



Model of Care for Dementia in Ireland

Summary in Plain English

Report Authorship

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1. Introduction and background

Dementia is a life-changing condition. The challenge of dealing with it involves the person living with dementia, their family and other supporters. This challenge occurs at every stage – from when symptoms first appear and getting a diagnosis, through to receiving the right care at the right time.

Over 64,000 people in Ireland currently live with dementia. As it is likely to affect a growing number of people in future, we need to develop better supports and services for them. The aim of the Dementia Model of Care is to fill the gaps in services that have been identified by people with dementia.

This Model of Care sets out a range of targets and practical advice on assessment, diagnosis, treatment, care and support of people with dementia. It has been drawn up, following a series of projects and consultations (2017-2019), by the HSE's National Dementia Office, an expert Advisory group, the Centre for Economic and Social Research on Dementia in Galway University Hospital, and the Dementia Services Information and Development Centre.

The Model of Care is for everyone who lives with dementia or thinks they may be starting to show signs of it – whatever their age, disability, gender, ethnicity, type of dementia or way of life. It includes care plans for people who may have young-onset dementia, and for people being treated for illnesses (co-morbidities) in addition to those affecting memory, thinking or behaviour.

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

- Diagnosis – setting out how doctors can diagnose and assess your condition
- Communicating a diagnosis of dementia – how and when healthcare professionals should explain to you and your family about dementia, and how you can tell other people about it
- Care planning – how you and the people supporting you can be involved in making choices about your care
- Treatment and support – five types of support you can get after diagnosis which include understanding and planning, staying connected, staying healthy, supporting cognition, and supporting emotional wellbeing

The model is based on five core principles: citizenship, person-centred approaches, integration, personal outcomes, and timeliness. These principles are taken into account at each stage in your care. We explain what they mean in the following sections.

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)

Diagram 1: Principles of the dementia model of care



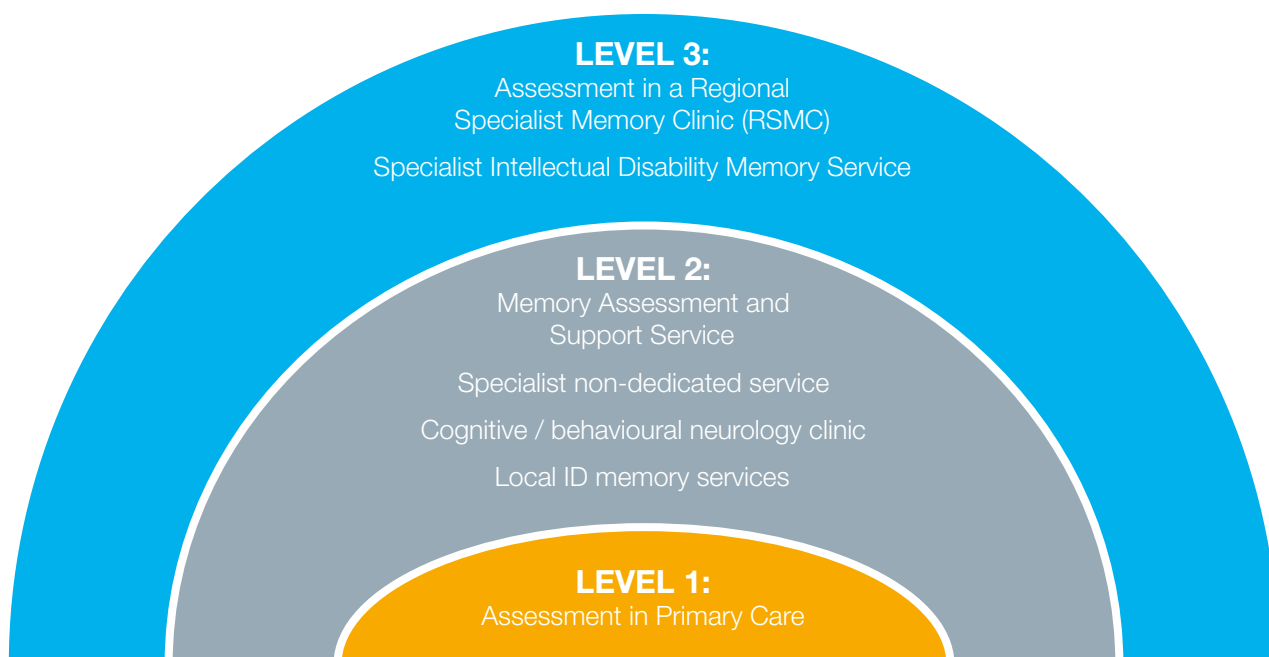
2. Diagnostic model

The first step towards receiving the right care and treatment by the right service is to get a full assessment and diagnosis. Dementia remains hugely undetected and under-diagnosed in Ireland. The benefits of early diagnosis are well recognised, but current assessment services vary widely across the country.

This is largely due to regional differences in the availability of memory services (and other specialisms), and to differences in the methods of diagnosis.

The Dementia Model of Care uses three levels of assessment, as outlined in the European research project “ACT on dementia” and in the diagram below.

Diagram 2: Three levels of assessment¹



Level 1: Assessment in Primary Care

You are assessed by a GP or another member of the primary care team, such as the practice nurse, occupational therapist, public health nurse or a professional from the new community health network. Level 1 assessment is generally for people with non-complex forms of dementia.

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

You are referred for assessment at a dedicated MASS clinic, or at a specialist but non-dedicated service at secondary level, or at a cognitive/behavioural neurological service. These services include support for people already diagnosed with dementia. They also offer a brain health (risk reduction) service for people with significant risk factors for dementia or people who have been diagnosed with dementia, subjective cognitive impairment or mild cognitive impairment.

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

Most people who need a cognitive or memory assessment will be assessed at a level 2 centre by MASS or another specialist service. However, you may be referred to a Regional Specialist Memory Clinic for assessment at tertiary (advanced specialist) level. This happens when you have a complex or unclear form of dementia, or where you wish to take part in a more detailed study of the causes of your condition.

The ways that people are referred to a MASS, and other assessment services and supports, after receiving a diagnosis of dementia are outlined in the diagram below.

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

Each section of the Model of Care includes a series of targets. These help us to improve services in general and achieve better outcomes for individuals.

*Please note that the below targets have been converted into plain english and the wording will differ from the wording of targets within the Model of care for Dementia in Ireland document.

Table 1: Assessment and diagnosis targets

Target 1	There should be a minimum of one Memory Assessment and Support Service (MASS) per local population of 150,000 people (that is, at least one MASS for three Community Health Networks), carrying out about 300 assessments a year.
Target 2	There should be a minimum of five Regional Specialist Memory Clinics (RSMCs) nationally, with two of these based outside Dublin, carrying out about 500 assessments a year at each site.
Target 3	There should be one National Intellectual Disability Memory Service (NIDMS), available to people from anywhere in Ireland through regional centres.
Target 4	<p>The minimum staffing levels of a Level 2 MASS should be:</p> <ul style="list-style-type: none"> • Consultant 1.0 • Senior neuropsychologist 0.5 • Senior / specialist registrar 1.0 • Advanced nurse practitioner 1.0 • Clinical nurse specialist 2.0 • Senior occupational therapist 1.0 • Senior physiotherapist 1.0 • Senior speech and language therapist 1.0 • Senior social worker 1.0 • Senior dietitian 0.5 • Neuro-radiologist 0.2 • Clerical support (Grade 4) 2.0 <p>A MASS may be headed by a single consultant, or two or more consultants may provide joint leadership based on team consensus.</p>
Target 5	<p>The minimum staffing levels of a level 3 Regional Specialist Memory Clinic should be:</p> <ul style="list-style-type: none"> • Consultant 2.0 • Senior / specialist registrar 2.0 • Advanced nurse practitioner 1.0 • Clinical nurse specialist 2.0 • Principal neuropsychologist 1.0 (principal specialist grade) • Clinical specialist occupational therapist 1.0 • Clinical specialist physiotherapist 1.0 • Senior social worker 1.0 • Senior dietitian 0.5 • Clinical specialist speech and language therapist 1.0 • Neuro-radiologist 0.2 • Clerical support (grade 4) 2.0 <p>*Depending on local resources, a RSMC may have a single consultant lead, or two (or more) senior professionals may provide a joint or integrated service.</p>
Target 6	The collection of data on dementia should be standardised in all services: (i) level 2 MASS (ii) cognitive/behavioural neurology clinics (iii) other specialist (non-dedicated) services and at (iv) level 3 regional specialist memory clinics.
Target 7	With their consent, 100% of people showing symptoms of suspected dementia should receive a comprehensive diagnostic assessment.

Table 1: Assessment and diagnosis targets

Target 8	<p>100% of people diagnosed with mild cognitive impairment should be offered a follow-up appointment* for reassessment every 12 to 24 months, until their condition has clearly stabilised or changed.</p> <p>*Follow-up cognitive monitoring can take place in primary care, where GPs can refer the case to either level 2 (MASS) or level 3 (RSMC) as appropriate. It can take place in MASS/RSMC if there is a high risk that the condition will get worse.</p>
Target 9	100% of people diagnosed with mild cognitive impairment should be offered specific interventions (treatments, procedures, advice or support) in a timely manner and in response to individual needs and preferences. This includes brain health interventions and cognitive therapies.
Target 10	100% of people aged under 65 with suspected dementia should be referred to a specialist service for assessment (level 2 MASS, level 3 RSMC or a cognitive/behavioural neurology service). This will include assessment by a neuropsychologist and neurologist, and will make supports available after a diagnosis.
Target 11	100% of people living with intellectual disability with suspected dementia should have access to a comprehensive and timely diagnostic assessment.
Target 12	100% of people living in residential care with suspected dementia should have access to a timely diagnostic assessment.
Target 13	For diagnostic assessment at level 1 (primary care), a person with suspected dementia 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 clinics, psychiatry of old age, and other older persons services) and level 3 (Regional Specialist Memory Clinics), a person with suspected dementia should be seen within six weeks of referral.
Target 15	80% of people who have had an assessment should receive their results within three months, including diagnoses of subjective cognitive impairment, mild cognitive impairment, dementia or other conditions, and any possible or probable sub-type of mild cognitive impairment or dementia.

3. Communicating a diagnosis of dementia

Every person who is having an assessment for suspected dementia should be offered the opportunity to receive their diagnosis.

During the first appointment, the team will want to find out how much you know about your condition, whether you know why you are having an assessment, and whether you consent to it. They need to consider how much information you would like at the initial assessment. They should also introduce the possibility that the tests might show you have a form of dementia, so that a formal diagnosis will not come as a shock.

After completing your assessment, the doctor and one other member of the team should offer to tell you whether you have a diagnosis or not.

The Model of Care sets out guidance for communicating a diagnosis. It is important that the meeting place is suitable

for a sensitive and private discussion, and enough time is allowed for it. If you are not ready to discuss your treatment at this point, you should be offered another appointment for two weeks later.

The Model of Care states that you should have a follow-up appointment between 4 and 8 weeks after getting your diagnosis. At this appointment, the team can answer your questions, check on your medications and arrange support for you. They can take extra steps if you have a complex form of dementia or if you are aged under 65.

You can get some immediate support at this point. This includes information that is relevant to your case. You will be given a point of contact, a follow-up appointment and details of your local Dementia Adviser Service.

Table 2 outlines the targets in the Model of Care on communicating a diagnosis of dementia.

Table 2: Targets for communicating a diagnosis

Target 16	100% of people who have been assessed for suspected dementia should have the opportunity to receive their diagnosis from a doctor and discuss the likely development (prognosis).
Target 17	In all healthcare settings, a doctor should give the diagnosis of dementia, with a nurse or other health and social care professional (HSCP) in attendance.
Target 18	<p>The professionals who should be in attendance when giving a diagnosis of dementia may vary:</p> <p>a. For communicating a diagnosis of young-onset dementia (YOD) or an unusual presentation of symptoms that may or may not be dementia:</p> <ul style="list-style-type: none"> • Consultant, specialist registrar or registrar, plus • Senior social worker <p>Plus other multidisciplinary team (MDT) members, as appropriate to the assessment findings and type of clinic.</p> <p>b. For communicating a diagnosis of dementia to those over 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: • Clinical nurse specialist (CNS) or advanced nurse practitioner (ANP) in dementia care • Occupational therapist • Social worker • Speech and language therapist (depending on diagnosis) • Neuropsychologist <p>c. For communicating a diagnosis of dementia to those over 65 at level 3 – RSMC: consultant or specialist registrar, plus one of the following:</p> <ul style="list-style-type: none"> • Senior social worker • Senior occupational therapist • Senior neuropsychologist • Senior speech and language therapist (depending on diagnosis)

Table 2: Targets for communicating a diagnosis

Target 19	The time needed for communicating a diagnosis of dementia will depend on each patient's needs and the complexity of their condition. When there are no complicating factors, at least 30 minutes should be allowed for the appointment; more complex or young-onset cases will need longer.
Target 20	100% of people who receive a diagnosis of dementia should be provided with individually tailored practical advice and information, both verbal and written.
Target 21	100% of people should be offered a follow-up appointment between 4 and 8 weeks after a diagnosis. People who are prescribed memantine or an acetylcholinesterase inhibitor will require a medication review 4 weeks after starting the treatment.
Target 22	100% of people should have an initial named point of contact after their diagnosis. They should not be discharged or referred to a support service without this.

4. Care planning

Planning for care starts when you get your diagnosis. Your assessment identifies what you find difficult and what treatments and other types of support you will need. When you first talk to the doctor or another healthcare professional about your diagnosis (during the communication of a diagnosis process), you can find out what immediate help is available.

At this meeting, the doctor will start planning your treatment and arranging support. Elements of your care plan may be put in place at this point. However, it will not be possible to outline the range of supports and treatments you may need in future years (unless the diagnosis is made at a very advanced stage). Therefore your care plan will evolve as your needs change over time.

The principles of the Model of Care outlined above are used to support the delivery of effective care planning processes, where the person is at the centre. For example, it is important to decide which goals or outcomes are important to you. Knowing what to aim for will help healthcare professionals to draw up your care plans, now and in the future.

Several things influence the way you live with dementia: your physical and mental needs, your personality and life

history, your social situation, and your relationships with other people. Everyone is different, so you will have a personalised support plan designed to meet your unique needs. Your plan will have clear aims and objectives. It will focus on things you can do rather than things you cannot do. It is based on the following principles:

- You and your main carer or supporter are central to making decisions and choices for yourself as independently as possible.
- Your support can be adapted to the stage of dementia and any other medical conditions (co-morbidities).
- Supports helping you and others to accept dementia as part of normal life.
- Your care givers and supporters treat you with dignity. They recognise your strengths, existing abilities and life history. They avoid focusing on your difficulties, and are sensitive to gender and culture.
- Your support network starts with your family and community, then calls on mainstream services, and finally uses formal health and social care resources to fill specific gaps.

Table 3 outlines the targets for care planning in the Model of Care.

Table 3: Care planning targets

Target 23	100% of people diagnosed with dementia should have a documented personalised care plan which includes drug prescriptions, other post-diagnostic treatments and psychosocial (mental, emotional and social) supports.
Target 24	100% of people diagnosed with dementia should be offered contact details for their local dementia adviser (DA). Where required, the diagnosing service should refer them to the DA.
Target 25	100% of people with young-onset dementia should be referred firstly to a social worker. They should also have access and referral to the full range of multidisciplinary team services.
Target 26	All care plans will be reviewed at least once every 12 months.

5. Dementia post-diagnostic support

Post-diagnostic refers to what happens after you receive a diagnosis of dementia. The Dementia Post-diagnostic Steering Group defined post-diagnostic support (PDS) 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 section in the dementia Model of Care is for healthcare workers as well as people with dementia, their carers and their supporters. It sets out examples of post-diagnostic supports that will meet a range of needs, and practical guidance on how these supports could be provided.

PDS has five ‘strands’ or themes, made up of a range of therapies, information and psychosocial measures (such as counselling or group activities). They can add up to a unique set of supports for you, your carers and your supporters from the days immediately after diagnosis and into the future.

The five strands of post-diagnostic support are:

- **Understanding and planning** – providing you, your carers and your supporters with information to help you understand your condition and plan for the future

- **Staying connected** – maintaining existing links and activities that help you remain emotionally and socially connected to other people
- **Staying healthy** – supporting a healthy lifestyle, and finding ways to prevent distress and disability and to promote your physical, social and emotional wellbeing
- **Supporting cognition** – keeping your mind active and maintaining your powers of thinking and understanding (cognitive abilities)
- **Supporting emotional wellbeing** – improving your emotional wellbeing to help you to remain positive at every stage of the dementia journey

You can be diagnosed with dementia at any point, from when early symptoms appear to when they are quite advanced. Your symptoms and needs can vary over time. Therefore, the five strands of support can all be useful at the same time, rather than one after the other.

Each strand includes supports which are relevant at every stage in dementia (for example, providing information), and other supports which are relevant at a particular stage (such as cognitive rehabilitation therapy).

PDS is for everyone with a diagnosis of dementia and their carers or supporters, whether you have early, moderate or advanced symptoms of dementia, or are approaching the end of your life. They are relevant whatever your age, gender and ethnicity or where you live. PDS can adapt to your needs, recognising that dementia is a progressive condition and that your needs can change over time, sometimes quite rapidly.

Table 4 outlines the targets for the PDS element of the Model of Care.

Table 4: Post-diagnostic targets

Target 27	As part of care planning and early post-diagnostic support, 100% of people with dementia (whatever their age or dementia sub-type), and their supporters and family carers, should be given information about opportunities to take part in relevant and appropriate research. Similarly, 100% of people with mild cognitive impairment should be told how to find out about taking part in research.
Target 28	100% of people with dementia, whatever their age, dementia sub-type and geographical location, should be offered a range of activities and supports in line with their preferences.
Target 29	The Dementia Understand Together programme should be resourced to further build understanding of dementia and help communities to take an inclusive approach to people living with it, with the aim of achieving long-lasting and sustainable change for those affected by dementia.
Target 30	Every person with dementia who is assessed as needing home care should have personalised, adaptable supports that meet their personal and psychosocial care needs in their home.

Table 4: Post-diagnostic targets

Target 31	Every homecare assistant caring for someone with dementia should have undertaken QQI accredited training on dementia. This requirement should be part of the HSE's home care tender scheme for private and voluntary providers.
Target 32	The five strands of PDS should be taken into account in providing day services for people living with dementia, as they provide the benefit of restorative care to the person with dementia, their family carers and supporters.
Target 33	Every memory technology resource room (MTRR) should be staffed by at least one senior full-time occupational therapist. This is to provide a range of PDS in the community as well as use the MTRR to promote understanding of and access to assistive technologies.
Target 34	Assistive technologies (AT) are currently not funded under existing funding streams such as those for aids and appliances, nor are they available on the medical card. A funding model should be developed to support greater access to, and use of, AT.
Target 35	Guidance on using AT should be updated so they can be used to best effect in supporting people with dementia. This guidance should also cover the use of telecare and telehealth technologies in dementia care.
Target 36	If a person with dementia has a family carer, the carer's own needs should be assessed so that a carer support plan can be developed.
Target 37	100% of supporters and family carers of people with dementia should be given information about the condition, and offered education and skills training.

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