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Evaluation of the Memory Matters Carlow/Kilkenny Community Dementia Project

HSE & GENIO DEMENTIA PROGRAMME





EVALUATION OF THE MEMORY MATTERS CARLOW/KILKENNY COMMUNITY DEMENTIA PROJECT

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Project Overview

Project Name: ‘Memory Matters’ project implemented by the Carlow/Kilkenny Service Provider Forum

Project Site: Counties Carlow and Kilkenny

Project Lead: Patricia McEvoy, Manager of Older Persons Services, HSE

Project Coordinator: Debra O’Neill

Consortium Name: Carlow/Kilkenny Service Providers Forum

Project Award Scheme and Value: This project was awarded €100,000 ‘Innovation Funding’ from Genio, as part of the Health Service Executive & Genio Dementia Programme 2013 Stream 2 funding for individualised supports in the community.

Project Start and End: September 2014 – September 2016

Period of Grant: 2 years

Website: www.genio.ie/dementia-community-projects





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Glossary of Terms & List of Abbreviations

Glossary of Terms

Assistive Technology

Any equipment or system used to maintain or improve functional abilities of people with cognitive, physical or communication problems.

Block Hours

Dedicated timeframes within the provision of home care of generally 2-3 hours per week that allow for reablement activities with the person with dementia as well as carer respite.

Dementia

A general term which describes a range of, generally progressive, conditions which cause damage to the brain, with damage affecting memory, thinking, language and the ability to perform everyday tasks.

Gatekeeper

A service provider who mediates or controls access to services and/or resources.

Home Help

Home help staff assist people to remain in their own home and to avoid going into long-term care. They support vulnerable people in the community who through illness or disability are in need of help with day to day tasks (e.g. essential personal care, washing, help at mealtime, etc.). Home help services can be provided by the HSE or private agencies.

Informal Carer

A person who provides care to a person with dementia outside of the framework of organised, paid, professional work (e.g. family member, friend, etc.).

Integrated Care Pathway

A methodology for the mutual decision making and organisation of care for a well-defined group of patients (in this case, people with dementia) during a well-defined period. The aim of an integrated care pathway is to enhance the quality of care by improving patient outcomes, promoting patient safety, increasing patient satisfaction, and optimising the use of resources.

Local Placement Forum

A multi-disciplinary senior clinical team consisting of public health nurses, old-age psychiatrists, geriatricians, home care package managers, and the Director of Nursing which reviews nursing home applications.

Media Campaign

A media campaign is a set of activities aimed at communicating specific messages to target audiences via various media.



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Multidisciplinary Team

A group of healthcare workers who are members of different disciplines, each providing specific services to patients, working on an interdisciplinary basis.

Nursing Home Support Scheme (Fair Deal Scheme)

A scheme of financial support for people who need long-term nursing home care to ensure that long-term nursing home care is accessible and affordable for everyone. The application process includes a care needs assessment and a financial assessment.

Quality of Life

A multidimensional evaluation of an individual's person-environment organisation including social, psychological, physical and environmental domains and more usually limited to health status measurement in healthcare research.

Reablement

The process of improving skills and confidence in maintaining or (re)gaining function, or adapting to the consequences of decreasing function.

Responsive Behaviour

Actions, words or gestures that can be used by people living with dementia as a means to communicate perspectives, needs and concerns of importance to them: for example, to communicate unmet physical or psychosocial needs or in response to a distressing environmental stimulus. Other terms that are sometimes used to refer to responsive behaviours include behaviours that challenge us, behavioural and psychological symptoms of dementia (BPSD), or more recently, distressed behaviours.

Service Provider

An individual providing care to a patient from the Health Service Executive, or non-statutory body/volunteer agency.

Service Users

Primarily refers to people who use dementia services as patients, and in some instances includes the informal carer.

Stakeholder

An individual involved in the conceptualisation, development, or implementation of the project, or an individual affected by the project (for example service providers, consortium members and service users).



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List of Abbreviations

AHP:	Allied Healthcare Professional
CNS:	Clinical Nurse Specialist
FG:	Focus Group
FU:	Follow-up interview
GP:	General Practitioner
HCP:	Homecare Package
HSE:	Health Service Executive
ICP:	Integrated Care Pathway
LTC:	Long-Term Care
MDT:	Multidisciplinary Team
OT:	Occupational Therapist
PCT:	Primary Care Team
PHN:	Public Health Nurse
PwD:	People with Dementia, Person with Dementia
POLL:	Psychiatry of Later Life
QoL:	Quality of Life
RGN:	Registered General Nurse
SI:	Single Interview





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Foreword

In 2012, as part of the wider HSE-Genio Dementia Programme, five sites around Ireland received funding to develop a range of community-based personalised supports which would enable people with advanced dementia to remain living in their homes for as long as possible. Two of these community sites took part in an evaluation study.

This report describes the evaluation of one of these community sites, the Memory Matters Carlow/Kilkenny Community Dementia Project. The project aimed to support up to 30 people with advanced dementia and complex needs to remain living well at home for longer. The evaluation found that the project was highly successful in achieving this aim, as 55 people with dementia and their families received Memory Matters supports, including reablement and respite supports delivered in a personalised way as well as the use of assistive technology.

The families greatly valued the flexible and personalised provision of home support hours and the enablement approach was viewed very positively by the individuals with dementia. The flexibility and personalisation in the provision of home support hours was achieved within the existing resources of community care services. The average weekly cost of the project supports and the HSE supports combined was about half the cost of nursing home costs in the area and was therefore significantly lower. However, the consideration of costs needs to take account of the fact that the vast majority of care was being provided by family and informal carers. It is essential to ensure that adequate support is available to family carers to enable them to continue providing care to their loved one and this project demonstrates how this might be achieved.

One of the novel aspects of this project was how, with a relatively small resource, the existing HSE services and structures were enhanced and modified to provide personalised and flexible support to people with dementia and their families, thus embedding this approach within existing services. This project is an important demonstration of how existing services can be changed to improve outcomes for people with dementia and their families cost effectively.

These key findings of the feasibility of supporting people with advanced dementia to remain at home through the provision of flexible, responsive and personalised home supports, and the cost effectiveness of this approach, are reflected in the findings of previous evaluations of other elements of the HSE-Genio Dementia Programme (Cahill et al., 2014, O'Shea and Monaghan, 2016).

I would like to thank the participants for sharing their experiences and insights with the research team. Their contribution will feed directly into the future planning and development of community-based dementia services. I also wish to acknowledge the excellent work of the research team from Trinity College Dublin and the National University of Ireland Galway, led by Dr Anne-Marie Brady. We are grateful for the support of the Atlantic Philanthropies in funding this research. We hope that these findings will inform the ongoing implementation of the National Dementia Strategy and will contribute to the momentum now evident in Ireland to enable people with dementia to remain living well at home and to support and their family carers and communities.

Dr. Maria Pierce,
Research Manager, Genio
July 2017



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Executive Summary

Introduction

Memory Matters was one of a number of community projects funded by the Health Service Executive (HSE) and the Genio Dementia Programme. Trinity College Dublin and the National University of Ireland Galway were commissioned to evaluate this two year project (2014-2016) that aimed to provide **flexible, person-centred** and **responsive home care** for people with advanced dementia and their families/informal carers, especially those with complex needs, using a reablement approach. This means that interventions should promote independence, be person-centred and strengths based with less emphasis on task-orientated approaches to care (Social Care Institute for Excellence 2011). The project aimed to place the service user at the centre of decision making in relation to home care.

Fifty-five people with dementia and their families/informal carers received Memory Matters supports including reablement and respite supports delivered in a personalised way. Dementia-specific educational initiatives were delivered to statutory and voluntary service providers in the region to improve their awareness and knowledge of dementia, and included reablement-specific **training** for home helps. Memory Matters also provided **assistive technology** solutions to assist the person with dementia to live as safely and independently as possible. Memory Matters included a media campaign to raise awareness of dementia in the Carlow/Kilkenny area.

Evaluation Aims & Approach

The aims of the evaluation were:

- To understand how individualised and flexible approaches to care in the community can improve service delivery and outcomes for people with dementia and their families
- To explore the roll-out of individualised supports and alignment with implementation of the National Dementia Strategy (Department of Health, 2014)

An exploratory mixed methods approach involving both quantitative and qualitative data analysis was used to provide a comprehensive evaluation of Memory Matters. The evaluation was underpinned by a framework called RE-AIM (Glasgow et al., 1999, Gaglio et al., 2013) which evaluated project activity in terms of reach, effectiveness, adoption, implementation, and maintenance. There were three key aspects of this process-focused evaluation:

1. Experience of dementia care – perspectives of service users and service providers
2. Compare cost of 'service as usual' to the cost of new approaches
3. Impact of the educational components



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Key Findings

Experience of the Person with Dementia

- People with dementia and families/informal carers stated a preference for the person with dementia to remain at home, which was associated with important benefits such as maintenance of ability, connection to life roles and interests, access to familiar environments and a sense of security.
- The project's objective to ensure that the person with dementia continued to live at home was achieved for two thirds of the active participants over the course of the project and participants and their families believed that the support from the project helped to keep them at home.
- Flexibility and individualisation in the provision of home support hours facilitated reablement activities, improved the quality of care experience and provided for carer respite, which were all perceived as beneficial.
- The participants viewed the reablement activities positively as they allowed for engagement with the person with dementia beyond physical care and included meaningful activities which helped maintain ability and created the potential for enjoyment, contentment, recreation and social connectivity.
- The project was successful in reaching 114 people with dementia and informal carers/families and 55 of those assessed and approved received enhanced services. Those who were not supported by the project were redirected to existing services.

Experience of Families

- Provision of flexible home support hours was of the greatest benefit to families and informal carers in terms of support and relief of carer strain.
- Recognising and assessing people with dementia and their families/informal carers as a unit of care facilitated the delivery of a targeted service.
- Families/informal carers' needs for flexible support were addressed by the project activity and their satisfaction with community dementia care services increased during the project.

Impact on Cost of Community Care

- Flexibility and individualisation in the provision of home support hours were achieved within existing resources of community care services.
- The vast majority of care for people with dementia supported by the project was provided by family members at no cost to the HSE.
- The **average weekly cost** of the project supports and HSE supports combined was **€607** (from €331 to €1,317) which is significantly lower than nursing home costs in the area (€1,172 to €1,478 per week).
- From the societal perspective, which includes the cost of informal care, the cost of living at home was less than nursing home care for over 80% of the participants.



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Impact of Technology

- The assistive technology provided under the project received mainly positive feedback as it provided reassurance for families/informal carers.
- The findings indicate there were some negative responses relating to the appropriateness and utility of the equipment in participants at an advanced stage of dementia. This is in keeping with findings from other studies.

Education and Training

- There was a high level of dementia awareness and knowledge among the service providers surveyed as part of the Memory Matters project after the provision of training.
- The educational initiatives emphasised a move away from task-orientated care and a move towards reablement for people with dementia. The feedback received from participants who attended the educational programmes was positive, with participants reporting increased confidence towards this approach to care.
- Education and training initiatives which focus on reablement are important in the provision of dementia care and are useful for all health care staff, especially those with high levels of patient contact.
- The core modules were well received and useful in stimulating interest in existing programmes that are part of the National Dementia Education Programme. They also demonstrated the effectiveness of targeted education initiatives that seek to communicate a central message to a relatively large number of people.
- The Memory Matters project had a wider impact on the community by inspiring the development of dementia-friendly services and facilities for people with dementia in the Carlow/Kilkenny area that exceeded what the project set out to achieve.

Memory Matters Facilitators: Learning

- The consortium, project lead and project coordinator functions were important for project set-up and roll-out; the project coordinator was a critical facilitator for project development and management of project activities.
- The consortium was a pre-existing forum that combined public, private and voluntary agencies and allowed for the coordination of resources across the agencies to generate individualised supports that met the multiple needs of participating people with dementia and their families/informal carers.
- The project has had a positive impact on home support service as home help and Occupational Therapist roles engaged in a wider interpretation of their function to support and enable individualised care.
- The additional Occupational Therapist position funded by Memory Matters supported the delivery of the project.
- The positive effects of reablement are intertwined with the positive effects informal carers experienced through the carer respite they received during reablement. It therefore helped the person with dementia to live at home for longer.

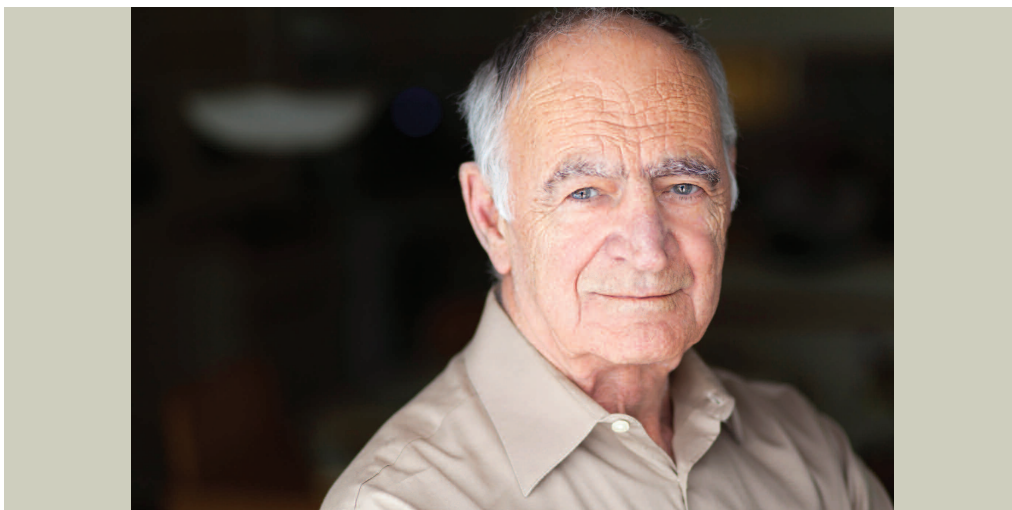
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Memory Matters Challenges: Learning

- Communication pathways were of great importance and require careful consideration and planning, particularly with a project roll-out across different counties.
- A shortage of suitably qualified manpower led to tension between assessed need for home care and availability of services, particularly around suitable supply of home helps.
- The selection criteria to access services provided under the project were targeted at those individuals at an advanced stage of dementia. For some service users this rendered the provision of a reablement approach to care challenging due to the late stage of dementia progression.

Sustaining Memory Matters

- The project's embeddedness in existing structures, such as the Carlow/Kilkenny Service Provider Forum, and the utilisation of services from within the healthcare system were a strong driver of its success. The reconfiguration of the existing home care resource is a key factor in sustaining the changes.
- The sustainability of the new approach to care was facilitated through a substantial modification of the Home Help Application Form which is now the official HSE referral form for all home help applications in Co. Carlow/Kilkenny.
- The 33 people who were still being supported at the end of the project continued to receive support.
- Projects such as Memory Matters are influenced by national developments in the provision of care in the community and to sustain will require visible commitment to the ongoing availability of flexible home care supports.
- For the duration of the project, all persons with dementia received priority one status for Occupational Therapy assessment (highest priority with a target to initiate assessment within 5 days of accepted referral). Following the project, people with dementia with complex needs referred by Public Health Nurses will be prioritised according to clinical need. Those with mild to moderate dementia will be identified for Occupational Therapy assessment through memory clinics.
- At the time of the project, there were concerns at national level regarding the availability of suitably qualified home helps which could potentially jeopardise the continued provision of an individualised and flexible approach to the design of home care packages advocated by this project. Approval by the Health Service Executive (HSE) to recruit home helps has been given since.





RE-AIM Framework

REACH

- The project was successful in reaching 114 people with dementia and informal carers/families and 55 of those assessed and approved received enhanced services. Those who were not supported by the project were redirected to existing services.
- The project reached many different service providers, in particular Public Health Nurses, Home Helps and Occupational Therapists.
- The educational initiatives and media campaign had a wide reach to increase dementia awareness among the Carlow and Kilkenny healthcare providers and community with approx. 550 service providers trained.

EFFECTIVENESS

- Sixty percent of participants continued to live at home over the course of the project even though they have been assessed as eligible for long-term care on entry to project, 30% went into long-term care and 9% passed away.
- The assessment of people with dementia and their families/informal carers as a unit was innovative and facilitated delivery of a more targeted home care service. The inclusion of the family/informal carer in the decision-making around care hours ensured that service provision considered families/informal carers' needs.
- The quality of care and support provided for people with dementia and their families/informal carers improved due to the flexibility of home supports within the project.
- The reablement approach to the care of the person with dementia allowed for meaningful engagement with people with dementia which supported the maintenance of ability and connection with life roles as well as enjoyment and contentment.
- The flexibility in the provision of supports, for example block hours to facilitate reablement and night services, were effective elements of the project in supporting the person with dementia and their families.
- The assistive technology installations proved helpful for many participants and families.

ADOPTION

- The consortium, project lead and project coordinator were important to the effective adoption of the project aims and enabled penetration of older people community care services.
- Existing community care structures were utilised to facilitate integration of more flexible approaches to dementia care delivery in community home care services.
- There are clear indications of a philosophical shift in thinking regarding the provision of more flexible and supportive approaches to dementia care among community service providers.

IMPLEMENTATION

- The project structures positively contributed to the implementation of the project within community care services.
- The geographical distribution and communication pathways posed a challenge to the project implementation. Healthcare teams in Kilkenny are located centrally whereas teams in Carlow are more dispersed. This resulted in a slower project roll-out in Co. Carlow and therefore project outcomes took longer to impact in this area.
- A strength of this project was the use of existing resources to deliver personalised home supports. This is important learning for wider roll-out. This occurred in the context of constrained community care resources and this wider systemic issue needs to be addressed for further roll-out.

MAINTENANCE

- The use of existing structures and resources, the training provided and the cultural shift that was achieved all support the potential ongoing maintenance of the impacts seen in this project. The people who were in receipt of supports at the end of the project continue to receive these supports.
- National developments in the provision of community care services have a strong impact on the sustainability of this type of supportive dementia care in the community.
- Maintenance of the palpable shift in culture and values towards more responsive dementia care strategies will depend on organisation support and on continued preparation of service providers for a dementia-specific role.
- The sustainability of the project gains may be constrained by healthcare resources for example available home helps, introduction of wait lists and the risk of prioritisation of physical care needs in the allocation of home care packages.



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Recommendations for Enhancing Dementia Care

- An individualised, person-centred, flexible and responsive approach to dementia care is recommended to improve the quality of care for people with dementia and their families.
- A personalised approach to the care of people with dementia can be beneficial at any stage of dementia.
- Working from within existing structures and resources, such as the Carlow/Kilkenny Service Provider Forum and HSE resources, is useful for project setup, implementation and sustainability.
- Considering the person with dementia and the family/informal carer as a unit of care, taking account of individual needs and preferences of both, and including the person, family/informal carer in care decisions is important for the delivery of a targeted service.
- Flexibility in the provision of community care services, especially regarding weekend and night services and block hours of care, should be considered to meet the needs of people with dementia and their families/informal carers and support the person with dementia to remain at home.
- A reablement approach to the care of people with dementia that supports the maintenance of ability can be beneficial at any stage of dementia.



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Memory Matters Key Achievements:

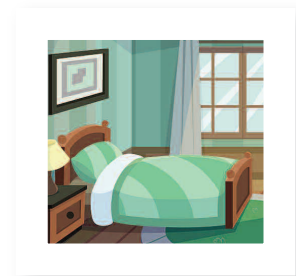
55 people with dementia and their families received Memory Matters supports, including reablement and respite supports delivered in a personalised way



The **flexibility** of home support hours was particularly beneficial to families and informal carers in alleviating carer strain



Flexible and individualised home support hours were delivered within the **existing resources** of community care services



60% of participants continued to live at home for the full duration of the project

The Memory Matters project inspired the development of **dementia-friendly services and facilities** in Carlow/Kilkenny beyond the scope of the project



38 assistive technology packages were installed with support from the project and the HSE



For the majority of project participants, the cost to the HSE of providing additional, flexible and responsive home care hours **was lower than** the cost of care in a long-stay residential setting



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1. Introduction

1.1. Dementia Care in the Community

In Ireland, it is estimated that there are approximately 55,000 people living with dementia (Health Service Executive, 2016b). Projections for the next thirty years suggest that the prevalence of the condition is due to increase steadily to reach a figure of up to 151,157 persons living with dementia in the country by 2046 (Pierce et al., 2014). This represents a significant social and economic challenge to society, policy and service delivery (Cahill et al., 2012). To address this growing concern the Irish Government published a National Dementia Strategy in 2014 (Department of Health, 2014) calling for a refocus of current service provision to address the needs of people with dementia (PwD) and their carers in a more responsive manner. The priority actions identified by the Strategy include:

- Building awareness and understanding
- Facilitating timely diagnosis and intervention
- Introduction of integrated services, supports and care for PwD and their carers
- Strengthening dementia training and education
- Better leadership to guide change in practice

The need for integrated approaches applies to hospital as well as community care. Cognisant of the fact that the care requirements of PwD change over time, integrated approaches allow service provision to be flexible yet seamless, with the central tenets of coordination, continuity and responsiveness (Woolrych and Sixsmith, 2013). Integrated care pathways and integrated care, are designed to formalise multi-agency working, and to increase quality and efficiency of care (Rees et al., 2004) while putting patient outcomes and experiences at the centre of the process (Health Service Executive, 2015a). Person-centred care, encompassing the personalisation and individualisation of services for PwD, is often seen as the 'gold standard' of dementia care. It consists of four key elements: 1) valuing PwD and their informal carers; 2) treating people as individuals; 3) looking at the world from the perspective of the PwD; and 4) a positive social environment for the PwD (Brooker, 2003). An important focus of person-centred care is the potential for communication and relationships to promote well-being in PwD (Downs, 2015). However, in a cross-country European examination of home care services for PwD, it was reported that while basic care needs are generally met, individualised care specific to the needs of the PwD is seldom provided (Bökberg et al., 2015).

It has been recommended that the care and support of PwD be underpinned by a reablement approach to care which focuses on what people are able to do (Clare, 2016). The aim for most PwD is to preserve and encourage a more functional state rather than achieving independence. Outcomes concentrate on the formation of routines, supporting the informal carer, and learning to live well with dementia rather than a decrease in the amount of support that is needed (Social Care Institute for Excellence, 2013). In the later stages of dementia, the emphasis might focus on enabling expression of preferences and optimising well-being as well as preserving dignity (Clare et al., 2010).

Cahill et al (2012) estimated that, of the people in Ireland who are living with dementia, 26,000 were living at home and assumed that, for each of these people, four family members are affected. The shift towards community care, combined with the ageing population and increased prevalence of chronic conditions, results in an increased



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burden of care for informal carers (Champlain Dementia Network, 2013). An increasing focus on home-based rather than institutional care internationally is well reflected in Irish policy though the supports to achieve this compare less well than in many other countries (OECD, 2011). For example, long-term leave for informal caring is not available in Ireland on a statutory basis as is the case in some OECD countries (OECD, 2011). Thus, long-term informal carers are likely to give up employment to continue their caring role and the impact of this in terms of financial and emotional burden extends well beyond their care giving career (Cronin et al., 2015). In addition, research points to poor health and well-being among Irish informal carers (O'Sullivan, 2008, O'Brien, 2009). In terms of the economic impact of dementia in Europe, some 56% of the total cost estimate of the €160 billion is represented by informal care (Wimo et al., 2011).

Estimating the home care utilisation rates for those aged 65 including those with dementia is challenging due to the complexity in community care services and health and social care infrastructure (Care Alliance Ireland, 2016). The cost of dementia in Ireland has been estimated at just over €1.69 billion per annum, 48% of which is attributable to informal care provided by family and friends to those living with dementia in the community (Connolly et al., 2014). A further 43% is accounted for by residential long-stay care, while formal health and social care services contribute only 9% to the total costs of dementia. Increasingly, however, the impact on the acute and long-term residential care sector is being recognised (Cowdell, 2010, Nolan et al., 2006). People with a diagnosis of dementia tend to have a significantly longer length of stay in hospital than those without dementia, a finding that holds across a number of co-morbidities. Applying European prevalence data for dementia to patients in the acute care sector in Ireland, suggests that the estimated cost of this extended length of stay associated with dementia is almost €200 million per annum in Ireland (Connolly and O'Shea, 2013). Given these figures, the implementation of innovative, efficient and cost effective supportive care strategies that speak to national priorities in the area of dementia care enabling more PwD to remain at home and that can be replicated in other areas are essential to enhance dementia care.

1.2 HSE & Genio Dementia Programme

Genio is a non-governmental organisation which works to bring together Government and philanthropy to develop, test and scale better ways of supporting people with disabilities, mental health difficulties and dementia to live full lives in their communities. The HSE & Genio Dementia Programme developed incrementally since 2012 with assistance from the Atlantic Philanthropies and the HSE, supporting the development of innovative service models to improve the range and quality of community based supports and services for PwD. Since 2011, innovation funding has been awarded to nine regional community-based projects focused on developing a range of personalised, flexible and responsive supports and services to help PwD to live well in their community for longer, and three projects developing integrated care pathways in acute hospitals (Genio, 2015).

The experience and learning from each project is shared through a learning network with a view to supporting sustainability and scaling. The findings and ongoing learning contribute to building leadership in the dementia sector, and will inform public policy and investment in the area with a view to supporting the implementation of the Irish National Dementia Strategy (Department of Health 2014).



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In 2013 innovation funding was awarded to three projects to develop integrated care pathways in acute hospitals (St James's Hospital, Mercy University Hospital and Connolly Hospital) and five projects to develop personalised supports in the community (Louth, Kilkenny, Mallow, Roscommon and Leitrim). The Memory Matters Carlow-Kilkenny Community Dementia project belonged to this latter group and aimed to establish enhanced supports for PwD and their carers in the community. Its target was to provide flexible and responsive support, including a reablement approach to care and alternative carer respite to 50 persons with dementia who presented with more complex needs, and their families, in order to enable them to remain in their own home.

In 2014, the authors of this report, under the leadership of Dr Anne-Marie Brady, were commissioned to evaluate the HSE & Genio Dementia Programme 2013 focusing on the three hospital sites and two of the community projects (Memory Matters in Carlow/Kilkenny and the Community Outreach Dementia Project Leitrim (CODPL)). This document reports the findings in relation to Memory Matters.

2. Development of the Memory Matters Project

The following description of the Memory Matters project represents a joint understanding of the project by the evaluation team and the project lead and project coordinator as it unfolded. It provides an overview of pre-existing services in the area and the project's organisation. The project aims are outlined followed by a description of the main Memory Matters project components.

The Memory Matters project was undertaken in counties Kilkenny and Carlow which have populations of approximately 99,180 and 56,875, respectively (Central Statistics Office, 2016). Both counties are a mix of urban and rural areas with 26% of people in Co. Kilkenny living in Kilkenny city, and 25% of people in Co. Carlow living in Carlow town. The available data suggests that there are 1,057 PwD living in Co. Kilkenny and a further 543 in Co. Carlow (Pierce et al., 2014). Of these, approximately 63% are living in the community. The number of PwD living in the community is expected to double in the next 20 years in view of the ageing population (Pierce et al., 2014).

2.1 Local Community Services

Counties Carlow and Kilkenny offer a range of community services for people over 65 years which were in place prior to the Memory Matters project. An overview of these services is provided in Table 1. There are also primary care centres in the area as well as hospitals.





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Table 1. Community Service Provision for the Elderly in Co. Carlow/Kilkenny

Services for Older People	Provider (Role)
Day Care Centres	Health Service Executive Alzheimer Society of Ireland
Befriending Service	Kilkenny & Carlow Contact
Public Health Nurse (PHN)	Health Service Executive Services include: <ul style="list-style-type: none"> • Home visits and care for older people • Care on discharge from hospital • Assessment for community care services and supports • Assessment for eligibility for the Nursing Home Support Scheme • Referrals to respite and day care
Occupational Therapist (OT)	Health Service Executive Services relevant to this project include: <ul style="list-style-type: none"> • Home safety assessment • Equipment needs for older persons
Psychiatry of Later Life (POLL)	Health Service Executive Services relevant to this project include: <ul style="list-style-type: none"> • Domiciliary-based assessments • Visits to people resident in public and private nursing homes
Home Care Package Services	Health Service Executive Carers Association (now Family Carers Ireland) Alzheimer Society of Ireland

The HSE operates a Home Care Package (HCP) scheme which is a set of services to enable older people to be cared for in their own home (Health Service Executive, 2010). The services may be provided by the HSE directly or by voluntary and private organisations (see Section 2.4.2).



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2.2 Memory Matters Project Governance and Organisation

The project was led by Patricia McEvoy, Manager of the Older Person Services Carlow/Kilkenny, and governed by Kilkenny Age Friendly County Limited which brings together key public, private and voluntary sector agencies under the auspices of the local authorities to ensure that their combined resources are used optimally in delivering necessary services to older people (Age Friendly Ireland, 2015). The Memory Matters Project was successful in its application for funding and received a two year grant of €100,000.00



Kilkenny Community Care Centre, James's Green, Kilkenny



Carlow Community Care Centre, The Shamrock, Carlow

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The Carlow/Kilkenny Service Providers Forum acted as the consortium for the project (see Appendix 1). Dementia consortia are locally developed associations that are formed to meet local needs and include a wide range of organisations and agencies to draw on local strengths (Keogh et al., 2016). The Service Provider Forum was established in 2010 and is a composite of statutory, community and voluntary organisations and the operational driver of all older people service initiatives. Most other projects in the HSE-Genio Dementia Programme had to establish a Dementia Consortium from scratch, i.e. begin a process of horizon scanning which involves identifying individuals who might be interested and identifying organisations/groups that are already in existence and have a similar mission (Keogh et al., 2016). The Memory Matters project was able to build on a structure which had already been established to develop its Consortium. The multi-stakeholder nature of the consortium harnesses the resources and energy of a wide range of organisations to support PwD (Keogh et al., 2016). The Memory Matters executive was a project-specific working group within the Service Providers Forum (see Appendix 1). The full consortium met seven times over the two-year duration of the project. The executive committee met four times over the same period. The full committee remained relatively stable, and members who resigned were generally replaced.

Three project-specific working groups supported specific aspects of the project on Training; Technology; and Home Help Applications Approval (see Figure 1).

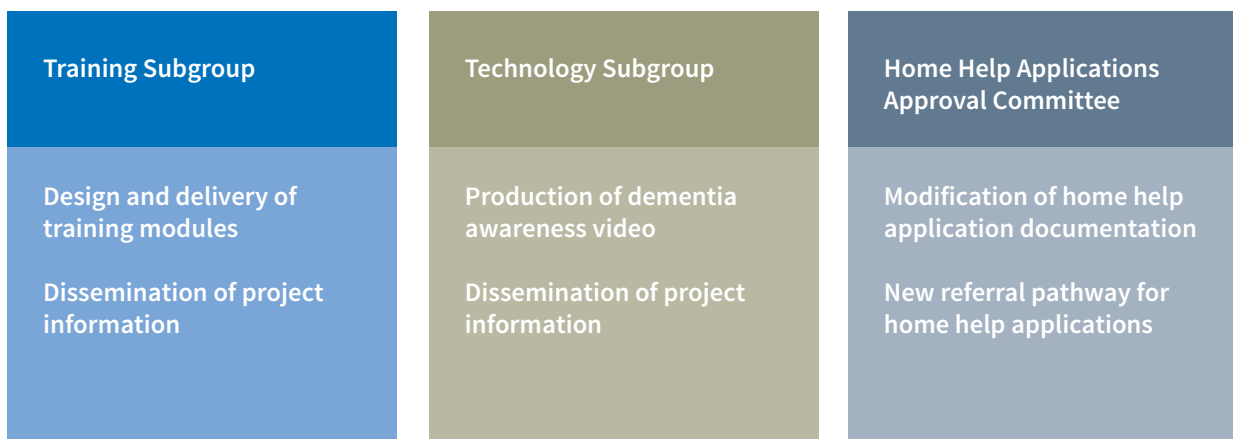


Figure 1. Overview of Memory Matters Project-specific Consortium Working Groups

A project coordinator was recruited and organised and managed the operation of the project, including the day-to-day management of project activities, and the coordination of the work across the various project subgroups, and had responsibility for the delivery of all project aims and objectives under the direction of the project lead. She facilitated the work of the consortium, which she regularly updated on project progress and implementation, as well as the executive committee. As project coordinator, she reported to the Service Provider Forum bi-monthly and submitted quarterly reports to Genio.

Memory Matters also funded an additional OT for one day a week (6 hours/week) for one year to support the delivery of the project.



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2.3 Objectives of the Memory Matters Project

The Memory Matters project aimed to bring about a philosophical change towards a person-centred approach to supporting people with advanced dementia at home. It sought to design and provide flexible and responsive home care support for PwD to enable them to continue to live at home. The originally stated objectives were as follows:

- 1. Support 50 individuals with complex care needs to reside at home and live good lives.**
 - Support 50 individuals with complex needs and their family/carer (100) to continue to reside at home and have good lives in the community.
 - Provide a range of home and community based respite services. Alternative respite and support packages available to all who have been identified for services.
 - Develop a range of social outlets that allow individuals and their carers to continue involvement in their hobbies. These will include Choir, Music, Art Club, Gardening etc. and will be set up through family resource centres and voluntary agencies. These clubs will use existing community and commercial facilities and be designed to meet the information, social connection and support needs of carers as well as PwD.
 - The community supports being developed by the project will be integrated into new care planning processes being developed by HSE for the discharge of PwD from nursing homes, acute hospitals and other settings. The focus will be on reablement - maintaining and regaining skills and confidence and enabling people to remain living in their own homes for as long as possible.
- 2. The potential contribution and personal choice of the PwD (and their family or advocate) will inform the planning and delivery of individual supports.**
 - Establish an advisory panel of PwD for the project who will be consulted on all aspects of its development and implementation.
 - The potential contributions and personal choice of the PwD (or their family or advocate as appropriate) will inform the planning and delivery of individualised supports.
- 3. Provide individual care packages that take account of carer's needs.**
 - Provide individual flexible home care packages that take account of the carer's needs.
 - The model will include a wide range of supports for carers which are flexible, responsive and reflect a range of needs (for example, support for carers through to intensive respite).
- 4. Provide dementia-specific awareness and training for statutory and voluntary agencies.**
 - To provide dementia-specific and awareness training for all statutory and voluntary agencies.
 - All HSE Home helps (100) and health professionals within the primary care teams (PCT's) will have received training by end of year 2. Introduce a reablement approach to home care service (100 HSE home helps will be trained in this approach to care) in conjunction with the OT department.

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5. Provide Assistive Technology where appropriate.

- 20 people will receive person-centred assistive technology & telecare packages. This will be augmented by the provision of social/network/dementia-friendly touch screen personal devices to encourage social engagement and boost memory activities.
- 10% (5) of the selected individuals will receive an electronic care plan. A small visibility study will be undertaken for the duration of the grant to determine the effectiveness of assistive technology in delivering care. As other providers in the sector were exploring the provision of this service, this objective was not pursued to avoid duplication and further assistive technology resources were provided instead.

6. Ongoing media and publication campaign.

- On-going media campaign – 24 infomercials will be developed and placed on local radio; 10 profile pieces in local print media; publication materials and a DVD will be produced.

2.4 Memory Matters Project Components

To meet these objectives, the following supports were put in place; individualised and flexible approaches to the deployment of home supports/home care packages to support reablement activities for the PwD and/or meet the informal carer needs; the provision of telecare and assistive technology; and educational initiatives to increase dementia care for staff (see Figure 2).



Figure 2. Overview of Memory Matters Project Components

The project commenced in September 2014 and ended in September 2016. Figure 3 provides an overview of project activity and relevant milestones during the project period.

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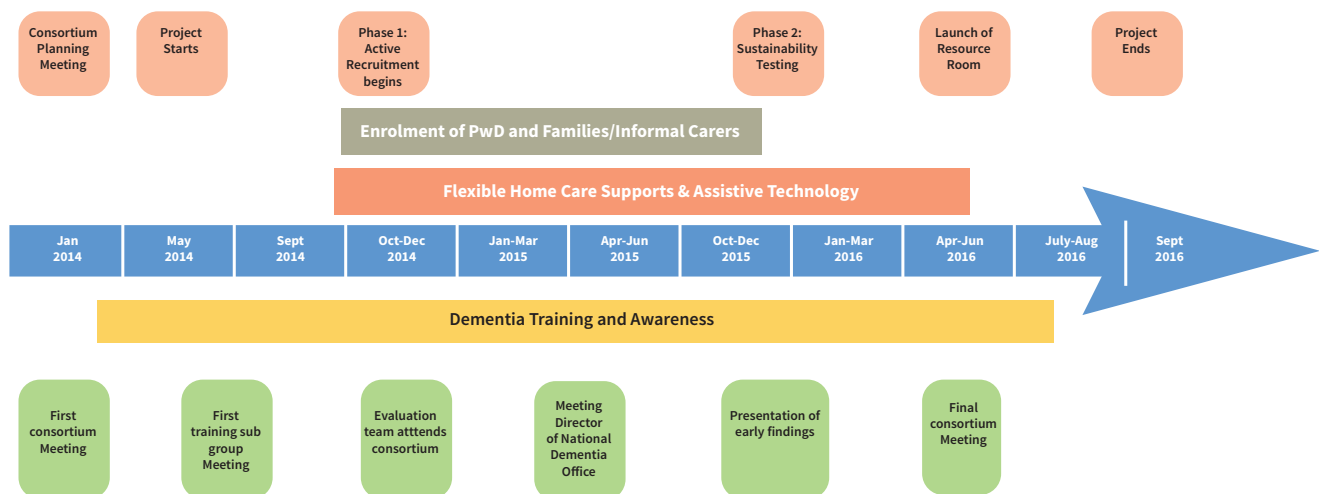


Figure 3. Overview of Project Activity and Milestones

2.4.1 Referral Processes

The project was divided into two phases: Phase 1 focused on identifying PwD who would be supported by the project over the period September 2014 to October 2015, and Phase 2 focused on embedding the changes achieved from the project into formal services. The initial aim of the project was to support 50 participants. In total, 114 PwD were referred to the project, 55 of whom were supported at any time, i.e. received Memory Matters services. The pathway used for referrals to the project and project inclusion criteria are detailed in Appendix 2.

The referrals to the project reflected proportionally the number of people in the respective areas with 60.5% (n=69) of referrals originating in Co. Kilkenny and 39.5% (n=45) in Co. Carlow². Acceptance of support from the project varied significantly, 59.4% (n=41) of those referred to the project in Co. Kilkenny also enrolled in it, while only 31.1% (n=14) of those referred in Co. Carlow were enrolled onto the project. Appendix 3 maps these referrals. Most of the referrals to the project were made by PHNs/Registered General Nurses (RGNs) (87%). Further detail on referrals to the project can be found in Appendix 2. Those who were referred to the project but declined by the Local Placement Forum (n=46) were re-directed to other services as they did not meet the criteria. Twenty-one of these followed the post-Memory Matters pathway in phase 2 which tested a new referral pathway that is now in use for home help service applications. As these 21 people were cared for in the standard system, they are not included in the numbers for the project evaluation.

² Based on CSO data (Central Statistics Office 2012), 63.6% of the overall Co. Carlow/Kilkenny population is located in Co. Kilkenny, and 36.4% in Co. Carlow.



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As the project was a pilot to establish whether the new approach to home care for PwD was effective, participants received Priority 1 status for OT assessment upon referral to the project, i.e. the assessment received highest priority within the service with a target to initiate assessment within 5 days of accepted referral. This allowed for the development of individualised care plans and bespoke training for home helps to assist the PwD in reablement activities.

2.4.2 Memory Matters - Flexible, Person-Centred Home Care Supports

The home care supports offered to participants on the Memory Matters project were provided through the existing HSE services and budgets for the Carlow/Kilkenny area and voluntary providers. The Home Care Package (HCP) scheme offered by the HSE is not means tested or dependent on a medical card, and there is no charge or contribution to be paid for the services provided. Each HCP differs since it is based on needs and the level of other supports available such as family members or friends. The package may include the services of nurses, home helps and various other services such as physiotherapy and OT as well as respite care or appliances. In order to determine whether a HCP is required, a Care Needs Assessment is performed by health professionals who recommend what services or supports are required above what is available from standard services.

Existing HSE community resources were 'reconfigured' and/or extended to support the range of family and informal help which may have been available to the person. The home care assessment considered the range of formal and informal supports that were available (see Appendix 6).

The home care support hours were flexible and could be allocated in block hours to allow for reablement activities and included weekend and night time services. The objective of reablement is to help people do things for themselves rather than the conventional home care approach of doing things for people (Social Care Institute for Excellence, 2011). Reablement encompasses consultation with the PwD and their informal carer and focuses on the PwD's strengths and using their preserved capabilities to protect and maintain quality of life (QoL), irrespective of their level of cognitive functioning (Mishra and Poulos, 2015).

The reablement approach facilitated engagement beyond the emphasis on physical care to include meaningful activities with the PwD which are specific to the person's interests and needs, providing a person-centred approach to care. In practice, this meant that while physical care using a more person-centred approach was provided, additional hours were also provided which focused on engaging with the PwD in meaningful activities that were planned in accordance with their specific needs.

The assessment of home care needs was an important part of the Memory Matters project. Once an application was approved by the Local Placement Forum the project coordinator conducted a home visit to ascertain their needs and the support that was available, and to seek consent from the PwD and the informal carer to gather project demographic data (see separate methodology reference document). The project coordinator also completed the Memory Matters Site Visit Form (see separate methodology reference document). This process captured the nature and type of existing supports for the PwD, and enabled the project coordinator to signpost and coordinate other supports that might be beneficial. Engagement with the person and their family took place to identify needs (see Appendix 4). After consultation with the PwD and their family or informal carer, and if there was a need for assistive technology, a referral was made to the assistive technology provider.



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As part of the development of this approach, an OT assessment was completed for participants. An additional OT was funded by Memory Matters for one day a week for one year to support the project. The OT assessments were completed by a total of 13 OTs and determined function and cognitive ability of the PwD, and an individualised reablement care plan was devised for each person. The average time spent on the OT assessment process was 3.8 hours per PwD. For the duration of phase 1, the OT assessment for all Memory Matters participants was carried out within five days of referral (Priority 1 status). Those with mild to moderate dementia were identified for OT assessment through the memory clinics. The OT assessment reports informed the home help allocations meeting (see Appendix 2), the forum through which the individualised plan for home care was planned and implemented. Following the project, the PwD with complex needs, i.e. progressing dementia, carer stress or elevated pressure sore risk (Waterlow > 12), will be prioritised according to clinical need.

An overview of services the PwD and their families received through the project is displayed in Table 2. Overall as of April 2016, an additional 332.25 hours of home care per week were provided as a result of the project. The allocation of home care support hours was adapted to be more individualised and responsive to PwD and family needs where resources and staff availability allowed. Many home help hours were reorganised to enable families to receive block hours, i.e. dedicated hours per week (generally 2-3 continuous hours) that were new to the system and allowed PwD to be supported to engage in reablement activities or were deployed to provide for carer respite. Where needed and possible, overnight and weekend support was also provided as required, and a small number of participants availed of night services. Guidelines for night services were developed by the project team (see Appendix 5). In some instances, additional access to formal day care hours were also negotiated through the project team including the provision of transport to and from the nearest day care centre.

Participants who were active under the project continued to receive the services designed by Memory Matters after the project ended unless they exited the project, generally by moving into long-term care (LTC). An analysis of service utilisation and cost is presented in Section 4.8: Costs of Care.

Table 2. Memory Matters Services

Service	Number of Participants	Pre Memory Matters (hours)	Initial Memory Matters Increase (hours)	Memory Matters Initial Package (hours)
Home visits by project coordinator	56	-	-	Approx. 84 hours**
Total OT hours including assessment and reablement supports	53	-	-	510.5 hours
Home care hours	55	304.25 hours per week (total*)	332.25 hours per week (total*)	636.50 hours per week (total*)****

*Overall weekly total for 55 active participants; **Travel time not included; ***Days based on 7.5 hours working day excluding travel;

****Initial home help hours only, excluding further increases

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2.4.3 Memory Matters – Assistive Technology

Assistive technology refers to any equipment or system that is used to maintain or improve functional abilities of people with cognitive, physical or communication problems (Stapleton et al., 2015). It was anticipated that assistive technology would be used to support the informal carer to look after the PwD and therefore enable them to live at home longer.

The project had funding to deploy assistive technology, referred to as assistive technology package, to support 20 PwD at home. However, demand was higher than this and in total, 38 assistive technology packages were installed. The first 20 packages were funded through the project, while the remaining packages were funded with assistance from the HSE. Recommendations regarding technological supports were made during the project coordinator's site visit using a standardised assessment form. The assistive technology installed under the project included falls detectors, smoke detectors, carbon monoxide detectors, bed occupancy sensor, pillow alert, personal alarms, and property exit sensors. Four of these packages were installed for couples in the same household. The median time from site visit to installation based on the time period October 2014 to December 2015 was 22 days. The most commonly installed devices were falls detectors and smoke alarms. At follow-up, more than three quarters of respondents (78.6%, 11/14) had assistive technology in place. Further information about assistive technology and costs involved is presented in Chapter 4.

2.4.4 Memory Matters – Training & Education

A wide range of educational initiatives formed part of the Memory Matters project, the aim of which was firstly to increase knowledge and awareness of dementia and secondly to introduce more person-centred practices with a focus on reablement and helping staff to engage effectively with the PwD and their family. The project intended to provide some level of education to all statutory and voluntary agencies and more advanced levels of education to those engaged directly with PwD referred to the project. The training comprised six levels of education which were overseen by the consortium training subgroup:



Figure 4. Memory Matters Training and Education Components



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An overview of the education programme is presented in Table 3. A description of the individual components is presented in a separate methodology reference document.

Table 3. Memory Matters - Education Programme

Name of Programme	Duration	Target Audience	Facilitators	Numbers Completed
General dementia awareness	1 hour	General public/ those with an interest in dementia	Project Coordinator	Approx. 1000*
Memory Matters 1	2 hours	Home Helps	Home Care Manager	175
Memory Matters 2	2 hours	Public Health Nurses Non-Governmental Organisations (NGOs)	Occupational Therapist	
Bespoke Reablement Training	1.5 hours	Home Helps	Occupational Therapist	49
Enhancing and Enabling Wellbeing for the PwD	2 days	Home Helps, Public Health Nurses, NGOs	Dementia Champions	154
Responsive Behaviour**	1 day	Staff caring for older PwD in acute, residential and community care settings who have completed the 2 day programme.		45

*Includes dementia awareness day as well as media campaign; **Introduced 2016

Memory Matters Module 1 & 2 were developed by the project. The training programmes “Enhancing and Enabling Wellbeing for the Person with Dementia” and “Responsive Behaviours” are part of the national dementia training programme and were available prior to and following the Memory Matters project. The project utilised the existing resources by coordinating the delivery of same and releasing staff to attend training. While these resources are available nationally, there was a perception in Carlow/Kilkenny that they may be under-utilised. The project was very successful in organising and maximising existing resources to enable this training, e.g. using those that had

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been trained as dementia champions as training facilitators and providers. Moreover, the coordination and release of staff was a substantial endeavour and the absorption of costs by the HSE was pivotal to enable this training.

Memory Matters also engaged with PCT coordinators in order to provide information about national online learning available to GPs through their local GP networks using Dublin City University's (DCU) Elevator Programme and the ICGP (Irish Charter of General Practitioners) online dementia training (O'Neill, 2016).

In addition to the provision of dementia training for healthcare staff, public events were held as part of the project, such as a presentation to the Older People's Forum on Dementia awareness (40 attendees), an information exchange meeting with social care students and lecturers at Carlow College (30 attendees), and a Dementia Awareness Project Update for medical professionals (8 attendees) at the West Kilkenny PCT meeting.

2.4.5 Memory Matters – Media Campaign

Area-specific dementia-friendly information leaflets were designed and distributed signposting services and activities, such as day care services, befriending organisations and other available supports for 11 individual areas across Carlow/Kilkenny (see Appendix 7). The leaflets were distributed via health centres, libraries and the Service Provider's Forum and covered four areas in Carlow (Tullow/ Rathvilly & Hacketstown, Bagenalstown and Carlow Town), and seven areas in Kilkenny (Castlecomer, Urlingford & Freshford, Callan, Graignamanagh, Paulstown/Gowran & Bennettsbridge, Thomastown and Kilkenny City). In addition, information leaflets were created that provided tips for friends and neighbours as well as businesses and retailers on how to interact with and assist a PwD (see Appendix 7). These leaflets also contained contact details for the Alzheimer Society of Ireland and provided a link to a video by DCU's Dementia Elevator Programme on coping skills for families and carers (<http://elevator-carers-coping-skills.com/>).

A project-specific Facebook page was created in 2014 which allowed for the online dissemination of information about the project, updates on current activities in the area as well as general information about dementia.



Figure 5. Memory Matters Facebook Page

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The Memory Matters project also produced a video, 'See Me – Memory Matters Dementia Project' (<https://www.youtube.com/watch?v=-CIHLLCgZzw&feature=youtu.be>) (see Figure 10), which was presented at the Annual General Meeting of the Kilkenny Older People's Forum in 2016 and was well received. By October 2016, the video had received 210 views.



Figure 6. Memory Matters 'See me' Video

Summary

Memory Matters aimed for a philosophical change towards a flexible and person-centred approach to the deployment of home care hours which included the provision of block hours, night and weekend services and a reablement approach. Home help services were sourced through formal services and voluntary providers. The provision of reablement required assessment by an OT who generated detailed reports and delivered bespoke training to home helps.

Thirty-eight individualised assistive technology packages were installed to assist participants. The educational component encompassed project-specific training as well as parts of the national dementia training programme. The media campaign included dementia-friendly information leaflets, a project-specific Facebook page, and a dementia awareness video. The following chapter outlines the methodology used for the Memory Matters evaluation.



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3. Methodology of Evaluation (Overview)³

As outlined in Chapter One, the authors of this report were commissioned to evaluate the Memory Matters project as part of a larger evaluation of the HSE & Genio Dementia Programme. The complexities of dementia care provision and the capacity of the health system to respond to these complexities are significant challenges for any project seeking to improve care and support for the PwD and informal carers in the community. An evaluation of such projects requires attention to the set-up, implementation process, impact and sustainability. The evaluation methodology adopted for this project was informed by action research with its emphasis on context, relationship, process and outcome, and a well-established evaluation framework, RE-AIM (Glasgow et al., 1999, Gaglio et al., 2013).

3.1 Aims

1. To understand how individualised supports in the community for dementia can change and improve service delivery and outcomes for PwD and their families.
2. To explore the roll-out of individualised supports and alignment with implementation of the National Dementia Strategy (Department of Health, 2014).

3.2 Objectives

- i. Examine the dementia journey for key stakeholders at baseline and following project implementation.
- ii. Evaluate the applicability and evidence base (effectiveness/efficacy) of the initiative in line with current policy trends at national and international level.
- iii. Assess the contribution of the initiative to the QoL and experience of participants including PwD, and their informal carers, agencies and healthcare professionals, and their degree of influence in developing the services.
- iv. Evaluate the process of adoption and development, influence on dementia policy, and stakeholder cooperation and implementation of the initiative.
- v. Evaluate the impact of implementation of the initiative on outcome measures as agreed with stakeholders, for example improved access to/from services, care delivery and efficiency in service provision. Assessment of organisational, stakeholder and community engagement as indicators of sustainability of such services to support PwD and their informal carers.
- vi. Compare costs of 'service as usual' to the costs of new approaches and initiatives.
- vii. Make recommendations to inform the implementation of the National Dementia Strategy and individualised community supports nationally.

3 For more detailed information, please see the accompanying methodology reference document

EVALUATION OF THE MEMORY MATTERS CARLOW/KILKENNY COMMUNITY DEMENTIA PROJECT

3.3 Methodology Overview

The evaluation is underpinned by an evaluation framework called RE-AIM (Glasgow et al., 1999). Using this framework (see Figure 7), project activity was evaluated in terms of reach, effectiveness, adoption, implementation, and maintenance (sustainability) (Gaglio et al., 2013). An exploratory mixed methods approach involving both quantitative and qualitative approaches was used to provide a comprehensive evaluation of Memory Matters. There were three key aspects of this process-focused evaluation methodology, as outlined in Figure 8.

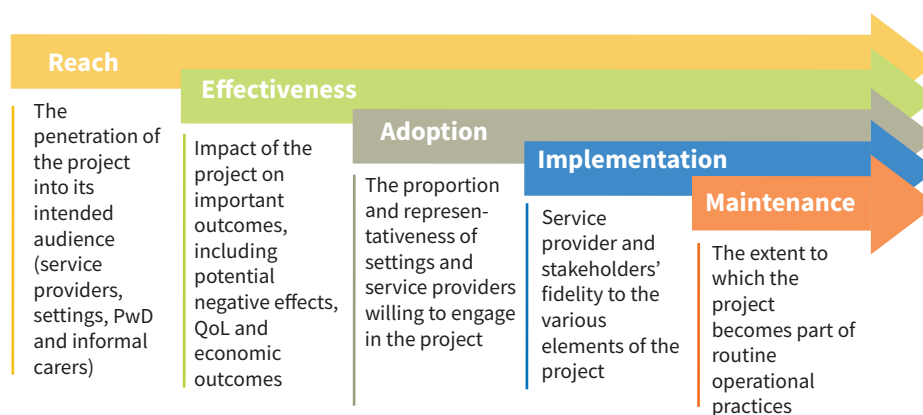


Figure 7. RE-AIM Framework Used in the Evaluation

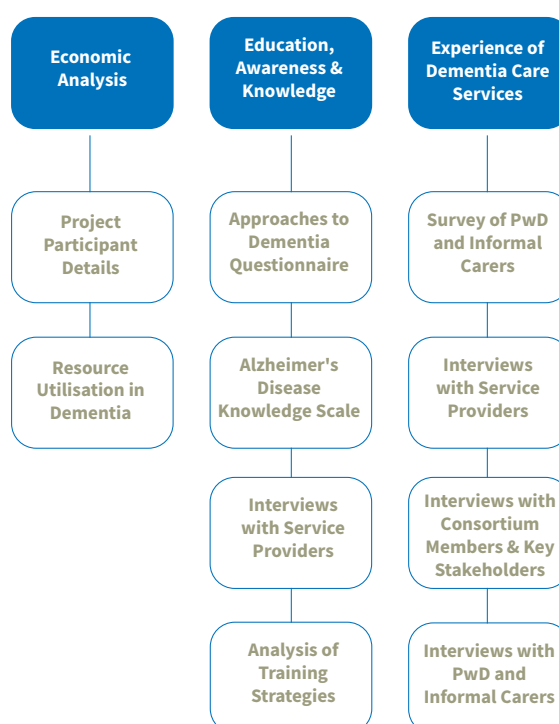


Figure 8.
Overview of Evaluation Method

EVALUATION OF THE MEMORY MATTERS CARLOW/KILKENNY COMMUNITY DEMENTIA PROJECT

The total numbers involved in each stage of data collection for the evaluation is provided in Table 4. While time one and two suggests two discrete data collection moments, data were collected throughout the project and many of the findings emerged because of this. Figure 9 provides an overview of the timeline of data collection in relation to project activities. Detailed information on the demographic details of evaluation participants are located within the separate methodology reference document.

Table 4. Overview of Sample Sizes in Data Collection Stages

Participant Group/Source	Time 1	Time 2
Economic analysis	-	49
Awareness and knowledge survey	80	-
Surveys of service users and informal carers	24	14
Interviews with service users and informal carers	9	9
Interviews with service providers (including consortium members & key stakeholders)	25	40

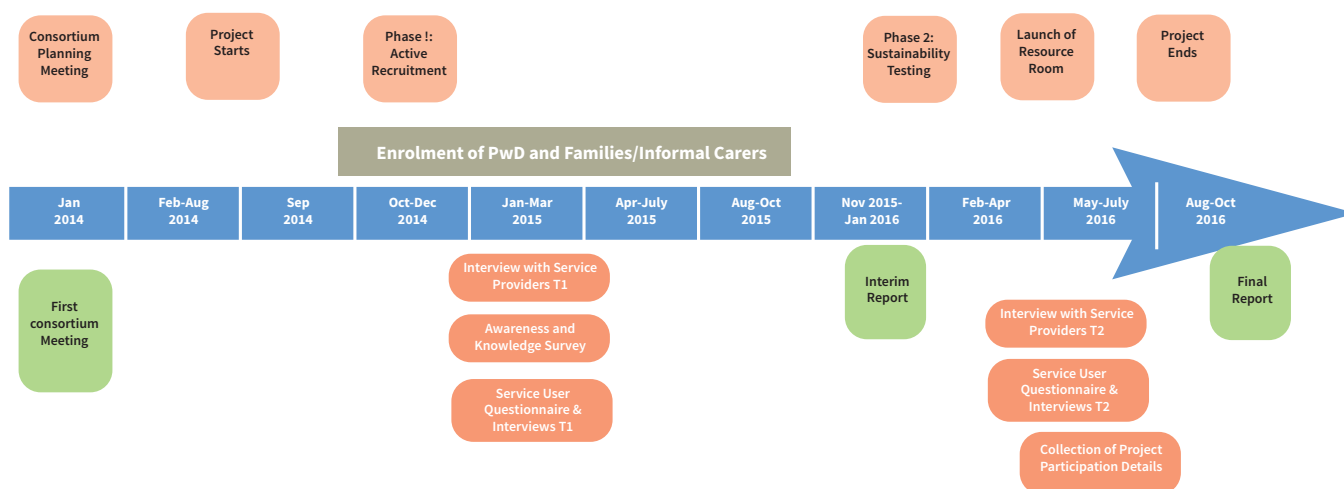


Figure 9. Timeline of Evaluation Data Collection and Project Activity

EVALUATION OF THE MEMORY MATTERS CARLOW/KILKENNY COMMUNITY DEMENTIA PROJECT

4. Findings

This chapter presents the findings that emerged from the evaluation of the Memory Matters project and explores the degree to which the project achieved its intended objectives. The evaluation findings are presented in relation to the experience of the PwD as well as their families and informal carers. It explores outcomes from the service provider perspective and describes findings from the educational initiative and costs of care.

Figure 10 outlines the various sub-sections within the Memory Matters project outcomes.



Figure 10. Memory Matters Carlow/Kilkenny Outcomes



EVALUATION OF THE MEMORY MATTERS CARLOW/KILKENNY COMMUNITY DEMENTIA PROJECT

Figure 11 provides an overview of referrals to Memory Matters over the duration of the project. The referral process is described in Section 2.1 and Appendix 6.

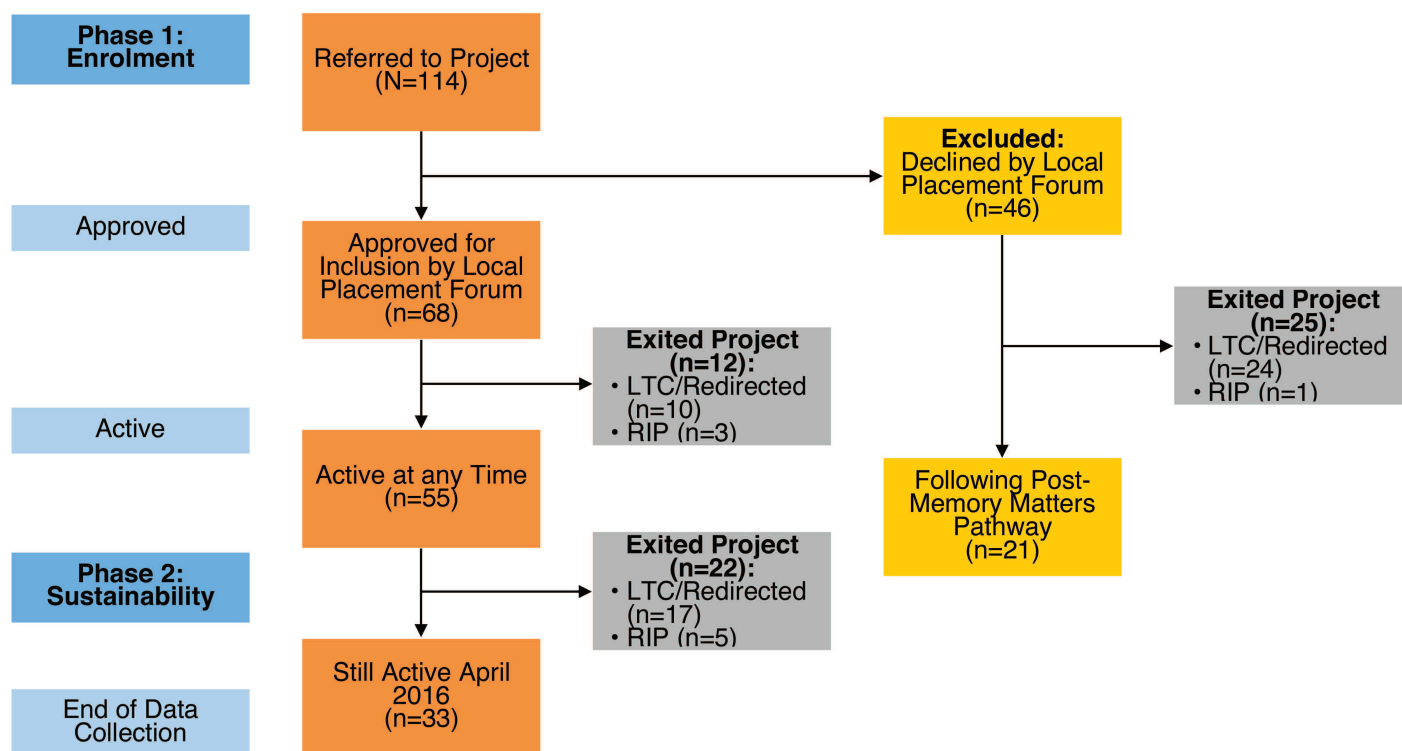


Figure 11. Overview of Referrals to Memory Matters⁴



EVALUATION OF THE MEMORY MATTERS CARLOW/KILKENNY COMMUNITY DEMENTIA PROJECT

4.1 Profile of Persons with Dementia

Memory Matters service users who agreed to take part in the evaluation completed a survey. Some also participated in interviews. Table 5 provides an overview of the PwD who participated in the evaluation. Just over one third of surveys (35%; n=8) were completed by both the PwD and a relative or friend, and 65% (n=15) were completed by a relative or friend on behalf of the PwD.

Table 5. Overview of Participating PwD at Baseline (N=24)

Participant Detail		Mean (SD)/ Percentage	Number of Responses
Age		82.4 (8.2)	23
Gender	Female	68%	15
	Male	32%	7
Dementia Diagnosis	Vascular Dementia	32%	7
	Alzheimer's Disease	27%	6
	Lewy Body Dementia	5%	1
	Other Dementia	18%	4
	Do not know	18%	4
Living Arrangements	Majority in own home (N = 18) N=5 lived in the home of a family member		
Informal Carer	Spouse	48%	11
	Child	30%	7
	Sibling	9%	2
	Other	13%	3
Activities of Daily Living (Barthel Score)	Possible range 0-20	10.3 (5.85)	20
Quality of Life (QoL-AD Score)	Possible range 13-52	28.4 (3.9)	21



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Table 6 reports on the dependency of PwD supported by the project based on scores for individual items in the Barthel Index. It illustrates some of the main difficulties encountered by the PwD in the sample in their day-to-day life. The overall Barthel scores revealed that at baseline half of the participants had a moderate to severe level of dependency. The participants experienced multiple difficulties across all the domains with the most commonly reported difficulties relating to grooming, dressing (n=20) and bathing (n=19). Most of the participants experienced some difficulty within the mobility domain and while less than half (n=8) described themselves as mobile, 77% (n=17) were not able to use the stairs independently.

Table 6. Barthel Index Scores at Baseline (N=24)

Activity of Daily Living	%	N
Grooming Need help with personal care	87%	20
Feeding Unable to feed alone or need help with cutting food etc.	39.1%	9
Moving from bed to chair Unable to move from bed to the chair or need help of one person	34.8%	11
Mobility Immobile or need help of one person to walk	52.1%	12
Dressing Unable to dress alone or need some help	86.9%	20
Stairs Unable to walk up and down the stairs alone	77.3%	17
Bathing Unable to take a bath or a shower alone	81.8%	19
Incontinence (regular or occasional) Bowels	81.8%	18
Bladder	69.5%	16
Toilet use Unable to use the toilet alone or need help	60.8%	14



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4.2 Experience of the Person with Dementia

The qualitative findings from the interviews demonstrated that both service providers and informal carers strongly believed the project had enabled PwD to remain in their homes for longer. This is demonstrated by the fact that 55 people were supported to remain at home despite having been assessed as needing LTC by the Local Placement Forum. Of these, 33 people were supported at home for the duration of the project and still at home at project end.

“Well definitely she’d probably would have been in long-term care I’d say because we wouldn’t have been able to, because she is kind of looked after from Monday to Friday and we’re able to manage the weekends. So she definitely would have ended up in long-term care I’d say.” (FU SI IC KK02)⁵

PwD and informal carers that were interviewed stated a clear preference for the PwD to remain at home, and service users and providers agreed that the project helped to facilitate this, and it might not have been possible to keep the PwD at home otherwise. Interview participants believed that remaining at home was associated with important benefits for the PwD, including helping to slow the progression of dementia and access to familiar environments and routines. A particular value noted by participants was that remaining at home facilitated access to the support of children and grandchildren living nearby, enabling both engagement and continued connection between the PwD and their loved ones.

“I do think support in the home is a huge factor in keeping them well, because for a lot of people it’s the familiarity, they’ve lost a lot of their memory but the familiar environment keeps them, you know gives them a sense of security I suppose. You know when they go somewhere different it can really take their confidence away and mix them up even more, you know when the place is unfamiliar and they can’t get used to it. You know I think she’s very content in her own home and hopefully will be able to keep doing it as long as we can, you know.” (FU SI IC KK15)

The familiarity of the home also provided a sense of security and helped the PwD to stay safe. Remaining at home lessened disorientation and was perceived to help retain cognitive abilities to a greater extent than might be possible in LTC.

I think keeping him in his own environment, I think it’s a slower, you know, and you know it’s not as rapid a progression as it might be if he went in to a home, you know.” (FU SI IC KK04).

Being in a familiar environment was associated with high levels of contentment as it was possible for PwD to engage in activities and pursuits that were relevant to them. Informal carers reported that the project had a positive impact on the quality of care provided to the PwD. The improvements emanated from the additional care hours and the night service made available through the project. The extra home help hours and formal carer availability enabled access to greater social contact for the PwD, and in many instances formal carers engaged in activities of interest to the PwD, as per the reablement approach. For those living alone it appeared to contribute to reduced social isolation.

5 FU: Follow-up interview; SI: Single Interview; FG: Focus Group; IC: Informal carer, KK0X: Unique participant identifier of PwD/informal carer; HH: Home Help



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“But you know for my mother definitely her quality of care and her quality of life I suppose has improved you know, yeah which is good.” (FU SI IC KK15).

“To have that little bit extra time to have the chat – a lot of them just love the chat, the company, you know.” (FG HH)

The planning of home care hours where possible sought to achieve consistency in care arrangements. This contributed to the development of trust between the formal carer, the PwD and their family. This increased familiarity meant that the formal carer was more knowledgeable about the individual needs of the PwD and was able to adapt and respond to care strategies appropriately. This was very helpful in reducing the stress burden of the PwD.

“And the other thing is too they, even though they have dementia they get to know you and they know your voice and they know this person is familiar to me. And that’s great, you know.” (FU FG HH)

“Having the same people, I think, going in to them because they get so used to you because with Alzheimer’s sometimes the people are, they’re frightened all the time because they don’t know who they are or where they are and you have to kind of talk to them... reassure them, you know, and they do get used to the one person going in every day, you know.” (FG HH)

“So she was able to go to her own home instead of coming to our homes, you know where she kind of was agitated and she knew she still had a dog, so she was always worried about the dog and things like that, you know where she went there and the carer and her went walking every evening.” (FU SI IC KK03)

The provision of block hours was found to be very beneficial to the PwD and the informal carer according to service providers and families. It allowed home helps more time with the PwD, enabling care to be structured around the needs of the PwD and families. While prior to the project, care plans were traditionally task-orientated and focused on meeting deficits in physical care needs, they now included an emphasis on encouraging independence where possible. Modest adjustments in available time and in staff training, such as bespoke reablement training, have enabled a more productive engagement by home helps with PwD, and, as recounted by home helps, care activities have expanded to include prompting and supporting rather than completing tasks for the person.

“She loves gardening, or cooking, so you would watch that and then she’d get fed up with that and then we’ll have the cards and she loves the paper.” (FU FG HH)

“She loves music so I put on YouTube, she loves Mario Lanza, I’ll Tell me Ma when I Go Home, all old stuff. They are on YouTube so she’d sing along and I do counting. (FU FG HH)

The comprehensive OT assessment allowed for the prescription of activities that build on activities that the person was previously engaged in and was encouraged to be involved in again with the assistance of the home help. These activities were entirely individualised, might have been occupational, and could include, for example, cooking, baking, and social outings. The project also sought to match formal carers and PwD where possible to engage in reablement activities of mutual interest, and this aspect of the individualised care was also found to be a positive outcome of the project implementation as has been reported by family members of the PwD.



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“But he loved to go to the matches and I mean when the young lad was hurling he was training the team and a selector on the team and so he is very interested in, you know GAA as such. And he loved music, so they were his two, you know passions if you like. So the girl that comes on a Tuesday evening, she would turn on the television, like TG4 now, there’d always be a match on. [...] And she’d talk about that to him or you know I have the Kilkenny People there and she’d read out bits of you know the sports pages and that kind of thing.” (FU SI IC KK05)

Box 1. Patricia and Gary’s Story⁶

Patricia is a 91 year old woman with vascular dementia living with her husband Gary (main carer) on a farm in a rural area. Their son Thomas and his family live on the other side of the farmyard and visit several times a day. Patricia worked as a nurse and enjoys company, and expresses a clear wish to stay at home. ‘I love it [living here], I don’t want to go anywhere’. Due to macular degeneration she has reduced vision and is prone to falling. Patricia is physically dependent and needs around the clock care which Gary provides although he finds this difficult and has reported feeling under pressure.

Prior to the Memory Matters project, Patricia received 1.5 hours of formal home help per day for physical care, one hour at lunchtime to get up and half an hour in the evening to help her to go to bed (total 9.5 hours). Over the course of the next three months her overall home care support was increased to 13.5 hours with twice weekly 2 hour afternoon visits to engage in reablement activities personalised to her wants and needs, for example painting her nails, engaging in conversation, keeping her company and reminiscing. The additional reablement hours provide some relief for Gary who can use the time to have a break or to do other tasks such as shopping. Gary reports that these hours are very important to him. One of the two hour blocks was moved to a Monday, and due to bank holidays throughout the year this reduces the number of block hours the family receives as the hours are not replaced.

The technology installed with the project included a bed occupancy sensor, fall detector, and emergency alarm. However, Patricia does not wear the falls detector because somebody is present at all times. One year into the project, the family is doing well and Patricia clearly enjoys being at home saying that she is happy there. Gary reports that without the additional support he receives from the project, he would not be able to continue to care for Patricia.

4.3 Experience of the Informal Carer and Families

Interviews with both informal carers and service providers revealed the difficulties associated with the provision of care. This included difficulties such as juggling the care of the PwD with other responsibilities; uncertainty and lack of clarity about the availability of services; the financial burden of care; isolation through confinement in the home; managing challenging behaviours; not being able to pursue one’s own work; and difficulties associated with increased frailty due to physical deterioration of the older carer. Most of the PwD required constant care and supervision, which tied down family carers who were left with little time for themselves (see Box 2). An overview of survey findings relating to informal carer burden and informal carer QoL is provided in the following tables.

⁶ The names of participants in individual case studies have been changed to protect their identity

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The scores on the assessment of carer burden (Zarit et al., 1985) were quite spread, representing a broad range in the degree of burden experienced, as illustrated in table 7. However, a substantial share of the participants reported moderate to severe levels of care burden at both baseline and follow-up.

Table 7. Distribution of Carer Burden Scores across Respondents

Carer burden (Zarit scale)	T1		T2	
	N	%	N	%
Little or no burden	2	9	2	15
Mild to moderate burden	8	36	3	23
Moderate to severe burden	10	45	8	62
Severe burden	2	9	0	0

Box 2. Anne and Lauren's Story

Anne, a 74 year retired nurse with dementia, is still very physically active. Her children were living nearby and shared her care, taking turns to have Anne in their homes overnight and bringing her back to her own home in the morning. All her children worked outside the home and had young families.

Before participating in the Memory Matters project, Anne received 45 minutes of home help in the morning and 30 minutes in the evening Monday to Friday (total 6.25 hours). She attended a day care centre every day to which the family contributed. The carers experienced high levels of stress as they had to juggle work, their own families, and looking after their mother. They reported that weekends and nights were particularly challenging.

Anne was referred to the Memory Matters project by the PHN in November 2014, and her home care package was increased to 17.75 hours per week. This included two hours in the evening five days a week and four hours on a Saturday. In the morning, the home help brought Anne on the bus to the day care centre and she also collected her from the bus in the evening to bring her home. Anne therefore did not have to go to her children's home where she got upset as she was worried about her dog. The family organised a rota and took turns to stay with her overnight. The home help went for walks with her every evening as walking was Anne's favourite activity. Through the additional hours, the family was freed up on Saturday mornings, which allowed them to concentrate on other activities.

This care arrangement continued for the next three months until following a fall and a stroke, Anne's doctor recommended full-time care in a nursing home. Her daughter Lauren, her main carer, reported that during her time in the Memory Matters project the flexibility from the personalised services enabled Anne to engage in her in favourite activity and greatly relieved stress among the family.

One of the biggest stressors for informal carers was the lack of support at night time and weekends. The flexibility and personalised approach to service offered through the project was exemplified by the provision of such services. A protocol for the provision of a night time service for PwD in the Carlow/Kilkenny area was introduced as part of Memory Matters (see Appendix 5). The guidelines provided general information about dementia and general advice

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on the provision of these hours as well as possible causes of sleeplessness and potential remedies. The request for night care was relatively modest. Three to four project participants were reported to be in receipt of night time services throughout the duration of the project to provide for informal carer respite, and generally this did not exceed one night every fortnight. The positive impact of the project on reducing carer burden was recounted by participants.

“Ahm, you know I suppose with the system in place, and you know help, it has made it easier, you know. I mean I can cope with things.” (FU SI IC & PwD KK04)

“For me and for my other siblings definitely, for peace of mind it has helped us hugely. And also less strain on our relationships I suppose with each other because you know if we’re rushing or if we feel that we’re tied to looking after her or feel we haven’t enough time to do it, you know it is stressful.” (FU SI IC KK15)

Informal carers’ QoL and health status were measured using the EQ-5D-3L tool (The EuroQol Group, 1990). Results revealed a broad range of scores regarding informal carers’ health-related QoL. The mean scores at initial interview and follow-up reflect some concerns with carer QoL (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression). Similarly, at both time points the burden of care on average was moderate to severe.

Carer health status was scored from ‘the worst health you can imagine’ (0) to ‘the best health you can imagine’ (100), with mean scores here signifying a relatively good health status. The initial average informal carer rating for health state was similar at follow-up, indicating a relatively steady state in average carer QoL over the time period. The number of respondents was low, however, and does not allow for definitive conclusions about project impact on carer health status or carer burden. Initial collection of survey data took place from April-July 2015 and follow-up data collected from May-July 2016.

Table 8. Summary of Survey Findings Related to Carer Burden, Quality of Life and Health

	Time Point	M	SD	Min	Max	N
Carer burden (Zarit carer burden; Possible range of scores 0-88)	Initial	39.8	15.0	9	68	22
	Follow-up	40.5	11.2	18	56	13
Carer health-related QoL (EQ-5D-3L; Possible range of scores 5-15)	Initial	7.0	1.7	5	10	23
	Follow-up	6.9	1.7	5	11	13
Carer health status (EQ-5D-3L; Possible range of scores 0-100)	Initial	69.5	22.6	20	100	24
	Follow-up	70.8	18.9	40	96	13

Informal carers’ satisfaction with services provided under the project was reflected in their responses to the satisfaction with community care services questionnaire. The percentage of participants that reported that they were either very satisfied or satisfied with the community care services provided to the informal carer or the PwD increased considerably over the duration of the project (see Table 9). Though initially a high level of satisfaction in relation to the way in which care workers helped the PwD was reported with 74% (17/23) either satisfied or very satisfied with this service, this rose to 100% (14/14) at follow-up. More than half (52%, 12/23) were satisfied with the reliability and consistency of services at time one, and this increased to 77% (10/13) at time two. At time one, almost three quarters of respondents (74%, 14/19) had assistive technology in place, with all of those who responded to the question (100%, 7/7) reporting that these devices were helpful.

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Table 9. Survey Findings on Satisfaction with Community Care Services – N (%)

	Time point	Very satisfied or satisfied	Neither satisfied nor dissatisfied	Very dissatisfied or dissatisfied	Don't know
Satisfaction with community care services provided to informal carer	Initial (N=23)	7 (30.4)	4 (17.4)	8 (34.8)	4 (17.4)
	Follow-up (N=14)	9 (64.3)	2 (14.3)	1 (7.1)	2 (14.3)
Satisfaction with community care services provided to PwD	Initial (N=23)	10 (45.5)	5 (22.7)	6 (27.3)	1 (4.5)
	Follow-up (N=14)	10 (71.4)	-	1 (7.1)	3 (21.4)

The percentage of respondents who stated that the community care services provided the right type of help more than doubled from baseline to follow-up (39.1%; 9/23 versus 85.7%; 12/14). In addition, the percentage of participants that reported that their needs and preferences as carers were taken into consideration rose from 52.2% (12/23) to 71.4% (10/14), and a similar increase was reported in relation to the community care services improving the overall QoL of the PwD. The percentage of respondents who stated that the PwD would not be at home without the assistance from the services increased from 56.5% (13/23) at baseline to 85.7% (12/14) at follow-up.

This satisfaction with community services was also reflected in interviews. The regularity of the services, i.e. knowing that somebody is coming at a particular time, was an important component. Some informal carers reported that the project helped reduce strain on family relationships. Many operated a rota system among family members to cover their parent's care. With the introduction of flexible home help hours it was possible to receive help outside the standard hours which helped reduce conflict and carer burden as reported by informal carers. However, many informal carers mentioned that more home help hours would be beneficial. Overall increases in care hours were relatively modest. Some informal carers recounted positive aspects associated with caring for their parent, such as giving back and becoming closer to siblings.

"And you know I just feel, you know I don't regret looking after my father, I think it is a great opportunity to be able to give something to your parents, you know, so I certainly have no regrets, you know, that that is something, that is something that you can't buy, you know." (FU SI IC KK02)

"And I think there is a positive thing even with my siblings, that you know we're all trying to help together on this, and we have so much to talk about because of this – so it kind of, it keeps us all together, and as well as that they are coming here more regular, they have a reason to, this is the homestead, and it brings them to and from, you know, looking after somebody." (FU SI IC KK02)

4.4 The Progressive Nature of Dementia

The Memory Matters project was designed to support people at an advanced stage of dementia and eligibility for LTC was one of the criteria for support. However, for many service users the provision of services came at a very late stage as participants were already on the margins of LTC. This rendered the provision of reablement difficult, and

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some service providers were of the opinion that the intervention was coming too late.

“[...] maybe that service might’ve been good for them maybe two years ago in the early onset.” (FU FG PHN II)

“So really we’re trying to get in earlier now. So while we would have provided maybe block hours and that, I think the girls were challenged a lot of the time as to what to do with the people because they might have been bed bound or you know.” (FU SI HH⁷ Coordinator I)

“When I started he was quite able to do activities and go for long walks but now he’s able to walk a short distance, It’s hard on him, it’s hard on him. So it depends on how he is that day, I could do anything or not. If he has a bad night which X is talking about he is sleeping during the day.” (FU FG HH)

“..she gave me and talking to the family different ideas of what the gentleman was interested in. While that happened for the first six to eight months that doesn’t happen now because he’s not able. You know, I introduced the cards, the hurling, the magazines, you know things like that. But sometimes he would say to you ‘why are you bothering me with that.’” (FU FG HH)

The deterioration generally encompassed cognitive, physical and functional decline. This kind of deterioration was inevitably out of the control of the project though nonetheless a key challenge that the project faced as the needs of the PwD and informal carer dyad changed in many cases over the course of the project. The project addressed this challenge by providing several increases in home help hours over the duration of the project in response to rising support need.

“So I suppose keeping someone at home, as the condition progresses, you know it becomes more difficult, you know. And I suppose it’s, at this stage, it’s kind of make or break, that people find, you know that, can I continue this?” (FU SI, IC & PwD, KK04)

Survey data revealed a slight decrease in functional status of participating PwD as measured by the Barthel Index of Activities of Daily Living (total possible range of scores 0-20) ($t(10)=2.94$, $p=.02$, $n=11$), and the decrease was statistically significant (see Table 10).

Table 10. Barthel Scores from Survey Data (n=11)

	Mean score	SD	Min	Max
Time One	10.3	5.9	0	20
Time Two	9.1	6.1	0	13

In line with the decline in activities of daily living, there was also a decline in the PwD’s QoL (as measured by the QoL-Alzheimer’s Disease [QoL-AD], see Table 11) (total possible range of scores 13-52), and the difference was statistically significant ($t(11)=2.55$, $p=.03$, $n=12$).

Table 11. QoL-AD Scores from Survey Data

	Mean score	SD	Min	Max	N
Time One	28.4	3.9	20	35	21
Time Two	26.7	3.4	19	32	13



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Box 3. Maureen and Margaret's Story

Maureen is an 81 year old woman with advanced vascular dementia who lives with her 84 year old husband Martin (main carer). Her children are sharing her care as Martin is unable to care for his wife on his own.

Maureen was referred to Memory Matters by the PHN in February 2015. Prior to the project, she received 6 home help hours per week, which was increased to 10 hours including weekly 2 hour afternoon visits to engage her in reablement activities such as reminiscence. Maureen also received assistive technology including a fall detector pendant and smoke alarm. She attends a day care centre 2 days a week, and the family pays privately for care on Friday evenings. At the weekend, Maureen receives 2 hours of support from Family Carers Ireland (formerly the Carers Association). Though the technology was reassuring in the beginning, Maureen repeatedly pressed the pendant button by accident at night which triggered calls to her son. As she did not remember the purpose of the device, she was not able to press the button in case of emergency, and its usefulness was therefore limited. Maureen eventually stopped wearing the device.

Although Maureen enjoys the reablement activities, her incontinence needs to be attended to during the 2 hours which reduces the time for engagement. The home help who provides the reablement activities is not replaced in case of illness or annual leave.

According to her daughter Margaret, the home helps are very busy and only have time to address Maureen's basic needs. Maureen's condition has deteriorated and her care needs have increased. However, the allocated home help hours have not changed, and the family is dependent on help from Family Carers Ireland. Margaret and her siblings find it hard to juggle caring for their mother and tending to their own families.

4.5 Service Provider Perspective

Prior to Memory Matters, home care packages/home help supports for PwD in Carlow/Kilkenny were carefully assessed due to the resource limitation of finance and availability of home helps. As evident in the baseline findings of the project, assessment for and deployment of home care hours almost exclusively focused on physical needs. The evidence from informal carers that participated in the evaluation demonstrated that the project succeeded in changing service provision for those PwD recruited to the Memory Matters project by offering flexible home care support that focused on person-centred care and a reablement approach while working from within existing resources.

The service providers who contributed to the evaluation were mainly PHNs, home helps or OTs, nearly all of whom worked in the public sector. They had on average 12 years of experience in their current occupation at initial data collection. Focus groups and interviews revealed that the project has contributed to bringing about a notable cultural change regarding the provision of services for PwD in the Carlow/Kilkenny area. The project not only changed the way in which services are delivered but also how they are construed by service providers. There is more openness among service providers to the possibility that the community care service can deliver more than was traditionally obtainable. Thinking around assessment for services has changed, and greater innovation in approaches to home care arrangements has become apparent at team meetings and in practice. Examples include the provision of night time respite, afternoon care to cover after school hours, weekend supports, bringing the PwD to the bus to the day care centre and collecting her from the bus in the evening, going for walks, etc.



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"I suppose the whole ethos changed around caring. But the fact that dementia, it was even taken a stage further. And they could actually develop the service around the person. Which wouldn't have happened any other way. Like it was literally time to task, task time. You know you were going in to do clinical need and that was it." (FU SI Manager I)

"You know that sometimes people with dementia, they would have never had an OT input. So I suppose it's trying to maintain as much independence as they can, you know and I suppose a lot of our time with them is kind of therapy focused in that the girls would get to know them and try and do things with them." (FU SI Consortium)

The gateway to the project for the vast majority of PwD was referral by PHN. Many of the home care support hours deployed during the course of the project exhibited innovative thinking and problem solving within the multidisciplinary team on ways to create care arrangements that not only meet basic safety and physical need, but were also concerned with both meaningful engagement for PwD where possible, and also responded to informal carer need where feasible.

The latter was particularly important for families as the assessment approach sought to understand how limited resources might be optimised to provide supports that can with time be adjusted to extend the family resources most effectively without creating excessive dependency on scarce home care resources. This meant that home help hours were sometimes deployed as a block of time or in the evening or at weekends. Block hours represented considerable innovation on the previous arrangements and were used for both, individualising the care for PwD and/or respite for the informal carer.

Box 4. George and Mark's Story

George is an 84 year old retired farmer with vascular dementia who lives with his elderly wife and adult son Mark (full-time carer) on the home farm. George is an active man who likes singing and was in a choir for many years. Recently, he has become more restless, and Mark was not able to leave his father unattended contributing to reported severe carer burden.

Prior to Memory Matters, George was receiving 45 minutes of home help Monday to Friday (3.75 hours per week). He was referred by the PHN to the project and over the next two months, his home care package was increased to 23 home help hours per week. This also involved an assessment for reablement activity by the OT.

He now receives three 30 minute visits per day to assist with physical activities and twice weekly 2 hour afternoon visits to engage George in reablement activities. These include walks in the garden, picking fruit, music and reminiscence. A home help stays overnight once a fortnight to give Mark an extended break. George also attends a day care centre once a week, if he feels up to it, and travels there on a mini bus from the Alzheimer's Society. The family pays for the day centre and the transport.

Assistive technology options (a panic button, fall detector, and bed sensor) were also provided by the project. In addition, Mark installed a remote audio monitor and camera in his father's bed room which he paid for privately. The technology allows Mark to sleep in a different room knowing that his father will be safe.

Over the duration of the project, George has become more restless and prone to falling. His physical appearance has not changed significantly, and he appears to be content apart from his restlessness. The activities provided through the reablement match his interests well and he seems to be enjoying them. Mark severely misses the block hours when the home help is on leave as she is not replaced. The family wish for George to continue to stay at home but this is reliant on the supports in place.



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The project has had an impact on the understanding of home helps' roles whose formal function is now acknowledged by home helps, home help coordinators, OTs, and PHNs to exceed the traditional focus on provision of physical care. Within the findings from focus groups with health professional groups was an appreciation of the importance of the unique and personalised relationship between PwD and home helps. This was greatly facilitated through consistency in deployment of home helps to support PwD and their families within the community. Among the home helps themselves was an understanding of a wider interpretation of the potential of their role to support and enable individualised care. The block hours provided through the project allowed home helps to engage with the PwD in a different way. The home help engagement changed to prompting and supporting the PwD rather than completing tasks for them.

".. and what I hope to do is encourage him to, I suppose they gave me a list of his pastimes and interests and try and encourage and bring those out in him." (FG HH)

"I think what's X drew on, the improvement in the carers and their approach to clients, I think that's really a positive move and, yeah, they're not maybe as inclined to go in and over support a client." (FU FG OT).

Interviews with service providers revealed that adjustment in the skill set among some home helps was needed to be able to respond to meet this need. The change-over was not always easy, however, the training provided by the project did assist service providers to make this transition.

"I'd say the challenges were the staff on the ground. I think a lot of them found it difficult to go in and sit with somebody. Or say activate somebody, or take them for a walk or whatever. And it was against the ethos of what they been doing maybe for twenty or thirty years." (FU SI Consortium)

Provision of Reablement

Considerable resources in the project were devoted to reablement care strategies through OT assessment and support. This was aided through the funding of an additional OT. In total, 53 OT assessments were undertaken with detailed assessment of the person's abilities for greater independence and/or maintaining or gaining functioning. This has led to a shift in the role and perception of OTs who are potentially more geared towards reablement when assessing a client. It is now possible to apply for home help hours for reablement which did not exist prior to the project. While it was traditionally difficult to get home help hours for PwD with relatively high physical functioning but strong cognitive impairment, the introduction of the block hours made it possible to receive supports for these people. However, the project focus on later stage dementia did render engagement difficult in some instances and this is an important learning point.

"....I had a, yeah, I couldn't probably suggest a case because the initial few that I did were part of the initial fifty and they were all very late stages dementia and weren't easy to engage with, so it became more about kind of personal care and supervision and the engagement was on a very basic level." (FU FG OT)



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OT Involvement

The project funded an additional OT for one day a week for one year to support the project. OTs were pleased to have the opportunity to realise the full potential of their role but there was some frustration among OT staff that their lack of representation at allocations meetings made it difficult to initiate reablement activation for some individuals as envisioned. In some instances their recommendations could not be implemented exactly as anticipated due to availability of suitable home helps at the most appropriate times. The work practices of OT services whereby patients are not retained on caseload over long periods may benefit from further consideration. The planning of reablement activity does require ongoing assessment and adaptation due to the progressive nature of dementia and may necessitate an OT review of ability of the PwD and support for home helps within the current organisational structure.

“I don’t think we probably had the time to stay involved with them maybe as long as we should have – so in terms of [...] knowing the impact, whether it had a good impact or not – we probably couldn’t say for sure because we have to kind of move on to, you know, more clients, you know, so quickly that we probably didn’t keep them open for that long to actually know if it was really working that well or not...” (FU FG OT)

“On one hand, the value of OT has been a little bit more recognised. And certainly on the ground, with the home help coordinators and the home helps.” (FU SI Manager I)

The importance of GPs was revealed in interviews, and the consortium might have benefitted from a representation of this group in particular as it relates to sustainability as the project aims to bring care decisions into primary care. It should be acknowledged that effort was made by the consortium to engage with the GP group.

Though the home visit by the project coordinator formed an important part of the project as it allowed for the individualisation of the care of the PwD through engagement with the person and their family to identify needs, it raised expectations from families that needed to be managed by PHNs:

“Yeah well I mean when the facilitator for [the project] called to me, I thought I won the lotto to be honest with you, when she said what would my requirements be and I had nothing at the time” (FU SI KK05).

PHNs were understandably cautious, aware of the potential limitations of community service delivery and therefore reluctant to make promises they could not fulfil as they were uncertain as to what could be provided.

Collaboration

In addition, the project generated enhanced collaboration between various healthcare groups. There is evidence of greater attention and discussion at multidisciplinary meetings around care provision arrangements than before. The PwD and the informal carer are the focus which is the tenet of person-centred care.

Box 5. Key Learning on Approaches to Home Care

- The importance of the family/informal carer and the PwD as a unit of care in planning service
- The potential of utilising existing community resources more innovatively
- The importance of flexibility in the provision of home support services and benefits of restructuring home help hours
- The potential of a reablement approach to dementia to care and the associated change in the role of service providers



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4.6 Education

4.6.1 Awareness and Knowledge of Dementia

The awareness and knowledge of dementia among service providers in the Carlow/Kilkenny area were assessed from January - July 2015 using the Approaches to Dementia questionnaire (Lintern, 2001) and the Alzheimer's Disease Knowledge Scale questionnaire (Carpenter et al., 2009) (see separate methodology reference document for additional survey findings). A total of 80 completed surveys were returned and were mostly completed by home helps (n=47) although a number of healthcare attendants, OTs, PHNs and other dementia service providers also returned the surveys. Most service providers had worked in their current jobs in excess of seven years and represented a well-experienced group. Three quarters of respondents had previous education in dementia, with the majority having trained in the last two years. The training was mostly described as short courses of less than one day. The level of education was reflected in the respondents' perception of their own knowledge of dementia with most respondents suggesting that they had some knowledge (n=58) or were very knowledgeable (n=20) about dementia. None of the respondents felt that they knew nothing at all about dementia. The Approaches to Dementia Questionnaire demonstrated overall positive attitudes to PwD indicating that the individuals who completed the surveys were more likely to engage with the PwD and to see them as sentient beings (Lintern, 2001). Overall there was a relatively high level of dementia knowledge among the respondents, with an average score of 22.8 (maximum score 30)⁸. While the responses to this survey reveal good levels of dementia knowledge overall, the scores in the 'Treatment and Management' and 'Caregiving' categories of the survey further demonstrate the respondents' positive attitudes towards PwD and their knowledge of the importance of person-centred approaches.

4.6.2 Education and Training

An important component of the Memory Matters project was education and training. The education component for the Memory Matters dementia programme comprised a range of educational initiatives from general dementia awareness raising to managing responsive behaviour. There were five levels of education and, in line with current approaches to dementia care, the emphasis was on moving away from the thinking about dementia as a disease. Throughout all of the related education programmes, helping the participants to communicate effectively with PwD and using more person-centred approaches was paramount. In addition, as the project allocated ring fenced hours for what were described as 'reablement' purposes, it was important for staff assigned to PwD within the project to know how to use these hours effectively. The suite of education initiatives that were delivered under the auspices of Memory Matters yielded considerable reach, with more than 500 completed evaluation forms submitted by the project team. Based on these, the numbers attending the various programmes can be seen in Table 12⁹.

⁸ A number of questions were incorrectly answered by a relatively large number of people. For example, the item 'Having high cholesterol may increase a person's risk of developing Alzheimer's disease' and 'Having high blood pressure may increase a person's risk of developing Alzheimer's disease' both from the risk factors subscale were incorrectly answered by 79% (n=77) and 78% (n=73) of the respondents respectively. However, these questions are described as having a strong difficulty index.

⁹ There is a slight discrepancy between the numbers presented here and those provided by the project team (O'Neill, 2016) as they are based on returned evaluation forms for training between September 2014 and April 2016. This accounts for the higher number of feedback sheets than attendants for Memory Matters 1.

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Table 12. Education Programmes and Number of Evaluation Forms Completed

Education Programme	Number of Attendants	Number of Completed Feedback Sheets
Public Awareness Event (Introduction to dementia)	1000	15
Memory Matters Module 1	175	186
Memory Matters Module 2	175	162
Enhancing and enabling wellbeing for the PwD	154	150
Responsive behaviour	45	9
Not specified	-	1
Total	1550	523

The public awareness campaign comprised a range of activities that included face-to-face meetings and awareness raising through the use of social media. Although there are only 15 evaluation forms reflected here, in excess of 1000 people received an introduction to dementia as part of the project (O'Neill, 2016). Presentations were made to a range of local voluntary and non-voluntary organisations in response to invitations from groups such as the PCT and the Men's Action Group Kilkenny. Information about the project was also disseminated through existing organisations within the area such as the Kilkenny age friendly county programme and the Alzheimer Society of Ireland. The many different approaches to the public awareness campaign meant that it was not possible to ascertain the exact number of attendees or to evaluate its effectiveness which accounts for the low number of evaluation forms reported here. Social media activities were also incorporated into the awareness campaign with the launch of a Facebook page and YouTube channel. The Facebook page received 40 'likes' over the duration of the project. The launch of the Memory Matters report in September 2016 also garnered considerable interest in the area with features in both the Kilkenny People, a press release from Department of Health and a radio feature on Carlow/Kilkenny local radio (KCLR). While the majority of the education programmes tied in with the National Dementia Education Programme and the Dementia Elevator, two approaches were specifically conceptualised and designed by Memory Matters. These consisted of Memory Matters (I and II) which was primarily aimed at home helps, although other staff did attend. In addition, OTs provided reablement training to some home helps in the home of the PwD in order to develop a bespoke response for that person.

Memory Matters I and II were described as core modules; in module one, 'Introduction to dementia, communication and responsive behaviour' participants were given some general information about dementia and then in module two, 'Reablement and dementia friendly environments', participants were provided with ideas about how they might introduce reablement in their daily work. These were both two-hours long as there was a desire to keep the modules relatively short to ensure that people could attend for the entire programme, and to avoid 'overloading' the participants. It was also recognised that there would be varying levels of knowledge among the people attending so an effort was made to keep the content at an appropriate level. However, completion of module I and module II were seen as an introduction to the National Dementia Programme and participants would be prepared to attend the 2 day programme should they wish to. In fact, many of the participants who completed the core modules, went on to attend more advanced programmes. While the Memory Matters core modules were primarily attended by home helps (98%), there were other staff at various levels that attended both the core modules and the other programmes that were available. This was seen as important by the project team as it meant that the underlying

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philosophy of the project was communicated to all grades of staff including those in managerial positions. In addition, encouraging attendance from a wide base meant that people who felt that they already ‘knew about dementia’ could be exposed to more recent developments in dementia care such as the move away from disease dominant models of intervention. Both modules were evaluated and a summary of that evaluation is contained in Table 13. Overall, the participants had a positive perception of the training and had praise for the facilitators. They specifically enjoyed the interactive nature of the course and valued the diversity of the people who were in attendance, which allowed them to view the care of the PwD from multiple perspectives. The participants were asked to rate their ability and confidence in a number of key areas pre and post the training. Analysis of the evaluation forms revealed that overall, there were marked improvements in the participants ability, confidence and comfort to talk to family members about dementia, manage patient questions about dementia and providing support and service to people with responsive behaviours.

Table 13. Evaluation of Memory Matters I and II

Memory Matters I	Usefulness in Daily Work (%)	Usefulness in Communicating (%)	Willingness to Mentor (%)	Ability to Mentor (%)
Not at all useful	3.9	2.9	1.7	2.9
A little or somewhat useful	5.5	8.6	6.8	5.8
Very or extremely useful	90.5	87.4	90.3	44.3
Memory Matters 2	Usefulness in Daily Work (%)	Usefulness in Communicating (%)	Willingness to Mentor (%)	Ability to Mentor (%)
Not at all useful	2.0	1.4	0.7	0.7
A little or somewhat useful	12.6	11.1	7.7	6.2
Very or extremely useful	85.4	87.6	91.6	93.1

The evaluations requested the respondents to indicate the three most important things that they learned during the programme. The most important thing that the participants reported that they learned related to interpersonal skills with many of the participants indicating that learning how to communicate with a PwD was an overall positive outcome from the training. In addition, attributes associated with person-centred care, such as dignity, respect and the promotion of independence featured strongly in the responses. The participants were asked to describe how their behaviour might change following the training and again many suggested changes in how they would communicate with PwD, which included being more patient and sensitive to the needs of PwD. Qualitative interviews conducted with the participants supported the findings from the evaluation surveys and gave a greater insight into how they were able to use the techniques they learned in their interactions with PwD. While the additional hours assigned to reablement were perceived as useful and the participants had a positive attitude towards the idea of reablement, there was a mixed response in terms of how it was implemented. Some participants used a range of techniques that had been suggested during the training, such as knitting, looking at photographs, or chatting with the PwD. Others participants attempted to integrate the reablement activities into their normal routine such as the promotion of independence during self-care, and involvement in domestic tasks, such as cooking and cleaning. All of the participants suggested that attending the training had increased their levels of confidence and comfort when caring for the PwD.

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As mentioned earlier, a number of home helps received bespoke reablement training from an experienced OT on a one to one basis within the PwD's home. In total, 49 home helps received this training and although attempts were made to recruit participants who received the bespoke training for evaluation purposes, only one qualitative interview was completed. This participant suggested that they found that while this one to one session was informative, useful and that it increased her confidence when working with PwD, it became increasingly difficult to engage in reablement interventions as the PwD's journey progressed. However, attempts were still made to engage with the person, and the participant described using her initiative to respond to this PwD's unique needs.

In total 150 evaluation forms were returned from individuals who attended the two-day 'Enhancing and Enabling the Wellbeing for the Person with Dementia', a response rate of 97%. The training programme was launched by the HSE in 2012 (Health Service Executive, 2012) and is part of the National Dementia Education Programme. These sessions were delivered by experienced dementia champions who were working in the region, which demonstrated use of existing resources within the area. The programme was attended by home helps, healthcare assistants, PHNs and other allied healthcare staff, such as OT. As with the core modules (Memory Matters I and II), these sessions were well evaluated and positively received. An additional day focusing on the management of responsive behaviours was also delivered to 45 staff, although the evaluation team received only nine completed evaluation forms. This training also aligned with the National Dementia Education Programme. In addition, improvements in the participants self-rated ability, confidence and comfort, similar to those reported for Memory Matters I and II were also reported post training. An overview of the evaluation of the 'Enhancing and Enabling the Wellbeing for the Person with Dementia', and the Responsive Behaviours programmes is presented in Table 14.

Table 14. Overview of Evaluations from Enhancing & Enabling and Responsive Behaviour Training

Enhancing & Enabling Well-being for PwD	Usefulness in Daily Work (%)	Usefulness in Communicating (%)	Willingness to Mentor (%)	Ability to Mentor (%)
Not at all useful	2.0	0	0	0
A little or somewhat useful	9.3	14.2	8.8	13
Very or extremely useful	87.3	82.3	87.8	82.3
Responsive Behaviours	Usefulness in Daily Work (%)	Usefulness in Communicating (%)	Willingness to Mentor (%)	Ability to Mentor (%)
Not at all useful	0	11.1	11.1	0
A little or somewhat useful	22.2	11.1	11.1	11.1
Very or extremely useful	77.7	77.7	77.7	88.8

Qualitative data from interviews with the participants supported the evaluation surveys and as with the Memory Matters modules, participants reported an increase in confidence and comfort when working with PwD and emphasised the importance of person-centred approaches during day-to-day interactions. Participants talked about the usefulness of the training, and described it as easy to follow and practical. They valued the common sense approaches suggested by the facilitators who they described as knowledgeable and experienced. The participants acknowledged that the facilitator's ability to speak from direct experience was effective and enhanced the quality and credibility of the training. There was some evidence that participants utilised some of the strategies they



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learned in their day-to-day work. For example, one participant talked about caring for a PwD who also had expressive aphasia in a different way following the training. Instead of finishing sentences for her, the participant now gives the PwD more time to speak during interactions. In another example, a participant described how her attitude towards 'challenging behaviours' had changed because of the training. This participant now conceptualised these as responsive behaviours and made a connection to how these behaviours are often in response to an unmet need. After completion of the training, the same participant stated that her overall attitude towards PwD had changed and that she now saw 'dementia in a different light'. Another participant described making environmental changes, such as increased signage, removal of clutter and use of colour in her area of practice. Most of the feedback about the training was positive. For some participants who were caring for a person with advanced dementia, the training was not relevant. However, these were in the minority as can be seen in Table 13 and Table 14 (n=7 for MM1; n=3 for MM2; n=3 for Enhancing & Enabling Well-being for PwD).

4.7 Assistive Technology

As outlined in Section 2.4.3, 36 assistive technology packages were arranged by the project. Feedback from informal carers regarding the technology was mainly positive. The main reason given was that the devices provided support and reassurance as the informal carer would be informed if the PwD had a fall or left the bed. According to participants, the emergency response unit and the fall detector were particularly helpful as they ensured instant notification.

"Great support to know that if Mam had a fall, the alarm would go off as she wouldn't have presence of mind to press a button." (FU Survey Response KK01)

"In particular the bed sensor is very helpful as my husband frequently tries to get out of bed and the people at Emergency Response are very good. I find I can relax when I go to bed knowing I have this technology." (FU Survey Response KK05)

"... the alarms to me was a good thing, as in it did, it does, it's a little bit reassuring in that if something did happen that they would or could, if they'd remember to do it or not, I don't know. And it was reassuring around the time when they did ring the button by accident." (FU SI IC KK18)

There was some negative feedback about the assistive technology by informal carers however, who felt that the technology was inappropriate as the PwD did not know how to use it. For example, one participant commented that the PwD frequently activated their personal alarm when assistance was not required. In addition, due to the project enrolment criteria, the need for assistive technology offered by the project reduced because of the loss of mobility in the later stages of dementia. These findings are similar to those of Cullen et al. (2016) in an evaluation of assistive technology and telecare in an Irish context.

The challenge with assistive technology (also referred to as telecare by the project team) reflected the tension between providing a service that was parallel to the existing services leaving some confusion about the screening processes. The ethical issues raised around the deployment of assistive technology without clinically assessed need by a healthcare professional and the inability of the OT to deploy technological supports even when clinical need has been established means that it is difficult to assume that technology will be embedded in standard services as a result of the project.



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"We were told that twenty people were eligible for it and suddenly I have no idea why some got it and some didn't being honest. I had identified it for some people. It was already in place. Perhaps not the most suitable set up of equipment." (FG OT)

"We provide equipment and you know if, on our own terms I suppose, we would have our own policies, procedures where we provide something and the way we follow-up on it and the way we maintain it and the information we give to the client on it and it's, it's very, very set. [...] I found that I went to people's houses and they're asking me questions about their sensory mast and their bogus alarms [...] when I'm not the one implementing it." (FG OT)

4.8 Costs of Care

The basic question in any economic evaluation is whether the extra cost of a programme, technology or intervention is worthwhile when the benefits of that intervention are considered. A positive outcome as regards an improvement in QoL and/or health may not be considered worthwhile if the costs of the intervention are considered very large. Conversely, a small improvement in a desired outcome might be considered beneficial if the cost of the intervention is very small.

As mentioned earlier, the Memory Matters project had several objectives. The key objective of relevance for economic analysis that the project hoped to achieve while it was in operation was to ease the burden on informal carers so that it was more likely that the PwD could continue to live at home rather than enter LTC. In assessing this objective and indeed the other objectives, our focus is solely on the 49 people¹⁰ who participated in the project and were still living at the time that the last data on the participants was collected (April 2016). Any participants who died over the course of the project were therefore excluded from this stage of analysis. Excluding the people who died during the course of the project will underestimate some of the project's effects, however. One participant who, although accepted on to the project, went directly into LTC before receiving any services from the project, was also excluded.

Based on the information that was provided by the Memory Matters team in June 2016, 33 of the 49 people who were in the project continued to live at home for the full duration of the project. That represents 67% of the participants and, while there is no specific criteria for declaring whether a particular rate is acceptable or not, 67% represents a considerable achievement as regards a basic objective. That 16 of the 49 ended up living in LTC underlines the vulnerable situation that this group of people and their families are in. Overall, the group is one where the balance of care issue is very much an ongoing one.

Was the project expenditure an efficient allocation of resources? This question can only be answered with reference to an alternative and by referring to an outcome or outcomes that are considered desirable. In this particular case, the most reasonable alternative to consider is that the participants would have moved to LTC. One of the original inclusion criteria for being selected for the project was that the person had to be eligible for the Nursing Homes Support Scheme (NHSS), commonly referred to as the Fair Deal. As regards outcomes, taking into account both the wishes of the PwD and their carer(s), the preferred outcome is that the PwD continues to live in the community rather than move to LTC. The limited available evidence suggests that society as a whole also prefers that people live at home. O'Shea and Kennelly (2008) found that, on average, people in Ireland were willing to incur higher taxation in order to fund a hypothetical care of the older person programme that was similar in many respects to the actual programme introduced in Co. Carlow/Kilkenny. It is assumed that a person's health state and need for specialised

¹⁰ Overall active participants (N=55) excluding participants who died (n=5) or moved into LTC before services started (n=1).

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health services would have been the same regardless of their living location so therefore the comparison is between the costs of caring for the person at home versus the cost of caring for the person in a nursing home.

Firstly, considering the issue from a societal perspective, the total costs of living at home are considered and compared to the cost of living in a nursing home. Later, the costs incurred by the HSE are considered on their own.

The costs of all the services for each participant were calculated – including the services available in the project, including informal care - that were being utilised to care for the person at home and added to the publicly provided services. The resulting aggregate includes HSE costs, project costs, project coordination costs, informal care, care purchased privately, as well as housing and personal consumption services. The total weekly cost of living at home for each of the 49 participants in the project was calculated. The distribution of this data is shown in Figure 12 and summary statistics are provided in Table 15. The total cost of living at home per week varies from a minimum of €653 to a maximum of €1,925. The average across the 49 participants is €1,137 and the median was €1,068.

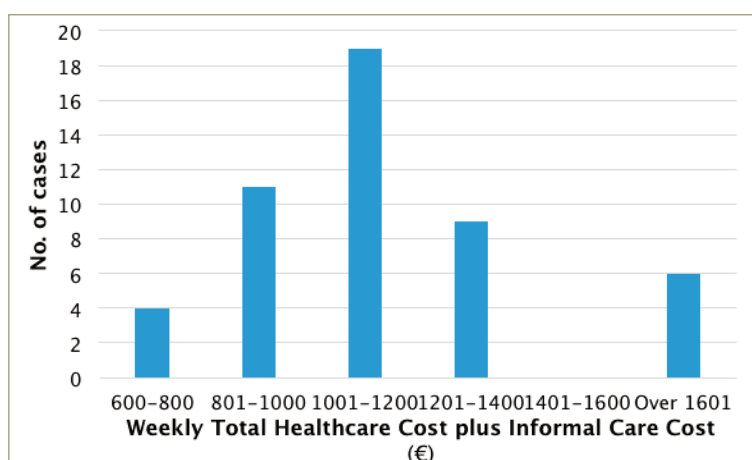


Figure 12. Costs of Living at Home: Societal Perspective

Table 15. Costs of Living at Home: Societal Perspective

Descriptive Statistics	Total Weekly Healthcare Costs plus Informal Care Costs
Minimum	€653
Maximum	€1,925
Range	€1,272
Mean	€1,137
Median	€1,068

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The HSE recently published the weekly cost of care in public nursing homes around the country (Health Service Executive, 2016a). There was a nursing home in Kilkenny with a weekly cost of €1,478 and one in Carlow with a weekly cost of €1,172. The weekly living at home costs were compared with the LTC costs for each person in the sample using the nursing home cost of the specific county that the participant was living in.

There were 16 people from Carlow in the project. For 11 of them, the cost of living at home was lower than the cost of the nursing home in Carlow. There were 33 people from Kilkenny in the project. In 29 cases, the cost of living at home was less than the cost of living in a nursing home in Kilkenny. In total therefore, and bearing in mind that there was a difference of over €300 in the weekly cost of the nursing home care in the two counties, the cost of living at home based on societal cost, was less than the cost of LTC for 40 of the 49 participants (82%).

This analysis assumes that the additional hours of home help obtained under the Memory Matters project complemented informal care provided by family and friends. The total cost of living at home was calculated on the assumption that the home help hours obtained via the project would reduce the hours of informal care provided by family and/or friends. This made no difference to the analysis.

The perspective taken so far is not necessarily the perspective that the HSE might take. The HSE is particularly concerned with the costs that it incurs in providing home care services or in providing residential care services in a nursing home. Therefore, in this section only those costs incurred by the HSE are focused on. The costs of all the services funded by the HSE including the cost of the services provided by the project were summed. This data is reported in Figure 13 and Table 16. The weekly costs ranged from €331 to €1,137 with an average of €607.

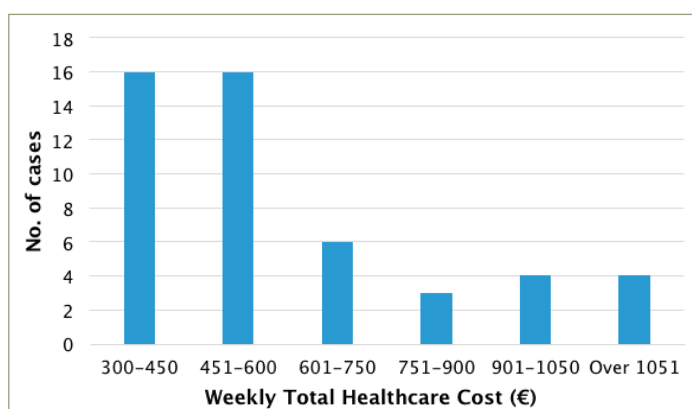


Figure 13. Weekly HSE Costs

Table 16. Weekly HSE Costs

Descriptive Statistics	Weekly HSE Cost Including the Cost of Project Supports
Minimum	€331
Maximum	€1,317
Range	€986
Mean	€607
Median	€539

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Under the NHSS, individuals are assessed regarding contributing towards the cost of their stay in a nursing home. According to a report on the NHSS (Department of Health, 2015), the average contribution by individuals towards their stay in public nursing homes was €285 in 2014. The net cost to the HSE of the average LTC was calculated as €1,193 in Kilkenny (€1,478 - €285) and €887 in Carlow (€1,172 - €285). There was only one case in each county where the cost of LTC was lower from the HSE's perspective. In 96% of the cases, the cost to the HSE of the services provided to the person at home was less than the cost to the HSE of the person being in LTC.

Of the 49 people that participated in the project, 16 were in LTC by the time the data collection process ended (April 2016) so there were 33 people living at home. Focusing on the 33 still living at home, the question is asked whether it is possible to conclude that the total amount of money spent on each person in that group was efficient use of resources. The focus is on total expenditure rather than weekly expenditure because the number of weeks that individuals were on the project varied considerably from 64 weeks in two cases to 28 weeks in six.

Firstly, the various project-specific costs for each of the 33 people were aggregated. This included the home help hours provided by the project, the OT visit, the project coordination costs and the costs of the assistive technology packages provided. The total across all 33 people is €266,285.

It could be assumed that without the Memory Matters project all 33 people would have moved to LTC. The total cost of that LTC for the HSE would have been equal to the net cost of LTC (i.e. taking into account a contribution from the NHSS) minus the costs that the HSE were already covering for the 33 people in question at the time that the project started. Summing over all 33 people, the total that the HSE would have spent on LTC is equal to €1,452,868 as illustrated in Table 17. This figure is almost 5.5 times the cost of the project calculated earlier.

Table 17. Project Support vs. LTC

Project support		Without project support	
Cost of HH hours, OT visits, project coordination and Telecare	€266,285	Cost of LTC (exclusive of Fair Deal contribution)	€1,634,548
		Existing HSE supports at start of project (e.g. PHN cost etc)	(€181,680)
Total project costs for 33 participants living at home	€266,285	Total potential cost of LTC	€1,452,868

Obviously, there is uncertainty about the counter-factual that was used in this analysis, i.e. presuming what would have happened without the Memory Matters project since we do not know how many participants who lived at home would have transitioned to LTC had the project not been in place. The project money would still have been a good expenditure from the HSE's perspective if at least 11 people were able to stay living at home rather than in LTC due to the project. The project is also likely to have delayed the move to LTC of at least some of the 13 people who did so and to the extent that it did, the cost savings to the HSE would have increased.



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While it is very likely that the cost of the project was a good use of resources from the HSE's perspective, the situation is more complex when a societal perspective is taken. On average just over half the weekly cost of living at home is made up by informal care. Some of these costs at least might not have been incurred in the absence of the project to the extent as the person would have moved to LTC where informal care costs would have been equal to zero. These 'savings' have not been estimated given that there is a general assumption that PwD prefer to live at home rather than in LTC and given that there is some evidence that the general public in Ireland are willing to pay for additional services to enable people to live at home (O'Shea and Kennelly, 2008).

4.9 Ripple Effects

The project has contributed to creating greater momentum to some parallel initiatives aimed at improving dementia care in the Carlow/Kilkenny area which were not planned, or anticipated in the early stages of the project. These included an assistive technology resource room, a dementia-friendly garden as well as a musical choir in a nursing home.

"And I think in the community, from the community point of services, it has actually acted as a catalyst, the project. And through the training and through the involvement a lot of the service providers now I think feel more confident, you know about inclusion of people with dementia in their day centres, in their befriending services, you know in other general activities rather than thinking that's for the Alzheimer's Society." (FU FG¹¹ Project Team)

Though not part of the original planning of the project, the technology resource room in Sacred Heart Hospital, Carlow, came about as a result of it. The establishment of the technology resource room was sponsored by Tunstall, Emergency Response (www.emergencyresponse.ie), and the Memory Matters project. The room is supported by the nurse-led Memory Clinic in the Day Hospital and an OT. The resource room allows PwD and their informal carers to familiarise themselves with available assistive technology. The technology includes, for example, bed sensors, door sensors, flood sensors, and medicine dispensers as well as signage, clocks, and calendars. The feedback by OT to the resource room has been largely positive. OT commented that the location of the resource room in a nursing home could be a deterrent for some service users as it might elicit a fear in PwD of being transitioned to residential care.

A dementia-friendly memory garden was created in Sacred Heart Hospital, Carlow, and launched in conjunction with the Memory Matters Resource Room at the hospital in June 2016. Though financed through the Friends of the Sacred Heart Hospital, it was inspired by the Memory Matters project, and the project coordinator was actively involved in its development. A second memory garden is in the process of being built at the hospital. A musical memory choir at Sacred Heart Hospital was also inspired by Memory Matters. Choirs have been associated with various benefits for PwD, and provide an opportunity for social inclusion and reminiscing as the memory for songs and music remains until the very late stages of dementia (Cuddy and Duffin, 2005).

The dialogue around the project increased focus on ways of enabling PwD to remain at home, and as a result increased attention on barriers to attending community supports, such as transport. One example came from PHNs, who recounted that a bus service was established to provide transport for PwD to a day care centre as many people were not using the centre because of transport issues. Though not funded through Memory Matters but through the Care of the Elderly budget, the bus service was established because of raised awareness of dementia needs in the community. The project also brought some momentum to a previously planned dementia-friendly environment in St. Columba's Hospital Thomastown, Co. Kilkenny, which is now the intended site for a second Technology Resource Room.

¹¹ FG=Focus Group



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By inspiring these developments, Memory Matters has had an impact on services and facilities available for PwD in the Carlow/Kilkenny area that exceeds what the project set out to achieve.

4.10 System Changes

Following the active recruitment (Phase 1), and in preparation for the exit of the project coordinator, the second phase of work of Memory Matters was dedicated to ensuring that the changes achieved through the project were embedded in the standard system (Phase 2). In close collaboration with the Home Help Applications Approval committee, the project team developed the referral pathway below (Figure 14) and a new Home Help Application Form (Appendix 6) for this purpose. The project coordinator function was replaced through the newly developed Home Help Application Form which offers a number of signposts to other supports within the family structure and the wider community.

Under the new pathway, referrals are still initiated by the PHN, but the PHN now completes the newly developed Home Help Application Form (see Appendix 6). This form has been re-developed as an outcome of the Memory Matters project and now contains an environmental assessment as well as a circle of contacts which lists supports and contacts available and identifies gaps or unmet needs. If an OT assessment is required, the PHN forwards the application form to the OT. PwD with complex needs will be prioritised for OT assessment according to clinical need. Those with mild to moderate dementia are identified for OT assessment by the memory clinics. The home help applications that require an OT assessment are now divided into urgent and non-urgent cases. Non-urgent cases await the OT report, and the application is only submitted to the allocations meeting if the OT assessment has been completed. For urgent cases, the home help application can be submitted to the allocations meeting for consideration of urgent services without the OT assessment which can be completed subsequently. The PHN then reviews the care plan, and if it is inadequate, a multidisciplinary assessment may be requested.

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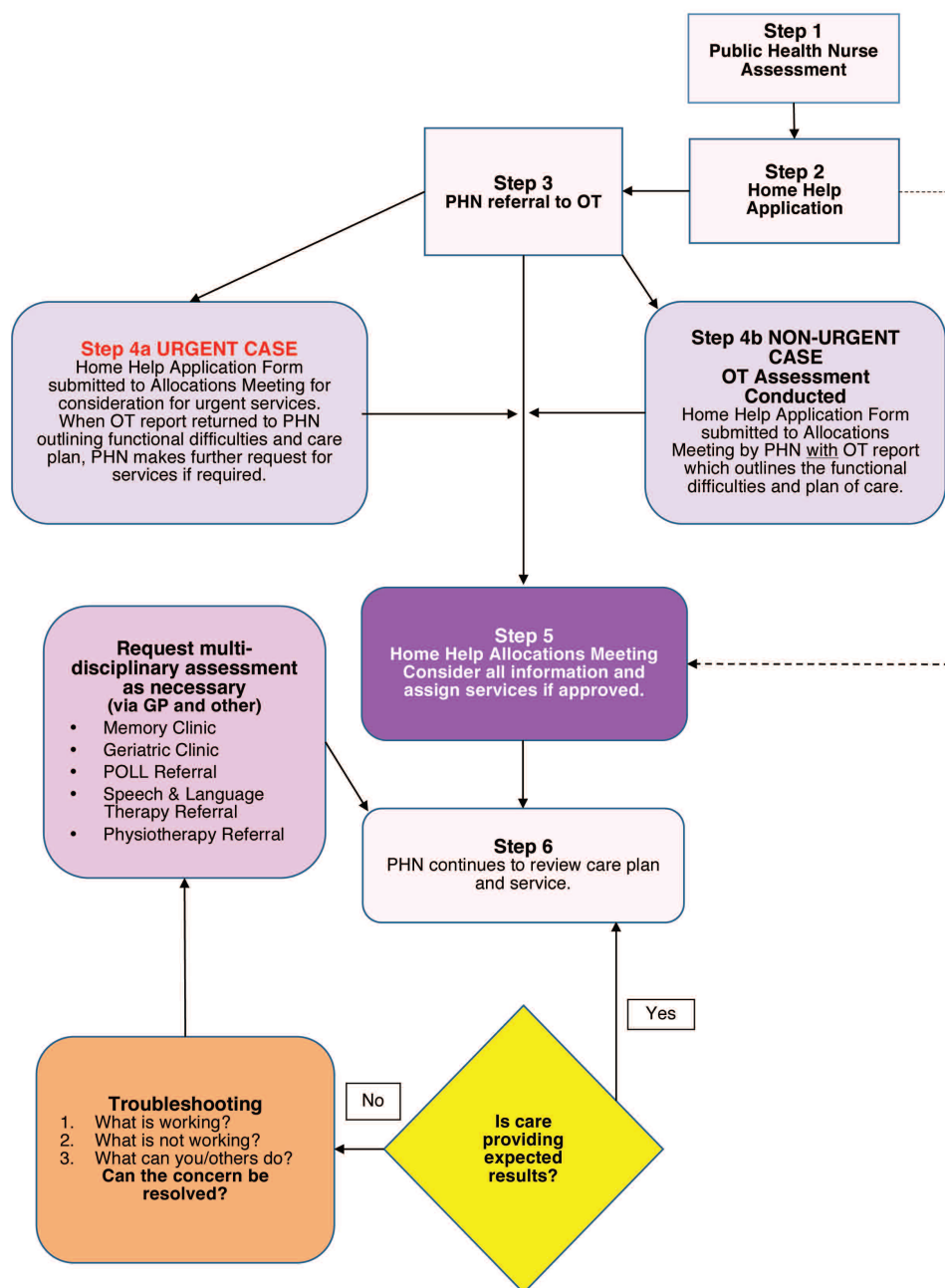


Figure 14. New Referral Pathway for Home Help Applications¹² (Phase 2)



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Box 6: Summary of Project Outcomes

- PwD and families/informal carers stated a preference for the PwD to remain at home which was associated with important benefits such as maintenance of ability, connection to life roles and interests, access to familiar environments and a sense of security.
- Fifty-five PwD participated in the project and were supported to remain living at home for periods from 28 weeks to 64 weeks. For this sample, supporting people to remain at home did not have an adverse effect on carer QoL or burden.
- Flexibility and individualisation in the provision of home support hours were achieved within existing community care services and helped to address families/informal carers' needs whose satisfaction with community dementia care services increased in the duration of the project.
- The provision of block hours of care was very beneficial to the PwD and the family/informal carer as it facilitated reablement activities, improved the quality of care and provided carer respite.
- The project has had a transformative impact on service providers, such as home helps and OTs, whose roles have broadened to allow for a wider interpretation of their function to support and enable individualised care.
- There was a high level of dementia awareness and knowledge among the service providers surveyed as part of the Memory Matters project.
- The educational initiatives emphasised a move away from task-orientated care and a move towards reablement for PwD. The feedback received from participants who attended the educational programmes was positive.
- The Memory Matters project had a wider impact on the community by inspiring dementia-friendly services and facilities available for PwD in the Carlow/Kilkenny area that exceeded what the project set out to achieve.
- The project was a good use of resources. Looking at costs from the HSE's perspective, the average weekly cost of the project supports and HSE supports combined was €607 which is significantly lower than nursing home costs in the area (€1,172 to €1,478 per week). From the societal perspective, which includes the cost of informal care, the cost of living at home was less than nursing home care for over 80% of the participants.



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5. Project Facilitators and Challenges

The project had a number of structures designed to maximise facilitation for change and these included the consortium, the project lead and the project coordinator role. Other facilitators and challenges to the project process arose and are discussed here in the context of learning from the project experience of developing individualised supports in the community.



Figure 15. Process of Developing Individual Supports in the Community

5.1 Role of Consortium

Kilkenny Age Friendly County Limited, the applicant organisation for the Memory Matters project, was well situated to accommodate this project as it was experienced in providing support for older people. Its operative arm, the Carlow/Kilkenny Service Providers Forum, consisted of a representation of statutory, community and voluntary organisations of all older people service initiatives and was therefore in a position to provide cross-sector collaboration. As an existing and functioning group, it eliminated the need for the establishment of a specific Dementia Consortium, which meant that the difficulties and delays associated with such a process were avoided. The Forum brought with it a strong representation and hence knowledge of services and supports in the Carlow/Kilkenny area including those for PwD and their families/informal carers. Through its involvement in age-friendly activities, such as meals on wheels, befriending services, health promotion, care and repair for older people, and a Carlow knitting party, the Service Provider Forum was well placed to support dementia-friendly activities related to Memory Matters.

5.2 Project Lead/Project Coordinator

As HSE Manager of Older Persons Services (Carlow/Kilkenny Primary Care and Continuing Care Services), the lead applicant was in a position to impact on the provision of services for PwD from within existing HSE structures. The lead applicant was a member of the Carlow Kilkenny Age Friendly Alliance and Chair of the Service Providers Forum, which enabled her to put services for PwD and their families/informal carers on the agenda of these organisations. It enabled her to organise integrated support through communication across all services within the forum which was essential for the project. In her role as HSE manager, the project lead was in a position to bring various health



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professionals on board. The project was facilitated by staff who were willing and ready to improve the care of PwD and working in areas with little staff turnover.

“And I think it was the right time for that change to happen because people were frustrated with the actual system that was available.” (FU FG Consortium)

The project coordinator was a critical facilitator for its development, set-up and roll-out and served as the face of the project. A multi-layered project like Memory Matters required a dedicated coordinator, and her experience in change management and knowledge of the area proved valuable. It was considered beneficial that the role was filled from outside the HSE structure to allow for an innovative approach, although this also posed challenges, for example in gaining an understanding of organisational structures, communication pathways and service provider roles within the HSE.

The project coordinator acted as the interface between the project and its participants. Her home visits allowed for the observation of PwD in their home environment. This facilitated the establishment of needs through the provision of information on the PwD's past and present and exploration of the informal carer's needs. The visits included recommendations for referrals to required services, such as OT, home care services, day care, voluntary services and assistive technology to implement the plan of care that had been agreed.

“..you'd need a [name of project coordinator] all the time I think for dementia patients, I really do. I think it was brilliant, she was out there at the coal face talking to the families and making them very much aware, spending time with them and you know just spending time with them..” (FU SI Consortium)

For the duration of the project, the project coordinator role was instrumental in generating the detailed assessment of individual patient circumstances, supports and needs. This was in addition to the standardised assessment undertaken by the PHN which is required to obtain support services. In the second stage of the project the PHN assessment was adapted so it contained more comprehensive information around alternative sources of care support which could potentially augment family/informal carer support.

5.3 Utilising Existing Structures and Services

Being embedded in existing structures and services was a strength for the project. The Carlow/Kilkenny Service Provider Forum, which served as the consortium, brought together stakeholders engaged in older persons' services that were in a position to put the new care model for PwD on the agenda within their organisations. The utilisation of existing services within the healthcare system further strengthened the realisation of the project's aims as change was affected from within a pool of present resources, such as a highly trained and engaged workforce, and allowed for a clear identification and engagement of key stakeholders.



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5.4 Achieving Cultural Change

The project generated a change in the approach to home care support with a shift from the traditional focus on physical care to a wider concept that included social care and allowed for home care support that is flexible and tailored to the needs of the PwD and their family/informal carer. It also enabled different forms of home help services, such as block hours, night time and weekend services. The fact that the home help hours were provided through existing resources bears well for the sustainability of the person-centred approach to care. The approach encouraged the collaboration between various healthcare groups which benefits the person at the centre of care and have potential for deployment in the wider health service.

The process of embedding changes in the provision of home help services for PwD has been facilitated through a substantive modification of the home help application form. PHNs were involved in the design and the development of the modified form which is now the official HSE referral form for this area (see Appendix 6). The Home Help Application form now includes a section to detail circle of contacts and supports as well as a home and environmental assessment. It prompts and assists in assessment and planning for care in the home, alerting to potential solutions and attempts to prompt innovation and use of family resources where possible.

“Yeah well it was very helpful for us here during our meetings, you know. We found the form is much more informative than our old one. I’m sure the nurses probably it’s a pain in the behind because it’s more time consuming, let’s talk straight about this (laugh). But for us, it was easier for us to make a judgment call as to whether hours should be passed or not passed you know.” (FU SI Consortium)

The Home Help Application form also allows opportunity for narratives and incorporates informal carer needs. In fact, the form acknowledges the unique interconnectedness between the PwD and informal carer need. The information is considered in great detail by the home help allocation team to determine the most effective use of resources. The form developed in collaboration with PHNs is regarded largely as a positive but can be viewed as time-consuming, and indeed there were instances where PHNs felt it may contribute to a delay in securing requested hours.

“What you’ll find with that circle then is it’ll come back to you. So in the circle you’ve a daughter there, what’s the daughter doing. Can that daughter not go in and do that. [...] and you’ll say, oh well in the circle you have, you know, can that son not go and in that circle you have.” (FU FG PHN II).

In two areas, home help allocations meetings currently review non-urgent home care applications within PCTs with a view to bringing some care decisions into primary care. Given the integral role of primary care from diagnosis throughout the PwD’s journey, this could further aid the sustainability of a person-centred approach to dementia care. PCT meetings allow for input from various professions and multidisciplinary decisions. The allocations meetings are chaired by the assistant director of nursing and attended by the Home Help coordinator, OT and physiotherapy, and occasionally have GP input. The allocations meetings occur more frequently on a weekly basis, and the PCTs meet on a monthly basis. This development is at an early stage and therefore its impact is yet to be determined.



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5.5 Resource Constraints

The Memory Matters project was undertaken in the context of carefully rationed community nursing services. Staff shortages in healthcare were commonplace, and further exacerbated by a national moratorium on recruitment. Therefore suitably qualified home help staff were in short supply with evidence of greater privatisation and reliance on agency care to supplement HSE home help manpower requirements with some disparities in training and consistency of staff noted as a result: “... as regards a team, you see, we have two people on a night time rota, and it is two different people every night, five nights a week.” (FU SI IC KK04).

“[...] you’re looking at going out to private agencies. And then they wouldn’t have had the [dementia-specific] training that our care givers would have had, do you know.” (FU SI Consortium)

The project was operating within a national context of resource constraints and the final months of the project coincided with a national mandated policy to restrict home care spending, prohibiting any overspend on a month to month basis (Care Alliance Ireland, 2016, O'Regan, 2016)¹³. As a result, home care managers were required to recycle hours from within existing resources to stay within budget each month. Therefore waiting lists were in operation in Kilkenny/Carlow at project end and physical care hours were prioritised. Those who were referred into the project had their services maintained or increased post project end. The PHNs can continue to refer for home care support that responds to the social, supervision or informal carer support needs but there may be a waiting period. Interviews with the nursing staff in both Kilkenny and Carlow revealed mixed views as to the feasibility of securing flexible home care hours enjoyed during the project in a climate of acute rationing.

Some nursing participants were quite optimistic that there was potential to secure home care hours according to assessed need for PwD. Others were less optimistic and believed there was risk that only physical care needs will once again be prioritised in the current climate. This can in turn influence the requests as PHNs are acutely concerned with avoiding raising false expectations among families to avoid disappointment.

“..they had one set of block hours and I looked for more and I got a letter, I’m going to get a letter I know saying that he’s on the waiting list but will get it eventually and the family are delighted to know that they’re going to have, rather than having a daily call of 45 minutes every morning to do tasks, the fact that she knows twice a week that she has 2 ½ hours to herself and that’s 4 hours where there will be 3.75 hours, it means more to her. (FU FG PHN)

“We’re kind of currently recycling at the moment because we have to prioritise acute admissions, palliative care, increasing services in the community from a health and safety perspective. So you know I suppose people with dementia are going on wait lists.” (FU SI Manager II)

“... it’s not going to happen. Because of the waiting lists and recycling of hours. The only hours that are being given out are the ones that are coming back in. And they’re being used solely for hospital discharges and palliative patients. So if you have somebody who needs three calls a day, a half an hour a day. You’re not going to put in three hours, when that’s six hours you could give to the patient.” (FU SI Manager I)

A cornerstone of the project goals was the OT assessment to develop individualised care plans and bespoke training for home helps to assist the PwD in reablement activities. To this end, additional OT hours were provided by the

13 As a consequence of pressure on emergency departments in the first quarter of 2016, spending on home help and support packages increased in order to free up beds. This resulted in a reduction in expenditure later in the year in order to address over spending. Thus, what some service providers perceived to be cutbacks in support packages was reported as a ‘rebalancing’ of spending by the HSE. Regardless, the embedding in standard services of increased supports that the project provided



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project. OTs engaged wholeheartedly with the project and undertook 53 assessments over the course of the project. Following the project, PwD with complex needs will continue to be prioritised according to clinical need for OT assessment. However, people with mild to moderate dementia will be identified for OT assessment through memory clinics and it might take longer until reablement can be activated.

Though an average 2-3 hours per week was dedicated to reablement per person, some home helps and OTs felt that more time was needed to work with the person. There was no annual leave or sick leave cover available for block hours dedicated to reablement, and this posed a problem for families/informal carers. It also highlighted the importance of these hours to the family/informal carer who experienced relief from the burden of caring.

“..this week actually the lady that calls in the afternoon for the interaction is actually away on holidays and hasn’t been replaced. [...] But I found this week the most difficult week so it just shows how a good thing.” (SI KK04)

“[...] but that’s the thing that’s missing, I think, is, is people and hours and, you know, so much can be achieved – where if we had more time to spend with these people and I think the approach of the project would have been much more achieved had we more time with the clients.” (FU FG OT)

“..they will know when I’m going on holidays so they have to arrange cover. But it will be prioritised and who would need cover. So basically my say HSE as in personal care, every day clients they would be covered. But the GENIO block hours will not be covered. (FU FG HH)

In conclusion, there were a lot of competing demands that constrained the availability of resources for the project in its final phase as summarised in Table 18.

Table 18. Identified Resource Shortages

Particular Service Needs	National Constraints
Flexible home help hours for reablement activities & carer respite	Staff shortages e.g. home support staff
Need for overnight and weekend service	Risk of prioritisation for home care hours to favour physical care, increased wait times and waiting lists
Need for OT assessment for reablement & for assistive technology	Limited OT availability leading to potential wait time for assessment and commencement of enhanced services



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5.6 Location and Communication

Geographical Variations

Healthcare teams in Kilkenny are located centrally with the HSE headquarters for Carlow/Kilkenny, whereas teams in Carlow are more dispersed due to their geographical location. This led to a somewhat slower roll-out of the project in Co. Carlow, with the result this county was slower to impact. Carlow participants also reported some challenges in securing staff to cover remote locations. Acceptance rates onto the project varied significantly between the counties with 59.4% (n=41) of those referred in Co. Kilkenny enrolled onto the project, while only 31.1% (n=14) of those referred in Co. Carlow were accepted onto the project. Experiences among healthcare staff as to what was available and provided under the project also differed whereby staff in Co. Carlow expressed lower expectations and less satisfaction regarding access to services than staff in Co. Kilkenny. As Kilkenny had introduced a roster for home helps, there might have been greater flexibility and availability in the provision of home help hours than in Carlow. The central location of healthcare teams within a local context (i.e. a county) may be a facilitator in bringing about the kind of system and culture change which was part of this project.

“Just from talking to nurses I know in parts of Kilkenny, it worked extremely well. [...] And it was really frustrating to hear that down here it wasn’t. We didn’t feel we were getting the same.” (FU FG PHN II)

“And that’s why it took so long for some, we didn’t have staff in certain areas to do the block hours, so say you had somebody looking for block hours and the carers in that area were all tied up with their half hour task-orientated calls, they were prioritised ...” (FU FG PHN I)

Communication Pathways

The referral pathway to the project and its inclusion criteria were not always clear to all stakeholders. Service providers suggested that a communication protocol would benefit clarity in relation to guidelines or criteria for referral. Some disparity was evident between the home help coordinators and OTs around the reality of constraints on service with variance in perception as to availability of home helps, timing of visits and the allocation of block hours.

“There’s still an awful lot of confusion and I think we’re really lacking in terms of documentation on it, like we still haven’t been handed anything so much as.. [...] a guideline or a pathway or a criteria for referral...” (FU FG OT)

Communication between the project and healthcare providers was perceived by some to be somewhat one-directional, and PHNs remarked on the lack of information following a referral, with the result that they were sometimes uninformed as to the patient status within the project. This was also reported by OTs as there was not a formal mechanism to report back on outcomes of their reports, in spite of the comprehensive nature and time-investment given to this activity. The challenges in executing home care packages did mean for some participants referrals took a long time to be processed. These challenges were considered in the second phase of Memory Matters and it is anticipated that as the referral process will now be hosted in the allocations meetings it will enable a more direct line of communication.

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Box 7: Key Learning on Project Facilitators and Challenges

- The consortium, project lead and project coordinator functions were important for project set-up and roll-out; the project coordinator was a critical facilitator for project development and management of project activities.
- The project's embeddedness in existing structures, such as the Carlow/Kilkenny Service Provider Forum, and the utilisation of services from within the healthcare system were strengths.
- National community care resource constraints led to tension between assessed need and availability of services.
- Differences emerged between Co. Carlow and Co. Kilkenny in relation to acceptance rates onto the project and perceived access to services, possibly due to the way services are organised in the two areas.
- The sustainability of the new approach to care is facilitated through a substantial modification of the Home Help Application Form which is now the official HSE referral form in Co. Carlow/Kilkenny.





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6. Discussion

The purpose of this chapter is to explore the wider implications for dementia care development that emerged from the findings of this evaluation. It explores the insights and learning from the Memory Matters project and the sustainability of the project activities and concludes with recommendations arising from the evaluation (Section 6.10).

6.1 Impact on the Experience of the Person with Dementia

In keeping with the National Dementia Strategy (Department of Health 2014), the core aim and objectives of the Memory Matters project focused on the establishment and maintenance of individualised, flexible supports for people with advanced dementia and/or complex needs and their families/informal carers in the community.

The PwD and their families/informal carers interviewed stated a clear preference for the PwD to remain at home even when the PwD was assessed as being eligible for nursing home care, families/informal carers were keen to avoid an admission to long-stay residential care. Sustaining PwD at home is an agreed preference for both families and health systems (Trepel, 2015). The findings suggest that many PwD, including those eligible for transition to LTC, could stay in the community longer through the provision of a service that is flexible and tailored to the needs of the individual PwD, informal carer and family. Furthermore, it is likely that some of the people who were admitted to LTC delayed their move to LTC due to their participation in the project.

The flexibility of services improved the quality of care of the PwD by allowing home helps dedicated time with the PwD. Contact with others is important for PwD, and lack of opportunity to talk or interact with other people can lead to reduced QoL (O'Rourke et al., 2015). A lack of company is one of the most reported unmet needs of PwD living at home (Miranda-Castillo et al., 2013).

The reablement approach facilitated engagement beyond the emphasis on physical care to include meaningful activities with the PwD which were specific to the person's interests and needs, exemplifying a person-centred approach to care (Genio, 2016). Reablement created the potential for maintaining abilities, for enjoyment and contentment through recreation and social connectivity, which many informal carers observed when the PwD was engaged in activities. The approach in tandem with a person-centred focus has been found to have great potential to contribute to the possibility of living well with dementia (Clare, 2016). The challenges in assessing QoL for PwD are well known (Bowling et al. 2015), however, and outcomes from the reablement approach cannot be quantified, as they are intertwined with the benefits attained through carer respite.

This project set out to test the feasibility of supporting people at later stages of dementia and/or with complex needs at home. This was in the context of the wider HSE-Genio Dementia Programme, where a number of projects provided community supports for people at every stage of the dementia journey and it was questioned whether it would be possible to do this regarding people with very advanced dementia. Though reablement was generally considered helpful, learning identified the late stage of dementia of some participants recruited for the project which meant that for some the interventions came too late, were under-utilised or not initiated due to illness or admission to long-term residential care. This was echoed in the evaluation of the other community project in the



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HSE/Genio Dementia Programme (Brady, 2017) and has important implications for the timing of the provision of supports for PwD. For reablement to be sustainable, early intervention and consistent care management is important. The availability of OT input in similar services around the country would need to be considered in the adoption of this approach, as this level of resource is not typically available.

6.2 Impact on Informal Carers/Families' Experience

Memory Matters challenged the very nature of support for PwD and their families/informal carers locally on several levels which included implicitly viewing the family/informal carer and PwD as the unit of care, giving greater scope and decision-making to informal carers to identify how best they can be supported in their particular contexts, and enabling a move away from the task-oriented care that characterises standard HSE home care supports. Family support is essential for keeping PwD in the community (Prince et al., 2016). Yet informal carers' expertise in caring for a PwD is often not acknowledged, and they are frequently not included in decisions regarding the PwD's care in spite of the importance of recognising the PwD and the informal carer as a unit in relation to care planning (Bloomer et al., 2014, Trepel, 2015, Jamieson et al., 2014). The project demonstrated strong benefits associated with families' input into the selection of hours and ensuing flexibility.

Assessment of the PwD and their informal carer as a unit of care facilitated the delivery of a targeted service that combined forces to the benefit of both. Flexibility and consistency of home care hours provided through the project were its most important feature in tackling carer burden, especially via the provision of block hours as well as weekend and night services. Overall satisfaction with community care services provided to the family/informal carer increased considerably over the duration of the project.

The allocation of block hours in particular was valuable and reported by both service providers and families to be extremely important to the PwD and the informal carer as they allowed for meaningful engagement with the PwD while simultaneously providing carer respite. As the drivers of carer burden differ from person to person, it is important to tailor interventions to the individual which underlines the importance of flexibility in the provision of carer support (Springate and Tremont, 2014, Sutcliffe et al., 2015).

6.3 Impact on Service Providers

Reablement approach led to a broadening of community service provider roles to include detailed assessments for reablement by OTs and the delivery of related activities by home helps. The widening of their roles was generally welcomed by both groups, although some related challenges may require consideration. In general OT involvement in home care is short term and existing work processes do not permit retention on caseload over long periods, in spite of the progressive nature of dementia. This presented a potential barrier for OTs in continuing the ongoing evaluation and care planning anticipated in response to the evolving clinical scenario. The wider role was challenging for home helps in some instances as it differed significantly from the traditional focus on physical care (Mishra and Poulos, 2015) with some requirement for modification of normal work practice and upskilling among this group. The training provided for home helps as part of the project went some way to address this, but ongoing planning for core competencies and professional development among home helps will be required to sustain the service as envisaged in the project goals.



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A change in the culture of dementia care provision in the community towards person-centred, flexible and individualised care was also observed among other healthcare staff. The application form for home help support was substantively modified under the project and now includes a circle of contacts and supports, as well as a home and environmental assessment which prompt a different approach to care solutions. The form aids decision-making and acknowledges the unique interconnectedness between PwD and informal carer needs. It may have the potential to inform a relational care approach by considering all participants in the relationship with the PwD and focusing on their interactions (Morhardt and Spira, 2013). The modified home help application form is now the official HSE referral form in Co. Carlow/Kilkenny and evidence of embedding the changes in the provision of home support services for PwD in the area.

6.4 Maximising Use of Community Care Structures

The project's use of existing structures to support its work and ability to achieve its objectives included a consortium, the Carlow/Kilkenny Service Provider Forum, and the use of the long-term placement forum to provide a gatekeeper role. The work of the consortium centred on recognition of the multi-agency and multi-disciplinary nature of community-based dementia care and the importance of in-reach and out-reach elements to avoid unscheduled admissions to hospital or transfer to nursing home care. Stakeholders represented various sectors thus facilitating the channelling of existing community resources (O'Shea and Murphy, 2014, Keogh et al., 2016) allowing for the coordination of HSE resources with those from the community and voluntary sector to generate individualised supports that met multiple needs of participating PwD and their informal carers in line with the consortium model advocated by Genio (Genio, 2016). It had strong engagement from key stakeholders in the service provision for older people from the outset and was an important facilitator to project roll-out and buy in locally as no single organisation appears to have the knowledge, skills and resources necessary to comprehensively support PwD and their families (Genio, 2016).

The stability of the consortium and the engagement of its membership were central to Memory Matters' effectiveness and adoption by the service provider agencies at and to ensure an integrated approach by all concerned. Evidence of adoption at consortium level included support from senior HSE administrators for embedding supports in standard services. Levels of engagement varied, however, and adoption by some stakeholders appears to have been limited. There has been little GP engagement with the project which might reflect GPs' tendency towards a focus on clinical work within their surgeries rather than tending to patients in their own homes and a lack of compensation for non-clinical work (Department of Health, 2016, O'Kelly et al., 2016, Health Service Executive, 2008).

The project coordinator's detailed assessment of individual needs, including social needs, in collaboration with the PwD and the families/informal carer facilitated the delivery of individualised, person-centred and comprehensive care as well as flexibility in approach. The centrality of this role might indicate the benefits of a case coordinator approach to dementia care which addresses complex needs of patients in the community (van der Plas et al., 2013, Rich et al., 2012, Reilly et al., 2015, Somme et al., 2012, Francke et al., 2015, Van Durme et al., 2016), and has also been found to reduce the likelihood of institutionalisation (Trepel, 2015).

There was some confusion regarding channels of communication in the community. This impacted on the Memory Matters project with some reports of deficiency in communication by PHNs who initiated referral to the project, and



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also among the various personnel and families as to the status within the project. In the earlier stages, this had a bearing in terms of causing delay and uncertainty as to when PwD were actually initiated into the project and may have resulted in the disparate rates of participants' approval for the project across the two counties as there was reportedly less project information provided in Co. Carlow. This seems to have been a function of project set-up difficulties and has been largely addressed through the development of the Home Help Application Form and allocations group which meets weekly and helps smooth communication.

6.5 Training and Education

The project contained an ambitious plan for different levels of education. Six different training programmes reached a large number of service providers and some voluntary agencies depending on their need and contact with PwD. Project-specific Memory Matters training (Modules I and II) were attended by a large number of home support staff who are an important target group for an education programme due to their high level of contact with PwD. The project-specific training was a prerequisite for the delivery of reablement activities to those PwD included in the project, and home support staff received bespoke reablement training under the guidance of OT which led to their upskilling and can be transferred to PwD outside the project. It is important to bear in mind, however, that this required considerable OT input and might be difficult to sustain in view of current resources if the project were to be rolled out nationally. Furthermore, home care staff might require significant support to maintain reablement activities over time given the nature and progression of dementia. Nonetheless, reablement was positively reviewed by both staff and service users and the additional time devoted to person-centred activities was valued. Memory Matters-specific training ceased with the end of the project, although a range of training is available through the HSE national dementia training programme and the Dementia Elevator training.

The two day training 'Enhancing and Enabling the Wellbeing of the Person with Dementia' was mainly attended by nurses and home care attendants. This training is part of standard HSE training, and it is therefore difficult to establish how many would have attended the programme in the absence of the project. Moreover, agency staff who frequently delivered out-of-hours support were not part of the training initiative. However, Memory Matters was successful in raising awareness of the national programmes that are available and it is likely that attendance was increased during this time. In addition, additional training in responsive behaviours was also facilitated using existing resources, which ensured that attendees were updated to reflect changes in the National Dementia Programme. The training was positively evaluated, and there was some evidence from feedback that trainees applied the principles that they learned within their work practice.

In addition to the educational initiative, the Memory Matters media campaign had the potential to reach a large audience. Its precise impact is difficult to establish, however. The low number of likes on the Memory Matters Facebook page may indicate that Facebook might not be the appropriate medium for older people. It might also indicate that families/informal carers did not have sufficient time to access online information. Moreover, poor broadband services in the country side might hamper access, and awareness of the Facebook page may not have been widespread.

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6.6 Assistive Technology

Although many participants embraced the provision of assistive technology through the project, views overall were mixed which is in line with previous findings (Beech and Roberts, 2008, Cullen et al., 2016). As the technology was deployed without clinically assessed need by a healthcare professional and parallel to existing services, embedding in standard services as a result of the project might not be achieved. Due to project enrolment criteria, the need for technology supports was less because of loss of mobility in the later stages of dementia. Timeliness in the provision of technology supports is important given that dementia is a progressive condition and support needs change over time and hence the importance of different forms of technological support (Cullen et al., 2016).

6.7 Financial Cost

The economic analysis compared two cost calculations to the cost of nursing home care as this was the most likely alternative for the project participants; firstly a **cost from the societal perspective**, which includes HSE costs, all project costs, informal care, care purchased privately and personal consumption costs and **costs from the HSE perspective**, which includes all HSE costs and all project costs. The nursing home costs in the area were between €1,172 and €1,478. In both cost scenarios, the costs for supporting the person at home were lower, with an average cost of €1,137 using societal costs and an average cost of €607 using only HSE and project costs. Overall, home care cost less than nursing home care for the over 80% of participants. This finding of lower costs for home care is not unusual (O'Shea and Monaghan, 2016). The challenge is how to resource the additional level of home support in a resource constrained environment.

6.8 Key Learning from the Project

The learning from the project has the potential to inform the implementation of similar projects and support the drive for a change in the culture of dementia care provision on a wider level.

Box 8: Summary of Key Learning from the Project

- Provision of flexible home support hours was of the greatest benefit to families/informal carers in terms of support and relief of carer burden.
- Reablement allowed for engagement with the PwD beyond the emphasis on physical care to include meaningful activities and created the potential for enjoyment and contentment through recreation and social connectivity.
- Considering the PwD and the family/informal carer as the unit of care while taking their individual needs into account is a valuable approach to care provision.
- A philosophical shift towards reablement within the community care strategy can influence the nature and deployment of home care support hours so they are suitably tailored to PwD's individual needs.
- The consortium and its executive brought together perspectives from public, private and voluntary agencies involved in the provision of services for older people which are in a position to continue to drive cultural, policy and system change, and demonstrate the potential of an integrated care approach.



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- Existing resources were reconfigured and extended to provide the supports in this project. The use of existing resources and structures, including educational initiatives, within the healthcare system offers a beneficial mechanism for achieving changes in service delivery and cultural change from within the system.
- Targeted educational initiatives including bespoke training can assist in the reorientation of care towards reablement for PwD as well as opening up opportunities for further training as part of the National Dementia Programme
- Education and training initiatives which focus on reablement are important in the provision of dementia care and should be made available to health care staff especially those with high levels of patient contact.
- Increased dementia awareness created by projects such as Memory Matters can inspire dementia-related activities in the area, such as an assistive technology resource room, dementia-friendly garden and musical memory choirs.
- The project's objective to ensure that the PwD continued to live at home was achieved for two thirds of the active participants over the course of the project and participants and their families believed that the support from the project helped to keep them at home.
- The economic analysis shows that home care costs less than nursing home care, although the availability of informal care which is 'free of charge' must be taken into account. When the cost of informal care is included, the cost of living at home was less than nursing home care for over 80% of the participants.

6.9 Sustainability of the Project Activities

Innovations in dementia care require shared ownership and cross-sector participation to embed enhanced systems of working and communication in dementia care practice. The degree of engagement of consortium members lends support for the sustainability of the achievements by the Memory Matters project in terms of multi-agency and multi-disciplinary collaboration. The project has been a valuable example in bringing together stakeholders from the HSE, for-profit and not-for-profit agencies involved in dementia care, support and advocacy. This argues for greater awareness of and collaboration between agencies and services. It also raises the potential of developing a new role for the consortium in building on the learning from Memory Matters and working to implement the National Dementia Strategy (Department of Health, 2014) by shifting its focus towards embedding the spirit of Memory Matters in the HSE's oversight and management of home care and redirecting existing HSE resources to support alternative service delivery as developed by the project (Keogh et al., 2016).

There is a risk, however, that unless the shift towards more flexibility and individualised supports is embedded in standard service by the gatekeepers to the service, the supports for the PwD and families/informal carer remain focused on physical care with minimal scope for flexibility and individualised care planning. The roster for home helps that was introduced in Kilkenny will be rolled out across Counties Carlow and Kilkenny, and will create greater opportunity to rotate staff and cover and thus support the maintenance of flexible home help hours.

A concern in relation to the ongoing reach and sustainability of the project is the ability of the OT services to sustain the level of commitment to assessment since the dedicated additional hours available as a result of the project are no longer available and wait lists for OT services are now in operation which prioritise more acute needs, i.e. needs around safety and high physical care as per local guidelines. The national strategy towards fiscal restraint in community care also poses a challenge to the sustainability of OTs proposing the block allocation of hours to



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provide dementia-specific care at the individual level. Non-urgent referrals of PwD to OT might now have to wait a considerable length of time which can have a negative impact on the ability to engage with reablement and an important window of engagement might be closed as dementia is a progressive condition, and people with a high need for assistance on referral to reablement are likely not to benefit as much as those with lower support requirements (Francis et al., 2011).

One of the hallmarks of the Memory Matters project was the comprehensive approach taken to ensure training of home helps and others on the process of reablement at considerable indirect costs to the HSE in terms of staff release and training costs. Given the increased use of agency staff, it is uncertain if such training will be maintained as part of the service contracts. An important success of the project was the ability to work within current resources in the design and deployment of home care supports. However, the health service had already undergone severe cuts to its budget at the time of the project, and community care services were limited (Phelan and McCarthy, 2016, Irish Medical Organisation, 2014). These national issues highlight a potential conflict between the innovative response to the needs of PwD and their families and informal carers developed under the project, and the availability of resources which emerged during the second part of the project. Of concern are the size of the pool of home helps, the lack of recruitment of home helps within HSE and the reliance and indeed capacity of agencies to provide the supports being provided by the project. There may not be ongoing suitable home helps for the project to provide reablement supports, and the post project services may not be able to provide the flexibility that families/informal carers have highlighted as a particular need.

The availability of home care services and the extent to which they allow for flexibility and individualisation is dependent on national policy. In early 2016, for example, spending on home help hours and HCPs increased under the Winter Initiative Plan in order to free up beds in hospitals as emergency departments were under severe pressure. The resulting overspend was balanced later in the year through a reduction in spending on community care services. This appeared to be a cutback in the availability of home care support while offsetting the earlier overspend but nevertheless directly impacted upon the availability of home care services during the latter part of the year (Alzheimer Society of Ireland, 2013). The yearly increase in the older population alone is putting increased pressure on a healthcare system that is already strained (Care Alliance Ireland, 2016). The embargo on recruitment in the health service has been lifted since the end of the project, and the recruitment of seventy home helps in the HSE for the Carlow/Kilkenny area has been approved. However, projects such as Memory Matters require a visible commitment to the ongoing availability of supports for PwD and families/informal carers as envisaged by the project. This provides impetus for a whole systems approach and underlines the fact that the care for PwD cannot be removed from systemic considerations. Economically, it appears to be cost effective to maintain PwD at home (Trepel, 2015). This was true for most of the participating PwD even when the informal carer cost was added to the equation.

The HSE has given a commitment to the implementation of the Irish National Dementia Strategy (Health Service Executive, 2014). The strategy identifies a number of key principles to underpin the health and social care services provided to PwD, their families and informal carers which include an integrated, population-based approach to dementia service provision, and the tailoring of services to deliver the best possible outcomes for PwD, their families and informal carers (Department of Health, 2014). The Memory Matters project team developed and tested a flexible, person-centred approach to dementia care in line with the objectives of the Irish National Dementia Strategy (Department of Health, 2014). In order to consider the sustainability of the project, national policy developments in the community service sector need to be taken into account. The following national policy and service developments are currently under way and have particular relevance to health and social care delivery for older persons:

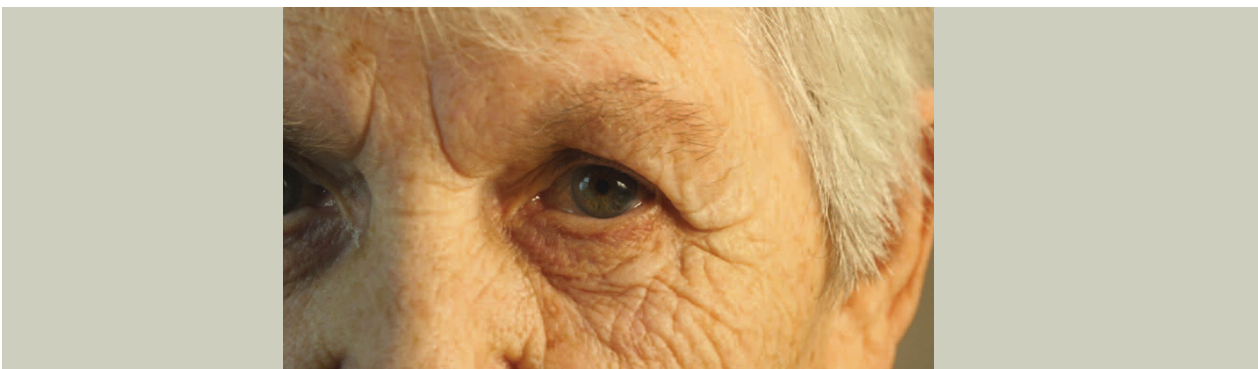
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- National Clinical Programme for Older People (Health Service Executive, 2013) which aims to support integrated care for older people and to support older people to live at home in the community
- The HSE National Service Plan (Health Service Executive, 2014, Health Service Executive, 2015b, Health Service Executive, 2016c) which outlines a focus on integrated person-centred care for older people with complex needs.
- Integrated care programme for older persons (Health Service Executive, 2015a)
- The Single Assessment Tool for Services for Older People (Health Service Executive, 2015c)

Increasing awareness of the importance of primary and continuing care and a departure from overreliance on tertiary care may bode well for future developments in the area of community care provision. However, the sustainability of projects such as Memory Matters will be reliant on a commitment on a national level to the continued provision of related resources.

Box 9: Summary of Project Sustainability

- The project consortium has the potential to build on the learning from the project and work towards the implementation of the National Dementia Strategy (Department of Health 2014) by focusing on embedding the project's spirit in the health service's oversight through its adoption of a person-centred, individualised approach to dementia care.
- National resource restraints may impact upon the reablement approach to care as well as service delivery as there is risk focus could shift back to physical care. There might be missed opportunities for reablement as dementia is a progressive condition, and interventions might come later than where they can be most effective.
- The continued provision of individualised supports might be jeopardised by a lack of home helps to provide reablement and flexibility in the provision of support.
- Projects such as Memory Matters are influenced by national developments in the provision of care in the community and require a visible commitment to the ongoing availability of supports.



14 The aim of the HSE's Winter Initiative Plan, is to adopt specific measures required to address the anticipated surge in activity and service demand during the winter months. This includes reducing the numbers of people waiting to be discharged from hospitals and who require specific supports and pathways to do so.



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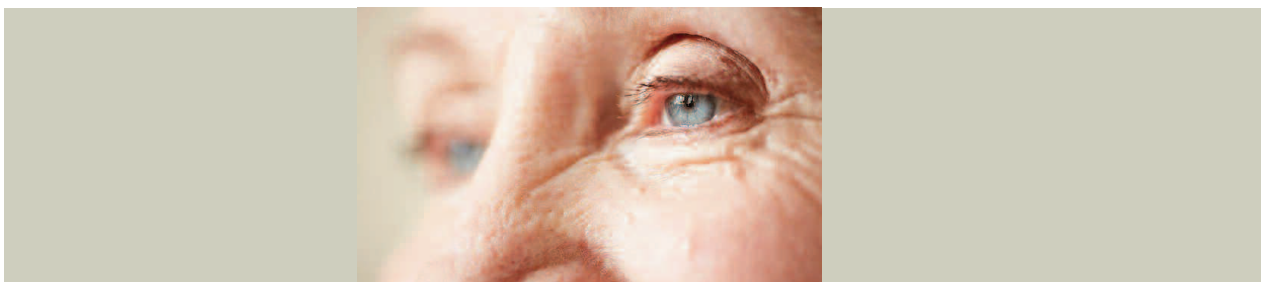
6.10 Conclusion & Recommendations

The Memory Matters project aimed to bring about innovation in the approach to the provision of home care services for PwD and families/informal carers working from existing resources, and this was achieved. Project participants reported great benefits of the flexible, individualised, person-centred approach to care that takes into consideration the families/informal carer's needs, and most were of the opinion that the PwD would not still be at home without the services. The economic analysis revealed that keeping the PwD at home was cost-effective for most participants even when informal care was included in the costing. The educational initiative brought about greater dementia awareness among the workforce, many of whom were upskilled through dementia-specific training, including reablement. Structures and systems need to be changed constantly, however, as the healthcare system is evolving. The sustainability of projects such as Memory Matters is dependent upon developments on national level. Recent developments in the area of service provision for older people, including PwD, appear promising but are contingent upon a commitment to provide the required resources.

Based on the learning from the Memory Matters, the following recommendations are made for the provision of care for PwD and their families/informal carers in the community (Box 10):

Box 10: Recommendations for Enhancing Dementia Care

- An individualised, person-centred, flexible and responsive approach to dementia care is recommended to improve the quality of care for PwD and families.
- A personalised approach to the care of PwD can be beneficial at any stage of dementia
- Working from within existing structures and resources, such as the Carlow/Kilkenny Service Provider Forum and HSE resources, is useful for project setup, implementation and sustainability.
- Considering the PwD and the family/informal carer as a unit of care, taking account of individual needs and preferences of both, and including the person, family/informal carer in care decisions is important for the delivery of a targeted service.
- Flexibility in the provision of community care services, especially regarding weekend and night services and block hours of care, should be considered to meet the needs of PwD and their families and informal carers, and support the PwD to remain at home.
- A reablement approach to the care of PwD that supports the maintenance of ability can be beneficial at any stage of dementia.





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Appendices

Appendix 1: Memory Matters Consortium and Subgroup Members

Table A1a: Service Providers Forum Members

Name	Organisation/ Role	Memberships
Patricia McEvoy, Interim Chair	Manager Older Persons Services - HSE	Chair of Forum Chair of Executive Consortium Chair of Training Sub Group Member of Carlow & Kilkenny Age Friendly County Alliances Member of Local Placement Forum
Teresa Hennessy	Senior Health Promotion Officer - HSE	Secretary of Forum Member of both Carlow & Kilkenny Age Friendly Alliances
Nickey Brennan	Kilkenny Age Friendly County Alliance	Chair of Kilkenny Alliance
Joan Doogue	Manager St. Fiacc's House, Carlow	Ordinary Member
Marian Manning	St. Lazarian's, Carlow	Ordinary Member
Anne Shorthall	Bagenalstown Family Resource Centre	Ordinary Member
Karl Duffy	Social Inclusion Manager, CCDP	Member of Carlow Age Friendly County Alliance Ordinary Member
Eilis Geraghty	Director of Nursing, Sacred Heart Hospital, Carlow HSE	Ordinary Member Member of Local Placement Forum
Edel Keogh	Senior Com Dev Worker- St Catherine's, Carlow	Ordinary Member Member of Carlow Age Friendly County Alliance
Claire Power	Manager Mt. Carmel Rep Supported Care Unit	Ordinary Member
Moirá Duggan	Kilkenny Leader Partnership	Ordinary Member Member of Kilkenny Age Friendly Alliance
Dr Mia McLaughlin	Consultant Old Age Psychiatrist	Ordinary Member Member of Local Placement Forum
Eleanor Doyle	Carlow/Kilkenny Contact	Ordinary Member Member of Carlow Age Friendly Alliance
Catherine O'Keeffe	HSE- Manager Occupational Therapy	Ordinary Member
Paula Brophy	Home Care Package Manager - HSE	Ordinary Member Member of Training Sub Group Member of Local Placement Forum



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Name	Organisation/ Role	Memberships
Dr Emer Ahern	Consultant Geriatrician, HSE Carlow & Kilkenny	Ordinary Member Member of Kilkenny Age Friendly County Alliance Member of Local Placement Forum
Margaret Moore	Carlow Co. Council	Ordinary Member Member of Carlow Age Friendly County Alliance
Stephen Murphy Catriona Bambrick	Fr. McGrath Centre, Kilkenny Senior Planner Kilkenny County Council	Ordinary Member Ordinary Member Member of Kilkenny Age Friendly County Alliance
Debra O'Neill	Genio Project Consultant	Ordinary Member Member of Kilkenny Age Friendly County Alliance Member of Training Sub Group
Bea Flavin Caroline Clifford	Kilkenny Age Friendly Seniors Forum Clinical Nurse Specialist Psychiatry of Old Age – HSE Carlow & Kilkenny	Ordinary Member Ordinary Member Member of Training Sub Group
Carmel Moran Aidan Fitzpatrick	Family Carers Ireland Carlow & Kilkenny Carlow Community Garda	Ordinary Member Ordinary Member Member Carlow Age Friendly County Alliance
Josephine Galway	Director of Nursing – St Columba's Thomastown	Ordinary Member Member of Local Placement Forum
Agnes Noud Noreen Barry	Manager Carlow Day Centre OT Dept. of Psychiatry of Later Life	Ordinary Member Ordinary Member Member of Training Sub Group
Shane Winters	Age Friendly Ireland	Ordinary Member Member of Kilkenny & Carlow Age Friendly Alliances
John Coonan Joe Butler Paul Maher	Kilkenny Age Friendly Seniors Forum Carlow Older Peoples Forum Carlow Older Peoples Forum	Ordinary Members Ordinary Member Ordinary Member



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Table A1b: Membership of the Consortium Executive

Name	Position
Patricia McEvoy	Chair of Consortium Executive/ HSE Manager of Services for Older People
Pat Grogan	Regional Manager Carer's Association
Waiting for replacement for Kate Brennan	Regional Manager of Alzheimer's Association
Nicky Brennan	Chairman of KAF and representative of AFC locally
Carer	Member of Executive of Older People's Forum, members of Service Providers Forum
Debra O' Neill	Project Consultant/Coordinator

Table A1c: Project Training Subgroup Members (O'Neill, 2016)

Name	Position
Noreen Barry	Occupational Therapist, Psychiatry of later Life/Dementia Champion/Trainer
Mairead Brophy	Occupational Therapy Manager, PCCC, HSE
Paula Brophy	Home Care Package Manager / Trainer
Caroline Clifford	CNS , Psychiatry of Later Life / Dementia Champion/Trainer
Majella Cunningham	Assistant Director of Public Health Nursing, HSE
Patricia McEvoy	Project Lead, Manager Older Person's Services, HSE
Debra O' Neill	Project Consultant, LinkAge Consultancy

Appendix 2: Memory Matters Referral Details

Referrals to the Memory Matters project during the active recruitment phase (Phase 1) followed the pathway shown in Figure A2. For phase 1, the Local Placement Forum was chosen as the deciding body on potential participants' inclusion in the project, as the Local Placement Forum is in charge of decisions regarding eligibility for the nursing home support scheme which was one of the inclusion criteria for the project (this inclusion criterion was relaxed during the course of the project). Potential participants who were referred to the project but declined for inclusion by the Local Placement Forum, mainly due to insufficient information, were redirected to other services, such as memory clinics or LTC, or referred back to the Primary Care Team (PCT) or GP as appropriate to their care needs. Some of those declined in phase 1 were later referred for home care support during phase 2 and followed the post Memory Matters pathway which tested the new referral pathway that is now in use for home help service applications (Figure 14). These referrals are considered to be embedded in the standard system and therefore not included in the numbers for the project evaluation.

EVALUATION OF THE MEMORY MATTERS CARLOW/KILKENNY COMMUNITY DEMENTIA PROJECT

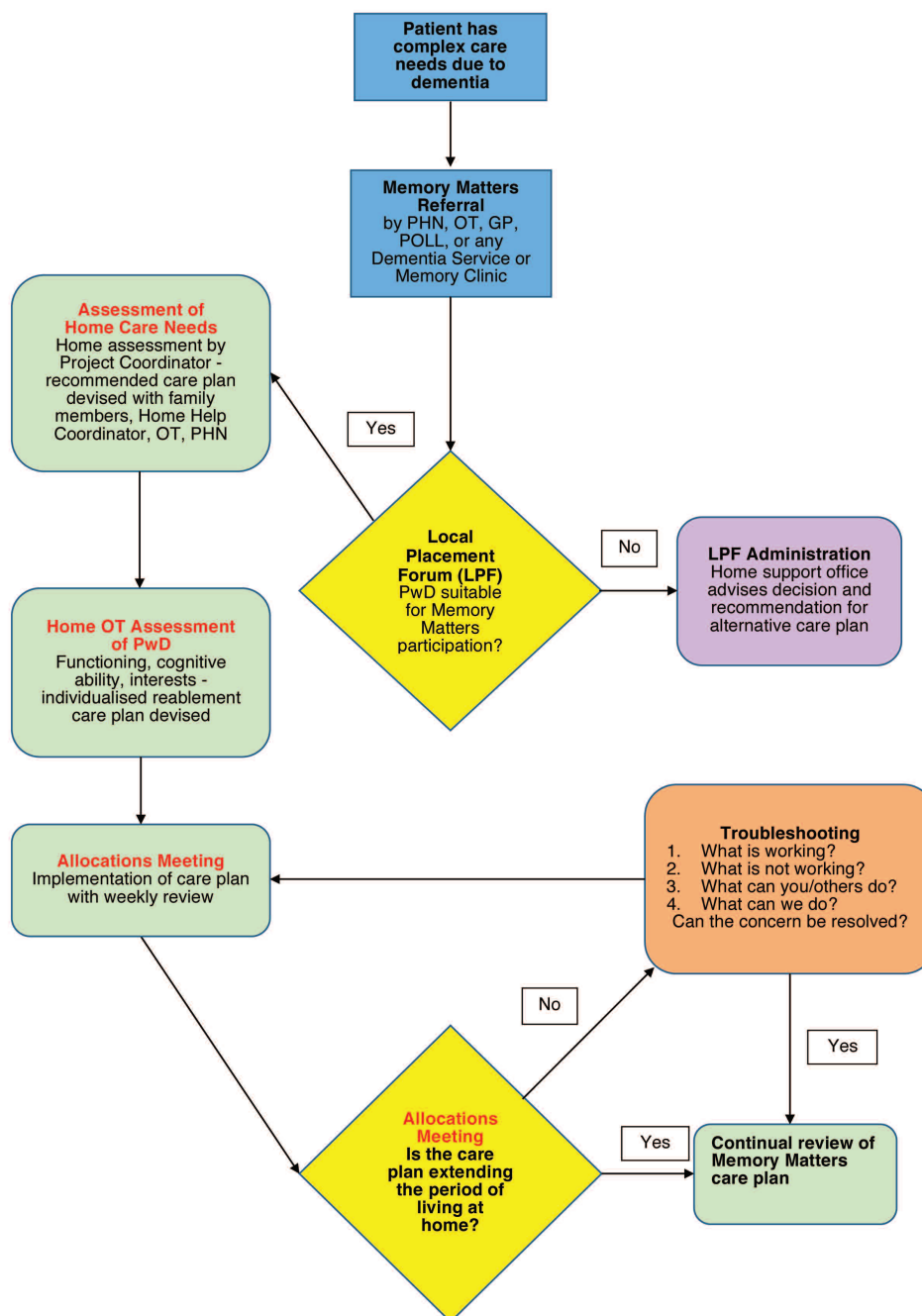


Figure A2a. Memory Matters Project Referral Pathway (Phase 1)

EVALUATION OF THE MEMORY MATTERS CARLOW/KILKENNY COMMUNITY DEMENTIA PROJECT

The Memory Matters Care Champion Referral Form (see separate methodology reference document) was distributed to Public Health Nurses (PHNs), Registered General Nurses (RGNs), Primary Care Teams (PCTs), memory clinics, OT services and Psychiatry of Later Life (POLL) and information about the project disseminated to facilitate referrals to the project. Once a requirement for a needs assessment was identified, the referrer completed the Memory Matters Care Champion Referral Form and submitted it to the Memory Matters project coordinator. Data collected by the project team revealed that most referrals (86.8%; 99/114) were from PHNs/RGNs. Other referring healthcare professionals included OTs, POLL, and community mental health nurses.

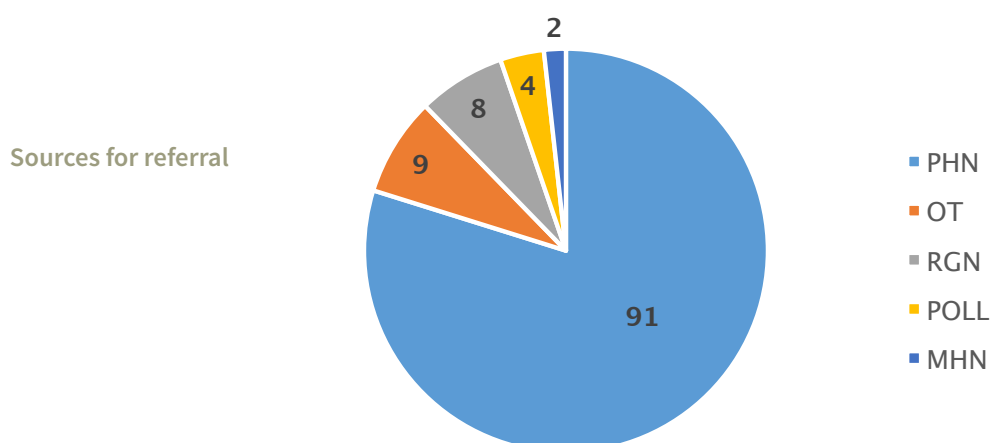


Figure A2b. Healthcare Professionals' Referrals to Memory Matters

Local Placement Forum

The referral was subsequently presented to the Local Placement Forum. The Local Placement Forum is a multi-disciplinary senior clinical team consisting among others of PHNs, old-age psychiatrists, geriatricians, HCP managers, and the Director of Nursing (see 1). It is an existing HSE structure which meets fortnightly to review nursing home applications and expanded its role for the duration of phase 1 to review suitability for participation in the Memory Matters project.

Inclusion criteria

In order to be eligible for inclusion in the Memory Matters project, in addition to a diagnosis of dementia and being over 65 years of age, a minimum of one of the following three criteria had to be met (see Appendix 6):

- The presence of comorbidities
- The PwD exhibiting responsive behaviours
- The PwD and the informal carer requiring complex care support

This project specifically targeted individuals at an advanced stage of dementia and therefore the potential participant also had to be eligible for the Nursing Homes Support Scheme¹⁵ (Fair Deal) and willing to participate in

¹⁵ The Nursing Homes Support Scheme (Fair Deal Scheme) is a scheme of financial support for people who need long-term nursing home care.

EVALUATION OF THE MEMORY MATTERS CARLOW/KILKENNY COMMUNITY DEMENTIA PROJECT

Allocations Meeting

The allocations meeting is an existing HSE structure that meets weekly to review all Home Help Services Applications and approve and plan HCPs/services for older persons in the community. The team consists of home help coordinators, the HCP manager and is chaired by the Assistant Director of Public Health Nursing. The role of the team members is to review the assessed care needs of a person in the community and plan the implementation of home care. The decision as to the nature and extent of the HCP to be deployed is made within this forum and will take cognisance of the feasibility and availability of resources with a view to maintaining the person at home. The allocation and nature of home care hours is under continuous review through the allocation committee in conjunction with the PHN service until such time as the person is discharged from community care services due to transfer to long-term residential care.

Appendix 3: Referrals to the Project and Enrolments by Area

Figure A3a.
Number of Referrals by Townland

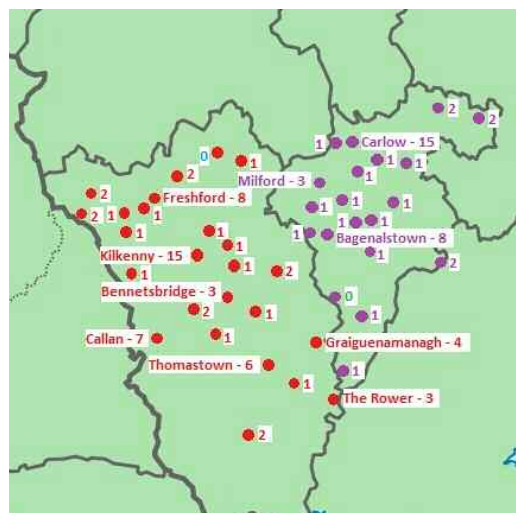
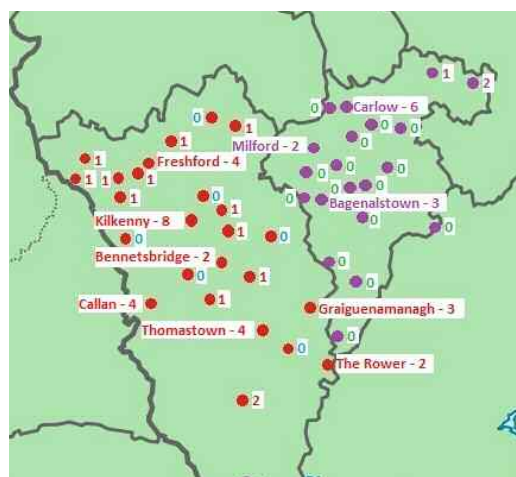


Figure A3b.
Number of Enrolments by Townland





EVALUATION OF THE MEMORY MATTERS CARLOW/KILKENNY COMMUNITY DEMENTIA PROJECT

Appendix 4: Project Coordinator Function

Narrative on Project Coordinator Function

Once a participant was approved at the local placement forum, the project coordinator carried out a home visit to work collaboratively with family and the PwD to build a picture of the person's and family needs. Meeting both parties in the person's home allowed the coordinator to gain greater understanding of the person and their past and present interests, their preferred routine, and what would help them.

Observation of the person's environment provided potential clues to areas of interest, such as family pictures and household chores. These clues prompted discussion to ascertain what was important to the person, and what their needs were. Engagement with family members and the PwD established what services were in place and how they were meeting the needs of the PwD and their family. Any additional needs and proposed solutions were discussed and a plan was developed that encompassed supports that were purposeful and supportive of the PwD whilst also meeting the needs of the carer. The project coordinator then referred to necessary areas such as OT, home care services, day care, voluntary services and assistive technology to implement the various elements of the plan of care that was agreed.





EVALUATION OF THE MEMORY MATTERS CARLOW/KILKENNY COMMUNITY DEMENTIA PROJECT

Appendix 5: Project Outcome: Guideline for Night Services

Home Help Department
Carlow/Kilkenny
Clinical HH Car/KK 001

Guidelines for Night Time Service for Persons with Dementia

It's important to remember that:

Dementia can cause changes in the behaviour of friends and loved ones. Such changes are very common, but they can place enormous stress on families and carers. Understanding why someone is behaving in a particular way may help families and carers to cope.

There are many reasons why a person's behaviour may change. Dementia is a result of physical changes in the brain, and these can affect the person's memory, mood and behaviour. Sometimes, behaviour may be related to these changes, but at other times, the behaviour may be triggered by changes in the person's environment, health or medication.

Understanding the cause will help you to decide which strategies may be helpful. Some carers find that keeping a log or diary helps them to see a pattern of behaviour that may be developing, and this helps them to identify the cause of the changes.

Due to the increasing demand for night time service and the increased costs associated with the provision of this service the service should be used as short term measure only (1 Month) to relieve carer's stress/ crisis or for assessment/ medication review.

Then the service must be reviewed by the MDT to establish how carers can be supported in a more sustainable manner for the long-term. The service may continue / reduce or other alternatives are considered.



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1. Direct Care(HSE) subject to the National Sleepover night rate
2. Indirect Care – Hourly Night Rates(22.00-08.00) as per 2016 Tender Prices (for office use only to ensure agency confidentiality)
 - Bluebird
 - Home Instead
 - Carer's Association
 - Clannad Care
 - Allied Therapeutic Homecare
 - Irish Wheelchair Association

Please note the 2 agencies listed below were not successful in the 2016 Tender and can only be used by HSE if the 6 agencies listed above can't facilitate the HSE request.

1. ASI
2. Comforter Keepers

To ensure that we are targeting the service to those most in need

The following points should be considered in all cases:

Medically

- What is the clinical presentation? i.e. night disturbances , responsive behaviours
- Is this a new behaviour?
- Has the person been referred to GP / Psychiatry of later life team for an assessment?
- What interventions have been prescribed?

Discussion with Carer and Person with Dementia to ascertain their needs

- Consider adjusting the existing service taking into consideration Day care and all other service in the community that are been provided to maximise the support provided
- Maximising Day care during the day could allow for the carer to be transferred to other times in the day
- Maximising family support – i.e. supporting rotas within the family – other siblings/children.

Environment

The environment of the person with dementia can cause sleeping problems in a number of ways including:

- The bedroom may be too hot or too cold.
- Poor lighting may cause the person to become disoriented.
- The person may not be able to find the bathroom.
- Changes in the environment, such as moving to a new home or having to be hospitalised, can cause disorientation and confusion.
- Has the Primary care team been involved e.g. OT / PHN / GP /Physio
- Has modifications been made to the bedroom living area as per best practice

Changes in the day time Routine may improve night sleeping pattern

- Increase activities / exercise
- Diet
- Reduce caffeine late in evening



EVALUATION OF THE MEMORY MATTERS CARLOW/KILKENNY COMMUNITY DEMENTIA PROJECT

Appendix 6: Project Outcome: New Home Help Application Form

Patients Name.....Address.....DOB.....

Carlow /Kilkenny Home Help Service Application



Full Name				Date of Birth	
Address				Medical Card Number	
Contact Number				GP Name	
Living Alone	With Spouse Only	With Family		GP Phone Number	
				Total No in Household	

Main Contact Person

Name				Relationship	
Key Contact Number(s)					
Do they reside in area?				Distance from applicant	
Next of Kin (if applicable)				Contact Number Next of Kin	

Current Services & Supports in Place

Services	Yes/No	Hrs/Day	Mon	Tues	Wed	Thur	Fri	Sat	Sun
Meals on Wheels									
Day Care									
Residential Respite									
Memory Clinic									
Geriatric Clinic									
Psychiatry of Later Life									
Kilkenny Carlow Contact									
Additional Home Help Hours :									
Carers Association									
Alzheimer's Assoc.									
Home Care Team									
Centre for Indep. Living									
Private Agency									
Wheelchair Assoc									
Other									

Home & Environment Assessment (Significant home, social, security or care needs which should be considered)
(examples: Isolated rural area, /access issues, steps / clutter or hoarding/ fire hazards / excessive pets/animals)

Difficulties experienced by Patient /Service User:

Difficulties experience by Carer:



EVALUATION OF THE MEMORY MATTERS CARLOW/KILKENNY COMMUNITY DEMENTIA PROJECT

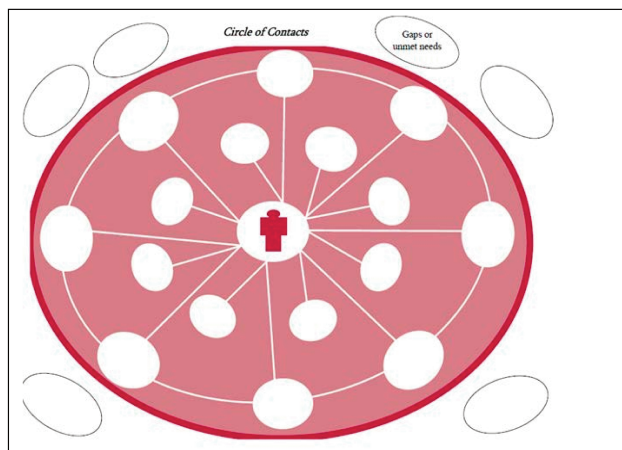
Appendix 6: Project Outcome: New Home Help Application Form

Patients Name.....Address.....DOB.....

Does client have a balanced circle of contact to support independent living in the community?
Indicate if support and contact is daily, weekly, monthly and what needs are unmet in your option.

Support & Contact Prompts

Family
Grandchildren
Neighbours /Friends
Daycare
Day Hospital
Meals on Meals Staff
Home Help
Nurse
Primary Care Team
Private Carers
Social Club / Hobby
Sports / Leisure
Church
Befriending Service
Telecare Support
Shopping/ Outdoors
Care & Repair Service
Telephone / Computer



Barthel Assessment:

Weighting Score	3	2	1	0	Score
Bowel		Continent	Occasional accident	Incontinent	
Bladder (preceding 24h)		Continent	Occasional Accident	Incontinent (catherised & unable to manage)	
Grooming			Independent	Needs Help	
Toilet Use		Independent	Needs some help	Dependent	
Feeding		Independent	Needs some help	Unable	
Transfer -from bed to chair and back	Independent	Minimal help needed	Major help(1-2 person) needed	Unable- no sitting balance	
Mobility	Independent	Walks with help of one person	Wheelchair independent	Immobile	
Dressing		Independent buttons, zips, and laces	Needs help, but can do half unaided	Unable	
Stairs		Independent up and down (may carry walking aid)	Needs help (verbal or physical carrying of aid)	Unable	
Bathing			Independent (getting in/out & washing self)	Dependent	
				Total Score	

Past Medical History	

History of Falls ☐ Responsive Behaviour ☐ Change in pattern Of behaviour ☐ MTS Score ☐



EVALUATION OF THE MEMORY MATTERS CARLOW/KILKENNY COMMUNITY DEMENTIA PROJECT

Appendix 6: Project Outcome: New Home Help Application Form

Patients Name.....Address.....DOB.....

Services & Supports Required:

Multidisciplinary Services:

Date of OT Referral (as standard)		Report attached	Yes		No	
Date of SLT Referral (if applicable)		Report attached	Yes		No	
Date of Psychiatry of Later Life referral request		Referring GP				
Date of Geriatric Clinic referral request		Referring GP				
Date of Memory Clinic referral request		Referring GP				

Aids & Devices required: (please tick. D = dementia specific support)

Profiling Bed		Other		Property Exit Sensor (D)	
Pressure Mattress		Standard Monitored Personal alarm		Monitored Automatic Fall Detector (D)	
Walking Aid		Monitored Smoke/Carbon Detector		Bed Occupancy Sensor Alert (D)	

Home Help Care and Reablement Plan						Mon	Tues	Wed	Thur	Fri	Sat	Sun
Washing/Showering												
AM		PM		Night								
Time:		Time:		Time:								
Getting client in/out of bed & dressing												
AM		PM		Night								
Time:		Time:		Time:								
Empty catheter bag / commode												
AM		PM		Night								
Time:		Time:		Time:								
Supervision of medication												
AM		PM		Night								
Time:		Time:		Time:								
Prepare/Serve Food												
AM		PM		Night								
Time:		Time:		Time:								
Fire/Ash/Fuel												
AM		PM		Night								
Time:		Time:		Time:								
Collect Meals (MOW or Private)												
AM		PM		Night								
Time:		Time:		Time:								
Support Physical Activity												
AM		PM		Night								
Time:		Time:		Time:								
Support Reablement Activity												
AM		PM		Night								
Time:		Time:		Time:								

Expected duration of Service	Review Date
Name Public Health Nurse	Area
Health Centre	
Signature	Date



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Appendix 6: Project Outcome: New Home Help Application Form

Patients Name.....Address.....DOB.....

All applicants have the right to self determination and capacity to do so it assumed unless otherwise proven. The applicant's preferences in receiving care to remain living at home must be sought and recorded here.

Has the persons care support preference been discussed with him/her? Yes ☐ No ☐
If No- provide a reason and identify with whom it has been discussed and outline

General Criteria

Living With	Age	Hospitalisation	Mobility	Continence
Alone	3 75+	4	Walking Stick	1 Urinary
Spouse /Older	70-74	3	Wheelchair	2 Faecal
Relative	65-69	2	Bed Bound	3 Urinary & Faecal
Family	1 -65	1		
Barthel Score	MTS	Medical Condition	Total Client score	
Less than 10	3 1-3	3 Palliative Care with Hospice	2	
11-15	2 4-6	2 Palliative Care	1	
16-18	1 7-9	1 Chronic illness	1	
18-20	0 9-10	0 Psych illness	1	
		Dementia	1	
			Priority 18-24	
			Wait Listed 13-17	
			No Service <-12	

Office Use Only

Priority		Service Required		Refused	
Category					
Older Person Services		Mental Health		Physical/Sensory Disability	
Intellectual Disability		Palliative Care		Other	

Services	Total Weekly Hours Approved	Date Services Commended	Review Date	
Home Help				
Double Home Help				
Name of Home Help				
Extra Comments/ Decision Rational				
Allocations Meeting Date				
Signed		Position	Date	
Signed		Position	Date	



EVALUATION OF THE MEMORY MATTERS CARLOW/KILKENNY COMMUNITY DEMENTIA PROJECT

Appendix 7: Project Outcome: Memory Matters Information Leaflets


Freshford- Urlingford Area Dementia Friendly Community

Are you caring for someone living with dementia or are you worried about your own memory? Could you do with some support or advice? There are a number of services and supports available to you in the Freshford/ Urlingford area.

Day Care Services

There are a number of Day Care Services in the area and some provide transport to and from their centre. As well as providing respite to carers, Day Care provides clients with meals, activities and a chance to socialise. Your Public Health Nurse or GP can refer you or contact the centre directly.

The Alzheimer Society
provide a dementia specific Day Care




services include games, exercise to music, dinner, sports and personal care and reflexology. Family Care Support Group, first Wednesday of each month, 4pm to 5.30pm. Alzheimer's Café for people living with dementia. Contact Ruth on 056 7771230 for information

Prague House: Freshford. Provides day care on Monday and Wednesday afternoon. Activities include bingo, music and exercise. Transport is available. Contact Sr. Bridget on 056-88322841.

Meals On Wheels are also provided by the centre Mon-Saturday for a nominal charge contact Sr. Bridget.

Mill Family Resource Centre, Urlingford
Provide a Care & Repaire service in the area manned by local volunteer handypersons who can complete small household tasks and repairs for older people. Contact Sue 056 - 8838466.

Freshford - Urlingford Dementia Friendly Community



Kilkenny & Carlow Contact

A Befriending and Support Organisation for Older People living alone. Befriending provides companionship for you or your loved one who may be feeling isolated or lonely. Contact Eleanor Doyle Coordinator Kilkenny Contact at 056-7751988 Ext 6 or Mobile 086-8530994.

Your local **Public Health Nurse** can offer support and advice about your care and the services that are available in your area and can be contacted at your local Health Centre:

Freshford Health Centre
(056-8832661- Opening Hours: Mon - Fri 9-12pm & 2-4pm)

Urlingford Health Centre
(056- 8831306 Opening Hours: Mon - Fri 9-10.30am)



You can also speak to your GP who can refer you to the local Memory Clinic

D.R.E.A.M. (Dementia Research Education Advocacy in Motion) is a national non profit /charitable movement run by people with Dementia for people with Dementia.


This peer to peer support group is for people with early stage dementia and meet the 1st and 2nd Friday of each month in St Patrick's Parish Centre, Loughboy, Kilkenny City from 11-1pm. Contact Joan on 087 9042967 for more information.

If you need advice, support or someone to talk to contact one of the National Helpline Numbers:

Alzheimer Society Helpline	1800 341 341
Senior Help Line	1850 440 444
Samaritans	1850 609 060
AWARE	1890 303 302
Carers Association Careline	1800 240 724

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive





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