

ENHANCED HOME SUPPORT SERVICES FOR PEOPLE LIVING WITH DEMENTIA

Date: 6th May 2021

Time: 14.15pm – 15.30pm

Introduction: Ms Kathleen Jordan, General Manager, Office of the Head of Operations, Services for Older People

Presenter: Ms Anne Quinn, Dementia Nurse Specialist, Living Well with Dementia

Host: Sinead O'Reilly, National Dementia Office

We will be with you shortly.

ENHANCED HOME SUPPORT SERVICES FOR PEOPLE LIVING WITH DEMENTIA

May 2021

Introduction

- The National Office - Services for Older People & National Dementia Office (NDO) have collaborated on an enhanced model of service delivery for home support clients with mild cognitive impairment or dementia.
- This Webinar will provide an overview of proposed changes.
- Questions can be submitted via the Q&A facility which will be addressed following the webinar and a FAQ document will be circulated to participants.
- We would ask that microphones are muted for the duration of the webinar.

Background

- Proposed changes to home support services aligns with Government Policy i.e. supporting people to live at home
- Research shows this is the preferred choice of people (Donnelly et al, 2016).
- Adopting a 'home first' approach 5 million additional home support hours will be provided in 2021, over and above the National Service Plan 2020 target.

Background

- Includes 230,000 hours to be provided in conjunction with the roll-out of a pilot home support scheme which will be undertaken in tandem with the enhancement of the older person service model, bringing the total quantum of home support to 24.26m hours in 2021.
- A minimum of 5% of the additional 2021 hours will be provided for people living with dementia.

Criteria

- (1) The person has a diagnosis of dementia or mild cognitive impairment
- (2) The person lives in the community
- (3) The person requires support at home
- (4) The family members are unable or are having difficulty providing care.

Background

- Current model of home support provision is heavily weighted towards personal care, which has been shown to disadvantage people living with dementia and family caregivers.
- Compelling evidence for resourcing provision of personalised psychosocial supports across the trajectory of dementia, including the personalised supports of lower intensity demonstrated by the HSE/Genio projects.

Background

- Evidence enhanced home care for people with dementia is:
 - Feasible for hospital discharge and admission avoidance;
 - Cost effective for most;
 - Responsive – potential to reach large numbers of people particularly at an earlier stage;
 - Able to provide demonstrable quality of life and subjective wellbeing gains for the person with dementia and family caregiver.

(Howard et al, 2019; Cullen & Keogh, 2018; O'Shea & Monaghan, 2016; O'Shea & Monaghan, 2015).

Impact of Covid-19

- Difficulties experienced by people with dementia and family caregivers exacerbated during the Covid-19 pandemic as formal day care and respite services suspended with evidence of:
 - Increased isolation;
 - Increase/Exacerbation of symptoms of dementia, including non-cognitive symptoms such as agitation, anxiety, apathy etc;
 - Additional burden on family carers and increased stress.
- We have looked at how best to respond to issues arising for people with dementia/family carers in the context of COVID but are relevant beyond this.



To look at ways we can enhance delivery of home supports we have worked together (*NDO & Services Older People Office*) and consulted with stakeholders working in services for older people services and NGOs/ Voluntary Agencies

Case for Enhanced Supports

- Approximately 64,142 people are living with dementia in Ireland (HSE Health Atlas, 2020).
- Estimated 19,742 - 35,736 people living with dementia in the community (6,000-10,000 living alone - Pierce et al, 2019).
- A study undertaken in 2016 in Dublin North Central found a high prevalence of dementia (37.1%) and CI (8.7%) amongst HCP users (O'Brien et al, 2019).

Case for Enhanced Supports

- Dementia affects a person emotionally/psychologically, socially, physically and cognitively.
- Frontline staff reporting that the current system which prioritises physical aspects of disability is negatively impacting people with dementia:

Quote

“I can see they are struggling but they don’t have physical care needs, they won’t get home support unless, I say they have a physical need – it forces you into a corner....”

Case for Enhanced Supports

- Main bulk of care provided by family
- Caring for the person with dementia poses a major risk for caregiver burden due to its progressive nature and long duration (Connors et al, 2019; ASI, 2017).
- Learning from the HSE/Genio-supported dementia specific initiatives (2011 – 2018)

It is not a new model



THIS IS NOT NEW

Rather, the focus is on **enhancing what is already in place**, by incorporating a more flexible, holistic approach that better accommodates the complex and changing needs of people living with dementia and family carers.

Enhanced Dementia Supports

- This is achieved by addressing both the person's personal or functional needs (ADL's) as well as their psychosocial needs.
- Psychosocial interventions can improve cognitive abilities, enhance emotional well-being and reduce behavioural symptoms by:
 - supporting ability e.g. practical strategies, cues, prompts, graded assistance;
 - supporting participation in meaningful activities e.g. interests & hobbies, tasks & chores, reminiscence;
 - supporting social engagement e.g. connection with community.

(Dickinson et al, 2017; Cullen & Keogh, 2018).

Key Elements Include:

- A sliding scale of intervention which includes personal/functional supports as well as psychosocial interventions;
- This allows for earlier intervention that scales up over-time or ends when the person is integrated into other community supports.
- Flexibility to allocate hours more suited to the person's needs and preference e.g. block hours, weekend hours, overnight.

Sliding Scale - three levels.

Level 1

- Aims to promote self-management by supporting the person to maximise/maintain abilities.
- Has little personal care requirements.
- Main focus is on supporting social engagement e.g. connecting the person and integrating them into existing community activities and supports.
- May require assistance i.e. cues and prompts with medication management and support with planning and organising e.g. around shopping, cooking, chores etc.
- Individuals at this level may need allocation of block hours i.e. (2-3 hours 1-2 times a week.
- Can be time limited e.g. where person has been supported to access other services e.g. day care, Men's Shed etc.
- Or, ongoing where continuous low intensity still required.

May also benefit from referral/signposting to other services such as cognitive therapies, memory technology resource rooms/assistive devices, peer support and client/carer psycho-education programmes.

Level 2

- In addition to level 1 requirements the person may need assistance with some ADL's such as bathing, dressing, toileting etc.
- Additionally, support may be required in the presence of non-cognitive symptoms of dementia and carer burden.
- May need support every day.

May also benefit from referral or signposting to other community support services, cognitive therapies, peer support, memory technology resource rooms/assistive devices, and family carer support programs and respite.

Level 3

- The person has a high level of personal care needs.
- They require support with all ADLs, including physical, emotional and social needs – may need support of more than one HCSA a few times per day.
- Support may also be required in the presence of non-cognitive symptoms of dementia and carer burden.

May also benefit from referral or signposting to other community support services, memory technology resource rooms/assistive devices, and family carer respite.

Assessment of Need

- InterRai will in the future replace the CSARS as the primary means of assessing the health and social care needs of people looking for support under the Home Support Services scheme.
- Supporting documentation has been developed that can be used alongside InterRai or CSARS in order **to support** assessment and delivery of dementia home supports i.e. **doesn't replace existing documentation or application processes.**

Supporting Documentation

1. Dementia Home Support Service Guidance Document –to help inform a personalised approach responsive to the diverse needs of people with MCI or dementia. Includes summary versions. For example:
 - i. Dementia Home Support Service Guidance Notes (Short Version) – to ensure relevant information is captured with regard to support needs of person with MCI or dementia.
 - ii. Dementia Home Support Service Guidance Notes (Long Version) – which can be completed and submitted as a means of supporting an application for home supports for a person with MCI or dementia;
 - iii. Schedule of Services Form – can be used to outline support response.

Supporting Documentation



Dementia Home Support Service Guidance Notes Form A

These guidance notes have been developed to support assessment and delivery of Dementia Home Supports and can be used alongside the InterRAI Assessment or Common Summary Assessment Report (CSAR). Where applicable this form can be submitted as supporting documentation when making an application for home support.
(The InterRAI Assessment will in the future replace the CSARs as the primary means of assessing the health and social care needs of people looking for support under the Home Support Services scheme).

Dementia Home Supports aim to maximise functional ability, promote independence and improve quality of life by providing graded levels of assistance to people living with dementia.

Eligibility Criteria for Dementia Home Supports:
The client (1) has a diagnosis of dementia or mild cognitive impairment (2) lives in the community (3) requires support at home (4) family members are unable or are having difficulty providing care.


Assessment for dementia home supports should be completed with the person and family member/care rep (where appropriate).

Name:	DOB:
Address:	Date:

Primary Care:	Contact No.:
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1.1 Dementia affects an individual physically, cognitively, psychologically and socially. Using these classifications the list below can be used alongside the InterRAI Assessment or CSARS to help identify the support needs of the person living with dementia.

CLASSIFICATION	SUPPORT NEED	Unmet Needs Please ✓
PHYSICAL SUPPORT NEEDS Staying Healthy	<ul style="list-style-type: none"> Nutritional Support: assisting/preparing/cooking food & drink; assisting/supervision with eating & drinking Engaging in healthy behaviours: managing health conditions, exercise Personal Care/Hygiene: assistance to wash/shower/bathe, dressing & undressing, continence care and any other additional personal care requirements Maintaining Safety: assistance with mobilising and using aids, maintaining a safe environment Managing Essential Household Tasks: assistance with essential tasks and chores 	
COGNITIVE SUPPORT NEEDS Supporting Cognition Maintaining Ability Understanding & Planning	<ul style="list-style-type: none"> Provision of Prompts/Queues/Reminders: to initiate and complete an action e.g. prompting medication or preparing a meal Planning and Organising the day/week & implementing practical strategies e.g. keeping a diary, using checklists/whiteboard, planning meals Maintaining Ability: support with personal care, cooking, shopping, tasks/chores Managing bills & money Planning ahead i.e. EPA / Wills / Driving / ACP 	
PSYCHOLOGICAL SUPPORT NEEDS Supporting Emotional Wellbeing	<ul style="list-style-type: none"> Understanding diagnosis and how to live well with dementia - confidence building Participation in meaningful activities i.e. interests/hobbies / roles Minimising impact of mood and behavioural changes / non cognitive symptoms dementia 	
SOCIAL SUPPORT NEEDS Staying Connected	<ul style="list-style-type: none"> Staying/Becoming Involved in community activities e.g. clubs/groups/organisations Continued involvement with friends/peers Being able to access local shop/church/library/memory cafe etc. 	

Dementia Home Support Service Guidance Notes Form B

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COGNITIVE SUPPORT NEEDS Supporting Cognition Maintaining Ability Understanding & Planning	<ul style="list-style-type: none"> Provision of Prompts/Queues/Reminders: to initiate and complete an action e.g. prompting medication or preparing a meal Planning and Organising the day/week & implementing practical strategies e.g. keeping a diary, using checklists/whiteboard, planning meals Maintaining Ability: support with personal care, cooking, shopping, tasks/chores Managing bills & money Planning ahead i.e. EPA / Wills / Driving / ACP
PSYCHOLOGICAL SUPPORT NEEDS Supporting Emotional Wellbeing	<ul style="list-style-type: none"> Understanding diagnosis and how to live well with dementia - confidence building Participation in meaningful activities i.e. interests/hobbies / roles Minimising impact of mood and behavioural changes / non cognitive symptoms dementia
SOCIAL SUPPORT NEEDS Staying Connected	<ul style="list-style-type: none"> Staying/Becoming Involved in community activities e.g. clubs/groups/organisations Continued involvement with friends/peers Being able to access local shop/church/library/memory cafe etc.



Supporting Documentation

4.0 SCHEDULE OF SERVICES; DESCRIBE CARE & SUPPORT RESPONSE			
Client Name:		DOB:	Date:
CARE & SUPPORT NETWORK Who from the person's Care and Support network will meet the person's support needs? (Please ✓)			
<input type="checkbox"/> FAMILY		<input type="checkbox"/> WIDER SOCIAL NETWORK	<input type="checkbox"/> LOCAL COMMUNITY GROUPS & ORGANISATIONS
Please complete the following section where a support gap still exists.			
	HEALTH & SOCIAL SERVICES What is the care and support response required?	FREQUENCY	TIME
PHYSICAL SUPPORT NEEDS			
COGNITIVE SUPPORT NEEDS			
PSYCHOLOGICAL SUPPORT NEEDS			
SOCIAL SUPPORT NEEDS			
CARERS SUPPORT NEEDS			
No of home support hours already in place (HSE):		Review date:	
No of additional hours requested (HSE):		Signed:	
TOTAL:			

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Case Example 1

- Mary, 76 years old diagnosed with Alzheimer's disease 2 years ago.
- Lives alone, her only daughter lives in the UK.
- Pharmacist rang GP concerned to say she wasn't picking up her medications on the right day.
- PHN called (first visit) and found:
 - Mary wasn't taking her medications properly because she wasn't collecting them from the pharmacy on time.
 - Out of date food in the fridge.
 - Mary having issues with urge incontinence and wasn't getting out to the shops as much as usual as she was afraid of 'an accident'.
 - Mary was still able to wash and dress herself but the PHN noted Mary appeared unkempt.
 - House was dusty and untidy.
- Mary admitted to being lonely and feeling anxious and afraid but refused to attend day care saying she never liked mixing in groups.
- Adamant she wanted to be able to do things for herself but had lost all confidence.

Likelihood of Adverse Event

- Assistance with personal care might not be available as Mary still able to wash & dress herself (*lack of motivation was the primary problem*).
- Likelihood she could refuse assistance with personal care even if it was offered (*many people with dementia will refuse support if they feel it interferes with their independence*).
- If support is seen as enabling and providing assistance with other issues of concern – more likely to be accepted.
- If other issues not attended to – risk to health if not taking meds, risk of infection, malnutrition, depression.
- Failure to provide support or refusal of support at this stage can lead to faster deterioration, loss of ability and potential crisis.

Enhanced Support Response

A blister pack for meds, appropriate incontinence wear and meals on wheels were organised.

Apart from Mary's physical care needs, as part of a personalised response it was also possible to address Marys psychological and social needs by allocating a HCSA for 2 hours twice a week to support Mary:

- by prompting/assisting with showering and personal care;
- to check what shopping was needed and accompany her to the local shop;
- to pick up her medications from the pharmacy on time;
- to prompt and assist Mary to complete chores and tasks in the house;
- to engage in activities of interest i.e. walking, visiting the local library.

The support provided was acceptable to Mary because it promoted her independence by adopting an enabling approach that maximised her ability, fostered her confidence and helped reduce her anxiety levels.

Case Example 2

The screenshot shows a digital interface for a case study. On the left, there is a profile card for Patrick Conway. It features a photo of an elderly man, a paperclip icon, and a teal header labeled 'About'. Below the header, it lists his name as 'Patrick Conway'. The main text on the card describes him as an 80-year-old retired carpenter living with his wife Mary, who is also 80. It mentions they have been married for nearly 60 years and have four sons, two of whom live locally. To the right of the profile card is a larger text area with two paragraphs. The first paragraph states that Mary has been Patrick's main carer since his diagnosis with Alzheimer's disease 4 years ago, but she has recently experienced health issues of her own and is struggling to cope. The second paragraph notes that their sons try to provide as much support as they can but work by day and are not always available. At the bottom of this text area, there is a hand icon with three dots above it, followed by the text 'Select each tab to learn more.' On the right side of the interface, there are three vertical tabs: 'About' (teal), 'Notes' (purple), and 'Supports' (red). A close button (an 'X' in a circle) is located in the top right corner of the interface.

About

Name:
Patrick Conway

Patrick, a retired carpenter, is 80 years old and lives with his wife Mary who is also 80.

They have been married for nearly 60 years and have 4 sons, two of whom live locally.

Mary has been Patrick's main carer since he was diagnosed with Alzheimer's disease 4 years ago but she has recently experienced some health issues of her own and is struggling to cope.

Their sons try to provide as much support as they can but work by day and are not always available.

Select each tab to learn more.

About
Notes
Supports

Taken from new HseLand Module

Enhanced Support Response

Issues identified:

- **Concentration & Memory:** Difficulty remembering recent events and completing certain tasks leading to increased irritability.
- **Planning & Organising:** Difficulty initiating actions, decreased motivation with tendency to sit in front of TV all day –now starting to get up in the middle of the night.
- **Personal Care:** Difficulty dressing unless clothes laid out for him, needs prompting to shower and shave.
- **Social interaction:** Has lost interest in usual activities e.g. going for a walk, meeting friends, gardening, DIY.
- **Carer Burden:** Patrick's wife feeling very anxious, tired and struggling to cope.

Goal: To build on Patrick's strengths and abilities and support him to take part in activities that are meaningful to him. Also to provide a break for his carer.

Response: Two hours twice a week to assist with showering, support participation in activities of interest e.g. going for a walk or gardening and providing a break for his wife.

To conclude

Enhanced Dementia Home Supports provide a personalised flexible approach to care that meets people's personal care and psychosocial needs, taking into account the non-cognitive symptoms of dementia.

It is not a new service, this approach builds on current services already in place but provides the scope and flexibility for a broader more holistic range of supports to people living with dementia.

Supporting Implementation

The supporting documentation has been developed as a resource to support clinicians currently involved in assessing and developing support plans for people living with dementia.

A short online module has been developed for Health Care Support Assistants working either directly for the HSE or for staff of approved home support providers that explains how Enhanced Home Supports can help meet the needs of people living with dementia. The programme is available now www.hseland.ie



Seirbhís Sláinte
Níos Fearr
& Forbairt

Building a
Better Health
Service

Dementia Enhanced Home Supports

A Personalised Approach

Let's begin

Module last reviewed: 26/11/2020



**Thank you for your
participation**