Rev. 2.0 - April 2021

Dementia Home Support Service

Guidance Document

dementia understand together

Building a Better Health Service | Seirbhís Sláinte Níos Fearr á Forbairt

Dementia Home Support Service Summary Form Guidance

1.0 INTRODUCTION

Dementia affects a person emotionally and socially as well as physically and cognitively. How these individual but interlinked elements are supported will impact on how well the person will be able to live with dementia and the quality of life that they may have. As dementia progresses individuals will require support incrementally. In the early stages people will require information, advice and support to maintain skills and confidence as well as connections with friends and community. Over time the person's ability to manage daily activities without help will decrease and they will eventually need constant supervision and help with all aspects of personal care and activities of daily living.

The current model of Home Care provision is heavily geared toward rating physical aspects of disability. This can disproportionally impact people living with dementia who may be well capable of getting up and dressed each day but may have difficulties with other aspects of everyday life as a result of impairment with their cognition. Many clinicians in recognising this anomaly find themselves in the difficult position where a client does not meet the criteria for home supports but who they recognise will, without the necessary support face the risk of more rapid progression of their dementia and possible slide toward early crisis.

In order to respond to the growing and increasing need around the provision of care in the home, an enhanced system of support has been developed, one that centres on the personalised needs of the person living with dementia as well as providing needed respite for family carers.

DEMENTIA HOME SUPPORTS

Evidence has shown that providing low levels of service/number of hours per week can improve quality of life for the person with dementia and their family carer and help maintain them at home for longer (Cullen & Keogh, 2018). Dementia home supports differ from 'in home day care' as they target the individual's personal and/or functional needs (ADLs) as well as their psychosocial needs. They focus positively on what people can do, given appropriate support, and on the possibilities for living well with dementia. Dementia home supports are proactive and targeted as described below:

What 'enhanced' supports are!

- Supports are goal orientated in response to identified needs.
- Focuses on physical and psychosocial needs.
- Supports ability i.e. enabling the person with dementia to function at his/her optimal level and maintain as much independence as possible in everyday activities. For example, supporting the individual's continued participation in meaningful activities such as household tasks, chores and hobbies.
- Aims to enhance resilience and emotional wellbeing by promoting community connection and social interaction.
- While supports are centred on the needs of individual's living with dementia in the first instance, an additional benefit is the respite provided for carers.

2.0 ELIGIBILITY CRITERIA FOR DEMENTIA HOME SUPPORT SERVICE

This service is aimed at people living with dementia in the community. The criteria for receipt of the service is as follows:

Figure 1: Eligibility Criteria

Criteria to access service	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.

3.0 PURPOSE

The assessment of need for both health and social needs is currently ascertained by completing the interRAI Assessment or Common Summary Assessment Form (CSARs), although in line with government policy the interRAI Assessment will in the future replace the CSARs. This guidance document has been developed to support assessment and delivery of dementia home supports. A user friendly version that can be used alongside the interRAI Assessment or CSARs when completing an assessment has also been developed i.e.

i. Dementia Home Support Service Guidance Notes (Form B) - can be used as a guide when assessing the support needs of individuals living with dementia (Appendix 1) or;

ii. Dementia Home Support Service Guidance Notes (Form A) - apart from helping to highlight the person's support needs Form A can be submitted where applicable as supporting documentation when making an application for home support services (Appendix 2).

4.0 SCOPE

This document applies to all healthcare staff undertaking a care needs assessment on behalf of clients requiring home support service.

5.0 PERSONALISED CARE & SUPPORT PLAN

A personalised care plan is designed with the person with dementia and their primary carer and aims to give choice and control to the person receiving care. It focuses on the will and preferences of the person and acknowledges that the person is best placed to know what they need and how those needs can be met. In line with the Assisted Decision Making (Capacity) Act 2015, capacity to make decisions is assumed unless shown otherwise, in which case any decisions made should be in line with the person's previously expressed wishes.

The starting point for a personalised care and support response is with the person with dementia, their needs and preferences and what is acceptable to them. It will include the person's natural support network in the first instance comprising friends and family, then local organisations/services and finally formal health and social care supports to fill identified gaps. There is a focus on early intervention which may reduce a need for more costly interventions later in response to crisis.

6.0 DEMENTIA HOME SUPPORT SERVICE GUIDANCE NOTES

The Guidance notes can be used alongside the interRAI Assessment or CSARs as a means of highlighting the support needs of individuals living with dementia and to inform development of a personalised care and support plan/schedule of services.

The person's support needs can be classified under Physical, Cognitive, Psychological and Social Needs (see figure 2). The greatest contributor to 'unmet need' for people with dementia is due to an emphasis on the provision of physical care at the expense of supporting psychological and social needs which may often be the most pressing needs initially (Hansen et al, 2017). This approach risks an earlier loss of independence for the person than would have been the case had they received appropriate help when needed. This is often referred to as 'premature disablement' something which people with dementia are particularly vulnerable to.

Focusing solely on physical care at the expense of the person's social and psychological needs can lead to a cascade of problems e.g. social withdrawal, loneliness, depression, behavioural changes, sleep disturbance. Additionally, unmet psychosocial needs can lead to reduced physical health; for instance, an unfulfilled need for social contact could lead to low mood, reduced appetite and malnutrition. Identification of need must therefore involve taking a broader approach concentrating on all aspects of a person's life and is the key to avoiding or reducing the risk of adverse events that can lead to crises resulting in hospitalisation and premature admission for long term care.

Figure 2: Classification

PHYSICAL Staying Healthy	Physical health, personal care, physical environment
COGNITIVE Supporting Cognition Maintaining Ability, Understanding & Planning	Thinking, remembering, understanding information, decision making, communicating, planning and organising, initiating and completing tasks
PSYCHOLOGICAL Supporting Emotional Wellbeing	Mental health, emotions, coping skills, self-esteem, confidence, behaviour
SOCIAL Staying Connected	Interactions with family, friends & community, relationships, cultural influences, beliefs

The 4 domains includes subheadings based on work currently being undertaken by the National Dementia Office on the developing 'Dementia Model of Care'.

Figure 3: DOMAINS

	SUPPORT NEED
PHYSICAL Staying Healthy	Dementia over time will impact on the person's ability to maintain adequate nutrition (i.e. forgetting to eat, poor food storage, shopping & cooking becomes more difficult), personal hygiene (i.e. forgetting, refusing or unable to wash, wearing soiled clothes, incontinence) health (i.e. forgetting or mixing up medication, forgetting appointments, not looking after existing health conditions such as diabetes) and safety (decreased ability to coordinate and interpret the home environment). Graded levels of assistance in response to emerging needs can offset crises and help maintain the person at home for longer.
COGNITIVE Supporting Cognition Maintaining Ability, Understanding & Planning	Focus positively on what people can do, given appropriate support i.e. help to overcome the practical difficulties that living with a cognitive impairment or dementia creates - includes prompts, reminders, practical strategies, graded assistance. People with dementia also have the right to make decisions about their care, so it is important that they are given relevant information and advice as needed and the opportunity to plan and record their wishes for the future while they still have the capacity.
PSYCHOLOGICAL Supporting Emotional Wellbeing	Mental health and wellbeing is as important as physical health and wellbeing for people living with dementia. Emotional distress and depression can be mitigated by increasing opportunities to engage in pleasurable interests and activities. Additionally, positive behaviour support based on understanding behaviour as an expression of need or distress can help to address non cognitive symptoms of dementia (verbal/physical outbursts, agitation, paranoia, delusions, hallucinations).
SOCIAL Staying Connected	Lack of social engagement is associated with loneliness, depression and faster cognitive deterioration. Support to maintain connection with family, friends and established community networks can improve quality of life and can also bring a stabilising and normalising experience to the person's life.

6.0 PROCEDURE: USING THE GUIDANCE NOTES

The Guidance Notes can be used alongside the interRAI Assessment or CSARs when assessing the care needs of people looking for dementia home supports. The focus is not centred solely on physical care but on all the aspects of a person's life where the person might need support. For example:

1.1: Support needs: are classified as Physical, Cognitive, Psychological and Social. To support the assessor a description of the type of supports that may be required are listed (middle column). This list can be used to help guide identification of the person's 'unmet needs' - if using Form A, please tick the column on the right hand side where appropriate.

1.2: What are the person's most pressing needs? Asking about the person's most pressing needs provides an opportunity for the person with dementia (and carer where appropriate) to express their needs in their own words i.e.

> Exploring all aspects of the person's life, ask what would help them that isn't already in place, to live as well as they can. The aim is to establish how important it is to the person, and what this tells us about the support they need. *For example, the person may want to prepare their own dinner but is unable because they are having difficulty planning meals and doing the shopping.*

1.3: Why are those needs not currently being met? Ask about any specific barriers or difficulties that exist i.e.

> Explore what challenges or concerns exist for the person with dementia and the family member/carer *i.e. the family may not be available to support the person during the day as they are working.*

1.4: How might those needs be met and by who? Part of the assessor's role involves supporting the individual and family/carer to think about who/what can help best meet their needs in a way that is acceptable to them. Look at the person's care and support network starting first with naturally occurring supports. For example:

- What are family members able to do, and want to do?
- Ask about the person's wider social network e.g. neighbours, friends and work or leisure colleagues. Discuss if they could be involved in supporting the person e.g. could a neighbour or friend help with shopping or offer to collect the person when going to church.
- Discuss what ordinary existing groups, organisations and services in the community are of interest to the person and can support them e.g. local shops, post office, sports/leisure groups.

1.5: Refer/Signpost to appropriate supports or services: Discuss what voluntary and community services are available that might meet the person's needs e.g. ASI, Support Groups, Men's Sheds, Meals on Wheels. Having a knowledge of local services/supports will help this process. However, it is acknowledged that clinicians cannot have knowledge of all available community activities and services. The option of referral to a dementia advisor (or other dementia specific support service) should also be discussed with regard to signposting.

2.0: Carer's Support Needs: Family carers play an important role in supporting people with dementia to continue living at home. Carers of people with dementia are known to suffer higher rates of caregiver burden than other carers (Connors et al, 2019; Pinquart and Srensen, 2003). Not being sure of what level of help the person needs (uncertain what to do or feels person looking for more help than is required), competing demands of other responsibilities (work and child rearing), nature of premorbid relationship (may have been strained prior to diagnosis) and feelings of depression, grief and isolation can lead to carer burnout. Signs of carer stress and burden include:

- Feeling lonely, isolated and overwhelmed
- Feeling constantly worried
- Sleep disturbance
- Feeling tired and run down
- Feeling sad or tearful
- Irritability, feelings of anger and overreacting to small issues
- New or worsening health complaints

Ask if the carer is having difficulty coping, or if their caregiving role is negatively impacting their physical and/or mental health. Consider the likelihood of the carer experiencing carer burden/ burnout if present circumstances remain unchanged. Discuss what would best support them in their caregiving role e.g. an allocation of 4 home care hours per week might best be delivered as block hours (i.e. 2 hours twice a week) rather than 45 minutes five days a week.

Various caregiver burden assessment tools e.g. The Zarit Burden Interview (Zarit et al, 1980) or the COPE Index (McKee et al, 2003) are available if additional information is required.

3.0: Care and Support Response/Level of Support Required: Finally, consider what health and social care services need to be involved with regard to the remaining gaps in support needs that exist for the person? 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. They provide greater flexibility to respond to changing and intensifying needs over time, by applying a sliding scale response. There are three levels of support as shown below (figure 4). In collaboration with the person living with dementia and carer (where appropriate) discuss how the care and response might be delivered.

Note: If using Form A please complete the relevant sections. May be submitted as supporting documentation when making an application for dementia home supports.

Figure 4: Three Levels of Support

LEVEL OF SUPPORT	SLIDING SCALE	PROFILE OF SUPPORT (including personal and psychosocial care and support)
1	Individuals at this level may need allocation of block hours (i.e. 2-3 hours) once or twice a week.	The primary focus of this level of support is 'goal-focused' in order to promote self-management by supporting the person to maximise/maintain abilities. The person has little personal care requirements but they may require assistance with medication management and support around shopping, cooking, chores etc. An essential element of this level of support is the promotion of social interaction and engagement e.g. connecting the person and integrating them into existing community activities and supports. In some cases it is possible to discontinue the service when the goal has been achieved e.g. renewed confidence in managing Activities of Daily Living following a diagnosis of dementia (which adversely affected the person's self-confidence) or when the client has started attending day care services or other community services such as Men's Sheds or other groups. The person may also benefit from cognitive therapies, assistive devices, peer support and both the person and care-partner may benefit from psycho-education programmes.
2	Individuals at this level may need assistance every day.	In addition to level 1 requirements the person may need assistance with some ADLs such as bathing, dressing, toileting etc. Additionally, support may be required in the presence of non-cognitive symptoms of dementia and carer burden. They may also benefit from community support services, cognitive therapies, peer support, assistive devices, and family carer support programs and respite.
3	Individuals at this level may need assistance a number of times a day and may require the assistance of more than one healthcare support assistant.	The person has a high level of personnel care needs. They require support with all ADLs, including physical, emotional and social needs. As above, support may also be required in the presence of non-cognitive symptoms of dementia and carer burden. They may also benefit from community support services, assistive devices, and family carer respite.

4.0: Schedule of Services: The purpose of the Guidance Notes is to help identify the support needs of the person with dementia. The 'Schedule of Services' (Appendix 3) can be used where applicable to outline how the support response will be delivered.

- Tick to indicate who from the person's care and support network (family, wider social network, local community groups & organisations) can meet any 'unmet need' where identified.
- Outline proposed support response from Health & Social Care Services where a gap in support exists e.g. *Level 1 support might involve the HCSA visiting the client twice weekly to support meal planning/preparation and support social engagement by helping the person access the library or church if that is their stated preference.*
- Document how often the support is to be provided i.e. frequency per day/week and for how long i.e. time/number of hours. *Allocation of block hours has the added advantage of providing a break for the family carer (where appropriate).*
- Document the:
  - Number of home support hours already in place if any (HSE)
  - Number of additional home support hours requested (HSE)

Appendix 1: Dementia Home Support Service Guidance Notes Form B

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 (CSARs).

(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 is 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).

1.1 Dementia affects an individual physically, cognitively, psychologically and socially. Using these classifications the list below can be 1. used alongside the interRAI Assessment or CSARS to help identify the support needs of the person living with dementia.

CLASSIFICATION	SUPPORT NEED
PHYSICAL SUPPORT NEEDS Staying Healthy	■ Nutritional Support: assisting/preparing/cooking food and drink; assisting/supervision with eating and 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	■ Provision of Prompts/Cues/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	■ 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	■ 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 café etc.

1.2 What are the person's most pressing needs - discuss what type of support would help them to maximise ability and live as independently as possible i.e. what is important to them (in their own words).

1.3 Discuss why those needs are not currently being met - i.e. any specific difficulties/ barriers.

1.4 Discuss how those needs can be met and by whom? - include the person's natural support network comprising in the first instance of family, then their wider social network i.e. friends/ neighbours/ colleagues and local community.

1.5 Refer or signpost as appropriate to the following supports or services:

COMMUNITY SERVICES

- Meals on Wheels
- Day Care
- Other

LOCAL GROUPS/ ORGANISATIONS

- Befriending
- Volunteer Service
- Men's Sheds
- Leisure/Social Group
- Resource Group
- Other

DEMENTIA SUPPORTS

- Dementia Specialist/Advisor
- Memory Resource Room
- Cognitive Rehabilitation
- Psychoeducation Programme
- Cognitive Stimulation Group
- Memory Cafe
- Alzheimer Society of Ireland
- Family Carers Ireland
- Peer Support Group
- Advocacy Services
- Other

2.0 Discuss the carer's support needs i.e.

- Is the carer having difficulty coping?
- Is caregiving having a negative impact on their physical health
- Is caregiving having a negative impact on their mental health & wellbeing
- What is the likelihood of the carer experiencing burnout if present circumstances remain unchanged
- What would support them in their caregiving role?

3.0 CARE & SUPPORT RESPONSE (Health & Social Care)

Consider the remaining gaps in support needs that exist for the person

Explore what level of support may be required

☐ LEVEL 1	☐ LEVEL 2	☐ LEVEL 3
The person requires support to improve or maintain existing ability. The aim is to promote self-management. Main focus is on supporting social engagement but may need prompts/support with medication management and other tasks.	In addition to level 1, the person requires assistance with personal care i.e. bathing, dressing, and toileting. May also require support in the presence of non-cognitive symptoms of dementia.	The person has a high level of personal care needs. They require help with all ADLs including physical, emotional and social needs. May also require support in the presence of non-cognitive symptoms of dementia.

Appendix 2: 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 (CSARs). 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 is 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 Carer:	Contact No.:

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		**Unmet Needs**
CLASSIFICATION	**SUPPORT NEED**	**Please ✓**
PHYSICAL SUPPORT NEEDS Staying Healthy	■ 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	■ Provision of Prompts/Cues/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	■ 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	■ 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 café etc.	

1.2 List the person's most pressing needs - discuss what type of support would help them to maximise ability and live as independently as possible i.e. what is important to them (in their own words).

1.3 Why are those needs not currently being met - i.e. list any specific difficulties/ barriers.

1.4 How might those needs be met and by whom? - include the person's natural support network comprising in the first instance of family, then their wider social network i.e. friends/neighbours/colleagues/local community

1.5 Refer/Signpost to the following supports or services: Please ✓

COMMUNITY SERVICES

- Meals on Wheels
- Day Care
- Other

☐ Other (describe)

LOCAL GROUPS/ ORGANISATIONS

- Befriending
- Volunteer Service
- Men's Sheds
- Leisure/Social Group
- Resource Group
- Other

☐ Other (describe)

DEMENTIA SUPPORTS

- Dementia Specialist/Advisor
- Memory Resource Room
- Cognitive Rehabilitation
- Psychoeducation Programme
- Cognitive Stimulation Group
- Memory Cafe
- Alzheimer Society of Ireland
- Family Carers Ireland
- Peer Support Group
- Advocacy Services

☐ Other (describe)

2.0 Carer's support needs: Please ✓

- Is the carer having difficulty coping?
- Is caregiving having a negative impact on their physical health?
- Is caregiving having a negative impact on their mental health & wellbeing?
- What is the likelihood of the carer experiencing burnout if present circumstances remain unchanged?
- What would support them in their caregiving role?

3.0 CARE & SUPPORT RESPONSE (Health & Social Care)

Consider the remaining gaps in support needs that exist for the person

Explore what level of support may be required

☐ LEVEL 1	☐ LEVEL 2	☐ LEVEL 3
The person requires support to improve or maintain existing ability. The aim is to promote self-management. Main focus is on supporting social engagement but may need prompts/support with medication management and other tasks.	In addition to level 1, the person requires assistance with personal care i.e. bathing, dressing, and toileting. May also require support in the presence of non-cognitive symptoms of dementia.	The person has a high level of personal care needs. They require help with all ADLs including physical, emotional and social needs. May also require support in the presence of non-cognitive symptoms of dementia.

Completed by:	Signature:
Role:	

Appendix 3: 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 ✓)

☐ FAMILY	☐ WIDER SOCIAL NETWORK	☐ 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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