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## Evaluation of the Memory Matters Carlow/Kilkenny Community Dementia Project

### Key Findings

HSE & GENIO DEMENTIA PROGRAMME





## EVALUATION OF THE MEMORY MATTERS PROJECT

### Introduction

Memory Matters was one of a number of community projects funded by the Health Service Executive (HSE) and the Genio Dementia Programme (Genio 2015). The project 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.

**Reablement** aims 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)

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 (PwD) 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.

Trinity College Dublin and the National University of Ireland, Galway were commissioned to evaluate this two year project (2014-2016) and its four components:

### Evaluation Aims & Approach

Flexible, Person-Centered Home Care Supports

Assistive Technology

Awareness and Education

Reablement

An exploratory mixed method involving both quantitative and qualitative approaches 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 assessed project activity in terms of reach, effectiveness, adoption, implementation and maintenance.

#### Some facts about dementia in counties Carlow/Kilkenny:

- Approximately 1,057 people live with dementia in Co. Kilkenny and a further 543 people in Co. Carlow (Pierce et al. 2014).
- About 63% of these live in the community.
- The number of people with dementia living in the community is expected to double in the next 20 years in view of Ireland's ageing population (Pierce et al. 2014)



## EVALUATION OF THE MEMORY MATTERS PROJECT

The evaluation examined the project's processes as well as its outcomes, looking at three key aspects:

**Experience of dementia care  
- perspectives of service  
users and service providers**



**Comparison of the cost of  
'service as usual' to the cost  
of new approaches**



**Impact of the  
educational  
initiatives**



- 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 re-directed 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.

### 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.

### 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 €1478 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.

### 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.





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### 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 dementia-friendly services and facilities available for people with dementia in the Carlow/Kilkenny area that exceeded what the project set out to achieve.

### Patricia and Gary's Story

Patricia is a 91 year old lady 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 package 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 reminiscence. 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.





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### 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 public health nurse 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 occupational therapist.

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.



### 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 (OT) 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 suitable qualified manpower led to tension between assessed need for home care and availability of services, particularly around suitable supply of home helps.
- Occupational therapists were operating under resource constraints prior to and during the project.
- 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, persons with dementia with complex needs referred by the Public Health Nurses will be prioritised according to clinical need. Those with mild to moderate dementia will be identified for OT assessment through memory clinics.
- At the time of the project, there were concerns at national level regarding the availability of 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 HSE to recruit home helps has been given since.







## EVALUATION OF THE MEMORY MATTERS PROJECT

### 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 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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