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**Inquiry into
Dementia:
Early Diagnosis and
Intervention**

**Submission by Blue Care
to
House of Representatives
Standing Committee on
Health and Ageing
on Dementia**

2 May 2012

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House of Representatives Standing Committee
on Health and Ageing on Dementia**

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1. Key Issues and Recommendations

As one of Australia's largest providers of residential aged and community care, Blue Care currently supports people living with dementia in 34 memory support units within Residential Homes. We also provide care and support for people living with dementia through 40 EACHD packages, 207 EACH packages, and 1,431 Community Aged Care packages, and through a range of in-house and centre-based respite throughout Queensland and northern New South Wales.

Early diagnosis and intervention is essential in order to provide positive outcomes for people that have dementia and their families. Early diagnosis and intervention will enable the person's care needs to be individualised based on an understanding of the person, their former life history, their past and current interests and their family and social structure. It is imperative that staff members have up-to-date and ongoing training in dementia care; are committed to working in aged care; and have a passion to provide the best possible outcomes for the individual person and family members.

Key issues and recommendations

- Overcoming barriers to diagnosis, especially to an early diagnosis. Barriers to diagnosis include the belief that memory problems are a normal part of ageing; the perceived stigma attached to dementia; the lack of a cure; and fear about the future. It is therefore imperative that there is additional funding for education for staff and for families to enable them to become more aware of the early signs and symptoms of dementia.

Blue Care also recommends additional funding to create additional positions for Memory Support so that every geographical area has a position that takes the lead in dementia care and is educated to the very highest level to become an expert in provision of Memory Support.

- Early diagnosis enables a person with dementia and their family to receive support in understanding and adjusting to their diagnosis of dementia; and to plan and prepare for their future in an appropriate way. This may include making legal and financial arrangements; advanced care directives; making changes to living arrangements; and finding out about aids and services that will enhance quality of life for people with dementia and their family and friends.

Blue Care recommends additional funding to further develop the available respite services. There is a need to investigate more suitable respite opportunities that are cost effective as included in the Australian Government's *Living Longer, Living Better, Aged Care Reform Package April 2012*.

- Evidenced based research shows that there are currently a range of medications for Alzheimer's disease which may be more beneficial if given early in the disease process. Whilst there is no cure at this stage, these medications can help to maintain daily function and quality of life as well as stabilise cognitive decline in some people.

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Further education for General Practitioners and other medical professionals is needed to assist with early diagnosis which will enhance the quality of life for people living with dementia.

Another avenue for early intervention is cognitive assessment and “brain training” for clients with an early diagnosis, to reduce the progression of dementia and the opportunity for involvement in drug trials and other preventative or stabilising treatments. Blue Care has identified a need to promote this in all the memory support services.

- One of the biggest issues that Blue Care experiences is the level of support for clients who live alone in the community that may or may not have a diagnosis of dementia, especially in rural and remote areas.

There is a need for increased Memory Support services across all geographical areas with access to tele-health and multi-disciplinary services in some of the more rural areas to ensure that people living with dementia improve their quality of life; have increased opportunities for social engagement and community participation; plan for their future; and receive awareness and communication on dementia.

- Caring for a person with dementia can result in interference with social networks; loss of paid employment; and disruption to community involvement; resulting in social isolation and deterioration of physical health.

The establishment of a Blue Care café at our Coopers Plains’ Respite Service was designed to promote the social inclusion of people with dementia and their carers in a relaxed secure environment and provide the opportunity for support, education and advice from professionals.

- Individual services tailored to the person’s individual needs will assist people to remain in the community longer; however, this requires additional resources to ensure consistency of staff and flexible service delivery. Flexible services can be provided when service providers are willing to think laterally – outside the square – and feel they are still supported by and comply with Government guidelines.

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2. Preface

The context for Blue Care's submission to the "House of Representatives Standing Committee on Health and Ageing on Dementia: early diagnosis and intervention" is set out as follows.

Blue Care is one of the largest not-for-profit providers of residential aged care and community care in Australia.

Blue Care currently supports people living with dementia in 34 memory support units within Residential Homes providing 557 beds and approximately 80% of residents (diagnosed/undiagnosed) in mainstream residential care, of which there are a further 3,843 beds.

207 EACH packages, and 1,431 Community Aged Care packages also provide care for people living with dementia. An additional 40 EACHD packages, and a range of in-house and centre-based respite throughout Queensland and northern New South Wales are currently provided for people living with dementia. There are currently 1,200 retirement living units, some of which will be occupied by people living with dementia who may be in the very early stages without a confirmed diagnosis.

The Blue Care Memory Support services for people living with dementia endorse the key characteristics of Blue Care's Tailor Made Service Model which includes:

- **Doing with not doing for**
The person living with dementia and their family has the choice and say in what, when and how they wish to receive services.
- **Flexible and proactive**
It is what suits the individual that is important for where and how services are provided, with easy access to services.
- **Partnerships and working together**
Working together with others to make sure the person living with dementia gets the best possible outcomes.
- **Being sustainable** as well as supporting people's immediate needs, a long term view to service delivery is taken, aiming to ensure support is viable. Sustainability also involves a respect for the environment, being mindful of reducing our footprints and minimising our impact.
- **Building from strengths**
Working with the individual's strengths and capabilities, allowing them to be all they can be, to live independently for as long as they can and to have a daily life that is fulfilling.

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- **Seamless and inclusive**
Transition and continuity across the full wellbeing and health continuum needs to be seamless. Supporting the person to age in place and continue to be connected with their community will be achieved by integrated and inclusive services provided across a range of sites.
- **Appropriate and accessible**
Respect for the individual's tradition, language and religion is central to our approach. Equitable access to services across Blue Care will be facilitated. Our commitment to 'Closing the gap' will guide our partnerships with Aboriginal and Torres Strait Islander people.
- **Local Solutions**
We aim to work with communities to deliver 'Tailor Made' local solutions. Just as each person is different so too are communities and we plan together how the service model is best applied and implemented.

The goal of Blue Care's Memory Support Services is to enable people living with dementia and their family:

- to be seen as a person in their own right first, before their dementia
- to be empowered and treated as an equal partner
- to achieve everything that is possible
- to be valued as a member of society
- to make choices about all aspects of their life
- to be recognised for their uniqueness, skills and achievements
- to receive excellent health care, healthy living programs and to remain as free as possible from unnecessary suffering
- to retain their diversity, dignity and independence
- to be cared for by well trained, knowledgeable and consistent staff.

3. Term of reference

How early diagnosis and intervention of dementia can

- 1. improve quality of life and assist people with dementia to remain independent for as long as possible***
- 2. increase opportunities for continued social engagement and community participation for people with dementia***
- 3. help people with dementia and their carers plan for their futures, including organising their financial and legal affairs and preparing for longer-term or more intensive care requirements.***

3.1 Barriers preventing early diagnosis and intervention

Blue Care recognises that obtaining a diagnosis of dementia can be a difficult, lengthy and intensive process. While circumstances differ from person to person, Blue Care supports Alzheimer's Australia's philosophy that everyone has the right to:

- a thorough and prompt assessment by medical professionals
- sensitive communication of a diagnosis with appropriate explanation of symptoms and prognosis
- sufficient information to make choices about the future
- maximum involvement in the decision making process
- ongoing maintenance and management
- access to support and services.

Blue Care understands that for some people there may be barriers to diagnosis, especially to an early diagnosis. Barriers to diagnosis can include the belief that memory problems are a normal part of ageing; the perceived stigma attached to dementia; the lack of a cure; and fear about the future. Blue Care recognises that early diagnosis and awareness about dementia are the first steps in designing management strategies, and as more effective treatments become available in the future, recognises that early diagnosis will become even more important.

Changes in memory and thinking ability can be very worrying for the person and their family and can be caused by several different diseases and conditions, some of which are treatable and reversible, including infections, depression, medication side-effects or nutritional deficiencies. The sooner the cause of dementia symptoms are identified, the sooner treatment can begin.

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Blue Care also recognises that early intervention reduces anxiety and depression by supporting the person to plan their future care and direct that care. Families are often anxious, along with their loved one, that independence is lost once services are introduced. It is important to confirm that services can actually increase independence.

Recommendations

It is therefore imperative that there is additional funding for education for staff and for families to enable them to become more aware of the early signs and symptoms of dementia. By doing so these signs will be detected resulting in early interventions to assist the person living with dementia to remain independent and have an improved quality of life.

Blue Care recommends additional funding to create additional positions for Memory Support so that every geographical area has a position that takes the lead in dementia care and is educated to the very highest level to become an expert in provision of Memory Support.

3.2 Early diagnosis and appropriate planning for the future

Blue Care understands that early diagnosis enables a person with dementia and their family to receive support in understanding and adjusting to their diagnosis of dementia and to prepare for their future in an appropriate way. This may include making legal and financial arrangements, advanced care directives, making changes to living arrangements, and finding out about aids and services that will enhance quality of life for people with dementia and their family and friends.

Early diagnosis can also allow the person to have an active role in decision making and planning for the future while they still have the ability to do so. It allows the person to plan services for themselves which can not only provide respite for families but assist the person living with dementia to be cared for longer within the community.

At the same time families can educate themselves about the disease and learn effective ways of interacting with the person living with dementia.

Research advises that family support groups are vital for families to learn more about dementia, and to meet with other families who can offer physical and psychological support.

Whilst Blue Care has developed Memory Support networks in many geographical locations, there is still a need to continue to grow these support networks so that every geographical area can provide support to families in partnership with other organisations such as Alzheimer's Australia Qld.

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Recommendations

Blue Care recommends additional funding to further develop the available respite services, as included in the Australian Government's *Living Longer, Living Better, Aged Care Reform Package April 2012*.

More suitable respite opportunities that are cost effective need to be investigated, as often the carer and care recipient would like to go together for a break but need to be supported to do so. Carers have reported using cruises and bus trips as respite where there are others around to support them. With increased community education this could work well in the early to mid stages.

3.3 Use of medications and assistive technologies increase opportunities for continued social engagement and community participation

Evidenced based research shows that there are currently a range of medications for Alzheimer's disease which may be more beneficial if given early in the disease process. Whilst there is no cure at this stage, these medications can help to maintain daily function and quality of life as well as stabilise cognitive decline in some people.

Early diagnosis allows for prompt access to medications and medical attention and may allow the person living with dementia to remain in a community setting for longer. Receiving an early diagnosis can also assist in the management of other symptoms which may accompany the early stage of dementia, such as depression or irritability. Reviewing the management of other medical conditions is also crucial, as memory problems may interfere with a person remembering to take important medications such as for diabetes, heart disease or high blood pressure.

Blue Care recognises that early diagnosis can assist with the assessment for assistive technologies that may also support the person in the community for longer and delay admission to a nursing home. It will also enable the person to build on their strengths and fully utilise available resources within their community e.g. art groups, exercise programs, swimming sessions, University of the third age, and choral and dance groups, which will assist people with an early diagnosis of dementia to connect with their community and avoid isolation.

Engaging the person in volunteering activities which are meaningful and worthwhile can also maintain the person's sense of worth and self esteem and encouraging them to develop reminiscence tools including sharing of memories, stories and personal histories has been known to assist with their end of life care.

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Recommendations

Further education for General Practitioners and members of the community is needed to enhance the quality of life for people living with dementia. The misunderstanding of the disease can result in unnecessary stress and uncertainty for the person and Blue Care recommends that additional funding is available to educate General Practitioners, dentists, shop assistants, fire, ambulance, transport providers and other community services.

Another avenue for early intervention is cognitive assessment and “brain training” for clients with an early diagnosis, to reduce the progression of dementia and the opportunity for involvement in drug trials and other preventative or stabilising treatments. Blue Care has identified a need to promote this in all the memory support services.

Blue Care has also experienced the need for an increase in psycho-geriatric assessments available for clients in many areas and increased practical behavioural support to assist both family and paid carers manage some of these more difficult behaviours that can arise in the home. Whilst the Dementia Behaviour Management Advisory Service (DBMAS) is an excellent resource, it is a very well utilised service and needs more resources to meet the current demand in residential, community and retirement living as well as the acute sector.

3.4 Social and Geographic Isolation and People Living with Dementia

One of the biggest issues that Blue Care experiences is the level of support for clients who live alone in the community that may or may not have a diagnosis of dementia. In many cases they have limited or low levels of family support which makes them very vulnerable in the community, particularly in rural areas. The person living with dementia often requires detailed case management and support and will often result in the need to advocate on their behalf to the guardianship tribunal for enduring power of attorney where there is impaired decision making capacity.

Blue Care recognises that the current level of care provided under the CACP and EACH packages do not adequately meet the needs of this group. Often this means that the only option of care is to consider residential care, usually at a point earlier than for clients who have family carers. As a result these clients often deteriorate very quickly after being moved from a familiar environment.

Blue Care recognises it is essential to work with these people at an early diagnosis to assist them to put in place alternative decision making options prior to their loss of capacity.

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Recommendations

There is a need for increased Memory Support services across all geographical areas with access to tele-health in some of the more rural areas to ensure that people living with dementia improve their quality of life; have increased opportunities for social engagement and community participation; plan for their future; and receive awareness and communication on dementia.

Blue Care recommends that Memory Support centres provide access to allied health services; nursing services and psycho geriatrician services; with support from behavioural experts, therapists, legal experts, dietitians, physiotherapists, and educators. Often rural areas do not receive the support that is provided in cities and surrounding areas, which disadvantages the person and their families.

A review of end stage accommodation and care services designed to accommodate the palliative nature of this condition also needs to be undertaken with particular attention being placed on pain management, hydration and nutrition.

3.5 How early diagnosis and intervention of dementia can increase opportunities for continued social engagement and community participation for people with dementia

Current statistics demonstrate Alzheimer's disease is increasing dramatically with a predicted 100million cases worldwide by 2050. This increase will have significant social cost for people with dementia and their carers. Caring for a person with dementia can result in interference with social networks, loss of paid employment and disruption to community involvement, resulting in social isolation and deterioration of physical health.

The use of Dementia Cafés as part of strategies of care for clients and their carers has been introduced overseas, (mainly situated in the UK), in a variety of settings including residential aged care facilities and community clubs/pubs, however it is a recent phenomenon in Australia. This informal model uses a psychosocial and educational approach to supporting people with dementia and their carers.

The establishment of a Blue Care café at Coopers Plains, Brisbane, was designed to promote the social inclusion of people with dementia and their carers in a relaxed secure environment and provide the opportunity for support, education and advice from professionals.

Participants in the pilot study were all carers of clients who attended the day respite centre and had been identified as at high risk through carer support groups and centre activities. Thirteen carers were interviewed (average age 80 years) and reported their greatest stress was derived from the considerable disruption to their normal social life and perceived poor access to information and services.

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The success of the Dementia Café for staff and carers was evaluated through written and verbal feedback, carer focus groups and a self report questionnaire. Carers reported that the café was a welcome social outlet benefitting both the carer and the client, while serving as a source of information and support. Staff found the café rewarding to work in, but identified the café would continue to evolve to meet the needs of clients and their carers (see detail in *Appendix One*).

3.6 Outcomes

Blue Care sees the outcomes possible with early diagnosis include:

- a reduction in the social stigma associated with dementia
- increased confidence of participants to engage in suitable activities to meet their requirements at a particular time
- extension of social networks and maintenance of existing networks
- an improved understanding of general health issues and the importance of maintaining good health for both the carer and the care recipient
- the development of partnerships and a sharing of expertise particularly between cultures
- increased professional development across services
- an understanding that “one size does NOT fit all” – each person living with dementia is different and therefore needs an individual care program which is continually reviewed to meet the ever changing needs of the person.

3.7 Case Example

Blue Care Respite Services' experience with people living with dementia

The majority of people referred to the Ashgrove and Henderson Centres (for Centre-based Day Care) have some level of dementia, from mild memory loss to high levels of confusion. Older people face increasing complexity of care when their spouse is also ageing. They may have their own health issues and be faced with complex high care needs for their partner. Referrals are also increasing for people who are younger – from the mid-fifties and sixties. For these people, work is generally a requirement, which places increased pressure juggling work commitments together with intensive care for their partner. There are often still children living at home who are still at school.

The families of people who come to our centres are generally highly stressed and struggling to manage the care of their family member. They are often unaware of the range of services that can be coordinated to offer families a tailored approach that suits their particular support requirements.

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There are also a number of men who have undertaken to care for a loved one. These men have chosen to become carers but they are often not equipped to take on the enormity of the caring role as well as household management roles.

Positive outcomes, however, can be achieved for people, even those with high levels of dementia. The care needs must be individualised and based on an understanding of the person, their former life history, their past and current interests, and their family and social structure. Staff members need to have up-to-date and ongoing training in dementia care, be committed to working in aged care, and to work with compassion, if best outcomes for the individual person and family members are to be achieved.

One-to-one support assists with building trust and encouraging the person to take part in appropriate activities. This approach encourages the person to join a small group where joint activities can provide a non-threatening interactive environment.

It is understood that success in maintaining quality outcomes may have a short window of opportunity, i.e. weeks or months before decline in health resumes. Case histories below outline the achievements for some families.

Case History 1

Peter was referred by his daughter and son who were concerned about the stress on their mother and the lack of interaction for Peter with other family members. Peter was initially resistant to coming to the centre and once there, preferred to sit alone rather than join in with small group activities. After a few weeks it was felt that Peter's reason for refusing to join in activities was due to his fear that he could no longer manage the task or game. Staff members introduced dominos (numbers and colours) which over the course of a few weeks, Peter became quite adept at playing. He was then encouraged to join a small group which often won. This was a turning point for Peter who showed a marked increase in his self-esteem and confidence.

Peter's family noted this change in their father, as did his wife. They stated that Peter was once again taking part in family activities and discussions, was much more animated and smiled much more than he had for some time.

The success with Peter continued for a period of almost twelve months before his health declined, placing high levels of stress on his wife and family. Review of Peter's care needs provided the opportunity to discuss the need for professional 24/7 care that most families are ill-equipped to cope with. Many families are unable to make the decision on residential placement without the support of their primary care provider. Peter passed away in an aged care facility but family members were all able to talk about the positive experiences they had over the last year or so of Peter's life. They felt that their father had been able to have meaningful experiences even though his dementia was advanced, and to be much more peaceful and calm even at the end stage of his life.

The achievements outcomes for this family required a shared understanding and quality case management between care services through to the residential care provider involved with the support for Peter and his extended family.

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Case History 2

There are currently a number of centre members (clients) at the Henderson Centre who have high levels of dementia. Whilst their backgrounds are wide-ranging, it is of note that some have had very high level careers in medicine, law and as captains of industry. These men require one-to-one support in a setting that is funded for 1 staff member to 4/6 clients. If one-to-one support is not provided to ensure they are meaningfully occupied, they can be disruptive for other centre members and unsettled, which is not a positive experience for them or others.

Greater flexibility to achieve positive outcomes is achieved when centres have access to a suite of service types including Social Support and In Home Respite. Families are often unaware the importance of taking advantage of a group of services to holistically provide for the person and family/carers. Case coordination between service providers for services in the home include Personal Care, Domestic Assistance and In Home Respite. It is particularly effective when a care worker can shower and prepare a person for their day and then to be able to bring them straight to the centre where staff can take over the caring role. This process means that there are less people involved in the process which can cause confusion. Working collaboratively with other services can increase the rest/ down time for carers, meaning their stress levels are minimised as much as possible.

Care coordination may include allied health personnel, continence support, community care services, centre-based care and residential respite. Many carers need to be encouraged to see block respite as a way of maintaining their own health and thus assisting with their being able to continue with their role as carer.

4. Appendices

4.1 Appendix One

*Evaluation of a Blue Care Dementia Cafe within a Dementia
specific Respite Service; a Pilot Study*

**EVALUATION OF A
BLUE CARE DEMENTIA
CAFÉ WITHIN A
DEMENTIA SPECIFIC
RESPITE SERVICE: A
PILOT STUDY**

Version 1
2/05/2012

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EVALUATION OF A BLUE CARE DEMENTIA CAFÉ WITHIN A DEMENTIA SPECIFIC RESPITE SERVICE: A PILOT STUDY

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Blue Care Community Services Brisbane Queensland Australia

Blue Care is one of Australia's leading providers of community health and residential aged care, across Queensland and Northern New South Wales.

As part of Uniting Care Queensland, the mission of Blue Care is to improve the health and wellbeing of individuals, families and communities as we:

- Reach out to people in need
- Speak out for fairness and justice
- Care with compassion, innovation and wisdom.

Abstract

Current statistics demonstrate Alzheimer's disease is increasing dramatically with a predicted 100million cases worldwide by 2050. This increase will have significant social cost for people with dementia and their carers. Caring for a person with dementia can result in interference with social networks, loss of paid employment and disruption to community involvement, resulting in social isolation and deterioration of physical health.

The use of Dementia Cafés as part of strategies of care for Clients and their Carers has been introduced overseas, (mainly situated in the UK), in a variety of settings including residential aged care facilities and community clubs/pubs, however is a recent phenomenon in Australia. This informal model uses a psychosocial and educational approach to supporting people with dementia and their carers.

The establishment of this café was designed to promote the social inclusion of people with dementia and their carers in a relaxed secure environment and provide the opportunity for support, education and advice from professionals. Participants in the pilot study were all carers of clients who attended the day respite centre and had been identified as at high risk through carer support groups and centre activities. Thirteen carers were interviewed (average age 80 years) and reported their greatest stress was derived from the considerable disruption to their normal social life and perceived poor access to information and services.

The success of the Dementia Café for staff and carers was evaluated through written and verbal feedback, conducting carer focus groups and a self report questionnaire. Carers reported that the café was a welcome social outlet benefitting both the carer and the client, while serving as a source of information and support. Staff (N=5) found the café rewarding to work in, but identified the café would continue to evolve to meet the needs of clients and their carers.

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AIM:

This Pilot Study will evaluate the informal carers' satisfaction with the Café and the staff perceptions regarding the usefulness of this initiative to improve the social inclusion of people with dementia and their informal carers.

Background Literature:

Dementia is increasingly a reality for many Australians as it is for the world wide population. The number of cases of dementia in a population is largely determined by its age structure as a population ages, the number of dementia cases increase disproportionately (1) What is commonly described as the 'baby boomer' bulge in the demographic profile means that the coming decade will see an acceleration of the impacts on ageing on dementia prevalence. In Australia, Queensland is experiencing a faster increase in the rate of dementia than other parts of Australia (2) Consequently Access Economics predict there will be more people with dementia in Queensland by 2050 than the whole of Australia in 2000. This increase is primarily driven by the combination of the ageing population and significant population growth with increases in migrations as well as large number of older people 'retiring to the sun' (3).

Carer Burden:

The increasing prevalence of dementia results in significant social costs for both people with dementia and their carers. Dementia has been described as a social condition as well as a medical one. It attracts stigma, social isolation and personal discrimination. Caring for a person with dementia is particularly challenging, with the progressive degeneration of person's cognitive capacity and ability to undertake the activities of daily living.

As dementias last, on average, eight years increasing dependence on their caregivers, together with unsafe and socially inappropriate behaviours create the need for constant supervision that poses a greater burden on caregivers. These people forego vacations and hobbies, have less time than other family members and often report work related difficulties. These factors may result in social isolation and a commensurate decrease in carer health related quality of life. Literature notes that there is insufficient recognition of the informal caregivers as part of the system surrounding dementia clients and that the problems of informal caregivers often remain invisible until there is a crisis.(4)

Dementia Cafes:

Carer burden for people who informally care for people with dementia impacts on the carer's quality of life. Support is needed to prevent informal care givers

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becoming overburdened and depressed. Dementia Cafes within respite services is viewed as a useful strategy and innovative approach to dealing with these issues and promoting the use of cafes that are dedicated to supporting the informal caregivers of people with dementia and the care recipient.

The purpose of these Dementia Cafes is to promote the social inclusion of people with dementia and their carers by offering education, support, informal advice and consultations by professionals in an informal manner.

This concept was developed by Dr Bere Miesen in the Netherlands in 1997. Miesen argued that it would be a good idea if those involved could meet each other in a 'relaxed forum to exchange experiences and to talk about dementia. The Dementia Café concept aims to break the pain of denial, and to acknowledge and provide space for the expression of emotions and practical difficulties that are involved in having and learning to continue to live with this chronic and long term illness. (5)

The attraction of the model includes the following:

- People with dementia and their carers and/or family members can be helped to normalise the experience of dementia
- The Café provides a secure base for people who may become socially isolated due the disease
- The non-clinical atmosphere provides more of a meeting of equals across service providers, people with dementia and their families and friends.

There are now 60 Dementia Cafes in the Netherlands. The first Dementia Café was opened in the United Kingdom in 2000. In 2010 there was two cafes in Australia both in the state of New South Wales.

This Project was initiated by Blue Care Staff at the Coopers Plains Day Respite Centre who identified a need for more support systems to improve the quality of life for their clients who were attending the respite centre and to support the clients' informal carers.

In 2010 plans were approved to construct a brand new dementia specific day respite centre at Coopers Plains in Brisbane Queensland. Staff were motivated to ensure the latest in design, environment, and strategies of care incorporated in the new facility.

A submission was then completed and approved from Perpetual Philanthropic Services (a private trust company in Australia) to establish a sensory garden, furnish a quiet room, evaluate current programs and strategies of care, and research, establish and evaluate a dementia café at Coopers Plains Day Respite Centre.

The proposal for Coopers Café was to provide an informal drop in type café one day per month (Saturday) with a structured program of client and carer education and information sharing. Program content would be agreed upon in collaboration with Blue Care Staff and their clients and informal carers.

Research Method

Participants: Informal Caregivers of persons with dementia and Blue Care staff from the Blue Care Day Respite Centre Coopers Plains

Recruitment: Both 'Carer' and 'Staff' participants were recruited through pre existing links established at the respite centre.

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Participation involved:

- **Carers:** Pre and post intervention assessment of care burden was assessed using the Carers Checklist (6)
- Individual interviews were held with care givers whose family members attended the day respite centre. (The purpose of this interview was to gauge the informal carers' opinions about the usefulness of the Cafe)
- **Staff:** Staff were asked to answer a survey regarding the usefulness of the Café.

Informed Consent: Informed consent was obtained from all participants prior to commencement of their involvement in the research process. Participants were provided with a Participant Consent Form which they were required to sign before participating in the study to indicate they have read and understood the information sheet. It was clearly stated in both the Participant Information Sheet and the Consent Form that participants could freely withdraw their involvement in the study at any time without providing a reason or without penalty. If they chose to withdraw from the project at any time all of their data would be excluded from analysis.

Data Analysis: Statistical analysis used the Statistical package for the Social Sciences (SPSS) Version 17 to summarise data. Survey data was presented as frequencies and percentages. Qualitative data from open ended questions, interviews and focus groups were examined by content analysis of key themes.

Research Outcomes Aims:

- Reduced isolation for informal carers of people with dementia
- Increased knowledge regarding a novel approach to supporting informal carers of people with dementia
- Contribution to ongoing evaluation of the effectiveness of services and practices provided by Blue Care
- Providing evidence of the effectiveness of Dementia Cafes that will inform future practice
- Development of a final research project report to the funding body Perpetual Philanthropic Services.

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