure and the worry.”

Several carers continue to regularly attend these carer support groups after the person they are caring for has been placed into a residential facility and even after they have died. As George (Case study 1) who now lives alone after his wife he had been caring for had been placed in residential facility more than six months prior to the interview said about the carers support group, Carer’s Catch-up, he has been attending for five years and is still attending:

“I need (Carer’s Catch-up) more now than ever before. I am lonely…I am introverted…I look forward to it because there’s not much else I do, except bowling once a week.”

George has recently been asked by MRT to assist a new carer in attending the carer support sessions by transporting him to the sessions.

The literature shows that interventions for caregivers of persons with dementia that involve groups are more effective in increasing social support whereas individualised interventions may be more effective as they can be easily adapted to the specific needs of the caregivers (Pinquart and Sorensen 2006). Combining the group activities with the one-on-one supports is consistent with good practice as the combination of individualised intervention with group work of MRT provide the advantages of both individualised and group approaches.

In addition, the continued home visits by MRT assists in encouraging both carers and PWD to attend these support and social activities and in many cases this has been shown to take weeks or months of continued encouragement and in most cases once the carer or PWD attends these activities they are reported by them as positive experiences.

Group support has been shown to be an effective intervention for people with mild to moderate dementia for both building on coping strategies and reducing psychological distress (Kasl-Godley and Gatz 2000). There are several examples from the in-depth interviews of MRT clients with dementia responding positively to group activities. For example, Bill (Case Study 3) who has withdrawn from old friends since being diagnosed with dementia and sees little of his children and grandchildren, talks of his attendance at a regular dementia social group he was referred to by MRT:

“I love it! I wouldn’t miss going down there…I have no fear of talking now and I used to be a quiet fellow, I wouldn’t speak up.”

Another man with dementia who has recently started as a client with MRT lives alone and was very isolated and reluctant to socialise as he was embarrassed by not being able to remember people’s names. MRT encouraged him to attend social activities, organised with a local dementia specific day respite centre that all participants wear name tags and attended the first session with him to ensure he was happy. His enjoyment of the activity and his continued voluntary attendance at the day respite was a surprise to stakeholders and his daughter (care-giver) alike.

Sandra (Case study 2) explained how Tom would not go to the group for people with dementia but regularly attended the combined Coffee and Chat group (for carers and PWD) with her. She was surprised that even recently with the dementia progressing and having
been in RAC for six months that on an outing together he pointed out the group venue from the car and remembered being there.

The model of the MRT also includes supporting the relationship between the carer and care recipient and relationships with other family members. Helping spouses understand and manage the unavoidable strains in the marital relationship has been recommended in the literature as a strategy to support caregivers and PWD (Monahan and Hooker 1995). MRT works with the carer and care recipient separately and then together as carers and PWD alike, talk about the improvement in the quality of their marital relationship as a result of the MRT intervention. As Nancy (Case study 3) says

“(MRT) explained the behaviours are not Bill’s fault but the disease and told me not to take it to heart. This has helped and Bill has had less outbursts as a result”

In addition to supporting spousal relationships, MRT facilitated relationships with other family members through the provision of information and direct contact with other family members to help them understand the situation and to support their relationships with the carer and PWD and encouraging and facilitating contact and communication. Involving other family members has been shown to be particularly important for the health of spousal caregivers (Schulz and Martire 2004). As George’s daughter (Case study 1) who lives interstate said:

“Have MRT involved was like having a team and it really took the pressure off me… they provided informative and educational guidance and their responses always had a positive bent… They gave information to my brother who was in denial and didn’t want to be involved…It was good because giving information to my brother helped him understand the seriousness of the situation."

MRT also actively encourage carers to keep in contact with family members as this contact often decreases as a result of caring for someone with dementia. As Sandra (Case study 2) who has children and grandchildren interstate says:

“ I have conversations with my children but I can’t see my grandchildren. (MRT) have been adamant that I go see my children and grandchildren.”

(3) Guiding clients in navigating systems required by their situation

The in-depth interviews showed that navigating the medical system and government systems of support and the legal system is overwhelming for many carers of PWD. The trauma of the dementia diagnosis and caregiver situation in which they are thrust coupled with increased isolation, reduction in social support and relationship strain which in many cases includes a role reversal, can make the necessary navigating of these systems difficult.

Carers talk about needing assistance with communicating with doctors and medical specialists, understanding, completing and submitting forms for carer vs such as carer’s allowances, assisting in understanding legal information including wills, end of life planning including enduring power of attorney, respite care and residential care applications, access to community support services and billing and general finances. The practical assistance and emotional support MRT provide facilitates successful navigation of these systems, providing additional avenues of support and assistance to carers and reducing the additional stress these issues can cause.
For example, Nancy (Case study 3) explained how she needed assistance communicating with a neurologist to assist in the specialist understanding the broader social situation of her husband and herself. Her husband had become violent as a result of dementia. MRT advised her of ways to present the specialist with information about what was happening at home. She wrote a letter and made sure that this was received by the specialist prior to her husband’s appointment. Nancy explains:

“Because of this letter, it meant the doctor changed tack with his treatment. I wouldn’t have done this without (MRTs) advice. I would not have known that this was okay. So straight away, the doctor talked about him going into care. This changed the course of our lives. This was a critical moment.”

George (Case study 1) explained that his wife used to do everything including managing the finances and filling in forms and that he has not done anything like this in this time. He says that one of the most important things about the MRT was the assistance they provided in filling out forms to access Centrelink allowances and respite services.

Nancy (Case study 3) talks about how MRT assisted with end of life planning. She was not prepared to take on medical guardianship because of antagonism from her husband’s family. MRT assisted by being a sounding board on the issue and assisting in the paperwork and providing emotional support through her husband’s opposition to this decision.

Susan (Case study 4) explains that MRT alerted her to other organisations she did not know about that she can link into, including Commonwealth Care Link Centre. She said: “I didn’t know anything about this sort of stuff before…They work with behaviour. This has been great. I have used it a couple of times. I am tearing my hair out…A person answers this, not a machine… (MRT) point me in the direction of people I needed at the time.”

By the time most people access MRT they are close to crisis point in dealing with their caregiver situation. As Sandra explains:

“They help with the paperwork because it is daunting. You only have to do one thing wrong…This was really important…helping with the paperwork for filling out for respite and permanent care and you are not in a state to do this.”

Increased client access to services as measured at eighth visit and exit from the service

The quantitative data shows that there was no increase in access to respite and non-respite services in the community over the first eight visits of MRT with the median rating of access to these services at both time points being “average” (n=7). However, by the time of exit from MRT service, 7 of 8 participants said their access to respite services had improved and 3 of 6 participants said their access to non-respite services had improved as a result of MRT. Seven carers strongly agreed and 3 agreed (n=10) that as a result of MRT service, they have a better knowledge of how to access dementia supports and services when they need them.

(4) Providing carers with support, guidance and a “sense of control” through the transition to residential care

The transition from home care to residential aged care (RAC) has been shown to be a highly stressful life event for the carer, person with dementia and other family members (Alzheimer’s Australia NSW 2012). For the carer and family, placing a person with dementia...
into RAC is often characterised by emotional upheaval and feelings of relief, loss, grief and guilt. For the person with dementia, the move to RAC can be disorienting, disempowering and emotional (Alzheimer’s Australia NSW 2012). The in-depth interviews supported this with the conversation around RAC placement often causing tears and discussion of loss, grief and guilt in carers.

Through their regular contact with carers and PWD from mild to moderate stages of dementia and the relationships of rapport and trust they have built with them, MRT workers are in a strong position to support a smooth transition to RAC that gives clients a sense of control over the situation. MRT are able to reinforce the four major attributes that have been shown to predict a positive experience when moving into residential care: (1) Anticipation, (2) Participation, (3) Information and (4) Exploration outlined by Nolan and others (Nolan, Walkerm et al. 1996).

(1) Anticipation: MRT raise the issue of RAC placement early in their discussions with clients and prepare both carers and PWD for the eventuality by gradually feeding them information about RAC through conversations about respite and progression of dementia. As this George (Case study 1) says:

“(MRT) were pressing me all the time to have respite, even when Joan was alright, as they knew Joan had to get used to respite as it (RAC) would eventually happen…They were doing a bit of “brainwashing” on Joan to bring her around to the idea of going into care….This was probably a good strategy.”

(2) Participation: MRT workers make sure that the person with dementia and their carer participate in the decision making process. For example, they suggest different options for respite which also have permanent care capacity and they discuss with the carer and PWD their specific needs and preferences. As Nancy (Case study 3) says:

“They took my husband to an aged care facility to have a look. They said to him that they would have taken him to others. This one was close to home and he had been in this one for day respite…If he decides to go to care then this is better. This is what happened.”

(3) Information: Information on respite and RAC is provided to clients early on including options and costs and both carers and PWD have the opportunity to ask more about this in regular home visits.

(4) Exploration: The alternative types of care available, range of care-homes and emotional responses to the prospect of placement by the carer and PWD are explored through MRT. The MRT workers take the carer, PWD and family members to look at local facilities and meet the staff enabling them to make an informed decision on placement in RAC. George’s daughter (Case study 1) explains that MRT took her parents and herself and her husband to different facilities which “helped alleviate a lot of fears as we could see that the homes aren’t as bad as you tend to think from media portrayals.”

In addition to covering the four major attributes to smooth the transition into RAC, MRT through their close working with clients and their families have a sound knowledge of the needs and obstacles of the family to decrease the stress of placement itself.

George’s daughter (Case study 1) describes how when her mother needed to be taken to RAC, MRT knew the specific family obstacles and assisted by taking her mother to RAC because her husband of 50 years, her carer, would not take her because he knew he
would be leaving her and it was too difficult for him emotionally. The daughter also knew that her mother would not get in the daughter’s car when it was time to go, so it was decided that she would go with the MRT workers. As the daughter explains:

“(MRT workers) had built her trust over the years… She wouldn’t (cooperate with family). She would nod and smile and cooperate (with MRT)…When they needed to take her to full time care, they knew that she would get into (MRT workers) car. So I met them at the centre…We thought dad would have picked her up again and taken her home… so (MRT workers) and I talked about it. We talked about a strategy…We took dad back to Sydney with us for a while.”

They were also able to arrange for the couple to attend one of the MRT social functions earlier that day so “mum and dad were able to have a nice outing together before the afternoon check in…Dad had been looking forward to the party and it meant he wasn’t sitting in the house with mum waiting for when she was being taken into care.”

Furthermore, MRT are able to provide emotional support for the transition through continued visits to both the carer and PWD and the support groups for carers to continue to attend before, during and after this transition. It has been shown that support through informal and formal support networks were associated with more positive experiences of moving a person with dementia into RAC (Alzheimer’s Australia NSW 2012).

The value of MRT reinforcing the major attributes shown to assistant client’s transition into RAC in their work with clients has also been demonstrated through examples of emergency respite care being more achievable and less stressful for PWD in cases where carer requires hospitalisation with little notice. For example, a stakeholder advised that when the carer husband of a PWD was admitted to hospital, as a result of the MRT service, the PWD was already aware of where she wanted to go for respite and the carer had already completed the paperwork after an early familiarisation visit to the RAC facility arranged by MRT.

**What is the impact of MRT on people with dementia and their carers QoL measurable through QOL instruments?**

The case studies and the literature both show the detrimental impact the progression of dementia has on the quality of life of both the PWD and the carer. The qualitative data shows the buffering effects of the MRT service on the effects of the dementia journey on quality of life.

The quantitative analysis showed no significant change in overall quality of life for either the carer or person with dementia from the first visit by MRT to the eighth visit, an average of 6 months later. This is not surprising given that by the time carers and PWD are referred to the MRT service the dementia is in many cases well progressed to at least a moderate stage.

The analysis of the QoL-AD administered to PWD, shows by contrast a decrease in QoL for PWD over the average six month period between surveys (p=0.09, 2-sided Wilcoxon signed-ranks test). Based on the survey results, five of the seven participants experienced a decrease in quality of life. The QoL-AD surveys administered to carers concurred with an overall decrease in PWD QoL as rated by the carers and with four of the seven demonstrating decreased QoL. Interviews with the MRT workers also concurred that the
PWD expressed in many cases a great awareness of decreased QoL at the time of the follow-up survey.

However, interestingly, the PWD consistently scored their quality of life, higher than their carer’s did. Table 1 below shows the median scores (and range) on QoL-AD for both PWD and carers at commencement of service and eighth visit.
### TABLE 1: Comparison of carer and PWD scores on QoL-AD (14 items)

<table>
<thead>
<tr>
<th>Time point</th>
<th>PWD</th>
<th>CARER</th>
</tr>
</thead>
<tbody>
<tr>
<td>At entry into MRT service</td>
<td>39 (32-44)</td>
<td>28 (22-32)</td>
</tr>
<tr>
<td>At eighth visit</td>
<td>35 (28-46)</td>
<td>29 (19-34)</td>
</tr>
</tbody>
</table>

The carer quality of life as measured by the AC-QoL tool showed no significant improvement in QoL from the first to the eighth MRT visit. The median score at entry was 60 and at eight visit 57. Based on suggested score interpretation, both scores suggest a mid-range reported quality of life (defined as scores between 41-80) (Elwick, Joseph et al. 2010).

The eight subscales of QoL contained in the AC-QoL tool were analysed separately for changes from entry into the service to the eighth visit. The “Ability to Care” was shown to significantly increase over the period of eight visits. “Ability to care” measures the extent to which the carer is able to provide care for the person they care for, how they cope with the caring role and how they feel about their competency to care. This is one of the main focuses of the MRT service as described through the case studies.

There were no other significant increases in carer quality of life. Table 2 below shows the median scores (with interpretation) at entry and eighth visit for each of the AC-QoL subscales.

### TABLE 2: Comparison of QoL-AD subscale scores

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Score at entry into service</th>
<th>Score at eighth visit</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Median (range)</td>
<td>Interpretation</td>
</tr>
<tr>
<td>Support for caring</td>
<td>10 (8-15)</td>
<td>MID RANGE QOL</td>
</tr>
<tr>
<td>Caring choice</td>
<td>4 (0-14)</td>
<td>LOW QOL</td>
</tr>
<tr>
<td>Caring stress</td>
<td>6 (0-15)</td>
<td>MID RANGE QOL</td>
</tr>
<tr>
<td>Money matters</td>
<td>8 (3-14)</td>
<td>MID RANGE QOL</td>
</tr>
<tr>
<td>Personal growth</td>
<td>8 (3-11)</td>
<td>MID RANGE QOL</td>
</tr>
<tr>
<td>Sense of value</td>
<td>6 (2-13)</td>
<td>MID RANGE QOL</td>
</tr>
<tr>
<td>Ability to care</td>
<td>10 (7-13)</td>
<td>MID RANGE QOL</td>
</tr>
<tr>
<td>Carer satisfaction</td>
<td>9 (2-12)</td>
<td>MID RANGE QOL</td>
</tr>
</tbody>
</table>

The MRT workers noted that that administration of the AC-QoL provided useful practical information as a diagnostic tool to assist in understanding areas of carer life for tailoring MRT support. In contrast, the QoL-AD resulted in reflection of both the PWD and carer of reality of their in many cases diminishing quality of life more generally. The MRT workers
reported this as less helpful in identifying areas for intervention and in some cases, a distressing experience for clients.

Are clients and stakeholders satisfied with MRT?

Clients and stakeholders of MRT alike communicated extremely high levels of satisfaction with MRT service and staff.

Client satisfaction

All clients interviewed expressed exceptional levels of satisfaction with the MRT service. When asked what could be improved about the MRT service, client comments included:

“We are privileged to have this group down here. Just put down on there, “They are a God send!”” Sandra (Carer)- Case Study 2

The daughter of George (Case study 1) said:

“Things were always done in a good way. The service was invaluable. Mum and dad would have been at the hospital more and mum would have been in care earlier without the program. Dad would have had health issues.”

All clients interviewed said they would unequivocally recommend the service to others and many expressed a desire to give back to the MRT service in a voluntary capacity because of all it had given them.

The only improvement suggested by clients was extension of the MRT service hours from three days a week. Clients provided examples of feeling that they needed to contact the MRT service for advice and guidance in crisis situations. Many felt comfortable contacting the Alzheimer’s Australia office on the two weekdays that MRT was unavailable but they expressed that weekends were difficult and in some cases would wait in preference to accessing help from services available on weekends (even though MRT staff had provided contact details of several other services including emergency numbers).

For example, George (Carer, Case study 1) said of a crisis he had experienced late on a Friday:

“I would have liked to have talked to (MRT staff) or even (Alzheimer’s Australia Office Staff), not some government phone line. I didn’t call any of the numbers I had been given. I just battled on.”

The exit satisfaction survey results (n=10) supported the qualitative findings of high levels of client satisfaction with the MRT service. The survey results show that of the ten clients completing an exit satisfaction survey:

- All 10 (100%) rated the quality of service they received as “Excellent”
- All 10 (100%) rated the quality of staffing as “Excellent”
- All 10 (100%) said that their needs were “fully met” by the MRT service.

Stakeholder satisfaction

The results of the online stakeholder survey show that of the nine stakeholders responding:

- All 9 (100%) rated the MRT service as “Excellent”
- All 9 (100%) were extremely satisfied with their professional relationship with the MRT
All 9 (100%) could provide examples of how the MRT has assisted clients living with dementia and their carers.

None of the stakeholders could provide an example of MRT being unsuccessful in providing assistance to clients.

Figure 3 below shows the stakeholder rating of the various aspects of service provided by MRT. The majority of stakeholders rating the MRT service as “Excellent” for each of the eight aspects covered by the survey.

**Figure 3: Summary of stakeholder satisfaction of aspects of MRT service**

In the open-ended responses to the online survey and in-depth phone interviews, stakeholders frequently described the MRT service and staff as: professional, effective, efficient, knowledgeable, supportive, open, capable, committed and communicative. There is a theme of great respect and value for both the MRT service and staff. As one stakeholder summarises the MRT service:

“It is a professional service that offers a unique and much needed service in the Bega Valley by providing respite and carer education for people with difficult behaviours related to dementia. The service is highly regarded and much valued by other service providers, clients and the community.”

All stakeholders demonstrated they clearly understood the goals and objectives of MRT. All stakeholders were able to provide concrete examples of how MRT has helped carers and PWD in the region. Consistent with the client comments, the only suggestion for improvement offered by stakeholders is to increase the hours of the service.
KEY RECOMMENDATIONS

The key recommendations from the evaluation of the Mobile Respite Team service include:

- The good practice, holistic and continuity of care approach of MRT with demonstrated value in increasing carer ability to care for PWD evidenced from both the current evaluation and literature continue in the Bega Valley.

- The name of the service be changed to better reflect the holistic model of the service of which “respite” is but one of six components.

- The MRT service and its effectiveness as evidenced in this evaluation and literature be promoted locally to services, GPs and specialists as part of improving local referral pathways.

- The documented model of MRT and evidence of effectiveness of this holistic approach in supporting and enabling carers and PWD presented in this evaluation report be used to inform Federal and state governments, including the Aged Care Reform Implementation Council for the development of Australia-wide approaches to increasing support for carers and addressing the increase of dementia in the Australian community consistent with an intended reform to provide more choice and control to older people and support for carers.

- For continued application of the model of dementia care support in Bega Valley and introduction of this model elsewhere in Australia particular attention be given to:
  - Appropriate staffing selection- The teamwork approach and relationship between members of the MRT staff team was a critical component of success;
  - Strengthening referral pathways through informing local services, doctors and relevant specialists of the service and the value of this holistic support.

- To promote and advocate for the inclusion of carer group support programs in RAC facilities.

- For continued service data collection and evaluation
  - Data collection systems be tailored to reflect the two worker/two client nature of work rather than inadequately record as one worker/one client intervention work;
  - To cease the use of QoL-AD instrument with PWD;
  - To continue to use the AC-QoL instrument as a diagnostic (to identify carer needs) and evaluation tool (to measure impact of service on carer QoL including ability to care)at regular intervals of the service (for example, at every eighth visit or every six months of service provided);
  - To continue to use Carer satisfaction surveys on exit from the service and enter and monitor satisfaction data.
REFERENCES


Alzheimer’s Australia (2-11). Pfizer Health Report Issue #45- Dementia, Pfizer Australia.

Alzheimer’s Australia NSW (2012). The most difficult decision: Dementia and the move into residential aged care. North Ryde, Alzheimer’s Australia NSW.


APPENDICES
APPENDIX 1

MRT Evaluation – CARER INSTRUMENT (INCLUDES AC-QoL)

Instrument to be administered at: (1) initial session, (2) at eighth visit

Complete this part prior to interview

<table>
<thead>
<tr>
<th>Carer name: _______________________________</th>
<th>Client (PWD) name: _______________________________</th>
</tr>
</thead>
<tbody>
<tr>
<td>Client code (AA): _________________________</td>
<td>Date: __________________________</td>
</tr>
<tr>
<td>MRT Worker: ______________________________</td>
<td>Assistance provided with survey:</td>
</tr>
</tbody>
</table>

Stage of participation (Please tick): 1. Entry 2. Exit 3. 3-month follow-up

Date of birth (Carer): _______________ Postcode: _______________ Gender: 1. Male 2. Female

Country of birth (Carer): _______________ Aboriginal or Torres Strait Islander: 1. Yes 2. No


The following questions ask about different aspects of your life as a carer. Please think about your experience as a carer within the last two weeks and please tick the box that applies next to each statement. There are no right or wrong answers; we are just interested in what life is like for you as a carer and how you feel about your role as a carer.

This questionnaire should not take longer than 15 minutes.

Please answer all questions as honestly as you can.

<table>
<thead>
<tr>
<th>Support for Caring</th>
<th>Never</th>
<th>Some of the time</th>
<th>A lot of the time</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q1. I have a good level of emotional support</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
</tr>
<tr>
<td>Q2. My needs as a carer are considered by professionals</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
</tr>
<tr>
<td>Q3. I am happy with the professional support that is provided to me</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
</tr>
<tr>
<td>Q4. I feel able to get the help and information I need</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
</tr>
<tr>
<td>Q5. I have all the practical support I need</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Caring Choice</th>
<th>Never</th>
<th>Some of the time</th>
<th>A lot of the time</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q6. I feel that my life is on hold because of caring</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
</tr>
<tr>
<td>Q7. My social life has suffered because of caring</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
</tr>
<tr>
<td>Q8. I feel I have less choice about my future due to caring</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
</tr>
<tr>
<td>Q9. I feel I have no control over my own life</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
</tr>
<tr>
<td>Q10. Caring stops me doing what I want to do</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
</tr>
</tbody>
</table>
### Caring Stress

<table>
<thead>
<tr>
<th>Question</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q11. I “feel” depressed due to caring</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q12. I feel worn out as a result of caring</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q13. I am mentally exhausted by caring</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q14. I am physically exhausted by caring</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q15. I feel stressed as a result of caring</td>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

### Money Matters

<table>
<thead>
<tr>
<th>Question</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q16. I worry about going into debt</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q17. I feel satisfied with my financial situation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q18. I am able to save for a rainy day</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q19. I worry about money</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q20. There is enough money in our house to pay for the things we need</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Personal Growth

<table>
<thead>
<tr>
<th>Question</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q21. I have become a more tolerant person through my caring role</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q22. Because of caring, I have learnt a lot about myself</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q23. Because of caring, I feel that I have grown as a person</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q24. I have experienced many positive things through caring</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q25. I feel that I have become a better person by caring</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

### Sense of Value

<table>
<thead>
<tr>
<th>Question</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q26. I feel valued by the person I am looking after</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q27. The person I look after respects me for what I do</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q28. The person I look after makes me feel good about myself</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q29. I get a lot from the person I am looking after</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q30. I am happy with my relationship with the person I am caring for</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Ability to Care

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Some of the time</th>
<th>A lot of the time</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q31. I am satisfied with the way I am caring</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q32. I can take care of the needs of the person I am caring for</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q33. I feel I am able to make the life of the person I am looking after better</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q34. I can manage most situations with the person I care for</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q35. I am able to deal with a difficult situation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Carer Satisfaction

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Some of the time</th>
<th>A lot of the time</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q36. Caring is important to me</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q37. I resent having to be a carer</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q38. I feel frustrated with the person I am caring for</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q39. I enjoy being a carer</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q40. I am satisfied with my life as a carer</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Using the rating scale below, please rate your current knowledge, abilities in the following areas and your access to support services

### Knowledge of dementia and abilities in dealing with it

<table>
<thead>
<tr>
<th>Question</th>
<th>Very poor</th>
<th>Poor</th>
<th>Average</th>
<th>Good</th>
<th>Very good</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q41. My understanding of the basics of what dementia is and how it affects the brain</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q42. How to effectively communicate with the person I am caring for</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q43. How to effectively communicate with other family members about dementia</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q44. How to manage troubling behaviour in the person I am caring for</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q45. How to problem solve difficulties that arise from caring for someone that has dementia</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q46. How to effectively use my relationship skills in general</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q47. My knowledge of how to access dementia supports and services when I need them</td>
<td></td>
<td></td>
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</tbody>
</table>
The following questions are about quality of life of the person you are caring for.

When you think about your relative's life, there are different aspects, some of which are listed below. Please think about each item, and rate your relative's current quality of life in each area using one of four words: poor, fair, good, or excellent. Please rate these items based on your relative's life at the present time (e.g. within the past few weeks) (Please tick responses)

<table>
<thead>
<tr>
<th>1. Physical health</th>
<th>Poor</th>
<th>Fair</th>
<th>Good</th>
<th>Excellent</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Energy</td>
<td>Poor</td>
<td>Fair</td>
<td>Good</td>
<td>Excellent</td>
</tr>
<tr>
<td>3. Mood</td>
<td>Poor</td>
<td>Fair</td>
<td>Good</td>
<td>Excellent</td>
</tr>
<tr>
<td>4. Living situation</td>
<td>Poor</td>
<td>Fair</td>
<td>Good</td>
<td>Excellent</td>
</tr>
<tr>
<td>5. Memory</td>
<td>Poor</td>
<td>Fair</td>
<td>Good</td>
<td>Excellent</td>
</tr>
<tr>
<td>6. Family</td>
<td>Poor</td>
<td>Fair</td>
<td>Good</td>
<td>Excellent</td>
</tr>
<tr>
<td>7. Marriage</td>
<td>Poor</td>
<td>Fair</td>
<td>Good</td>
<td>Excellent</td>
</tr>
<tr>
<td>8. Friends</td>
<td>Poor</td>
<td>Fair</td>
<td>Good</td>
<td>Excellent</td>
</tr>
<tr>
<td>9. Self as a whole</td>
<td>Poor</td>
<td>Fair</td>
<td>Good</td>
<td>Excellent</td>
</tr>
<tr>
<td>10. Ability to do chores around the house</td>
<td>Poor</td>
<td>Fair</td>
<td>Good</td>
<td>Excellent</td>
</tr>
<tr>
<td>11. Ability to do things for fun</td>
<td>Poor</td>
<td>Fair</td>
<td>Good</td>
<td>Excellent</td>
</tr>
<tr>
<td>12. Money</td>
<td>Poor</td>
<td>Fair</td>
<td>Good</td>
<td>Excellent</td>
</tr>
<tr>
<td>13. Life as a whole</td>
<td>Poor</td>
<td>Fair</td>
<td>Good</td>
<td>Excellent</td>
</tr>
</tbody>
</table>

THANK YOU FOR YOUR PARTICIPATION: THIS QUESTIONNAIRE WILL HELP US IMPROVE OUR SERVICE
MRT Evaluation

INTERVIEWER INSTRUCTIONS FOR QUALITY OF LIFE INSTRUMENT PWD

Quality of Life-AD: Instructions for Interviewers

Instrument to be administered at: (1) initial session, (2) at exit from MRT and (3) 3 months follow-up.

Prior to the interview, complete the first part of the form (in the grey box).

The QOL-AD is administered in interview format to individuals with dementia, following the instructions below. Hand the form to the participant, so that he or she may look at it as you give the following instructions (instructions should closely follow the wording given in bold type):

I want to ask you some questions about your quality of life and have you rate different aspects of your life using one of four words: poor, fair, good, or excellent.

Point to each word (poor, fair, good, and excellent) on the form as you say it.

When you think about your life, there are different aspects, like your physical health, energy, family, money, and others. I’m going to ask you to rate each of these areas. We want to find out how you feel about your current situation in each area.

If you’re not sure about what a question means, you can ask me about it. If you have difficulty rating any item, just give it your best guess.

It is usually apparent whether an individual understands the questions, and most individuals who are able to communicate and respond to simple questions can understand the measure. If the participant answers all questions the same, or says something that indicates a lack of understanding, the interviewer is encouraged to clarify the question. However, under no circumstances should the interviewer suggest a specific response. Each of the four possible responses should be presented, and the participant should pick one of the four.

If a participant is unable to choose a response to a particular item or items, this should be noted in the comments. If the participant is unable to comprehend and/or respond to two or more items, the testing may be discontinued, and this should be noted in the comments.

As you read the items listed below, ask the participant to tick her/his response. If the participant has difficulty ticking, you may ask her/him to point to the word or say the word, and you may tick it for him or her. You should let the participant hold his or her own copy of the measure, and follow along as you read each item.

1. First of all, how do you feel about your physical health? Would you say it’s poor, fair, good, or excellent? TICK whichever word you think best describes your physical health right now.

2. How do you feel about your energy level? Do you think it is poor, fair, good, or excellent? If the participant says that some days are better than others, ask him or her to rate how she/he has been feeling most of the time lately.

3. How has your mood been lately? Have your spirits been good, or have you been feeling down? Would you rate your mood as poor, fair, good, or excellent?

4. How about your living situation? How do you feel about the place you live now? Would you say it’s poor, fair, good, or excellent?

5. How about your memory? Would you say it is poor, fair, good, or excellent?

6. How about your carer (husband, wife, son, daughter) and your relationship with your husband/wife/son/daughter caring for you? Would you describe it as poor, fair, good or excellent?
7. **How about your family and your relationship with family members? Would you describe it as poor, fair, good, or excellent?** If the respondent says they have no family, ask about brothers, sisters, children, nieces, nephews.

8. **How do you feel about your marriage? How is your relationship with (spouse’s name)? Do you feel it’s poor, fair, good, or excellent?** Some participants will be single, widowed, or divorced. When this is the case, ask how they feel about the person with whom they have the closest relationship, whether it’s a family member or friend. If there is a family caregiver, ask about their relationship with this person. If there is no one appropriate, or the participant is unsure, score the item as missing. If the participant’s rating is of their relationship with someone other than their spouse, note this and record the relationship in the comments section.

9. **How would you describe your current relationship with your friends? Would you say it’s poor, fair, good, or excellent?** If the respondent answers that they have no friends, or all their friends have died, probe further. **Do you have anyone you enjoy being with besides your family? Would you call that person a friend?** If the respondent still says they have no friends, ask **how do you feel about having no friends—poor, fair, good, or excellent?**

10. **How do you feel about yourself—when you think of your whole self, and all the different things about you, would you say it’s poor, fair, good, or excellent?**

11. **How do you feel about your ability to do things like chores around the house or other things you need to do? Would you say it’s poor, fair, good, or excellent?**

12. **How about your ability to do things for fun, that you enjoy? Would you say it’s poor, fair, good, or excellent?**

13. **How do you feel about your current situation with money, your financial situation? Do you feel it’s poor, fair, good, or excellent?** If the respondent hesitates, explain that you don’t want to know what their situation is (as in amount of money), just how they feel about it.

14. **How would you describe your life as a whole. When you think about your life as a whole, everything together, how do you feel about your life? Would you say it’s poor, fair, good, or excellent?**
Complete this part prior to interview

Client name: ____________________________ Carer name: _________________________________
Client code (AA): ___________________________ Date: ____________________________
Location: _________________________________ Interviewer: ________________________________

Stage of participation (Please tick): 1 □ Entry  2 □ Exit  3 □ 3-month follow-up

Date of birth (PWD): ____________ Postcode: ____________ Gender: 1 □ Male  2 □ Female

Country of birth: ____________________ Aboriginal or Torres Strait Islander: 1 □ Yes  2 □ No

Marital status: 1 □ Never Married  2 □ Widowed  3 □ Divorced  4 □ Separated  5 □ Married/Defacto  6 □ Not stated/unknown

Administer the 14 questions below according to the attached standard instructions (Please tick responses)

<table>
<thead>
<tr>
<th>Question</th>
<th>Poor</th>
<th>Fair</th>
<th>Good</th>
<th>Excellent</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Physical health</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Energy</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Mood</td>
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<tr>
<td>4. Living situation</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>5. Memory</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Family member Carer</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>7. Family</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>8. Marriage</td>
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<tr>
<td>9. Friends</td>
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<tr>
<td>10. Self as a whole</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>11. Ability to do chores around the house</td>
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<td></td>
<td></td>
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<tr>
<td>12. Ability to do things for fun</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>13. Money</td>
<td></td>
<td></td>
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<tr>
<td>14. Life as a whole</td>
<td></td>
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</tbody>
</table>
APPENDIX 3
BEGA VALLEY MOBILE RESPITE TEAM
SATISFACTION SURVEY

Your feedback upon completion of our visits is important to help us improve our services. All responses will be kept confidential.

1. When you first needed to use our service/s did you find that we: (Please tick appropriate box)

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. were easy to find</td>
<td>1</td>
<td>2</td>
<td>9</td>
</tr>
<tr>
<td>b. explained our services clearly to you</td>
<td>1</td>
<td>2</td>
<td>9</td>
</tr>
<tr>
<td>c. explored your needs and tried where possible to meet them</td>
<td>1</td>
<td>2</td>
<td>9</td>
</tr>
<tr>
<td>d. consulted you about your preferences</td>
<td>1</td>
<td>2</td>
<td>9</td>
</tr>
<tr>
<td>e. offered to refer you to other services you might need</td>
<td>1</td>
<td>2</td>
<td>9</td>
</tr>
<tr>
<td>f. respected your decisions</td>
<td>1</td>
<td>2</td>
<td>9</td>
</tr>
</tbody>
</table>

2. How do you rate the quality of the service that you received?

- excellent (always of a high standard) 5
- good (consistent standard) 4
- average (needs some improvement) 3
- below average (needs attention) 2
- poor (leaves a lot to be desired) 1

3. In general, did you find the work of our staff:

- excellent (things were done consistently well and without conflict) 5
- good (in general things went smoothly) 4
- average (sometimes there were hiccups but nothing major) 3
- below average (regular problems or inconveniences) 2
- poor (always difficult) 1

4. Since receiving this service, do you feel that access to the following has changed for you? (Please tick appropriate box).

<table>
<thead>
<tr>
<th></th>
<th>Got worse</th>
<th>Stayed the same</th>
<th>Improved</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. My access to respite services in the community</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>b. My access to non-respite support services in the community</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>9</td>
</tr>
</tbody>
</table>

5. To what extent did the service meet your needs?

- needs fully met 1
- needs partially met 2
- needs not met at all 3

6. If your needs were not met by our current services, what could have helped? (If you need more room, please use a separate piece of paper and attach to the back.)

------------------------------------------------------------------------------------------------------------------

------------------------------------------------------------------------------------------------------------------
7. Please rate the extent to which you agree with the following statements about how the service has increased your knowledge of dementia and abilities in dealing with it. (Please tick the appropriate box)

<table>
<thead>
<tr>
<th></th>
<th>Statement</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>a.</td>
<td>I have a better understanding of the basics of dementia and how it affects the brain</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>b.</td>
<td>I am able to communicate more effectively with the person I am caring for</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>c.</td>
<td>I am able to communicate more effectively with other family members about dementia</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>d.</td>
<td>I am more able to manage troubling behaviour in the person I am caring for</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>e.</td>
<td>I am better at problem solving difficulties that arise from caring for someone who has dementia</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>f.</td>
<td>I am more effective in using my relationship skills in general</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>g.</td>
<td>I have a better knowledge of how to access dementia supports and services when I need them</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

8. What did you like most about our service?

................................................................................................................................................
................................................................................................................................................

9. Is there anything about our service you would like to see improved?

................................................................................................................................................
................................................................................................................................................

10. Please feel free to add further comments.

................................................................................................................................................
................................................................................................................................................

Thank you for taking the time to provide us with valuable feedback. If your needs change in the future please contact us to enquire if we can assist.
Mobile Respite Team service Evaluation 2013: Stakeholder survey

1. MRT Stakeholder survey

1. What is your general image of the Mobile Respite Team service?

2. How well do you know the main activities?

3. How familiar are you with the goals and objectives?

4. Please describe the relationship between yourself/your organisation and the Mobile Respite Team

5. How satisfied are you with the RELATIONSHIP between the Mobile Respite Team and yourself?
   - Extremely satisfied
   - Somewhat satisfied
   - Neither satisfied or dissatisfied
   - Somewhat dissatisfied
   - Extremely dissatisfied
   
   Comments?

6. What are the good things about your relationship with the Mobile Respite Team?

7. What are the things about your relationship that could be improved?

8. How would you rate the Mobile Respite Team service?
   - Excellent
   - Very Good
   - Fair
   - Poor
   - Very Poor

   Comments?
9. What are the good things about the Mobile Respite Team service?

10. How could the Mobile Respite Team service be improved?

11. Can you provide any examples of how the Mobile Respite Team has assisted clients living with dementia and their carers?
   - Yes
   - No
   If yes, please briefly describe

12. Can you provide any examples of how the Mobile Respite Team has been unsuccessful in providing assistance to clients living with dementia and their carers?
   - Yes
   - No
   If yes, please briefly describe

13. Please rate the Mobile Respite Team service in the following 8 areas.

<table>
<thead>
<tr>
<th>Area</th>
<th>Very poor</th>
<th>Poor</th>
<th>Fair</th>
<th>Very good</th>
<th>Excellent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provision of education about dementia to carers?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Provision of support to carers?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Provision of support to people living with dementia?</td>
<td></td>
<td></td>
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<tr>
<td>Provision of information about relevant community support services?</td>
<td></td>
<td></td>
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<tr>
<td>Referral to appropriate community services &amp; resources?</td>
<td></td>
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<tr>
<td>Building the capacity of carers to deal with behavioural issues?</td>
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<tr>
<td>Assisting the carer to manage broader family relationships impacted?</td>
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<tr>
<td>Assisting the transition to residential care where appropriate?</td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>Comments?</td>
<td></td>
<td></td>
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</tbody>
</table>
14. Are there any other comments or suggestions you would like to make?

15. Would you be willing to participate in a 30 minute phone interview as part of the evaluation of the Mobile Respite Team service (These will take place in June-July 2013)?

☐ Yes
☐ No
If yes, best contact number for you
