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# **Effective Restorative Home Support for Older People Living with Dementia and Their Caregivers: A New Zealand Case Study**

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Additional information is available at the end of the chapter

<http://dx.doi.org/10.5772/intechopen.73165>

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## **Abstract**

Home support programmes provide services to enhance the well-being of both people living with dementia and their family/caregivers. There is limited research into the effectiveness of these home support programmes. This chapter reports on a small-scale study undertaken in New Zealand aimed at identifying factors that constitute effective restorative home support services for people living with dementia and their caregivers. A restorative home support approach aims to meet an individual's daily needs as well as promoting activity and independence. Data collection was undertaken in two phases, firstly, an international literature review identified a range of positive outcomes for participants of restorative home support programmes, such as improving functional outcomes, improving quality of life and reduced rates of institutionalism. Secondly, mixed methods were used to elicit views of multiple stakeholders. Quantitative survey data was reported using descriptive statistics and thematic pattern analysis was performed on the qualitative data. Ten key factors of effective home support services were identified under three broad categories: Client and Caregivers, Community and Organisational. These findings raise issues around what constitutes effective restorative home support and may inform debate internationally and lead to better outcomes for clients and their caregivers.

**Keywords:** effective restorative home support, dementia, mixed methods, client-focused, community

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## **1. Introduction**

New Zealand society, like much of the developed world, is experiencing a steady increase in the number of older people within the community living with dementia. Internationally, the

number of people affected by dementia is anticipated to rise exponentially as the world population ages. Global improvements in health care and living standards have contributed to people living longer, and this represents a significant challenge to health and social services [1]. A recent World Alzheimer Report noted that in high income countries approximately half the people living with dementia receive a diagnosis and in middle and low income countries under 10% receive a diagnosis [2]. With increased awareness of dementia in communities, it is likely to lead to more cases of dementia diagnosis. It is estimated that 46.8 million people worldwide are living with dementia and that this number is likely to increase to 131.5 million in 2050 [2].

Due to limited resources and policy development, the provision of services for individuals living with dementia in many developing countries is minimal. In contrast, many developed countries have formulated, or are in the process of developing, policies and services aimed at supporting the needs of individuals living with dementia and their family/caregivers. While the management of dementia care varies globally, home-based support is typically a leading component of government policy as it is viewed as a cost effective support measure [3, 4].

Dementia is not a single disease, it is caused by a variety of brain illnesses that affect memory, thinking, behaviour and ability to perform everyday activities, and is usually of a chronic progressive nature [3]. Dementia is a costly condition from its social, economic, and health dimensions, and numerous nations are formulating strategies such as home support to manage this development such as the provision of home support [1].

Although the levels of provision and nature community-based services vary between nations, the challenges faced by each government in maintaining and improving services, in the context of a rapidly ageing population and changing expectations, remain similar [5]. Community-based services for people living with dementia include home support services offering assistance with domestic tasks, meals, transport, medication administration, and personal care; day programme services that provide leisure, learning and respite activities; support groups in dementia education initiatives; and range of medical support services. International research reveals that the provision of quality community-based services for people with dementia can postpone the need for institutionalised care [6].

Traditionally, home support services for older adults have often emphasised well-meaning dependency model service provision and encourage maintenance and support only [7]. Under this model, as support workers and allied health staff held a task orientated attitude that prioritising getting the job done and doing as much as they could for the client. The service orientation often lacked an emphasis on the promotion of healthy daily routines, exercise, social interaction, autonomy and assisting individuals to undertake the own daily needs [5].

Recent progressive changes in home support practices are, in part, grounded in the developments that occurred over the past three decades in the care of people living with disabilities [8]. Today the concepts of normalisation, engagement with the community, and empowerment, permeated approaches to the management of people with intellectual, psychiatric and physical needs. A number of developed countries propose that home support services catering for the needs of older adults required a similar progressive change of attitude [8] and following this trend a number of new models of care have been developed. Examples of home support models focused on optimising client functioning and independence, is an integrated

component of service provision, include the (primarily) Australian-based active service model [9], the United Kingdom-(UK) based reablement programme [10] and the United States of America (USA) restorative model [11].

The next section details international research findings: investigating the impact of restorative care initiatives, the needs of family caregivers supporting someone living with dementia, and the needs of paid caregivers supporting someone living with dementia.

### **1.1. Restorative care**

International research assessing the impact of restorative care programmes has largely been undertaken in the United States of America (US) and focused upon older adults living within a residential care settings – the results have identified a range of positive outcomes for participants including maintaining and improving functional outcomes, improved quality of life and independence, and psychological gains; a range of positive outcomes for caregivers have also been identified including increased satisfaction and knowledge of restorative care, and increased outcome expectations [12].

A small number of international studies have investigated the impact of restorative care within a community setting. An Australian-based study compared the outcomes of 100 older adults aged 60+ years (without a dementia condition) who participated in a short-term restorative home-care programme directed at optimising functioning, promoting healthy ageing and encouraging the self-management of chronic diseases; with 100 older adults who received the usual home-care services [8]. Research participants were interviewed at the commencement of the programme and at a 3 month and 1 year follow-up. The research found that individuals participating in the restorative programme showed improvements on all personal outcome measures compared with the control group. The researchers commented that “participants who received restorative home care showed greater improvement in their self-care, home management and mobility scores” ([8], p. 198).

A US-based study paired 691 older adults aged 65+ years, without a severe cognitive impairment, and receiving a restorative home care programme through a single restorative staffing unit; with 691 similar aged/gendered adults receiving the ‘usual’ home care programme across five other staffing units [11]. All support staff (restorative and non-restorative) were employed by the same provider. The research identified that older adults participating in the restorative home care programme were significantly more likely to remain living at home and to have a reduced likelihood of visiting an emergency department. The restorative care participants also showed higher levels of self-care, home management and mobility. The researchers commented that the success of the restorative model was supported by an “enhanced sense of teamwork and improved coordination among the home care staff, the reorientation toward maximizing patients’ functional independence, and the inclusion of patients, families and home care staff in setting goals” ([11], p. 2104).

A United Kingdom (UK) based study evaluated the impact of a home support programme that incorporated restorative care elements [13]. The experiences of 29 older adults recently discharged from hospital and supplied with a follow-up 6 week restorative home support programme, were compared with a control group of 25 (similar) older adults receiving the conventional community

support services. The home support participants were found to have spent fewer days in hospital and more days at home over a subsequent 12 months following the intervention.

A narrative review was undertaken in 2015 of four prevalent models of home support for community dwelling persons living with dementia. The four models included: Case Management (may increase use of community-based services and delay institutional care; Integrated Care (results in greater use of community-based services, decrease in hospital days, however, the clinical effects are unknown); Consumer Directed Care (known to increase satisfaction with services and have little effect on clinical outcomes); Restorative Home Care models research has demonstrated that an individual's functions and quality of life improve, however, there is very limited research that has included people living with dementia. It was also noted there is a dearth of research that compares the outcomes and impact of models of care for people living with dementia and their family/caregivers [14].

Evaluations on restorative home support services have identified advantage in providing timely interventions, education and assistive technologies to encourage older people to develop increased levels of independence and activity [5].

## **1.2. Caregivers supporting someone living with dementia**

Globally, care from relatives, including partners, children and extended family provides the foundation of support for people living with dementia [15]. Research has identified that caregivers looking after a family member with dementia are in most need of extra support [16].

Some researchers have contended that policy makers and health service providers often give little recognition to the vast savings they achieve through dementia care services being provided free of charge by family (and friend) caregivers [17]. A European study evaluated the experiences of family caregivers across five European Union countries and found that caregivers looking after an individual with severe dementia typically spent in excess of 10 hours daily in caring tasks and one-third of all caregivers devoted 14 hours or more each day to caring tasks [15]. The research also revealed that while it is commonly understood that cognitive problems – memory and confusion- are known to be associated with the onset of dementia, many carers were unaware of the behavioural symptoms such as aggression and personality changes which often occur and can cause the person with dementia to behave out of character; and create a great deal of stress and challenge for caregivers [15].

Among some researchers and policy analysts there has been a call for a “fundamental re-orientation towards caregivers and caregiver supports... beginning with viewing caregivers as a critical health human resource in a system that [increasingly] depends on their contributions in order to function” ([17], p. 103). This re-orientation recognises that with a growing older-adult population, the health system in many developed nations will increasingly be reliant upon family members to provide the first level of care for people living with dementia.

Peter Stoltz and colleagues [18] reviewed the international literature identifying the needs of family members who care for an elderly person living at home (the majority of studies involved family members caring for a dementia-affected person) and found strong evidence showing that family-based caregivers: have a variety of learning needs about their family member's



condition; wish to network in groups with other caregiver peers, for social and/or learning needs; desire periodic respite from their caregiving responsibilities; often experience a range of negative emotions associated with their caregiving responsibilities – typically feelings of burden, stress and worry; fear social isolation both for themselves and their family member.

While caregivers valued the external support provided to them and their dementia-affected family member, many studies revealed that caregivers often experienced support services has been ‘given’ to them, rather than being negotiated and individually tailored to meet their needs; and while such forms of support were often well intended, it was not always appropriate for the cared-for the person’s or caregiver’s needs [18].

Similar findings were identified by Siobhan Reilly and colleagues [19] from the Cochrane Collaboration in their review of the dementia research literature commenting that:

“Services are often organisationally highly fragmented, coming from a wide range of sources both formal and informal, including from health and social care services, family, friends and neighbours. As a consequence the picture of resource provision for the older person may be a series of piecemeal contributions from a range of different services, with no one having an unambiguous responsibility for taking a broader view of need beyond their own particular remit. Assessment and care plans tend, therefore, to be ‘service oriented’ rather than ‘client-centred’, piecemeal and not holistic, defining needs in terms of available services of care rather than individual problems” ([19], p. 3).

A Canadian study evaluating the experiences of family members caring for a person with dementia also identified a need for an integrated continuing care model that included the person living with dementia and the caregiver as partners in care. The researchers reported that the provision of appropriate and consistent support services – assistance with personal care, meals, homemaking and respite – were very influential in extending the period of time that family caregivers could maintain care within the family residence [20].

A recent Irish review explored the concept of respite care and how it relates to people with dementia and their caregivers. It is widely recognised that respite gives the carer a physical break and consequently a mental break from the person living with dementia. The researchers noted that respite can be viewed as both as service and an outcome. They argued there is a lack of clarity around the concept of respite and it is currently only understood in relation to the carer experience and consequently that this is potentially harmful to both planning and delivery of person-centred dementia care. They further suggested that a name change from respite care to restorative care in order to highlight the significance of offering mutual, individualised health and social services that will enhance care relationships [21].

### **1.3. Paid home support staff working with someone living with dementia**

The Canadian study also identified that the high turnover of professional and non-regulated home support personnel could often lead to an inconsistency of service provision [20]. Other issues affecting the standard of service provision provided by support staff included limited training, lower wages than colleagues in an acute care settings, few benefits and limited supervision [22].

## 2. The New Zealand context

This section consists of three parts: Part one reports on the New Zealand policy environment that has shaped government responses and subsequently social service providers' responses to older people living with dementia and their caregivers. Part two examines New Zealand research on the restorative model. Part three reports on research undertaken on home support staff.

### 2.1. Policy environment

The latest 'Economic Impact of Dementia' report authored by Deloitte [23] and commissioned by Alzheimers New Zealand, suggests there will be approximately 170,000 New Zealanders living with dementia by 2050, up around 300 percent on current figures of 62,000. The report highlights the significant economic impact of dementia with the costs of supporting dementia diagnosed people could reach nearly \$5 billion by 2050. It is suggested that new models of care that delay entry into residential care have the potential net benefit of \$22 million a month, leading to substantial savings over time. The economic impact report is a key information source on the size and scale of the dementia challenge in New Zealand and is used to inform decision-making around dementia policy [23].

The New Zealand policy framework for senior home-based support is primarily founded upon two Government strategy documents: the Ministry of Social Development's New Zealand 'Positive Ageing Strategy, 2001' and the Ministry of Health's 'Health of Older People Strategy, 2002'. The Positive Ageing Strategy promotes the concept of positive ageing, affirms the value of older members of society, and highlights the importance of issues such as access to health services, financial security, independent living, the physical environment and personal safety. The Health of Older People Strategy details an integrated continuum of care, which seeks to ensure that all relevant health and disability services are coordinated in such a way that older peoples' needs are appropriately met "at the right time, in the right place and from the right provider" [24].

In recognition of the increasing challenge of burgeoning numbers of older adults diagnosed with dementia, the New Zealand Ministry of Health released in 2013 the 'New Zealand Dementia Care Framework' to initiate and coordinate dementia services for people living with dementia in the caregivers/families [25].

The vision of the framework is to ensure: people living with dementia, their family are valued partners in an integrated health and support system. They are supported throughout their journey with dementia, to enable them to maintain and maximise their abilities, optimise their sense of well-being and have control over their circumstances [25]. While the national framework recognises that many individuals living with dementia may ultimately require residential care facilities, the framework actively promotes community-based services that support those individuals living with dementia to remain living at home and home-based support services are a central component of this approach. The Framework is not directly based upon the restorative model of care, it does advocate for a person-centred and people directed approach that includes many restorative like principles ensuring that people living with dementia and the families/caregivers are respected, valued and are engaged partners in care planning, receive clear communications and education that enable them to be engaged at all levels of decision-making, and able to self-determine many aspects of their lives [25].

## 2.2. Restorative model

Research undertaken in 2012, compared the experiences of almost 600 older people at risk of permanent institutionalisation: one half were provided with the usual level of support care and the other half were provided with a strong care-management intervention designed to facilitate independent living [26]. Individuals were tested at 3, 6, 12, 18 and 24 months; and the results showed that older people receiving the care-management intervention had a significantly reduced rate of permanent institutionalisation and risk of mortality. The authors suggested that the intervention benefits could also be due to a “higher level of coordinated care, which offered more comprehensive support and early crisis resolution” and an improved “relationship between the participants care manager and GP” ([26], p. 726).

A recent randomised trial of restorative home care for frail older people undertaken by a team of researchers at the University of Auckland, aimed to “establish the effectiveness of a restorative home support service on institutional-free survival in frail older people referred for need assessment.” ([27], p. 27). A secondary outcome of the research was that the health of the informal caregiver was also investigated. Their trial concluded that restorative home care may reduce mortality in older people, potentially lower the rate of institutionalisation, as well as improve carer’s well-being ([27], p. 33).

An Auckland based study evaluated the impact of a restorative home care service for older adults aged 65+ years in the Auckland region [28]. Older adults and their caregivers were identified via a home care agency and a clustered randomly to receive a restorative home care intervention (n = 93) or the usual home care support service (n = 93). In contrast to the traditional home support service, the restorative home care programme was more flexible in its delivery and focused upon promoting functional status and improved quality of life. The research findings revealed that older adults participating in the restorative-based programme demonstrated a significant improvement in health related quality of life and there was some evidence of improvement in social contact. Key aspects of the intervention contributing to these findings included: “goal facilitation and development of personalised support plans, the coordinators enhanced input and support, and improved training for support workers” ([28], p. ii).

## 2.3. Home support staff

While paid caregivers are essential to the provision of home support services, there are ongoing difficulties in recruiting and retaining good staff due to poor working conditions and inadequate training opportunities. The Auckland based study [28] also evaluated the experiences of support staff engaged in the controlled trial in Auckland that allocated 93 older adults and their caregivers to a restorative home care intervention, with a similar sized group receiving the usual home care support. The research findings revealed that the restorative intervention had a substantial positive impact on the participating staffs sense of job satisfaction – primarily due to an improved provision of training, increased support and supervision, and more flexibility in work tasks. This improvement in caregiver work satisfaction lead to a substantial reduction in the turnover of staff participating in the restorative intervention. The researchers noted that in spite of the improvements achieved through the restorative intervention, a majority of staff identified issues in relation to their working conditions including low wages, no reimbursement for travel time between client visits and a lack of guaranteed work hours [28].



Throughout New Zealand there are 22 Alzheimers Societies whose role is to promote education and awareness, and to provide support and advocacy for people with dementia and their caregivers. Kirkman [29] surveyed and collected interview data from 48 women employed as community workers with Alzheimers Societies throughout New Zealand. Despite their low pay, part-time work and the lack of recognition of their professional qualifications, many workers were satisfied with their role as they felt they were making a difference for people with dementia and their families. Overall, Kirkman found a “gendered” patterning of paid and unpaid care for people with dementia commenting that this “reflects the traditional view that women are carers both inside families and outside them as well” and that “what is needed as we plan for the dementia epidemic’ is recognition of the value of the work that women have done as paid and unpaid cares” ([29], p. 14).

In New Zealand home support services are predominately offered by non-government organisations (NGOs) that offer a range of home support services (from personal care to respite care for carers). The NGOs often have receive government funding for eligible clients Needs Assessment and Service Coordination Co-ordination service (NASC) via the District Health Boards who are funded by the Ministry of Health. Additionally, NGOs attract self-funded clients. NGOs are guided by the implementation of the New Zealand Dementia Care Framework [25].

### **3. Research on factors that constitute effective home support services for people living with dementia and their caregivers**

Impact Research New Zealand was commissioned by Presbyterian Support Northern (PSN), a large NGO delivering social services to the upper half of the North Island in New Zealand to undertake research aimed at identifying: What factors constitute effective restorative home support services for people with dementia and their caregivers? How do these factors integrate into the National Dementia Care Framework?

#### **3.1. Research design**

A case study design was undertaken, data was collected from key sites in the upper half of the North Island. Case studies allow researchers to focus on the case, in this instance on key Enliven sites in the upper North Island. Case study allows for a holistic and real world approach ([30], p. 4).

In an attempt to answer the overarching research question the research, a mixed methods were utilised [31]. Two stages of data collection were employed to identify the key factors that constitute effective restorative home support services for people living with dementia and caregivers.

In stage one, a literature review was undertaken to identify the research evidence for best practice in home support care. A literature review is a critical examination of the research evidence and enables researchers to place their research question in context with previous research findings, refine research methods and analysis, avoid unnecessary replication of previous studies, and build upon previous research evidence [32]. A combination of New Zealand and international research literature was incorporated into the review, with a particular focus upon home support services incorporating restorative care principles. International research

evidence was gathered from countries with similar social dynamics to New Zealand including Australia, the United Kingdom, the United States and Canada. In addition to providing an overview of best practice elements, the review helped inform the questions for the fieldwork.

In stage two, mixed methods using a combination of qualitative and quantitative methods were used to gather a comprehensive range of data from Enliven clients and the caregivers/families, Enliven home support staff and senior managers, along with key stakeholders in the community who are recognised as experts in the field of dementia care home support services and social/health policy implementation were invited to participate in the research. Qualitative research methods used in the project included semi-structured telephone and focus groups interviews. Semi-structured interviews allow research participants to liberally discuss their thoughts, feeling and experiences about a particular research topic. This process enables researchers to gain rich insights into the 'meaning' individuals formulate about their experiences. Focus groups are an effective means of gathering data across a group of people – this process helps to identify differences and similarities in people's experience and opinions through discussion and participant interaction. Quantitative research methods used in the project included the administration of a paper-based survey questionnaire. Questionnaires are an efficient method for capturing data from a range of key informants in different locations.

### **3.2. Study setting**

Enliven first delivered restorative home- support services under the Community First restorative model established in Hamilton in 2002, as a Ministry of Health funded 'Ageing in Place' pilot programme. In 2009, Enliven was successful in securing a contract to deliver Auckland District Health Board's Enhanced Home Support Services for people over 65 years. This contract introduced a (restorative-like) strengths-based approach promoting client independence using formal goal setting and flexible packages of funding to ensure a right place and right time experience for older people.

Over time Enliven restorative home support services have progressively been expanded across the PSN region to include five DHB areas: Auckland, Counties Manukau, Waikato, Lakes, and Bay of Plenty. During this time Enliven has continued to build capacity to support clients who might otherwise be in residential care to remain in their own homes, and this encompasses people living with various high and complex needs including dementia.

Additionally, Enliven has incorporated restorative principles within its day programmes – as a component of socialisation and mobility goals, as well as providing mental stimulation and general enjoyment. Day programmes also assist caregiver needs and stress, through providing respite time.

### **3.3. Sampling, recruitment of participants and data collection methods**

Fieldwork data gathering methods included: telephone and face-to-face semi structured interviews; focus group interviews, and the administration of a paper-based questionnaire. Research participants included: a selection of Enliven clients diagnosed with dementia and their families/caregivers; a selection of Enliven managers and staff; as well as a number of key community stakeholders. All participants were nominated by Enliven senior managers and each data collection method selected for the different groups under study were agreed to as

being appropriate and would provide the researchers with sufficient data to answer the overarching research question.

### **3.4. Ethical considerations**

Impact Research NZ has a code of ethics that is in line with the Association of Social Science Researcher (ASSR) standards and requires that work is carried out with professionalism, integrity, good judgement, and in a way that contributes positively.

The researchers were experienced in conducting sensitive enquiry with vulnerable people. The researchers acknowledged that some people living with dementia and their families/caregivers have experienced distress and care was taken to not inadvertently cause harm or distress in any way to those taking part.

Due to the variable capabilities of some people living with dementia, clients were informed that the telephone interview and questionnaire could be completed by the client living with dementia, the client's primary caregiver/family, or a combination of both. All interviews were recorded and transcribed.

Participants were informed both verbally and in writing about the purpose of the research, the names of the researchers/agency conducting the research, and contact details of responsible persons for questions and/or complaints. An explanation of what involvement entailed, their right not to participate and to withdraw their consent, their access to the information they gave, and to receive a summary of the research results, was provided. Informed consent was gained from all participants prior to data collection and their right to cease the interview at any time was reiterated at the commencement. All interviews were recorded and transcribed.

Care has been taken to preserve the anonymity of participants by removing any identifiable information and ensuring that information is not linked to any individual participants or organisations. Researchers have adhered to the 'duty of confidentiality', which means that no identifying information from participants has been shared with other parties. Any third parties who may be given access to research data (the transcriber) was asked to sign a confidentiality agreement.

All hard copy data was kept in locked storage at Impact Research NZ premises and was only be accessible to Impact Research NZ researchers. All electronic data, including any digital recordings of interviews, were password protected and only accessible to Impact Research NZ researchers. All data is kept for at least 3 years following the completion of the project and then destroyed.

### **3.5. Analysis**

The range of data collection methods used allowed for triangulation of the common themes across the data set. A thematic pattern analysis was performed on the qualitative data from telephone and face-to-face interviews, focus group interviews, and responses to open-ended questionnaire questions. This process involved reading the transcripts and comments to establish keywords and emerging themes, and repeat readings to check and refine established themes. Themes are then organised into broad categories and selected quotes from respondents' accounts are used to illustrate the themes. Care is taken to de-identify individual quotes to protect participant anonymity. Analysis of the data using constant comparison between cases provides a distillation of

Participants	Number of participants identified	Number of participants	Participant selection criteria	Data collection methods
<b>All interviews were semi-structured</b>				
Enliven clients diagnosed with dementia and their family/caregivers	30	22	<ul style="list-style-type: none"> <li>• Clients with early onset dementia through to moderate dementia. Clients new to the Enliven service and clients who had been receiving Enliven services for some time.</li> <li>• Clients situated in city, town and rural settings.</li> <li>• Clients from various ethnicities such as Māori, Pacific, European and Asian.</li> </ul>	<p>Telephone interviews elicited information on how well the service is being received and what could be improved.</p> <p>Paper-based questionnaire covered: demographics age, ethnicity, sex, geographic location, length of time since dementia diagnosis, length of time with home-support. Additionally, 10 closed questions using a five point Likert scale covered: the care plan, aspects of service delivery, and suggestions for improvements.</p>
Enliven home support staff	15	10	Enliven Area Managers were asked to nominate 15 Enliven staff – team leaders and home support staff – to participate in focus group interviews	Staff focus groups held in two city locations: Auckland and Hamilton. The interviews covered their views on the provision of restorative care, what works well, challenges, training, data collection and reporting, how the service could be improved.
Enliven managers	7	7	General Manager Enliven Enliven Area Managers	<p>Face-to-face interview 40–60 minutes covered the strategic direction of restorative care</p> <p>Telephone interviews of 40–60 minutes duration covering implementation, strategic overview, the factors that make up effective restorative, issues of culturally appropriate care, staff recruitment and retention, training, funding issues, quality measures for home support, and potential future service developments</p>
Key stakeholders	11	11	<p>Community services – Age Concern, Senior Line, Alzheimers Auckland.</p> <p>DHB services – Gerontology services (×2), Assessment services, Mental Health Services for Older People, Dementia Services Project, Access Network, Community Geriatric Services.</p> <p>MoH – Needs Assessment and Service Coordination Agency.</p>	<p>Telephone interviews or face-to-face interviews</p> <p>Stakeholder interviews explored a range of home support issues including how best to meet the current needs of people living with dementia and their families through home support, best practice in provision of home support, the need for essential/specialist staff training; and the projected future needs of this client group. All interviews were recorded and transcribed</p>

**Table 1.** Summary of participants numbers, selection criteria and data collection methods.

participants' experiential knowledge. Augmenting the interpretation of these findings is a critical commentary drawn from the research literature relating to the features of effective home support services for people living with dementia and their families/caregivers.

Quantitative data gathered from the client questionnaires was entered into an Excel database for statistical analysis and used to generate descriptive tables and figures. Quality checks were undertaken to ensure the data was complete, free of distortions and ready for analysis. Data was then entered into our Excel database to generate descriptive statistics (**Table 1**).

## 4. Research findings

Ten key factors supporting effective restorative home support services for people living with dementia and their caregivers were identified and these are factors are grouped under three primary headings: Clients and Caregivers, Community, and Organisational. The subsequent discussion section will detail how these factors are consistent with the research literature and fit within the national dementia care framework.

### 4.1. Clients and caregivers

The majority of clients were aged between 75 and 94 years (36% aged 75–84 years and 36% aged 85–94 years), were female and identified as New Zealand European. The over representation of female clients is consistent with New Zealand females living longer than males. One third of clients had been diagnosed with dementia for over 3 years, almost half diagnosed for 1–3 years, and the remainder for 1 year or less. Just over half of clients had received home support care for 1 year or more. Dementia impacted ‘moderately’ on one-half of clients and ‘significantly’ on one-third of clients.

The majority of clients lived with family/caregivers, while a few clients with early onset dementia lived on their own with home support services being an essential component of their ability to remain living independently. All clients had received a NASC assessment that allowed them to access government-funded services from Enliven and linked to goals in an agreed care plan. The majority of clients received Enliven home support services on a daily basis.

The objective of Enliven home services is to support clients to remain living in their own home for as long as possible and with the greatest amount of dignity and independence that their circumstances allow, and this goal was highly valued by clients, caregivers, staff and key stakeholders alike. While all parties recognised that dementia was a progressive illness; there was a strong desire for clients to be supported to live at home, as long as the primary caregiver/family was able to cope with the situation and the client’s safety was not compromised.

Factor 1: Client outcomes.

*Effective home support services for people living with dementia ensure that the needs of the client are upheld at all times, that clients are treated with respect, that client outcomes are integrated into realistic service care-plan goals, and that caregivers/family are included in service planning.*

Enliven places clients and their caregivers/families at the centre of their service provision. The aim of Enliven restorative home support services is to achieve client outcomes that assist clients to remain living in their own home and to maintain physical, cognitive and social wellbeing. A majority of clients/caregivers identified four aspects of the Enliven service that were most



important to them: their relationship with home support staff, the capability and professionalism of home support staff, the liaison/communication across home support staff (and Enliven), and the service care-plan developed with the service coordinator. Clients and caregivers wish to be treated with dignity, and to ensure that the client is viewed as a total person, e.g. someone who has had a full life, with rich experiences and capabilities. Clients and caregivers discussed the importance of home support staff liaising with one another (often through the client's log book), to ensure that all staff were kept updated of any developments in the client's life.

A number of clients, caregivers and key stakeholders also remarked on the importance of the client's service-plan having some flexibility built into it, so that support workers have opportunities to undertake alternative (appropriate) tasks for the client as required; a number also recommended that a small proportion of the client's home support time be specifically allocated for the client's/caregiver(s) discretion, to be used as they think most appropriate.

#### Factor 2: Caregiver needs.

*Effective home support services for people living with dementia recognise that the primary caregiver(s) of a person living with dementia (often) require regular periods of respite if they are to sustain their role, and require consistent communication from support workers and other Enliven staff regarding their loved-one's experience/condition.*

Caregivers remarked that they strongly valued opportunities to have a period of time out from their loved one; as this provided them with an opportunity to undertake other necessary tasks, maintain relationships with family and friends, and to have some personal time. Similarly, key stakeholders and staff commented on the importance of the primary caregiver's role, commenting that many home support clients living with dementia were only able to remain living at home due to the commitment of their caregiver (along with the provision of various support services). An integrated dementia care service supporting people living with dementia to remain in their own homes needs to provide appropriate levels of support for clients and caregivers alike.

Caregivers also reported on the importance of being regularly updated by home support staff (and other Enliven staff as appropriate) about their loved-one's day/experience and any other issues that may arise during the provision of home support services. For example, caregivers expressed a strong desire to be informed on how their loved one responded during the support worker's visit and for support staff to also communicate this information with each other (for the client's benefit).

#### Factor 3: Cultural issues.

*Effective home support services for people living with dementia recognise the cultural need of clients and their caregivers/families.*

The PSN Enliven geographical region covers a wide mix of culturally diverse populations. As a consequence, each of the regional managers has worked very hard to develop service and staff capacity to meet the particular cultural needs of their area. Service coordinators endeavour, when possible, to match support workers with clients of the same ethnicity. A client reported on the value of this approach when English was a second language. Key stakeholders also discussed the importance of developing culturally sensitive services that respect the ethnic needs of clients and their caregivers/families.

## 4.2. Community

Factor 4: Dementia education.

*Effective home support services for people living with dementia provide caregivers/families and clients with educational dementia-based resources and opportunities to attend educational programmes.*

Numerous key stakeholders and staff discussed the importance of dementia education for clients and their caregivers/families during all stages of the client's condition. While Alzheimers NZ are the national provider of dementia-related education, there is opportunity for Enliven to work with Alzheimers NZ to expand this service for Enliven clients and their caregivers/families. A staff member remarked that if Enliven employed its own dementia care specialist, then the organisation would be in a position to deliver dementia education programmes as a component of its integrated dementia care service.

With systematic dementia-care training opportunities, Enliven staff, at all levels of the organisation, would be in a stronger position to provide clients and their caregivers/families with dementia-related information. Staff would also be better positioned to know where to refer clients to for other allied support services.

Factor 5: Comprehensive community-based integrated dementia care services.

*Effective home support services for people living with dementia are integrated into regional DHB-initiated dementia care pathways and are predicated upon clients receiving a specialised Needs Assessment and Service Coordination (NASC) assessment.*

Key stakeholders and Enliven senior managerial staff discussed the importance of people living with dementia receiving a specialised dementia assessment as early into their condition as possible. An early diagnosis of dementia provides the dementia-affected person and their family with an enhanced opportunity to understand the cognitive and behavioural changes that are occurring, and increased opportunities to access available medical and social support services in an integrated manner.

Effective home support services for people living with dementia are (as funding allows) integrated into a comprehensive range of community-based services.

Enliven has developed a range of initiatives to support older adults within the community, including day programmes, walking groups, swimming groups, café conversation groups, men's groups, interactions with church volunteer groups, and home-share care programmes (to name a few). Staff and key stakeholders remarked that these community-based services are formulated to promote restorative-care for client wellbeing through physical and cognitive stimulation, and social connectedness within the community – and that there were opportunities for home support clients to more fully engage with these services.

## 4.3. Organisational

Factor 6: Organisational leadership.

*Effective home support services for people living with dementia requires organisational leadership that maintains a strategic vision incorporating the principles of restorative care, familiarity with the*

*national dementia care framework, promotes staff education and training in dementia care, and maintains strong relationships with key regional stakeholder organisations.*

Enliven was viewed by many clients, caregivers and key stakeholders as a leading provider of home support services. To be a leading provider of restorative home support services for people living with dementia and their caregivers/families; Enliven leadership will need to ensure a strategic vision linking to appropriate policies and resources that facilitate the best services for dementia clients and their caregivers/families. Senior staff will also need to effectively share this vision/initiative with Enliven staff at all levels of the organisation.

A number of staff noted that in order for Enliven to strengthen its position as a leading provider of community services to people living with dementia at home, senior management will need to increase expertise in dementia care, and that a specialist dementia-care position could be created to provide training and support for staff, thus building staff capacity. It was also noted by staff that given the limited budget for home support staff training, senior management will need to be innovative in the way they utilise (existing) resources to achieve best practice goals.

Staff and key stakeholders discussed the importance of Enliven maintaining relationships with key regional stakeholder organisations, e.g. DHB, MOH, NASC, Alzheimers NZ, community health professionals and community groups. Many staff and key stakeholders remarked that Enliven is well positioned to engage with emerging DHB-facilitated dementia care pathways and to promote integrated community-based services for people living with dementia.

Factor 7: Workforce capability and development.

*Home Support Care: Effective home support services for people living with dementia employ home support staff with a positive and respectful attitude towards clients/caregivers and are well-trained in home support care for people living with dementia and their caregivers.*

A majority of clients and caregivers remarked that the qualities and skills of the support worker staff they interacted with was an important feature of the Enliven home support service: for example, the support worker's ability to understand of the client's needs, the manner in which they interacted with the client, their ability to communicate clearly with the client/caregiver(s), their knowledge of the client (e.g. what the client likes, their past and preferences); alongside the support worker's competency in undertaking various domestic, house-keeping and personal tasks. Effective home support staff also liaise with other home support staff who are working with the client (often through the client logbook), to ensure important client-related information is passed on, and that clients and caregivers are not required to repeat themselves for every new worker.

Restorative Care: Effective home support services for people living with dementia ensure staff at all levels of the organisation receive education and training in restorative care.

Enliven has a strong tradition of training staff in restorative care principles and there was an acknowledgement from staff that ongoing monitoring of restorative practices was required to uphold the quality of Enliven service provision. Key stakeholders also acknowledged that many aspects of the restorative care model are a feature of the national dementia care framework – although it must be noted that the national framework does not use the terminology 'restorative care'.

**Dementia Care:** Effective home support services for people living with dementia ensure that home support staff and service coordinators receive training in dementia care and participate in regular case-review meetings to discuss client management issues.

Enliven staff at all levels of the organisation strongly supported an expansion of staff training opportunities in dementia care; with many recommending the employment of a dementia care specialist to work directly with senior staff and service coordinators, and to overview support worker training and case-review meetings. A majority of key stakeholders remarked on the growing importance of dementia trained, and well supervised/supported, home support personnel.

A majority of respondents, across all respondent groupings, discussed the importance of consistent staffing personnel for people living with dementia and the difficulties it can cause when clients are faced with changing staff personnel. While many home support staff had worked for Enliven for many years, Enliven managers acknowledged that the service experienced a turnover of home support staff and that this situation created ongoing difficulties in maintaining staff training levels/requirements.

Managers and key stakeholders identified a range of factors that impact upon home support staff retention rates including a modest pay rate, split and reduced working hours, unreliable income (due to clients being absent), and transport issues. Managers also acknowledged that home support work can be a difficult and that not everyone is suited to assisting clients with personal hygiene tasks, cleaning, and dealing with challenging client behaviours.

The Enliven service covers a range of diverse ethnic communities across the greater Auckland, Waikato and Bay of Plenty regions. As a consequence, Enliven actively endeavours to maintain an ethnically diverse home support staff group, and service coordinators attempt to meet clients' various language and cultural needs.

**Factor 8: Organisational database.**

*Client Data: Effective home support services for people living with dementia require an organisational database that identifies and tracks clients living with dementia.*

Currently, the Enliven home support client database is able to identify the number of home support clients presenting with a diagnoses of dementia; it cannot however, detail dementia-diagnosed clients across age and ethnicity groupings. The database is also not updated of changes in a client's dementia condition over time. Senior managers and service coordinators, along with DHB funders, need to be able to track client details to ensure that clients are receiving appropriate services. Being able to access and track client data, enables senior managers to monitor changes in client population demographics, and therefore to be able to employ staff and develop services to match the client population.

**Staff Data:** Effective home support services for people living with dementia require an organisational database that identifies and tracks the number of dementia-affected clients each support worker is engaged with, and the level of dementia-care training each support worker has undertaken.

Currently, the Enliven home support database is not able to accurately identify the number of home support clients living with dementia each support worker has on their caseload and the range of services these clients are receiving. Senior managers and service coordinators, along



with DHB funders, need to be able to track support worker case-load details to ensure that clients are receiving appropriate service provision from well trained staff. It was noted that Enliven intended to upgrade its current databases as funds became available.

Factor 9: Organisational communication.

*Effective home support for people living with dementia requires the service provider to maintain good communication processes with clients and their caregivers/families.*

Many caregivers commented on the importance of being able to communicate effectively with home support staff and service coordinators when various care issues arose. Key stakeholders also remarked on the significance of clients and caregivers being able to approach service providers, and the importance of having well developed mechanisms to collect client and caregiver feedback.

Factor 10: Organisational Evaluation.

*Effective home support for people living with dementia requires the service provider to undertake regular service evaluations.*

All managers stressed the importance of Enliven's commitment to evaluating its provision of home support services. Service assessment took a range of forms including informal evaluation undertaken through client, caregiver/family and staff feedback. Regular Formal evaluations are undertaken through service coordinator case-reviews and service Results Based Assessment (RBA) evaluation. All key stakeholders remarked on the importance of service providers evaluating service delivery.

## 5. Discussion

This section details the principal conclusions arising from the research findings and the research literature. It commences with an overview of the context that dementia services currently exist within. It then features central components of best practice in delivering home support for people living with dementia and their caregivers.

As the post Second World War baby boomer population progressively ages and New Zealanders live longer, the demand for older adult support services will continue to grow. While residential facilities for seniors, including hospital-affiliated residences, will meet a proportion of this demand; it is home support services assisting older people to remain living in their own home (in conjunction with other community-based services supporting quality of life) that will service much of this need. The popularity of non-residential support is driven by the wish of many older adults to remain living within their own home for as long as possible, and by governmental policy supporting this preference as a cost effective (budgetary) option.

The national dementia care framework is predicated upon the best practice principles of providing proactive, accessible and integrated services that are flexible and client-centred [25]. Over the past decade, Enliven has integrated the principles of restorative care into its home support services. There is a great deal of commonality between the principles of restorative care and the national dementia care framework principles. Both models advocate for client-centred services



that are flexible in delivery; that set (manageable) goals for clients that encourage physical, mental and social stimulation; empower clients and their families to maintain control over their circumstances; and maximise client's abilities and sense of wellbeing.

### **5.1. Staff training in dementia care**

With the increasing number of home support clients presenting with dementia-related symptoms, there was agreement from home support staff, managers and key stakeholders, that home support staff working with a person living with dementia require specialised training in dementia care. This finding is strongly supported by the research literature, with numerous studies revealing that the quality of care provided to people living with dementia is, in part, predicated upon the level of specialised dementia-care training staff receive [18, 19].

A number of staff and key stakeholders remarked that, in their opinion, DHBs had a responsibility to supply service providers with adequate levels of funding to ensure that home support staff dementia-care training requirements were met.

### **5.2. Integrated Community-Based Dementia Care Services**

#### *5.2.1. Client needs*

Alongside the two primary community care services of home support services and community day programmes; Enliven has also developed a number of other community-based initiatives to support older adults within the community, including walking groups, swimming groups, café conversation groups, men's groups, interactions with church volunteer groups. All these community-based services are designed to promote the restorative care principles of maintaining client wellbeing through physical and cognitive stimulation, social connectedness within the community, and support to maintain independence within the home.

The international research literature supports the remarks of many key stakeholders and staff that a comprehensive range of community-based services supplied to people living with dementia, has the potential to slow dementia symptoms and to prolong the period of time these individuals can remain in non-residential care [5, 8, 11, 13].

#### *5.2.2. Caregiver needs*

The research literature is unequivocal in its finding that the length of time that a person living with dementia can remain in their own home is frequently dependent upon the capacity of a key individual, or individuals, to maintain a primary caregiver role, and that the provision of community support services may often be as important for the caregiver and it is for the client [17, 33]. This position was strongly supported by comments from participants in this study.

Caregivers remarked that they valued the opportunity to have a period of time out from their loved one; as this gave them, as the primary caregiver, an opportunity to undertake other necessary tasks, maintain relationships with family and friends, and to have a personal break. Caregivers remarked that home support services helped to reduce their levels of stress and to sustain their role as a caregiver.

Similarly, all managers, staff and key stakeholders commented on the importance of the primary caregiver's role, remarking that many home support clients living with dementia were only able to remain living at home due to the commitment of their caregiver, along with the provision of Enliven services.

#### *5.2.3. Dementia education*

Numerous key stakeholders and staff participating in this study discussed the importance dementia education for people living with dementia, and their caregivers/families. This finding is strongly supported by the research literature and also a key component of the national dementia care framework [19, 25].

While Alzheimers NZ are funded to be the primarily New Zealand provider of dementia-related education, there is opportunity for Enliven to work with Alzheimers NZ to expand this service for Enliven clients and their caregiver/families – with the organisation providing exclusive educational services for Enliven clients.

#### *5.2.4. Leadership*

Many Enliven senior managers are members of regional social service and/or dementia care networks – some of these networks are working with local DHBs to plan regional dementia service provision. International research shows that the greater the integration of clients services the better the general outcomes for clients [19], and this finding is a central principle of the national dementia care framework i.e. requesting local services to work more closely together for the benefit of the client. These dynamic supports Enliven senior and middle management initiating and maintaining links with key stakeholder organisations within their region.

#### *5.2.5. Funding*

Key stakeholders and Enliven managerial staff identified that that the home support industry suffers from a high turnover of staff due to funding issues. Similar findings have been found in New Zealand [30] and overseas [19]. Enliven staff identified a range of financial/organisational factors impacting upon home support personnel retention rates, including a modest pay rate, split and difficult working hours, unreliable income due to staff not being paid if the client was absent, and transport issues.

Many clients and caregivers participating in this study remarked that they valued building a relationship with their home support staff and found it very frustrating when they were presented with a high turnover of home support personnel. Home support staff are often the 'face' of the organisation and Enliven is therefore judged by the quality and consistency of its support staff.

#### *5.2.6. Evaluation*

Enliven has good service evaluation processes in place. International research highlights the importance of service evaluation [7, 12] and this theme is incorporated into the national dementia care framework [25]. All managers stressed the importance of Enliven's commitment to evaluating the quality and appropriateness of its home support services. Service evaluation took

a range of forms including informal and formal evaluation processes. Informal evaluation is undertaken through client and caregiver/family feedback, along with support worker comment. Formal evaluation is undertaken through regular service coordinator assessments with clients and caregivers/families (every 3–12 months depending upon need) and service RBA evaluation.

## 6. Conclusion

While dementia is an escalating global problem and governments look to how best to meet the increasing demand on their public health and social services, some local solutions may influence future decision making. This research highlighted how a local provider sought to find its own solution to the question: ‘What are the factors that constitute an effective restorative home support service for people living with dementia and their families/caregivers?’ A review of their current design and delivery of home support for people living with dementia and their caregivers led to the identification of 10 factors influencing the delivery of effective home support for their clients and their caregivers. These factors may have implications internationally, as we look to provide globally best practice in home support. These implications may include: policy and practice that keep the needs and well-being of the dementia diagnosed person and their caregiver central to all decision making and keeping track of their progression; the provision of adequate funding to ensure a skilled workforce to meet the home support demand; acknowledging clients’ ethnic diversity and responding in appropriate ways; and further investigation into a range of home support models to ensure appropriate integrated quality community services.

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