Model of Care for Dementia in Ireland

Background and Principles
Dementia Diagnostic Model
Dementia Assessment and Diagnostic Pathway
Giving a Diagnosis of Dementia
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Foreword from the Chief Clinical Officer, Health Service Executive

On behalf of the Health Service Executive and the Enhanced Community Care Programme, I am pleased to present to you our Dementia Model of Care. The Model of Care sets out, the approach to support our clinicians to deliver dementia assessments and services for people with dementia and their families. These assessments and services are in line with Government Policy as outlined in Sláintecare and the HSE Corporate Plan 2021 – 2024.

Our key focus continues to be the provision of safe health and social care services to enable people with dementia to live as independently as possible in their own homes and communities. At present it is estimated that there are approximately 64,000 people currently living with dementia in Ireland; this number is expected to rise to 150,000 by 2045. A diagnosis of dementia can be an extremely traumatic life event for both the person diagnosed and their families and carer's. The Model of Care supports the end to end pathway for the person with dementia and will ensure the health system possesses the capability to respond quickly to a person's needs and offers exceptional support and care. This Model of Care is focused on ensuring access to care through a standardised and equitable process and aims to deliver a minimum of:

- One National Intellectual Disability Memory Service (NIDMS), with national access, performing approximately 200 assessments per year.
- Five Regional Specialist Memory Clinics (RSMCs) nationally, with two of these based outside of Dublin, performing approximately 500 assessments per year
- One Memory Assessment and Support Service (MASS) per local population of 150,000 people performing approximately 300 assessments per year.

The Model of Care sets out a range of targets and practice recommendations to advance the treatment, care and support for people living with dementia in Ireland. Care pathways, timely diagnosis and early intervention will provide an opportunity for the person with dementia and their families to be part of the journey in planning for their future needs and engage with the decision making process around these needs. Evidence has shown timely diagnosis provides positively for the person with dementia and healthcare provider and enables individualised services tailored to meet the person's needs. These early supports will further support our Acute Hospital System with Admission Avoidance and timely discharge for people with dementia. The Model supports the involvement of the person with dementia in research and this is particularly important in the context of continuous advances in care, both pharmacological and non-pharmacological interventions.

I would like to acknowledge the support Minister Butler and the Department of Health for their ongoing support in relation to the enhancement of dementia services in Ireland. In addition I would like to thank the membership of the Dementia Workstream members, our colleagues in the ECC programme and colleagues working across the full health service delivery system, our voluntary, statutory and educational partners whose advice and expertise has informed the completion the Dementia Model of Care.

Dr. Colm Henry

Chief Clinical Officer
HSE

Introduction from the Clinical Lead, National Dementia Services and the Assistant National Director, Services for Older People

On behalf of the Enhanced Community Care Programme and the Dementia Workstream we are delighted to present the Dementia Model of Care. The Model of Care seeks to place Ireland to the fore internationally in our approach to brain health, cognitive impairment and dementia and ensure the delivery of timely and effective assessment and the enhancement of integrated dementia services in Ireland. The core of the Model is ensuring a person-centered approach to the delivery of dementia services in Ireland, involving the person with dementia in from the first stage of diagnostics through to post-diagnostic supports.

The Model of Care recognises the role and value of those working across primary care, secondary care and tertiary-level services, and the important contribution from supporting social care services. The Model ensures the delivery of an integrated care pathway where the needs of the individual are met according to their complexity, aiming always to support the person with dementia to maintain their autonomy. It also emphasises timeliness of response, and equity of access so that nobody affected by dementia is left behind; irrespective of age, disability, gender, ethnicity, dementia sub-type or living circumstance. The Model of Care provides guidance and expertise to our clinical teams through the delivery of 37 outcome based targets that focus on the pace and nature of diagnostic work-up, best practice in the communication of a diagnosis, immediate care planning, as well as longer-term post diagnostic support.

The Model of Care builds on work underpinned by the Dementia Strategy (2014) and was developed under the governance of a multidisciplinary Advisory Group and Consultancy Group, with contributions from the Centre for Economic and Social Research on Dementia and the Dementia Services Information and Development Centre. We would like to acknowledge with thanks the input of all that have contributed to the Model of Care, including Prof. Suzanne Timmons, previous Clinical Lead for Dementia Services ,our current and past members of the National Dementia Team, people living with dementia and their families,the Diagnostic Project Steering Committee and Post-diagnostic Support Project Steering Committee, and most recently the Dementia Workstream Group, HSE, Voluntary, Statutory and Educational partners.

We would like to thank Minister Butler and our Department of Health colleagues; Dr. Colm Henry; Dr Siobhán Ní Bhriain, Pat Healy and the National Enhanced Community Care Programme Team and Paul Maloney and the National Dementia Services Team for their support in finalising the Model of Care.

As science and medicine evolve, we are entering an era where personalised preventive strategies and broader public health narratives will become increasingly important regarding brain health. Furthermore, on the horizon are therapies which could potentially slow the course of some of the neurodegenerative diseases which lead to dementia. The Model acknowledges these developments, whilst maintaining a clear focus on serving the needs of those for whom these interventions and innovations will not be applicable. The landscape of dementia care is evolving in a positive way across civic, societal and medical platforms and we hope and believe that this Model will contribute very significantly to this progress.

Dr. Seán O'Dowd

**Consultant Neurologist
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Diagrams

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Glossary of Terms

Acetylcholinesterase inhibitors

An acetylcholinesterase inhibitor or anticholinesterase is a drug that inhibits the acetylcholinesterase enzyme from breaking down acetylcholine, a neurotransmitter involved in neuron signalling that is important for cognition. They are sometimes referred to as cognitive enhancing drugs, or cognitive enhancers.

Activities of daily living

Everyday aspects of normal life; for example, shopping, maintaining a home and personal care, mobility, toileting and language skills.

Advance Healthcare Directive

In relation to a person who has capacity, this means an advance expression made by the person, in accordance with section 84, of his or her will and preferences concerning treatment decisions that may arise in their respect if he or she subsequently lacks capacity, and in relation to a designated healthcare representative, this means the advanced expression under which the representative was designated as such representative (Assisted Decision-Making (Capacity) Act, April 2023).

An Advance Healthcare Directive is an advanced expression made by a person with a decision-making capacity, which sets out their preferences concerning healthcare treatment decisions that may arise if a person subsequently lacks decision-making capacity. An advance healthcare directive must include a number of formalities to be valid and applicable.

Alzheimer's disease

Alzheimer's disease is a progressive neuro-degenerative condition. The symptoms of dementia are usually impaired memory, thinking and / or behaviour. It is a result of plaques and tangles in the brain, which result in a group of symptoms that lead to a decline in mental function severe enough to disrupt daily life (adapted from American Psychiatric Association).

Assessment

Information is collected to identify the person's needs and to formulate a treatment or care plan.

Assisted decision-making

A person may appoint a decision-making assistant – typically a family member or carer – through a formal decision-making assistance agreement to support him or her to access information or to understand, make and express decisions. Decision-making responsibility remains with the person.

Assistive technology

Refers to products, equipment and systems that can enhance and facilitate everyday living for someone with physical, sensory or cognitive disability.

Behavioural and Psychological Symptoms of Dementia

These are frequently the expression of unmet needs of the person with dementia. Behavioural symptoms include agitation, restlessness, aggression, walking, shouting and hoarding. Psychological symptoms include anxiety, apathy, depression, delusions, hallucinations (McGowan et al. 2019).

Care partner

A care partner provides assistance to an individual with a health condition to meet their self-care needs. A care partner is an individual chosen by the person to support them and may change over time.

Carer (Family)

Refers to a person who provides regular, unpaid personal assistance to a friend or family member with a long-term illness, health problem or disability. A carer is an individual chosen by the person to support them and may change over time.

Clinician

A clinician is a doctor, nurse practitioner, or other healthcare professional who treats patients directly.

Cognitive Rehabilitation Therapy

Individually tailored intervention, working on personal goals, often using external cognitive aids and some learning strategies.

Cognitive Stimulation Therapy

A brief group-based treatment for people with mild to moderate dementia, which involves sessions of themed activities, aimed at actively stimulating and engaging people with dementia, whilst providing an optimal learning environment and the social benefits of a group therapy.

Communicating a diagnosis of dementia

The task of telling someone the diagnosis of an illness or other problem as a result of an investigation of their symptoms of their symptoms.

Community Health Network

A Community Health Network will deliver primary healthcare services across a population of 50,000 people. It will consist of between 4-6 primary care teams, with GPs involved in delivering services, working together in multi-disciplinary teams to deliver the vision of Sláintecare to provide the right care, in the right place at the right time.

Community care

Care that is provided to a person in their own community, supporting them to live at home. It includes services such as formal home care, day care, meals on wheels, etc.

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Co-morbidity

Where a person has two or more diseases or conditions occurring at the same time.

Decision-making Capacity

A person's ability to understand, at the time that a decision is to be made, the nature and consequences of the decision to be made by him or her in the context of the available choices at that time. A person lacks the capacity to make a decision if he or she is unable (a) to understand the information relevant to the decision, (b) to retain that information long enough to make a voluntary choice, (c) to use or weigh that information as part of the process of making the decision, or (d) to communicate his or her decision (whether by talking, writing, using sign language, assistive technology, or any other means) or, if the implementation of the decision requires the act of a third party, to communicate by any means with that third party (Assisted Decision Making (Capacity) Act, April 2023).

Delirium

An acute change in cognitive function characterised by inattention that has an organic cause and is likely to be reversible or preventable.

Dementia

Dementia describes a range of cognitive, behavioural, and psychological symptoms that can include memory loss, problems with reasoning and communication, and changes in personality that impair a person's ability to carry out daily activities (NICE, 2018).

Dementia with Lewy Bodies

Lewy body dementia is an umbrella term for any dementia where there are Lewy bodies (i.e. alpha-synuclein protein accumulations in the brain). It often presents with thinking, movement and behavioural changes and typically visual hallucinations.

Designated healthcare representative

A designated healthcare representative is a person named by the directive-maker, in his or her advance healthcare directive, to exercise certain powers as set out in the advance healthcare directive.

Frontotemporal Dementia

A progressive neuro-degenerative condition associated with atrophy (shrinking) of the frontal and / or temporal anterior lobes of the brain. The symptoms of FTD include changes in behaviour or problems with language. Spatial skills and memory often remain intact initially but then decline over time.

Health and Social Care Professional

Under the Health and Social Care Professionals Act, 2005 the following people are designated as health and social care professionals: dietitians; psychologists; occupational therapists; social workers and speech and language therapists. Other professions are also included in this category.

Late Onset Dementia

Refers to dementia, which develops after the age of 65 years.

Mild Cognitive Impairment (MCI)

Mild cognitive impairment, or prodromal dementia, is characterised by impairment in cognition that is not severe enough to require help with activities of daily living. MCI is distinguished from dementia by the preserved ability to function in daily life and maintain independence; however, MCI is associated with an increased risk of developing dementia (Stephan et al. 2015).

Multi-disciplinary

Refers to professionals who are involved in the care of people working in partnership across disciplines or fields of expertise.

National Dementia Strategy

Published by the Department of Health in 2014, the NDS sets out priority areas and actions to address dementia in Ireland at a national level.

Non-cognitive Symptoms of Dementia

Often referred to as behavioural and psychological symptoms of dementia – see definition above.

Patient

Refers to a person who is receiving a health or medical care intervention/service.

Person living with dementia

Refers to a person who is experiencing the symptoms of dementia, has undergone formal assessment and received a dementia diagnosis.

Prevalence

Refers to a statistical concept for the number of cases of a disease that are present in a particular population at a given time.

Primary Care

Primary Care is all of health or social care services that are in the community, outside of hospital. It includes GPs, Public Health Nurses and a range of other services.

Psycho-education

Programmes for individuals or groups of people that involve an explicitly described educational interaction.

Psycho-social

Involves aspects relating to social and psychological behaviour; often used in relation to psycho-social intervention and supports.

Responsive behaviour

This is a subset of behavioural and psychological symptoms of dementia that refers to the expression of unmet need and / or a response to a stimulus in the environment and / or Psycho-social needs and / or responses to the approach of care providers.

Subjective memory complaint

Refers to self-reported problems with memory that may or may not present with objective cognitive impairment (measured via tests and assessments).

Symptom

A physical or mental problem that a person experiences that may indicate a disease or condition.

Vascular dementia

In vascular dementia, changes in thinking skills sometimes occur suddenly following strokes that block major blood vessels in the brain. Thinking problems may also begin as mild changes that worsen gradually as a result of multiple minor strokes or other conditions that affect smaller blood vessels, leading to cumulative damage.

Young Onset Dementia

Refers to dementia when it occurs in people under the age of 65 years.

Note on terminology

The DEEP (The Dementia Engagement and Empowerment Project, 2015) guidelines on language about dementia states that many people with dementia dislike the terms ‘dementia patient’ or ‘service user’ or ‘client’ when these are used generically to refer to all people with dementia. This is because they imply that the individual is nothing more than this. It is preferable to therefore use ‘person with dementia’ or ‘person living with dementia’.

These terms are used throughout this Dementia Model of Care; however, as per the DEEP guidelines ‘patient’ is used when referring to a person in a hospital or when they are using a healthcare service.

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Acronyms

AAT	Animal-Assisted Therapy
AChEI	Acetylcholinesterase Inhibitor
ACP	Advance Care Planning
AD	Alzheimer's Disease
ADLs	Activities of Daily Living
ADM	Assisted Decision Making
ALS	Amyotrophic lateral sclerosis
AMAU	Acute Medicine Assessment Unit
ANP	Advanced Nurse Practitioner
APOE	Apolipoprotein E
ASI	Alzheimer Society of Ireland
AT	Assistive Technology
BPSD	Behavioural and Psychological Symptoms of Dementia
CAA	Cerebral Amyloid Angiopathy
CAMHS	Child and Adolescent Mental Health Service
CBD	Corticobasal Degeneration
CBI	Cambridge Behavioural Inventory
CBT	Cognitive Behaviour Therapy
CESRD	Centre for Economic and Social Research on Dementia
CHN	Community Health Network
CHO	Community Health Organisation
CMHT	Community Mental Health Team
CNS	Clinical Nurse Specialist
CRT	Cognitive Rehabilitation Therapy
CSF	Cerebrospinal fluid
CST	Community Specialist Team
DA	Dementia Adviser
DEEP	Dementia Engagement & Empowerment Project
DLB	Dementia with Lewy Bodies
DMT	Disease Modifying Treatment
DOH	Department of Health
DSIDC	Dementia Services Information and Development Centre
DSM-5	Diagnostic and Statistical Manual of Mental Disorders
DSS	Decision Support Service
ECC	Enhanced Community Care
ED	Emergency Department
EDS	Eating, Drinking, Swallowing
EEG	Electroencephalogram
EMG	Electromyography
FTD	Frontotemporal Dementia
FTE	Full-time Equivalent
GMS	General Medical Services
GP	General Practitioner
HD	Huntington's Disease
HSCP	Health and Social Care Professional
HSE	Health Service Executive
ICPOP	Integrated Care Programme for Older People
ID	Intellectual Disability

IHI	Individual Health Identifier
InterRAI	International Resident Assessment Instrument
LOD	Late Onset Dementia
LTC	Long Term Care
MASS	Memory Assessment and Support Service
MC	Medical Card
MCI	Mild Cognitive Impairment
MD	Mild Dementia
MDS	Movement Disorder Society
MDT	Multi-disciplinary Team
MHSOP	Mental Health Service for Older People
MIS	Memory Impairment Screen
MMSE	Mini-Mental State Examination
MNA	Mini Nutritional Assessment
MND	Motor Neurone Disease
MoC	Model of Care
MoCA	Montreal Cognitive Assessment
MTRR	Memory Technology Resource Room
NCSD	Non-Cognitive Symptoms of Dementia
NDO	National Dementia Office
NDS	National Dementia Strategy
NIA	National Institute on Aging
NICE	National Institute for Health and Care Excellence
NIDMS	National Intellectual Disability Memory Service
OT	Occupational Therapist
PCA	Posterior Cortical Atrophy
PCT	Primary Care Teams
PD	Parkinsons Disease
PDD	Parkinson's Disease Dementia
PDS	Post-diagnostic Support
PET	Positron Emission Tomography
PHN	Public Health Nurse
POA	Psychiatry of Old Age
POLL	Psychiatry of Later Life
PPA	Primary Progressive Aphasia
PSP	Progressive Supranuclear Palsy
RCF	Residential Community Facility
RCT	Randomised Controlled Trial
RHA	Regional Health Area
RSMC	Regional Specialist Memory Clinic
RT	Reminiscence Therapy
SCD	Subjective Cognitive Decline
SCI	Subjective Cognitive Impairment
SCIE	Social Care Institute for Excellence
SLT	Speech and Language Therapist
SMC	Subjective Memory Complaint
SMI	Subjective Memory Impairment
SnDS	Specialist Non-Dedicated Service
SW	Social Worker
WHO	World Health Organization
WTE	Whole-time Equivalent
YOD	Young Onset Dementia

Model of Care 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 in each site.
Target 3	There should be one National Intellectual Disability Memory Service (NIDMS), with national access and regional outreach.
Target 4	The minimum composition of Level 2 Memory Assessment and Support Service: • *Consultant 1.0 WTE • Senior Neuropsychologist 0.5 WTE • Senior/Specialist Registrar 1.0 WTE • Advanced Nurse Practitioner 1.0 WTE • Clinical Nurse Specialist 2.0 WTE • Senior Occupational Therapist 1.0 WTE • Senior Physiotherapist 1.0 WTE • Senior Speech and Language Therapist 1.0 WTE • Senior Social Worker 1.0 WTE • Senior Dietitian 0.5 WTE • Neuro-radiologist 0.2 WTE • Clerical Support (Grade 4) 2.0 WTE *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
Target 5	The minimum composition of Level 3 Regional Specialist Memory Clinic: • *Consultant 2.0 WTE • Senior/Specialist Registrar 2.0 WTE • Advanced Nurse Practitioner 1.0 WTE • Clinical Nurse Specialist 2.0 WTE • Principal Neuropsychologist 1.0 WTE • Clinical Specialist Occupational Therapist 1.0 WTE • Clinical Specialist Physiotherapist 1.0 WTE • Senior Social Worker 1.0 WTE • Senior Dietitian 0.5 WTE • Clinical Specialist Speech and Language Therapist 1.0 WTE • Neuro-radiologist 0.2 WTE • Clerical Support (Grade 4) 2.0 WTE

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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 proposed use of a 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	100% of people diagnosed with MCI offered follow-up appointment* for reassessment of cognition every 12–24 months, until stability or progression is evident. *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.
Target 9	100% of people diagnosed with MCI should be offered specific interventions and supports in a timely manner and in response to identified need and respecting each individual's preferences. These include brain health interventions and cognitive therapies.
Target 10	100% of people aged under 65 years with suspected dementia are offered referral to a specialist service for assessment (Level 2 MASS, Level 3 RSMC, or Cognitive / behavioural Neurology Service), where there is access to a Neurologist , neuropsychology assessment and an established pathway to post-diagnostic support.
Target 11	100% of people living with intellectual disability with suspected dementia should have access to a timely comprehensive 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), 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.
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	Regardless of setting, a physician, with a Health and Social Care Professional (HSCP) or nurse in attendance, should deliver the diagnosis of dementia.

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Target 18

Communicating a diagnosis of dementia

For communicating a diagnosis of Add Young Onset Dementia (YOD) or atypical presentation:

- Consultant, Specialist Registrar or Registrar, plus
- Senior Social Worker

In addition, other Multi-disciplinary Team (MDT) members as indicated based on the assessment findings and clinical context.

For communication 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:

- Consultant, Specialist Registrar or Registrar, plus one of the following:
  - » Dementia -CNS/ANP
  - » Occupational Therapist
  - » Social Worker
  - » Speech and Language Therapist (depending on diagnosis)
  - » Neuropsychologist.

For communication of a diagnosis of dementia to those over the age of 65 at Level 3 – RSMC

- Consultant or Specialist Registrar, plus one of the following:
  - » Senior Social Worker
  - » Senior Occupational Therapist
  - » Senior Neuropsychologist
  - » Senior Speech and Language Therapist (depending on diagnosis).

Target 19

The time allocation for the communication of a diagnosis of dementia will be influenced by patient-specific needs and complexity. When the person has a dementia with no complicating factors, a minimum of 30 minutes should typically be allocated for the meeting; longer slots will be required for more complex cases or young onset presentations.

Target 20

100% of people should be provided with individually tailored practical advice and information following the communication 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 diagnosis. Those prescribed memantine or an acetylcholinesterase inhibitor will require a medication 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.

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 with young onset dementia should be referred in the first instance to a social worker along with appropriate access and referral to the full range of MDT.

Target **26**	At a minimum, the person's care plan will be reviewed every 12 months.
Target **27**	As part of care planning and early post-diagnostic support, 100% of people with dementia, irrespective of age or dementia subtype, and their supporters / family carers should be offered information about relevant and appropriate research opportunities. Similarly, 100% of people with MCI should be offered signposting to research participation.
Target **28**	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 **29**	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 **30**	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 **31**	Every home care assistant caring for someone with dementia should have undertaken QQI accredited training in dementia. This requirement should be linked to the HSE's home care tender for private/ voluntary providers.
Target **32**	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 **33**	Every Memory Technology Resource Room (MTRR) should be staffed by at least one senior full-time OT 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. Synergies between the MTRR and MASS / RSMCs should be encouraged as part of the post-diagnostic pathway.
Target **34**	Assistive technologies (AT) are currently not funded under existing funding streams such as aids and appliances, nor are they available on the medical card. A funding model for AT should be developed to support greater access to and use of AT.
Target **35**	Updated guidance on the use of AT is required to ensure the optimum use of such technologies in supporting people with dementia. This guidance should also cover the deployment of telecare and telehealth technologies to support people with dementia.
Target **36**	A family carer needs assessment should be carried out to identify the needs of family carers (if there is a carer involved) which informs the development and delivery of a carer support plan.
Target **37**	100% of supporters / family carers of people with dementia should be informed about and offered education and skills training.

SECTION 1

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1.1. Introduction to the Dementia Model of Care

This Dementia Model of Care outlines care pathways within the Irish health and social care system for people living with dementia from identification of symptoms / signs, through to assessment, diagnosis, communicating a diagnosis, care planning and post-diagnostic support.

The model presents a range of targets and practice recommendations to advance the treatment, care and support for the thousands of people living with dementia in Ireland. The model may require review to inform and update pathways as evidence emerges on the effectiveness of disease modifying treatment (DMT) options and to support the roll-out of any modifiable interventions, which may come on stream in the future.

Dementia is a life-changing condition and requires responses to support people across the illness trajectory, from the point of concern about 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 will be a challenge for both diagnostic and post-diagnostic services and there is a requirement that care pathways are carefully considered, costed and implemented.

The model is underpinned by a series of core principles, which are revisited at each point in the pathway. This is to ensure that people living with dementia are at the centre of considerations relating to service design and recommendations related to care practices; also to ensure that they receive timely and equitable access to assessment, diagnosis and post-diagnostic support regardless of the location of a service, the type of dementia they have, their age, their ethnicity, any other disability or co-morbidity, or their gender.

Dementia is also extremely individualised, and each person's needs will differ, depending on their experience of symptoms, their social situation, their age at onset of dementia, their overall health status, their personality, and their preferences. As a result, a range of personalised and coordinated supports are required to enable people to adapt and cope with the onset of dementia and its progression.

The Irish National Dementia Strategy (NDS), published in 2014, set out 35 actions across six priority areas, underpinned by the two core principles of personhood and citizenship. The NDS sets out how dementia should be addressed nationally. Since its publication, extensive work has been undertaken across sectors and disciplines to:

- raise awareness of dementia.
- improve care services.
- increase our understandings of how people can be better supported to live with dementia.
- upskill and train key stakeholders, including GPs, primary care teams, family carers / supporters, HSCPs, nurses and home support workers.

The Dementia Model of Care presented in this report builds on this evidence and brings together best practice in relation to dementia diagnosis, communicating a diagnosis of dementia and post-diagnostic support. The model has been developed within the context of Sláintecare (2020–2023) and the health reform agenda, where delivering the right care, in the right place, at the right time, given by the right team, is a central principle. In addition, the HSE Corporate Plan 2021 – 2024 focuses on key challenges within the health system, with an acknowledgement that there is a lack of services to enable our ageing population to maintain their independence and live well in the community. It also states that we must achieve better health outcomes for everyone. The Dementia Model of Care meets this challenge. The model places the person with dementia at the centre of care planning and decision- making, promoting an outcome-focused approach that meets each of the aims of the HSE corporate plan, where:

- People can access the right care, at the right time and in the right place and will feel empowered, listened to and safe.
- We will work as one team, supported to do the best we can for patients, service users, their families and the public.
- You can have trust and confidence that the organisation is run well.
- You are supported to live well, and you feel connected with your community.

Implementation of this Dementia Model of Care will also assist Ireland in meeting the targets set out by the World Health Organisation's Global Action Plan on Dementia (2017-2025), across six action areas:

- Action area 1: Dementia as a public health priority.
- Action area 2: Dementia awareness and friendliness.
- Action area 3: Dementia risk reduction.
- Action area 4: Dementia diagnosis, treatment, care and support.
- Action area 5: Support for dementia carers.
- Action area 6: Information systems for dementia.

Family carers and supporters are the backbone of the care ecosystem for people living with dementia. It is estimated that for every one person with dementia, there are three others supporting those living with the condition and providing care. The Dementia Model of Care outlines pathways of care that promote autonomy, timeliness, outcome-focused, person-centred and citizenship approaches for people living with dementia; the care pathways will also be enablers for family carers / supporters also. The vision statement of the National Carers Strategy 2012 is that "Carers will be recognised and respected as key care partners. They will be supported to maintain their own health and wellbeing and to care with confidence. They will be empowered to participate as fully as possible in economic and social life". This is echoed in the Dementia Model of Care, care planning (aligning with the assisted decision-making legislation), that their needs should be assessed and that there should be targeted dementia education and training for family carers / supporters.

This Dementia Model of Care is applicable to all people living with dementia. However, more detailed models of care are required to fully address concerns of specific groups such as people living with both dementia and intellectual disability, as well as a model for long-term residential care, which is outside the remit of this current work.

1.2. Navigating through the Model Report

This Dementia Model of Care has five key sections.

The first is the model for diagnostic services, which crosses three levels:

1. Primary care
2. Secondary care – Memory Assessment and Support Services, cognitive / behavioural neurology services and other specialist non-dedicated services, and
3. Tertiary care – Regional Specialist Memory Clinics. The latter utilises the skills of highly experienced health and social care professionals to arrive at differential diagnoses.

The second section describes the diagnostic pathway of care across these three levels, describing the assessment processes required in each.

The third section provides recommendations and guidance on communicating a diagnosis of dementia, which is outlined as a process that begins at the first contact with the person during the initial assessment. It is commonly cited that a person's experience of receiving a diagnosis of dementia can affect their experience of dementia throughout the disease trajectory. Considerations are given in this section to communicating a diagnosis across primary, secondary and tertiary care.

The fourth section focuses on care planning and immediate post-diagnostic support. Care plans involve personalised approaches and follow-up assessments. Immediate post-diagnostic supports are those interventions, which need to be in place immediately following a diagnosis of dementia, e.g. information, point of contact and planned therapeutic interventions.

The fifth and final section is a broader consideration of the dementia post-diagnostic care pathway. It outlines the needs of people across three tiers. Tier 1 is where people are diagnosed or living with very early dementia and the primary focus is supporting self-management of the condition, moving up to Tier 2 and Tier 3 as the person's needs increase. Five strands of post-diagnostic support are also outlined which should be considered for all people with a diagnosis, irrespective of age, disability, dementia subtype, ethnicity, gender, where they live and at what point they are in respect to the care continuum.

The principles of the model are applied across each section and outline how they inform the implementation of the approach. Importantly, there are measurable targets set out across each of the sections. In addition, there are a series of practice recommendations under each section, which support appropriate implementation of the model.

1.3. Dementia Prevalence

Dementia is not a normal part of the ageing process, but age is the main risk factor. As our population ages, the number of people living with dementia will also increase and it is now viewed as a global health priority (WHO, 2012). Worldwide, it is estimated that there are over 50 million people living with the condition (WHO, 2017); with approximately 9.9 million people developing dementia annually (Revez, 2019). In Ireland, increasing prevalence is also evident and it is estimated that there are approximately 64,000 people living with dementia (HSE, 2020); with 7,752 new cases every year (Pierse et al. 2019). If current trends continue, the projected prevalence of dementia is estimated to increase to 150,000 people by 2045 (HSE, 2020).

Table 1: Estimated prevalence of dementia by gender 2020 and 2045

	Estimated Prevalence 2020			Estimated Prevalence 2045		
Age	**Male**	**Female**	**Total**	**Male**	**Female**	**Total**
0–4	0	0	0	0	0	0
5–9	0	0	0	0	0	0
10–14	0	0	0	0	0	0
15–19	0	0	0	0	0	0
20–24	0	0	0	0	0	0
25–29	0	0	0	0	0	0
30–34	299	159	458	376	187	563
35–39	348	189	537	373	188	561
40–44	373	194	567	334	170	504
45–49	348	177	525	315	161	476
50–54	319	161	480	298	154	452
55–59	286	147	433	293	159	452
60–64	255	1,180	1,435	336	1,679	2,015
65–69	1,993	1,601	3,594	3,130	2,618	5,748
70–74	2,964	3,687	6,651	4,892	6,214	11,106
75–79	4,576	5,484	10,060	8,824	10,530	19,354
80–84	5,790	8,205	13,995	13,798	18,534	32,332
85+	7,019	18,389	25,408	24,634	51,936	76,570
TOTAL	24,570	39,573	64,143	57,603	92,530	150,133

Source: Health Atlas Ireland, HSE (data generated 2020)

In addition, there is a significant number of people who are aged under 65 years living with dementia, estimated at 5,200 from extrapolating UK data (Carter, 2022). This is commonly referred to as Young onset Dementia (YOD). People with YOD are more likely to have rarer dementia subtypes and hence presentations (Fox et al. 2020). This is compounded by life-stage characteristics such as financial and childcare responsibilities and challenges accessing appropriate post-diagnostic supports (Fox et al. 2020).

Furthermore, prodromal states of dementia are highly prevalent amidst middle- and older-aged populations with an estimated prevalence of 6% over the age of 50 years (Sachdev et al, 2015). Such prodromal states are often referenced as Mild Cognitive Impairment (MCI).People with an intellectual disability (ID) require particular consideration, as they have a significantly higher risk of developing dementia when compared to the general population (Strydom et al. 2013). People with Down Syndrome, the most widely known frequent cause of ID, are at higher risk, with prevalence figures at 50% in the over 50s and greater than 75% in people aged 65 years and over, with an average age of onset of dementia in the early 50s (McCarron et al. 2017, Sinai et al. 2018).

1.4. What is Dementia?

Dementia is a chronic, multi-factorial 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 (WHO, 2017).

See **section 2.6.2** for the American Psychiatric Association 5th Edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) diagnostic criteria for dementia.[1]

There are over 400 subtypes of dementia, with the most common form being Alzheimer's disease, followed by vascular dementia and mixed Alzheimer and vascular dementia. Other common forms of dementia include Dementia with Lewy Bodies (DLB), Fronto temporal Dementias and less common types such as Huntington's disease, Parkinson's disease dementia and Creutzfeldt-Jakob disease (O'Shea et al. 2018). Alcohol-related brain damage, linked to its direct neurotoxic effects and to other risk factors including head injury, concomitant smoking and other addictions, poor diet (especially thiamine deficiency), etc., can cause dementia and have an additive effect to other dementia pathologies (Ridley et al. 2013).

Mild neurocognitive disorders are also recognised, previously referred to as Mild Cognitive Impairment (MCI) or prodromal dementia. This is characterised by cognitive impairment that is not severe enough to require help with Activities of Daily Living, but it is associated with an increased risk of developing dementia (Stephan et al. 2015).

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[1] The DSM-5 redefines dementia as a 'major neurocognitive disorder (NCD)'; however, the term 'dementia' is still commonly accepted and will be used throughout this Dementia Model of Care.

Table 2: Common subtypes of dementia

Dementia type	Common Symptoms and Signs
Alzheimer's disease	Gradual onset with continuing decline (over 2–20 years). Short-term memory loss is a classic early feature followed over time by problems with attention, orientation, language, comprehension, visuo-spatial perception as well as mood changes.
Vascular Dementia*	Vascular Dementia exhibits a more stepwise decline. The person may experience gait abnormalities, display signs of vascular disease and focal neurological signs.
Mixed Dementia*	In the most common form of mixed dementia, the abnormal protein deposits associated with Alzheimer's disease coexist with blood vessel problems linked to vascular dementia. Alzheimer's disease can also coexist with Lewy bodies.
Dementia with Lewy Bodies	Person may have fluctuating cognition / alertness, hallucinations that are typically visual (but can be auditory, tactile, etc.) and / or evidence of Parkinsonism.
Parkinson's Disease Dementia	Unlike DLB, movement problems usually precede cognitive symptoms by years. Orientation is typically well preserved and memory issues reflect retrieval more than memory storage issues.
Progressive Supranuclear Palsy and Corticobasal Degeneration	Progressive Supranuclear Palsy (PSP) and Corticobasal Degeneration (CBD) are often classified as Parkinsonian disorders, but are due to tau pathology. Features overlap with a frontal-type dementia, often with impulsivity, speech fluency issues, swallowing difficulties and prominent falls along with the hallmark vertical gaze palsy in PSP and apraxia in CBD).
Frontotemporal Dementia (FTD)	Generally develops at a younger age (around 60), is more likely to be hereditary and is the cause of 10-12% of cases of dementia with onset under 65 years. Can present with changes in behaviour such as disinhibition, loss of social awareness and loss of insight, and / or with speech being prominently affected (problems generating words / sentences or in understanding words / sentences). Can overlap with Motor Neurone Disease in up to 15% of cases.
Huntington's disease (HD) dementia	Along with the hallmark involuntary motor movements (chorea), people with HD can develop depression, obsessive-compulsive thoughts and personality changes. In HD dementia, executive function is particularly impaired, along with language and memory.
Alcohol related cognitive syndromes	A spectrum of disorders ranging from cognitive impairment which can stabilise or improve with abstinence, through to Wernicke-Korsakoff Syndrome, which is specifically a consequence of thiamine deficiency and frequently results in irreversible dementia characterised by profound anterograde amnesia and confabulation.

*Note: Whilst being the second most common cause of dementia in clinical / population-based studies, pure vascular dementia accounts for only c.10% of cases in clinicopathological series. More commonly, vascular pathology coexists with neurodegenerative processes such as Alzheimer's disease.

A commonly cited symptom of dementia is short-term memory loss, but it is not the only one. DSM-5 describes the symptoms of dementia and the different subtypes across six domains, including:

- Complex attention – includes sustained attention, divided attention, selective attention and information processing speed.
- Executive function – includes planning, decision-making, working memory, responding to feedback, inhibition and mental flexibility.
- Learning and memory – includes free recall, cued recall, recognition memory, semantic and auto-biographic long-term memory and implicit learning.
- Language – includes object naming, word finding, fluency, grammar and syntax and receptive language.
- Perceptual motor function – includes visual perception and perceptual motor coordination.
- Social cognition – includes recognition of emotions, theory of mind and insights.

Beyond these six domains, some people living with dementia also report sensory changes, with greater sensitivity to light and sound. People can also experience changes in the ability to communicate, as communication function is underpinned by all six cognitive domains listed above. However, the nature and severity of the person's communication impairment will be unique to them and influenced by their underlying dementia subtype and external factors.

People living with dementia have also reported significant psycho-social effects of living with the condition. Dementia, for example, can impact on a person's sense of self (Norberg, 2019). It can reduce their confidence and they can experience social stigma, which can negatively impact their health and wellbeing (Kim et al. 2019, Riley et al. 2015, Milne 2010a). Stigma can prevent the person from acknowledging symptoms and obtaining the help they need to continue to live a good quality of life (ADI 2012). The negative perceptions of individuals and society to dementia may lead to the isolation of people with dementia and their family carers / supporters, thereby reinforcing and extending isolation caused by the effects of the disease (ADI 2012). These negative experiences can further hasten the person's withdrawal from social life.

While many of the symptoms of dementia relate to cognitive change, others do not, such as anxiety, apathy, depressive symptoms, delusions, and hallucinations. People living with dementia can experience agitation, restlessness, aggression, pacing, shouting and hoarding. These symptoms may represent an unmet need, or a response to a perceived threat. There are many different terms used to describe these types of symptoms, including Behavioural and Psychological Symptoms of Dementia, 'Non-Cognitive Symptoms of Dementia (NCSD)' (McGowan et al. 2019) or responsive behaviours. In addition, FTD can involve pronounced symptoms and behaviour relating to frontal lobe dysfunction such as impulsivity, disinhibition, reduced empathy, apathy, or ritualistic / compulsive behaviour.

The relationship between mental health difficulties and dementia is also complex and is increasingly discussed in the literature as one of importance in dementia care (Onyike 2016, Regan 2016, RCPsych 2018). Thirty per cent of dementia assessment referrals have diagnosed mental health symptoms (Volpe et al. 2019), and the majority of people with the condition will experience some form of mental health symptom during the course of their dementia, which significantly impacts on quality of life (Onyike 2016). Specifically, depression is associated with an increased risk of dementia, with the recent Lancet review reporting an almost two-fold risk. It noted the added complexity of depression being part of the dementia prodrome wherein depression could be a very early symptom of an evolving dementia rather than a true risk factor (Livingstone et al, 2020).

1.5. Current Context of Dementia Care

Despite supporting evidence on the benefits of timely diagnosis and early intervention (Woods et al. 2003, Banerjee and Wittenbery 2009), dementia remains under-diagnosed in Ireland (Cahill et al. 2012, O'Shea et al. 2018), with less than 50% of those living with dementia ever receiving a diagnosis (Revez et al. 2018). Furthermore, data from INAD-2 suggest that subtyping of dementia is suboptimal with only 51% of cases having a specific dementia subtype identified (Bracken-Scally et al. 2020).

To date, there are no targets to guide service design and delivery in Ireland. Targets can set out optimal waiting times for comprehensive assessment and diagnosis, for example, which can guide clinical practice and service redesign. The self-reported waiting times for assessment in January 2017, across 19 memory clinics, ranged from four weeks to one year (Gibb and Begley 2017). The Clinician's Survey of Dementia Diagnostic Processes and Practices (NDO 2019) highlighted issues with waiting times for urgent referrals across diagnostic services, identifying variations in clinician groups, with Neurology[2] having the longest waiting time (up to two years) and Psychiatry of Old Age having the shortest waiting time (one to two weeks). For people with ID there are additional difficulties in accessing appropriate assessment and diagnostic support services due to the need for specialist memory assessment that accounts for their pre-existing cognitive impairment.

A step to access post-diagnostic support and intervention is a diagnosis of dementia. A timely diagnosis can open the door to a care pathway. Timely diagnosis and intervention afford the person the opportunity to plan for the future, enabling them to engage in decision-making around their care, giving them earlier access to services and supports. The aim should be to support people diagnosed with dementia to continue living their usual life for as long a time as possible. However, evidence shows inconsistencies and geographical inequity in the provision of post-diagnostic support, whereby, for example, cognitive therapies, opportunities for peer support and learning are not routinely provided across the country, with a lack of opportunity to access appropriate therapies, training and education on dementia care, including specialist post-diagnostic supports for people with ID and dementia.

In addition, the community-based dementia-specific mapping project, undertaken by the National Dementia Office (NDO) and the Alzheimer Society of Ireland in 2017, and the national audit of dementia services (Keogh, Pierse and O'Shea, 2020) showed geographical inequities in the provision of dementia-specific community-based services across the country. Findings showed discrepancies in the provision of community interventions to support people with dementia living at home. The mapping project found that the most common service available in the community was dementia day care followed by supports for family carers such as peer groups and carer training.

1.5.1 Building an evidence base and increasing awareness

The National Dementia Office (NDO), established in 2015 within the Health Service Executive, is responsible for overseeing the implementation of the NDS and the 35 actions outlined in the strategy. Two key projects were commenced by the NDO in 2017 – namely, the diagnostic and post-diagnostic support projects. The aim of these projects was to investigate current and good practice in relation to (i) dementia diagnosis and (ii) supports for people once they have been told their diagnosis.

Given the significant knowledge gap within the Irish context, these projects initially focused on the generation of evidence to support modelling best practice care. Outputs from the projects included:

- Post-Diagnostic Support for People with Dementia and their Carers: A Literature Review (O'Shea et al. 2018).

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[2] Note that this data was collected in 2019 prior to the establishment of a number of cognitive / behavioural neurology clinics where waiting times are much shorter.

- Dementia Diagnostic Services for Ireland: a Literature Review (Revez et al. 2018).
- Clinician Survey: Dementia Diagnostic Processes and Practices in Ireland (NDO 2019).
- Evaluation of the National Dementia Post-Diagnostic Support Grant Scheme (Pierce et al. 2019).
- Young Onset Dementia: A Review of Diagnostic and Post-diagnostic Processes and Pathways (Fox et al. 2020).

A wider evidence base, generated to support the implementation of the NDS, also informs the Dementia Model of Care and includes the following publications:

- Development of a Model for the National Dementia Registry (Hopper & Bowen 2021).
- Evaluation of the Role, Contribution and Value of the Memory Technology Resource Room (MTRR) (Cullen 2020).
- Evaluation of the Framework for Dementia: Understand Together in Communities (Galvin et al. 2020).
- Second Irish National Audit of Dementia Care Acute Hospitals (Bracken-Scally et al. 2020).
- The Impact of a National Public Awareness Campaign on Dementia Knowledge and Help-Seeking Intention in Ireland (Hickey et al. 2019).
- Diagnosis and Management of Dementia in General Practice (Foley et al. 2019).
- Non-Cognitive Symptoms of Dementia (NCSD) Guidance on Non-pharmacological Interventions for Healthcare and Social Care Practitioners (McGowan et al. 2019).
- Dementia Continuum of Care Report (O'Shea et al. 2019).
- Evaluation of the Alzheimer Society of Ireland Dementia Adviser Service Report (Coffey et al. 2018).
- A Guide to Memory Clinics in Ireland (Gibb and Begley, 2017).
- Dementia – Intensive Home Care Package Evaluation (Keogh et al. 2018, Howard et al. 2018).
- Dementia Specific Services in the Community Mapping Public and Voluntary Services (NDO / ASI, 2017).
- Outputs from the PREPARED project: https://dementiapathways.ie/publications/prepared

These resources, alongside other national and international evidence, as well as consultations with people living with dementia, family carers, clinical groups, HSCPs, nurses and their representative groups and guidance from an expert advisory group from across disciplines and sectors (see Appendix F Consultant Groups) have informed the development of the Dementia Model of Care. The model also builds on the committed efforts of many stakeholders and is based on our current understanding of what can work well for people living with dementia and for their carers / supporters.

The Dementia Understand Together programme has been a key enabler to the development of the Model of Care. A primary focus of the programme is to increase awareness and understanding of dementia and to address the social stigma that can negatively affect a person's health and wellbeing. The first phase of the Dementia Understand Together programme was a national awareness campaign, which included radio and TV advertisements. The national campaign, led by the HSE in partnership with the Alzheimer Society of Ireland, Age Friendly Ireland, Genio and, more recently, the Dementia Services Information and Development Centre and Age and Opportunity, has made strides in increasing people's understanding of dementia. It has communicated key messages, which challenge the myths that surround the condition, as well as encouraging people to talk about it, to look for help when needed, and has increasingly focused on the development of dementia-inclusive communities.

1.6. About the Dementia Model of Care

The Dementia Model of Care sets out the optimum care and support pathways for people living with dementia, from the point of concern when first noticing symptoms (e.g. change in cognition, behaviour, memory, mental health, mood or personality) to receiving a variety of supports in the community and at home. It describes adaptable pathways of care that maximise the use of existing structures, the enhancement of current services and new service requirements. It also outlines integrated working across services and personalised care to reach the outcomes most important for each individual.

Specifically, the model includes guidance on:

- Dementia assessment and targets for diagnostic services.
- An outline of the dementia diagnostic pathway and the required assessment service infrastructure, describing three levels within the assessment and diagnostic pathway.
- Guidance on best practice and key steps in communicating a diagnosis of dementia.
- Recommendations on the key elements of personalised care planning.
- Targets and recommendations on early post-diagnostic support and details on the dementia post-diagnostic care pathway with examples of supports and interventions, which can be provided across five strands of support.

The Dementia Model of Care is a framework to bring together a wide range of services into a coherent pathway. Its purpose is to support people to navigate the system and to realise the outcomes, which are most important to them. It aims to reduce waiting times to specialist services, with easier and timely access to appropriate assessment, diagnosis and continuous post-diagnostic support. The model supports practitioners to diagnose dementia and identify / prescribe appropriate supports. The model also takes into consideration the evolving Irish healthcare system, the principles and approach of Sláintecare and the current

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delivery of care where people may receive care and support in different care settings and by different services but where 'home first' is a primary focus.

1.6.1 Key groups for consideration

As stated above, the Dementia Model of Care addresses the needs of all people living with dementia, irrespective of age, disability, gender, ethnicity, dementia subtype or living circumstance. It sets out pathways of care for people with 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 or other specialist non-dedicated services (SnDS). It also considers the needs of people with an ID who have dementia.

The progressive nature of dementia and the low rates of early diagnosis mean that many people receive a diagnosis in the later stages of the condition. They may also be resident in long-term care where access to support requires a different pathway.

The care pathway, therefore, requires tailoring for each individual, being cognisant that their needs will change over time. The post-diagnostic pathway, in particular, is therefore not prescriptive but is dynamic and individually tailored, based on personalised assessment, which is reviewed as the person's needs change.

1.6.2 Target audience for the Model of Care

The aim of the Dementia Model of Care is to improve services and clinical responses to meet the needs of people living with dementia and their carers / supporters / family members. There are a range of professionals who engage in the assessment, diagnosis and delivery of post-diagnostic supports. In addition, there are advocates who include people with dementia and family carers / supporters.

Target audience

- Doctors involved in diagnosis, assessment, the communication of a diagnosis of dementia and treatment, e.g. GPs, Geriatricians, Psychiatrists of Old Age and Neurologists.
- Nurses and HSCPs who are involved in assessment of the individual as well as communicating a diagnosis to the person and their family / carers / supporters and providing post-diagnostic interventions and treatments. These can be based in general practice, community and / or primary care, memory assessment services, cognitive / behavioural neurology clinics, specialist non-dedicated services, community-based mental health teams, etc.
- Service providers across community, voluntary, acute, primary and integrated care, who deliver post-diagnostic supports, including day services and home care.
- Service planners across public, voluntary and private sectors who design and develop services and supports for people living with dementia and their families / carers / supporters.
- People living with dementia.
- Supporters, carers and family members.
- Dementia advocates and advocacy groups who voice the concerns and issues arising for people living with dementia and family carers / supporters.
- Policymakers at a national level across government departments.
- Divisions within the Health Service Executive who are developing strategies and policies to bring about change. This includes personnel involved in the National Health Service Reform Agenda and those whose remit includes intellectual disability.

A range of implementation resources will be developed to support roll-out of the model, including materials for service planners/managers.

1.7. The Dementia Model of Care Principles

Five key principles underpin the Dementia Model of Care. The development of these principles is part of our journey to deliver quality care. However, as new evidence emerges and our understanding and insight improve on effective dementia interventions and personalised approaches, these principles will need to be updated. They are, however, intrinsic to the implementation of the current model and to related and developing services.

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Diagram 1: Five principles underpinning the Dementia Model of Care

Citizenship	You are entitled to equitable access to assessment, treatment and degree of care the same way as other citizens; you are involved in decision-making processes.
Person-centred Approach	You are viewed, treated and valued as an individual with dignity and respect; your autonomy and personhood is at the centre of care provision.
Integration	You experience assessment, treatment and care in a coordinated, integrated way that focuses on your individual needs, delivered by the right professional / service in the right way at the right time, in partnership with yourself and your chosen family carer / supporter where possible.
Personal Outcome-focused	The care and support you receive centres on promoting your autonomy, identifying and delivering your desired outcomes wherever possible.
Timeliness	You receive assessment, diagnosis, commnunicating a diagnosis and post-diagnostic support in a timely way, with continuity of care, enabling optimum outcomes. Timeliness is facilitated by equity where services / supports are available and accessible across the country.

1.7.1 Principle 1: Citizenship

Brannelly (2011) states that citizenship is both a status and a practice. As a status, citizens have rights as bestowed upon them by the State, including the right to access health and social services. As a practice, being a citizen infers being part of a community and therefore having responsibilities and obligations to that community. Dementia can affect a person's cognition and communication, and, as a result, people living with dementia have been positioned as passive actors and their full rights as citizens have not always or consistently been realised. Active citizenship in relation to dementia is seen as a move to participation and inclusion in care, research and governance.

Principle: You are entitled to equitable access to assessment, treatment and degree of care the same way as other citizens, where you are involved in decision-making processes.

1.7.2 Principle 2: Person-centred care

The principle of person-centred care is fundamental to good dementia care. This involves taking an individualised approach, recognising and valuing each person's dignity, respecting them and tailoring responses to their unique needs. This means knowing the complete person, their beliefs, interests, likes/dislikes and their values (Fazio et al. 2018); and seeing the world from the perspective of the person with dementia, recognising and accepting their reality, understanding them and what they are communicating, thus validating the subjective experience that is being perceived as the reality for the individual (Brooker 2003).

A person-centred approach also creates a positive social environment. It is a valued concept of preserving human dignity and autonomy (Berenbaum et al. 2017), in which the person with dementia can experience relative wellbeing with opportunities for meaningful engagement. This involves effective communication and centres on enabling the person with dementia to function at his / her optimal level, considering their objective impairments resulting from dementia, and for them to remain engaged with an appropriate interpersonal and social context (Clare 2016). This moves us away from a deficits approach to dementia, where the emphasis is on what the person has lost to a focus on what the person can still do, and towards a 'strengths-based approach'. There is an obligation on service providers to enable and facilitate optimal functioning, which includes effective symptom management.

Fundamental to person-centred care is an acknowledgement of personhood. Kitwood defines this as *'a standing or status bestowed upon one human being by others in the context of particular social relationships and institutional arrangements. It implies recognition, respect and trust.' (Kitwood 1997: 8)* Personhood is the right of every human being; this includes people living with dementia, regardless of their mental capacity at any given time. It is through relationships with others that a full sense of being a person evolves and, as a result, personhood is a product of relationships with others and can be nurtured or diminished, depending on whether the person is being valued or depersonalised (Smebye and Kirkevold 2013).

Principle: You are viewed, treated and valued as an individual with dignity and respect, where your autonomy and personhood are at the centre of care provision.

1.7.3 Principle 3: Integration

The WHO (2016) states that 'integrated person-centred health services are health services that are managed and delivered so that people receive a continuum of health promotion, disease prevention, diagnosis, treatment, disease-management, rehabilitation and palliative care services, coordinated across the different levels and sites of care within and beyond the health sector, and according to their needs throughout the life course'. The HSE's approach to integrated care includes the patient perspective as an organising principle of service delivery. Integrated, patient-centred care focuses is based on illness prevention, patient empowerment, and multi-disciplinary cross-service care planning and delivery; with the aim of addressing fractures in the system, which have resulted in people falling through these cracks.

A large proportion of people with dementia are living with co-morbidities or require a range of health, social and rehabilitative services. This requires that the person's care is delivered in a coordinated, integrated way that focuses on their individual needs; delivered by the right practitioner in the right way at the right time. For example, depending on the presenting symptomatic experience, it could mean that assessment and treatment is under a GP, specialist Neurologist, Psychiatrist of Old Age or Geriatric service. As a result, an integrated care approach is required where coordinated working takes place across disciplines.

Within social and community care, the voluntary sector plays an integral role in the provision of dementia care. Integrated working is required across services to ensure there is no duplication of service or duplication of unnecessary assessment. Such a coordinated system is supported by integrated information structures and effective communication between professional colleagues and service providers.

Principle: You experience assessment, treatment and care in a coordinated, integrated way that focuses on your individual needs, delivered by the right professional / service in the right way at the right time, in partnership with you and your chosen family carer / supporter where possible.

1.7.4 Principle 4: Personal outcome-focused approach

Wherever possible, outcome-focused services and supports aim to achieve the aspirations, goals and priorities identified by individuals (e.g. people living with dementia and family carer / supporters) (Glendinning et al. 2008). A personal outcome-focused approach, therefore, aims to shift engagement with people who use services away from service-led, input-orientated approaches. This is achieved by working towards specific outcomes identified by the person, and where they are unable to express or communicate their desired outcomes, their will and preferences are sought, in line with the Assisted Decision Making Act (2015). These actions will be undertaken during assessment, planning, delivery and review, with a central focus on promoting the autonomy of the individual.

Principle: The care and support you receive centres on promoting your autonomy, identifying and delivering your desired outcomes wherever possible.

1.7.5 Principle 5: Timeliness

Timely diagnosis and early intervention are advocated for within clinical guidelines and national strategies as enabling planning for the future, the involvement of relevant support organisations and potentially relieving the psychological distress experienced by carers (Foley et al. 2019). Timely intervention also improves outcomes for the individual, as well as for their families / carers / supporters and can impact positively on the system.

Timeliness can also be connected and facilitated by equity, where services and supports are available and accessible in a timely way to people regardless of their age, gender, disability, ethnicity or sexuality. This also speaks to geographical equity and the provision of services that are available and accessible to all citizens within a given region.

Principle: You receive assessment, diagnosis, communicating a diagnosis and post-diagnostic support in a timely way, with continuity of care, enabling optimum outcomes. Timeliness is facilitated by equity whereby services / supports are available and accessible across the country.

Palliative care principles

In addition to the above, palliative care principles have been considered within the Dementia Model of Care, which includes a focus on the quality of life of people with life-limiting conditions and their families, not only by treating their physical symptoms but also by attending to their psychological, social and spiritual needs. Palliative care is applicable for people of any age and may be integrated at any point in the disease trajectory from diagnosis through the continuum of care to bereavement.

The principles of palliative care include a focus on quality of life, maintaining good symptom control, a holistic approach, and open and sensitive communication with patients, carers and professional colleagues.

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Appendices

SECTION 2

DEMENTIA DIAGNOSTIC MODEL

2.1. Section Introduction

The timely assessment of dementia involves people being able to recognise potential symptoms / signs of dementia and to seek assessment and intervention. It then involves making and sharing a diagnosis, being considerate of the person's choices around this, at a time and in a way that is most appropriate for the physical, emotional, psychological, medical and other needs of the individual and their family. This then leads to the development of a personalised care plan, co-produced with the person (and their family/carer / supporters as appropriate) (see Section 5 Care Planning) and the subsequent implementation of an individualised therapeutic and supportive post-diagnostic pathway of care (see Section 6 Post-diagnostic Support).

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.

This section will outline the current national context for assessment and diagnostic services, which justifies the need for reform and the development of a national dementia diagnostic model, before then introducing the model developed for the Irish context. This model is inclusive of all people requiring diagnostic assessment, irrespective of their age, gender, disability, ethnicity, dementia subtype or living situation. Specific diagnostic considerations are outlined for certain groups. In addition, commonalities, which apply across diagnostic services, will be explored, with targets and practice recommendations for assessment and diagnosis outlined.

2.2. Current Dementia Diagnostic Services

Despite the known benefits of a timely diagnosis and early intervention, dementia remains hugely undetected and under-diagnosed in Ireland. Two separate Irish hospital-based studies (Cork and Dublin) had very similar findings, with only 36% of the people aged 70 and over with dementia admitted to hospital having ever received a formal diagnosis (Timmons et al. 2015, Briggs et al. 2017). This contrasts with the approximately 70% diagnostic rates in England, Scotland and Northern Ireland (Alzheimer's Research UK 2018). Revez et al. (2018) summarise the evidence that giving a diagnosis of dementia does not have a significant negative effect on people living with dementia and their families and communicating a diagnosis may actually be associated with reduced anxiety levels for the person with dementia.

Currently in Ireland, there is a lack of a uniform process across diagnostic services, with large variations in waiting times, Multi-disciplinary Team (MDT) involvement, and the type of services on offer (Gibb and Begley 2017, NDO 2019). Inequity of access to diagnostic services also exists, with no dedicated memory clinics in 50% of counties in 2017. As of May 2023, there are four Regional Specialist Memory Clinics (RSMCs) operational, one at St James's Hospital, and the other at Tallaght University Hospital with two further RSMC's planned for Galway University Hopsital and the Mercy Unviersity Hospital, Cork. In addition, the National Intellectual Disability Memory Service (NIDMS) operates out of Tallaght University Hospital. Both have the MDT skill-mix needed to assess and diagnose more complicated presentations. The more complex and often unmet needs of people with intellectual disabilities required a unique approach building on existing capacity/experience in order to establish a national resource. Another important resource is a number of ID services providers with specific expertise and MDTs to support assessment of memory concerns and provide post-diagnostic support to people with ID attached to their service. Next steps are for these services to make referrals to and obtain advice from the NIDMS for cases with complicating factors.

There are also some locally based ID memory services offering assessment and more extensive post-diagnostic supports. In addition to the above, there are a number of cognitive / behavioural neurology-led clinics nationally. There has been significant investment in Memory Assessment & Support Services (MASS), these services will generally assess and treat older persons with a typical and clear presentation. To date, 10 MASS sites have been funded through the National Service Plan (NSP) 2021, NSP 2022 and NSP 2023. It is envisioned that continued expansion of this diagnostic model will be supported by comprehensive implementation plans including annual submissions as part of the HSE NSP process.

The accurate diagnosis of dementia can be challenging. A single type of dementia can present differently for different individuals in the initial stages. As outlined in Section 1, there are also several hundred subtypes or causes of dementia, albeit most of these are rare. People presenting with Young Onset Dementia (YOD) encounter even more diagnostic challenges, associated with subtle cognitive deficits, high likelihood of a rarer dementia type and unique social factors (Fox et al. 2020). In addition, several non-dementia conditions can present in a similar way to dementia. These include delirium, depression/anxiety, hypothyroidism, certain vitamin deficiencies and normal ageing (Foley et al. 2019). Less common presentations can also be challenging to diagnose, whether as a dementia and / or a dementia subtype. These presentations include:

- atypical presentations, such as posterior cortical atrophy variant of AD (visual perception issues)
- prominent non-cognitive symptoms, e.g. mood or behaviour changes
- younger people with suspected dementia
- where there is a history of a significant head injury
- rapidly progressive symptoms
- intellectual disability
- chronic neurological disorders
- complex psychopharmacology

- communication disorders and medical co-morbidities, including visual and hearing impairment.

Given the complexities and challenges identified across all ages, the dementia diagnostic model provides clear guidance to support clinicians in conducting a comprehensive assessment, leading to a timely diagnosis and appropriate individualised post-diagnostic supports. Added to the current shortfall in diagnostic service capacity is the projected annual increase in the incidence of dementia in Ireland (see Table 1 above). This predicted increase in people living with dementia requires this Dementia Model of Care to undergo regular review as demand for services increases; combined with any new and emerging evidence, which will inform care pathways such as any future modifiable treatments. This has implications in costing the model and for future implementation.

2.3. Diagnostic Model

Taking into consideration the available evidence, recommendations and views from consultations, the Diagnostic Project Steering Committee (2017–2019) reached agreement on a dementia diagnostic model appropriate for use within the Irish context. The model is informed by the European research project Act on Dementia. Act on Dementia was a three-year EU joint action project aimed at promoting collaborative actions among Member States to improve diagnostic rates, enhance quality of life, and improve accessibility to post-diagnostic supports and services for people living with dementia and their carers (Krolak-Salmon et al. 2019). The model has three levels of assessment (see Diagram 2):

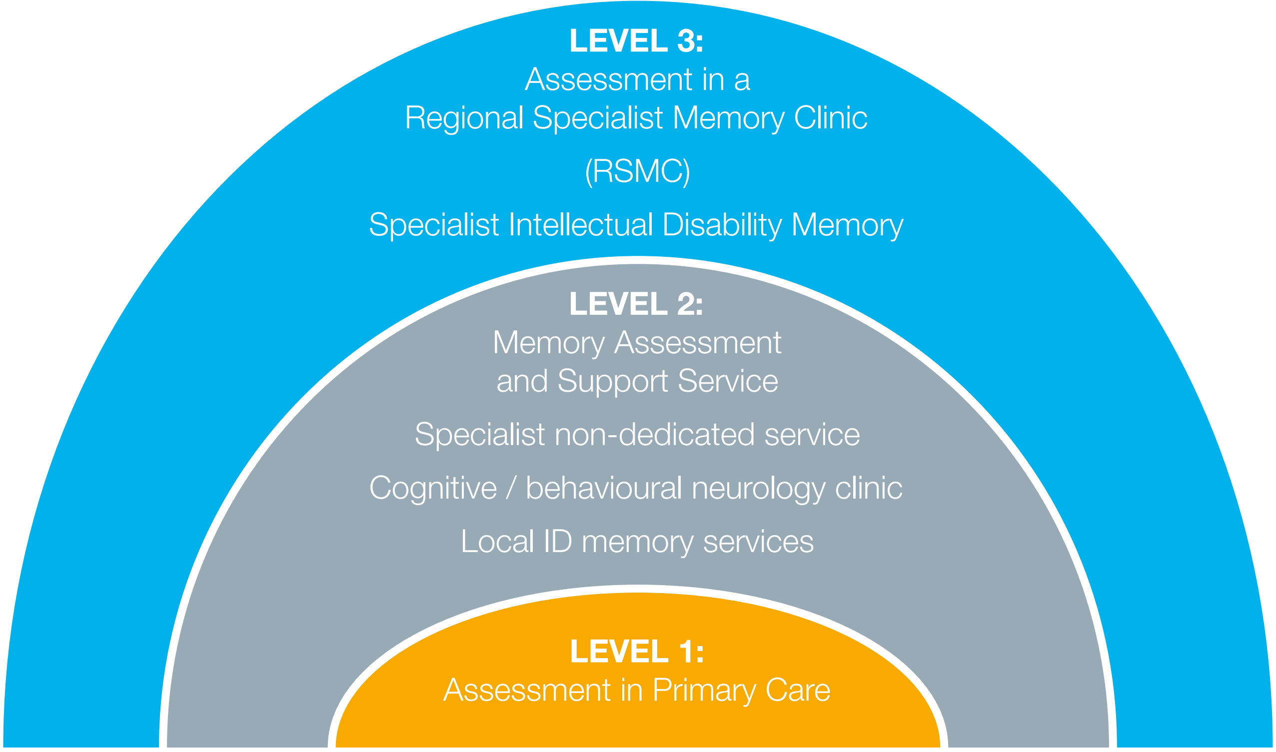
Level 1: Assessment in Primary Care

Level 2: Assessment in a Memory Assessment and Support Services (MASS) or other specialist service

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

Depending on the person's symptomatic presentation, their assessment and treatment may be led by different specialist services at Level 2. This could be the Memory Assessment and Support Services, older person's acute and outpatient clinics, cognitive / behavioural neurology services, or Psychiatry of Old Age services (out-patient clinics, acute care and mental health services). The core principle of integration is central to the appropriate provision of any individual's care in such scenarios to ensure there is appropriate triaging of patients to the right service and cross-referral for access to appropriate treatment, including access to post-diagnostic support.

Diagram 2: Dementia diagnostic model



Level 1: Assessment in Primary Care

This involves assessment carried out by a GP which may or may not include support and information from any of the Enhanced Community Care (ECC) Programme services, including local Community Specialist teams for older people (ICPOP) and other disciplines within the Community Healthcare Network (CHN) model such as the Practice Nurse, Occupational Therapist and Public Health Nurse,. This usually takes place in the primary care setting. However, depending on individual circumstances such as level of frailty, etc., the assessment may take place in the individual's home or in a community healthcare facility or residential care setting. Where appropriate, people diagnosed in primary care can be referred to the local MASS to avail of brain health assessment/interventions and / or post-diagnostic support services, ensuring equal access to services (see 2.6 below for information on brain health and PDS services connected to the MASS). There are some people who will be diagnosed in residential care where travel to a memory service would be too stressful. In a similar way, people with another primary co-morbidity or a life-limiting condition may get no added benefit from attending the MASS. The decision on appropriateness of referral to MASS is at the discretion of the primary care physician. In such instances, where the person is not referred to a MASS, the GP is the point of contact.

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

Dedicated clinic/service: In Ireland, these are currently mainly provided by geriatricians with a special interest in dementia and are usually called either 'memory clinics' or a MASS, with some provided by Old Age Psychiatrists, and / or a service where there is joint working. There is also a more recent development of cognitive / behavioural neurology services seeing those with YOD and less common presentations at a dedicated clinic (often termed cognitive / behavioural neurology clinics).

Specialist non-dedicated service (SnDS): This includes Older Persons, Neurology and Psychiatry of Old Age (POA) 'generic' out-patient clinics where there is no cohorting of patients by presentation or diagnosis, and the responsible consultant is usually not supported by a dedicated MDT with expertise in dementia, and there may be limited time assigned for communicating a diagnosis of dementia and care planning. Older person's services incorporate community-based and, to a lesser degree, domiciliary assessment. POA/Mental Health Services for Older People are community-based and frequently provide domiciliary-based assessments.

Locally based Intellectual Disability Memory Clinic/ Service: These are specialist clinics which have been established within ID services who have a particular interest and expertise in dementia and intellectual disability. They are generally supported by a psychiatrist with a special interest in dementia and ID and can often be led by ANPs/ CNSs in dementia and supported by a multi-disciplinary team that includes psychology, speech and language, physiotherapy, occupational therapy and social work. These ID memory services may support assessment and post-diagnostic supports and may integrate brain health into their care planning. This level 2 clinic may refer to the National Intellectual Disability Memory Service at level 3 for specialist consultation or support.

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

Based in tertiary care, diagnostic assessment in a Regional Specialist Memory Clinic is generally intended for younger, atypical or unclear presentations that require a more detailed assessment, or where the person wishes to participate in a more detailed and specific aetiological evaluation. Such a clinic may also provide a Level 2 service for the local population in the absence of a local MASS and subject to sufficient resources. However, it is envisioned that the RSMC will usually refer to the local MASS. The RSMC integrates brain health into their service as part of immediate care planning but will offer referral to the individual's local MASS for PDS and for more sustained brain health intervention if required.

2.3.1 Note on coordination of care

Overall, coordination of the person's care will reflect their range of co-morbidities and other issues. For some people, where dementia is the only condition requiring treatment, care will be provided by the MASS. Where dementia is part of another pre-existing neurological condition, coordination of care rests with the neurology or other relevant service, Parkinson's service or relevant other. Where dementia is one of multiple co-morbidities the person's care will be coordinated by the original treating team, e.g. older persons, Psychiatry of Old Age, GP/primary care team, Community Specialist Teams for older people (ICPOP). For further details on care planning, see Section 5.

While specialist education and clinical expertise is a prerequisite for staff practicing in memory assessment services (Level 2 and level 3) it is likewise expected that HSCPs practicing in non-dementia specific roles avail of dementia-specific education to support and inform their practice. Dementia-specific education programmes must empower participants to adopt a person-centred and human-rights based approach to care. Current dementia-specific education programmes accessible nationally include: the National 2 Day Programme entitled 'Enhancing and Enabling Wellbeing for the Person Living with Dementia' and the three-hour primary care programme entitled 'Dementia Care in Primary Care – An Interprofessional Approach'. Community Health Network Managers can liaise with local Centres of Nursing & Midwifery Education (CNME) regarding availability of dementia-specific training locally for HSCP attached to primary care teams.

Practice Recommendations

- HSCPs working in non-dementia specific roles must participate in dementia-specific education programmes to inform and support practice.
- All dementia-specific education programmes must empower participants to adopt a person-centred and human-rights based approach to care.

2.4. Targets for Dementia Diagnostic Services

As outlined above, variations currently exist in the availability of Level 2 and Level 3 services nationally, creating a disparity in both availability and accessibility of services, often resulting in people who present with atypical or unclear presentations of suspected dementia having to travel long distances to acquire a specialist diagnostic assessment. Based on current population diagnostic needs and views from consultations (see Appendix E), as well as speaking of the health reform agenda to deliver care closer to home, the following capacity for diagnostic assessment services was agreed (see Targets 1–3). These targets include existing memory assessment services and cognitive / behavioural neurology clinics and will ensure equity of access to diagnostic services nationally.

Additional resources will be required to meet future diagnostic demands due to demographic changes and including any disease modifying treatments (DMTs)[3] when approved; therefore, these targets should be reviewed within two years. A supplementary document will be required to outline key activities/interventions associated with the roll-out of DMTs, when approved.

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 in each site.
TARGET 3	There should be one National Intellectual Disability Memory Service (NIDMS), with national access and regional outreach.

2.4.1 Multi-disciplinary Team (MDT) composition

MDT composition will vary across Level 2 and Level 3 assessment services. Following extensive consultation, the MDT composition, including the scale and whole-time equivalent (WTE) of each post, for existing and newly developed memory assessment services, was reached (see Target 4 and Target 5 below). This MDT composition is reflective of (i) current demand, (ii) the need to support integrated approaches, (iii) assessment by the right professionals, at the right time and in the right way, and (iv) the necessary intervention level. However, based on future possible changes in demand, particularly the possible availability of DMTs, Targets 4 and 5 should also be reviewed within two years.

People living with dementia will often require additional resources depending on their assessed need, such as counselling, which will continue to be accessed through existing services, such as in community healthcare networks and ambulatory care hubs. In particular, MDT members will liaise with and refer to local Dementia Advisers, Community Dementia Clinical Nurse Specialists and community-based Social Workers, as appropriate (see Section 6 for more details on PDS).

To ensure that the varied and often complex needs of the person with dementia and their families are addressed, all HSCPs attached to the MASS and RSMC should be at senior grade or higher, having acquired a comprehensive knowledge base and significant clinical expertise in the field of dementia. Consultants appointed to these services should have sub-specialist expertise in dementia/ neuro-degenerative diseases. Bracken-Scally et al. (2020) recommends in the second *Irish National Audit of Dementia Care in Acute Hospitals (INAD-2)* report that any dementia-specific medical, nursing, or HSCP post should have a minimum of a Postgraduate Diploma in Dementia Care on appointment or undertake this within the first year of taking up the post.

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[3] Disease-modifying treatments (DMTs) target the pathogenic pathway of Alzheimer's disease and other neurodegenerative proteinopathies, which may delay the onset or progression. DMTs need to be initiated before the development of moderate-to-severe dementia, implying a need to identify suitable people early in the disease process, including in MCI, and to ascertain subtype, even in MCI. DMTs are still under extensive research.

TARGET 4	The minimum composition of Level 2 Memory Assessment and Support Service: • Consultant 1.0 WTE • Senior Neuropsychologist 0.5 WTE • Senior/Specialist Registrar 1.0 WTE • Advanced Nurse Practitioner 1.0 WTE • Clinical Nurse Specialist 2.0 WTE • Senior Occupational Therapist 1.0 WTE • Senior Physiotherapist 1.0 WTE • Senior Speech and Language Therapist 1.0 WTE • Senior Social Worker 1.0 WTE • Senior Dietitian 0.5 WTE • Neuro-radiologist 0.2 WTE • Clerical Support (Grade 4) 2.0 WTE

*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.

TARGET 5	The minimum composition of Level 3 Regional Specialist Memory Clinic: • *Consultant 2.0 WTE • Senior/Specialist Registrar 2.0 WTE • Advanced Nurse Practitioner 1.0 WTE • Clinical Nurse Specialist 2.0 WTE • Principal Neuropsychologist 1.0 WTE • Clinical Specialist Occupational Therapist 1.0 WTE • Clinical Specialist Physiotherapist 1.0 WTE • Senior Social Worker 1.0 • Senior Dietitian 0.5 WTE • Clinical Specialist Speech and Language Therapist 1.0 WTE • Neuro-radiologist 0.2 WTE • Clerical Support (Grade 4) 2.0 WTE

*Due to the higher level of complexity, the RSMCs require dedicated input from a Geriatrician, Cognitive / behavioural Neurologist and Psychiatrist of Old Age. Depending on anticipated diagnostic needs and complexity, decisions can be made locally as to which discipline/service is the most appropriate to lead the diagnostic assessment for a given patient and who is best placed to participate at the consensus meeting.

The MDT composition listed above is integral to the diagnostic and therapeutic activities of a MASS or RSMC, such as diagnostic assessment and tests, diagnosis, the communication of a diagnosis of dementia, brain health assessment and interventions, and care planning. For the MASS, therapeutic activities will also include cognitive and psycho-social interventions, as appropriate, and other post-diagnostic support. Target 18 below identifies the MDT roles and functions for the good communication of a diagnosis of dementia, while Section 5.5 briefly describes the MDT roles and functions associated with brain health interventions and post-diagnostic support.

The MDT outlined above is the minimum recommendation for all new Memory Assessment and Support Services and the enhancement of existing memory assessment services.

2.4.2 Function of MDT members in diagnostic assessment

Integrated, collaborative and multi-disciplinary approaches to dementia care are central to the approach, where MDT members will work together to identify trans-disciplinary skills and shared learning to meet the needs of each patient in an efficient manner. Evidence shows that integrated and collaborative working allows for a rapid response to the assessment and management of individuals with dementia in a person-centred manner (Onyike 2016, Martin et al. 2020, Volpe et al. 2020).

The MDT members with specific functions in relation to **diagnostic assessment,** listed below are:

***Consultant:** The consultant is the clinical lead for the MDT and the service, including research and audit. The function of the consultant includes but is not limited to:

- Initial triage of incoming referrals
- Diagnostic assessment
- Interpreting results/outcomes of the diagnostic work-up
- Making a formal diagnosis.

*While any consultant might see a person with a primarily amnestic (memory) problem, within an integrated dementia diagnostic service, it is expected that referrals will be triaged so that a particular consultant takes the lead for an individual person's initial diagnostic work-up, depending on the person's presentation and the time resource for that consultant in the service. For example, the geriatrician might initially see an older person, or a person with complex medical co-morbidities; a neurologist, may see a younger person or any person with complex non-amnestic symptoms; a Psychiatrist of Old Age, may see a person with prominent altered behaviour or suspected altered mood, apathy or psychosis. Each service is expected to agree pathways within the service to access the necessary consultant input for an individual person's needs, based on initial referral details and subsequent initial assessment.

Registrar: The registrar's role supports the diagnostic work-up and the formulation of diagnosis and management/treatment plans and provides training for future clinic capacity. Their function includes but is not limited to:

- Diagnostic assessment, including lumbar puncture for cerebrospinal fluid (CSF)
- Interpreting results/outcomes of the diagnostic work-up
- Making a formal diagnosis under consultant supervision.

Clinical Nurse Specialist (CNS): offers practitioners a career pathway incorporating professional development within an inter-professional team structure. The specialty area is a defined area of nursing practice. This specialist practice encompasses a major clinical focus of care to patients or clients and their families in hospital, community and outpatient settings. The specialist nurse works with medical, pharmacy and Health & Social Care Professional colleagues (NCNM, 2008). The Office of the Nursing & Midwifery Services Directorate (ONMSD) developed a Framework for the Establishment of Clinical Nurse / Midwife Specialist Posts: Intermediate Pathway - 4th edition to guide in the development of CNS posts.

Advanced Nurse Practitioners (ANP): Advanced nurse practice nursing is defined as a career pathway for registered nurses, committed to continuing professional development and clinical supervision, to practice at a higher level of capability as independent, autonomous and expert practitioners. Advanced Nurse Practitioners (ANPs) clearly articulate domains of knowledge and skills specific to the area of gerontology and have met the regulatory Board's Criteria for Registration to enter the Advanced Practice Division of the Register (NMBI, 2017). Building on the additional competences achieved for nurse registration, the standards and requirements specify the competences required to register as an Advanced Nurse Practitioner (ANP), thus facilitating a career pathway for nurses who commit to the challenges and opportunities of achieving higher levels of capability. The National Clinical Programme for Older People (NCPOP) developed a Clinical Guidance Framework to provide a clear pathway for the development of ANP roles, assist ANPs to identify their developmental needs and to define a common set of capabilities for ANPs Older Persons built around NMBI's six domains of competence.

An autonomous ANP in Gerontology is accountable and responsible for advanced levels of decision-making and the management of a patient caseload. The crucial factor in determining advanced nursing practice is the level of decision-making and responsibility, rather than the nature or difficulty of the task undertaken by the practitioner. Nursing knowledge and experience will continuously inform the ANP in gerontological decision-making. The ANP works in collaboration with medical or other healthcare professionals (NMBI, 2017).

Neuropsychologist: The neuropsychologist contributes to the differential diagnosis, especially in atypical or unclear presentations through the assessment of memory, cognitive functioning, and behavioural and emotional changes. The role includes:

- The administration and interpretation (including consideration of pre-morbid function) of comprehensive neuropsychological testing to assess the degree of impairment and cognitive profile
- Identification of other possible causes of cognitive/ functional/behavioural decline such as depression or delirium
- Contributing to the diagnostic consensus meeting.

Occupational Therapist: The Occupational Therapist, contributes to the differential diagnosis and overall holistic assessment of the patient through:

- Cognitive assessment
- Functional assessment
- Holistic needs assessment
- Assessment of risk/safety (including driving) where indicated
- Contributing to the diagnostic consensus meeting.

Neuro-radiologist: Their role in the diagnosis process, especially in the rarer dementias or atypical presentations, includes:

- Providing guidance in choosing the correct imaging test to aid diagnosis
- Interpreting neuro-imaging studies in the clinical context to inform diagnosis.

Inclusion of the Physiotherapist role – what are the roles & responsibilities?

Physiotherapist:

The Physiotherapist contributes to the differential diagnosis and overall neurological assessment of the patient. Physiotherapists support individuals to develop, maintain and restore movement and function. They:

- Support people to stay physically active.
- Promote a healthy lifestyle to maximise quality of life.
- Prevent falls and fractures.
- Manage pain.
- Reduce manual handling risk for carers / supporters.

Speech and Language Therapist: Their role in the diagnostic processes, especially in those presenting primarily with language deficits, includes:

- Undertaking assessment of communication to clarify the nature and severity of deficits
- Facilitating the assessment of the patient by others where communication may be a barrier
- Contributing to the diagnostic consensus meeting for selected patients
- Undertaking swallow assessment as part of initial needs assessment, where indicated.

Dietitian: The dietitian's input at the assessment and diagnostic stage is to:

- Undertake nutritional assessment and identify the nutritional needs of the individual.

Practice Recommendations

Members of the MDT will work together to identify trans-disciplinary skills and shared learning to meet the needs of each patient in an efficient manner.

For information on which members of the MDT might be present at the communication of a diagnosis of dementia

Background and Principles
Dementia Diagnostic Model
Dementia Assessment and Diagnostic Pathway
Giving a Diagnosis of Dementia
Care Planning and Immediate Post-Diagnostic Support
Dementia Post-Diagnostic Support
Appendices

meeting (where the diagnosis is told to the person) see Target 18.

For information on the roles of the different disciplines in post-diagnostic support, please see Section 5.

2.4.3 Dementia data

The HSE Corporate Plan 2021–2024 outlines the need for robust data, information to support planning, and decision-making and to monitor the impact of interventions on services and on outcomes for patients. In relation to dementia data nationally, there is an information gap relating to patient characteristics, service utilisation, treatment courses and outcomes for those living with dementia. As part of the Dementia Model of Care, there is an onus on specialist services to collect standardised data on dementia to support developments in these areas and to manage and monitor the implementation of the model's targets.

The *Development of a Model for the National Dementia Registry* (Hopper and Bowen 2021), commissioned by the National Dementia Office, outlines a recommendation for the roll-out of standardised data for dementia across service sites. An important output from this project will be the identification of an agreed minimum dataset, which should be rolled out and used by specialist services. There is a responsibility among the MDT to gather and manage standardised data pertaining to their service and patient characteristics.

TARGET 6

The collection of data on dementia is 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 proposed use of the dementia minimum dataset.

2.5. Scope of the Diagnostic Model

This diagnostic model applies to any person presenting with symptoms suggestive of dementia, irrespective of age, gender, disability, ethnicity or care setting. This recognises that everyone has the right to a timely diagnostic assessment and post-diagnostic support. The model acknowledges that specific considerations are required within the diagnostic pathway for key groups, as highlighted below, to ensure the pathway is inclusive of everyone's diagnostic needs.

Fundamental to respecting the individual's autonomy and in line with the Assisted Decision Making Capacity Act (April 2023), the model assumes the individual has capacity to make decisions with regard to participating or not participating in the diagnostic assessment process unless proven otherwise.[4] Prior to commencement of assessment, an explanation of the diagnostic process and possible outcomes must be provided to the individual, ensuring informed consent is obtained for each aspect of the assessment and individual autonomy respected and upheld (NICE, 2018). This involves the process of communicating a diagnosis of dementia commencing at the first meeting/initial assessment. The physician ascertains how much the person knows about their problem, what level of insight do they have? What are their wishes in relation to the level of detail they would like if the assessment results showed that they have dementia? The physician, HSCP and nurse(s) need to be aware that a person's wishes in relation to the level of detail they would like, could change over time and the person's opinion should be sought throughout the assessment process. (See Section 4.2 for more details).

TARGET 7

With their consent, 100% of people presenting with symptoms of suspected dementia should receive a comprehensive diagnostic assessment.

Practice Recommendations

- Process of communicating a diagnosis of dementia begins at the initial assessment.
- The person is informed about the process of assessment and is provided with written and verbal information on what to expect, to support their decision-making and active involvement in their care.
- The information should be provided in the person's preferred language, including sign language, using a professional interpreter where necessary. In some circumstances, simplified explanations, pictures or communication aids may also be required.

Useful Resource:

Lost in translation? Good practice guidelines for HSE staff in planning, managing and assuring quality translations of health-related material into other languages

2.5.1 People with early cognitive symptoms

The early signs and symptoms of dementia can be subtle, often subjective in nature, difficult to detect, and can vary considerably from one person to another. Early-stage dementia is not always characterised by memory impairment or impaired reasoning. Depending on the dementia subtype, initial symptoms may involve changes in mood or language, while for others a significant change in personality may occur [see section 2.5.2]. Some people presenting cognitive symptoms may not fulfil the criteria for a dementia syndrome on assessment, but may fulfil the criteria for Subjective

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[4] Under the ADM (2015), a person lacks capacity to make a decision if he/she is unable to understand the information relevant to the decision; to retain that information long enough to make a voluntary choice; to use or weigh that information as part of the process of making the decision; to communicate his or her decision (whether by talking, writing, using sign language, assistive technology, or any other means) or, if the implementation of the decision requires the act of a third party, to communicate by any means with that third party.

Cognitive Impairment (SCI), sometimes referred to as Subjective Memory Impairment (SMI), Subjective Cognitive Decline (SCD) or pre-Mild Cognitive Impairment (MCI).

There is no consistency in how SCI is defined, however, the term relates specifically to:

- The person noticing a memory issue
- Detailed cognitive tests are normal.

TARGET 8	100% of people diagnosed with MCI offered follow-up appointment* for reassessment of cognition every 12–24 months, until stability or progression is evident. *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.

TARGET 9	100% of people diagnosed with MCI should be offered specific interventions and supports in a timely manner and in response to identified need and respecting each individual's preferences. This includes brain health interventions and cognitive therapies.

Between 50% and 80% of older individuals (70+) who perform within normal range on cognitive tests, report some form of perceived cognitive decline when asked. Longitudinal reports suggest people with SCI are at an increased risk of progression to MCI and dementia (Jesson et al. 2014, Mendonça et al. 2015).[5]

When considering MCI, the term 'mild' is used for comparison to the more severe cognitive and functional symptoms associated with dementia and does not imply that the individual only experiences mild symptoms. "The DSM-5 (APA 2013) provides guidance on the diagnosis of MCI, indicating that "a diagnosis of MCI requires evidence of modest cognitive decline from a previous level of performance in one or more cognitive domains, preferably documented by standardized neuropsychological testing, with preserved function". MCI can be further categorised as amnestic MCI (with memory impairment) and non-amnestic MCI (problems with language, attention, perception, executive functioning, or a combination of these problems).

The identification of MCI is very important, as it is associated with a much higher risk of developing dementia in the future, which can be, to a degree, attenuated or delayed by brain health interventions and cognitive therapies (and also potentially by DMTs, if available in Ireland in the future). The cumulative risk of progression to dementia in MCI has been estimated to range from approximately 22% to 39%, with the majority of individuals developing Alzheimer-type dementia (Mitchell and Shiri-Feshki 2009). This data was published prior to the adoption of AD biomarker ascertainment in MCI, where positivity confers a far higher risk of progression to dementia. However, not everyone with MCI will develop dementia; some will remain stable or even return to normal cognition (Roberts et al. 2014, Barnes et al. 2014). The risk of progression is higher with amnestic deficits on cognitive testing (i.e. poor short-term recall), with about 10–15% per year going on to develop Alzheimer's disease. People with amnestic MCI who are identified as being at high risk of progression need to be carefully followed up, with personalised brain health interventions and access to cognitive therapies as appropriate [see section 6 for further details of post-diagnostic support].

In the last decade, cerebrospinal fluid (CSF) analysis was incorporated into routine work-up for patients presenting MCI. It is a validated biomarker in the distinction of AD pathology from a non-AD process. See Appendix C for further information on CSF. The potential for use of Disease Modifying Therapies (DMT) in MCI may have significant implications for future clinical care pathways.

Practice Recommendations

Where clinical indicators of MCI are identified, a clinical assessment based on the DSM-5 diagnostic criteria (APA 2013) for MCI should be carried out to confirm the diagnosis.

2.5.2 People with language, behaviour, motor and other presentations (non-amnestic dementias)

A proportion of people who present with suspected dementia, especially among people who are aged under 65 years, may not experience memory impairment as their main symptom or most prominent problem (i.e. with an amnestic syndrome), and instead may present with difficulties or changes in one or more of the following:

- language
- visuo-spatial functioning or perception
- behaviour
- executive functioning

This is often termed non-amnestic syndrome. The latter would include 'variant' presentations of Alzheimer's disease (such as behavioural/dysexecutive Alzheimer's disease, logopenic aphasia, posterior cortical atrophy); behavioural and language variants of frontotemporal dementia (FTD) and those with overlapping FTD-Amyotrophic Lateral Sclerosis (ALS); the Lewy Body dementias (both Dementia with Lewy Bodies (DLB) and Parkinson's Disease Dementia (PDD); the primary tauopathies (Progressive Supranuclear Palsy (PSP) and Corticobasal Syndrome/Degeneration (CBS/D); complex vascular dementias such as Cerebral Amyloid Angiopathy (CAA) and CADASIL; Huntington's disease (HD),

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[5] A meta-analysis study found that those with SCI had an annual conversion rate of 6.6% to MCI and a 2.3% conversion rate to dementia, while over a 4-year period, 24.4% of those with SCI developed MCI and 10.9% developed dementia (Mitchell et al. 2014).

and other rarer neuro-degenerative, neuro-genetic and neuro-metabolic disorders.

Although the prevalence of these conditions is much lower than that of amnestic dementias, when put together they represent a substantial group of people requiring specialist diagnostic assessment.

Among people who have Alzheimer's disease, a proportion will present with non-amnestic syndromes as a variant presentation.[6] Other forms of dementia that present with a non-amnestic syndrome include Dementia with Lewy Bodies (DLB), frontotemporal dementia, and the atypical Parkinsonian syndromes (Progressive Supranuclear Palsy; Corticobasal Degeneration).

Although the average age for someone with FTD is 58 years, it is known to be underestimated in people aged over 65 years. Impairment in executive function and behavioural/ personality change can be mistaken as mood-related or primary psychiatric phenomena. As a result, all people aged over 40 years presenting with acquired speech and language difficulties should be referred to a specialist service.

Similarly, there is a known underestimation of Dementia with Lewy Bodies, and of atypical Parkinsonian syndromes (PSP, CBD), with under-recognition of cognitive and behavioural change. At a primary care level, GPs and non- specialists need to have a high index of suspicion for possible dementia amongst those who present with unexplained falls, gait disturbance and / or subtle features of Parkinsonism, in the context of cognitive decline.

People experiencing non-amnestic symptoms require timely referral to specialist memory diagnostic assessment services and are generally not suitable for assessment in primary care or a non-dedicated service. Depending on the individual circumstances, the assessing service will usually be the nearest RSMC (where there will be integrated neurology, older persons and POA input and a range of highly skilled MDT members); or a stand-alone cognitive / behavioural neurology clinic if not integrated with the nearest RSMC or MASS (especially for people aged under 65).

Regardless of a person's age, the key is that the assessing service has an adequate skill-mix to meet the person's specific diagnostic needs, or, if not, will refer onwards without delay. In practice, for a referrer who is unsure of the best service, the local MASS can quickly triage the case (sometimes needing to do some initial fact-finding or preliminary assessment) and divert to other diagnostic services if more appropriate (e.g. to a generic Psychiatry of Old Age Service if there are prominent behavioural symptoms).

Practice Recommendations

- For people with language, behaviour, visuo-spatial and other presentations (non-amnestic), a Level 2 MASS can triage and decide on the most appropriate diagnostic pathway for the person (e.g. to a RSMC, a cognitive / behavioural neurology clinic, or a POA service). Alternatively, where the GP has identified the syndrome as predominantly non-amnestic, direct referral to an RSMC is also appropriate.
- Dementia-specific education/training for GPs, nurses and HSCPs must include dementia syndromes that present with language, behavioural, motor and other presentations (non-amnestic symptoms), thus supporting timely recognition of a suspected dementia and the timely referral to an appropriate diagnostic service.

2.5.3 Young Onset Dementia (YOD)

In Ireland, dementia in people aged 65 years or under has been reported to account for up to 10% of all cases (Pierce et al. 2014). Although Alzheimer's disease is the most common subtype of YOD, a lower proportion of cases are due to Alzheimer's disease in YOD than in Late Onset Dementia (LOD), with a much higher proportion of FTD and other dementias, associated with non-amnestic presentations [see section 2.5.2 above]. In addition, genetic causes also play a far greater role in YOD than in LOD. For people with intellectual disability and Down Syndrome living with dementia, 50–75% are under the age of 65 years.

Evidence highlights that younger people with suspected dementia experience significant difficulties acquiring a timely diagnosis, with reports of considerable delays and inaccuracies (Fox et al. 2020).

Dementia in younger/middle-aged adults is often viewed as complex for a variety of reasons, such as:

- Rarer subtypes
- Symptoms often non-memory related
- Pre-existing intellectual impairment
- May be linked to genetic or metabolic disease
- May have young children
- May be still in employment
- May be financially supporting the family
- Associated with increased carer stress and relationship difficulties.

'Young Dementia UK' developed an optimum care pathway for YOD, providing explicit recommendations for diagnosis that are broadly reflective of the recent NICE guidelines for diagnosing dementia (NICE 2018, Carter et al. 2018). Fox et al. (2020) provides evidence-based recommendations for the diagnostic processes of YOD in Ireland, informing the model and applied to the diagnostic pathway (see Appendix B for referral pathway for person with suspected YOD).

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[6] For example, behavioural/dysexecutive phenotype, logopaenic aphasia, posterior cortical atrophy. Variant presentations of AD are more prevalent amongst younger-onset patients with AD.

TARGET 10

100% of people aged under 65 years with suspected dementia are offered referral to a specialist service for assessment (Level 2 MASS, Level 3 RSMC, or Cognitive/ behavioural Neurology Service), where there is access to a neuropsychologist assessment and neurologist and an established pathway to post-diagnostic support.

Practice Recommendations

Any person with a cognitive syndrome in the context of a known or suspected familial neurodegenerative disease should be referred to a specialist service for assessment (Level 3 RSMC, or cognitive / behavioural neurology clinic).

2.5.4 People living with intellectual disabilities

Dementia associated with Down Syndrome is a common sub-group of people with YOD, where Alzheimer's disease occurs at a much younger age, compared to the general population. By the age of 40 years, almost all adults with Down Syndrome will have sufficient senile plaques and neuro-fibrillary tangles for a neuro-pathological diagnosis of Alzheimer's disease, although they may not all show clinical symptoms at this time (Lamar et al. 2011). In Ireland today, it is estimated that about 700 people have Alzheimer's disease related to Down Syndrome (Cahill et al. 2012, Pierce et al. 2014). However, this figure is likely to be much higher given the evidence derived from recent studies (McCarron et al. 2017a, McCarron et al. 2017b).

Diagnosing dementia in people with an intellectual disability is complex because the person may already have difficulties in areas such as memory, language, and ability to attend independently to self-care needs. The assessment tools used to aid the diagnosis of dementia in the general population are not appropriate for people with Down Syndrome. Therefore, there is a need to observe and identify specific changes in each respective person, comparing early-assessed baseline with periodic reassessments.

A diagnosis of dementia can be made with a high degree of accuracy where there is good and reliable information available across a number of areas, including social, physical and mental health history. The most valuable information to assist with diagnosis comes from the history of change described by family or carers who have known the person for quite a long time. Changes in other aspects of behaviour are also relevant, such as changes in personality, mood, and general loss of interest in day-to-day events. These are sometimes the first changes observed and reported by family or staff.

An annual brain health check is recommended for adults with Down Syndrome from 40 years in order to capture the person's optimal function and performance. This baseline can be used as a measure against which future functional and cognitive decline can be assessed.

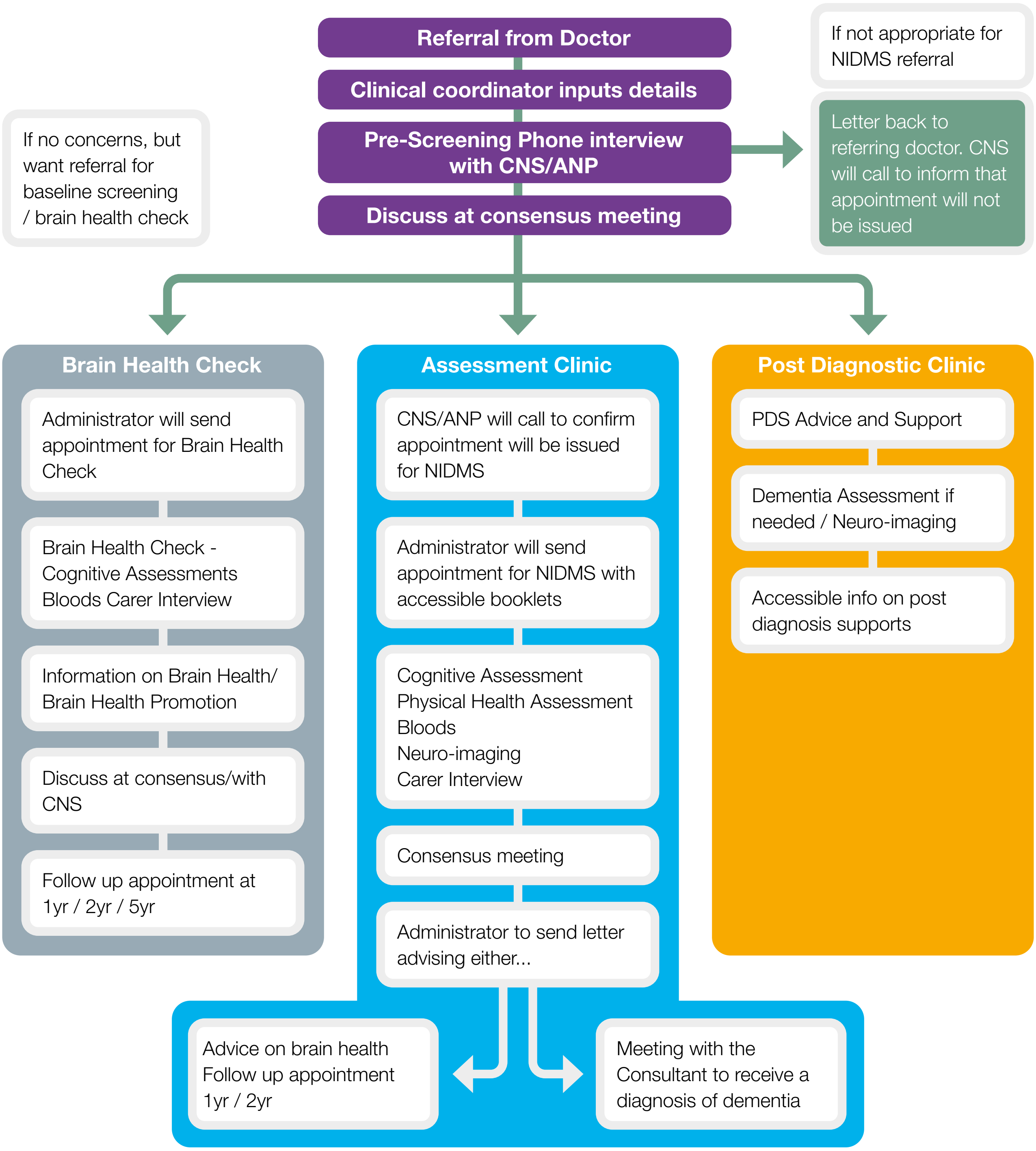
The National Intellectual Disability Memory Service (NIDMS), based in Tallaght University Hospital, Dublin, provides access to specialist memory assessment, comprehensive diagnostic work-up and post-diagnostic support for persons presenting memory concerns. This new National Intellectual Disability Memory Service is available to all persons with Down Syndrome and persons with ID from other aetiologies throughout Ireland. The NIDMS will provide regional satellite centres of support, linked to the main NIDMS clinic and will work in partnership with existing regional services. The NIDMS aims to support best quality outcomes for each person with ID diagnosed with dementia in Ireland and their carers / supporters.

The NIDMS provides a brain health assessment, diagnostic work-up and dementia diagnosis for people with an ID from across the country. It will provide support clinics already existing within ID Services for atypical and unclear presentations and will assist in standardising the dementia assessment and improving uniformity in the diagnostic process. This will be achieved by maximising the use of existing memory service structures and to enhance current ID services. As there are already several established local ID-specific memory services, it is envisaged that these services and the NIDMS will work in partnership, sharing resources and expertise, and to develop standardised approaches to assessment and diagnosis. The NIDMS will seek to address the current inequity of access to memory assessment for people with ID not attached to ID services and / or where ID services do not have the capacity.

TARGET 11

100% of people living with intellectual disability with suspected dementia should have access to a timely comprehensive diagnostic assessment.

Diagram 3: Referral process and care pathway (NATIONAL ID MEMORY SERVICE)



2.5.5 People in residential care

Some people first present with symptoms suggestive of dementia while living in residential care. Many people in residential care have dementia and never receive a formal diagnosis (Cahill et al. 2012, Revez et al. 2018). Everyone with suspected dementia has the right to a diagnosis, regardless of where they live. Those presenting with symptoms of dementia while living in residential care, often highlighted by family members and / or care staff, require initial assessment at Level 1, usually conducted by the GP with medical responsibility for that Residential Community Facility (RCF) or for that particular resident. The GP will follow the diagnostic pathway and adhere to the step-by-step guidance provided for assessment at Level 1.

Depending on presentation, the GP may directly diagnose the resident with dementia (expected to occur often), or may decide in exceptional circumstances that a diagnosis will not improve the person's quality of life or influence current/ future care (e.g. very limited life expectancy). For residents with more complicated presentations, and who require a diagnosis, this may require input from the MASS to confirm diagnosis, and subtyping if possible and relevant. However, if the resident is known to, or is receiving care from, Mental Health Services for Older People/POA, OPD, or cognitive /

behavioural neurology services then, for continuity of care, it would be more appropriate to refer the resident back to the specific service for a specialist diagnostic opinion. Otherwise, and particularly where the resident is very frail and / or has likely advanced dementia, the most appropriate diagnostic service would be one that provides a needs-based outreach service to that RCF, such as POA or Older Person's services outreach teams, therefore avoiding the stress of travelling and assessment in an unfamiliar environment. Similarly, it may not be appropriate to try to ascertain a subtype, or to subject the resident to brain imaging. However, clinical examination, blood tests, and medication review to rule out reversible causes are usually appropriate.

Whatever the decision, it is important to include the resident and their carer / supporter in discussions regarding the preferred pathway, ensuring the provision of choice and that equal access is being afforded.

TARGET 12	100% of people living in residential care with suspected dementia should have access to a timely diagnostic assessment.

Practice Recommendations

Onward referral to either Level 2 MASS or other secondary care service should be determined on a case-by-case basis for people living in residential care who are suspected to have dementia, upholding equal access to services, irrespective of age, disability, or care setting, but also being cognisant of the person's preference, and / or life expectancy, and the likely impact of the secondary level assessment process on that particular resident's care and quality of life.

2.5.6 People with complex co-morbidities and / or poor mental health

As dementia incidence increases with age, many people with dementia will also have medical co-morbidities and / or poor mental health. People with multiple or complex co-morbidities, who present to primary care services with symptoms suggestive of dementia, can create significant diagnostic challenges for some GPs. Where GPs do not feel confident in diagnosing dementia directly, the decision on who to refer to may be influenced by the person being well known to, or under the active care of, a generic service (Old Age Psychiatry, Older Persons, Neurology). In this situation, for continuity of care, it would be reasonable to seek diagnosis within that service instead of a dedicated MASS/RSMC/cognitive / behavioural neurology clinic unless there are specific mitigating circumstances, i.e. they are younger and have an atypical presentation. The decision is dependent upon many variables, such as:

- Level of frailty, physical and mental health status
- Level of complexity of presentation
- The ability to travel
- Geographical location of the MASS versus generic services
- Support network, etc.

Case example in practice:

- Onward referral to local Old Age Psychiatry services for the individual presenting primarily with possible severe non-cognitive symptoms of dementia (NCSD), such as distressing psychotic symptoms, on a long background of Parkinson's disease
- Retention within the Parkinson's clinic service of an individual with memory recall issues on a long background of Parkinson's disease.

Practice Recommendations

Onward referral to Level 2 MASS, other secondary care services or RSMC should be determined on a case-by-case basis for people with complex co-morbidities and / or mental health issues, cognisant of the person's preference and upholding equal access to diagnostic services. Consideration should also be afforded to the impact of the secondary level assessment process on that individual's care, quality of life, and / or life expectancy.

2.5.7 People with dementia in an acute setting

Some people with dementia may need to attend an acute setting/Emergency Department (ED), often in potential crisis. An integrated care pathway for a person with known dementia who presents acutely or in potential (medical) crisis has been developed by a national working group in 2020 and is available here. This pathway includes alternatives to hospital attendance, and outlines an overarching pathway for a person with dementia when they need to attend the acute setting. Within this overarching pathway, there is a specific dementia pathway for use in the ED/Acute Medical Assessment Unit (AMAU). This pathway is closely linked to the national delirium algorithm for use in the ED/AMAU, available here, with a common dementia/delirium care bundle used for simplicity in the busy ED/AMAU setting. This pathway includes direct discharge home from the ED/AMAU, following dementia specialist staff and / or front-door frailty team involvement as appropriate/available, and a GP letter to allow linkage back to the local memory service as required.

If a person with dementia is subsequently admitted to a hospital ward, there is a more detailed dementia care pathway to be followed during their stay, and this includes timely discharge planning, consideration of the need for follow-up with memory services in the community (e.g. for distressing non-cognitive symptoms; carer burden/burn out; rapidly progressing course; need for future care planning; unmet dementia symptoms, etc.). There is also a focus on information exchange with community services, including memory services, and palliative care services as appropriate.

If a person in hospital has suspected dementia, there is an established pathway to diagnosis; this is available here. This pathway includes some pointers as to the most appropriate service to assess the person in the community once they are recovered (the usual pathway), and indicators of

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Care Planning and Immediate Post-Diagnostic Support
Dementia Post-Diagnostic Support
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when in-patient review may be required. All acute hospital groups and individual acute hospitals have received the national pathways described above, which can be adapted locally as needed to suit the particular local context within the hospital and the community. All hospital–community dementia pathways are best supported by hospital staff with appropriate training in dementia care and a hospital dementia quality improvement team at hospital and / or group level. Another key requirement is hospital and ward-level dementia champions and specialist dementia staff to facilitate good in-patient care but also close liaison and integration with local dementia diagnostic and post-diagnostic services and other community-based services, so that there is seamless and integrated community–hospital–community care for the person with dementia.

Note - people who receive a diagnosis at a private clinic should be sign-posted to relevant post-diagnostic support and private practice should follow the approach and guidance included in the MoC.

2.6. Commonalities across the Three Levels of Assessment Services

Regardless of where the person receives a diagnosis, there are commonalities to the diagnostic process that need to be considered across the three levels of assessment. These include:

- Waiting times
- Use of diagnostic criteria
- Exclusion of differential diagnoses of dementia
- Review of medications that may impair cognition
- Brain health interventions
- Communicating a diagnosis of dementia
- Pharmacological treatments for dementia subtypes
- Immediate post-diagnostic supports including cognitive therapies.

2.6.1 Waiting times

To date in Ireland, there are no specific targets in relation to waiting times for assessment and diagnosis, and there is significant variation across current diagnostic services. Limited evidence is available to underpin such targets. The Secretary of State for Health in England made a public commitment in 2014 that waiting times for initial appointments should be no longer than six weeks (with no time specified from first appointment to actual diagnosis). The UK Memory Clinic Accreditation Standard stipulates that initial contact is made within two weeks of referral and diagnosis within the locally specified target timeframe, which in England is six weeks and Wales twelve weeks (Copeland et al. 2018).

Given the identified benefits of a timely diagnosis, development of waiting time targets for both the initial assessment and confirmation of diagnosis, across the three levels of assessment, is a critical starting point in the development of the model and associated diagnostic pathway for Ireland. Based on the limited available guidance and views from consultations, a target that 80% of people receive a diagnosis within three months was set. This target affords flexibility for the additional time required for more complex presentations. Using the national electronic referral system (e-referral) when making referrals to Level 2 specialist services and RSMC, and direct access of GPs to imaging to support Level 1 assessment in primary care, have been identified as facilitators of achieving waiting time targets.

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.

2.6.2 Dementia diagnostic criteria

The most commonly applied diagnostic criteria are within the American Psychiatric Association's fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (APA 2013). Research findings indicate the DSM-5 diagnostic criteria for dementia has improved overall diagnostic rates (Tay et al. 2015, Eramudugolla et al. 2017).

Table 3 below summarises the DSM-5 diagnostic criteria for dementia.

Table 3: DSM-5 Dementia diagnostic criteria (APA 2013)

Evidence from the history and a clinical assessment that indicate significant cognitive impairment in at least one of the following cognitive domains: 1. Learning and memory 2. Language 3. Complex attention 4. Perceptual-motor function 5. Social cognition
The impairment must be acquired and represent a significant decline from a previous level of functioning.
The cognitive deficits must interfere with independence in everyday activities.
In the case of neuro-degenerative dementia such as Alzheimer's disease, the disturbances are of insidious onset and are progressive, based on evidence from the history or serial mental status examinations.
The disturbances do not occur exclusively during the course of delirium.

It is also recommended to use validated criteria to support clinical judgement when diagnosing dementia subtypes. The National Institute for Health and Care Excellence (NICE 2018) recommend using the following:

- International consensus criteria for dementia with Lewy bodies (McKeith et al. 2017)
- International criteria for frontotemporal dementia (primary non-fluent aphasia and semantic dementia) (Gorno-Tempini et al. 2011)
- International Frontotemporal Dementia Consortium criteria for behavioural variant frontotemporal dementia (Rascovsky et al. 2011)
- NINDS-AIREN criteria (National Institute of Neurological Disorders and Stroke and Association Internationale pour la Recherche et l'Enseignement en Neurosciences) for vascular dementia (Román et al. 1993)
- NIA criteria (National Institute on Aging) for Alzheimer's disease (McKhann et al. 2011)
- Movement Disorder Society (MDS) criteria for Parkinson's disease dementia (Dubois et al. 2007)
- International criteria for Creutzfeldt-Jakob disease (Zerr et al. 2009).

The DSM-5 (APA 2013) also provides guidance on the identification of dementia subtypes and lists medical conditions that result in progressive dementias such as Huntington's disease and others that may or may not be progressive, such as multiple sclerosis. With over 400 subtypes of dementia identified, Table 2 above provides a summary of the prevalence and symptoms associated with the more common subtypes.

2.6.3 Exclusion of differential diagnoses of dementia

Practice Recommendations

- In all cases of suspected dementia, apply the DSM-5 (APA 2013) diagnostic criteria for dementia and use validated criteria to support clinical judgement when diagnosing subtypes.
- Where subtyping is not possible, the clinician will document the reason clearly (e.g. very advanced dementia or overlapping features).

The differential diagnosis of dementia requires careful consideration across all levels of diagnostic assessment. As previously mentioned, distinguishing between age-related cognitive decline, Subjective Cognitive Impairment (SCI), Mild Cognitive Impairment (MCI) and dementia is required. Other differential diagnoses are delirium and depression.

Depression can present similarly to dementia, with evidence of cognitive and functional decline, known as 'pseudo-dementia'. This usually resolves when the depression responds to treatment. However, depressive symptoms are very common in dementia, and can precede the onset of the condition. Therefore, not all people presenting with depression and cognitive complaints have pseudo-dementia, as some may have dementia and co-morbid depression and others may have dementia presenting initially as depression. Screening tools for depression in the older person are available to guide clinicians and HSCPs with the differential diagnosis.

Delirium and dementia can be difficult to distinguish where the clinician does not know the person's usual cognitive and functional status. Delirium is a fluctuating disturbance that affects attention, awareness and alertness, with acute onset of days or hours, representing a change from usual status for the individual, while dementia is chronic and progressive in nature and doesn't particularly affect alertness (DoH 2019). The DSM-5 (APA 2013) provides diagnostic criteria for delirium (see Appendix E).

Practice Recommendations

- Where clinical indicators of delirium are identified, a clinical assessment based on the DSM-5 diagnostic criteria for delirium (APA 2013) should be carried out to confirm diagnosis, identify and treat cause and / or refer for urgent assessment and management (e.g. to a rapid access clinic, AMAU or ED, depending on severity and risk to the person/others).
- Where clinical indicators of dementia remain following the adequate treatment of depression or delirium, a clinical assessment based on the DSM-5 diagnostic criteria for dementia (APA 2013) should be repeated to confirm the diagnosis.

2.6.4 Review of medications that may impair cognition

Many medications that are commonly prescribed for symptoms such as pain, depression, psychosis, hypertension, Parkinson's disease, urinary incontinence, and asthma, are associated with an increased anticholinergic burden and noradrenergic effects, with the potential for harm increasing with age and frailty (NMIC 2011, NICE 2018). The side effects of these drugs can include cognitive impairment, drowsiness, and delirium (Ruxton et al. 2015). Anticholinergic drugs block the action of acetylcholine, a chemical messenger that plays a vital role in memory and attention. Weigand et al. (2012) suggest that anticholinergic medicines more than double the risk of MCI and accelerated memory and language decline in those predisposed to AD. Foley et al. (2019) provide guidance for GPs on medications associated with increased anticholinergic burden and noradrenergic effect, highlighting areas of potential concern as outlined below in table 4.

Table 4: Medications associated with increased anticholinergic burden and noradrenergic effect

Anticonvulsants	Some anticonvulsants impair cognition.
Antidepressants	Risk highest in tricyclic antidepressants. Withdrawal delirium also occurs.
Antipsychotics	Those with high anticholinergic burden may impair cognition.
AntiParkinsonian	Risk highest with anticholinergics, but also can occur with other drugs: dopamine agonists, COMT inhibitors or amantadine.
Cardiac drugs	Including digoxin and calcium antagonists.
Corticosteroids	Risk is dose related.
Hypnotics / sedatives	More common with long-acting benzodiazepines.
Opioid analgesics	All opioids can cause problems; risk highest with Pethidine.
Anticholinergics	E.g. bladder relaxants, antihistamines, tricyclic antidepressants.

Practice Recommendations

Diagnostic assessment should include a medication review to identify and minimise use of drugs that may adversely affect cognitive functioning.

2.6.5 Brain health interventions

Preventing or delaying dementia or modifying the course of the disease process using brain health interventions, requires both the early identification and the proactive management of dementia risk factors (WHO 2019a). Risk factors for dementia are often referred to as non-modifiable and modifiable. Non-modifiable risks are those outside of the person's control and include sex, age and genetic predisposition, while modifiable risks are characteristics of the person's lifestyle such as smoking and alcohol intake, which the individual can change. Livingston et al. (2020) suggest that approximately 30% of all dementia is preventable by addressing modifiable health and lifestyle risks important for overall physical health. This supports earlier findings from a population-attributable risk model which estimated that one in every three cases of Alzheimer's disease may be related to the presence of modifiable risk factors (Livingston et al. 2017). *The Lancet* report on Dementia Prevention, Intervention and Care suggests that modifying risk factors might prevent or delay up to 40% of dementias (Livingston et al. 2020).

The NDO (2019) issued key messages for healthcare professionals on dementia risk reduction, drawing on the evidenced-based recommendations and guidelines of the WHO *Risk Reduction of Cognitive Decline and Dementia: WHO guidelines* (WHO 2019a). Table 5 summarises the evidence-based recommendations on risk reduction of dementia from the WHO (2019a).

Table 5: Guidelines on risk reduction of cognitive decline and dementia

Strength of recommendation	To reduce risk of dementia in 'healthy' people of any age
Strong (should be done)	• Physical activity – best type not yet conclusive, but probably aerobic • Smoking cessation – limited evidence as yet that this will reduce risk of dementia, but given the overwhelming benefit of cessation, this is strongly recommended
Conditional (i.e. may be beneficial)	• Mediterranean diet (high in vegetables, fish, seeds, olive oil; low in red meat) • Managing diabetes • Managing hypertension • Interventions to reduce or cease hazardous and harmful drinking

Strength of recommendation	To reduce risk of dementia in 'healthy' people of any age
Conditional	Additional age-specific recommendations: • Managing dyslipidaemia and interventions for overweight/obesity may reduce the risk of later dementia in middle-aged people • Cognitive training may reduce the risk of dementia in older people The following may reduce the risk of progressing to dementia in people who already have MCI: • Cognitive training in older adults • Mediterranean diet • Physical activity • Interventions to reduce or cease harmful drinking

Practice Recommendations

- Cognisant of the need to proactively prevent, delay or modify the disease process, clinicians will either offer referral for brain health interventions available locally (such as referral to the smoking cessation support service or the community dietitian) or will offer referral to the local MASS for brain health assessment/interventions. **This particularly includes people with SCI and MCI where motivation may be high to modify their risks.**
- Clinicians will use every opportunity to identify those at risk of developing dementia and offer brain health interventions to reduce or minimise these risks. **This particularly includes people with SMI and MCI where motivation may be high to modify their risks.**

2.6.6 Communicating a diagnosis of dementia

An intrinsic part of making a diagnosis of dementia is communicating the diagnosis, at a time and in a way that is appropriate for each individual, ensuring a person-centred approach continues throughout the diagnostic journey. Communicating a diagnosis of dementia ensures that the person living with dementia can avail of post-diagnostic information, education and support to prepare and guide them in making decisions about their future care and to manage their ongoing and changing experience of the condition. The process of communicating a diagnosis of dementia begins at the initial assessment where it is ascertained how much insight the person has into their problem, how much information the person would like if they subsequently receive a diagnosis of dementia, whether the person is able to consent to the assessment process, and what measures to put in place to support decision-making.

Communicating a diagnosis of dementia across the three levels of assessment is discussed in detail in Section 4 of this Model of Care, providing best practice guidance/recommendations for informing people of their diagnosis[see section 4 below on communicating a diagnosis of dementia].

2.6.7 Pharmacological treatments for dementia subtypes

Currently, only four cognitive enhancing drug treatments are available, three consisting of acetylcholinesterase inhibitors (AChEIs), donepezil, rivastigmine, galantamine, and an NMDA receptor antagonist, memantine. The mode of action of AChEIs results in the increased concentration levels and duration of the neurotransmitter acetylcholine in the brain by inhibiting the breakdown of the cholinesterase enzyme, thus improving communication between nerve cells. Evidence suggests that AChEIs are of some benefit in terms of improvements in cognition and Activities of Daily Living (ADLs) (Rodda and Walker 2009). The most common side effects of AChEIs are gastrointestinal involving; nausea, vomiting, diarrhoea and abdominal pains. Most commonly, these symptoms are experienced on initiation and titration and are usually transient. AChEIs may induce sinus bradycardia and aggravate pre-existing sinus node disease and atrioventricular block (AV block); therefore, it is advisable that an ECG is carried out prior to initiation of treatment. The main side effects of memantine include dizziness, headache, constipation, drowsiness, and hypertension.

It is paramount that the individual is informed of the possible risks and benefits of medications, informing and aiding their autonomous decision-making, thus respecting their right to be involved in the decision process.

The NICE clinical guideline (NG97) on 'Dementia: assessment, management and support for people living with dementia and their carers' has detailed recommendations on the pharmacological treatment of cognitive symptoms in dementia, summarised in the Department of Health's National Clinical Guideline *'Appropriate prescribing of psychotropic medication for non-cognitive symptoms in people with dementia'* (DoH 2019):

- The NICE guideline recommends the three AChEIs as options for managing mild to moderate Alzheimer's disease (AD). Memantine can be considered as adjunctive treatment in moderate AD, and should be offered as adjunctive treatment in severe AD, while memantine monotherapy is an option for managing moderate AD for those intolerant of or having a contraindication to AChEIs (NICE 2018), or as monotherapy for severe AD.
- The NICE guideline also recommends that clinicians should offer donepezil or rivastigmine to people with mild to moderate dementia with Lewy bodies (galantamine only if these not tolerated) and should 'consider' donepezil or rivastigmine in severe disease. Clinicians should consider memantine for people with

dementia with Lewy bodies if AChEIs are not tolerated or are contraindicated.

- Clinicians should only consider AChEIs or memantine for people with vascular dementia if they have suspected co-morbid AD, Parkinson's disease dementia or dementia with Lewy bodies.
- Clinicians should not offer AChEIs or memantine to people with frontotemporal dementia, or cognitive impairment caused by multiple sclerosis.

Table 6 provides guidance on initiation and titration of these drugs for GPs (Quinn et al. 2017).

Table 6: Drug treatment in dementia: initiation and titration dosages

Drug treatment	Dosage and titration guide
Donepezil	Initially 5mgs daily for 4–6 weeks, titrating to 10mgs daily, if tolerated.
Rivastigmine tablets	Initially 1.5mgs twice daily, titrating in 1.5mgs twice daily in increments of 2 weeks to 6mgs twice daily, if tolerated.
Rivastigmine Patch	Initially 4.6mgs/24hrs for 4–6 weeks, titrating to 9.5mgs/24hrs, if tolerated.
Galantamine tablets	Initially 4mgs twice daily, titrating in increments of 4mgs twice daily every 4 weeks to a max. dose of 12mgs twice daily, if tolerated.
Galantamine XL tablets	Initially 8mgs daily, titrating in increments of 8mgs daily every 4 weeks to max. dose of 24mgs daily, if tolerated.
Memantine	Initially 5mgs daily for one week, titrating by 5mgs weekly to maintenance dose of 20mgs daily, if tolerated

Practice Recommendations

In all cases, the NICE recommendations for pharmacological treatment of dementia subtypes should be considered.

The advent of Disease Modifying Treatments (DMTs) targeting the pathogenic pathway of Alzheimer's disease and other neuro-degenerative proteinopathies, which may delay the onset or progression, will be considered across the diagnostic pathway. Unlike the cognitive enhancing treatments currently available, DMTs need to be initiated before the development of moderate-to-severe dementia, implying a need to identify suitable people early in the disease process, including in MCI, and to ascertain subtype, even in MCI. Although DMTs are still under extensive research, it is imperative that clinicians support early diagnosis (particularly of MCI) and ensure that diagnostic investigations such as plasma and CSF biomarkers are accessible as part of the assessment process.

2.6.8 Consider immediate post-diagnostic supports

People diagnosed with dementia are unique beings, with individual and personalised post-diagnostic needs requiring a range of tailored post-diagnostic supports. These are outlined in more detail in Section 5 where the five strands of post-diagnostic support are presented in detail. These strands include:

- Understanding and planning
- Staying connected
- Staying healthy
- Supporting cognition
- Supporting emotional wellbeing.

Receiving immediate post-diagnostic supports in the form of information, sign-posting or formal interventions can help the individual and their family/carer / supporter move forward and plan for the future. There should be continuity of care, with these supports transitioning into broader, more targeted post-diagnostic interventions as the person's needs change. An extensive presentation of post-diagnostic supports is outlined in Section 6 of this report [see section 6 on post-diagnostic support].

2.7. Underpinning the Principles

The overarching principles of the Dementia Model of Care , as outlined in the introduction, are applied throughout the diagnostic model as shown in Diagram 4 below.

Diagram 4: Applying the Dementia Model of Care principles to the diagnostic model

Citizenship	All people with suspected dementia are given equal access to assessment and diagnostic services. They are supported throughout the process in decision-making relating to their care.
Person-centred Approach	All people undergoing assessment are viewed, treated and valued as indviduals, with dignity and respect; their wishes are actively sought throughout the diagnostic process.
Integration	Dementia diagnostic services are delivered in a coordinated and integrated way, focusing on the diagnostic needs of each individual with suspected dementia.
Personal Outcome-focused	The assessment and diagnostic process focuses on the desired outcomes for each individual and supporter, where they are listened to and heard.
Timeliness	The assessment and diagnostic process will progress in a timely and responsive manner, respecting and maintaining autonomy and supporting continuity of care.

2.8. Summary of Targets and Practice Recommendations for the Diagnostic Model

The targets and practice recommendations identified in this section are collated in Table 7. These apply to the three levels of assessment, which are further outlined in the following section.

Table 7: Summary of diagnostic targets and practice recommendations

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 in each site.
Target 3	There should be one National Intellectual Disability Memory Service (NIDMS), with national access and regional outreach.

Targets	
Target 4	The minimum composition of Level 2 Memory Assessment and Support Service: • *Consultant 1.0 WTE • Senior Neuropsychologist 0.5 WTE • Senior/Specialist Registrar 1.0 WTE • Advanced Nurse Practitioner 1.0 WTE • Clinical Nurse Specialist 2.0 WTE • Senior Occupational Therapist 1.0 WTE • Senior Physiotherapist 1.0 WTE • Senior Speech and Language Therapist 1.0 WTE • Senior Social Worker 1.0 WTE • Senior Dietitian 0.5 WTE • Neuro-radiologist 0.2 WTE • Clerical Support (Grade 4) 2.0 WTE *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
Target 5	The minimum composition of Level 3 Regional Specialist Memory Clinic: • *Consultant 2.0 WTE • Senior/Specialist Registrar 2.0 WTE • Advanced Nurse Practitioner 1.0 WTE • Clinical Nurse Specialist 2.0 WTE • Principal Neuropsychologist 1.0 WTE • Clinical Specialist Occupational Therapist 1.0 WTE • Clinical Specialist Physiotherapist 1.0 WTE • Senior Social Worker 1.0 • Senior Dietitian 0.5 WTE • Clinical Specialist Speech and Language Therapist 1.0 WTE • Neuro-radiologist 0.2 WTE • Clerical Support (Grade 4) 2.0 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 proposed use of a dementia minimum dataset.
Target 7	With their consent, 100% of people presenting with symptoms of suspected dementia should receive a comprehensive diagnostic assessment.

Targets	
Target 8	100% of people diagnosed with MCI offered follow-up appointment* for reassessment of cognition every 12–24 months, until stability or progression is evident. *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.
Target 9	100% of people diagnosed with MCI should be offered specific interventions and supports in a timely manner and in response to identified need and respecting each individual's preferences. These include brain health interventions and cognitive therapies.
Target 10	100% of people aged under 65 years with suspected dementia are offered referral to a specialist service for assessment (Level 2 MASS, Level 3 RSMC, or Cognitive / behavioural Neurology Service), where there is access to a Neurologist, neuropsychology assessment and an established pathway to post-diagnostic support.
Target 11	100% of people living with intellectual disability with suspected dementia should have access to a timely comprehensive 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), 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.

Background and Principles
Dementia Diagnostic Model
Dementia Assessment and Diagnostic Pathway
Giving a Diagnosis of Dementia
Care Planning and Immediate Post-Diagnostic Support
Dementia Post-Diagnostic Support
Appendices

Practice recommendations
HSCPs working in non-dementia specific roles must participate in dementia-specific education programmes to inform and support practice.
All dementia-specific education programmes must empower participants to adopt a person-centred and human rights based approach to care.
Members of the MDT will work together to identify trans-disciplinary skills and shared learning to meet the needs of each patient in an efficient manner.
The process of communicating a diagnosis of dementia begins at the initial assessment (see further details in section 4 on informing people of a dementia diagnosis).
The person is informed about the process of assessment and is provided with written and verbal information on what to expect, to support their decision-making and active involvement in their care.
Information should be provided in the person's preferred language, including sign language, using a professional interpreter where necessary. In some circumstances, simplified explanations, pictures or communication aids may also be required.
Where clinical indicators of MCI are identified, a clinical assessment based on the DSM-5 diagnostic criteria (APA 2013) for MCI should be carried out to confirm the diagnosis.
For people with language, behavioural, visuo-spatial and other presentations (non-amnestic), a Level 2 MASS can triage and decide on the most appropriate diagnostic pathway for the person (e.g. to a RSMC, a cognitive / behavioural neurology clinic, or a POA service).
Dementia-specific education/training for GPs, nurses and HSCPs must include dementia syndromes that present with language, behavioural, motor and other presentations (non-amnestic symptoms), thus supporting timely recognition of a suspected dementia and the timely referral to an appropriate diagnostic service.
Any person with a cognitive syndrome in the context of known or suspected familial neurodegenerative disease should be referred to a specialist service for assessment (Level 3 RSMC, or cognitive / behavioural neurology clinic).
Onward referral to either Level 2 MASS or other secondary care service should be determined on a case-by-case basis for people living in residential care who are suspected to have dementia, upholding equal access to services, irrespective of age, gender, disability, or care setting, but also being cognisant of the person's preference, and / or life expectancy, and the likely impact of the secondary level assessment process on that particular resident's care and quality of life.

Practice recommendations
Onward referral to Level 2 MASS, other secondary care services or RSMC should be determined on a case-by-case basis for people with complex co-morbidities and / or mental health issues, cognisant of the person's preference and upholding equal access to diagnostic services. Consideration should also be afforded to the impact of the secondary level assessment process on that individual's care, quality of life, and / or life expectancy.
In all cases of suspected dementia, apply the DSM-5 (APA 2013) diagnostic criteria for dementia and use validated criteria to support clinical judgement when diagnosing subtypes.
Where subtyping is not possible, the clinician will document the reason clearly, e.g. very advanced dementia or overlapping features.
Where clinical indicators of delirium are identified, a clinical assessment based on the DSM-5 diagnostic criteria for delirium (APA 2013) should be carried out to confirm diagnosis, identify and treat cause and / or refer to an AMAU for urgent assessment and management (e.g. to a rapid access clinic, AMAU or ED, depending on severity and risk to the person/others).
Where clinical indicators of dementia remain following the adequate treatment of depression or delirium, a clinical assessment based on the DSM-5 diagnostic criteria for dementia (APA 2013) should be repeated to confirm the diagnosis.
Diagnostic assessment should include a medication review to identify and minimise use of drugs that may adversely affect cognitive functioning.
Cognisant of the need to proactively prevent, delay or modify the disease process, clinicians and / or HSCPs will either offer referral for brain health interventions available locally (such as referral to the smoking cessation support service or the community dietitian) or will offer referral to the local MASS for brain health assessment/interventions. This particularly includes people with SCI and MCI where motivation may be high to modify their risks.
Clinicians will use very opportunity to identify those at risk of developing dementia and offer brain health interventions to reduce or minimise these risks. This particularly includes people with SMI or MCI where motivation may be high to modify their risk.
In all cases, consider the NICE recommendations for pharmacological treatment of dementia subtypes.

SECTION 3

DEMENTIA ASSESSMENT AND DIAGNOSTIC PATHWAY

3.1. Section Introduction

The previous section introduced the dementia diagnostic model for Ireland, which provides the foundation for the development of a comprehensive diagnostic pathway to be applied across non-specialist and specialist dementia diagnostic services. This section of the Dementia Model of Care outlines the technical elements of the diagnostic pathway, incorporating targets and practice recommendations for an inclusive, comprehensive assessment across the three levels. The pathway is underpinned by the overarching principles and provides guidance and structure without being prescriptive, emphasising flexibility and fluidity, while being responsive to the needs of each individual presenting with suspected dementia for initial assessment, where assessment at the right time by the right team is of utmost importance.

This section will firstly look at Level 1 assessment in primary care, providing step-by-step guidance to support the direct diagnosis of dementia at primary care level. There is also guidance on onward referral pathways to either Level 2 or Level 3 assessment services for the more complex, atypical, or unclear presentations.

Within the model, the next level of assessment in the diagnostic journey refers to Level 2 where assessment takes place in a Memory Assessment and Support Service (MASS) or other specialist service. The pathway will also include step-by-step guidance for the diagnosis of dementia in generic secondary care services, for people with known neuro-degenerative conditions that are often complicated by dementia, or with complex co-morbidities.

This section will then provide the technical elements of Level 3 diagnostic assessment, which takes place in a Regional Specialist Memory Clinic (RSMC).

The pathway development drew on multiple sources, including:

- Available research evidence
- The NICE clinical guideline (NG 97) for the assessment, management and support of people living with dementia and their carers (NICE 2018)
- The Irish Guidance Document for the Diagnosis and Management of Dementia in General Practice (Foley et al. 2019)
- The views collated from consultations
- Advisory group member's expertise.

The diagnostic pathway will be illustrated in table format at each level of assessment, with step-by-step guidance for a comprehensive assessment, giving flexibility in areas such as assessment tools, medical investigations and onward referral structures, which can be tailored to individual needs and circumstances.

3.1.1 Consent

It is essential that appropriate consent is gained from the person before any investigations regardless of the level of assessment (primary, secondary or tertiary). Consent must go hand-in-hand with the provision of clear information about the processes and possible outcomes involved and therefore often involves a continuous process of informing people of results, updates, proposed interventions or changes to treatment.

Consent can be given in several ways: verbally; non-verbally; in writing; or by implication. It is important that healthcare workers clearly record and document the conversation that was had around consent, how it was explained and discussed and the agreement arrived at with the person. In some circumstances, for example, before performing a lumbar puncture, it is important that written consent is obtained and placed in the healthcare record. Consent can be withdrawn at any time before or during any intervention, treatment or assessment and this should also be recorded in the healthcare record.

Adults are presumed to have decision-making capacity in relation to consent unless there is evidence to the contrary. The 'functional' approach to capacity must be taken, that is, it is both issue and time specific and that a lack of capacity to make decisions in one area does not necessarily mean that a person lacks capacity to make decisions in other areas.

Healthcare workers should support people to make their own decisions. Information about interventions or treatments should be provided in a way that is understandable to the individual and enables them to make their own decision.

For more detailed information, it is recommended that healthcare staff read the current iteration of the HSE's National Consent Policy.

3.2. Level 1 Assessment – Diagnosis in Primary Care

The GP is responsible for carrying out the assessment of dementia in primary care. Where there is a GP with a particular interest and knowledge of dementia within a practice, a local arrangement could be made that this GP would accept in-house referrals from their colleagues. Practice nurses, where available, can support GPs in the assessment process through:

- History taking
- Conducting cognitive assessments
- Collecting blood and urine samples
- Following up on results
- Performing the ECG.

This can facilitate a less rushed and more person-centred approach, with nurses affording the necessary time to progress at the individual's pace. Level 1 assessment in primary care is illustrated in Table 8 below. Additional information is also provided to guide clinicians in the application of the targets and practice recommendations, which underpin the pathway, into their diagnostic practices.

Despite concerns regarding barriers such as attitudes, beliefs, skills, low confidence and lack of training which can lead to low diagnostic rates or delayed diagnosis in primary care, GPs are recognised as key stakeholders in the timely detection of dementia. This can involve the direct diagnosis by the GP, or the completion of the necessary screening prior to onward referral to either Level 2 or Level 3 assessment services. GPs are familiar with the person's overall health status, preferences and social context. They also have an existing healthcare relationship that has the potential to provide continuity of care across the pre-diagnostic to post-diagnostic transition (Revez et al. 2018).

Fundamental to a positive outcome, the assessment is required to progress at the individual's pace. Lack of time has been highlighted as a barrier to GPs undertaking a dementia diagnostic assessment. However, some GPs have successfully allocated a number of consultation slots together to facilitate the diagnostic process, while others gather the necessary information from several consultations to arrive at a diagnosis. In relation to low confidence to assess and diagnose dementia in primary care, research suggests that clinical guidelines can enhance confidence and knowledge (Waldorff et al. 2003, Downs et al. 2006, Pimlott et al. 2009). In Ireland, a guidance document providing clinical guidance and supporting evidence in dementia diagnostic practices in general practice has been in existence since 2014 (updated in 2019) entitled *'Dementia: Diagnosis and Management in General Practice'* (updated in 2019: Foley et al. 2019), and remains a rich information and guidance resource for GPs. In addition, many GPs have attended dementia-specific training workshops as part of the PREPARED project, including dementia diagnosis and post-diagnostic care (Foley and Jennings 2016).

Most people will initially approach their GP to discuss concerns such as being forgetful, having communication difficulties, and / or changes in behaviour. In other situations, a family member may contact the person's GP to express these concerns because the person is too afraid, in denial, or has lack of insight. This initial contact can be the hardest step for people on the road to a diagnosis and therefore it is important that, where possible, for moral support, a supportive other/family member/friend accompany them.

Table 8: Level 1 assessment in primary care

Level 1: Initial Assessment in Primary Care Summary of Interventions and Pathway
The person is firstly informed about the process of assessment and is provided with written and verbal information on what to expect prior to the first appointment. The process of informing a person of a diagnosis of dementia begins at the first point of contact with the person. It is important to establish if the person has insight into their condition and that they know why they are attending for assessment.
Informed consent to proceed is attained at this point. • Establish what the person knows, or thinks they know about their condition • Establish if they are aware of the purpose of the assessment and what the possible outcomes might be • Do they have mental capacity to consent to any assessment-related procedures? • What measures are being implemented if the person shows they do not have capacity to consent? • Establish how much information the person would like to know about the assessment process and about any subsequent diagnosis that is made • History taking: patient's self-report and where possible, a collateral history, (Section 3.2.2) • Family history: crucial if suspected YOD

Level 1: Initial Assessment in Primary Care Summary of Interventions and Pathway

If dementia is still suspected

- Physical examination [see section 3.2.3]
- Neurological examination [see section 3.2.4]
- Cognitive assessment [see section 3.2.5 and table in Appendix E]
- Appropriate investigations [see section 3.2.6 and table in Appendix E]
- Medication review [see section 2.6.4]
- Check for functional impairment (problems in paying bills, shopping, handling money, using appliances, etc.)
- Check for safety concerns (driving, leaving door unlocked, cooker on, vulnerability, etc.).

No evidence of any dementia/SCI/MCI – PATHWAY STOPS!

- Provide feedback on assessment and offer reassurance
- Offer guidance on brain health interventions; recommend physical exercise and smoking cessation, if relevant [see section 2.6.5].

Diagnosis is Subjective Cognitive Impairment/Mild Cognitive Impairment

- Communicating a diagnosis
- Offer information on SCI/MCI, oral and written
- Offer reassurance that the person may not develop dementia [see section 3.2.7].
- Cognitively impairing medications should be tapered/discontinued and an alternative prescribed, where possible [see section 2.6.4]
- Depending on individual needs and wishes, offer referral to MASS for brain health services
- Discuss the desire to participate in/access clinical trials; arrange referral to MASS (Level 2) or RSMC (Level 3) to facilitate participation
- For MCI only: Record diagnosis in person's clinical records, creating a red flag for 12–24 monthly reviews for cognitive monitoring, until stability or progression is evident
- For MCI: Consider immediate post-diagnostic needs [see section 2.6.8 and section 6 PDS].

Diagnosis is Dementia

- Communicating a diagnosis of dementia [link to Section 4]
- Provide oral and written information on dementia, specific to subtype [see Target 7 practice recommendations]
- Discuss pharmacological treatment options depending on subtype [see section 2.6.7)
- Cognitively impairing medications should be discontinued and an alternative prescribed, where possible [see section 2.6.4]
- Consider immediate post-diagnostic needs; signpost to local supports and services [see section 2.6.8 and PDS section]
- For early-stage (i.e. mild) dementia, offer referral to MASS for brain health, cognitive therapies and / or PDS services depending on individual needs and wishes [see PDS section 6], e.g. Memory Technology Resource Room
- Refer the person to a Dementia Adviser for further information on dementia and on local services and support [see PDS section 6]
- Discuss the desire to participate in/access clinical trials; arrange referral to MASS (Level 2) or RSMC (Level 3) to facilitate participation
- Co-produce a care plan incorporating immediate treatment plans, brain health interventions, identification of an appropriate person to act as 'point of contact', follow-up plans and PDS [see care planning section 5]
- Where a person is not ready on the day, following the communication of a diagnosis, to make a decision about commencing cognitive enhancing medications or non-pharmacological interventions, there is a planned follow-up within two weeks to re-discuss, when they have had time to reflect on the diagnosis and treatment options. Further follow-up should then take place as per Target 21
- Arrange a follow-up appointment in 4–6 weeks to review, address acceptance and understanding, discuss need for referral to additional post-diagnostic support services, assess tolerance and effect of AChEIs, memantine, or any medication changes, etc.

Level 1: Initial Assessment in Primary Care Summary of Interventions and Pathway

Special populations

- People presenting with early cognitive symptoms / sMI/MCI (see section 2.5.1)
- People with language, behaviour, visuo-spatial and other presentations (non-amnestic dementias) [see section 2.5.2]
- Suspected Young Onset Dementia [see section 2.5.3]
- People with learning disabilities with suspected dementia; refer to NIDMS for diagnostic assessment (see referral pathway) [see section 2.5.4]
- People with multiple medical co-morbidities and /or poor mental health, possibly well known to, or under the active care of, secondary care services [see section 2.5.6]
- Suspected dementia in people residing in residential care [see section 2.5.5]

3.2.1 Beginning the process of communicating a diagnosis of dementia

Communicating a diagnosis of dementia is a process that begins at the first contact with the person. Thinking about communicating a diagnosis of dementia begins before any assessment or cognitive testing has taken place. How much does the person know about their problem, what level of insight do they have? What are their wishes in relation to the level of detail they would like if the assessment results show that they do have a dementia?

It is helpful to outline to the person at the outset that cognitive tests and a range of different assessment tests help to build a picture. One of the things the tests might show is that they have a dementia. If this is the case, would they want to know about it or would they prefer you shared it with their family?

3.2.2 History taking

History taking is the fundamental first step in the process of diagnosis. Where the individual has limited English proficiency, an interpreting service can be arranged with their consent through the HSE. Good practice guidelines are available to support the use of interpreting services (HSE 2009). In addition to the individual's self-report, a collateral history from a family member or from someone who knows the person well is essential as the person experiencing the symptoms may not be able to give an accurate history, or may not have insight into changes noted by others. Specific attention should be paid to the following areas:

- Mode of onset: assess for delirium if onset acute/sub-acute
- Speed and course of progression (gradual, stepwise, plateau); needs urgent specialist review if rapidly progressive (via AMAU/ED referral if necessary)
- Pattern of cognitive impairment (memory, language, executive functioning, attention, visuo-spatial, etc.)
- Presence of non-cognitive symptoms of dementia (NCSD) or responsive behaviours
- Impact of symptoms on daily life
- Risk concerns (driving, cooking, leaving house inappropriately, open fire, etc.)

Family history is essential for a person with suspected YOD. Although not all cases of YOD are inherited, some forms of AD, vascular dementia and frontotemporal dementia have genetic links.

To establish a diagnosis of dementia, the clinician is looking for a history of progressive cognitive changes over time in two or more cognitive domains, severe enough to interfere with the individual's ability to carry out their day-to-day activities.

3.2.3 Physical examination

The physical examination will include assessment of hearing, vision, blood pressure, pulse, and other general indicators of health or disease. The findings may suggest an aetiology for the dementia, for example, dementia resulting from vascular disease may be accompanied by focal neurologic findings with hypertension or obesity.

When conducting a physical examination consider:

- Potentially reversible causes of cognitive impairment (hypothyroidism/vitamin B12 deficiency)
- Possible differential diagnosis (delirium/depression)
- Cardiovascular risks (blood pressure, diabetes, obesity) and indicators of harmful alcohol intake
- Falls risk – has patient fallen in past six months.

3.2.4 Neurological examination

A neurological examination is essential to elicit signs, which may explain the individual's cognitive and functional decline. Examination includes the motor system, reflexes, gait, sensory functioning, coordination and speech. The presence of focal neurological signs or deficits may suggest a vascular contribution to the cognitive syndrome. Parkinsonian features and speech disturbances are particularly important to consider and document, again suggesting a process other than amnestic AD.

3.2.5 Cognitive assessment

A cognitive assessment measures how the brain is functioning in relation to memory, attention, language, executive functioning, visual and spatial perception/motor skills. In addition to the MMSE (Mini-Mental State Examination) currently used by 50% of GPs due to availability, three other screening tools have been identified as clinically and psychometrically robust for use in primary care (see Appendix E: Mitchell et al. 2011, Foley and Jennings 2016, Foley et al. 2019). The Montreal Cognitive Assessment (MoCA) is another cognitive assessment tool to consider. It takes longer to complete but gives information on several cognitive domains. Depending on time availability and preferences, GPs can select one of these cognitive assessment tools to provide evidence of cognitive impairment and aid diagnosis.

It is imperative that dementia is not ruled out on the basis of results from cognitive testing alone, and that interpretation of results takes into account other factors known to affect performance, including educational level, age, language and any sensory impairments, mental health illness, performance anxiety, or physical/neurological problems. Results of cognitive testing should be recorded in the person's records for future comparisons and included in any referral documentation to Level 2 and Level 3 assessment services. See Appendix E for details of Cognitive Assessment Tools for Primary Care, adapted from Foley et al. 2019.

3.2.6 Appropriate investigations in primary care

Investigations are performed to identify co-morbid conditions and to exclude reversible causes of cognitive and functional impairment. The investigations recommended for primary care are outlined in Appendix E (Foley et al. 2019; Gibb, 2019). Neuroimaging is viewed as an essential element of the assessment process; however, this may not always be appropriate (e.g. very advanced frailty, complex medical co-morbidities or advanced dementia). The NICE guideline notes that brain imaging may not always be needed for those presenting with moderate to severe dementia, if the diagnosis is clear (NICE 2018). It also does not specify the imaging type best suited to primary care diagnosis.

The Dementia Model of Care Advisory group concluded that an MRI scan is the preferred modality to assist with early diagnosis and detect subcortical vascular changes. However, a CT brain scan may be appropriate if an MRI scan is not available in a timely manner or is not appropriate (e.g. contraindication like pacemaker, metal implant, claustrophobia, unlikely to tolerate for another reason, or the goal of imaging is to rule out large structural brain disease rather than to support dementia subtyping). Where brain imaging is not appropriate or the patient declines the offer of attending for brain imaging, the clinician will document the reason clearly. Results of all investigations should be included in referral documentation to Level 2 and Level 3 assessment services.

3.2.7 No evidence of dementia/ subjective cognitive impairment

If there is no evidence of dementia or mild cognitive impairment at this point of assessment, the concerned individual and family may only require reassurance. At this point, the diagnosis may be SCI, where the person was worried about their memory, but objective tests are normal. In such cases it is prudent to ask the patient to return if concerns persist or worsen, as a small proportion will develop MCI or dementia in subsequent years. The diagnosis may be another condition, like personality disorder, primary mental health issue, hearing loss mistaken for poor memory, etc., in which case the dementia diagnostic pathway will stop for this person as no follow-up appointments are indicated for dementia (they may be required for the other condition).

Where modifiable risk factors for dementia are identified during initial assessment, it is crucial that the clinician and / or HSCP affords time to offer advice and guidance on brain health interventions to reduce or eliminate these risks, thus preventing or delaying the individual developing dementia in the future. The person who was concerned about their memory may be very receptive to personalised brain health interventions to reduce or eliminate modifiable risk at this time. This may include referral to services such as a dietitian, smoking cessation support services, and addiction services. Depending on individual needs and wishes, offer referral to MASS for brain health services (see Section 2.6.5 for additional guidance on brain health interventions).

3.2.8 Diagnosis is mild cognitive impairment

It is paramount to reassure the patient that progressing to dementia is not a foregone conclusion for a significant cohort of people with MCI. However, knowing that there is an increased risk of developing dementia allows an individual to put their legal and financial affairs in order. There are currently no approved medications for the treatment of MCI (although potential disease modifying treatments for AD-MCI are undergoing regulatory review in 2023). It is likely that developments in disease-modifying treatments for this cohort will demand more rigorous clinical phenotyping and a biomarker-based diagnostic approach as standard in MCI.

AChEIs have not shown any lasting benefit in delaying or preventing progression to dementia and are not recommended for MCI (NICE 2018). The mainstay of treatment for MCI is addressing any identified modifiable dementia risk factors and encouraging the patient to engage in physical exercise and cognitive therapies, such as Cognitive Stimulation Therapy (CST), Cognitive Training (CT) and Cognitive Rehabilitation (CR) [see PDS section 6]. The increased risk of progressing to dementia supports the need for monitoring of cognitive status over time (see Section 2.6.1 for additional information on MCI and follow-up recommendations).

3.2.9 Diagnosis is dementia

Communicating a diagnosis of dementia, including target and practice recommendations to guide good practice, is addressed in detail within this model [see section 4]. At a minimum, the person will require written and oral information on their diagnosis, a follow-up appointment and a single point of contact following their diagnosis.

The Dementia Model of Care addresses post-diagnostic supports, for all stages of the dementia continuum in Section 6 [see PDS section 6]. The importance of an individualised and flexible approach, moving at the individual's pace, is reiterated across both sections.

A co-produced care plan is required to outline the agreed follow-up plan. Good practice in care planning is outlined in more detail in Section 5. In addition, a holistic assessment to identify the appropriate and desired post-diagnostic supports should be undertaken to support the care planning process and identify appropriate referral to programmes and services, as required.

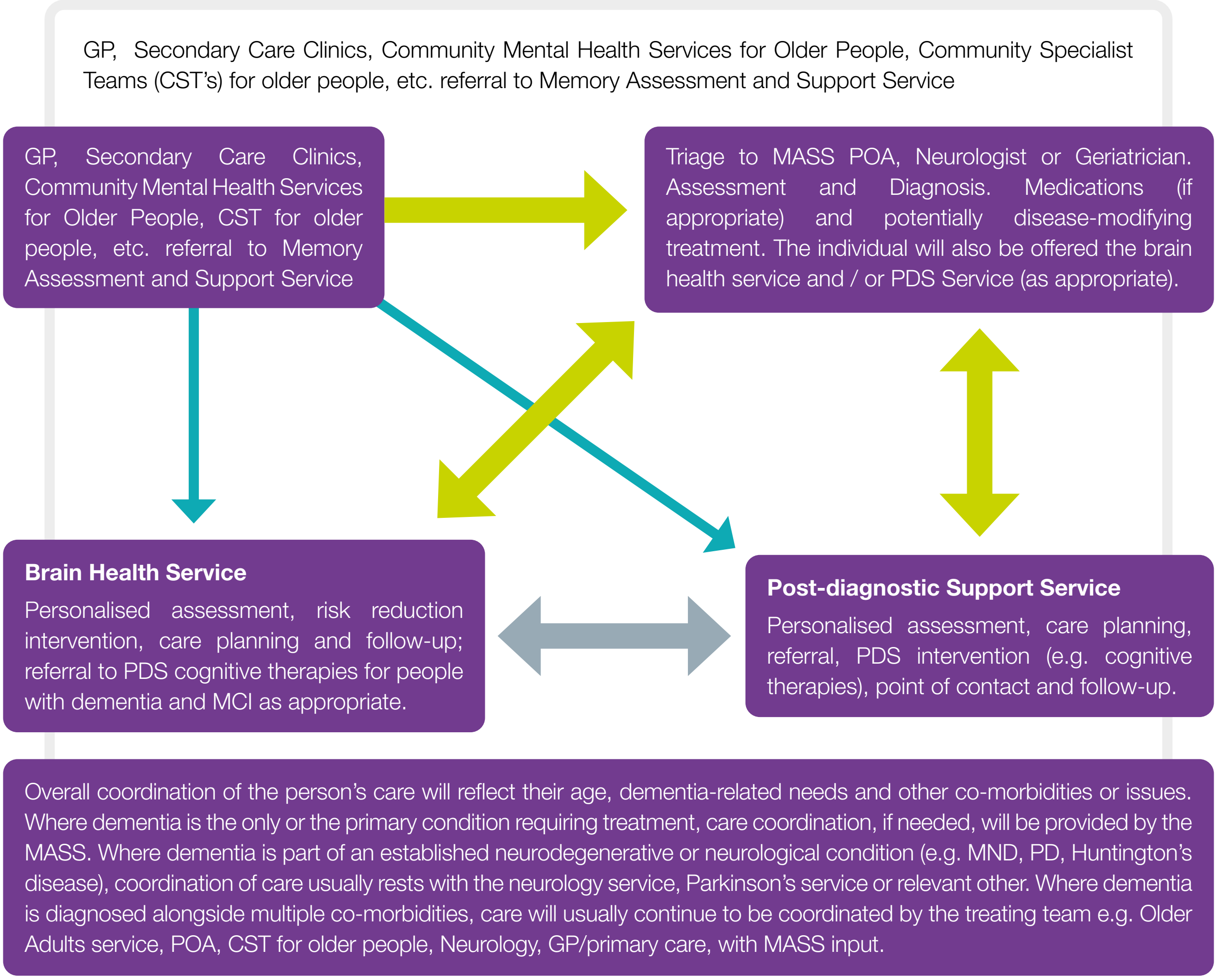
Depending on individual needs and wishes, offer referral to MASS post-diagnostic services. Also ensure that an appropriate person has been identified to act as a 'point of contact' for the individual. This is outlined in significant detail in Section 6 [see PDS section 6].

3.3. Level 2 Assessment – Memory Assessment and Support Service (MASS)

Dementia diagnostic assessment at Level 2 typically refers to a comprehensive assessment, carried out by the MDT, in a MASS. Diagnostic assessment at a dedicated cognitive / behavioural neurology clinic, if for some reason is not integrated within a MASS or RSMC, is also considered at Level 2. However, a dedicated service for suspected dementia is not always appropriate for the individual (see below), and so the model includes assessment in specialist secondary care services, which are not dedicated for people with suspected dementia, within Level 2. The key for either setting is a comprehensive assessment/investigation, accurate diagnosis, excellent communicative practice and integrated provision or referral for brain health assessment/interventions and post-diagnostic supports, whether within the diagnosing service (MASS) or outside it (cognitive / behavioural neurology service, mental health services for older people, older persons services).

People are referred to MASS by either their GP or colleagues from secondary care services, for the assessment of dementia, including subtyping. The MASS also accepts referrals into the pathway for brain health and post-diagnostic services for those diagnosed in other services such as primary care, older persons, neurology, Psychiatry of Old Age services, and the Regional Specialist Memory Clinic (RSMC), ensuring equal access to services (see Diagram 5 below for the MASS model). Referral for PDS is dependent on assessment and diagnostic work-up. Criteria for referral to the brain health service include people diagnosed with Subjective Cognitive Impairment, Mild Cognitive Impairment and Mild Dementia.

Diagram 5: Pathway to MASS and to brain health and PDS services



GP, Secondary Care Clinics, Community Mental Health Services for Older People, Community Specialist Teams (CST's) for older people, etc. referral to Memory Assessment and Support Service

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

Triage to MASS POA, Neurologist or Geriatrician. Assessment and Diagnosis. Medications (if appropriate) and potentially disease-modifying treatment. The individual will also be offered the brain health service and / or PDS Service (as appropriate).

Brain Health Service

Personalised assessment, risk reduction intervention, care planning and follow-up; referral to PDS cognitive therapies for people with dementia and MCI as appropriate.

Post-diagnostic Support Service

Personalised assessment, care planning, referral, PDS intervention (e.g. cognitive therapies), point of contact and follow-up.

Overall coordination of the person's care will reflect their age, dementia-related needs and other co-morbidities 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 diagnosed alongside multiple co-morbidities, care will usually continue to be coordinated by the treating team e.g. Older Adults service, POA, CST for older people, Neurology, GP/primary care, with MASS input.

The diagnostic assessment in a MASS is comprehensive, involving an MDT skill-mix that is either part of the MASS team or readily accessible to the MASS. A MASS is capable of diagnosing less common presentations, including YOD, noting that the latter should almost always also be assessed in detail by a cognitive-behavioural neurologist and a neuropsychologist. The diagnostic assessment will progress at the individual's pace and may require a number of consultations, with various MDT members, including a consensus meeting, which is essential to inform further assessment planning (e.g. proceeding to CSF analysis) or to reach agreement on the diagnosis and the required immediate treatment and post-diagnostic support needs. The number of assessment and MDT consensus meetings may vary on a case-by-case basis, depending on complexity of presentation, investigations required, etc. Based on the diagnostic needs/complexity of case, decisions can be made at local level as to the MDT skill-mix required for thorough assessment of the person and the most appropriate clinicians and HSCPs to participate in consensus meetings.

3.3.1 The MASS post-diagnostic support service and brain health service

Following an assessment and diagnosis, the person will either be referred to the full PDS service within the MASS (if diagnosed with dementia), or for cognitive therapies only within the PDS service (if diagnosed with MCI), or to the brain health service (if diagnosed with SCI, MCI, or mild dementia and there are lifestyle risks for dementia identified). These two services will be led by the MASS Dementia-ANP/CNS, with input from other MDT colleagues.

The MASS brain health service will provide personalised assessment, risk reduction intervention, care planning and follow-up (and referral to PDS cognitive therapies for people with mild dementia or MCI as appropriate).

The MASS post-diagnostic service will offer personalised assessment, care planning, referral, PDS intervention (e.g. cognitive and other therapies), and will arrange a point of contact and follow-up. Attendance at this service will be an opportunity for the person to discuss any concerns following their diagnosis and for the MDT staff to clarify and provide further information and guidance. The personalised assessment will lead to the development of the care plan [See section 5 for further information on care planning].

MASS community CNS works closely with PHNs, GPs and other members of the primary care team in the local community, providing specialist advice and support. This close working relationship might include virtual and shared sessions with other members of the MASS team as appropriate.

Access to the PDS service and to the brain health service is not limited to those who receive a diagnosis at the MASS. Following assessment and full diagnostic work-up, referrals to these services can be made from primary care, older persons, neurology and POA non-dedicated services, cognitive-behavioural neurology clinics, and Regional Specialist Memory Clinics.

3.3.2 Electronic e-referral system

A national electronic referral system (e-referral) is being rolled out for referrals from GPs to MASS and RSMCs by Healthlink/HSE (pilot completed 2020). This supports:

- A quicker response to referrals
- Appropriate triage of patients for referral
- Improved communication of key information between referrer and memory clinic
- First appointment being more effective and efficient for the patient.

3.3.3 MASS diagnostic assessment

The diagnostic assessment in a MASS is comprehensive, involving an MDT skill-mix that is either part of the MASS team or readily accessible to the MASS. The MASS may be capable of diagnosing less common presentations, including YOD, noting the latter should almost always be assessed in detail by a specialist cognitive neurologist and neuropsychologist, and as such, unless these skillsets are embedded in the MASS, young onset and non-amnestic cases should be referred to Level 3 RSMC. Access to Psychiatry expertise is also important in behavioural-onset syndromes. The diagnostic assessment will progress at the individual's pace and may require a number of consultations with various MDT members, including a consensus meeting, which is essential as this will inform future assessment planning (e.g. CSF analysis) or reach agreement on the diagnosis and the required immediate treatment and post-diagnostic support needs. The number of assessment and MDT consensus meetings may vary on a case-by-case basis, depending on complexity of presentation, investigations required, etc. Based on the diagnostic needs/complexity of case, decisions can be made at local level as to the MDT skill-mix required, integration of services, and the most appropriate clinicians and HSCPs to participate in consensus meetings.

Referrals are required to be triaged, to ensure timely assessment, but also to ensure that the MDT skill-mix can meet the individual's diagnostic needs. Where the referral letter or initial assessment indicates that the diagnosis will be challenging due to a high level of complexity, MASS will promptly refer onwards to a RSMC (Level 3). The Level 2 MASS dementia diagnostic pathway is outlined in Table 9 below.

Table 9: Level 2 assessment – MASS

Level 2: Memory Assessment and Support Service (MASS) - Summary of Interventions and Pathway
Step 1: Referral Triage e-referral/referral letter for suitability for diagnostic assessment by MASS. If deemed too complex in relation to available MDT skill-mix, promptly refer onwards to RSMC (Level 3 assessment), informing the patient and the referrer of this decision. Review e-referral/referral documentation for results of previous laboratory investigations, cognitive screening, brain imaging if performed, and clinical notes where available, to support diagnosis and / or subtyping of dementia. Appointment letter for patient to provide a clear explanation of the assessment process (and likely duration), advise patient to bring with them their current medications, glasses/hearing aids and supportive other person, and a map with directions to the clinic attached to aid way-finding and minimise anxieties.
Step 2: Initial consultation • Establish what the person knows, or thinks they know about their condition • Establish if they are aware of the purpose of the assessment and what the possible outcomes might be • Do they have mental capacity to consent to any assessment-related procedures? • What measures are being implemented if the person shows they do not have capacity to consent? • Establish how much information the person would like to know about the assessment process and about any subsequent diagnosis that is made Begin process of communicating a diagnosis of dementia (see Section 3.3.1) History taking (see Section 3.3.2) • Patient's self-report • Collateral history – include informant questionnaire • Family history, if suspected YOD • If presenting as acutely unwell, perform delirium screen » Cognitive assessment [see Appendix E] » Physical examination [see section 3.2.3] • Neurological examination [see section 3.2.4 and Appendix G] » Medication review [see section 2.6.4] » Assessment of psychological function and mood [see Appendix E] • Assess for NCSD and responsive behaviours [see Appendix E] Assess functional status • Check for problems in paying bills, shopping, handling money, using appliances, etc. • Check for safety concerns such as driving hazardously, leaving door unlocked, leaving cookers on, vulnerability, etc. • Consider referral to OT for in-depth assessment, if indicated » Nutritional screen [see Appendix E] » Assess carer resources and coping [see Appendix E] » Consider the need for additional investigations, brain imaging, CSF analysis, etc. [see Appendix E] • Consider involvement of cognitive / behavioural neurology and / or neuropsychology for targeted assessment, particularly if diagnosis and / or dementia subtype remains unclear, atypical or non-amnestic presentation, or person is <65
Step 3 Brain imaging/CSF analysis, etc. These are usually performed at a separate visit, typically in an acute hospital. See text below for recommendations [see section 3.3.6]

Level 2: Memory Assessment and Support Service (MASS) - Summary of Interventions and Pathway

Step 4: Clinical consensus meeting – diagnosis formulation and consensus

- Collate all results and assessment outcomes.
- Feedback from MDT members.
- MDT discuss findings.
- Consensus reached on diagnosis.
- Plan agreed for communicating a diagnosis of dementia (incorporating the wishes of the person with dementia).
  - For less common/atypical/unclear presentations (including complex YOD) refer onwards to RSMC (Level 3) for diagnosis / subtyping. Inform referring doctor of assessment outcome/plan.

Step 5: Medical consultation: communicating a diagnosis/onward referral/care planning/follow-up plans [see section 4 and PDS section 6]

No evidence of any dementia/SCI/MCI – PATHWAY STOPS!

- Provide feedback on assessment and offer reassurance.
- Offer guidance on brain health interventions; recommend physical exercise and smoking cessation, if relevant.
- Inform GP/referring doctor of assessment outcome.

Diagnosis is Subjective Cognitive Impairment/Mild Cognitive Impairment

- Communicating a diagnosis of dementia [see section 4].
- Offer information on SCI/MCI, oral and written [see PDS section 6].
- Offer reassurance that the person may not develop dementia [see section 3.2.7].
- Follow-up by brain health service within the MASS [see PDS section 6].
- Cognitively impairing medications should be tapered/discontinued and an alternative prescribed, where possible [see section 2.6.4].
- Discuss the desire to participate in/access clinical trials; arrange referral to RSMC (Level 3) to facilitate participation if needed.
- For MCI only: record diagnosis in person’s clinical records, creating a red flag for 12–24 monthly reviews for cognitive monitoring, until stability or progression is evident (can be with GP, or with MASS if higher risk of progression).
- For MCI: consider immediate post-diagnostic needs [see section 2.6.8 and link to PDS section 6].
- Inform GP/referring doctor of diagnosis and agreed management/treatment.

Diagnosis is Dementia

- Continue process of communicating a diagnosis of dementia [see section 4].
- Offer oral and written information on dementia, specific to subtype [see PDS section 6].
- Discuss and agree on pharmacological treatment options [see section 2.6.7].
- Cognitively impairing medications should be discontinued and an alternative prescribed, where possible [see section 2.6.4].
- Consider immediate post-diagnostic supports [see section 2.6.8 and link to PDS section 6].
- Refer the person to a Dementia Adviser for further information on dementia and on local services and support [see PDS section 6].
- Co-produce a care plan incorporating immediate treatment plans, brain health interventions, identification of an appropriate person to act as ‘point of contact’, follow-up plans, and PDS [see PDS section 6].
- Follow-up by brain health service within the MASS [see PDS section 6].
- Follow-up by post-diagnostic services [see PDS section 6].
- Discuss desire to participate in/access clinical trials; arrange referral to RSMC (Level 3) to facilitate participation if needed.
- Inform GP/referring doctor of outcome of assessments, probable diagnosis, agreed treatment, and follow-up plan.

Level 2: Memory Assessment and Support Service (MASS) - Summary of Interventions and Pathway

- Where a person is not ready on the day of receiving a diagnosis to make a decision about commencing cognitive enhancing medications or non-pharmacological interventions, there is a planned follow-up within two weeks to re-discuss, when they have had time to reflect on the diagnosis and treatment options. Further follow-up should then take place as per Target 21.
- Arrange a follow-up appointment in 4–8 weeks to review, address acceptance and understanding, discuss need for referral to additional post-diagnostic support services, assess tolerance and effect of AChEIs, memantine, or any medication changes, etc.

Diagnosis is YOD – in addition to above

- Where genetic cause is considered, offer to refer the patient for genetic screening and counselling (typically via a cognitive / behaviour neurologist).
- The person receives follow-up from social worker who will work with the person to further develop their personalised care plan.

3.3.4 History taking

In addition to the guidance provided at Level 1 assessment [see section 3.2.2], history taking within the MASS uses informant questionnaires as part of obtaining the collateral history. Incorporating informant questionnaires with cognitive assessment has been shown to be an effective dementia and MCI assessment method, including the identification of risk factors (see Appendix E. Common informant questionnaires include the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE), the Alzheimer's Questionnaire (AQ) and the Dementia Screening Interview (AD8). Any of these can be used. The IQCODE is used widely as a screening tool for dementia, helping to distinguish between cognitive declines associated with dementia versus normal ageing versus subjective cognitive impairment. The AQ and the AD8 have been shown to be useful in the detection of dementia and MCI, with a positive result indicating the need for a comprehensive dementia assessment. Appendix E outlines the minimum clinical assessment required at a MASS, assuming that the referrer has done initial work up (detailed bloods, and CXR, MSU as indicated) to rule out reversible causes.

3.3.5 Clinical investigation

Imaging: The advisory group concluded that an MRI scan is the preferred modality to assist with early diagnosis and detection of subcortical vascular changes. It is important to request an MRI with coronal views of the hippocampi (i.e. coronal and sagittal cuts) and T1 and T2 weighted imaging. Depending on the degree of suspicion for vascular dementia, FLAIR sequences and diffusion weighted imaging can be considered, while gradient echo can help identify angiopathies and vasculitis.

However, a CT brain scan may be appropriate if an MRI scan is not available in a timely manner or is not appropriate (e.g. contraindication like pacemaker, metal implant, claustrophobia, unlikely to tolerate for another reason, or the goal of imaging is to rule out large structural brain disease rather than to support dementia subtyping). Where brain imaging is not appropriate or the patient declines the offer of attending for brain imaging, the clinician will document the reason clearly.

Clinical neuro-physiology: While not used routinely in the diagnosis of dementia, an EEG can be very useful when indicated, suggesting/supporting a metabolic, auto-immune, or infectious encephalopathy. EEG may also be useful in differentiating DLB from AD, if other investigations haven't clarified the diagnosis and is included as a supportive diagnostic biomarker in the 2017 DLB Consortium Diagnostic Criteria. An urgent EEG is indicated if there is rapid cognitive / behavioural decline, a suspicion of temporal lobe seizure activity, or non-convulsive seizures masquerading as hypoactive delirium. An EMG may be indicated if FTD is suspected and there is a suspicion of concurrent MND.

CSF examination: Until recently, CSF examination has not been routinely used in dementia diagnosis where the clinical presentation suggests a clear diagnosis, or pursuing a subtype would not alter the person's care or quality of life. It is used to support subtyping in people with suspected YOD, atypical presentations, or non-amnestic presentations, and where there is a rapidly progressive decline or other differentials need to be excluded. Increasingly however, CSF neurodegenerative biomarkers are used to subtype prodromal / MCI states, and in mild dementia, and this practice is likely to expand further with the advent of potential disease-modifying therapies where biomarker evidence of a particular disease process (e.g. amyloid in the case of AD) will be required. Appendix C gives guidance on the indications for CSF examination and requesting particular screening.

Genetic testing: Appendix D gives guidance on genetic testing as part of the diagnosis of suspected dementia.

3.3.6 Additional clinical investigations to determine dementia or MCI subtype

Where the assessments and structural brain imaging do not delineate the diagnosis or subtype, the clinician, in association with the person, will need to consider additional investigations. This may include Cerebrospinal Fluid (CSF) analysis and / or functional brain imaging (FDG-PET; SPECT) or amyloid-PET imaging. With the increasing availability of clinical trials, and likely near-future availability of disease modifying treatments, the need to reach a definite diagnosis including subtype, and to diagnose MCI, means that more advanced brain imaging modalities and CSF analysis need to be increasingly used in the assessment process, particularly in suspected MCI/mild dementia. Although age alone should not be an exclusion factor to diagnosis / subtyping/clinical trials/research, it is particularly important that people with suspected YOD undergo thorough investigations to inform accurate diagnosis / subtype. If this is not available in the MASS, the person needs referral to either a RSMC (Level 3) or a cognitive / behavioural neurology clinic.

The 2018 NICE guidelines recommend additional diagnostic investigations, specific to the suspected subtype, where diagnosis remains unclear, summarised in Table 10.

Table 10: Summary of NICE guidelines on additional diagnostic procedures

Suspected condition	Investigation of choice
Alzheimer's disease	FDG-PET* (or perfusion SPECT if FDG-PET unavailable) *or* CSF total tau (+/- phosphorylated-tau 181) **and** amyloid beta 1–42 (+/- amyloid beta 1–40). Consider adding the second option if diagnosis still unclear
Dementia with Lewy bodies	I-FP-CIT SPECT (also known as a DAT scan) or consider I-MIBG cardiac scintigraphy if SPECT unavailable
Frontotemporal dementia	FDG-PET or perfusion SPECT
Vascular dementia	MRI (or CT if MRI is unavailable or contraindicated)

3.4. Dementia Diagnosis in Other Care / Specialist Services

Dementia diagnosis in secondary care refers to diagnostic assessments that takes place occasionally in acute hospital wards (including acute psychiatry wards), and more usually in out-patient clinics, by geriatric medicine, cognitive / behavioural neurology clinics or mental health services for older people/POA services. Also included are Psychiatry of Old Age clinics based in community settings and regularly facilitating domiciliary assessments, although not technically based in secondary care.

This diagnostic pathway may be the most appropriate, if available locally, for the frail older person with multiple complex medical co-morbidities or mental health difficulties, who presents with dementia, or for a person with an established neuro-degenerative disease that is known to cause dementia (e.g. Parkinson's disease). This pathway facilitates continuity of care where the person is known to the service or under active follow-up, with an established MDT–patient–family relationship. The three disciplines above have significant experience and knowledge in dementia diagnosis. However, they may lack the personal skill, or access to the necessary investigations and MDT skill-mix necessary to assess the more challenging presentations of dementia, in which case the person could be referred to a RSMC or a MASS. The optimum service for diagnostic assessment for a person depends on the level of complexity of their cognitive/ non-cognitive presentation, their other co-morbidities, overall health status, and the available MDT skill-mix in the non-dedicated service.

Where concerns of dementia are expressed or observed while the individual is in acute care, occasionally it may be appropriate to fully assess and diagnose the patient during hospitalisation, but generally, it is recommended that assessment of dementia takes place when the individual is discharged and back to usual health, allowing more complete and accurate assessment. The treating hospital team is responsible for arranging this follow-up, as per the agreed national pathway for suspected dementia in acute care (see section 2.5.7). GPs should be informed of the suspected diagnosis on discharge as well as the follow-up plan.

The person presenting for diagnostic assessment to Psychiatry of Old Age, Cognitive / behavioural Neurology, or Geriatrician-led services may have been specifically referred from their GP (with initial diagnostic work-up completed to rule out/treat any reversible causes of cognitive decline completed). Others may be attending the service for the management of other conditions such as Parkinson's disease, falls, frailty, cardiac conditions, and mental health concerns, when symptoms suggestive of dementia are first observed or reported.

In general, the pathway for the MASS (Table 9) serves as a useful guide for the assessment of a person at a non-dedicated specialist service, adapted for the individual's own context. Appendix E outlines clinical investigations that may be indicated, but clearly, the patients seen in non-dedicated services are very heterogeneous, so generalisation is difficult. Thus, structural imaging may not always be necessary in presentations of moderate to severe dementia, of a long duration, where the diagnosis is clear and other reversible causes have been excluded. However, in general, almost everyone will require structural brain imaging, either MRI brain or CT brain. Similarly, subtyping may not always be possible or indicated, taking into consideration the impact of diagnostic investigations on the particular individual, their quality of life, and / or their life expectancy; but for most patients, the subtype should be determined.

3.5. Level 3 Assessment – Regional Specialist Memory Clinic

Assessment at Level 3 is generally for complex, atypical, unclear cases, suspected YOD, and / or where the person wishes to participate in a more detailed and specific aetiological evaluation. Level 3 assessment is based in a Regional Specialist Memory Clinic (RSMC) and carried out by experts in the field of dementia. Level 3 comprises a rich multi-

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disciplinary skill-mix, sufficient to meet the varied needs of each individual and their family, from diagnostic assessment, communicating a diagnosis and referring on to post-diagnostic supports. The diagnostic assessment process in Level 3 requires a number of clinical consultations to complete the comprehensive assessment, while also allowing for MDT consultation and consensus meetings along the assessment journey. Table 11 illustrates the diagnostic pathway for Level 3 assessment. Referrals to Level 3 assessment services can come from local or national catchment areas, direct from the individual's GP (Level 1), from acute hospitals, or from non-dedicated specialist services or MASS (Level 2). Those presenting with suspected YOD are accepted into all Level 3 assessment services, regardless of the lead physician's discipline.

The specialist diagnostic pathway (Table 11) is presented in steps, given the need for detailed assessment, imaging, MDT discussions and consensus meetings. Steps 1 and 2 are referral and initial assessment. Step 3 describes the consensus meeting, where all the information gleaned from Steps 1 and 2 are collated and discussed, leading to the formulation of a working diagnosis. This will then inform Step 4, identifying any additional investigations required, and where necessary, more targeted assessments by specific MDT members, for clarification of diagnosis and dementia subtyping. Step 5 describes the second MDT consensus meeting, if required, where all relevant information is examined and discussed, leading to the confirmation of diagnosis, and preparation for communicating the diagnosis of dementia to the patient and supportive other.

Table 11: Level 3 assessment – Regional Specialist Memory Clinic

Summary of Interventions and Pathway

Step 1: Referral

- Referrals arrive to a centralised reception, and are triaged for appointments depending on clinical details and request urgency (routine/urgent). The referral clinical information provided on the e-referral system will map onto the assessment proforma.
- Appointment letter to patient to provide a clear explanation of the assessment process (and likely duration); advise patient to bring with them their current medications, glasses/hearing aids and supportive other; provide a map with directions to the clinic attached to aid way-finding and minimise anxieties.
- Review e-referral/referral documentation for results of previous laboratory investigations, cognitive screening, brain imaging if performed, and clinical notes where available, to support diagnosis and / or subtyping of dementia.

Step 2: Consultation 1 – with one or more MDT members

The person is firstly informed about the process of assessment and is provided with written and verbal information on what to expect, so they are empowered throughout the diagnostic pathway.

The process of informing a person of a diagnosis of dementia begins with establishing the person's understanding of their problems and insight into their condition. See section 3.3.1 above for further information on the process of communicating a diagnosis of dementia.

History taking

- History taking [see section 3.2.2]
- Patient's self-report
- Collateral history; include informant questionnaire [see Appendix E]
- Family history, if suspected YOD
  - » Physical examination [see section 3.2.3]
  - » Medical review; if presenting as acutely unwell perform delirium screen
  - » Cognitive assessment [see section 3.2.5]
  - » Medication review [see section 2.6.4]
  - » Neurological examination [see section 3.2.4]
  - » Assessment of psychological function and mood [see Appendix E]
  - » Assess functional status; consider OT assessment, if indicated
  - » Check for problems paying bills, shopping, handling money, using appliances, etc.

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Summary of Interventions and Pathway

- » Check for safety concerns such as driving, leaving door unlocked, leaving cookers on, vulnerability, etc.
- » Assess for NCSD and responsive behaviours [see Appendix E].
- » Nutritional screen [see Appendix E].
- » Consider the need for additional investigations; brain imaging, CSF analysis, etc.
- » Consider involvement of neurology and / or neuropsychology for targeted assessment, particularly if diagnosis and / or dementia subtype remains unclear or atypical presentation or suspected YOD.
- » Assess carer resources and coping [see Appendix E].

Step 2a: Structural brain imaging [see section 3.3.5]

Step 3: Clinical Consensus Meeting (working diagnosis formulation)

- Collating of assessment outcomes and test results, including imaging
- Feedback from MDT members
- MDT discussion
- Consensus agreed on working diagnosis and direction of assessment process, e.g. additional investigations, etc.

No evidence of dementia / SCI / MCI – PATHWAY STOPS!

- Offer reassurance
- Offer guidance on risk reduction; recommend physical exercise and smoking cessation, if relevant
- Inform referral doctor / GP of assessment outcome.

Where dementia, SCI or MCI remains suspected, continue with assessment process.

Step 4: Consultation 2 – with one or more MDT members

- Targeted Functional Assessment – OT
- SLT Assessment
- Targeted neuropsychological testing or review
- Neurologist review as indicated
- Assessment of current support and social care needs by SW
- Suspected MCI – refer for audiology assessment (not for mild dementia).

Step 4a: Extra clinical investigations

- Consider the need for additional investigations: brain imaging, CSF analysis, etc., as outlined in Appendix E

Step 5: MDT consensus meeting (confirmation of diagnosis)

- Collate all results and assessment outcomes
- Feedback from MDT members
- MDT discuss findings
- Consensus reached on diagnosis
- Plan agreed for communicating a diagnosis of dementia (incorporating the wishes of the person with dementia).

Summary of Interventions and Pathway

Step 6: Medical consultation (communication of a diagnosis and care planning) [see section 4 & section 5]

Diagnosis is Subjective Cognitive Impairment/Mild Cognitive Impairment

- Communication of diagnosis [see section 4]
- Offer information on SCI / MCI, oral and written [see PDS section 6]
- Offer reassurance that the person may not develop dementia [see section 3.2.7]
- Follow-up by brain health service within the MASS [see PDS section 6]
- Cognitively impairing medications should be tapered / discontinued and an alternative prescribed, where possible [see section 2.6.4]
- Discuss the desire to participate in / access clinical trials; arrange referral to RSMC (Level 3) to facilitate participation if needed
- For MCI only, record diagnosis in person's clinical records creating a red flag for 12–24 monthly reviews for cognitive monitoring, until stability or progression is evident (can be with GP, or with MASS if higher risk of progression)
- For MCI, consider immediate post-diagnostic needs [see section 2.6.8 and link to PDS section 6]
- Inform GP / referring doctor of diagnosis and agreed management / treatment

Diagnosis is dementia

- Communication of diagnosis [see section 4]
- Offer oral and written information on dementia [see PDS section 6]
- Discuss pharmacological treatment options depending on subtype [see section 2.6.7]
- Consider immediate post-diagnostic needs [see section 2.6.8 and link to PDS section 6]
- Refer the person to a Dementia Adviser for further information on dementia, support, and information on local supports and services
- Depending on individual needs and wishes, offer referral to local MASS for follow-up by post-diagnostic services and access to community-based supports [see PDS section 6]
- Discuss desire to participate in / access clinical trials; arrange referral to same if agreed
- Agree a 4–8-week follow-up plan, whether Regional Specialist Memory Clinic / MASS / generic secondary care / GP to review progress, address acceptance and understanding, discuss need for referral to additional post-diagnostic support services, assess tolerance and effect of AChEIs and other medication changes, etc.
- Inform GP / referring doctor of relevant results, e.g. MRI, neuropsychological or occupational therapy assessment, probable clinical diagnosis, agreed treatment, and follow-up arrangements

Diagnosis is YOD – In addition to above

- Where genetic cause is considered, offer to refer patient for genetic screening / counselling
- Person receives follow-up from social worker who will work with the person to develop their personalised care plan.

Table iv, Appendix E, outlines the typical assessments and common tools that will be used at the RSMC, noting that more detailed testing may need to be performed for any domain, given the patient's particular history and circumstances, and the results of initial tests.

3.6. Underpinning the Principles

The overarching principles of the Dementia Model of Care, as outlined in the introduction, underpin the diagnostic pathway in a number of ways as outlined in Diagram 6 below.

3.7. Section Summary

This section of the Dementia Model of Care outlined the technical elements of the diagnostic pathway across the three levels of assessment e.g. Level 1 at primary care; Level 2 at Memory Assessment and Support Services (and specialist, but non-dedicated services) and Level 3 at Regional Specialist Memory Clinics. The section outlined the key steps for assessment at each of these levels and presented information on appropriate screening / assessment tools.

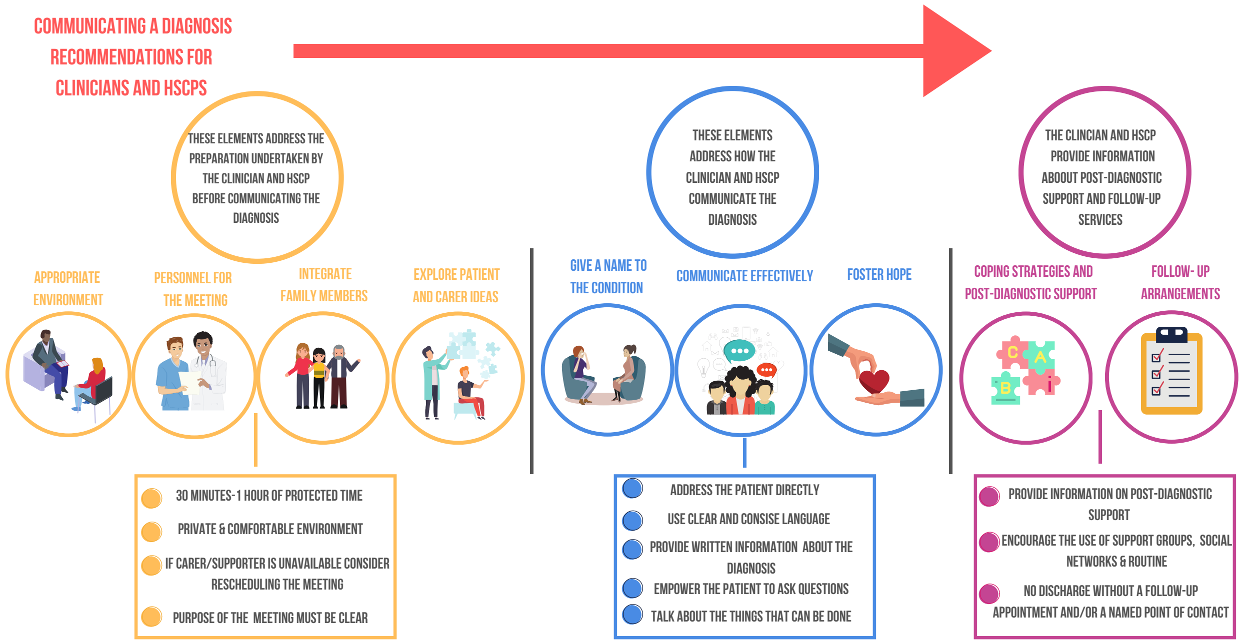
Diagram 6: Applying the Dementia Model of Care principles across the assessment and diagnostic pathway

Citizenship	People with suspected dementia have equity of access to memory assessment services across the diagnostic pathway, irrespective of age, geographical location, gender, co-morbidity, or setting in which they live.
Person-centred Approach	The needs, views, autonomy and wishes of each person with suspected dementia will be sought and respected across all levels of diagnostic assessment.
Integration	The level of diagnostic assessment required, including onward referral decisions, will be informed by integrated working across teams and disciplines to ensure the right assessment and treatment by the right team / service.
Personal Outcome-focused	The diagnostic process will focus on achieving the desired outcome for the person and their supportive other.
Timeliness	The diagnostic process across all levels will progress in a timely and responsive manner, respecting and maintaining autonomy, and supporting continuity of care, with timely referral and access to appropriate testing.

SECTION 4

GIVING A DIAGNOSIS OF DEMENTIA

Diagram 7: Summary of communicating a diagnosis of dementia pathway



> ‘In caring for people with dementia and working with caregivers over the years, I have been struck at times by how less important the diagnosis is when contrasted to what you might be able to do for the person or family. Doctors can labour over the communication of the diagnosis but spend little time focusing on treatment and management. Part of this is because of the sense of nihilism when confronted with a diagnosis of dementia and the feeling that we have few tools to effect change. Sometimes we fail to appreciate the importance of instilling hope and we can transfer our own sense of hopelessness to the person and their family. Patients and families need to have hope that something can be done, hope of a cure, an intervention, something to improve quality of life; even the hope of not being abandoned and being offered support and help is important.’ (Lawlor 2018)

4.1. Section Introduction

The World Alzheimer Report 2011 found that most people with dementia do not receive their dementia diagnosis (Prince et al. 2011) and that they are denied the possibility of either themselves or their family making choices or gaining appropriate help (Donegan et al. 2017). For those who receive a diagnosis, it can often be late, when people are already experiencing difficulties with their cognition and decreasing quality of life (Brooker et al. 2014). For those who reach the point of diagnosis, the average journey time from thinking that something may be wrong to beginning the process of diagnosis is around three years (Chrisp et al. 2011).

In recent years there has been a strong and steady movement towards early or timely diagnosis of dementia (Carpenter and Dave 2004, Werner et al. 2013), and countries who have strategies that encourage timely diagnosis have higher rates of people being diagnosed earlier (ALCOVE 2013). Most ethical guidelines strongly promote the communication of a diagnosis of dementia to the person based on the ‘principle of autonomy’ (Fisk et al. 2007), and in recent years there has been a move towards how, rather than when, a diagnosis of dementia should be communicated (Milby et al. 2017).

There are a number of models for breaking bad news (Baile et al. 2000, Derksen et al. 2006, Narayanan et al. 2010, Tuffrey-Wijne 2012) which can inform the approach for the Dementia Model of Care. Revez and colleagues recommend that the behaviours identified by Lecouturier et al. (2008) could be used as a framework to educate HSCPs in Ireland on issues around communicating a diagnosis of dementia (Revez et al. 2018). Lecouturier et al. (2008) identified eight best practice behaviours. (see Diagram 8)

Diagram 8: **Eight best practice behaviours adapted from Lecouturier et al. 2008**

Adapted from Lecouturier *et al.* 2008

Alongside Lecouturier et al.'s (2008) model, the guidance outlined below on communicating a diagnosis of dementia is informed by a number of other sources, including:

- An extensive literature review including 'Dementia Diagnostic Services for Ireland: a literature review' (Revez et al. 2018)
- The views and experiences of people and carers / supporters who have experienced a diagnosis of dementia
- Opinions of clinicians and HSCPs who regularly give diagnoses of dementia as part of their job.

Similarly to the rest of the Dementia Model of Care, the guidance is presented across a series of targets, practice recommendations and best practice tips. Resources and references also appear across this section. The content focuses on preparations and what doctors and HSCPs can do in advance of the meeting to communicate the diagnosis of dementia. The behaviours and actions of the clinician(s) and HSCP(s) during this meeting are outlined and how these can optimise outcomes for the person. In addition, the section describes recommendations relating to immediate post-diagnostic support and follow-up, as well as focusing on the needs of distinct groups, e.g. people living in residential care, people with YOD and anti-discriminatory practices.

The primary target in relation to communicating a diagnosis of dementia is:

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.

Practice Recommendations

As per an earlier recommendation, the process of communicating a diagnosis of dementia should begin at the first contact with the person.

4.2. Preparations for the Clinician(s) prior to communicating the diagnosis

Communicating a diagnosis of dementia can be challenging; even more so if appropriate care and attention is not taken. The meetings are often emotionally charged and can be very stressful for all involved. As a result, all professionals who are potentially in a position to give a diagnosis of dementia should know how to do so in a knowledgeable, compassionate and respectful manner.

Just like their patients, every doctor, nurse and HSCP is different, with different skill sets, different communication styles and different attitudes towards conditions such as dementia and how best to respond to them. What all doctors, nurses and HSCPs do have in common when it comes to communicating a diagnosis is knowledge. They know the results of the assessment and investigation in advance of the patient and this knowledge provides opportunity; opportunity to prepare properly for the meeting, to anticipate what will be needed to begin formulating a plan for future care and support and to decide how best to imbue hope in the person.

As stated in section 2, the process of communicating a diagnosis begins at the first meeting with the person, where the clinician establishes if the person has insight into their problem and if they know why they are attending for assessment.

- Establish what the person knows or thinks they know about their condition.
- Establish if they are aware of the purpose of the assessment.
- Does the person have the mental capacity to consent to any assessment-related procedures?
- What measures will be implemented if the person shows they do not have capacity to consent?
- Are additional measures needed around decision-making support?
- Establish how much information the person would like about the assessment process and about any subsequent diagnosis that is made.

This will ensure that a respectful patient–doctor relationship is established from the beginning and should ensure that any possible dementia diagnosis does not come as a complete surprise to the individual. It is important that the person understands the process that they are embarking on and what the possible outcomes are, including a possible diagnosis of dementia.

This scenario will become more complex if the person lacks insight into their condition and may call into question their capacity to consent to the diagnostic process. Detailed advice, if required, should be sought from the Decision Support Service.

Once assessment and testing are completed, the clinician and HSCP can prepare for the meeting where the diagnosis will be given. This involves consideration of practical arrangements in relation to the time and location of the meeting, establishing the individual's preferences for receiving a diagnosis, raising the possibility that dementia might be a diagnosis and planning the best approach to use in the meeting (Lecouturier et al. 2008).

Practice Recommendations

- All meetings where a diagnosis is given should take place in a quiet and comfortable setting.
- Privacy is paramount and staff should ensure that the conversation cannot be overheard from outside of the room.
- The seating arrangements and room layout should be prepared in advance.

4.2.1 Appropriate environment

The setting for the meeting should be appropriate for a 'sensitive and private discussion' (Buckman et al. 2005). Trying to find the most appropriate setting for this meeting can be challenging and alternatives may need to be sought. For example, a waiting room or a training room could be adapted for the purpose.

Best practice tips

- Attempt to secure a quiet, non-clinical room away from areas of high footfall.
- Consider delivering the diagnosis in the person's own home if appropriate.
- Ensure there is enough seating for those attending.
- Avoid confrontational seating arrangements.
- Avoid artificial barriers such as a desk or table between clinician, HSCP and the person.
- Adjust the seating height of chairs, if possible, to ensure parity between clinicians, HSCP and the person.
- Privacy is essential. It is not appropriate to communicate a diagnosis behind curtains or where the conversation is audible to others.
- Décor should be neutral and calming (e.g. no medical pictures on wall).

4.2.2 Personnel for the meeting where a diagnosis of dementia is given

Ideally, the same person who is known to the patient and who has met them during their assessments should be the one who communicates the diagnosis (Derksen et al. 2006). Studies also suggest that patients and caregivers prefer hearing a dementia diagnosis from a professional with whom they have a relationship, regardless of whether they have dementia-specific expertise (Robinson et al. 2011).

TARGET 17	Regardless of setting, a physician, with a HSCP and / or nurse in attendance, should deliver the diagnosis of dementia.

Two people being present at the meeting allows for pooling of knowledge and expertise, which can be of benefit to both the person and their carer / supporter. It also allows the doctor and HSCP / nurse to share the emotional burden of communicating a diagnosis of dementia. If under time pressure, it provides an opportunity for the doctor to step back from the meeting at an appropriate point and allow the HSCP or nurse to utilise the rest of the time appropriately.

Best practice tips

- Where at all possible and practicable, the same physician who conducted the previous meeting(s) and assessments should deliver the diagnosis.
- Request the assistance of an experienced practice nurse or a HSCP for the meeting where a diagnosis is given.
- Consider seeking assistance from the local primary care team, hospital, MASS or RSMC if no HSCP available locally.
- If no practice nurse or HSCP is available, consider seeking the assistance of a Dementia Adviser if available.

The target below outlines the suggested staffing requirement for the meeting to communicate a diagnosis across the different levels.

TARGET 18

Staffing recommendations for the process of communicating a diagnosis of dementia

For communicating a diagnosis of YOD or atypical presentation:

- Consultant, Specialist Registrar or Registrar, plus
- Senior Social Worker

Plus other MDT members (e.g. Neuropsychologist) as indicated based on the assessment findings and clinical context.

For communicating a diagnosis of dementia to those over the age of 65 at Level 2 – MASS, cognitive / behavioural neurology clinic or specialist non-dedicated service:

- Consultant, Specialist Registrar or Registrar, plus one of the following:
    - CNS/ANP
    - Occupational Therapist
    - Social Worker
    - Speech and Language Therapist (depending on diagnosis)
    - Neuropsychologist

For communicating a diagnosis of dementia to those over the age of 65 at Level 3 – RSMC

- Consultant or Specialist Registrar, plus one of the following:
    - Senior Social Worker
    - Senior Occupational Therapist
    - Senior Neuropsychologist
    - Senior Speech and Language Therapist (depending on diagnosis).

4.2.3 Time

TARGET 19	The time allocation for communication of the diagnosis will be influenced by patient-specific needs and complexity. When the person has a dementia with no complicating factors, a minimum of 30 minutes should typically be allocated for the meeting; longer slots will be required for more complex cases or young onset presentations.

Practice Recommendations

For the most complicated presentations and / or those requiring complex post-diagnostic interventions, a minimum one-hour time slot is recommended, with the option of return visits to ensure the completion of all relevant actions.

The issue of the amount of time available to medical practitioners can be problematic. Derksen and colleagues suggest a minimum of 30 minutes to communicate a diagnosis of dementia. This is case and setting dependent and will vary (Derksen et al. 2006). At a primary care level, by planning ahead and using creative scheduling of appointments it should be possible to accommodate the small number of people diagnosed with dementia at this level.

Regional Specialist Memory Clinics should automatically plan for longer meetings and anticipate arranging further appointments.

Best practice tips

- The process of communicating a diagnosis of dementia should be in protected time without interruptions.
- Clinicians should consider scheduling meetings at the end of their surgery/clinic time to accommodate any overruns. This may reduce the time pressure on the clinician, the person and carer(s)/supporter(s).
- If the doctor is accompanied by an experienced HSCP or nurse then they may attend the first part of the meeting to discuss the assessment results, deliver the diagnosis, prescribe any medications and address any outstanding issues (e.g. cessation of driving) before leaving. The HSCP/nurse will then continue with the immediate post-diagnostic advice and support and deal with any questions raised. This style of meeting should be agreed with the person and carer / supporter at the start.

Complex cases and those requiring significant post-diagnostic psycho-social inputs may require additional clinic appointments.

4.2.4 Integrating family members

Practice Recommendations

- It is strongly recommended that where practicable and possible the person receiving the diagnosis is accompanied by a carer / supporter.
- Failure of a carer / supporter to attend may be enough to postpone the meeting where a diagnosis of dementia is given.

Having a good knowledge and awareness of the person and their family can be a considerable advantage for clinician(s) and HSCP(s). It allows them to tailor the communication process and any subsequent information to the particular individual and their supporter. Most studies indicate that the majority of carers are in favour of the communicating of a diagnosis and it is important that they are involved at the earliest opportunity in the diagnostic process (Pinner and Bouman 2003, Lin et al. 2005). It is also common for people with dementia to experience problems with recall, and having a support person with them can help with this (Frank et al. 2006, Bradford et al. 2011, Mastwyk et al. 2014).

Sometimes it can be difficult to identify who the most appropriate support person is and how to involve them. The appropriate support person should be someone chosen by the person with dementia and it should be confirmed that the person is happy for them to be present when the diagnosis is given. This can help to avoid situations where there may be coercion or duress. Ensuring that both the person and any of their potential supporters are clear about the purpose of the original assessment can help in this identification process. It is also important to respect the person's guidance in this matter.

Best practice tips

- In many conditions of dementia, poor memory is likely to be one of the most obvious presenting complaints. It is important, therefore, that an accompanying family member / supporter is in attendance for the communicating of a diagnosis of dementia.
- If the person has no carer / supporter then a follow-up plan of support needs to be arranged prior to the planned meeting.
- Clinicians and HSCPs should be wary of inadvertently colluding with the accompanying individual or family.

Personal knowledge or acquaintance with the person and / or their family should not discourage the clinician from communicating a diagnosis.

4.2.5 Exploring patient and carer / supporter ideas

Practice Recommendations

- Clinicians should ensure that the person and carer/ family member / supporter(s) are told the purpose of the meeting.
- Clinicians should ascertain how much or how little information the person would like to hear (as per earlier practice recommendation where the process of communicating a diagnosis of dementia begins at the first contact).

The communicating of a diagnosis of dementia should be a person-centred process that maintains the person's integrity and fosters a realistic sense of hope (Lee and Weston 2011). This person-centred approach requires that the process is tailored to the abilities and psycho-social resources of the person with dementia and their caregiver (Aminzadeh et al. 2012). Exploring both the person's and carers / supporter's thoughts about a possible diagnosis can help to draw out the feelings and expectations that both parties have and this can influence the clinicians approach to the communication of a diagnosis of dementia itself. Discussions should take place about how much information the person would like about the diagnosis and prognosis, if they want to know their diagnosis at all and the implications of this (Lecouturier et al. 2008). This process should begin at the first appointment for assessment and decision support or advocacy services should be used if indicated.

The vast majority of people with dementia and their carers want to know the diagnosis (Pinner and Bouman 2003, Byszewski et al. 2007, Mastwyk et al. 2014). However, there is always a possibility that people may not want to know the diagnosis for cultural reasons, a perception that they won't be able to cope, stigma or a lack of formal and informal social support (Aminzadeh et al. 2012). If this is the person's own choice and they have made the decision themselves, it should be respected but explored further (Aminzadeh et al. 2012). This requires examining the personal outcome that is important for each individual, and not making assumptions.

Additionally, a carer / supporter or family member may oppose the communicating of a diagnosis of dementia being made to the person. This also needs to be explored but it should not prevent the communication of the diagnosis to the person (Carpenter and Dave 2004, Bamford et al. 2004, Byszewski et al. 2007). It is important to ascertain the personal outcome for the individual in relation to being told their diagnosis.

Always direct the conversation at the person whose views you are trying to ascertain, and when conversing with the person, try to ensure that the carer / support person does not speak for them. Although there are many benefits for a timely diagnosis, it is important to place the person's needs and right to choose at the centre of the process (Brooker et al. 2014).

Best practice tips

- Does the person and their carer / supporter understand why they are attending?
- What do they think is causing the memory and / or cognitive problems? (In some cases, where there is insight, the person might already have surmised what the diagnosis is).
- Establish how much they would like to know about the investigations and the results (including the diagnosis).
- Does the person and their carer / supporter require additional assistance with decision-making?

If the carer / supporter insists on a diagnosis not being given then this issue should be explored with them prior to the planned meeting. N.B. Carer / supporter opposition is not a sufficient reason for not communicating a diagnosis of dementia.

4.2.6 Communicating a diagnosis when there is a genetic component

The communicating of a diagnosis of a dementia that has a genetic component will often have a more complex and emotionally charged dynamic as the ramifications of the diagnosis can reverberate far outside the individual sphere, sometimes encompassing numerous generations of a family, past and future.

The 'pre-meeting' advice that has been discussed throughout Section 3 are still valid when communicating a diagnosis of a genetic dementia. Finding an appropriate environment, Integrating family members (with the person's permission) and exploring the person and caregiver's response to the diagnosis are all essential ingredients to the process of communicating a diagnosis of dementia.

Sufficient time should be allocated, for these complicated and often-difficult circumstances, both the doctor and HSCP should be experienced professionals, preferably with prior experience of these types of meetings. The doctor and HSCP must ensure that they have extra, protected time allocated, should that be needed, e.g. at least one hour. As both the person with dementia and their caregiver may have complex questions to ask, both about the diagnosis and its wider implications, it is recommended that both the doctor and HSCP stay for the full meeting.

Clinicians and HSCPs may also need additional time for themselves in order to 'decompress' if the meeting has been emotionally fraught.

Following the communication of a diagnosis of dementia, written information is provided to the person about the diagnosis and about possible post-diagnostic supports. This information may differ from that given to those diagnosed with non-genetic dementias. In which case, the doctor, nurse and HSCP should source this material beforehand and have it ready to dispense at the appropriate time.

At the meeting itself, the main elements of the process will remain as previously stated. With regards to naming the condition, as the individual will have already agreed to genetic testing they should already have been made aware of the potential result. Best practice should include the person having received genetic counselling [see Appendix D] prior to their testing and so the person should be fully aware of the implications of the diagnosis. Despite being forewarned, clinicians should not shy away from naming the condition *unless* the person has expressed a wish not to be told. As with all situations where a diagnosis of dementia is communicated, clinicians should always check that the person still wants to receive the results of the testing and be ready to break off if the person declines.

Communicating information about a genetic dementia will require skill, knowledge and experience. Sharing the knowledge that a person has a condition with no medical treatments beyond symptomatic medications is always difficult. The individual may already have a strong suspicion of what lies ahead as they might have witnessed grandparents, parents and siblings experiencing similar symptoms. Partners, spouses and children will experience a different array of emotions on hearing the news.

Clinicians must be certain of the accuracy of their information around the risk of inheriting a genetic variant of dementia, as erroneous or equivocal advice could have serious consequences for the person and their families.

In these circumstances, the possibility of imbuing hope may seem futile. However, as with those being diagnosed with a YOD, there is information and practical advice that may bring solace and some degree of assurance about the future.

Depending on the condition and its severity, it may be the case that the person has many years of life ahead of them in which to continue working, enjoying family life and engaging in hobbies and sport. They may have the opportunity to plan and organise for this life and make decisions for the future, and this sense of agency can bring with it a certain amount of reassurance.

> *'Prepare for the probable, work for the possible and hope for the future.'*
>
> (Ronan Smith, author and member of the Irish Dementia Working Group)

The amount and type of post-diagnostic support information given at the meeting will depend on the person and caregiver's frame of mind and any questions or concerns that are raised. For instance, a person worried about their work or finances may be relieved to know that they may have access to social welfare, insurance payouts or employee rights and protections. Having this information available in a 'take-home' format should form part of the clinician's and HSCP's preparation for the meeting. Additional meetings are likely to be needed to offer further information and support.

Throughout the meeting, clinicians and HSCPs should not underestimate the individual's emotional (or physical) reaction to actually hearing their suspicions confirmed. For those with siblings and children, the emotional response can be compounded with guilt and worry about what their future will hold. Following the communication of a diagnosis, clinicians may suggest referral to professional counselling services and this information should be provided as a matter of course during the meeting.

If a direct blood relative is in attendance then they too may become acutely concerned as to their own health prospects going forward and have demanding questions of their own. It may not be possible to adequately answer some of these questions and clinicians should recommend that the blood relative attend genetic counselling themselves.

Clinicians will have to consult with the person (and carer / supporter, if involved in the meeting) regarding who they may or may not wish to share the results with as this too can have far-reaching implications.

The challenge for clinicians and HSCPs is how to best respond to these scenarios. Certainly, it will require knowledge, skill and tact but also a willingness to embrace the emotional response and to help the individual and their supporter to work through the initial impact of the diagnosis.

Practice Recommendations

Further information is required to inform additional staffing and resourcing to address genetic counselling therefore it is recommended that as part of the MoC implementation programme a a needs analysis is undertake to inform future resource allocation.

4.3. Considerations for the Clinician (Behaviours and Actions)

Consensus across a number of studies is that the communication of a diagnosis of dementia is an evolving process that includes providing information and support tailored to a person's own individual needs, with support over time (Moniz-Cook et al. 2006, Byszewski et al. 2007, Langdon et al. 2007, Manthorpe et al. 2011, Robinson et al. 2011). There are a number of considerations around the behaviours of the clinician that can have a positive benefit/ outcome for each person. Doctors found that emphasising any positive findings before delivering bad news was a good strategy for gradually leading the person with dementia to the bad news (Kissel and Carpenter 2007).

4.3.1 Give a name to the condition

Practice Recommendations

- The diagnosis must be delivered in clear and concise language that is easily understood by the person and carer / supporter.
- Name the subtype of dementia (if known) and avoid euphemisms.
- The diagnosis should be provided in writing, preferably in a clear, type-written format.

In the majority of cases, a progressive and upfront communication of the diagnosis is the most constructive approach based on the person's communication styles and preferences (Fisk et al. 2007, Byszewski et al. 2007). Some people will suspect dementia, while others will not and it is this latter group who need special preparation and attention to minimise adverse reactions (Byszewski et al. 2007, Aminzadeh et al. 2012).

In some situations, depending on subtype and / or level of impairment, the person diagnosed with dementia may lack insight into their condition or be in denial of their deficits. These scenarios often require a great deal of skill and experience to negotiate successfully. When communicating a diagnosis to a person who lacks insight and an awareness of what is being said to them, clinicians will find that they increasingly direct the conversation towards the carer / supporter. Attempts should be made at every stage to involve the person with dementia and any input they make, pertinent or otherwise, should be acknowledged with respect.

Clinicians will need to be consistent in their views and it is important not to be seen to be taking the side of, or colluding with, the carer / supporter while, at the same time, tacitly acknowledging their input. Keep in mind that carers / supporters can often bear the brunt of clinician's missteps following the communication of a diagnosis.

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- Ensure that the person with dementia and the carer / supporter can hear you clearly. If hearing is an issue, consider having a personal listening device and headphones (e.g. Bellman Maxi Personal Listening device) or a Bluetooth enabled hearing device available for patient use.
- Name the condition, e.g. 'Alzheimer's disease' and the terminology* should then be explained in language that is understandable. It may help to relate the symptoms of the condition to the changes in the person's abilities. For example, how their forgetfulness causes them difficulties remembering what groceries to buy.
- Maintain eye contact with the person when communicating the diagnosis. The diagnosis should never be directed toward the carer / supporter.
- Ensure that the diagnosis and subsequent information is communicated in a manner that is understandable to the individual. This could mean through the use of interpreters, simplified explanations, pictures and symbols or the use of communication aids.
- Try and give a balanced report of the results by highlighting strengths and weaknesses.
- Don't apologise ('I'm sorry to inform you that you have Alzheimer's disease') as this can sound insincere.
- Be prepared for the person and carer's / supporter's reactions and respond appropriately. These can run through a gamut of emotions from shock and fear right through to relief.
- Acknowledge the person and carer's / supporter's emotions.
- Check their understanding of what they have been told. Understanding the diagnosis is one of the most important goals and some would argue the main goal when delivering a diagnosis (Bennett et al. 2019).
- Invite questions.

Provide the diagnosis in a written format.

***Comment on terminology**

The increasing use of CSF biomarkers and other improvements in the ability to diagnose people with dementia at increasingly earlier stages has brought with it both advantages and disadvantages. One of the disadvantages has been a complication in some of the terminology being employed. For example, in some circumstances clinicians have been attempting to explain the differences between a diagnosis of Alzheimer's *disease* and Alzheimer's *dementia.* This situation might occur following a lumbar puncture where the CSF biomarker indicates an Alzheimer's disease profile. However, the patient and collateral informant are not endorsing any functional impairment and, as a result, the clinician and / or MDT are reluctant to disclose that the patient has an actual dementia at this stage. Quite often, the diagnosis of Alzheimer's *disease* is made in order to offer the person access to the acetylcholinesterase inhibitors at an early stage.

These kinds of scenarios have the potential to cause significant confusion for both the patient and the carer / supporter, and clinicians will need to pay special attention as to how they explain this rather nuanced diagnosis / situation.

The use of nuanced diagnoses such as 'probable' or 'likely' Alzheimer's disease should also be avoided where possible. If the clinician and / or MDT are convinced that the person has a dementia but the aetiology is unclear, then the patient and carer / supporter should be informed that they have a diagnosis of dementia and this diagnosis should be given in writing as well as verbally. If the aetiology or subtype is unknown at this point, then this can also be mentioned to the patient and carer / supporter provided that it does not lead to confusion over the main diagnosis of dementia.

In certain circumstances, it may be necessary to attempt to reframe a person's understanding of the particular dementia diagnosis. For example, on hearing the words 'Alzheimer's disease' some people may start to envisage an immediate catastrophic loss of ability. In these cases, it is often useful to try to establish what the person's/carers experience of the condition is. Clinicians can then explain what the person and carer / supporter might realistically expect to experience in the short to medium term. People are often surprised that many conditions of dementia are slowly emergent and only progress at a gradual pace.

Below is a list of information that may help reframe people's expectations:

- Conditions such as Alzheimer's disease, especially in older people, tend to be slow in developing.
- Significant change can often be unlikely in the short to medium term if the person has been diagnosed relatively early. In other words, a person's deficits over a 12-month period might be marginal.
- People will often live with rather than die of dementia.

- Encourage them to manage the symptoms as they arise.
- Encourage them to prioritise quality of life over deficits.
- Challenge any nihilistic attitudes by encouraging them to focus on remaining skills and abilities.
- Suggest practical strategies to limit areas of difficulty (e.g. a diary to manage appointments).
- Choose to highlight positive aspects from the assessments.

Similar to the above is the 'recognition of difficulties' approach. This is where the diagnosis is given and clinicians take a practical look at the difficulties that the person has and talks about how to avoid or minimise these areas. At the same time, they would highlight areas of strength and discuss how these might help to compensate for the areas of difficulty.

4.3.2 Communicate effectively

Practice Recommendations

- All information, including the diagnosis, should be provided in writing as well as verbally.
- Information should be relayed in language that is understandable to both the person and carer / supporter and be free from medical jargon.

Allow sufficient time both to convey all the necessary information and to respond to any questions raised.

The basic principles of effective communication are closely tied to the preparatory work recommended prior to the communication of a diagnosis of dementia. This includes scheduling enough protected time so that clinicians are not rushed in their delivery and can explain in full the diagnosis and possible prognosis as well as allowing time for any questions from the person and / or carer / supporter. It is recommended that when communicating a diagnosis it is person-centred and takes account of the person's expectations and expressed wishes (O'Malley et al. 2019). For the person, a poorly communicated diagnosis can increase anxiety and stress and increase the likelihood of poorer health outcomes (Baile et al. 2000).

Using language that is complex and technical can prevent the person and their caregiver from understanding what is happening and prevents them from acquiring enough information to make informed decisions about their future care (Adams and Gardiner 2005). Clinicians should, where appropriate, use plain language, avoid the use of jargon and acronyms (CESRD 2020) and explain complicated medical assessments and terminology. Short, simple sentences should be used where possible; four to six word statements are probably best understood (Weirather 2010).

Preparing the environment is also conducive to effective communication. Having a quiet, private room will help to ensure that the person and carer / supporter are able to hear what is being said to them. If either party has a hearing impairment then a portable loop system, a personal listening device or another Bluetooth enabled device, should be available. Likewise, large print versions of any written materials should be available for those with visual impairments.

Adjust seating positions so that the person and carer / supporter can clearly see the health professional's full face and without discomfort from glare. Clinicians should not sit with their backs to a window as this can create a halo effect which obscures the face.

The outcomes of the assessment should be in a written format to support the verbal communication of the diagnosis. This should also be prepared in advance and given to the person and carer / supporter at the end of the meeting.

Non-verbal communication

Although it may be challenging to do when giving the diagnosis, it is important to maintain eye contact with the person and to avoid speaking solely to the carer / supporter (Murphy and Gair 2013). People prefer that doctors sit down (Zulman et al. 2020), show openness by avoiding crossing arms and legs, lean forward to show interest and nod their heads to show active listening to their concerns (Hashim 2017).

Be sensitive to non-verbal cues such as the person making movements or facial expressions that might suggest they want to be part of the conversation (Adams and Gardiner 2005).

Active listening

Sensitivity and listening skills are 'essential attributes for doctors' (Mastwyk et al. 2014), and during the meeting where a diagnosis is given, doctors should 'listen intently and completely'. This conveys openness, reduces the anxiety of the person with dementia and decreases the incidence of 'doorknob syndrome' where the person raises a concern after the meeting is thought to have finished (Zulman et al. 2020). In a memory clinic setting, persons appreciated the longer interactions and the listening skills of expert staff with years of experience in this area (Cahill et al. 2008).

Use of language

The language used when a diagnosis of dementia is communicated is of paramount importance. It has to be understandable to both the person and carer / supporter and should not include any medical jargon that is not supported by plain English explanations.

In situations where the person does not speak or understand English, a professional interpreter should be used. It is not recommended that a family member be used for this task. Interpretation services will need to be booked in advance and clinics will have to plan to accommodate this. In circumstances where a person may be experiencing other difficulties relating to understanding and comprehension, other techniques should be employed such as simplified explanations, pictures or specialised communication aids. Advice from communication specialists, such as Speech and Language Therapists, may need to be sought.

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Clinicians should try to be as sensitive as possible in their use of language when communicating the diagnosis and explaining its meaning. Certain words and phrases should be avoided. For example:

- 'Suffering' from dementia
- 'I am sorry to tell you that you have ...'; apologies can sound insincere
- The use of the word 'shrink' or 'shrinkage' when describing atrophy; try using 'loss of volume' instead

The use of the word 'deterioration' or 'deteriorate' to describe reduced abilities over time; alternatives such as 'dis-improvement' may be more suitable.

If explaining that there is no current cure for dementia this should be balanced out with a statement that offers honest and realistic hope. For example, it may be possible to discuss practical ways in which a person can manage the symptoms.

Due to the prevailing stigma and nihilistic outlooks about dementia, many people can have false notions of what the diagnosis means. It is not unusual for people to believe that their condition will rapidly worsen, leading them to forget who family and friends are and resulting in a sudden loss of independence.

In all meetings where a diagnosis of dementia is given there should be an emphasis on what can be done to help someone rather than what cannot be done.

Useful resources for communication

- Alzheimer Europe's perception and portrayal of dementia www.alzheimer-europe.org/reports-publication/2013-alzheimer-europe-report-ethical-issues-linked-perceptions-and-portrayal
- DEEP language guide https://dementiavoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf
- Alzheimer Australia's Language Guidelines www.dementia.org.au/sites/default/files/language-guidelines.pdf

4.3.3 Foster hope

Practice Recommendations

- Foster realistic hope; weigh the discussion towards what can be done for the person/carer / supporter and what the person/carer / supporter can do for themselves.
- Encourage people to maintain as normal a life as possible by maximising remaining abilities and skill sets and by compensating and developing strategies for areas of difficulty.
- Encourage the person to stay active and involved in their community.

> *'It's a depressive illness, it destroys virtually the cornerstone of life, of living really if they allow it to and of course the biggest thing is hope, and if you destroy the hope there's nothing else but gloom and despair.'*
>
> (George, from Stokes et al. 2014).

In many ways, the fostering of hope is the most important aspect of the process of communicating a diagnosis of dementia. It is vital that the person and their carer / supporters are able to walk out of the meeting with a realistic but hopeful outlook on the future.

In Poyser and Tickle's systematic review (2018), the importance of doctors offering hope was a theme across six studies, with doctors recognising that offering 'realistic' hope was important and 'necessary when delivering bad news' (Phillips et al. 2012). In the absence of a cure, giving people with dementia hope can also be of huge benefit in improving their quality of life and helping to support and maintain function (Walrath and Lawlor 2019). To help people to feel more hopeful, doctors need to develop empathy and a greater understanding of dementia and what it might be like to 'walk in their shoes' (Lawlor 2018). In adjusting to their diagnosis, many people with dementia try to maintain as normal a life as possible while developing new strategies to cope with the many changes dementia brings; hope is a key element in this adjustment (Clare 2002).

Incorporating a degree of hope into the communication of a diagnosis of dementia can involve a number of processes, including the reframing of people's perceptions of dementia. It also includes describing the treatments and interventions that can be of help to the person as well as suggesting what the person and carer / supporter could do for themselves.

Research in the field of chronic illnesses that has examined interventions that targeted hope, such as cognitive-behavioural and other supportive psycho-social supports have shown some promising findings (Madan and Pakenham 2014). It is essential that clinicians, when communicating the diagnosis, 'balance the opportunities against the difficulties' so that people with dementia and their families feel more hopeful about their future lives with dementia (Walrath and Lawlor 2019).

Achieving this balance can be done in a number of ways. Lawlor (2020) points out that medication and lifestyle interventions can limit further damage to the brain in conditions such as vascular and mixed dementia. Similarly, treating other co-morbidities (hypertension, depression, etc.) that may be present and addressing issues of polypharmacy can positively affect how the disease progresses. These actions show the person with dementia that things can be done to help them and reinforces the message of hope in a real and tangible way.

The development of coping strategies, including the use of diaries, calendars, sticky notes, written reminders etc., offer people with dementia the opportunity to maximise their independence and maintain self-confidence and self-esteem and offer hope for the future. These various strategies, including details of post-diagnostic support groups, should be discussed with the person with dementia and their caregiver either during the meeting where the diagnosis is given or in a follow-up meeting and written details provided. Post-diagnostic support and interventions are outlined in greater detail in Section 6.

Best practice tips

- Medications (see Section 2.6.7) [link to section 2.6.7 under the diagnostic pathways for information on prescribing acetylcholinesterase inhibitors or memantine]; also consider medication to address any symptomatic treatments that may be indicated (e.g. statins, aspirin, anti-depressants, etc.).
- Give practical advice on supporting the main presenting problems, e.g. memory, cognition, language, etc.
- Promote brain health; the three core aspects of good brain health are mental, physical and social activity.
- Personalised dietary advice.
- Promote 'normalisation'; for people with disabilities, this is the principle of keeping patterns of life and everyday activities as close as possible to their regular circumstances and way of life [see PDS section 6].

People who have been recently diagnosed may benefit from hearing about the experiences of other people living with dementia who are taking a proactive approach to life. The following links may be useful:

- Alz Talks at www.youtube.com/channel/UCQchRMJ7fSy8ukfc9HF2PJw
- Maureen's Story: www.youtube.com/watch?v=4R4EWERCtMc

4.3.4 Giving a prognosis

Practice Recommendations

- Offer a prognosis based on the clinician's knowledge of the individual and their condition.
- Explain that any prognosis is specific to the individual. This can discourage comparisons with others and keep the discussion person-centred.
- Discuss non-pharmacological treatment/programmes/interventions as part of the prognosis.
- Discuss pharmacological treatment as part of the prognosis, outlining any potential risks and benefits.
- Respond truthfully and sensitively to any questions raised.

Addressing prognosis is often the hardest part of the meeting, for all parties. Research findings show that people who have been diagnosed with dementia can be unprepared for just how progressive dementia is, and the impact of various behavioural and psychological presentations (Stokes et al. 2014). Problems understanding the prognosis associated with dementia have been linked to 'a lack of forewarning' and an absence of detailed information about dementia and what the future might hold (Aminzadeh et al. 2007, Robinson et al. 2011, Stokes et al. 2014). Work by Porensky et al. (2016) reported that patients who were given a positively framed cancer prognosis in terms of reoccurrence and mortality believed they had better outcomes and experienced less anxiety and negative effects post-consultation in comparison to those who experienced a negatively-framed diagnosis.

It is important for the professionals to find the correct balance between honesty and sensitivity. Undue optimism can be as harmful as undue pessimism, so it is important that the professionals are realistic about the person's prognosis without being unnecessarily nihilistic in outlook. Doctors should consider and reflect on the potential impact the diagnosis may have on the person and how it will affect and change their lives, from living arrangements, to employment, to their current responsibilities, including family and financial obligations (Murphy and Gair 2013).

Best practice tips

- Don't project too far into the future.
- Discuss how physical health and general lifestyle can affect memory and cognition (e.g. stopping smoking, cutting alcohol intake, improving diet to avoid blood pressure difficulties, diabetes, etc.).
- Advise the person and carer / supporter about good mental health. Untreated anxiety and depression can exacerbate memory and cognition problems.

Alert the person and carer / supporter to the risks of infection and delirium, e.g. conditions such as chest infections or kidney infections can cause increased confusion and behavioural change and, if untreated, could lead to a delirium.*

*Delirium is a serious medical emergency and can lead to permanent brain damage. Delirium can present in a very similar way to dementia, so carers should be advised to seek urgent medical attention if the person with dementia undergoes a rapid decline in their cognitive state; the person has difficulties paying attention or staying focused and / or the condition fluctuates significantly during the day.

For more information please visit: https://dementiapathways.ie/care-pathways/acute-hospital-care/integrated-care-pathways-and-delirium-algorithms

Responding to reactions

It is common for the person diagnosed with dementia and, in some cases, the carer / supporter to be both shocked and distressed by the news. During a meeting where a diagnosis is given people reported feeling anxious, sad, embarrassed and scared of the unknown (Bennett et al. 2019). This is understandable and clinicians should acknowledge the emotional responses that ensue. However, the professionals need to be aware that this heightened emotional response could affect the person's recollection and understanding of the diagnosis. This should be sensitively explored at any subsequent meetings. For some people, anger and denial

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may appear over the following weeks and months and not at the initial meeting when the diagnosis was first communicated (Derksen et al. 2006).

Clinicians should also be aware that this initial reaction appears to be relatively short-lived (a matter of weeks) and does not cause problems in the longer term.

4.3.5 Facilitate people to ask questions

Practice Recommendations

- Provide an open forum where patients and carers / supporters feel empowered to ask questions and seek further information.
- Suggest topics if no questions are forthcoming.
- Provide contact details (including name, phone number, email and related service) so that people can make contact and ask questions in the future.

After the diagnosis has been named it is important that there is protected time to allow the person and their carer / supporter to express their emotions (Murphy and Gair 2013). They will need this time to try and understand the implications of their diagnosis and it is important that honest answers are given in response to their questions (Murphy and Gair 2013, Tuffrey-Wijne 2012).

Clinicians should be prepared for regularly recurring questions such as 'What is the difference between Alzheimer's disease and dementia?' and 'Can I still drive?'

Best practice tips

- Provide honest answers to the questions as this will build trust.
- Try and discourage people catastrophising about events that may or may not happen in the future.
- If the person and carer / supporter are having difficulty thinking of questions to ask, clinicians could try suggesting topics themselves.

On occasion, it may become apparent that a person and / or carer / supporter needs to speak to the clinician(s) or HSCP(s) on their own. Try to ensure that you have consent for this to happen. In some clinical settings, it would be common practice for the person to have an ECG (electrocardiogram) prior to being commenced on an acetylcholinesterase inhibitor. This may provide a natural break in the process to allow both the person and the carer / supporter to talk with the clinician or HSCP individually and in private. However, other breaks could be arranged to accommodate separate conversations.

4.4. Immediate Post-diagnostic Support and Follow-up

Both the WHO and Alzheimer Disease International outline the importance of post-diagnostic support in enabling people with dementia and their caregivers to come to terms with the disease, plan for the future and make the best use of their current circumstances (O'Shea et al. 2018). Post-diagnostic support (PDS) is vital in helping people to develop coping strategies in the early stages of dementia. Section 6 of this Model of Care provides more detail on a range of dementia post-diagnostic supports, and the five strands that should underpin PDS are outlined. There are, however, a series of immediate PDSs that should be addressed when the diagnosis is communicated, including:

- Information provision
- Follow-up appointment
- Single point of contact

4.4.1 Information provision

TARGET 20	100% of people should be provided with individually tailored practical advice and information following the communication of a diagnosis of dementia. This should be made available both verbally and in written format.

Practice Recommendations

- Provide individually tailored practical advice and information following the communication of a diagnosis of dementia.
- The information should be provided in the person's preferred language, including sign language, using a professional interpreter where necessary. In some circumstances simplified explanations, pictures or communication aids may also be required.
- Every person should be offered a referral to their local Dementia Adviser (see Target 23).

Murphy and Gair (2013) suggest that doctors should understand the content of the information they are about to deliver and rehearse and anticipate any questions that might be asked during the meeting. Doctors should not make assumptions about what information they think the person will need and be able to remember based on their cognitive difficulties. This can lead to the person feeling marginalised and assuming that the reason the information wasn't directed to them was because of their cognitive impairment (Karnieli-Miller et al. 2012). Information about treatment options, post-diagnostic supports and services and other important information that will help people plan for the future should be tailored to the person and given to them during the meeting where the diagnosis is given or, if not possible, at the follow-up meeting. It is helpful to give the person with dementia and their caregiver a written copy of all the information discussed; this has the additional benefit of helping the person with dementia to remember what was said during the meeting (Derksen et al. 2006).

A key aspect of information provision at this stage is around planning for the future. This can appear daunting to those recently diagnosed with dementia, and clinicians and HSCPs should be prepared to deal with these matters at subsequent meetings. However, this may not always be possible and immediate post-diagnostic advice and information can have a significant impact on people's lives.

Best practice tips

- Recommend that utility bills are put in joint names so that any difficulties with services, bills, etc. can be easily rectified. (Utility companies will only discuss issues with the named bill payer.)
- Check that a will has been made.
- Suggest that the person and carer / supporter consider an enduring power of attorney. This is good advice for everyone and this need not be purely directed at the person.
- Inform the person of the Assisted Decision Making (Capacity) Act, April 2023, the Decision Support Service and Advance Healthcare Directives.
- Recommend using the Think Ahead document, or something similar, to support decision-making.
- Driving: In line with the current RSA Medical Fitness to Drive Guidelines* (2022), all drivers given a diagnosis of dementia will have to notify the National Driver License Service and their car insurance company about the change in their medical status. A formal driving assessment is generally an integral part of assessment and review but the overall decision regarding driving safety rests with the treating doctor. Advise both the patient and the carer / supporter about social welfare entitlements**, e.g. Carers Allowance, Invalidity Pension, etc. More information can be obtained from www.citizensinformation.ie/en/.
- Advise patient and carer / supporter of the Medical Card (including the discretionary Medical Card) and the GP Visit Card.
- Provide contact numbers for local and national Alzheimer Society of Ireland services and other support services local to them.
- Offer advice about the Seniors Alert Scheme if appropriate.

***Additional information on driving cessation**

Many people with dementia choose to stop driving as they start to lose confidence in their own abilities. However, on some occasions a doctor might have to recommend that a person stop driving. In these circumstances, doctors and MDTs should be prepared with knowledge or suggestions of transport alternatives to help the person to remain as independent as possible. It might be useful to suggest that the substantial savings that could be made from not driving (road tax, insurance, fuel, service and repairs) could be set aside in a 'mobility' fund and be used to pay for taxis, etc.

****Additional social welfare information**

In certain circumstances a person diagnosed with a dementia may qualify for the Long Term Illness Scheme. There are a number of qualifying conditions for the scheme and these include Parkinsonism. Those diagnosed with Parkinson's Disease Dementia and Lewy Body Dementia may qualify for the Long Term Illness Scheme.

4.4.2 Provide information on coping strategies

As mentioned above, post-diagnostic support is outlined in more detail in Section 6. However, there are some practice recommendations that can be adopted to address coping strategies at the time of the meeting where the diagnosis of dementia is given and these are outlined below.

Practice Recommendations

- Encourage the use of support groups to help increase knowledge about a condition, for peer support and to combat social isolation; provide contact details for same.
- Encourage the use of social networks and community amenities to remain socially connected.
- Promote daily routines and simple memory aids to minimise everyday difficulties.

Clinicians and HSCPs should provide all relevant information in written/printed format where possible as patients and carer / supporters may forget the majority of what they are told.

Be aware that support can take many forms, and the availability of support services will vary depending on location. Time should be spent exploring what is important to the person; what areas they are struggling with and what outcomes are important to them. There is some evidence of the effectiveness of multi-component interventions; for example, in a variety of formats that can benefit the individual and the care dyad, including education, support groups, skill building and cognitive rehabilitation (Pinquart and Sörensen 2006, Gallagher-Thompson and Coon 2007, Thompson et al. 2007, Moon and Adams, 2012, Elvish et al. 2013, Van't Leven et al. 2013), with previous studies also advocating the involvement of both the person with dementia and their caregiver in care planning wherever possible (Lyons et al. 2002).

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People with mild to moderate symptoms who are living in the community are increasingly turning to mainstream activities in addition, and groups that are not 'dementia-specific'. This should be encouraged and facilitated where possible. See the Dementia Post-diagnostic Support Section for further information on support services.

4.4.3 Follow-up arrangements

Milby and colleagues suggest that follow-up sessions might be a good way to address the emotional distress experienced by some people with dementia (Milby et al. 2017). Clinicians and HSCPs who offered follow-up sessions felt they made a difference because people could talk about issues they could not discuss at the initial meeting due to a lack of time (Kissel and Carpenter 2007, Poyser and Tickle 2018).

TARGET 21	100% of people should be offered a follow-up appointment 4–8* weeks following a diagnosis. Those prescribed memantine or an acetylcholinesterase inhibitor will require a medication review four weeks after starting the treatment.

Practice Recommendations

- The doctor and HSCP should discuss and agree ongoing future management of their condition with the person and supporter.
- Arrange a follow-up appointment* for the person and carer / supporter. No individual diagnosed with dementia should be discharged from a service without an appropriate follow-up (or the offer of a follow-up) arrangement. Depending on the individual case, this meeting may be with the doctor and / or the HSCP.
- Where a person is not ready on the day that the diagnosis is given to make a decision about commencing cognitive enhancing medications or non-pharmacological interventions, there is a planned follow-up within two weeks to re-discuss, when they have had time to reflect on the diagnosis and treatment options. Further follow-up should then take place as per Target 21.

*The 4–8 week follow-up appointment may take place:

- At the place of diagnosis, e.g. primary care, MASS or specialist memory service to provide an opportunity to have additional questions addressed;
- With personnel from the MASS, Dementia Adviser or another clinician to review the information that was provided at the time and to receive more detailed information; or
- With personnel from the MASS, Dementia Adviser or another clinician to formulate a care plan if that is needed at that point and if that is what the person wants.

4.4.4 Point of contact

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.

Practice Recommendations

For many people in the first 3–6 months following diagnosis, the point of contact will be a member of the MASS, for example. This point of contact will change as the person's dementia progresses and their primary needs are met in another service [see care planning section 5].

Diagram 9: Applying the Dementia Model of Care principles to immediate post-diagnostic support

Citizenship	The person with dementia and their carer / supporter have a right to receive a diagnosis if that is their preference, with equal access to information and immediate post-diagnostic support.
Person-centred Approach	The process of preparing the person for the diagnosis begins at the first contact with the person and the diagnosis is delivered in a person-centred way, cognisant of their dignity, autonomy and personhood.
Integration	The person is offered referral to appropriate PDS programmes and interventions and signposted to community supports, where there is integrated working across disciplines and service providers.
Personal Outcome-focused	n order to determine the preferences of the person in relation to receiving a diagnosis, this is ascertained throughout the assessment process. It is established what needs they have and what outcomes are important to them.
Timeliness	The person is told the results of their assessment in a timely manner and care planning begins in accordance with the person's readiness for pharma and non-pharma interventions.

4.5. Considerations for Different Groups

4.5.1 Anti-discriminatory practice

Discrimination is not just offensive; it is also against the law. Dementia is considered a disability and, as such, the human rights of the person are protected against discrimination. Gender, disability, age, ethnic origin, skin colour, nationality, sexuality and / or religious belief are areas of likely discrimination and hence require thoughtful consideration.

Gender

With regard to gender, ensure that you provide the same information to men, women and non-binary people equally unless there is an indication for it, e.g. a Men's Shed or The Irish Countrywomen's Association. Otherwise, reflect on possible biases; for example, an activity has no gender, whether it is knitting or woodcarving.

Disability

How information is imparted and access to supports should be considered in the case of disability (physical, sensory, intellectual).

- Consider large print for documents and leaflets for people with visual impairments.
- Consider hearing loops and listening devices for people with hearing impairments and arrange sign language interpretation if needed.
- Consider communication needs and styles of people with ID. Materials available on dementiapathways.ie.
- Consider environmental accessibility facilities (ramps, lifts) for people with physical disabilities.
- Consider wayfinding and the difficulties of navigating the built environment.
- Ensure that patient information leaflets are clear and written in easily understood language.
- Do not make assumptions based on the level of education that a person has attained (higher or lower) or presumed knowledge of particular subjects or topics.

Ethnicity

With regard to ethnicity and nationality, consider:

- A language interpreter if the person's first language is not English and you are not sure that they fully understand the information being given to them
- Printing information and leaflets in the language the person understands best
- Cultural issues, services and information – do not assume that certain cultures or communities behave in certain ways

- Cultural meanings and roles – examine the meaning of the word ‘dementia’ in their culture/language as it can mean different things to different cultures
- Cultural perceptions of disabilities vary widely and this requires consideration when communicating a diagnosis

Medical practitioners, nurses and HSCPs need to be conscious of any biases arising from their own beliefs, past experiences or background.

4.5.2 The communication of a diagnosis of dementia to a person in long-term care

The general principles of communicating a diagnosis of dementia to a person who is residing in a nursing home or long-term care setting are the same as for those living in the community, and the practice recommendations and best practice tips should be applied for those living in residential care.

However, additional care should be taken to find the appropriate setting for the meeting – a location that it is comfortable, quiet and ensures privacy. Sufficient protected time should be set aside to explain the assessment, test results and to deliver the diagnosis.

Issues of post-diagnostic support will necessarily involve working with the long-term care establishment but consideration on what personal outcomes are important to the person should also be reached. The person’s care plan will need to be updated (see Care Planning Section 5).

It is recommended that the person has a family member with them for support during the process of communicating a diagnosis of dementia. However, consent will still be required unless the person has been formally assessed as requiring decision-making support. Consent will also be required to share the diagnosis with the staff of the long-term care establishment in order that they can optimise ongoing care and support.

4.6. Communicating a Diagnosis of Young Onset Dementia

People aged under 65 years with suspected dementia experience significant difficulties acquiring a timely diagnosis, with reports of considerable delays and inaccuracies (Fox et al. 2020). While many of the recommendations are the same or similar to communicating a diagnosis to someone with Late Onset Dementia, additional considerations are required when communicating a diagnosis of dementia to this group. It is often viewed as more complex, due to:

- Rarer subtypes
- Symptoms often non-memory related
- May be linked to genetic or metabolic disease
- May have young children
- May be still in employment
- May be financially supporting the family
- Associated with increased carer stress and relationship difficulties

The person may have experienced a longer journey to get to the meeting and there should be an awareness of this by clinician and HSCP.

Practice Recommendations

- The communicating of a diagnosis of dementia to a younger person should be carried out in a cognitive / behavioural neurology clinic, RSMC or a well-resourced MASS or neurology service.
- In line with *Young Onset Dementia: A Review of Diagnostic and Post-diagnostic Processes and Pathways* (Fox et al. 2020), the process should include both an experienced doctor and senior social worker , plus protected time and space.
- A follow-up meeting is also recommended 4–8 weeks after the initial diagnosis is given.
- As for all people receiving a diagnosis of dementia, a person with a young onset dementia should not be discharged or referred on without a named point of contact [as per Target 25].

4.6.1 Advanced preparation

It is likely that the younger person will have undergone more extensive testing, including neuropsychological assessment, brain imaging and the taking of cerebral spinal fluid, and in some instances genetic testing, in order for the clinicians to be certain of the diagnosis. As this is likely to involve more clinic visits, it offers the opportunity to prepare the person and the carer / supporter for the possible bad news to come.

Although Alzheimer’s disease remains the predominant cause of dementia in the under 65 age group, this age cohort will also see more of the rare forms of dementia such as Frontotemporal Dementia (FTD), Primary Progressive Aphasia (PPA), Posterior Cortical Atrophy (PCA) and Corticobasal Degeneration (CBD). These are complex conditions that can be difficult both to describe and explain. It can also be difficult to source appropriate and understandable written materials for such conditions so these should be prepared in advance.

The range of potential social and financial supports for people with YOD is also different from the older age cohort. Appropriate social supports are often difficult to find and practitioners may be forced to ‘think outside of the box’ in order to come up with solutions for specific individuals. For example, mainstream dementia-specific services may be populated predominantly by older people and be deemed unsuitable for someone in their early 50s. Clinicians and HSCPs will need to spend time both before and after communicating the diagnosis thinking about other possibilities, working with the individual about what supports are of interest to them and what is their preferred personal outcome regarding engagement with any support.

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Likewise, the financial implications of a working age diagnosis of dementia can be extremely complex and, again, thought is required as to the best possible advice to give to the individual and their family. This may involve a good working knowledge of the social welfare system, existing employment law as it pertains to people with disabilities and insurance, including mortgage protection policies, income protection policies and specified illness cover.

There is also the increased likelihood of school age children being affected by a parent being diagnosed with a young onset dementia. Clinicians and HSCPs will need to be prepared to offer advice on both the communication of a diagnosis to children and also on the ongoing emotional and psychological support that a child may require to deal with its repercussions. This will include knowledge of the roles played by TUSLA (regarding child protection and welfare), the National Educational Psychological Service (NEPS) and the Child and Adolescent Mental Health Service (CAMHS).

4.6.2 Environment

As with all meetings where a diagnosis is given, the setting is important. A private, quiet, and comfortable setting should be utilised. Comfortable seating should be available and in sufficient numbers for those attending. Be aware that the person may request additional supporters to be in attendance on the day, and a discussion on who will be attending should take place in advance.

4.6.3 Time

Due to the complexities and potential emotional impact of a diagnosis of YOD, a minimum of one hour should be set aside for the communicating of the diagnosis. The time should be protected and uninterrupted if at all possible. Additional follow-up appointments of similar duration are also recommended depending on the individual case.

4.6.4 Integrating family members

Dementia is not a diagnosis that a person should carry on their own. All efforts should be made to involve family members / supporters in the process and with the ongoing support. If no support is available at the pre-arranged appointment then it is recommended that a more suitable date and time is organised when the necessary support will be available.

4.6.5 Communicating a diagnosis of young onset dementia

The diagnosis should be unambiguous. It should be delivered clearly and concisely in language easily understood by the person and carer / supporter. It must be accompanied by written information and advice that is pertinent to the individual situation.

The initial process of communicating the diagnosis of young onset dementia should be similar to that outlined above for older adults:

- Deliver the diagnosis clearly and without ambiguity.
- Name the condition, e.g. ‘Alzheimer’s disease’, and explain the terminology in language that is understandable.
- Keep eye contact with the person and not their carer / supporter unless addressing them directly.
- Try to give a balanced report of the results by highlighting strengths and weaknesses.
- Don’t apologise (‘I’m sorry to inform you that you have Alzheimer’s disease’) as this can sound insincere.
- Be prepared for the patient’s and carer / supporter’s reactions. These can run through a gamut of emotions from shock and fear right through to relief.
- Acknowledge their emotions.
- Check their understanding of what they have been told.
- Invite questions.
- Give easily understood explanations in plain, jargon-free language.
- Provide the diagnosis in written format.
- If there is a possibility of a genetic diagnosis, this should be clearly explained, including referral to a genetic counsellor if necessary.

Target 24 outlines that every person diagnosed with YOD should be referred to a social worker (with their consent). This is particularly important if they have not already been involved in the process. The practice recommendation is that a senior social worker attends the meeting where the diagnosis is communicated.

4.6.6 Responding to the emotional response to the diagnosis

Unsurprisingly, there is often a more pronounced emotional response when people learn of a diagnosis of young onset dementia as they are faced with their own mortality, the loss of hopes and dreams and possibly concerns about partners, children, employment and housing. Addressing people’s reactions in these scenarios can be daunting but it is important to give people the chance to express themselves emotionally rather than trying to contain it. There is no blanket response, and clinicians and MDTs have to try to judge what is the right move at the right time. For example, it may be necessary for clinicians and MDTs to leave the room for a few minutes to allow the person and their supporter some time for themselves, or it may be necessary to simply sit in silence for a while to let the emotions flow unchecked. It will also be down to staff skill and judgement to decide when to step back in and begin to deal with people’s hope and fears in a practical and supportive manner.

4.6.7 Giving the prognosis and fostering realistic hope

The information and advice given at this stage will differ from that given to the older age cohort. YOD is a life-limiting condition but it is hard to be definitive about life expectancy, as this will vary depending on the subtype. People with a YOD are more likely to be diagnosed with a rarer or genetic form of the condition. All of these factors can affect survival rates.

Concentrating on what is likely to occur in the short to medium term and focusing on supporting remaining skills and abilities will be the most effective response at this stage.

As with communicating a diagnosis to the older age cohort, there should be a concentration on what can be done for the individual and the carer / supporter rather than what is not possible. This includes:

- Medication: Consider prescribing appropriate medication(s) for the diagnosed condition(s). These could include acetylcholinesterase inhibitors or memantine, statins, hypertensive medication, treatment for diabetes, etc. Also, consider treating any other symptoms such as anxiety or depression.
- Offer advice, recommendations or referral for hearing and vision loss.
- Brain health: the three core aspects of good brain health are mental, physical and social activity. Mental activity can range from puzzle books to learning a musical instrument or a new language. Mental activity should provide a challenge but should not be stress inducing.
- Physical activity guidelines suggest that a person should exercise approximately 30 minutes per day for 4–5 days a week. The exercise should involve an elevated heart rate and the person getting a little out of breath. The activity could take the form of a brisk walk or something more strenuous. The type of physical activity will depend on the individual and any health conditions that they may have.
- Social activity encourages people to stay engaged and connected with friends, family and their local communities.
- A suitable diet, for example, a Mediterranean diet.
- Promote 'normalisation'; for people with disabilities, this is the principle of keeping patterns of life and everyday activities as close as possible to their regular circumstances and way of life.

See section on post-diagnostic support for further information on supports that can enable people to live as well as possible.

4.6.8 Immediate post-diagnostic advice and information

It is recommended that the physician, nurse and / or HSCP should provide some advice and information following the communication of a diagnosis of dementia. The information should be tailored towards the specific needs of the patient and carer / supporter. Inappropriate advice or suggestions will be viewed as unhelpful. It will be important to schedule additional meeting(s) to deal with the often complex difficulties that can arise from a diagnosis of a young onset dementia. All information should be provided verbally and supported in a format that the person understands.

The information and advice given to a patient with young onset dementia and their carers / supporters often differs to that given to those with an older onset. It may be important to give some advice quickly and coherently as it may have a major bearing on the person's future. For example, in a situation where the initial referral for assessment came from a company's occupational health department or where the diagnosis will have to be immediately declared to an employer, it may be necessary to offer advice that will protect the patient.

Employment advice

If a person diagnosed with YOD is still in employment, then initial advice should be for the person to take their time in making decisions about their future.

Major long-term decisions about employment should not be made for several weeks following a diagnosis unless this is in the best interest of the person and their family, or if the person is a risk to themselves or others.

It may be necessary for the person to take 'sick leave' during this period while a plan of action is developed.

Dementia is a disability and, as such, people with dementia have certain protections within Irish and European legislation, including in employment law:

> *'Individuals who are diagnosed with dementia and are still in employment may need assistance to remain at work. The employer is obliged to take "appropriate measures" to enable the person with a disability to carry out their work on an equal footing with others. For example, this might mean offering flexible working hours or giving the person certain tasks and substituting others with the employee's consent.'*
>
> (Gibb et al. 2019)

This can be a complex area and the person with dementia may need to seek the advice of their trade union or another professional body, an employee assistance officer, or even a solicitor with experience in employment law. People with dementia should be encouraged to remain in employment if this is what they wish to do. If they choose to stop working then they should seek to terminate work in a way that will provide the most positive outcome for them. This may include sick pay, redundancy payments or pension packages. Again, expert advice is recommended.

Financial advice

It may be possible at the meeting to allay some of the immediate fears a person might have about their financial situation. There are various insurance policies and protections that people may have that could help to lessen the impact of a diagnosis of dementia and remove some stress and anxiety from their lives. These are some of the more common ones that physicians or HSCPs might suggest:

- Mortgage protection policies – these policies often cover more than the death of the policy holder. Many now include specified illnesses such as Alzheimer's

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disease or permanent disability. Those with rarer forms of dementia should seek the guidance of a medical expert in assisting them in their discussions with the insurance company.

- Income protection policies – these are designed to pay a percentage of a person's income if they are unable to work through illness or disability.
- Critical (or Serious) illness cover – this provides a tax-free lump sum if you are diagnosed with a particular illness or disability.
- Specified illness cover – these can be stand-alone policies or linked to mortgage protection type policies.
- Life insurance/life assurance – some policies pay out early if a person is diagnosed with a terminal condition.

There are a number of provisions within the social welfare structure that can offer financial support to a person diagnosed with dementia and their families. Detailed advice should be sought from Citizen's Information, Free Legal Advice Centres or directly from a Department of Employment Affairs and Social Protection (DEASP) representative.

For additional post-diagnostic advice, see section 6.

4.6.9 Explore coping strategies

Practice Recommendations

Encourage both the person with dementia and the carer / supporter to attend local support groups, including peer support groups. Provide this information in written/ printed format where possible.

The development of coping strategies is closely linked with the fostering of hope in the immediate post-diagnostic scenario. The type of strategies suggested will vary depending on both the subtype of dementia and the level of impairment. For those with mild impairments, encouraging the person to make very limited changes to their lives (i.e. normalisation) coupled with interventions such as cognitive rehabilitation therapy (CRT) may be the best initial coping strategy. For others, it may require more complex supports and services to retain levels of independence.

Carers and supporters may require education and peer support in addition to formal services in order to manage their role.

4.6.10 Follow-up arrangements

Practice Recommendations

Arrange a follow-up appointment for the person and carer / supporter. This meeting should be with the same clinician(s) and HSCP(s). Every person should have a named point of contact following the diagnosis.

Best practice tips

- Referral on to other professions and services may also be necessary, and this should be discussed and done with the agreement of the person with dementia and their supporter.
- Regular and ongoing meetings should be offered to those diagnosed with young onset dementia. The frequency of the meetings will be dependent on the complexities of the case and the wishes of the person.
- For tertiary level services, it may be necessary to transfer the person to the nearest MASS to receive the necessary ongoing inputs.

4.6.11 The communicating of a diagnosis of dementia to children and young people

Dementia fundamentally affects the ways in which a family works and it 'questions our understanding of what it is to be a child or young person' in those challenging circumstances (Hall 2016). Evidence suggests that parental dementia can lead to significant emotional, mental and psychological issues (Allen et al. 2009, Barca et al. 2014, Gelman and Rhames, 2016) and often with very little resources to help them understand how dementia will affect their lives (Sikes and Hall 2018), they can feel neglected by their extended family and healthcare professionals (Barca et al. 2014, Gelman and Rhames, 2016). The needs of children will vary according to their age and their parent's or grandparent's condition, with older children often taking on the biggest caregiving role regardless of gender (Gelman and Rhames 2016).

A person with dementia and / or the carer / supporter may request assistance in the explaining of a diagnosis to their (school age) children or other relatives. This will often require considerable skill and judgement and could lead to significant repercussions for the families involved. In the case of children, the communication of this news should be done in the presence of other adults who are either related to or well known to the child(ren) and can offer appropriate support.

Careful planning and the sourcing of relevant information will be necessary prior to these meetings. They should always include the person with dementia and their carer / supporter as well as clinicians and HSCPs.

Offering the child/children additional and ongoing support is essential and referral on to specialist services, e.g. psychology, is highly recommended.

When communicating a diagnosis to children and young people:

- Be honest and open.
- Set aside protected time that is free from distractions.
- Explain the diagnosis and what it means for their family in age-appropriate language.
- Check to see what their baseline understanding is and correct any misunderstandings that they might have.
- Be open to lots of questions.
- Acknowledge their feelings.
- Don't dismiss their worry.
- Reassure them.
- Find ways that they can connect with the parent or grandparent who has dementia.

4.7. Section Summary

This section of the Dementia Model of Care outlines key considerations in relation to communicating a diagnosis of dementia.

Table 12: Summary of targets and practice recommendations for communicating a diagnosis of dementia

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	Regardless of setting, a physician, with a HSCP or nurse in attendance, should deliver the diagnosis of dementia.
Target 18	**Communicating a diagnosis of dementia** For communicating a diagnosis of YOD or atypical presentation: • Consultant, Specialist Registrar or Registrar, plus • Senior Social Worker In addition, other MDT members as indicated based on the assessment findings and clinical context. For communication 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: • Consultant, Specialist Registrar or Registrar, plus one of the following: » Dementia -CNS/ANP » Occupational Therapist » Social Worker » Speech and Language Therapist (depending on diagnosis) » Neuropsychologist. For communication of a diagnosis of dementia to those over the age of 65 at Level 3 – RSMC • Consultant or Specialist Registrar, plus one of the following: » Senior Social Worker » Senior Occupational Therapist » Senior Neuropsychologist » Senior Speech and Language Therapist (depending on diagnosis).
Target 19	The time allocation for the communication of a diagnosis of dementia will be influenced by patient-specific needs and complexity. When the person has a dementia with no complicating factors, a minimum of 30 minutes should typically be allocated for the meeting; longer slots will be required for more complex cases or young onset presentations.
Target 20	100% of people should be provided with individually tailored practical advice and information following the communication 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 diagnosis. Those prescribed memantine or an acetylcholinesterase inhibitor will require a medication 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.

Practice recommendations
All meetings where a diagnosis is given should take place in a quiet and comfortable setting.
Privacy is paramount and staff should ensure that the conversation cannot be overheard from outside the room.
The seating arrangement and room layout should be prepared in advance.
For more complicated presentations, a time slot of up to an hour may be required, with the option of return visits to ensure the completion of all relevant actions.
For the most complicated presentations and / or those requiring complex post-diagnostic interventions, a minimum one-hour time slot is recommended, with the option of return visits to ensure the completion of all relevant actions.
It is strongly recommended, where practicable and possible, that the person receiving the diagnosis is accompanied by a carer / supporter.
Failure of a carer / supporter to attend may be enough reason to postpone the meeting where the diagnosis of dementia is given.
Clinicians should ensure that the person and carer/ family member / supporter(s) are told the purpose of the meeting.
The physician, nurse or the HSCP should ascertain how much or how little information the person would like to hear (as per earlier practice recommendation where the process of communicating a diagnosis of dementia begins at the first contact).
The diagnosis must be delivered in clear and concise language that is easily understood by the person and carer / supporter.
Name the subtype of dementia (if known) and avoid euphemisms.
The diagnosis should be provided in writing, preferably in a clear, type-written format.
All information, including the diagnosis, should be provided in writing as well as verbally.
Information should be relayed in language that is understandable to both the person and carer / supporter and be free from medical jargon.
Allow sufficient time both to convey all the necessary information and to respond to any questions raised.
Foster realistic hope; weigh the discussion towards what can be done for the person/carer / supporter and what the person/carer / supporter can do for themselves.
Encourage people to maintain as normal a life as possible by maximising remaining abilities and skill sets and by compensating and developing strategies for areas of difficulty.

Practice recommendations
Encourage the person to stay active and involved in their community.
Offer a prognosis based on the clinician's knowledge of the individual and their condition.
Explain that any prognosis is specific to the individual. This can discourage comparisons with others and keep the discussion person-centred.
Discuss non-pharmacological treatment/programmes/ interventions as part of the prognosis.
Discuss pharmacological treatment, outlining any potential risks and benefits.
Respond truthfully and sensitively to any questions raised.
Provide an open forum where patients and carers / supporters feel empowered to ask questions and seek further information.
Suggest topics if no questions are forthcoming.
Provide contact details so that people can make contact and ask questions in the future (including name, phone number, email and related service).
Provide individually tailored practical advice and information following the communication of a diagnosis of dementia, provided verbally and in written format.
The information should be provided in the person's preferred language, including sign language, using a professional interpreter where necessary. In some circumstances simplified explanations, pictures or communication aids may also be required.
Every person should be offered an appointment with their local Dementia Adviser (see Target 23).
Encourage the use of support groups to help increase knowledge about a condition, for peer support and to combat social isolation.
Encourage the use of social networks and community amenities to remain socially connected.
Promote daily routines and simple memory aids to minimise everyday difficulties.
The physician, nurse and / or HSCP should discuss and agree ongoing future management of their condition with the person and supporter.
Arrange a follow-up appointment for the person and carer / supporter; no discharge from a service should happen without this.
Where a person is not ready on the day that the diagnosis is given to make a decision about commencing cognitive enhancing medications or non-pharmacological interventions, there is a planned follow-up within two weeks to re-discuss, when they have had time to reflect on the diagnosis and treatment options. Further follow-up should then take place as per Target 21.

Practice recommendations
For many people in the first 3–6 months following diagnosis, the point of contact will be a member of the MASS, for example. This point of contact may change and the primary needs may be met in another service as the person's dementia progresses.
The communication of a diagnosis of dementia to a younger person should be carried out in a cognitive / behavioural neurology clinic, RSMC or a well-resourced MASS or neurology service.
In line with *Young Onset Dementia: A Review of Diagnostic and Post-diagnostic Processes and Pathways* (Fox et al. 2020), the process should include both an experienced doctor and senior social worker, plus protected time and space.
A follow-up meeting is also recommended 4-8 weeks after the initial diagnosis is given for people aged under 65 years.
As for LOD, all people diagnosed with YOD should receive a follow-up meeting 4–8 weeks after a diagnosis is given and they should not be discharged or referred from the service without having a named point of contact.
Encourage both the person with dementia and the carer / supporter to attend local support groups, including peer support groups. Provide this information in written/printed format where possible.
Arrange a follow-up appointment for the person and carer / supporter. This meeting should be with the same clinician(s) and HSCP(s). Every person should have a named point of contact following the diagnosis.

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SECTION 5

CARE PLANNING AND IMMEDIATE POST-DIAGNOSTIC SUPPORT

5.1. Section Introduction

The development of a care plan begins during the process of diagnosis and any subsequent process of communicating that diagnosis to the individual. The tests and assessments that are carried out will identify specific needs and potential treatments and psycho-social supports that may address these needs. The point at which the diagnosis is given is an opportunity to address what can happen in the immediate term.

Section 4 described how initial supports, treatment planning and early post-diagnostic support are provided or initiated as part of the process where a diagnosis is communicated. Elements of the care plan may be put in place at this point. For example, pharmacological treatments may be prescribed and information provided as part of this process. 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 where the diagnosis is given (unless the diagnosis is made at a very advanced stage). This section addresses the development of a care plan and what this process might look like over the course of dementia.

People can receive a diagnosis at any point on the dementia continuum. As a result, it is important to keep in mind a number of broad groups within this context:

- People with early cognitive symptoms/mild dementia
- People with moderate dementia
- People living with advanced dementia
- People living with dementia in residential care.

In addition, there are people with additional needs which will influence the content of the care plan, such as people with young onset dementia, people with multiple co-morbidities and people with intellectual disability. Finally, it is essential that the care plan is dynamic, evolving and changing as the person's needs and priorities change.

5.2. Developing a Care Plan

One of the aims of the Dementia Model of Care is to address shortcomings in diagnosis, the communication of the diagnosis and post-diagnostic support that have been identified by people with dementia and to standardise care-ensuring equity across the country. Key shortcomings identified by those living with the condition include:

- Not knowing who to contact if new or additional supports are required
- The difficulty of navigating a complex system that is disjointed.

Many of the elements for care are in place within the evolving health and social care system, but they are not identified in an understandable process or pathway and they are not sufficiently integrated or joined up. There are issues of equity of access depending on geographical location, age and subtype of dementia. The thinking behind the care plan is not to implement entirely new systems or ways of working, but to adapt current practice to best meet the needs of people with dementia and carers / supporters.

An effective way to do this is to embody the principles underpinning the Dementia Model of Care in the process of developing a care plan (see Diagram 10 below).

Diagram 10: **Applying the Dementia Model of Care principles to care planning**

Citizenship	The person and carer / supporter should have equitable access to the required supports and treatments in their area, based on their need. The person is centrally involved in decisions relating to support and treatment (with support if necessary).
Person-centred Approach	The supports and treatments included in the plan are based on a knowledge of the person's life story and experience and reflect the person's priorities and how they wish to be valued.
Integration	The person has a named point of contact at every stage (which may change as the person's needs change). The person experiences good continuity of care. Referrals and transitions to other services are managed and supported by the services involved, to be as seamless as possible.
Personal Outcome-focused	The supports and treatments included in the plan are based on the outcomes chosen by the person and carer / supporter in consultation with a clinician and HSCP and are focused on maintaining quality of life, indpendence and wellbeing. The desired outcomes should be explicitly stated in the plan.
Timeliness	The supports and treatments included in the plan are appropriate to the person's needs and symptoms at their point on the dementia continuum. Changes to the plan are made in a timely way to respond to changing needs and symptoms.

5.2.1 Personalised care planning

A person's experience with dementia will be influenced by their physical and cognitive needs, their personality and life history and their social environment, such as the presence or absence of a family carer / supporter. Personalised supports provide a tailored response designed to meet the unique needs of the person with dementia and their carer / supporter. A personalised support plan has a clear objective and purpose, with a move away from passive deficit-focused supports to active ability-focused supports (Howard et al. 2019). 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.

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.

Practice Recommendations

- Wherever a diagnosis is made and care planning initiated, there should be documented evidence that the person with dementia and carer / supporter have been involved in the decision-making process. Decision-making support, as necessary, is provided to the person so they can be involved in the care planning process.*
- Consideration should be given to the use of a personalised profile such as 'This is me' so that full information on the person is considered in the care planning process.
- Where relevant, available information from an existing interRAI assessment should be used to support the development of the care plan.

- A family carer needs assessment should be carried out to address the needs of the primary carer (if there is a carer involved) – as per target 35.
- In planning post-diagnostic support, careful attention should be paid to the target recipient(s) (e.g. person living with dementia, carer / supporter or both), the modality, the setting and the level of support, to ensure the best fit between the needs of the person and carer / supporter, and the support provided (see PDS section).
- In all cases, the care planning process should consider post-diagnostic support under the following areas:
  - understanding and planning
  - staying connected
  - supporting cognition
  - staying healthy
  - supporting emotional wellbeing.
- The diagnosing / disclosing service will refer the person on to appropriate post-diagnostic support in the community, e.g. Public Health Nurse, Community Dementia Clinical Nurse Specialist, local community and voluntary supports.
- Every person, from any service, should be offered a referral to their local Dementia Adviser (see Target 24) who can provide further links and referrals to post-diagnostic supports as the person's needs and readiness change.
- Information on advance care planning and the Decision Support Service should be provided at this initial stage and explored in more detail.
- Every effort should be made to avoid the person undergoing duplicate tests and assessments by different services / practitioners. Assessment results should travel with the person between services.

*As well as being in line with the principles in this Model of Care, the Assisted Decision Making (Capacity) Act (April 2023) has been enacted, which maximises a person's right to make their own decisions, with legally recognised supports, whenever possible. The Act marks a move away from the concept of acting in the person's best interests to identifying their will and preferences. The Decision Support Service will, from 2022, provide decision-making support to people with dementia where necessary.

5.3. Core Support Following Diagnosis

Regardless of where the diagnosis is made or at what point in the dementia continuum, every person should receive:

1. Information that is relevant to their needs and symptoms and life circumstances
2. A follow-up appointment 4–8 weeks following diagnosis (unless not appropriate, in which case an alternative follow-up appointment or pathway must be documented)
3. A named point of contact.

These issues were addressed in detail in Section 4 above. A summary of the targets and practice recommendations related to these three immediate post-diagnostic supports are repeated in table 13 below:

Table 13: Targets and practice recommendations relating to core immediate post-diagnostic support

Target	Practice Recommendation
Target 20 100% of people should be provided with individually tailored practical advice and information following the communication of a diagnosis of dementia. This should be made available both verbally and in written format.	• Provide individually tailored practical advice and information following the communication of a diagnosis of dementia. • Information should be provided in the person's preferred language, including sign language, using a professional interpreter where necessary. In some circumstances simplified explanations, pictures or communication aids may also be required. • Every person should be offered an appointment with their local Dementia Adviser (see Target 24). • Where a person is not ready on the day of the diagnosis to make a decision about commencing cognitive enhancing medications or non-pharmacological interventions, there is a planned follow-up within two weeks to re-discuss, when they have had time to reflect on the diagnosis and treatment options. Further follow-up should then take place as per Target 21.

Target	Practice Recommendation
Target 21 100% of people should be offered a follow-up appointment 4–8 weeks following a diagnosis. Those prescribed memantine or an acetylcholinesterase inhibitor will require a medication review four weeks after starting the treatment.	• The physician, nurse and / or HSCP should discuss and agree ongoing future management of their condition with the person and their supporter. • Arrange a follow-up appointments for the person and their carer / supporter. No individual diagnosed with dementia should be discharged from a service without an appropriate follow-up (or the offer of a follow-up) arrangement. Depending on the individual case, this meeting may be with the physician, nurse or the HSCP or all.
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.	• For many people in the first 3–6 months following diagnosis, the point of contact will be a member of the MASS, for example. This point of contact will change as the person's dementia progresses and their primary needs are met in another service.

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.

Practice Recommendations

A description of the Dementia Adviser service will be provided to the person and their family/carer / supporter to ensure they have an understanding of the service. This information will be provided in both written and verbal format.

Further development of the DA service should adopt a population-based approach to ensure the equitable distribution of services and supports.

The role of the Dementia Adviser is to provide locally based and individualised information, signposting, and emotional support to people diagnosed with dementia and their carers / supporters, at all stages of their journey, from diagnosis through to end-of-life.

Specifically the Dementia Adviser will:

- Co-develop an information plan with the person with dementia and their family/carer / supporter to identify their information, support and service needs, and actively review this plan at agreed intervals
- Support clients to identify strategies to manage day-to-day life with a focus on activity and participation
- Identify and support access to appropriate services and supports
- Assist and support the person with dementia and their immediate family/carer / supporter to navigate the health and social care systems as required
- Proactively assist and support the person, their family and carer / supporter to consider planning for the future, with a focus on legal, financial and advance care planning.

The Dementia Adviser can take referrals from services including GPs, community-based health and social care services, medical specialists (neurologist, geriatricians and / or psychiatrists of old age) and referrals from the MASS or RSMC, as well as self-referrals.

5.3.4 5.3.1 Core supports for people with Young Onset Dementia

TARGET 25

100% of people with young onset dementia should be referred in the first instance to a social worker along with appropriate access and referral to the full range of MDT.

Given the age profile of people with young onset dementia, the social worker is well placed to provide advice and support on issues relating to work and supporting children/young adults. The person should be referred to this service if the social worker has not been actively involved in the diagnostic process and the meeting where the diagnosis was given. The social worker will play a crucial role in developing the care plan for the person living with dementia and consider the needs also of the carer / supporter.

5.4. Who will develop the Care Plan?

A health and social care professional will develop the care plan. The development of any care plan should involve, and have the agreement of, the person with dementia. In many cases, the involvement of a carer / supporter in the development of the care plan will also be important but this must be with the consent of the person with dementia whenever possible.

Responsibility for developing the care plan will depend on where the assessment and diagnosis is made:

Level 1: Primary Care

Where the diagnosis is made in a primary care setting or within a Residential Care Facility by a GP (possibly with a Practice Nurse in the former), elements of the care plan are described in the initial management of dementia section of the Irish College of General Practitioners Guidance Document on Dementia (2019). Responsibility for the development and review of the care plan will remain with the GP/primary care team unless the person has been referred on to another clinical service. The ongoing point of contact will be the GP (or another person within the primary care team (e.g. PHN) if the person resides in the community). The GP will have direct access to the local Dementia Adviser to refer the person, and also to the MASS brain health service and post-diagnostic support service if appropriate.

Level 2: MASS, cognitive / behavioural neurology clinic or non-dementia dedicated specialist service

For a person diagnosed within a MASS, the MASS post-diagnostic support service (outlined in Section 2) will offer each person a follow-up appointment to discuss any concerns following the diagnosis and to clarify and provide further information and guidance. At this appointment, a personalised assessment will be carried out, leading to the development of the care plan. Referral to the Dementia Adviser will be offered to all, as well as a MASS referral to the relevant post-diagnostic service, as indicated by the assessment and care planning process and agreed with the person.

Cognitive / behavioural neurology clinics or Specialist non-Dedicated Services (SnDS) (neurology, older persons and POA) will similarly be responsible for the development and review of the care plan. The ongoing point of contact will be agreed within the service and communicated to the person (typically the consultant or specialist nurse for the service). The diagnosing service will have direct access to the local Dementia Adviser to refer the person, and also to the MASS brain health service and post-diagnostic support service. This onwards referral to these MASS services will not be appropriate for a minority, but otherwise it is important that the person with dementia has access to the MASS PDS and brain health service, just as if they had been diagnosed within that MASS.

Level 3: Regional Specialist Memory Clinic

Diagnosis within a RSMC may take place at some distance from where the person lives. In this case, there will be a clear referral pathway back to the person's local MASS (more usual pathway); GP (on occasion); or to a local non dementia-dedicated specialist service (e.g. for primarily neuropsychiatric or other non-amnestic symptoms); for the care plan to be developed in the most appropriate local service. The GP should be copied on all correspondence. Where a RSMC is local to the person and the RSMC MDT has capacity to do so and decides that it is better for the person (e.g. a rare form of dementia/highly complex case), the RSMC MDT will undertake the care planning and will refer the person directly to the DA and to a local PDS. In this situation, ongoing responsibility for the care plan will need to be agreed, e.g. the RSMC, DA, MASS, local non dementia-dedicated specialist service, etc.

5.4.1 Delivering, managing and reviewing the care plan

Responsibility for the implementation, ongoing review and management of the care plan will depend on where the person is on the dementia continuum. It will also depend on the complexity of each case and the person's 'primary need'. The MASS, for example, will not be responsible for providing and managing care for all those diagnosed from the point of diagnosis until the end of life. There are a multitude of services in the community which may more appropriately take responsibility for providing and managing care for people with dementia over time and these are described in Section 5.5 below. The practice recommendations for Target 22 describe this evolving process and the importance of a proper handover of care to other services or for agreed joint working. For example:

- Someone with mild symptoms may self-manage for a period, along with the core information/support offering described in Targets 18–20. The availability of a named point of contact will enable the person to seek more support when required, and they will also be reviewed at regular intervals as per Target 22. They will also have access to a Dementia Adviser for support and information. They are likely over time to progress to receiving some of the post-diagnostic supports from the five strands described in the PDS section. These individuals will remain under the care of the MASS PDS service (or SnDS) until their care is more appropriately provided and managed by another service.
- Someone receiving a significant amount of home support (home care, enhanced home care, etc.) may still be linked to the MASS or SnDS but is likely to have more extensive and regular contact with the PHN and / or home care coordinator/home care service.
- Someone with significant psychosis or other Non-cognitive Symptoms of Dementia (NCSD) may be primarily under the care of the Psychiatrist of Old Age and the Mental Health Services for Older People MDT.
- Someone with an intellectual disability who is within a disability service may receive additional support from

that service (with the disability service staff receiving extra training/support from dementia specialist services).

- Someone aged over 65 living with complex co-morbidities and / or other needs may be supported by the case manager in the local Integrated Care for Older People team.
- Someone in residential care will receive their ongoing review and management within the RCF, with RCF staff supported as needed by a local Older Persons or Mental Health Service for Older People MDT.
- The person with YOD may remain under the care of the team who communicated their diagnosis and give immediate post-diagnostic support. This would typically be a RSMC, cognitive-behaviour neurology clinic, or MASS, but could be a SnDS if the person had a preceding known neuro-degenerative condition (e.g. HD, PD, MND) which needs ongoing SnDS care, in which case the ongoing dementia care planning forms part of wider overall care planning. Where the local MASS can more appropriately take over care and care planning (particularly for people with YOD living at a distance from the diagnosis service), this will be arranged locally.

TARGET 26

At a minimum, the person's care plan will be reviewed every 12 months.

Practice Recommendations

- This review will be carried out by a member of the MASS PDS Service, or other relevant HSCP/nurse, depending on where the person is on the care pathway.
- While the MASS PDS Service will develop the initial care plan for people who have been diagnosed at the MASS or the linked RSMC, the PDS Service will not automatically review all care plans within 12 months. Because people will be diagnosed at different points in the dementia continuum, many will have moved on to other services (for example home care) or will be in regular contact with their primary care service (e.g. GP and PHN). It will be the responsibility of these services, which have the closest and most regular contact with the person, to review and update care plans.
- As a person's needs increase and / or change over time, their main point of contact and responsibility for care planning may move to another service, or an additional service may become integrated into the delivery of treatment and support. To maintain continuity of care, it is essential that a proper handover is made to any new services, by the original service. It should not be left to the person or their family to organise and manage this process. Any change of service must be documented on referral and on handover.
- Alternatively, joint working between two services may best meet the person's needs, and protocols should be in place to support this.
- To avoid duplication and repeat assessments, which can cause unnecessary distress to the person, results of pertinent investigations and cognitive assessment should be included in onward referral documentation. Once a diagnosis is confirmed, the focus should be on how the person and the carer / supporter perceive how any changes affect them in real life. Repeated assessments for the purposes of benchmarking are of little practical help to the person.

5.5. Different Roles and Services

The functions of the different roles of diagnostic aspects of the MASS have been described in Section 2 and the co-located brain health and post-diagnostic support services in Section 3. A wide range of existing roles and services in primary care, social care and specialist community-based services can provide support to people living with dementia. These are described here in more detail.

5.5.1 Primary care and community based services for older people

Existing services in primary and community care have a primary focus on the physical and medical needs of people with dementia and it is essential that post-diagnostic supports are integrated into this overall system. This includes, for example, accessing discipline-specific interventions beyond diagnostic assessment and work-up, for identified clinical needs post-diagnosis, such as from OTs, physiotherapists, dietitians, speech and language therapists, and others; and remaining under the care of a GP for ongoing health needs, including access to medication. Maintaining contact with primary care teams is particularly important for people with young onset dementia.

There are many different clinicians and HSCPs, with different roles, in a variety of services, who, working as part of a multi-disciplinary team, can potentially play a role in supporting the person with dementia and carer / supporter at different points in the dementia continuum. They can also play a role in supporting the person around advance care planning:

Dietitians support people with dementia with nutrition and diet. They:

- Assess nutritional needs and advise on balanced diet to ensure the person can meet their nutritional requirements.
- Support diet and brain health interventions to manage weight loss or gain, and muscle or nutrient losses.
- Provide interventions and support in situations when non-cognitive symptoms of dementia affect dietary intake.

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- Provide interventions and support to people with dysphagia and on modified texture diets.
- Guide family members and carers / supporters to help a person with dementia to enjoy mealtimes and to receive appropriate nutrition.
- Support the person living with dementia and their family in decision-making and advance care planning with regard to nutrition and hydration management.

Community Dementia Clinical Nurse Specialist:

This specialist works collaboratively with colleagues to provide ongoing support to people living with dementia in the community who have advancing dementia, complex needs or clinical care requirements (e.g. people in Tier 2 or Tier 3 as per approach outlined in Section 6). Specifically, they:

- Undertake person-centred assessment.
- Support care planning.
- Deliver clinical care in the community.
- Monitor care given to people with a diagnosis of dementia.
- Liaise and work collaboratively with the relevant MDT, consultant and / or GP about the ongoing care of the person with dementia.
- Coordinate investigations, treatment, therapies and follow-up for the person with dementia.

Occupational Therapists (OTs) support people to maintain independence and to participate in everyday activities. Occupational therapists:

- Can help the person to continue performing day-to-day tasks.
- Provide guidance around driving and work.
- Train in skills and strategies to enhance memory function.
- Assess and advise on adaptations and equipment to improve safety and functioning (including reducing falls and pressure ulcers).
- Identify activities and local resources to promote wellbeing and social interaction.

Physiotherapists support individuals to develop, maintain and restore movement and function. They:

- Support people to stay physically active.
- Promote a healthy lifestyle to maximise quality of life.
- Prevent falls and fractures.
- Manage pain.
- Reduce manual handling risk for carers / supporters.

Psychologists assess memory, cognitive function, behaviour and mental health. They:

- Support the management of psychological, emotional and behaviour changes.
- Identify other reasons for cognitive and non-cognitive difficulties, such as delirium and depression.
- Provide education on diagnosis and therapeutic supports for people with dementia and their families.
- Provide memory-focused therapy such as reminiscence therapy.

Public Health Nurses (PHNs) provide a range of health services in the community including:

- Nursing care in the person's home.
- Advice and assistance to the person and their family.
- Acting as an important point of access for other community care services such as home. support, home care packages, meals on wheels, day-care, respite care and other services
- Having a role in coordinating services for the person.

Social Workers work in partnership with individuals and their families to maximise their full potential and wellbeing. They:

- Support the person and family with the emotional and psychological impact of dementia.
- Provide information on dementia and coping strategies.
- Help to draw up care plans and coordinate community services, including day centres, respite and meal services.
- Provide advice and information on social welfare, financial and legal issues, including advance care planning and access to Free Legal Advice Centres.
- Identify activities and local resources to promote wellbeing and social interaction.
- Act as advocates on behalf of clients in relation to a variety of social issues.

Speech and Language Therapists diagnose and manage communication and eating, drinking and swallowing (EDS) difficulties in consultation with the MDT. They:

- Facilitate the person with dementia to communicate their needs, wants and preferences.
- Maximise communication access and potential enhancing quality of life
- Provide communication interventions, education and training to enhance communication function of the person with dementia and their family
- Assess and manage eating, drinking and swallowing difficulties associated with dementia
- Support the person with dementia and their family in decision-making and advance care planning in palliative care.

These HSCPs are members of primary care teams and are located in health centres and primary care centres in the community. They are also members of Integrated Care Teams and connected to acute service departments. There are also Dementia Advisers around the country, and, with increased numbers across the next 12 months, they will have national coverage.

Dementia Advisers (DAs): DAs work with people with dementia and their families in an individualised way to:

- Provide information and advice throughout the dementia journey.
- Help connect the person with dementia supports and services.
- Help connect the person with local groups and services.
- Support the community to be more dementia-inclusive.

A Dementia Adviser does not have a case management role but can be a continuous point of contact for the person, supporting links and liaison with different clinical services. They will play a particular role for people who are in Tier 1, where the primary focus is self-management with support from family, friends and peers, support from community and voluntary organisations.

5.5.2 Social care services

Home support coordinators, home support workers and day care managers can also be involved in supporting the person with dementia to live at home.

Home care coordinators work closely with members of the primary care team and network team to:

- Organise and manage the provision of the home support service in a specific area.
- Supervise, coordinate and support home care workers.
- Input into the assessment and ongoing monitoring of the non-clinical needs of clients.

Health Care Support Assistants work with the local home support team and liaise with the person's family to:

- Provide support in personal care tasks such as washing, dressing and toileting.
- Provide support with light household tasks.
- Provide social care and engagement with the person in activities.

Day care managers work closely with members of the primary care team and voluntary providers to:

- Manage and coordinate a range of activities in a day care setting for older people and people with dementia.
- Liaise with HSCPs/nursing in the primary care team in relation to the clinical needs of attendees.

HSCPs in the Memory Technology Resource Rooms (MTRRs) are a relatively new resource in the community. MTRRs are facilities, which display a wide range of Assistive Technologies (ATs). In this role, HSCPs:

- Provide an in-depth assessment for, and consultation on, assistive technology for people with dementia or people with other memory difficulties and their family members and carers / supporters.
- Provide guidance on technology selection and information on how the different equipment works.
- Provide advice on activities for the person with dementia, information on memory strategies and signposting to other services in the community.

5.5.3 Specialist community-based services

Enhance Community Care Programme

The Enhanced Community Care (ECC) Programme focuses service delivery towards general practice, primary care and community-based services where community healthcare networks (CHNs), community specialist teams for older persons and community specialist teams for chronic disease work in an integrated way with the National Ambulance Service and acute services to deliver end-to-end care, keeping people out of hospital and embracing a 'home first' approach. The development of MASS, RSMC's and the NIDMS as part of the new model of care will align and integrate, where appropriate, with the above services ensuring end to end care for the person with Dementia.

In relation to community services, it should be noted that community boundaries will change as the Regional Health Areas (RHA) become operational in 2024. Significant consideration has been given towards the implememhtaion of the RHA's in the development of this Model of Care and indeed chosen MASS and RSMC site locations to ensure equity of access across Ireland. The vision of the RHA is to facilitate comprehensive integrated, person-led, community-first health and social care through the alignment of acute and community-based services.

Mental Health Services for Older People and Psychiatry of Old Age

Depending on the person's symptoms and needs, they may be under the care of a Mental Health Service for Older People (MHSOP) or an adult Community Mental Health Team (CMHT). Members of this team typically comprise a consultant psychiatrist, community mental health nurses, psychologist, occupational therapist and social worker. Their role includes advising on best practice in management, supporting and educating patients, staff and carers as well as identifying and managing psychosis, depression, anxiety and delirium.

The mental health policy *Sharing the Vision* (Department of Health 2020) recommends that:

> *Individuals who require specialist Mental Health Services for Older People (MHSOP) should receive that service regardless of their past or current mental health history. People with early onset dementia, e.g. young onset dementia, should also have access to MHSOP.*

Community Specialist Teams for Older People

The aim of the Community Specialist Teams for Older People is to support older persons to live in their own community by:

- Providing timely access to health and social care that allows older persons to receive the right level of care, in an appropriate location, ideally at primary care level.
- Targeting patients over 75 with high-level needs including frailty, dementia and high falls risk, and

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facilitate early discharge and hospital avoidance as well as complex case management in patients' homes.

- Interacting with existing hospital and community-based multi-disciplinary teams, adopting a case management approach.
- Incorporating a care planning approach that is person-centred, longer term, coordinated and includes user and carer / supporter input.
- Developing clinical network hubs that have been established to have a centralised location and process for multi-disciplinary teams to discuss the needs of older people with frailty and complex care needs, ensuring daily liaison between teams.

Palliative Care Teams

Within the healthcare system, there are three levels of palliative care provision, with increasing specialisation from Level 1 to Level 3:[7]

- Level 1: Provided in any location or setting by all healthcare professionals as part of their role, using a palliative care approach to all care for a person with dementia.
- Level 2: Provided in any location, using a palliative care approach by HSCPs who have additional knowledge of palliative care principles and use this as part of their role.
- Level 3: Provided by healthcare professionals who work solely in palliative care services, and who have extensive knowledge and skills in this specialty. This includes the Nurses for Night Care service provided by the Irish Hospice Foundation.

Typically, palliative care in the community is provided in two ways: as part of the work of primary care teams (Palliative Care Level 1 and 2) and by a specialist palliative care team (Palliative Care Level 3).

5.6. What is Included in a Care Plan?

The care plan should be a brief record of the decisions made regarding care for the next 9 to 12 months. This may be quite brief if the person is diagnosed early in the disease and has no additional complications, or it may be more detailed and complex. The person's needs and priorities for the next 9 to 12 months should be recorded, along with the appropriate supports to support these, and what the desired outcome is for each issue. Consideration should be given to the use of a personalised profile such as 'This is me' so that full information on the person is considered in the care planning process.

At a minimum, it is expected that the care plan will include:

- The wishes and preferences of the person with dementia (and carer / supporters, as appropriate) as well as their priorities for the coming months.
- Details of the point of contact for the person with dementia during the period of the care plan.
- Plans for information to be provided to both the person and carer / supporter, relevant to their needs and point on the dementia continuum.
- Plans for information to be provided to both the person and carer / supporter on brain health, and a referral to a brain health intervention if appropriate.
- Initial post-diagnostic support that is indicated by the person's preferences, needs, point on dementia continuum and other circumstances, and referral to same.
- Documentation of any conversations about Advance Care Planning (ACP) and place of care preferences, and a plan for support or assistance for decision-making to facilitate ACP as required. Information given to the person about ACP, or plans made to begin ACP, or the ACP itself and / or place of care preferences.
- Post-diagnostic support that is indicated for the family carer / supporter based on their needs and preferences and referral to same, e.g. carer training, peer support, emotional and psychological support, etc.
- Plan for medications relating to dementia, including who prescribes and reviews.
- Clear plans for maintaining links to existing services, e.g. for people with co-morbidities.

To avoid duplication and unnecessary burden on the person and family carer / supporter, the care plan should make maximum use of assessments already conducted as part of the diagnostic process and / or assessments carried out as part of the InterRAI process.

5.7. Signposting to Research

Research is cited as one of the six Priority Action Areas of the National Dementia Strategy; the public consultation process undertaken highlighted the need for research and evidence as a priority for service planning and delivery as well as the need for further investment into research on the cause, cure and care of dementia. There are many different types and aims of research projects in dementia; from studies into biomarkers of disease, disease trajectories, epidemiological studies or studies that involve a pharmacological or non-pharmacological intervention, through to those that look at the lived experience of those with dementia, or which chart unmet needs or service gaps.

Patient and public involvement is recognised as a key component in the design of research studies and improves the relevance and quality of the output. Patients and their caregivers also report a sense of empowerment derived from research participation, and having the option of this involvement supports ongoing active citizenship.

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[7] www.hse.ie/eng/services / publications/clinical-strategy-and-programmes / palliative-care-services-development-framework.pdf

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Initiatives such as the Alzheimer Society of Ireland's "TeamUp for Dementia Research" and the launch of the Dementia Trials Ireland network underscore greater awareness of the need for, and willingness to participate in dementia research in Ireland.

TARGET 27

As part of care planning and early post-diagnostic support, 100% of people with dementia, irrespective of age or dementia subtype, and their supporters / family carers should be offered information about relevant and appropriate research opportunities. Similarly 100% of people with MCI should be offered signposting to research participation.

Practice Recommendations

It is important that clinicians, nurses and HSCPs involved in diagnosing and treating people with dementia and MCI be familiar with relevant, active research programmes.

5.8. Section Summary

Care planning is instrumental to the provision of person-centred care. This section has outlined the process around this, where the person is at the centre of the care planning process. It is important to access the personal outcomes which are important to the person to inform the content of the care plan and focus of ongoing and future care.

A summary of the targets and practice recommendations related to care planning are outlined in the table below.

Table 14: Summary of targets and recommendations related to care planning and immediate PDS

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 with young onset dementia should be referred in the first instance to a social worker along with appropriate access and referral to the full range of MDT.
Target 26	At a minimum, the person's care plan will be reviewed every 12 months.
Target 27	As part of care planning and early post-diagnostic support, 100% of people with dementia, irrespective of age or dementia subtype, and their supporters / family carers should be offered information about relevant and appropriate research opportunities. Similarly 100% of people with MCI should be offered signposting to research participation.

Care Planning Practice Recommendations
Wherever a diagnosis is made and care planning initiated, there should be documented evidence that the person with dementia and carer / supporter have been involved. Decision-making support, as necessary, is provided to the person so they can be involved in the care planning process.
Consideration should be given to the use of a personalised profile such as This is me so that full information on the person is considered in the care planning process.
Where relevant, available information from an existing InterRAI assessment should be used to support the development of the care plan.
In planning post-diagnostic support, careful attention should be paid to the target recipient(s) (e.g. person living with dementia, carer / supporter or both), the modality, the setting and the level of support to ensure the best fit between the needs of the person and carer / supporter and the support provided.
In all cases, the care planning process should consider post-diagnostic support under the following areas: • Understanding and planning • Staying connected • Supporting cognition • Staying healthy • Supporting emotional wellbeing.
The diagnosing / disclosing service will refer the person on to appropriate post-diagnostic support in the community, e.g. Public Health Nurse, Community Dementia Clinical Nurse Specialist, local community and voluntary supports.
Every person, from any service, should be offered a referral to their local Dementia Adviser (see Target 24) who can provide further links and referrals to post-diagnostic supports as the person's needs and readiness changes.
Further development of the DA service should adopt a population-based approach to ensure the equitable distribution of services and supports.
Information on advance care planning and the Decision Support Service should be provided at this initial stage and explored in more detail.

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Care Planning Practice Recommendations
Every effort should be made to avoid the person undergoing duplicate tests and assessments by different services / practitioners. Assessment results should travel with the person between services.
A description of the *Dementia Adviser* service will be provided to the person and their family carer / supporter to ensure they have an understanding of the service. This information will be provided in both written and verbal format.
The care plan review will be carried out by a member of the MASS PDS Service, or other relevant nurse, HSCP, depending on where the person is on the care pathway.
While the MASS PDS Service will develop the initial care plan for people who have been diagnosed at the MASS or the linked RSMC, the PDS Service will not automatically review all care plans within 12 months. Because people will be diagnosed at different points in the dementia continuum, many will have moved on to other services (for example, home care) or will be in regular contact with their primary care service (e.g. GP and PHN). It will be the responsibility of these services, which have the closest and most regular contact with the person, to review and update care plans.
As a person's needs increase and / or change over time, their main point of contact and the responsibility for care planning may move to another service, or an additional service may become integrated into the delivery of treatment and support. To maintain continuity of care, it is essential that a proper handover is made to any new services by the original service. It should not be left to the person or their family to organise and manage this process. Any change of service must be documented at referral and at handover. Alternatively, joint working between two services may best meet the person's needs, and protocols should be in place to support this.
To avoid duplication and repeat assessments, which can cause unnecessary distress to the person, results of pertinent investigations and cognitive assessment should be included in onward referral documentation. Once a diagnosis is confirmed, the focus should be on how the person and the carer / supporter perceive how any changes affect them in real life. Repeated assessments for the purposes of benchmarking are of little practical help to the person.
It is important that clinicians, nurses and HSCPs involved in diagnosing and treating people with dementia and MCI be familiar with relevant, active research programmes.

SECTION 6

DEMENTIA POST-DIAGNOSTIC SUPPORT

6.1. Section Introduction

This part of the Dementia Model of Care describes the post-diagnostic pathway following the diagnostic process, and care planning. There is an ever-expanding list of interventions, therapies, information and approaches, which are collectively described as 'post-diagnostic supports' for people with dementia. This developing field is very welcome but presenting a comprehensive list in this Model of Care is a significant challenge when trying to describe these supports in a way that is understandable and user-friendly.

This section of the Dementia Model of Care categorises post-diagnostic support into five strands and describes examples of supports and interventions within the five strands, 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 section also outlines the scope of post-diagnostic support and its role within the wider ecosystem of dementia care. Considerations around the planning and delivery of post-diagnostic support are also described.

The Dementia Post-diagnostic Steering Group defined post-diagnostic support as supports that would:

> *'… 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 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.

6.2. Five Strands of Dementia Post-diagnostic Support

As there is currently no cure for dementia, providing tailored support for the person and their carer / supporter from diagnosis to end of life takes on particular importance. There are many different supports, therapies and interventions that may be appropriate for the person and carer / supporter but there is no single classification framework for post-diagnostic supports and they are grouped together in many different ways (Gaugler et al. 2016, Keogh et al. 2019). This makes it difficult for people with dementia and family carers / supporters to be aware of what is available and what might be useful for them. It also makes it difficult for practitioners to identify what might best meet the needs and priorities of a particular person at a particular time.

The background work to inform the development of the post-diagnostic support pathway has already been described (see Section 1). In addition, reviews of psycho-social interventions for people with dementia (Guss et al. 2014, McDermot et al. 2018, Keogh et al. 2019), family carers (Gaugler et al. 2016), and a European consensus paper on the operationalisation of the concept of social health and dementia (Droes et al. 2016) were consulted to compile an exhaustive list of post-diagnostic supports. This work, alongside consultations with people living with dementia and family carers / supporters, and guidance from the model's expert advisory group, has informed the development of the Dementia PDS pathway. Evidence is constantly being developed and the Model of Care will need to be reviewed so that emerging evidence on the effectiveness of new or existing post-diagnostic treatments and interventions can inform and update this pathway

Adopting a pragmatic and practice-based approach has resulted in a list of post-diagnostic supports, organised here into descriptive categories, based on the primary purpose of the service / intervention / support. Some supports occur in more than one category as they are multi-purpose; for example, personal profiles support personhood but also aid future planning. Clear specification on the purpose of each post-diagnostic support is made; however, the accountable services or roles, such as Dementia Advisers, or settings such as a Memory Technology Resource Room (MTRR) or a day service are not included, as the purpose is to link post-diagnostic support to specific needs and personal priorities, while bearing in mind that the support could be adapted and implemented in different service / care contexts.

Five 'strands' of post-diagnostic support have been identified. These strands work together to address the varied and changing needs of the person, the carer / supporter and the family, at different stages of the dementia continuum:

1. **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
2. **Staying connected:** focused on maintaining existing connections and interventions which provide additional support to maintain emotional and social connectedness
3. **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 psycho-social wellbeing
4. **Supporting cognition:** interventions which can maintain cognitive abilities as well as providing other benefits
5. **Supporting emotional wellbeing:** supports and interventions, which can enhance emotional wellbeing throughout the dementia continuum.

6.2.6 Using the five strands of support

The PDS pathway describes the main post-diagnostic supports, which are widely used in practice (such as information) or have some evidence base. However, there are acknowledged weaknesses in the evidence base for post-diagnostic supports. There are several reasons for this:

- Some interventions are newly developed and the evidence base is in its early stages.
- There is a small number of randomised controlled trials and low levels of research generally in this area relative to others.

This does not mean that these interventions are not useful or potentially effective. Although many supports are listed in each strand below, this does not imply that every person with dementia should receive all or even some of these supports. Some supports will be more or less relevant depending on the person's own preferences, their needs as identified in the care planning process and their own personal circumstances. Due to the progressive nature of dementia, the individual's needs will change over time, so the provision of post-diagnostic support should be dynamic, undergoing regular reviews.

Many post-diagnostic supports are used together in what is sometimes called a multi-component intervention. For example, information may be provided, along with counselling and support for the person and their carer (Waldorff et al. 2012). In practice though, many of the supports described in the five strands will be used sequentially as needs change and in different combinations at different times. As well as the primary purpose that is described in this list, many post-diagnostic supports can also have a prophylactic function as they can include strategies for preventing distress and disability and promoting health and psycho-social wellbeing (Gibb et al 2019).

Many of the supports and interventions described in the five strands can also play a central role in potentially preventing or ameliorating non-cognitive symptoms of dementia (NCSD). The report on NCSD (McGowan et al, 2019) provides clear, accessible and practical guidance on the use of non-pharmacological interventions for non-cognitive symptoms. This guidance is a companion document to National Clinical Guideline No.21 "Appropriate prescribing of psychotropic medication for non-cognitive symptoms in people with dementia". The publication of these two companion guidance documents sets out a more holistic approach to the issue of non-cognitive symptoms. Many of the supports outlined in Tables 15-20 below can play a preventive role in NCSD. Certain issues can be addressed, such as person-centred care, support for both formal and family caregivers, effective communication skills and environmental adaptations, that will minimise the risk of NCSD occurring. If and when NCSD do occur, then having these factors addressed is likely to give any subsequent interventions a better chance of success (McGowan et al. 2019).

While the majority of NCSD (70%) fall into the mild or non-distressing categories and generally don't require specialist input (Brodaty et al. 2003), mental health services for older people (MHSOP) have a particular expertise in addressing NCSD, with a long-standing practice of putting the patient at the centre and getting a real understanding of their life story and their reality. MHSOPs have a role in advising on best practice in managing, supporting and educating patients, staff and carers as well as identifying and managing psychosis, depression, anxiety and delirium which can all impact on the person with dementia. MHSOP teams work across acute hospital, community and care settings as well as the person's own home and are in a unique position to support the person with dementia along the dementia continuum.

As well as the core offering of post-diagnostic support (Targets 20–22, Sections 4, 5), a number of targets have been formulated to direct the provision of post-diagnostic support (as outlined below). One of these pertains specifically to those who have received a diagnosis of MCI.

TARGET 28	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. *One or more of the interventions and supports described in Tables 15 – 20 below may be appropriate.

Practice Recommendations

- Timely access to post-diagnostic support is considered, based on the needs and preferences of the person and carer / supporter (where appropriate), regardless of age, dementia subtype and geographical location. Restrictions should be based on suitability for the person (e.g. MCI or dementia) rather than age-based. Post-diagnostic support should be tailored as required for younger age groups.
- All supports recommended and received should be documented in the care plan.

6.3. Scope of the PDS Pathway – Who is it for?

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. Therefore, the five strands are not linear and it is not intended that they be 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 everyone with a diagnosis of dementia and their carers / supporters, from people experiencing very early symptoms of dementia, through to those with moderate or advanced symptoms, to end of life. These supports are relevant to people regardless of their age, gender, 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.

6.3.1 Young onset dementia

All of the supports described in the five strands are relevant for people with young onset dementia. However, it is important to ensure that supports are-appropriate for this group, for example, by tailoring or providing specific supports for the partners and children of people with young onset dementia and ensuring supports are age appropriate.

There are considerations required at the point in time where the diagnosis is communicated to the person, in particular relating to information on social welfare and employment rights. These and others are outlined in Section 4. In addition, all people with young onset dementia should be offered a referral to a social worker for additional assessment, planning and care coordination (as per Target 25).

6.3.2 People with intellectual disability

The supports described in the five strands are also relevant for people with intellectual disability who are diagnosed with dementia, although additional support may be required for the person and supports may need to be tailored.

The model is proportionate to the overall population of people living with dementia, which includes people with ID but the model is not ID specific. Recognising the unique issues for people with ID the NIDMS based in Tallaght Hospital co-created a suite of resources and accessible support materials: Easy-read, open access publications co-created by researchers, service providers, and people with intellectual disability, are available on the NIDMS website: www.tcd.ie/tcaid/research/NIDMSbrochures.php

There is a section on www.dementiapathways.ie which includes further information/resources on ID and dementia.

6.3.3 People in residential care

Some people may enter residential care with a diagnosis of dementia but we know that dementia in residential settings is under-diagnosed (Cahill et al. 2012). Estimates suggest that about half of those in residential care have dementia, whether diagnosed or not (O'Shea et al. 2017). Section 2.5.5 describes the process and pathway for the diagnosis of dementia in residential care settings. It is essential that people with dementia in these settings also have access to appropriate post-diagnostic supports which are tailored to their needs, and examples of such supports can be found throughout the five strands described in this document. The care plan for each person living with dementia in LTC should include considerations for the five strands of post-diagnostic support, where these can be personalised to the individual's needs and preferences within the context of the long-term care facility.

6.3.4 People with complex co-morbidities

As dementia incidence increases with age, many people with dementia will also have other physical and mental health conditions. The interaction between these conditions, their treatments, and their dementia can lead to complex presentations and needs. The involvement of relevant specialities in the diagnostic process (e.g. geriatric medicine, neurology and POA services) should facilitate seamless engagement through to the delivery of post-diagnostic support as necessary. There is an increased prevalence of dementia in association with specific conditions, such as Parkinson's disease. It is important that services establish local pathways for such conditions so that people with dementia diagnosed by SnDS services and GPs can be referred to the MASS for PDS, or can directly access post-diagnostic supports which are appropriate to their needs.

6.3.5 People with Mild Cognitive Impairment (MCI)

Section 2 describes the targets and recommendations for people with MCI in relation to diagnosis. The relevance of specific interventions, such as brain health interventions and cognitive therapies for people with MCI is outlined, and these interventions are highlighted within the five strands described below.

Reminder: TARGET 9

100% of people diagnosed with MCI should be offered specific interventions and supports in a timely manner and in response to identified need, respecting individuals' preferences. This includes brain health interventions and cognitive therapies.

6.4. PDS within the Broader Ecosystem of Care

PDS will be delivered within a broader 'ecosystem of care' which includes formal health and social care services as well as many supports, groups and activities provided by the community and voluntary sector. Access to all of the formal service elements within the broader ecosystem of care (home support, day care and restorative care) should be available to people with dementia regardless of age, gender and geographical location. These services should be tailored as appropriate for people with YOD. Many of the post-diagnostic supports described within the five strands of support are based on existing activities and supports and emphasise the importance of the person continuing their previous interests and activities and remaining connected to their community.

6.4.1 Dementia Understand Together

In recent years, an important development has been the Dementia Understand Together programme which focuses on mobilising people in villages and towns across the country to take action to support people with dementia and their families. The Dementia Understand Together programme aims to increase awareness and understanding of dementia and address the social stigma that can negatively affect a person's health and wellbeing. The first phase of the Dementia Understand Together programme was a national campaign that included TV advertising featuring people with dementia and carers / supporters.

This programme focuses on a collaborative approach, with numerous stakeholders, enabling and supporting communities to be inclusive of people living with dementia. *People living with dementia and their families are at the heart of this work.*

At present the Dementia Understand Together programme is working with national partners from the public, private and voluntary sectors, including businesses, academics and national community groups who are raising awareness through their branch networks, conducting training for staff members, reviewing, and developing their services. This is in addition to community champions at a grassroots level who are also working to change the current culture around dementia and create long-lasting change. The community champions do valuable work locally in mobilising existing community organisations and resources to support people with dementia.

TARGET
29

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.

Practice Recommendations

- The Dementia Understand Together programme will grow as a collaborative and networking model to facilitate change, with the voice of people living with dementia at its centre.
- The Dementia Understand Together programme is an important medium for communicating key messages to increase understanding of the lived experience of dementia and to increase awareness of brain health and emerging disease-modifying factors and treatments.
- A programme of work is to be undertaken to translate the most commonly used dementia information materials to other languages to ensure accessibility for people where English is not their first language.

The examples of post-diagnostic support described within the five strands of support outlined below focus on supports within the definition, i.e. 'interventions, therapeutic treatments and activities'. Arguably, current services (home support, day care and respite), while fulfilling many other functions, also provide post-diagnostic support for people with dementia and carers / supporters. These services play a vital role for both the person with dementia and carer in staying connected, staying healthy, supporting cognition and supporting emotional wellbeing. The post-diagnostic support pathway described here is designed to enhance and augment these services and not to replace them. It is essential that the Model of Care is embedded within this existing ecosystem of care.

6.4.2 Primary Care

General Practitioners are often the first healthcare professionals to be consulted when dementia is suspected by the person or their families. Regardless of where the diagnosis is made, the GP remains the primary health professional for the person and their family. The GP, along with the PHN and other members of the primary care team, have an ongoing role in the support of the person with dementia and their family, especially around post-diagnostic support. While early PDS is coordinated through the MASS, this does not override the primary relationship with the person's GP and other members of the PC team.

In relation to PDS, the role of the GP and primary care team can include:

- The provision of some PDS, for example information;
- Referral on to PDS in the local community. This requires a good knowledge of the range of health and community and voluntary services and supports. Social prescribing may play a role here also (see 6.4.3 below);
- Collaborative and integrated working with other HSCPs to ensure a seamless and holistic response for the person and their family, for example working with the local Dementia Adviser or working with the community-based CNS from the MASS as necessary;
- Liaising and working with other services to ensure the full range of PDS is available to the person and their family in a timely manner e.g. the MTRRs, home care services, etc.

The MASS community-based dementia-CNS works closely with PHNs, GPs and other members of the primary care team in the local community, providing specialist advice and support. This close working might include virtual and shared sessions with other members of the MASS team as appropriate.

6.4.3 Social prescribing

Social prescribing recognises that health is heavily determined by social factors. It offers GPs and other health professionals a means of referring people to a range of non-clinical community supports which can have significant benefits for their overall health and wellbeing. Following a referral from a healthcare professional, the person has a consultation with a link worker or Social Prescribing Coordinator. The coordinator works with the person to identify activities or groups they would like to try and an agreed referral to a local community activity is made. Examples include art, cookery, meditation, GAA, men's sheds, music, drama, walking groups and

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many more. Social prescribing has the potential to address a range of social, emotional or practical needs for people with dementia and their carers. It aligns very strongly with the principles of the Model of Care as it explicitly includes the co-production of a 'social prescription' i.e. the person works with their link worker to find solutions which will improve their health and wellbeing, often using services provided by the voluntary and community sector

Social prescribing services are available in over 30 locations around the country, supported by Slaintecare, Healthy Ireland and the HSE as well as community based organisations such as Local Development Companies and Family Resource Centres. Social prescribing projects are funded differently in every area and are free at the point of use for the individual (Building the capacity for Social Prescribing, HSE, 2021).

Social prescribing links well with Dementia Understand Together. It offers a framework for linking the person with dementia and their carer, both together and separately, into organisations and groups which provide many of the PDS described in the five strands and many benefits have been described. The community and voluntary sector is a vital partner in social prescribing as many of the supports and activities are provided from within that sector.

6.4.4 Home support

While the Home Support Service has typically had a focus on personal care, an enhanced model of service delivery for home support clients with dementia has recently been developed (https://dementiapathways.ie/care-pathways/home-care). This model of service delivery can be implemented through the use of personalised care and support plans. The service focuses on addressing personal and / or functional needs (ADLs) as well as psycho-social needs.

Psycho-social interventions as part of a client's Home Support Plan include supporting ability, social engagement and participation in meaningful activities (such as hobbies, household tasks and chores). Home support provides a vital service for family carers, assisting with the physical duties of caring as well as providing a break from caring duties.

The Department of Health's review of Home Care is also an opportunity to further develop appropriate home-based supports for people living with dementia in the community and speaks to the reform agenda within the Health Service of enhanced community care. In preparation for the regulation of home care and the development of standards, HIQA has recently published an analysis of the current landscape of homecare in Ireland, highlighting key areas that require further consideration (HIQA, 2021). They have also developed draft standards for home care, which went out for public consultation in 2021.

The NDO in partnership with DCU developed a dementia education programme for home care assistance – *Dementia Care and Support. This received level 5 QQI accreditation in 2021. It is currently being rolled out across the country funded under Dormant Accounts through the Department of Health from 2023 onwards.*

TARGET 30	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 31	Every home care assistant caring for someone with dementia should have undertaken QQI accredited training of dementia. This requirement should be linked to the HSE's home care tender for private / voluntary providers.

6.4.5 Day care

Day care is an important service for older people in Ireland, providing a vital social outlet as well as other benefits. Day centres primarily have a psycho-social focus and they can have a role in meeting physical care needs through the provision of meals, with some day centres also providing nursing, personal or therapeutic care. Day care also provides a break for family carers.

Day care centres cater for people with a wide range of dependency levels: 42% of attendees have a low level of dependency; 35% have a medium level of dependency; and 22% have a high or maximum level of dependency. One fifth of day care users have dementia. Some centres are only for people with dementia and others provide 'dementia-specific days'. An evaluation of the role of Dementia-specific day care identified that it is highly valued by both people with dementia and their families but there is considerable unmet demand for places (Pierce et al., 2020). Social isolation is the main reason for referral to daycare. For people with dementia, carer respite is cited as the main reason for referral (Pierse, Keogh and O'Shea, 2019). Management and staff working in dementia-specific day care consider the purpose of their service is equally to provide care and support to persons with dementia and to provide respite for family carers (Pierce et al., 2020).

Day care centres provide a wide range of activities, and they vary widely across a range of attributes including size, client profile, buildings, staffing and funding. There are significant disparities in the number of day care places across CHO areas and there are also differences in the distance people need to travel to get to a centre within CHO areas. To maintain the current level of service, 25,000 new places will be required over the next ten years.

A more detailed analysis of day services recommended that an integrated and adequately resourced national plan for day care provision should be developed, reflecting equitable response to current levels of social need among older people in Ireland (Pierse, Keogh and O'Shea, in press). The report also recommended that a national day care centre coordinator be appointed to:

- support local HSE and voluntary organisations in the development of new projects

- prioritise investments in buildings and staffing at locations with maximum benefit-cost ratio
- conduct annual surveys of service delivery
- develop national guidelines on best practice
- develop better links with primary care services and personnel.

The importance of day centres for family carers was recognised, with the recommendation to develop parallel support structures for carers, including peer support opportunities, training programmes, information sessions and general health awareness programmes, including advice on nutrition and sleep. In terms of people with dementia it was recommended that where possible, dementia specific services should be provided in the same day centre complex as services for people without dementia. There is a lack of strong evidence on the optimum day care model for people with dementia and older people. The report seeks to take a pragmatic approach to identifying and building on the benefits of providing day services for people with dementia and older people in an integrated way, while providing for the unique needs of both groups, including people with young onset dementia.

Work is underway in the HSE to develop day care so that it is more widely available and more responsive to the changing expectations and needs of older people and people with dementia. There is significant potential for at least some elements from all five strands of post-diagnostic support to be provided within day care settings. With suitable premises and staffing, day centres could also act as 'hubs' for a variety of community activities and services, which would make these accessible to attendees and also broaden the appeal and use of day care centres.

TARGET 32

The five strands of post-diagnostic support should be considered in the provision of day services for people living with dementia; having a dual benefit of restorative care to both the person with dementia and their family carer / supporter.

6.4.6 Restorative care / Respite:

Work on dementia respite care in Ireland showed that the term was differently understood by providers and carers and this mismatch in perspectives made it more difficult for family carers to seek and accept help labelled as 'respite'. The term 'restorative care' is a better fit for the notion of mutual benefit for both the carer / supporter and the person, and does not position the person with dementia in a stigmatising way; for example, as someone from whom a break is needed (O'Shea et al, 2017). Restorative care is an important service for both the person and carer / supporter and should be seen as a part of the array of post-diagnostic support for both. The provision of restorative care can take several forms (O'Shea et al, 2019). Enhanced day care (for example when blocks of two or more hours are provided) can provide a break from caring duties, as with day care. Overnight respite is occasionally provided at home but more typically in a residential care setting. There is a lack of data on the type and amount of 'respite care' provided for people with dementia in Ireland. We also know little about the amount of need for respite and what form of respite.

To inform future developments of appropriate models of respite and restorative care, a comprehensive review of respite care for people with dementia in Ireland is required in order to develop appropriate levels of restorative and respite care into the future. This review should take a broad definition of respite.

6.4.7 Memory Technology Resource Rooms (MTRRs)

MTRRs are a relatively new resource in the community. 30 MTRRs operate around the country and these facilities showcase a wide range of Assistive Technologies (ATs). They are staffed by an OT or other HSCP who provides an in-depth assessment for, and consultation on, assistive technology for people with dementia or people with other memory difficulties and their family members and carers / supporters. The staff member can also provide guidance on technology selection and information on how different equipment works. A visit to the MTRR also provides an opportunity for advice on activities for the person with dementia, information on memory strategies and sign posting to other services in the community. Depending on the staff resource and suitability of premises, post-diagnostic supports such as cognitive therapies, support groups and other activities can also take place in the MTRR.

There has been a significant increase in the use of telecare and telehealth technologies to support the care of older people and people with dementia at home. Given the rapid increase in new technologies and the increasing acceptance of telecare and telehealth technologies, targets in this area in particular, should be reviewed and updated regularly.

TARGET 33

Every MTRR should be staffed by at least one senior full time OT / HSCP 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 34

Assistive technologies are currently not funded under existing funding streams such as aids and appliances, nor are they available on the medical card. A funding model for AT should be developed to support greater access to and use of AT.

TARGET 35

Updated guidance on the use of assistive technologies is required to ensure the optimum use of such technologies in supporting people with dementia. This guidance should also cover the deployment of telecare and telehealth technologies to support people with dementia.

6.4.8 The built environment

There are also factors within the wider environment – specifically the physical environment such as building design, environmental adaptations and the interpersonal environment created by staff – that have a significant impact on people with dementia. Universal design which includes the needs of people with dementia, and staff training are important for creating an environment within which post-diagnostic support can operate optimally. However, they do not come within the definition of post-diagnostic support and are not addressed in detail in this Model of Care. Details on dementia-inclusive and universal design can be found here and here.

6.4.9 Family carers / supporters

Behind this formal ecosystem of care is a structure of support from family carers which forms the main source of care provision for people living with dementia in the community. The degree of family support depends on numerous factors including the stage of dementia the person is at, the available formal supports which are engaged with the person and the availability of families to provide care. The PDS pathway outlined here is relevant for family / carers and supporters but they have distinct needs in relation to support and in terms of dementia education and training.

TARGET 36

A family carer needs assessment should be carried out to identify the separate needs of family carers (if there is a carer involved) which informs the development and delivery of a carer support plan.

TARGET 37

100% of supporters / family carers of people with dementia should be informed about and offered education and skills training.

6.4.10 Continuum of care – from home to residential care

It is recognised that there are essentially only two choices in relation to care setting for people with dementia at the moment – home care or residential / nursing home care (O'Shea, et al. 2019).

Residential care is provided in approximately 566 private, voluntary and HSE-run nursing homes and centres, with approximately 32,657 places. While there are regulations and standards governing the provision of residential care, there is no agreed 'model' of residential care for people with dementia in Ireland. Residential care is a vital part of the ecosystem of care for people with dementia and the Model of Care explicitly covers people in residential care (see section 6.3.3).

The need for a range of appropriate long-term care options to accommodate the diverse needs of people with dementia in Ireland was recognised in the National Dementia Strategy (Department of Health, 2014). O'Shea, Keogh and Cooney, (2019) examined the evidence for appropriate alternatives to the current residential care model for people with dementia in the future. The National Dementia Office and described existing and innovative models (commissioned it. Among the recommendations of the report were that an adequate supply of a range of housing options should be available at a designated geographical level in order to provide for the preferences and needs of people with dementia as they age. It also recommended that people with dementia should not be required to make multiple moves to access different levels of support. As far as is practicable, supports should come to the person, including home support services, assistive technologies and housing adaptations to facilitate ageing in place.

The development of a model of residential care for dementia is beyond the scope of this Model of Care. However, it is recommended that further work is undertaken to identify agreed models of residential care for people with dementia, which are evidence informed, based on the person's preferences and which meet the range of needs of people with dementia.

In addition, progress is also needed in the development of a range of housing and long-term care options to accommodate the diverse needs of people with dementia.

6.5. Planning and Delivering Post-diagnostic Support

In sections above, the immediate post-diagnostic supports have been outlined. Specific targets underpin these core offerings:

- Target 20: Provision of information that is relevant to their needs, symptoms and life circumstances
- Target 21: A follow-up appointment 4–8 weeks following diagnosis
- Target 22: A named point of contact.

As well as clinical assessments, the care planning process emphasizes the importance of determining the needs, priorities and wishes of the person and carer / supporter. The choice of post-diagnostic support(s) to be delivered is also determined by a number of questions:

- Who is the support for?
- How will it be provided?
- In what setting?

- What level or intensity of support is required?
- How will post-diagnostic support be delivered safely?

These considerations are described in more detail below.

6.5.1 Target recipients – who is the support for?

There are four potential beneficiaries for post-diagnostic support and it is helpful to be as specific as possible in order to tailor the support to the beneficiary:

- The person with dementia only (i.e. the post-diagnostic support is designed for the person on their own).
- The family carer / supporter only (i.e. the post-diagnostic support is designed for the carer / supporter on their own).
- The dyad (i.e. the support is for the person with dementia and the carer / supporter together).
- The wider family group.

Some post-diagnostic supports are designed for more than one target beneficiary (for example, information for the person, carer and wider family). The tables describing the five strands of post-diagnostic support set out who is the main 'target' or beneficiary of the support. This is based on evidence or usual practice or both.

6.5.2 Modality – how will the support be provided?

There are two considerations in terms of how support is provided. The first is whether the intervention is designed to be delivered as a group intervention or a one-to-one intervention. Some interventions can be provided in both ways, for example, information can be provided one-to-one in a session with a Dementia Adviser or as part of a group session such as a support group. Group interventions have the additional advantage of providing peer support and creating opportunities for mutually supportive relationships to form. However, some forms of support are more appropriately delivered one-to-one, such as future planning.

The second consideration in modality is whether the intervention can be delivered online as a virtual intervention as well as in-person. The COVID-19 pandemic has led to a much greater emphasis on the possibility of online delivery of support. A benefit to this modality is that it has created an opportunity for people who are frail, have medical co-morbidities or limited mobility to avail of a wider range of support. There is little formal evidence for the online delivery of most of the interventions and supports described in the tables below. Practice in many areas is still developing in terms of the online delivery of many interventions and supports, with innovation and learning taking place in real time.

Clarity on the modality helps to tailor the support to the person. Some individuals do not like group settings, or a group setting may not be appropriate for other reasons. Similarly, some people may not have the technology to take part in online delivery or may find it difficult to engage with this form of delivery. The needs, preferences, gender and culture of the person should be taken into account when deciding the ideal modality, which may change over time.

6.5.3 Providing support – where and what level of support?

The modality can influence where the post-diagnostic support is provided. For example, it is possible to deliver a one-to-one intervention in the person's home, but group interventions have to be delivered in some other setting (unless it is a virtual or online group). Some supports need specific equipment for their delivery and so may need to be delivered in a clinical setting. Settings include:

- Person's / Carers home
- Day centre or similar
- Memory Technology Resource Room (MTRR)
- Residential care setting
- Health setting such as primary care centre, day care centre, dementia hub, etc.
- Non-health or social setting, e.g. café, Men's Shed, library, etc.

The concept of 'stepped care' is increasingly used in the provision of health and social care that cuts across sectors and settings; for example, in the new mental health policy *Sharing the Vision* (Department of Health 2020).

Tier 1	Self-management, support from family, friends and peers, support from community and voluntary organisations. This level of support typically occurs in the person's own home and other informal or social settings.
Tier 2	More formal and structured support from community and voluntary organisations and interventions from clinicians and specialist teams. Typically takes place in community healthcare settings.
Tier 3	More specialised interventions from clinicians and specialist services (e.g. mental health service for older persons). These typically take place in a range of healthcare settings.

6.5.4 Staying safe – safeguarding considerations

There is a framework of targets, policies and procedures in the health and social care sector for the safeguarding of adults who may be at risk of abuse, harm and exploitation, including:

- National Standards for Adult Safeguarding developed by HIQA and the Mental Health Commission (2019)
- The HSE national operational policy Safeguarding Vulnerable People at Risk of Abuse – National Policy & Procedures (2014)

This guidance needs to be followed in the provision of post-diagnostic support. The principles underpinning the targets and operational policy are broadly reflective of those outlined in this Model of Care. Of particular importance is the principle of proportionality, whereby the least intrusive response appropriate to the risk presented should be taken. An online training module has been made available for training in National Standards for Adult Safeguarding.

6.6. Detailed Description of PDS – the Five Strands

6.6.1 Understanding and planning

- Information accessed by the person and carer / supporter
- Peer support groups / individual peer-to-peer supports
- Facilitated information provision (e.g. Dementia Cafés) and signposting (e.g. Dementia Advisers)
- Personalised profile
- Carer training
- Planning for the future
- Advanced care planning and advanced healthcare directives
- Decision-making arrangements (includes assisted decision-making)
- Psycho-education
- Resolving conflict (including mediation and family therapy)

6.6.2 Staying connected

- Peer support; this includes informal one-to-one peer support as well as peer support groups, and Dementia Cafés
- Keeping up hobbies and interests
- Dementia-specific and dementia-inclusive community-based activities
- Staying in work
- Assistive technologies, e.g. phone calls, video calls such as FaceTime, Zoom, etc.
- Interactive projection systems
- Therapeutic interventions to support communication, e.g. conversation coaching
- Life story work
- Reminiscence therapy

6.6.3 Staying healthy

- Health promotion and brain health
- Meaningful activities and occupation; these include all activities from activities of daily living to arts and crafts, work-related tasks such as household chores and gardening, and organised activities such as games
- Self-management interventions – group programmes based on a psycho-social group rehabilitation model
- Exercise interventions
- Promoting and maintaining nutrition and hydration
- Telecare and staying safe; for example, technologies such as remote monitoring and emergency alarms
- Telehealth; for example, monitoring systems for blood pressure, blood sugar, etc.
- Providing support with non-cognitive symptoms of dementia (NCSD)

6.6.4 Supporting cognition

- Meaningful activities and occupation
- Cognitive stimulation therapy
- Cogs Club
- Cognitive training
- Cognitive rehabilitation therapy (CRT)
- Assistive technologies
- Pharmacological treatments

6.6.5 Supporting emotional wellbeing

- Sensory approaches such as aromatherapy, massage and touch therapies
- Meaningful activities
- Creative arts therapies including approaches which use dance, art, music and drama
- Animal-assisted therapies including pet therapy
- Other psycho-social interventions, e.g. horticulture, doll therapy, etc.
- Mindfulness and yoga
- Counselling and psychotherapeutic interventions, e.g. for specific issues related to diagnosis, or for issues such as stress management, anxiety or depression
- Family / systemic therapy
- Behaviour support interventions

The table below outlines each strand, providing examples and explanations across the tiered levels, audience and modality.

Table 15: Examples of supports and interventions to assist in understanding and planning

Level of support	Example	Audience	Modality
Tier 1	**Information accessed by the person and carer / supporter** There is a wide range of information that can be readily accessed by the person themselves and their carer / supporter and other family members. This includes websites, printed information, films, TV and radio programmes and all other types of information. Recommended resources are listed on Understand Together and the ASI website.	Person Carer / supporter Family	Initiated by the person / with carer / family members Virtual
	Peer support groups The aim of support groups is to provide a reassuring, confidential and safe place to talk to others with self-experience about how dementia affects them. The focus is on sharing experiences and strategies and forming mutually supportive relationships. Support groups are usually for one target group, i.e. for people with dementia or for the dyad or for carer / supporters or families. Peer support can also take place as a one-to-one conversation.	Person Carer / supporter Dyad Family	Group Virtual In-person
Tier 2	**Facilitated information provision and signposting** This describes supports and interventions that are organised and facilitated, usually by a HSCP. This type of session can be one-to-one, for example with a Dementia Adviser, or in groups, such as Dementia Cafés. Signposting is an important feature, where a health or social care professional provides information about other services, provides information in the form of a leaflet or booklet, or informs the person where he or she can obtain further information or support.	Person Carer / supporter Dyad Family	Group One-to-one Virtual In-person
	Personalised profile For practitioners and others who may be providing care and support to the person with dementia, the better they know and understand the person, the more likely the success of tailored interventions. Tools such as This is me can be used to record details about a person who can't easily share information about themselves, and can be used in any setting – at home, in hospital, in respite care or in a care home. The Getting to Know Me form aims to give hospital staff a better understanding of patients with dementia who are admitted either for planned treatment, such as an operation, or in an emergency. These tools can have an important role in care planning. NCSD: Person-centred care is fundamental to the prevention of NCSD and a detailed knowledge of the individual as 'a person', their likes, dislikes, preferences and life story is fundamental to person-centred care. See Guidance on Non-cognitive Symptoms of Dementia.	Person	One-to-one Usually in person
Tier 3	**Carer training** A number of Family Carer Training courses are available in Ireland. These programmes broadly aim to increase family carers' knowledge of dementia, to develop their caring skills, and to enable them to cope and respond more confidently to their family members' needs. Carer training is particularly important in enabling carers to understand and address responsive behaviours. In-person courses also provide opportunities for carers to meet other carers and share their experiences, although currently all courses are delivered online. NCSD: Training for family carers is a cornerstone of preventing NCSD. See Guidance on Non-cognitive Symptoms of Dementia	Carer / supporter Family members	Groups Virtual In-person

Level of support	Example	Audience	Modality
Tier 3	**Planning for the future** Planning for the future enables the person to prepare for and influence events that may happen. There are booklets and tools to help in the process, for example, from the Alzheimer Society of Ireland (ASI) https://alzheimer.ie/wp-content/uploads/2018/11/ASI-Plan-For-the-Future-2016_-web.pdf. The Think Ahead form (Irish Hospice Foundation) provides a practical template for recording future wishes around healthcare as well as legal and financial information https://hospicefoundation.ie/wp-content/uploads/2018/10/Think-Ahead-May-2018-Logo-Change-only.pdf. Planning carried out by the person themselves, with their carer / family, although the Dementia Adviser is an important resource to assist in the process.	Person Can involve: Carer / supporter Dyad Family	One-to-one Usually in-person
	Advance care planning and healthcare directives An advance care plan is written when a person with dementia and their doctor or other healthcare professional wish to record the outcome of the advance care planning discussion. An advance healthcare directive is a record made by a person, who has capacity, of their will and preferences concerning specific treatment decisions in the context of an anticipated deterioration in their condition, with loss of decision-making capacity. An advance healthcare directive is legally binding; therefore, certain formalities must be followed when a person writes down what treatments they would refuse in the future and the circumstances in which the refusal is intended to apply. Resources on advance healthcare directives can be found here: https://hospicefoundation.ie/wp-content/uploads/2021/01/Advance-Care-Planning-for-Health-and-Social-Care-Professionals-CareInform.pdf	Person	One-to-one
	Decision-making arrangements (includes assisted decision-making) The Assisted Decision Making (Capacity) Act April 2023 establishes a statutory framework to support decision-making by adults who have difficulty in making decisions without help. The Act also enables people to plan, while they have capacity to do so with Enduring Powers of Attorney and Advance Healthcare Directives. In circumstances where a person may be finding it difficult to exercise their decision-making capacity, they are entitled to support to help them make their own decisions. The Act establishes tiers of decision support, each with varying levels of responsibility, depending on the relevant person's needs. The type of support should be tailored to the person's own circumstances, communication means and to the specific decision. Decision support arrangements are monitored by the Decision Support Service (DSS). Decisions can be about personal welfare, property affairs or both. The DSS is currently being established. Further information can be found at www.mhcirl.ie/DSS	Person	One-to-one

Level of support	Example	Audience	Modality
	Psycho-education Psycho-educational interventions have two key components: an education component, which focuses on imparting clear and specific information and knowledge about different aspects of dementia; and a therapeutic component, which supports participants to manage circumstances related to the condition. This may involve helping people to build coping skills, dealing with emotions following a diagnosis or addressing responsive behaviours. Psycho-education is a formal, structured intervention delivered by a trained healthcare professional and is distinct from the support groups and information-giving interventions described above. Detailed guidance on delivering psychoeducation is available.	Usually family carer / supporters or dyads	Usually groups Has been adapted to one-to-one, dyad and family interventions Usually in-person
	Resolving conflict In cases where disagreements or disputes arise about current or future arrangements, consideration should be given to referring the family for family therapy or to engaging a trained mediator to assist in resolving conflict.	Person Carer / supporter Dyad Family	One-to-one with the relevant parties together Usually in person

Diagram 11: Applying the Dementia Model of Care principles to understanding and planning

Citizenship	Information and support that is provided to assist understanding and planning should affirm the personhood and autonomy of the person with dementia. Information should be freely available and widely accessible.
Person-centred Approach	Information is tailored to the recipient, taking into account levels of literacy, cultural background, disability, including sensory impairment, level of understanding and cognitive symptoms. Be guided by the person themselves as well as ensuring that opportunities are seized to provide information at a time that allows for future planning.
Integration	Use opportunities in the delivery of all services to provide information, to address queries and to signpost and refer the person, carer and family to appropriate sources of support and information.
Personal Outcome-focused	The information provided and the way in which it is provided should meet the needs, priorities and desired outcomes of the person and carer at that time, should assist in their understanding and should enable them to plan as necessary.
Timeliness	Recipients need the right information at the right time. Don't overwhelm the recipient with too much information at any one time. Allow time for information to be understood and acted upon, to address questions and for information to be repeated if necessary.

Table 16: Examples of supports and interventions to assist in staying connected

Level of support	Example	Audience	Modality
Tier 1	**Peer support** One-to-one peer support usually occurs informally, when a person with dementia or carer / supporter makes contact with a peer, often through a mutual connection or through meeting a peer at a conference or an event. Peer support groups have already been described in the Understanding and Planning section. As well as being a source of information, peer support groups also provide opportunities for social contact and forming new relationships based on 'being in the same boat'. Dementia cafés are informal, once monthly meetings for anyone who is affected by dementia. People living with dementia, their families and friends, healthcare professionals, and people who are interested in supporting a dementia-inclusive community, are all welcome to attend. Dementia cafés are run by local voluntary steering committees, and are free of charge. Age-appropriate peer support should be provided for people with young onset dementia, their partners and children.	Person Carer / supporter Dyad Family	One-to-one Group Virtual In-person
Tier 2	**Keeping up hobbies and interests** One of the six key actions in the Dementia: Understand Together in Communities campaign is to support the person to keep up hobbies and interests. Staying active with sports, hobbies and other leisure activities is an important component of quality of life. People with dementia may need encouragement not to stop the things they enjoy when they get a diagnosis. They may need additional support to continue these activities as their dementia progresses. The availability of dementia-inclusive activities can support the person in maintaining their usual activities.	Person Can include: Carer / supporter Dyad Family	One-to-one Group Virtual In-person
	Dementia-specific community based activities While it is important to remain involved in previous activities, it may also be helpful for the person to engage in community-based activities that are specifically for people with dementia, such as dementia social clubs and dementia-inclusive activities. Exercise classes, dementia choirs and befriending are examples of such dementia-specific activities. Age-appropriate dementia-specific activities for people with young onset dementia should be provided.	Person Can include: Carer / supporter Dyad Family	Group One-to-one Virtual In-person
	Staying in work Although many people with dementia may no longer be active in the workforce, for those who are working, in particular people with young onset dementia, it is essential that information, guidance and support are provided to remain in work if that is what the person wishes. Specialist advice on employment law as it pertains to be people with disabilities should be provided, along with advice on social welfare and other supports that may be available to support continuation in work. See section on Employment Advice.	Person Can include carer / supporter, Dyad Family	One-to-one Virtual

Level of support	Example	Audience	Modality
Tier 3	**Assistive technologies** The simplest technology for staying connected, and one everyone is familiar with, is a voice call on the telephone. Mobile phone and smartphone technology opens up the possibility of staying connected via mobile phone call, text message, email and features which use images of those on the 'call' such as FaceTime, Skype, Zoom, etc. The use of this smarter technology requires broadband access as well as a device such as a mobile phone, tablet or computer. The person needs to be familiar with how to use this technology or have access to someone who can assist them. Adapted phones and tablets are now available which make the devices easier to use. These can be demonstrated at the local Memory Technology Resource Room (MTRR). See here for a list of MTRR locations.	Person Can include: Carer / supporter Dyad Family	Virtual
	Therapeutic interventions to support communication Communication skills are integral to relationships, at the core of social interaction and key for quality of life. Communication difficulties can emerge early in dementia, and the ability to communicate can deteriorate as dementia progresses. A number of interventions are designed to optimise the cognitive communication skills of the person with dementia as well as their communication partners. An example developed in Ireland is Conversation Coaching for People with Dementia (Dooley 2016, Dooley et al. 2018). This communication intervention is a defined six-week community-based programme which delivers education and communication training for people with dementia and their communication partners in both one-to-one and group sessions. It provides opportunities to explore the communication changes experienced in dementia, identify individualised support strategies and restore communication confidence.	Person Carer / supporter Dyad	One-to-one Groups In-person
	Interactive projection systems These systems consist of a high-quality ceiling projector, infrared sensors, a loudspeaker and a processor with which interactive games are projected on to a table. Interactive projection systems have been developed for use in care institutions, day care, and public libraries and have been reported to stimulate people with dementia, encouraging them to move more and interact socially. One example is Magic Table, which has been installed in some libraries and nursing homes in Ireland. Interactive projection systems may be a useful intervention in the management of NCSD (see Guidance on Non-cognitive Symptoms of Dementia).	Person	One-to-one Groups In-person
	Life story work Life story work is an activity in which the person with dementia is supported by staff and / or family members to gather and review their past life events and build a personal biography. It can help the person to share their stories and enhance their sense of identity. This is especially useful when they are having difficulty sharing this information themselves. Life story work can help to encourage better communication and an understanding of the person's needs and wishes. This can inform their care and ensure that it is provided in a positive and person-centred way. Life story work may be a useful intervention in the management of NCSD (see Guidance on Non-cognitive Symptoms of Dementia).	Person Can include: Carer / supporter Family	One-to-one Usually in-person

Level of support	Example	Audience	Modality
	Reminiscence therapy Reminiscence therapy involves discussing events and experiences from the past. It aims to evoke memories, stimulate mental activity and improve wellbeing. Reminiscence is often assisted by props such as videos, pictures and objects. It can take place in a group or be done with a person on their own, when it often results in some form of life-story book being created. It is usually done with residents in care homes but can also be done in the person's home. There is some evidence that RT can improve quality of life, cognition, communication and possibly mood in people with dementia in some circumstances. RT is recognised as a useful intervention in the management of NCSD (see Guidance on Non-cognitive Symptoms of Dementia).	Person Can include: Carer / supporter Family	One-to-one Group Usually in-person

Diagram 12: Applying the Dementia Model of Care principles to staying connected

Citizenship	Being connected to a community and being recognised as a valued member of that community reaffirms our sense of citizenship. An emphasis on maintaining existing connections and activities enables people with dementia to maintain their role as citizens.
Person-centred Approach	Supports provided to stay connected are based on the preferences of the person and their stage on the dementia continuum. The continuation of existing activities and interests in mainstream settings is emphasised and supported for as long as possible.
Integration	Informal and person-initiated ways of staying connected are recognised and valued in the person's care plan. HSCPs and formal services provide support and integrate these activities as necessary into the overall plan.
Personal Outcome-focused	Support to stay connected meets the social and emotional needs identified by the person and carer in the most appropriate way for them.
Timeliness	Encouragement and support to stay connected and to 'keep doing what they were doing' are provided as part of the process where the diagnosis is communicated and throughout the dementia continuum. Opportunities to introduce new PDSs to remain socially and emotionally connected should be identified as abilities change.

Table 17: Examples of supports and interventions to assist in staying healthy

Level of support	Example	Audience	Modality
Tier 1	**Health promotion and brain health** People with dementia and carer / supporters should be provided with relevant information and advice on physical activity, diet, alcohol consumption, smoking and managing hearing loss, and encouraged and supported to follow this advice. This may involve providing details of local exercise groups, smoking cessation groups, etc. Tips and activities to support brain health are also available. Brain health and health promotion interventions are also appropriate for people with MCI.	Person Carer / supporter	Group One-to-one Virtual In-person
Tier 2	**Meaningful activities and occupation** Partaking in meaningful activities bolsters the self-esteem of every human being, and continuing with meaningful activities is particularly important for the person with dementia and their carer / supporter. People with dementia and carer / supporters should be encouraged not to 'stop doing' but to maintain their usual activities. Meaningful activities range from activities of daily living, sport or exercise activities (e.g. golf, walking, swimming or attending sports), leisure activities (e.g. crafts, men's sheds, art, music, etc.) to social activities (e.g. choir, book club, meeting for coffee / a drink, befriending). These activities can be modified and additional support provided as the person's abilities change. Other activities might be newly introduced such as involvement in a dementia working group or becoming involved in research or similar activities. Occupational tasks such as household chores, gardening and other skills-based tasks help maintain occupational identity. Voluntary work may also be helpful in maintaining a person's skills, abilities and occupational identity. Support to remain in work should be provided as appropriate, particularly for people with young onset dementia (see relevant section in Staying Connected). Being involved in meaningful activities can help prevent and manage NCSD (see Guidance on Non-cognitive Symptoms of Dementia).	Person Carer / supporter Dyad	Group One-to-one Virtual In-person
	Self-management interventions Several supports have been described in these tables which involve self-management, such as accessing information, health promotion, support groups, etc. There is also evidence for specific self-management interventions, which are group programmes based on a psycho-social group rehabilitation model and on self-management principles. Groups are facilitated by trained professionals and develop self-management capabilities such as problem-solving skills, self-efficacy, and mastery through facilitated information provision, education and peer support (e.g. Toms et al. 2015, Lakkonen et al. 2016).	Person Carer / supporter Dyad	Group One-to-one Virtual In-person
Tier 3	**Exercise interventions** While individuals may be involved in exercise as part of the meaningful activities described above, an exercise intervention is a more formal programme facilitated by a trained professional. There is good evidence that exercise with sufficient intensity improves global physical and cognitive functions and activities of daily living skills for people with dementia (McDermott et al. 2018). Group exercise programmes can confer additional social benefits. Specific exercise programmes, such as those run by Siel Blue, have been designed for people with dementia or for people with mobility or other health issues.	Person Dyad	One-to-one Groups Usually in person Virtual

Level of support	Example	Audience	Modality
	Telecare Telecare is the use of technologies such as remote monitoring and emergency alarms to create a safer environment and enable the person with dementia to live independently at home for longer. See Guidance on Assistive Technology for more information.	Person	One-to-one Virtual
	Telehealth Telehealth monitoring is the remote exchange of physiological data between a patient at home and medical staff to assist in diagnosis and monitoring. It includes (among other things) a home unit to measure and monitor temperature, blood pressure and other vital signs for clinical review at a remote location (for example, a hospital site) using phone lines or wireless technology. Examples of telehealth devices are blood pressure monitoring, blood glucose monitoring and medication reminder systems. These systems are increasingly being used to monitor chronic conditions such as diabetes and high blood pressure. The person with dementia or carer / supporter may need support to use these systems effectively.	Person	One-to-one Virtual
	Providing support for behaviours that challenge Many of the supports and interventions already described in the five strands contribute to the prevention and management of NCSD. Prevention is a key intervention for NCSD and five interventions have been described as potentially preventing or minimising NCSD and its impact. These are person-centred care, support for family carer / supporters, staff skills and support, effective communication skills, and environmental adaptations. These and other interventions and strategies are described in detail in Guidance on Non-cognitive Symptoms of Dementia.	Person Can involve: Carer / supporter Family	One-to-one Usually in-person

Diagram 13: Applying the Dementia Model of Care principles to staying healthy

Citizenship	'Access gaps' to specific forms of healthcare and support (e.g. if the person does not have a medical card) should be addressed. Telecare and telehealth can be particularly useful in providing access to supports to stay healthy.
Person-centred Approach	People with dementia should be supported to self-manage their health for as long as possible.
Integration	Post-diagnostic supports and other treatments provided for the person with dementia should be closely integrated into the HSCPs and services which address the physical and psychological health needs of the person.
Personal Outcome-focused	Opportunities to meet several outcomes through the provision of post-diagnostic supports and interventions focused on staying healthy should be identified. For example, support for exercise promotes health, provides meaningful activity and can provide social connection.
Timeliness	The introduction of AT is particularly sensitive to timing, depending on the technology and the needs to be addressed. Too early and it may be intrusive; too late and it may not confer any benefit (see Guidance on Assistive Technology).

Table 18: Examples of supports and interventions to assist in supporting cognition

Level of support	Example	Audience	Modality
Tier 2	**Meaningful activities and occupation** Activities and occupation play an important role in maintaining cognition. Several examples and interventions are described in Table 17.	Person Carer / supporter Dyad	Group One-to-one Virtual In-person
	Cognitive Stimulation Therapy (CST) Cognitive stimulation is a cognitive-based non-pharmacological intervention that targets cognitive and social function (Clare 2003). The range of activities in CST includes discussion of past and present events and topics of interest, word games, music and practical activities. CST is usually undertaken in a group setting with small groups of people with dementia, typically facilitated by trained staff. It is delivered in 14 themed one-hour sessions, usually two sessions weekly or in one two-hour session weekly. CST is an appropriate intervention for people with MCI.	Person	Group In-person
	Cogs Club Cogs Club is a form of CST developed to provide CST over a longer period (www.cogsclub.org.uk/home/). Like CST, it is structured and uses thematic sessions, but differs from CST in that the one-hour session is extended to a day of activity, music and fun.	Person	Group In-person
Tier 3	**Cognitive Rehabilitation Therapy (CRT)** Cognitive rehabilitation is aimed at improving cognitive functioning in everyday life and supporting people to achieve the everyday goals that matter to them. In goal-oriented cognitive rehabilitation, a person with dementia works with a trained health professional over a number of sessions to identify goals that are personally relevant and seeks to achieve these by devising and implementing strategies. Goals may include remembering recent events, reducing repetitive questioning or remembering people's names. Family carer / supporters often also attend the sessions. Assistive technology or memory aids may be used to provide environmental prompts. CRT is an appropriate intervention for people with MCI.	Person Dyad	One-to-one Limited evidence of use in groups In-person
	Cognitive Training (CT) CT involves guided practice of a set of structured tasks to train cognitive processes and abilities. A structured programme of a set of tasks is designed to involve various cognitive functions such as memory, attention, language, or executive function. The difficulty of the tasks is tailored to the individual performance level. Tasks may be presented in paper and pencil or computerised form, or may involve analogues of activities of daily living; for example, calculation exercises and money counting to train domestic finances handling. Trained instructors or health professionals can carry out individual or groups sessions with people with dementia. Cognitive training is an appropriate intervention for people with MCI.	Person Dyad	Group One-to-one In-person
	Assistive technologies Technology to aid cognition and memory ranges from 'no-tech' such as signage in the home or residence to electronic memory aids such as calendar clocks, item locators and medication dispensers. MTRRs can provide advice and demonstrations of appropriate technology. A summary list of potential devices can also be found in Chapter 2 of Implementing Assistive Technology in Dementia Care Services: A Guide for Practitioners.	Person	One-to-one Virtual In-person
	Pharmacological treatments Details of pharmacological treatments which support cognition can be found in section 2.6.7.	Person	

* Access to pharmacological and non-pharmacological interventions to support cognition will be through post-diagnostic pathways which may offer some or all of the above modalities.

Diagram 14: Applying the Dementia Model of Care principles to supporting cognition

Citizenship	A range of post-diagnostic interventions which support cognition are accessible and available to all people living with dementia.
Person-centred Approach	Interventions to support cognition reinforce and maintain existing abilities and address the goals and priorities of the person.
Integration	Cognitive interventions are ideally integrated into the provision of other support, for example, through a MTRR or a day centre.
Personal Outcome-focused	Different types of cognitive intervention are designed to address different needs, thus care should be taken to refer the person to the intervention that will most effectively meet their needs at that time and which will meet the outcomes they have identified as important for them.
Timeliness	The selection of interventions to support cognition is related to the severity of the person's symptoms, thus a timely referral to an appropriate cognitive intervention enables the person to benefit maximally from this form of support.

Table 19: Examples of supports and interventions to assist in supporting emotional wellbeing

Level of support	Example	Audience	Modality
Tier 1	**Sensory approaches** Sensory approaches aim to stimulate the senses through the provision of visual, auditory, olfactory or tactile stimuli, therefore providing an alternative to cognitive-based activities. Examples include aromatherapy, massage / touch therapy, light therapy, and multi-sensory therapy which uses combinations of therapies, also known as snoezelen therapy. Aromatherapy uses scents to promote health and wellbeing, typically using essential oils distilled from plants, administered through massage therapy, aromatic baths or vaporisation. It is widely used to relieve stress and anxiety, alleviate pain and nausea, and to promote sleep. The term 'massage therapy' describes a wide variety of techniques that vary in the manner of application of the touch, pressure and intensity of the intervention. It is generally performed by 'massage therapists' to deliver therapeutic massage therapy and / or administer body treatments for relaxation, health, fitness and remedial purposes. In health and long-term care settings, hand massage is a common form of intervention. Light therapy is an effective and non-invasive method of improving sleep patterns. Studies have shown that it aids conditions of depression, agitation and also shows improvements in older adults with dementia. Interventions such as the Magic Table is also a sensory approach. Further detail on these therapies can be found in Guidance on Non-cognitive Symptoms of Dementia.	Person	One-to-one In person

Level of support	Example	Audience	Modality
Tier 1	**Meaningful activities** The importance of meaningful activities was described in the Staying Healthy section, and activities also play a key role in supporting emotional wellbeing. It is important to distinguish between these activities, such as music, art, gardening, etc., and the therapeutic application of activity. Music as entertainment, art as a goal-oriented task (i.e. making something) and enjoying a garden space are all important activities in themselves which can bring great pleasure to people with dementia, particularly when communication and other abilities are compromised. These activities may take place in a residential care setting (such as a sing-along or listening to music) or may involve visits to other settings such as art galleries or concerts. The therapeutic application of these activities is a distinct activity, involving trained professionals and some of these therapies are described below.	Person Dyad	One-to-one Group In-person Virtual
Tier 2	**Creative arts therapies** Many approaches have been described, which involve the therapeutic use of the arts to improve the quality of life of people with dementia, including dance, art, music, drama, clown therapy and more. Trained professionals engage in a therapeutic relationship with the person, either one-to-one or in groups, and the main goal of the therapy is self-expression. Creating (through art, music, etc.) is the way in which the person expresses or communicates their thoughts and feelings. Art supplies or musical instruments are tools to enable self-expression and there is no right or wrong way to use them. The emphasis is on what the creative output communicates for or about its creator, not necessarily, on how it looks or sounds, or whether it turns out as expected. The therapist and the client focus on the process and experience of making the music or art. The process can be just as important as the finished piece.	Person	One-to-one Group In-person
	Animal-assisted therapies Animal-Assisted Therapy (AAT) refers to goal-directed, structured encounters with animals with the purpose of improving wellbeing and quality of life under the direction of a trained person. It can involve therapeutic encounters with a range of animals as well as toy animals and robot animals.	Person	Group One-to-one In-person
	Other psycho-social interventions Other interventions which can support emotional wellbeing include horticulture / garden therapy, doll therapy and more. Further details of these interventions can be found in Guidance on Non-cognitive Symptoms of Dementia.	Person	One-to-one Usually in person
	Mindfulness and yoga Mindfulness is a skill that can be developed with training and is defined as an awareness that arises through paying attention, on purpose, in the present moment, and non-judgmentally (Kabat-Zinn 1990). Mindfulness-based interventions have been shown to improve psychological wellbeing in both healthy and clinical populations. Training is typically delivered over eight weeks in groups. Benefits have been shown for both the person with dementia and the carer / supporter. The combination of breathing and gentle movement in yoga can also be beneficial for people with dementia, and adaptations such as chair yoga have been made to make the practice more accessible.	Person Dyad	Training typically in group – practiced alone or in groups In person or virtually

Level of support	Example	Audience	Modality
	Counselling and psychotherapeutic interventions Counselling and psychotherapy are two forms of ‘talking therapy’ which should be considered for people with dementia or family members who are struggling on a personal level with problems and feelings arising from a diagnosis and the effect of dementia on their lives and personal relationships including anticipatory grief. There are different types of counselling and psychotherapy to choose from, depending on the issue for the person / carer / supporter: 1. Post-diagnostic counselling is a process of providing support with coming to terms with a diagnosis of dementia. It also involves thinking about a person’s needs and working out the next steps in their treatment. 2. Anxiety management, sometimes called stress management, is an intervention, which aims to help the person with worry, stress and anxiety. One type of technique used in anxiety management is relaxation. Relaxation refers to techniques, which can help a person to deal with stress, worry and anxiety. Cognitive behaviour therapy (CBT) is also often used to help people to manage overwhelming feelings of stress and anxiety, and there is evidence that this can be helpful for the person and carer / supporter in managing anxiety. 3. Psycho-education has been described in Strand 1: Understanding and Planning and can play a role in helping people to build coping skills, deal with emotions following a diagnosis or deal with behaviours that challenge (see guidance here).	Person Carer / supporter Dyad Family members	One-to-one Groups Virtual In-person
	Family therapy Refers to a range of psychological interventions for individuals, couples and families based on systemic concepts and theory. They are designed to help people to make changes in their thinking, behaviour and understanding to relieve distress, improve the quality of their important relationships, and make positive changes (Benbow and Sharman 2014). Four roles have been suggested for therapy in relation to families living with a dementia: family therapy may be a useful way of supporting families in making major decisions; as an adjunct to other treatments; to assist in crisis resolution and to address family difficulties in medico-legal cases; and as a source of techniques, which can be applied in other areas of practice (techniques include understanding the family life cycle, and asking family members to describe what has been tried in response to problems and found not to work). The inclusion of children in family therapy may be particularly helpful for people with young onset dementia.	Carer / supporter Family	One-to-one Group Usually in-person
	Behaviour support interventions The importance of prevention as an intervention for NCSD has been described earlier. Where preventative approaches are unsuccessful and NCSD remain, the accepted best practice in dementia care now requires that every effort is made to address NCSD through non-pharmacological approaches before considering the possible use of medications. Frameworks such as RAGSTER provide a comprehensive and individualised approach to addressing NCSD (see Guidance on Non-cognitive Symptoms of Dementia). Medications can also be prescribed as part of the appropriate management of non-cognitive symptoms. A National Clinical Guideline has been prepared to guide practice in this area: appropriate prescribing of psychotropic medication for non-cognitive symptoms in people with dementia – National Clinical Guideline No. 21.	Person	One-to-one

* *The above interventions to support emotional wellbeing may be available through a number of services. Patients with more complex needs will typically be linked with their local Mental Health of Older Persons services.

Diagram 15: Applying the dementia post-diagnostic supports to delivering emotional wellbeing

Citizenship	Supporting the person to make decisions around their care affirms their citizenship and personhood. Seeking and valuing the person's and carer's input and acting on it are part of this process.
Person-centred Approach	Valuing the person and treating them with dignity and respect has a direct impact on their emotional wellbeing. It is also important to be aware of the wellbeing of the carer and family as this can have a direct impact on the wellbeing of the person.
Integration	Informal support such as participating in meaningful activities and remaining socially connected is a valuable source of emotional support. However, more formal support from counselling services or mental health services should be integrated into the overall support for the person and carer if and when required.
Personal Outcome-focused	It is important to determine what emotional needs are to be addressed and what outcome the person seeks in relation to emotional wellbeing in order to get the right fit of support or intervention for the person.
Timeliness	The person and carer can obtain the most benefit from the right form of emotional support at the right time. For example, counselling soon after diagnosis can be helpful for the person and carer, while an intervention like family therapy may be helpful when difficult decisions have to be made.

6.7. Summary of the PDS Pathway

In contrast to the diagnostic pathway, it is not appropriate to 'prescribe' a standardised single pathway for post-diagnostic support. People have different individual needs and life circumstances which prohibit a highly standardised pathway. People may also be diagnosed at any point on the dementia continuum, with early symptoms or quite advanced symptoms. The range of supports in the five strands has been described to take account of this. In addition, the concept of 'tiers' of support is set out in this 'pathway', along with possible target groups for whom these supports may be appropriate. This diagram also takes into account existing service infrastructure that may be appropriate. The tiers are not exclusive but are based on the assumption that someone with complex needs, which directs them to Tier 2 or Tier 3, should also be given the opportunity to access supports and interventions from the other tiers.

As with all parts of the Dementia Model of Care, this pathway is dynamic, to take account of changing needs. As set out in the model, regular review is required to ensure that post-diagnostic support is relevant over time and so that the person with dementia and carer / supporter have opportunities to access different supports and interventions as their needs change. This is described in the section on care planning.

Table 20: Sample PDS pathway including level of support, potential support and target groups

Level of support	Potential settings and services	'Target' groups
Tier 1 Support	• Community-based supports such as Dementia cafés • Community champions and related activities in *Understand Together in Communities* programme • Dementia Advisers • Peer support groups, social clubs, carer training • Cognitive rehabilitation connected to MASS or MTRR • GP, primary care team and others (for health promotion and information)	• First line of 'referral' for people with MCI and mild symptoms of dementia • Valuable source of support for people with moderate symptoms of dementia • Relevant for all carers / supporters of people with dementia
	• MASS • MTRR – CR and early AT • GP, Primary care and Integrated care	
Tier 2 Support	• MASS • MTRR • Members of primary care teams • Counselling in primary care service • Dementia Advisers • Day care • Personalised home care	• First line of 'referral' for people with moderate and advanced symptoms of dementia • Some interventions may be relevant for people with early symptoms of dementia • Supports that should also be provided to / available for people in residential care
	• MASS • MTRR – CR and early AT • GP, Primary Care and Integrated Care	
Tier 3 Support	• Community Specialist Teams for older people (ICPOP) • Ambulatory care hub • Mental Health Services for Older People • 'Intermediary care' (e.g. personalised home care) • Palliative care teams	• For all people with dementia as needs increase and / or become more complex

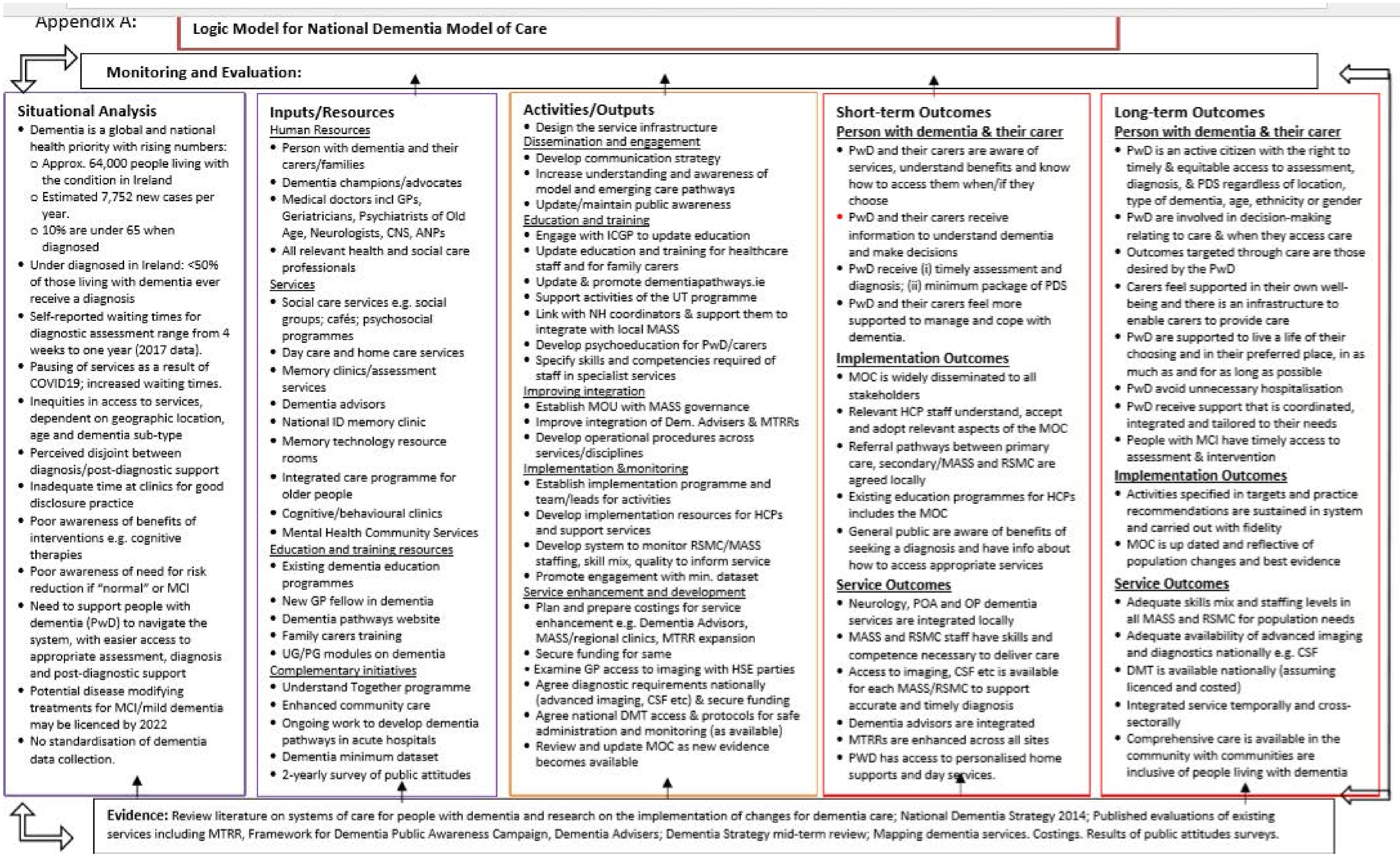
Table 21: Summary of post-diagnostic targets and practice recommendations

Post-diagnostic Targets	
Target 28	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 29	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 30	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 31	Every home care assistant caring for someone with dementia should have undertaken QQI accredited training of dementia. This requirement should be linked to the HSE's home care tender for private / voluntary providers.
Target 32	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 33	Every MTRR should be staffed by at least one senior full-time OT 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. Synergies between the MTRR and MASS/RSMC's should be encouraged as part of the post diagnostic pathway.
Target 34	Assistive technologies are currently not funded under existing funding streams such as aids and appliances, nor are they available on the medical card. A funding model for AT should be developed to support greater access to and use of AT.
Target 35	Updated guidance on the use of AT is required to ensure the optimum use of such technologies in supporting people with dementia. This guidance should also cover the deployment of telecare and telehealth technologies to support people with dementia.
Target 36	A family carer needs assessment should be carried out to identify the needs of family carers (if there is a carer involved) which informs the development and delivery of a carer support plan.
Target 37	100% of supporters / family carers of people with dementia should be informed about and offered education and skills training.

Post-diagnostic Practice Recommendations
Timely access to post-diagnostic support is considered, based on the needs and preferences of the person and carer / supporter (where appropriate), regardless of age, dementia subtype and geographical location. Restrictions should be based on suitability for the person (e.g. MCI or dementia) rather than age-based. Post-diagnostic support should be tailored as required for younger age groups.
All supports recommended and received should be documented in the care plan.
The Dementia: Understand Together programme will grow as a collaborative and networking model effecting change, with the voice of people living with dementia at the centre.
The Dementia: Understand Together programme is an important medium for communicating key messages about dementia, brain health and emerging disease modifying factors and treatments.
A programme of work is to be undertaken to translate the most commonly used dementia information materials to other languages to ensure accessibility for people where English is not their first language.

APPENDICES

Appendix A:



Appendix A: **Logic Model for National Dementia Model of Care**

Monitoring and Evaluation:

Situational Analysis
- Dementia is a global and national health priority with rising numbers:
  - Approx. 64,000 people living with the condition in Ireland
  - Estimated 7,752 new cases per year.
  - 10% are under 65 when diagnosed
- Under diagnosed in Ireland: <50% of those living with dementia ever receive a diagnosis
- Self-reported waiting times for diagnostic assessment range from 4 weeks to one year (2017 data).
- Pausing of services as a result of COVID19; increased waiting times.
- Inequities in access to services, dependent on geographic location, age and dementia sub-type
- Perceived disjoint between diagnosis/post-diagnostic support
- Inadequate time at clinics for good disclosure practice
- Poor awareness of benefits of interventions e.g. cognitive therapies
- Poor awareness of need for risk reduction if "normal" or MCI
- Need to support people with dementia (PwD) to navigate the system, with easier access to appropriate assessment, diagnosis and post-diagnostic support
- Potential disease modifying treatments for MCI/mild dementia may be licenced by 2022
- No standardisation of dementia data collection.

Inputs/Resources

Human Resources
- Person with dementia and their carers/families
- Dementia champions/advocates
- Medical doctors incl GPs, Geriatricians, Psychiatrists of Old Age, Neurologists, CNS, ANPs
- All relevant health and social care professionals

Services
- Social care services e.g. social groups; cafés; psychosocial programmes
- Day care and home care services
- Memory clinics/assessment services
- Dementia advisors
- National ID memory clinic
- Memory technology resource rooms
- Integrated care programme for older people
- Cognitive/behavioural clinics
- Mental Health Community Services

Education and training resources
- Existing dementia education programmes
- New GP fellow in dementia
- Dementia pathways website
- Family carers training
- UG/PG modules on dementia

Complementary initiatives
- Understand Together programme
- Enhanced community care
- Ongoing work to develop dementia pathways in acute hospitals
- Dementia minimum dataset
- 2-yearly survey of public attitudes

Activities/Outputs
- Design the service infrastructure

Dissemination and engagement
- Develop communication strategy
- Increase understanding and awareness of model and emerging care pathways
- Update/maintain public awareness

Education and training
- Engage with ICGP to update education
- Update education and training for healthcare staff and for family carers
- Update & promote dementiapathways.ie
- Support activities of the UT programme
- Link with NH coordinators & support them to integrate with local MASS
- Develop psychoeducation for PwD/carers
- Specify skills and competencies required of staff in specialist services

Improving integration
- Establish MOU with MASS governance
- Improve integration of Dem. Advisers & MTRRs
- Develop operational procedures across services/disciplines

Implementation &monitoring
- Establish implementation programme and team/leads for activities
- Develop implementation resources for HCPs and support services
- Develop system to monitor RSMC/MASS staffing, skill mix, quality to inform service
- Promote engagement with min. dataset

Service enhancement and development
- Plan and prepare costings for service enhancement e.g. Dementia Advisors, MASS/regional clinics, MTRR expansion
- Secure funding for same
- Examine GP access to imaging with HSE parties
- Agree diagnostic requirements nationally (advanced imaging, CSF etc) & secure funding
- Agree national DMT access & protocols for safe administration and monitoring (as available)
- Review and update MOC as new evidence becomes available

Short-term Outcomes

Person with dementia & their carer
- PwD and their carers are aware of services, understand benefits and know how to access them when/if they choose
- PwD and their carers receive information to understand dementia and make decisions
- PwD receive (i) timely assessment and diagnosis; (ii) minimum package of PDS
- PwD and their carers feel more supported to manage and cope with dementia.

Implementation Outcomes
- MOC is widely disseminated to all stakeholders
- Relevant HCP staff understand, accept and adopt relevant aspects of the MOC
- Referral pathways between primary care, secondary/MASS and RSMC are agreed locally
- Existing education programmes for HCPs includes the MOC
- General public are aware of benefits of seeking a diagnosis and have info about how to access appropriate services

Service Outcomes
- Neurology, POA and OP dementia services are integrated locally
- MASS and RSMC staff have skills and competence necessary to deliver care
- Access to imaging, CSF etc is available for each MASS/RSMC to support accurate and timely diagnosis
- Dementia advisors are integrated
- MTRRs are enhanced across all sites
- PWD has access to personalised home supports and day services.

Long-term Outcomes

Person with dementia & their carer
- PwD is an active citizen with the right to timely & equitable access to assessment, diagnosis, & PDS regardless of location, type of dementia, age, ethnicity or gender
- PwD are involved in decision-making relating to care & when they access care
- Outcomes targeted through care are those desired by the PwD
- Carers feel supported in their own well-being and there is an infrastructure to enable carers to provide care
- PwD are supported to live a life of their choosing and in their preferred place, in as much as and for as long as possible
- PwD avoid unnecessary hospitalisation
- PwD receive support that is coordinated, integrated and tailored to their needs
- People with MCI have timely access to assessment & intervention

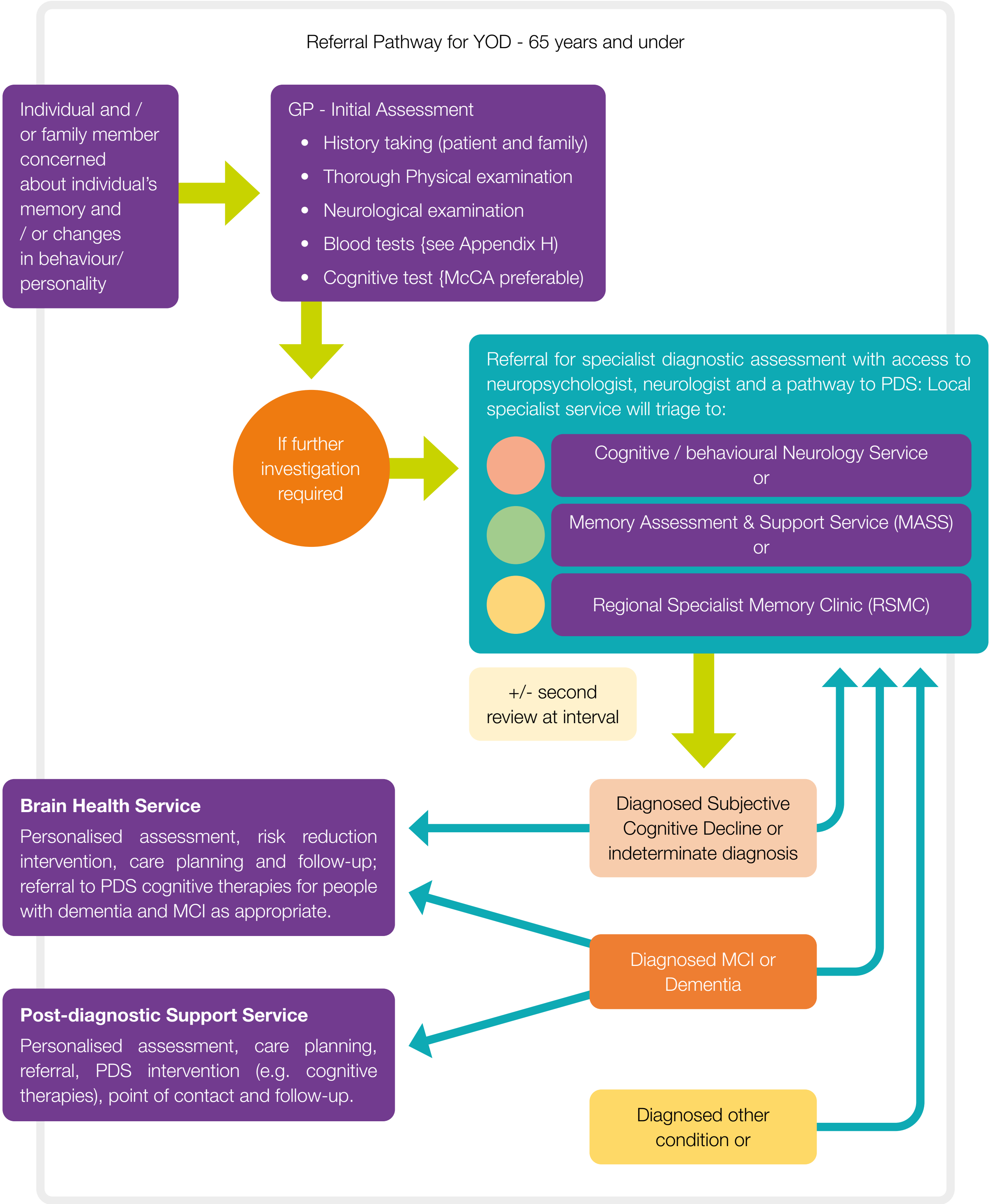
Implementation Outcomes
- Activities specified in targets and practice recommendations are sustained in system and carried out with fidelity
- MOC is up dated and reflective of population changes and best evidence

Service Outcomes
- Adequate skills mix and staffing levels in all MASS and RSMC for population needs
- Adequate availability of advanced imaging and diagnostics nationally e.g. CSF
- DMT is available nationally (assuming licenced and costed)
- Integrated service temporally and cross-sectorally
- Comprehensive care is available in the community with communities are inclusive of people living with dementia

Evidence: Review literature on systems of care for people with dementia and research on the implementation of changes for dementia care; National Dementia Strategy 2014; Published evaluations of existing services including MTRR, Framework for Dementia Public Awareness Campaign, Dementia Advisers; Dementia Strategy mid-term review; Mapping dementia services. Costings. Results of public attitudes surveys.

Appendix B:

Referral pathway for young onset dementia (people aged under 65 years)



Referral Pathway for YOD - 65 years and under

Individual and / or family member concerned about individual's memory and / or changes in behaviour/ personality

GP - Initial Assessment

- History taking (patient and family)
- Thorough Physical examination
- Neurological examination
- Blood tests {see Appendix H)
- Cognitive test {McCA preferable)

If further investigation required

Referral for specialist diagnostic assessment with access to neuropsychologist, neurologist and a pathway to PDS: Local specialist service will triage to:

Cognitive / behavioural Neurology Service
or

Memory Assessment & Support Service (MASS)
or

Regional Specialist Memory Clinic (RSMC)

+/- second review at interval

Diagnosed Subjective Cognitive Decline or indeterminate diagnosis

Diagnosed MCI or Dementia

Diagnosed other condition or

Brain Health Service

Personalised assessment, risk reduction intervention, care planning and follow-up; referral to PDS cognitive therapies for people with dementia and MCI as appropriate.

Post-diagnostic Support Service

Personalised assessment, care planning, referral, PDS intervention (e.g. cognitive therapies), point of contact and follow-up.

Appendix C:

Appropriate use of CSF testing

(content provided by National Clinical Programme for Neurology (NCPN))

Cerebrospinal fluid analysis has long been deployed in the neurological work-up of rapidly progressive dementias to exclude or confirm aetiologies such as prion disease, autoimmune/paraneoplastic encephalitis, vasculitis or subacute infective processes. However, the last decade has seen CSF analysis incorporated into routine work-up for patients presenting with MCI. Quantification of CSF ß-amyloid, phospho-tau and total-tau are validated biomarkers in the distinction of AD disease pathology from a non-Alzheimer's disease process. This is now reflected in numerous position papers (Jack et al. 2016) and clinical guidelines, such as those published in 2018 by an expert workgroup convened by the Alzheimer's Association (Shaw et al. 2018). The latter suggested that six particular indications represented appropriate use of CSF testing:

1. Patients with subjective cognitive complaints (cognitively unimpaired based on objective testing) but who are considered to be at increased risk for AD.
2. MCI that is persistent, progressing, and unexplained.
3. Patients with symptoms that suggest possible AD.
4. MCI or dementia with an onset at an early age (<65).
5. Meeting core clinical criteria for probable Alzheimer's disease with typical age of onset.
6. Patients whose dominant symptom is a change in behaviour (e.g. Capgras Syndrome, paranoid delusions, unexplained delirium, combative symptoms, and depression) and where AD diagnosis is being considered.

The use of CSF analysis has particular discriminatory value in predicting whether AD is the underlying pathology in patients presenting with behavioural/dysexecutive symptoms, language or visuo-perceptual disturbances and should always be considered in patients presenting with these syndromes (Miller et al. 2016).

Strong consideration should also be given to CSF AD biomarker quantitation in patients considered to have a vascular basis to their cognitive syndrome, particularly where this is based on imaging findings. Microvascular change is common and a diagnosis of AD or mixed AD/VaD may be missed unless consideration is given to a neuro-degenerative process underlying the cognitive presentation, as this will thereafter influence management.

CSF AD biomarker analysis is also occasionally used to assess for AD co-pathology in patients with Lewy body dementias as the presence of the latter has prognostic value, albeit does not typically alter management (Ferreira et al. 2020). Estimation of CSF neuro-filament light (NfL) chain levels are likely to also be incorporated as markers of neuro-degeneration in future clinical and research criteria in dementia; for example, to satisfy the 'N' criteria in the A/T/N framework (Jack et al. 2016), and in the distinction of FTD from FTD psychiatric 'phenocopies'. It is also likely that newer techniques such as RT-QuIC will hasten protein-specific diagnostics in prodromal or early symptomatic patients with pre-motor symptoms of Parkinson's disease and atypical Parkinsonian syndromes. As such, whilst CSF biomarker analysis should be considered for many patients presenting with cognitive symptoms, particularly in those whose management may be altered immediately or in the short-term by potential access to clinical trials or licensed disease-modifying treatments (DMTs), its appropriate use should best be directed at MASS or RSMC level with neurology expertise in guiding the appropriate selection of cases and result interpretation.

Appendix D:

Genetic testing

(content provided by National Clinical Programme for Neurology (NCPN))

Loy et al. (2014) outlines that 25% of all people aged 55 years and older have a family history of dementia, stating that for many the family history is due to genetically complex disease, where "many genetic variations of small effect interact to increase risk of dementia" (pp 828). This polygenic effect cannot currently be characterised and does not impact upon clinical practice.

In a small number of families there will be an autosomal dominant family history of early-onset dementia. Loy et al. (2014) states that this is often due to mendelian (monogenic) disease, caused by a mutation in a dementia gene. With the potential for future Disease Modifying Treatments, a greater onus will be placed on identifying individuals who may be suitable for future treatments. Knowledge of at-risk or carrier status will also have significant impact on numerous life decisions such as financial affairs and family planning.

Genetic testing is fraught with potential pitfalls and should only be considered with neurology experience and expertise. The Huntington's Disease Society of America's 'Guidelines for Genetic Testing for Huntington's Disease (HD)' is considered by many to be the gold standard for genetic testing for adult onset neuro-degenerative conditions.

In practice, a ≥3-generation family history should be obtained, with specific attention to the age of onset of any neurologic and / or psychiatric symptoms, type of dementia and method of diagnosis, current ages, or ages at death (especially unaffected relatives), and causes of death. Age of onset is a key consideration. For example, a person who develops Alzheimer's disease under the age of 60, with affected family members across three generations, has an 86% risk of a mendelian gene causing the disease (Rovelet-Lecrux et al. 2016). By contrast, an individual with Alzheimer's disease onset over 65 years, with two first-degree relatives with similar presentations, only have a 1% risk of the same.

APP, PSEN1 or PSEN2 are the three known causative genes for Alzheimer's disease. Whilst an association between the APOE ε4 allele with Alzheimer's disease is well recognised, because the ε4 allele is neither necessary nor sufficient to cause AD, numerous consensus statements and articles have recommended against using APOE genotyping for predicting Alzheimer's disease risk.

FTD is a much more heritable disorder, with 10–30% of patients having autosomal dominant family histories. However, clinically, it can be very heterogeneous and therefore demands careful ascertainment of family history, including psychiatric history. Three causative genes explain over 80% of cases of frontotemporal dementia in families with a strong autosomal dominant family history: MAPT, GRN, and C9orf72. In a UK study, 88% of patients with the strongest autosomal dominant family history carried such mutations (Rohrer et al. 2009). These families were characterised as having at least three affected family members in two generations specifically with frontotemporal dementia, motor neuron disease, or one of the Parkinson's plus syndromes (corticobasal syndrome or progressive supranuclear palsy). Additionally, one affected person must also be a first-degree relative of the other two affected family members. For the patient group in which three or more family members had dementia in general, but not satisfying the aforementioned criteria, 41% had mutations. The probability of finding a mutation for patients with only one family member with dementia depended on the age of onset of the relative. 31% of patients with one relative with dementia before the age of 65 years had mutations. By contrast, only 13% of patients with one relative with dementia after the age of 65 years had mutations.

The American College of Medical Genetics and the National Society of Genetic Counsellor's 2011 guidance for genetic testing in suspected familial Alzheimer's disease (Goldman et al. 2011) underscores the importance of clinical experience and expertise in genetic testing and the availability of genetic counselling, suggesting:

- Genetic testing for AD should only occur in the context of genetic counselling and support by someone with expertise in this area.
- Symptomatic patients: Genetic counselling for symptomatic patients should be performed in the presence of the individual's decision support representative or family member.
- Asymptomatic patients: A protocol based on the International Huntington's Association and World Federation of Neurology Research Group on Huntington's Chorea Guidelines is recommended.

Overall, given the specialty's broad experience and expertise in the process of testing for and diagnosing genetic conditions, genetic testing in dementia should only be conducted at a MASS or RSMC with neurology expertise.

Appendix E:

Cognitive assessment tools and recommended investigations

Table i: Cognitive assessment tools for primary care, adapted from Foley et al. 2019

Mini-Mental State Examination (MMSE) (Folstein et al. 1975)	The MMSE measures orientation, immediate memory, attention and calculation, recall, various aspects of language and visuo-spatial skills. However, it shows age, cultural and educational bias. Scored out of 30, a score of <24 may in some cases indicate dementia. It may take up to 10 minutes to complete. There are copyright restrictions on the use of the MMSE.
General Practitioner Assessment of Cognition (GPCOG) **(Brodaty et al. 2002)**	Unlike other brief assessment instruments, the GPCOG consists of a four-component patient assessment and a brief informant interview (six questions), specifically designed for use in primary care. Taking five minutes to complete, it is psychometrically robust, and relatively free of educational bias. It includes orientation to time, a clock drawing task, report of a recent event and a word recall task.
Mini-Cognitive Assessment Instrument (Mini-Cog) **(Borson et al. 2000)**	A brief assessment tool designed for primary care use, it assesses two aspects of cognition: short-term recall and clock drawing. It takes 3–5 minutes to complete and performs comparably to the GPCOG, also being relatively free of educational bias.
Memory Impairment Screen (MIS) **(Buschke et al. 1999)**	This is a 4-item assessment test that takes approximately four minutes to complete. The MIS is especially appropriate for use with ethnic minorities, as it does not show educational or language bias.
Montreal Cognitive Assessment (MoCA) **(Nasreddine et al. 2005)**	This is a short cognitive assessment tool with high sensitivity for detecting early cognitive impairment. It is particularly useful in discriminating between individuals with MCI and normal cognitive functioning, and the cognitive domains assessed are useful for people with non-AD dementia. It takes at least 10 minutes to complete and its specificity is relatively low.

Table ii: Recommended investigations in primary care

Routine Blood Screen	FBC	LFT	Serum Folate and B12
	ESR/CRP	TFT	Iron Profile
	U&E	Fasting Glucose	Vitamin D
	EGFR	HbA1c (if diabetic)	
	Fasting LipidsSyphilis Serology and HIV testing if considered at risk	Calcium	
Medical Investigations	Chest X-Ray and MSU if clinically indicated		
Brain Imaging	• MRI brain scan is the usual imaging modality; request MRI with coronal view of the hippocampi, i.e. coronal and sagittal cuts; T1 and T2 weighted imaging; FLAIR; gradient echo; and diffusion weighted imaging. • CT brain is indicated for selected cases (e.g. contraindication to MRI; where accessing MRI would cause unnecessary burden relative to benefit)		

Table iii: Level 2: Cognitive assessment tools and dementia-relevant screening tools

Informant Questionnaires	• Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) • The Alzheimer's Questionnaire (AQ) • Dementia Screening Interview (AD8) • Cambridge Behavioural Inventory (CBI)
Cognitive Assessment Tools[8]	Brief cognitive assessment (10 mins): • Montreal Cognitive Assessment (MoCA) • Mini-Mental State Examination (MMSE) Comprehensive assessment tools: • Addenbrooke's Cognitive Examination (ACE-III) • Rowland Universal Dementia Assessment Scale (RUDAS) Complementary measures to further probe targeted cognitive domains: • Delayed Word Recall test (DWR) • Verbal Fluency Test (VFT) • Frontal Assessment Battery (if suspected FTD/ dysexecutive syndrome)
Clinical Observations	• Weight and Height – Body mass index (BMI) • Pulse / blood Pressure/O2 Sats/Respirations
Delirium Screening	• Rapid clinical test for delirium (4AT)
Mood, Behaviour and Non-Cognitive Screening	• Geriatric Depression Scale (GDS) if cognition is reasonable • Hospital Anxiety and Depression Scale (HADS) • Cornell Scale for Depression in Dementia (CSDD) if cognition is poor (both person and carer rate items) • Neuropsychiatric Inventory Questionnaire (NPI-Q; carer-rated) • Cambridge Behavioural Inventory (CBI)
Functional Assessment	• The Lawton-Brody Instrumental Activities of Daily Living (IADL) scale • Barthel Index • Physical Self-Maintenance Scale (PSMS)
Nutritional Screening	• The Mini Nutritional Assessment (MNA) • Malnutrition Universal Screening Tool (MUST)
NCSD Assessment	• Neuropsychiatric Inventory Questionnaire (NPI-Q) • Cohen Mansfield Agitation Inventory (CMAI)
Carer Status	• Zarit Burden Interview (ZBI)

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[8] The MMSE, MoCA and ACE-III are not interchangeable and the decision to employ one over the other should be informed by the case review at the Triage/Step 1 and by presentation on testing. When using the MMSE or MoCA, scores must be interpreted with reference to existing Irish demographic corrected norms (Kenny et al. 2013). There is also a requirement to register and train to use the MoCA in a clinical setting.

Table iv: Level 3: Cognitive assessment tools and relevant screening tools

Informant Questionnaires	• Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) • The Alzheimer's Questionnaire (AQ) • Dementia Screening Interview (AD8) • Mayo Sleep Questionnaire (MSQ) • Cambridge Behavioural Inventory (CBI)
Physical Observations	• Weight and Height – Body mass index (BMI) • Pulse / blood Pressure/O2 Sats/Respirations
Cognitive Assessment Tools[9]	Brief assessment: • Montreal Cognitive Assessment (MoCA) • Mini-Mental State Examination (MMSE) Comprehensive assessment: • Addenbrooke's Cognitive Examination (ACE-III) • Rowland Universal Dementia Assessment Scale (RUDAS) Complementary measures to further probe targeted cognitive domains: • Delayed Word Recall test (DWR) • Verbal Fluency Test (VFT) • Frontal Assessment Battery (if suspected FTD/dysexecutive syndrome)
Neuropsychological Assessment	The selection of neuropsychological tests should be decided by the neuropsychologist involved in the case, based on factors such as reason for referral, initial cognitive assessment findings, and brain imaging if already conducted. Examples of tests include the Repeatable Battery for the Assessment of Neuropsychological Status (RBANS).
Delirium Screening	• Rapid clinical test for delirium (4AT)
Mood, Behaviour and Non-Cognitive Screening	• Geriatric Depression Scale (GDS) if cognition is reasonable • Hospital Anxiety and Depression Scale (HADS) • Cornell Scale for Depression in Dementia (CSDD) if cognition is poor (both person and carer rate items) • Neuropsychiatric Inventory Questionnaire (NPI-Q; carer-rated) • Cambridge Behavioural Inventory (CBI)
Nutritional Screening	• The Mini Nutritional Assessment (MNA) • Malnutrition Universal Screening Tool (MUST)
Functional Assessment	• The Lawton-Brody Instrumental Activities of Daily Living (IADL) scale • Barthel Index • Physical Self-Maintenance Scale (PSMS) • The Assessment of Motor and Process Skills (AMPS) • The Naturalistic Action Test (NAT)
NCSD Assessment	• Neuropsychiatric Inventory Questionnaire (NPI-Q) • Cohen Mansfield Agitation Inventory (CMAI)
Carer Stress	• Zarit Burden Interview (ZBI)

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[9] The MMSE, MoCA and ACE-III are not interchangeable and the decision to employ one over the other should be informed by the case review at the Triage/Step 1 and presentation on testing. When using the MMSE or MoCA, scores must be interpreted with reference to existing Irish demographic corrected norms (Kenny et al. 2013). There is also a requirement to register and train to use the MoCA in a clinical setting.

Appendix F:

Advisory Group and Consultant Groups

Name	Title	Organization
Ms. Mary Manning (Chair)	General Manager	National Dementia Office
Dr. Helen Rochford Brennan	Expert by experience	Irish Dementia Working Group
Prof. Sean Kennelly	Geriatrician	Tallaght Hospital and Clinical Partner on ID and Dementia Project
Ms. Ann Twomey	Family carer	Dementia Carers Campaign Network
Dr. Siobhan Hutchinson	Neurologist	St James's Hospital
Ms. Catherine Daly	Occupational Therapist	HSE, Primary Care South Dublin
Ms. Sharon Richardson	Dementia Project Manager	HSE, CHO 1
Dr. Ronan O'Caoimh	Geriatrician	Mercy Hospital Cork
Ms. Susan O'Reilly	RANP	Connolly Hospital, Dublin
Ms. Samantha Taylor	Head of Risk, Compliance & Dementia Advisory Services	Alzheimer Society of Ireland
Ms. Anne Quinn	Dementia Nurse Specialist	HSE, Clonmel Living Well with Dementia
Dr. PJ Hartnett	General Manager of the ICPOP programme	Health Service Executive
Dr. Sarah Donnelly	Social Worker/Lecturer	University College Dublin
Dr. Tony Foley	GP	ICGP
Dr. Suzanna Dooley	Speech & Language Clinical Specialist	Loughlinstown Hospital
Ms. Teresa Stenson / Ms. Mary McKeon	Dietitian	Nutrition & Dietetic Rep
Prof. Geraldine Mc Carthy	Psychiatrist of Old Age	Sligo Mental Health Services
Dr. Bill Fox	Psychologist	POA, neurology and gerontology
Dr Siobhan Kennelly	Consultant Geriatrician	Clinical Lead for HSE Older Persons Clinical Programme
Prof. Suzanne Timmons	Geriatrician & Clinical Lead (NDO and MoC content development group)	National Dementia Office
Mr Matthew Gibb	Director (member of MoC content development group)	Dementia Services Information and Development Centre
Ms. Grace Kelly	Dementia Nurse Consultant, Co. Donegal (member of MoC content development group)	N/A
Dr. Fiona Keogh	Senior Research Fellow (member of MoC content development group)	Centre for Economic and Social on Dementia, Nui Galway
Dr. Emer Begley	Project Lead & content development group	National Dementia Office

During the development of the Model of Care and the previous Diagnostic and Post-diagnostic Projects consultations were held with the following groups:

- Irish Dementia Working Group
- Division of Neuropsychology
- Faculty of Psychiatry of Old Age
- Neurology Group
- St James's Memory Clinic
- Irish Association of Speech and Language Therapists
- Clinicians group engaged / interested in Brain Health
- Meath and Louth Memory Clinics
- Memory Technology Resource Room Project Lead
- Dementia Understand Together National Coordinator
- National Office Human Rights and Equality Policy, HSE
- Integrated Care Programme for Older People

Diagnostic Project Steering Committee (2017-2019)

Name	Title	Organization
Dr. John Linehan (Chair)	Specialist	Older Person Services , HSE
Prof Brian Lawlor	Consultant Old Age Psychiatrist	St James Hospital, Dublin
Dr. Rónán O' Caoimh	Consultant Geriatrician	University Hospital Galway/Mercy University Hospital Cork
Dr. Sean Kennelly	Consultant Physician	Tallaght Hospital, Dublin
Ms. Aine Coe	OT	Naas General Hospital
Dr. Alberto Blanco	Senior Clinical Psychologist / Neuropsychologist	Memory Clinic Services Louth / Meath
Dr. Suzanna Dooley	Speech and Language Therapist	Dept of Clinical Speech and Language Studies, TCD
Ms. Evelyn Reilly	Clinical Nurse Specialist Dementia	Intellectual Disability
Dr. Aisling Denihan	Consultant Psychiatrist	Older Person Services
Ms. Aisling Coffey	Principal Social Worker	St. Mary's Hospital, Dublin
Ms. Mairead Creed	Assistant Principal Officer	Services for Older People, Department of Health
Dr. Helen Rochford Brennan	Expert by Experience	Irish Dementia Working Group
Ms. Susan O'Reilly	Dementia Nurse Specialist	Connolly Hospital, Dublin
Ms. Catherine Daly	Occupational Therapist	Rathfarnham Primary Care Team, HSE
Dr. Siobhan Hutchinson	Consultant Neurologist	St. James Hospital, Dublin
Dr. Brian Meade	GP	Irish College of General Practitioners
Dr. Justin Kinsella	Neurologist	St. Vincent's Hospital
Ms. Nuala O Connell	Family Carer	Dementia Carers Campaign Network
Mr. Pat McLoughlin	CEO	Alzheimer Society of Ireland
Ms. Patricia Barr	Service Manager	CHO1 Community Hearing Service
Mr. Sean Brennan	Senior Clinical Psychologist	HSE
Mr. Matthew Gibb	Director	DSiDC
Ms Anna de Suin	Project Lead	National Dementia Office
Prof. Suzanne Timmons	Clinical Lead	National Dementia Office

Post-diagnostic Support Project Steering Committee (2017-2019)

Name	Title	Organization
Ms. Kathy Ryan	Expert by Experience	Irish Dementia Working Group
Prof. Suzanne Timmons	Clinical Lead / Geriatrician	University College Cork and Mercy University Hospital and National Dementia Office, HSE
Ms. Judy Williams	Family carer	Dementia Carers Campaign Network
Dr. Tony Foley	General Practitioner	University College Cork and PREPARED Project
Ms. Joyce Jones	Occupational Therapist	Loughlinstown Hospital
Ms. Siobhan Cahill	Community Dementia Care Co-coordinator	St Finbar's Hospital, Cork
Ms. Grace Kelly	RANP	Mental Health Services, Donegal
Mr. Matthew Gibb	Social Worker and Director	Dementia Services Information and Development Centre
Ms. Samantha Taylor	Clinical Lead for HSE Older Persons Clinical Programme	The Alzheimer Society of Ireland
Ms. Mairead Creed	Services for Older People	Department of Health
Ms. Helena McGuire	Primary Care Specialist	Health Service Executive
Dr. Brian Creedon	National Clinical Lead for Palliative Care	Health Service Executive
Ms. Aideen Lawlor	Speech and Language Therapist	St Mary's, Dublin North city, HSE
Prof Mary McCarron	ID specialist	Trinity College Dublin
Ms. Mary Manning (Chair)	General Manager	National Dementia Office
Dr. Emer Begley	Project Lead	National Dementia Office

Dementia Workstream Group (2023-present)

Name	Title	Organization
Sean O'Dowd	NDO Clinical Lead	National Dementia Office HSE
Janette Dwyer	Assisstant National Director	Services for Older People, Change & Innovation, HSE
Andy Heffernan	CEO	Alzheimer's Society of Ireland
Dr Marwa Elamin	Consultant Neurologist	Galway University Hospital
Dr Tim Dukelow	Consultant Geriatrician	Mercy University Hospital, Cork
David Hanlon	National Clinical Advisor Primary Care	HSE
Frank Morrison	Head of Service Older Persons	HSE, CHO 1
Emer Ahern	NCAGL Older Persons	Clinical Design & Innovation, HSE
Susan Kenny	General Manager Home Support	HSE
Deirdre Lang	Director of Nursing/National Lead Older Persons Services/Clinical & Integrated Programmes	HSE
Matthew Gibb	Director of DSiDC and MSW	DSiDC and St James's Hospital, Dublin
Prof. Geraldine McCarthy	Consultant in Psychiatry of Old Age	HSE, CHO 1
Maria Barry	General Manager	Tipperary University Hospital
Stephan Murphy	QI ADON	University Hospital Limerick
Paul Maloney	Programme Manager	National Dementia Office

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Background and Principles
Dementia Diagnostic Model
Dementia Assessment and Diagnostic Pathway
Giving a Diagnosis of Dementia
Care Planning and Immediate Post-Diagnostic Support
Dementia Post-Diagnostic Support
Appendices