



Building a
Better Health
Service

Seirbhís Sláinte
Níos Fearr
á Forbairt

Model of Care for Dementia in Ireland

Draft Summary Document · August 2021



Centre for **Economic
and Social Research
on Dementia**



1. Introduction and Background

For an individual, their family and other supporters, dementia is a life changing condition that requires responses to support the person across the illness trajectory. This is from the point of concern about their cognitive, non-cognitive or behavioural symptoms, to receiving a diagnosis, through to early intervention and the provision of the right care at the right time. The projected increase in the number of people who will develop dementia in the future requires reform and further development of existing diagnostic and post-diagnostic services. The aim of the Dementia Model of Care is to address shortcomings in the diagnosis, disclosure and post-diagnostic supports (PDS) that have been identified by people with dementia.

This Dementia Model of Care (MoC) sets out 32 targets, and a series of practice recommendations, to advance the assessment and diagnosis of anyone with suspected dementia, and also the treatment, care and support of the 64,143 people currently living with dementia in Ireland. The model is informed by the work and outputs of the diagnostic and post-diagnostic projects led by the National Dementia Office between 2017-2019 and by an expert Advisory group and consultations with key stakeholders. It was developed by the National Dementia Office (HSE) in conjunction with the Centre for Economic and Social Research on Dementia in NUI Galway and the Dementia Services Information and Development Centre.

Dementia is a chronic, multifactorial and progressive condition. It is not a disease in itself but an umbrella term for a range of conditions which cause changes to the brain. Dementia has physical, psychological, social, and economic consequences for the person, their carers, supporters, families, and society generally (World Health Organisation, 2017).

The MoC addresses the needs of all people with suspected dementia or living with dementia, irrespective of age, disability, gender, ethnicity, dementia sub-type or living circumstance. It sets out pathways of care for people with possible young-onset dementia and those with co-morbidities where they have another primary condition and are receiving specialist care outside of memory or cognitive/behavioural neurology services.

There are four key elements to the Dementia Model of Care. These include:

- A diagnostic model which includes pathways to diagnosis and guidance on assessment for clinicians.
- Guidance on disclosure, drawing on national and international best practice.
- Care planning and guidance on personalised care planning processes that are inclusive of the person with dementia and their supporter/carer.
- Post-diagnostic treatment and support across five strands of support.

The model is underpinned by a series of five core principles – citizenship, person-centred approaches, integration, personal-outcomes and timeliness. These are revisited at each point on the care pathway.

Diagram 1: Principles of the Dementia Model of Care



2. Diagnostic Model

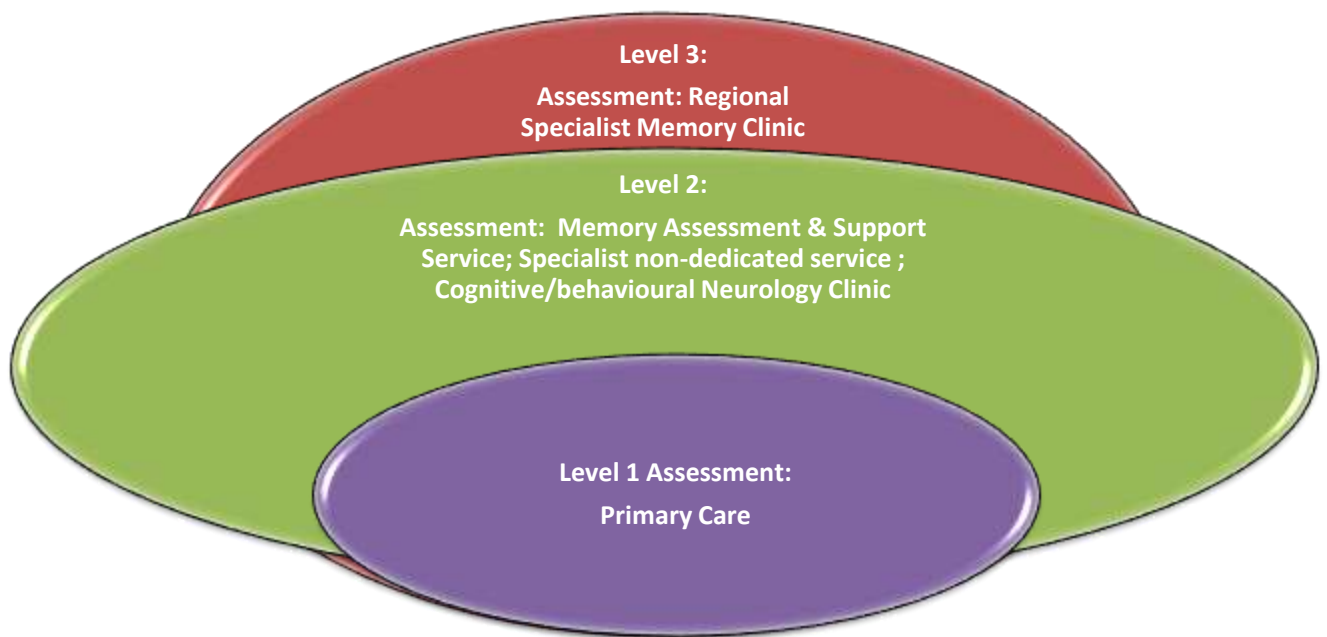
An entry point to receiving the right care and treatment by the right service is receiving a comprehensive assessment and diagnosis. Dementia remains hugely undetected and under-diagnosed in Ireland. The significant benefits of a timely dementia diagnosis are well established; however, there remains wide variation across current assessment services. This includes:

- Inequity in the availability of memory (and other specialist) services.
- Lack of uniformity in diagnostic practices.

The Dementia Model of Care is informed by the European research project “ACT on dementia”¹, which outlines three levels of assessment as shown in the diagram below.

¹ Krolak-Salmon, P., Leperre-Desplanques, A. & Maillet, A. (2019). *ACT on Dementia. Work Package 4: Diagnosis and post-diagnosis support for neurocognitive disorders*. Version of 30/10/2019.

Diagram 2: Three levels of assessment



Level 1: Assessment within Primary Care

Assessment is carried out by a GP with or without the support of other disciplines within the Primary Care Team such as the Practice Nurse, Occupational Therapist, Public Health Nurse and emerging Community Health Network model and roles therein. People who receive assessment and care at Level 1 will generally have a non-complex presentation of dementia.

Level 2: Assessment in a Memory Assessment and Support Service (MASS) or other Specialist Services

The person is referred for assessment at a dedicated clinic/service (MASS), or at a specialist but non-dedicated service at secondary level, or at a cognitive/behavioural neurological service. The MASS service includes a post-diagnostic support service for people diagnosed with dementia. In addition, people with significant risk factors for dementia or who are diagnosed with Subjective Cognitive Impairment (SCI), Mild Cognitive Impairment (MCI) or dementia, can access a brain health (risk reduction) service through the MASS.

Level 3: Assessment in a Regional Specialist Memory Clinic (RSMC)

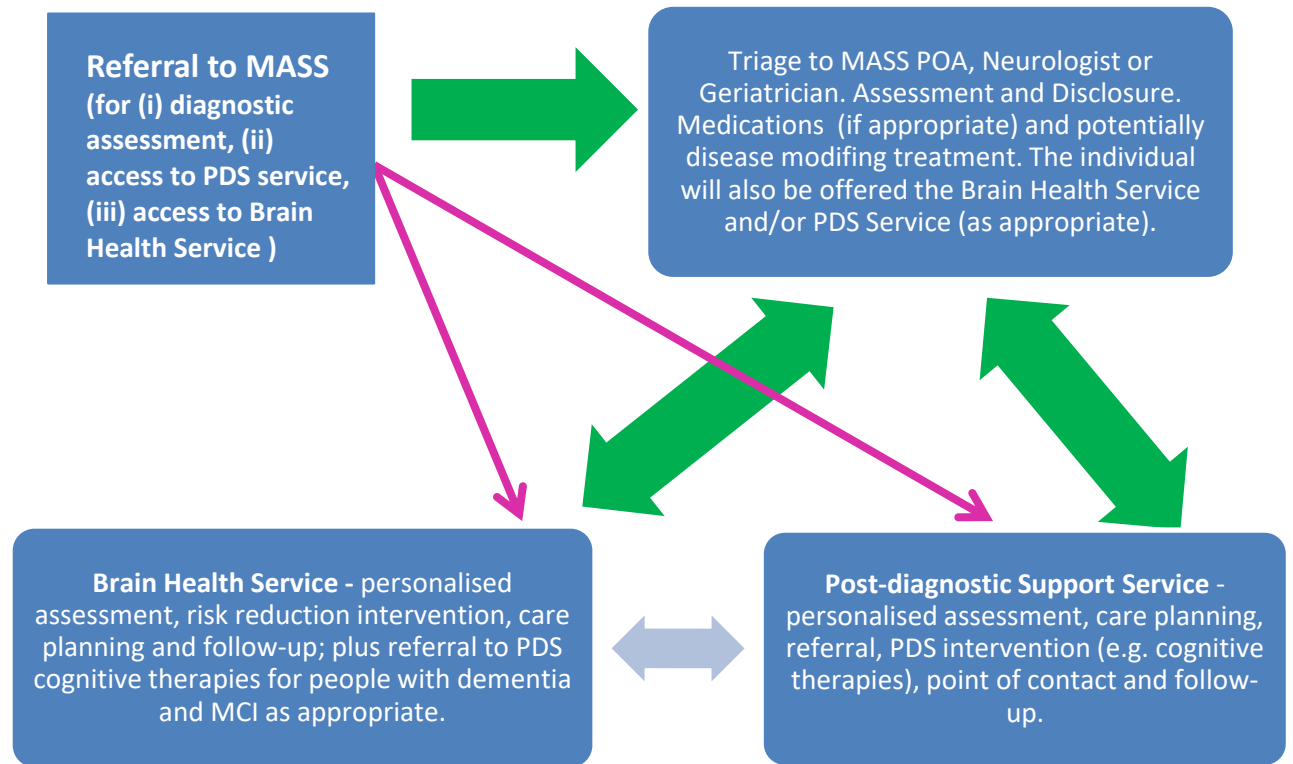
Based in tertiary care, the person is referred for assessment at a Regional Specialist Memory Clinic when there is a complex or unclear presentation, or where the person wishes to participate in a more detailed and specific aetiological evaluation.

A large proportion of people presenting with a need for a cognitive/memory assessment will receive their assessment at level 2 (MASS or other specialist service).

Referral to the MASS assessment, brain health and post-diagnostic services are outlined in the diagram below.

Diagram 3: Referral pathways to Memory Assessment and Support Services

GP, Secondary Care Clinics, Community Mental Health Services for Older People, ICPOP etc. referral to Memory Assessment and Support Service



Overall coordination of the person’s care will reflect their age, dementia-related needs and other comorbidities or issues. Where dementia is the only or the primary condition requiring treatment, care coordination, if needed, will be provided by the MASS. Where dementia is part of an established neurodegenerative or neurological condition (e.g. MND, PD, Huntington’s disease), coordination of care usually rests with the neurology service, Parkinson’s service or relevant other. Where dementia is non-complex and one of multiple comorbidities, care will usually continue to be coordinated by the treating team e.g. Older Adults service, POA, ICPOP, Neurology, GP/primary care, with MASS input

As outlined above, each section of the MoC includes a series of targets. These are to guide service development and to support improved outcomes for individuals.

Table 1: Assessment and Diagnostic Targets

Target 1	There should be a minimum of one Memory Assessment and Support Service (MASS) per local population of 150,000 people (i.e. three Community Health Networks), performing approximately 300 assessments per year.
Target 2	There should be a minimum of five Regional Specialist Memory Clinics (RSMCs) nationally, with two of these based outside of Dublin, performing approximately 500 assessments per year.
Target 3	There should be one National Intellectual Disability Memory Service (NIDMS), with national access and regional outreach, performing approximately 200 assessments per year.
Target 4	<p>The composition of Level 2 Memory Assessment and Support Service:</p> <ul style="list-style-type: none"> • *Consultant 0.5 WTE • Senior Neuro-psychologist 0.5 WTE • Specialist Registrar 1.0 WTE • CNS/ANP 3.0 WTE • Senior Occupational Therapist 0.5 WTE • Senior Speech and Language Therapist 0.5 WTE • Senior Social Worker 0.5 WTE • Senior Dietitian 0.5 WTE • Neuro-radiologist 0.2 WTE • Clerical Support (Grade 4) 1.0 WTE <p>*Depending on local resources, a MASS may have a single consultant lead, or two or more disciplines may provide a joint or integrated service while also supporting consensus (0.2 Geriatrician, 0.2 Psychiatrist of Old Age, 0.1 Neurologist).</p>
Target 5	<p>The MDT composition of Level 3 Regional Specialist Memory Clinic:</p> <ul style="list-style-type: none"> • *Consultant 1.0 WTE • Senior Registrar 1.0 WTE • CNS/ANP 3.0 WTE • Senior Neuro-psychologist 1.0 WTE (principle specialist grade) • Senior Occupational Therapist 0.5 WTE (clinical specialist grade) • Senior Social Worker 1.0 • Senior Dietitian 0.5 WTE • Senior Speech and Language Therapist 0.5 WTE (clinical specialist grade) • Neuro-radiologist 0.2 WTE • Clerical Support (Grade 4) 1.0 WTE
Target 6	The collection of data on dementia to be standardised at (i) Level 2 MASS, (ii) Cognitive/behavioural Neurology Clinics, (iii) Specialist non-dedicated Services and at (iv) Level 3 Regional Specialist Memory Clinics with the use of the dementia minimum dataset.
Target 7	With their consent, 100% of people presenting with symptoms of suspected dementia should receive a comprehensive diagnostic assessment.
Target 8	<p>100% of people diagnosed with MCI offered follow-up appointment* for reassessment of cognition every 12–24 months, until stability or progression is evident.</p> <p>*Follow-up cognitive monitoring can also take place in primary care, where GPs can initiate the re-referral pathway to either Level 2 (MASS) or Level 3 (RSMC), as appropriate, or in MASS/RSMC if higher risk of progression is identified.</p>
Target 9	100% of people diagnosed with MCI should be offered specific interventions and supports, tailored to their needs, including brain health interventions and cognitive

	therapies.
Target 10	100% of people aged under 65 years with suspected dementia are referred to a specialist service for assessment (Level 2 MASS, Level 3 RSMC, or Cognitive/behavioural Neurology Service), where there is access to a neuro-psychologist assessment and an established pathway to post-diagnostic support.
Target 11	100% of people living with an intellectual disability with suspected dementia should receive a diagnostic assessment.
Target 12	100% of people living in residential care with suspected dementia should have access to a diagnostic assessment.
Target 13	For diagnostic assessment at Level 1 (primary care) the person should be seen within two weeks of seeking an appointment.
Target 14	For diagnostic assessment at Level 2 (MASS and other specialist services including cognitive/behavioural neurology clinic, POA and Older Persons services) and Level 3 (Regional Specialist Memory Clinics) the person should be seen within six weeks of referral.
Target 15	80% of people who have undergone an assessment should receive their results within three months, be this subjective cognitive impairment, mild cognitive impairment, dementia, or other, and including the possible/probable subtype of any MCI/dementia where relevant.

3. Disclosure

Every person who has undergone an assessment for suspected dementia should be offered the opportunity to receive their diagnosis. The process of disclosure should begin at the first contact between the person and the assessing clinician. At this point the clinician investigates how much the person has insight into their condition, whether they know why they are attending for assessment and whether they can consent to the process. It is important to establish how much information the person would like at the initial assessment and to introduce the possibility that tests might show they have a form of dementia, so that a formal diagnosis does not come as a shock.

The Model of Care sets out guidance for disclosing a diagnosis. An important step of this process is preparing the setting for the disclosure meeting, ensuring that it is appropriate for a sensitive and private discussion. In addition, an appropriate amount of time should be allocated for this meeting. If the person is not ready to engage around their treatment course at this point, a follow-up should take place two weeks later.

The disclosure section also outlines that all people who receive a diagnosis should receive a follow-up 4 – 8 weeks later to address any queries and for questions to be answered. This is also an opportunity to review any medications prescribed and to initiate post-diagnostic support. There are additional requirements for people who have complexity in the presentation of their dementia or who are aged under 65.

Immediate post-diagnostic support is also offered at this point. This includes information that is tailored to the individual. They are provided with a point of contact and a follow-up appointment. They should also receive information on their local Dementia Adviser Service to ensure they are supported after receiving their diagnosis.

Targets connected to the disclosure element of the MoC are outlined below:

Table 2: Disclosure Targets

Target 16	100% of people who have undergone assessment for suspected dementia should be afforded the opportunity to receive their diagnosis and to meet with a medical practitioner to discuss their prognosis.
Target 17	A clinician, with a HSCP in attendance, should deliver the diagnosis of dementia.
Target 18	<p>Staffing recommendations for the disclosure process</p> <p>For disclosure of a diagnosis of YOD or complex presentation:</p> <ul style="list-style-type: none"> • Consultant, Specialist Registrar or Registrar, plus • Senior Social Worker. <p>For disclosure of a diagnosis of dementia to those over the age of 65 at Level 2 – MASS, cognitive/behavioural neurology clinic or specialist non-dedicated service:</p> <ul style="list-style-type: none"> • Consultant, Specialist Registrar or Registrar, plus one of the following: <ul style="list-style-type: none"> ○ CNS/ANP ○ Occupational Therapist ○ Social Worker ○ Speech and Language Therapist (depending on diagnosis) ○ Neuro-psychologist. <p>For disclosure of a diagnosis of dementia to those over the age of 65 at Level 3 – RSMC</p> <ul style="list-style-type: none"> • Consultant or Specialist Registrar, plus one of the following: <ul style="list-style-type: none"> ○ Senior Social Worker ○ Senior Occupational Therapist ○ Senior Neuro-psychologist ○ Senior Speech and Language Therapist (depending on diagnosis).
Target 19	When the person has a dementia with no complicating factors, a minimum of 30 minutes should be allocated for the disclosure meeting.
Target 20	100% of people should be provided with individually tailored practical advice and information following the disclosure of a diagnosis of dementia. This should be made available both verbally and in written format.
Target 21	100% of people should be offered a follow-up appointment 4–8 weeks following a disclosure. Those prescribed memantine or an acetylcholinesterase inhibitor will require a medical review four weeks after starting the treatment.
Target 22	100% of people should have an initial named point of contact following their diagnosis. A person diagnosed with a dementia should not be discharged or referred to post-diagnostic support without this.

4. Care Planning

The development of a care plan begins during the process of diagnosis and disclosure. The assessments that are carried out will identify specific needs and potential treatments and psychosocial supports that may address these needs. The disclosure meeting is an opportunity to address what can happen in the immediate term.

Initial supports, treatment planning and early post-diagnostic support are provided or initiated as part of the disclosure process. Elements of the care plan may be put in place at this point. However,

it will not be possible to outline the range of supports and treatments that a person may require over a number of years at the point of diagnosis and disclosure (unless the diagnosis is made at a very advanced stage). Therefore the care plan is an evolving plan as the person’s needs change overtime.

The principles of the Model of Care outlined above are used to support the delivery of effective and person-centred care planning processes, where the person is at the centre of the care planning. It is, for example, important to determine the personal outcomes which are important to the person to inform the content of the care plan and the focus of ongoing and future care.

A person’s experience with dementia will be influenced by their physical and cognitive needs, their personality and life history and the social psychology that surrounds them. Personalised supports provide a tailored response designed to meet the unique needs of the person with dementia. A personalised support plan has a clear objective and purpose, with a move away from passive deficit-focused supports to more active ability-focused supports². It includes the following characteristics:

- The person with dementia and their primary carer/supporter are central to designing ‘what they need’, where their autonomy is promoted.
- The supports are flexible and responsive to the stage of illness and the co-morbidities that exist.
- Supports reinforce a normalising approach to dementia.
- Practice focuses on maintaining dignity, recognising the strengths, existing capacities and life history of the person, avoiding an exclusive focus on deficits, and is gender and culturally sensitive.
- Building a support network using family and community supports, then mainstream services, and finally formal health and social care supports to fill identified gaps.

The targets connected to the care planning section of the MoC are outlined in the table below.

Table 3: Care Planning Targets	
Target 23	100% of people diagnosed with dementia should have a documented personalised care plan which includes pharmacological interventions, post-diagnostic treatments and psycho-social supports.
Target 24	100% of people diagnosed with dementia should be offered contact details for their local Dementia Adviser (DA) and, where required, referral to the service should be facilitated by the diagnosing service.
Target 25	100% of people diagnosed with Young Onset Dementia should be offered referral to a social worker.
Target 26	At a minimum, the person’s care plan will be reviewed every 12 months.

² Howard, E., Quinn, A. & Cohen, A. (2019). *Developing Integrated Personalised Supports for People with Dementia Part 3: Recommendations based on learning from the implementation of a programme across eight sites in Ireland*. Dublin: Genio/Health Service Executive.

5. Dementia Post-diagnostic Support

The Dementia Post-diagnostic Steering Group defined post-diagnostic support in the following way, as supports that:

...enable and assist people with dementia and their families to live a life of their choosing throughout the continuum of dementia. Post-diagnostic supports include interventions, therapeutic treatments and activities that build on strengths and abilities; helping to maintain and enhance quality of life” (Dementia Post-diagnostic Steering Group, 2018).

The PDS pathway element of the dementia MoC is aimed at practitioners in a range of disciplines and settings, as well as people with dementia and carers/supporters. It provides examples of post-diagnostic supports to meet a range of needs, and practical guidance on how supports might be delivered.

The range of psychosocial interventions, therapies and information are included in five strands of PDS. Each describes examples of supports and interventions; creating a unique set of supports and interventions for the person and their carer/supporter from the period immediately following diagnosis to end of life.

The five ‘strands’ of post-diagnostic support are identified as:

- **Understanding and planning** – supports are focused on providing information to the person and carer/supporter, with specific interventions around future planning and promoting understanding of the condition;
- **Staying connected** –focused on maintaining existing connections and interventions which provide additional support to maintain emotional and social connectedness;
- **Staying healthy** – specific focus on supporting healthy behaviours. In addition, many post-diagnostic supports include strategies for preventing distress and disability and promoting health and psychosocial wellbeing;
- **Supporting cognition** – interventions which can maintain cognitive abilities as well as providing other benefits;
- **Supporting emotional wellbeing** – supports and interventions which can enhance emotional wellbeing throughout the dementia continuum.

People with dementia can be diagnosed at any point in the dementia continuum, from when they are experiencing quite early symptoms to when symptoms are quite advanced, and symptoms and needs can vary over time. Therefore, the five strands are not linear - it is not intended that they are delivered one after the other. Each strand has supports which are relevant throughout the dementia continuum (for example, the provision of information), and other supports which are relevant at a particular stage (such as Cognitive Rehabilitation Therapy).

The post-diagnostic support pathway is for **all** those with a diagnosis of dementia and their carers/supporters, from people experiencing early symptoms of dementia, through to those with moderate or advanced symptoms, to those at the end of life. They are relevant to people regardless of their age, gender, and ethnicity or where they live. The post-diagnostic support pathway is

dynamic, recognising that dementia is a progressive condition and that an individual’s needs can change over time, sometimes quite rapidly.

The targets connected to the PDS element of the MoC are outlined in the table below.

Table 4: Post-diagnostic Targets	
Target 27	100% of people with dementia, irrespective of age, dementia subtype and geographical location, are supported to choose from a range of activities and supports that are tailored to their preferences.
Target 28	The Dementia Understand Together programme should be resourced to further build understanding of dementia and support communities to be inclusive to achieve long-lasting and sustainable change for those affected by dementia.
Target 29	Every person with dementia assessed as requiring home-based care should be provided with personalised and flexible supports that meet both their personal and psycho-social care needs in their home.
Target 30	The five strands of post-diagnostic support should be considered in the provision of day services for people living with dementia, having the dual benefit of restorative care for both the person with dementia and their family carer/supporter.
Target 31	Every Memory Technology Resource Room (MTRR) should be staffed by at least one senior full time Occupational Therapist/Health and Social Care Professional in order to provide a range of post-diagnostic supports in the community as well as fulfil the functions of the MTRR around understanding and access to assistive technologies.
Target 32	100% of supporters/family carers of people with dementia should be informed about and offered education and skills training.

To read the full range of practice recommendations please refer to the main Draft Model of Care document.

Summary of Practice Recommendations	Page number in Draft Model of Care Document
Diagnostic practice recommendations	Pages 53 and 54
Disclosure practice recommendations	Pages 105 – 107
Care planning practice recommendations	Pages 121 and 122
Post-diagnostic support practice recommendations	Page 155

Submit comments on the Draft Model of Care for Dementia in Ireland to dementia.office@hse.ie by the 21st of September 2021. Use the official consultation feedback form which is on www.dementiaphways.ie.