

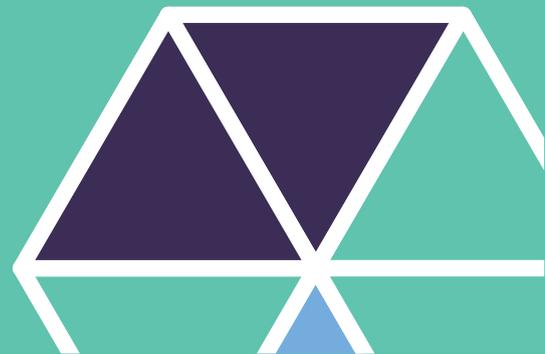


## DEMENTIA CARE IN PRIMARY CARE

- AN INTERPROFESSIONAL APPROACH -

# A GUIDE FOR WORKSHOP FACILITATORS

## Revision 1- 2020



# Facilitator's Workshop Guide

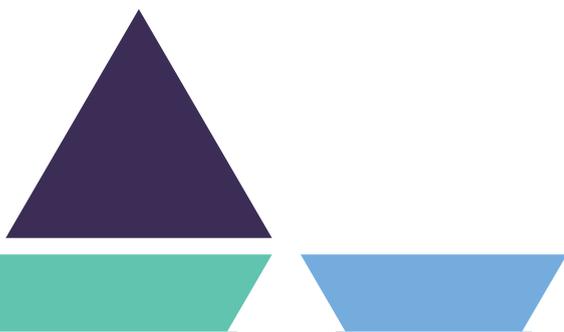
Whilst every effort has been made by the authors to ensure the accuracy of the information and material contained in this document, errors or omissions may occur in the content. This guidance represents the view of the authors, which was arrived at after careful consideration of the evidence available at time of publication. This document is in the public domain and may be used and reprinted without permission except those copyrighted materials that are clearly noted in the document. Further reproduction of those copyrighted materials is prohibited without the specific permission of copyright holders.

Suggested Citation: Quinn A, McLoughlin K, Thackeray K, Jennings A, Boyle S and Foley T. *Dementia Care in Primary Care – An Interprofessional Approach: Facilitator's Workshop Guide*. Primary Care Education, Pathways and Research of Dementia (PREPARED), University College Cork, 2017.

Originally developed as part of the **PREPARED** project (NDS, 2014) **PRIMARY CARE, EDUCATION, PATHWAYS AND RESEARCH OF DEMENTIA** (National Dementia Strategy, 2014). The Department of General Practice, University College Cork.

*This is the first review of the programme. It was commissioned on behalf of National Dementia Office and undertaken by Grace Kelly, Dementia Training & Consultancy in 2020.*

*The review incorporates feedback from surveys and interviews with programme facilitator's; participants; and key stakeholders from primary care.*



## > About PREPARED

The PREPARED project (Primary Care Education, Pathways and Research of Dementia) was based in the Department of General Practice in University College Cork (UCC) and was a collaboration between the Department of General Practice, the Irish College of General Practitioners (ICGP) and Dublin City University (DCU). PREPARED aimed to support GPs and Primary Care Team healthcare professionals nationally in the delivery of integrated, multidisciplinary dementia care.

The PREPARED project was jointly funded by the Atlantic Philanthropies and the Health Service Executive (HSE) as part of the Irish National Dementia Strategy.

## > Contact Details for the National Dementia Office

Dementia.office@hse.ie  
www.dementiapathways.ie

## > Acknowledgements

### Revision 1

On behalf of the National Dementia office we would like to acknowledge and thank the following people who reviewed/contributed to the revision of the programme

Grace Kelly Dementia Training and Consultancy.

Anne Quinn RGN RNP RANP Dementia.

Programme Facilitators

Programme Participant's

The PREPARED team would also like to thank Trish O'Sullivan, Sheena Cadoo and Siobhan Cahill (HSE), as well as all of the healthcare professionals who participated in the workshop test sites in Kinsale, Co. Cork, Blackrock, Cork City and Cashel, Co. Tipperary. To colleagues at University College Cork and in the HSE National Dementia Office who reviewed the workshop material and offered us their invaluable, expertise (2017).

## > Contents:

Introduction .....	04
Background .....	06
Inter-professional learning and collaborative practice .....	06
About this guide.....	07
How to use this guide .....	07
Icon glossary .....	08
Final preparation: Suggested equipment & materials.....	08
Suggested timetable .....	09

### WORKSHOP

#### Dementia in Primary Care – An Inter-Professional Approach

Video clip .....	10
Case study – Tom. Parts 1, 2, 3 .....	45
Project ideas .....	58
Case study handouts.....	60
References .....	63

## Background

Population ageing across Europe means that the number of people living with dementia will grow in future decades with consequent implications for care provision, care burden and public expenditure. The stated aim of Irish government policy on dementia is to enable people living with dementia to remain living at home for as long as possible (1). However, empirical evidence suggests that people living with dementia, experience significant difficulty accessing appropriate community care services (2-7). Cahill et al found that services offered for people living with dementia in Ireland were fragmented, poorly coordinated, inflexible and inequitable (8). That being said, recent years have seen positive developments with the publication of a National Dementia Strategy (2014) and projects jointly funded by Atlantic Philanthropies and the HSE which thus far have been reviewed positively (1).

A National Dementia Education Needs Analysis undertaken by DCU in 2013/2014 reported knowledge gaps throughout the care trajectory and at all levels of expertise that had the potential to impact negatively on the care provided for people living with dementia. Furthermore, it indicated inconsistency in the presence of skills required to make alternative options realistic, or to use resources creatively, together with a need for an improved culture in which to embed change (9). The National Dementia Strategy seeks to address these issues through the identification of key principles to underpin and inform services provided to people living with dementia and their families and care partners. One of these key principles is that all staff engaging with people with dementia across all health and social care settings should be appropriately trained (1).

### Interprofessional Learning & Collaborative Practice

*'Many health workers believe themselves to be practicing collaboratively, simply because they work together with other health workers. In reality, they may simply be working within a group where each individual has agreed to use their own skills to achieve a common goal. Collaboration, however, is not only about agreement and communication, but about creation and synergy. Collaboration occurs when two or more individuals from different backgrounds with complementary skills interact to create a shared understanding that none had previously possessed or could have come to on their own. When health workers collaborate together, something is there that was not there before' (10).*

The World Health Organization (WHO) has highlighted the importance of interprofessional education and collaborative practice in developing a health workforce that is able to meet the complex health challenges facing the world (10). Research indicates that inter-professional education enables effective collaborative practice which in turn optimises health-services, strengthens health systems and improves health outcomes (11, 12). Patients have reported higher levels of satisfaction, better acceptance of care and improved health outcomes following treatment by a collaborative team (13).

Collaborative practice works best when it is organised around the needs of the population being served and takes into account the way in which local healthcare is delivered.

## ➤ About this guide

This guide is designed to assist workshop facilitators in the preparation, facilitation and evaluation of the dementia workshop, designed to be an interactive, inter-professional learning experience for members of Primary Care Teams. The guide contains workshop materials, including PowerPoint® presentation slides with supporting facilitator notes and detailed referenced explanatory notes.

The workshop content has been informed from several sources including a literature review of educational interventions in primary care and a needs analysis of allied healthcare professionals. The views of a sample of individuals from different disciplines working in local primary care teams were also sought. The workshop content is prepared for all community-based health professionals and is intended to ensure a general basic knowledge of dementia across the disciplines working in a primary care setting. It aims to support participants in reviewing relationships between their professions, enhance mutual understanding and explore ways to combine their expertise towards improving delivery of services for people living with dementia and their families.

The workshop content covers five areas:

- Knowledge of dementia
- Understanding roles and responsibilities
- Team functioning and collaboration
- Inter-professional communication skills
- Supporting the person with dementia and their family

This guide is not a comprehensive primary care dementia curriculum. Rather, the content of the training materials is based on prioritised dementia-specific educational needs of primary care and community-based health professionals. Other excellent educational resources are available, many of which we have referenced.

[www.dementiaphways.ie](http://www.dementiaphways.ie)

## ➤ How to use this guide

You will need to read the manual carefully before delivering the workshop and ensure that the key learning points for each slide are presented.

The PowerPoint® presentation consists of:

- Clinical information about dementia, prevalence, subtypes, symptoms, diagnosis and management.
- Case studies covering timely diagnosis of dementia and post diagnostic support, moderate and advanced dementia and symptom management, exploring the role of the interdisciplinary team in supporting the person living with dementia and their family
- Structured questions that can be explored through group work.

The format of the workshop was designed to be delivered as a three-hour workshop to small groups of staff in primary care teams (in one or two separate sessions). The workshop materials can be adapted to suit larger groups in different settings, or through webinar conferencing. In order to be delivered virtually, the facilitator will need to modify the elements of each workshop accordingly. Furthermore, the materials within the workshop guide can be adapted for individualised self-study.

## Icon glossary



### KEY POINTS

THESE ARE THE ESSENTIAL SUMMARY POINTS, TO BE DISCUSSED BY THE FACILITATOR WITH THE GROUP, ALONGSIDE EACH POWERPOINT® SLIDE



### BACKGROUND

THIS IS DETAILED INFORMATION THAT EXPLAINS AND SUPPORTS THE RATIONALE UNDERPINNING THE KEY POINTS



### REFERENCES AND BIBLIOGRAPHY

THESE REFERENCE LISTS SUPPORT THE FACTS WITHIN THE BACKGROUND INFORMATION



### GROUP DISCUSSION

THIS PROMPTS THE FACILITATOR TO INVITE A GROUP DISCUSSION ON A SPECIFIC, SALIENT QUESTION

## Workshop Preparation: Suggested Equipment and Material

### For the Workshop Facilitator:

- › PowerPoint® slides – USB stick and back up paper copy
- › Laptop
- › Projector
- › Copy of facilitator workshop guide
- › Attendance register
- › Name badges
- › Flipchart paper
- › Blutac
- › Markers

### For Workshop Participants:

- › Workshop evaluation questionnaires
- › Handouts of PowerPoint® slides
- › Copy of case study 1,2 and 3 for discussion
- › Handouts of accompanying literature, leaflets, online resources and initiatives

# WORKSHOP OVERVIEW

TOPIC	SUGGESTED TIME ALLOCATION
WELCOME AND INTRODUCTION (INCLUDING VIDEO, BACKGROUND TO PREPARED PROJECT, AND INTRODUCTION OF DEMENTIAPATHWAYS.IE WEBSITE)	25 MINUTES
OVERVIEW OF DEMENTIA	40 MINUTES
BREAK	15 MINUTES
CASE STUDY	70 MINUTES <ul style="list-style-type: none"> <li>• PART 1: 10 MINS GROUPWORK, 10 MINS DISCUSSION (INCLUDING LEARNING POINTS)</li> <li>• PART 2: 15 MINS GROUPWORK, 10 MINS DISCUSSION (INCLUDING LEARNING POINTS)</li> <li>• PART 3: 15 MINS GROUPWORK, 10 MINS DISCUSSION (INCLUDING LEARNING POINTS)</li> </ul>
DISCUSSION – ‘DEMENTIA PROJECT IDEAS’	25 MINUTES <ul style="list-style-type: none"> <li>• 15 MINUTES GROUPWORK</li> <li>• 10 MINUTES DISCUSSION</li> </ul>
SUMMARY, RESOURCES, CONTACTS, THANK YOU	5 MINUTES
TOTAL DURATION	180 MINUTES
NMBI CEU’s	3 CREDITS

SLIDE 1



- › Facilitator introduction and thank participants for making time to attend.
- › Introduce a short video clip about the PREPARED project that offers insight into living with dementia, caring for a person living with dementia and the roles of Primary Care and Health and Social Care Professionals in the community.
- › Video clip available: [Primary Care Pathways & Research of Dementia \(PREPARED\)](#)



- › Ask participants to introduce themselves and to share **one positive aspect of their role in providing care for the person living with dementia in the community and state one challenge.** Record these on flipchart paper. It is important that participants are asked to state these quickly as opposed to spending too long going into detail.
- › State that one of the aims of the workshop is that participants will gain a better understanding of each other's roles and use this knowledge to promote better outcomes for people living with dementia and their families.
- › Highlight that at the end of the workshop there will be time to look at 'project ideas' and to explore working more closely together in order to promote more of the positive interventions and address some of the challenges identified.
- › Emphasise the importance of dementia care in the community – increasing prevalence and human/ societal impact, and highlight the challenges and opportunities in the primary care setting.



Dementia is a topic of increasing concern because of a variety of factors, including increasing prevalence rates, the significant societal and human impact of dementia and because of rapidly rising costs to healthcare systems.

**PREVALENCE:**

- › Prevalence of dementia increases almost exponentially with age, nearly doubling every five years from the age of 65 years onwards. A report published in the UK stated that one in three people born in 2015 will develop dementia unless risk factors are controlled (14).
- › There is no register for incidence of dementia in Ireland. Estimates are based on OECD comparisons. Current estimates for people living with dementia in Ireland are over 64,142(15). Approximately 4,434 have early onset dementia – under 65 years (8).
- › People with a learning disability are at greater risk of developing dementia at a younger age.
- › Numbers are expected to rise to 150,131 by 2045 with dementia now being one of the key health challenges of the 21st Century (15).

### HUMAN AND SOCIETAL IMPACT:

- › Dementia is one of the most severe and devastating disorders we face. The effect on quality of life is far greater than that of other chronic illnesses (17).
- › However, the impact of dementia is wider than the emotional and physical impact on the individual. There is a significant social cost to dementia care, as the majority of people with dementia live at home, cared for by family members.
- › Many carers experience high levels of stress and burden, social isolation, financial pressure and grief. From an economic perspective, dementia is a costly condition, calculated at €1.69 billion per annum (8), which is a huge cost given its duration, disease burden and level of disability over time.

### DEMENTIA IN PRIMARY CARE: CHALLENGES AND OPPORTUNITIES

- › The World Health Organisation (18) advocate for the need to strengthen health systems based on the principles of primary health care. This is one of the most urgent challenges around the world and especially relevant with regard to provision of dementia care.
- › Cahill et al found that dementia care was inadequate with critical links often missing in the chain of services available to meet the complex needs of people with dementia (8).
- › However, they proposed that *'Ireland now has a golden opportunity to become a world leader in dementia care and to learn from the successes and failures of other countries...'* (8).
- › Educational and skills development is one of a number of components essential to enable the widespread service reform required, in order to improve quality and consistency of dementia care.

## Workshop Aims

1. Background to PREPARED Project
2. To provide a generic overview of dementia and issues arising in care in the community
3. To promote interdisciplinary collaboration
4. To explore 'project ideas'

dementia pathways

SLIDE 2



Today's workshop will include a:

- › Background to PREPARED Project
- › Brief overview of dementia
- › Emphasise that the overall aim is to foster a deeper understanding of each other's roles in caring for a person living with dementia, improve our knowledge of dementia, and promote interdisciplinary collaboration, seen as critical to improving outcomes for people living with dementia in the community
- › Inform the group that the 'project ideas' concept involves considering small changes that could be introduced by teams or individuals that may improve dementia care provision, and/or team collaboration/efficiency with regard to the care of people living with dementia.



The aim of this workshop is to foster a deeper understanding of each other's' roles in caring for a person living with dementia, and to provide education on dementia and issues arising in care in the community. The workshop also aims to promote interdisciplinary collaboration considered as critical to ensuring improved outcomes for people living with dementia and their families /carers.

### INTER-PROFESSIONAL COLLABORATION:

Poor inter-professional collaboration can have a negative impact on the quality of patient care (19). Collaborative practice allows sharing of expertise and perspectives to form a common goal of restoring or maintaining an individual's health and improving outcomes while combining resources (20).

### PROJECT IDEAS:

At the end of this workshop participants are asked to take time to reflect on introducing a change with the potential of improving team collaboration and forming a common goal of improving outcomes for people living with dementia in the community. Participants may choose to address any of the challenges identified during the introductions at the start of the workshop or any other emerging issue of relevance.

## Description of Content

1. Why and how the workshop was designed
2. Interprofessional learning and collaboration
3. Workshop content
  - Overview of dementia
  - Case Study
  - Project Ideas

dementia
pathways



- › Rationale for workshop development
- › Interprofessional learning allows understanding of other professions and one’s own role with regard to dementia care, together with a sharing of expertise and perspectives
- › Overview of workshop content



### WHY PRACTICE-BASED WORKSHOPS?

Findings from a national dementia education needs analysis report included a recommendation for the provision of general dementia education but more particularly practical upskilling to enable practitioners improve outcomes for people living with dementia (9).

Research suggests that individuals learn best when the educational process is practice relevant, interactive and when the existing expertise and experience of the learner is recognised, respected and used as a resource in training (21).

### INTER-PROFESSIONAL LEARNING:

Inter-professional education occurs *“when two or more professions learn with, from and about each other in order to improve collaboration and quality of care”* (22).

Healthcare systems worldwide are facing increased challenges with regard to the care provided for people living with dementia and the competencies of healthcare professionals required to meet this demand (8, 9, 23). Currently the main focus of healthcare is largely on illness and treatment, however, people living with dementia need care and support that also takes their daily functioning and well-being into consideration. Inter-professional education is necessary to realise this shift in professional behaviour. Evidence indicates that inter-professional education can play a pivotal role in enhancing the competencies of professionals in order to provide care that is both effectively integrated and well-coordinated (23).

### WORKSHOP CONTENT:

To identify the educational needs of healthcare practitioners with regard to dementia, the empirical literature was consulted, and feedback obtained from staff representing individual disciplines working in primary care in Ireland. Furthermore, national and international dementia guidelines were reviewed and issues arising in care identified. Research relating to the views of people living with dementia and family carers were also considered.

Eight key areas were identified for inclusion in the workshop:

- › Dementia, assessment and management (pharmacological and non-pharmacological)
- › Risk factors for dementia
- › How memory works
- › What do people with dementia want/need? What do carers want/need?
- › Supporting the individual
- › Supporting carers
- › PCT roles and responsibilities
- › National and international initiatives



Demonstration of [www.dementiaphways.ie](http://www.dementiaphways.ie)



The Dementia Pathways website was developed by the PREPARED project in UCC as part of the implementation of the National Dementia Strategy. Originally developed as a resource for primary care health and social care professionals, in recent months it has been further developed to contain clinical and educational resources and guidance for all Irish medical practitioners and health and social care professionals who work with people living with dementia. The website now falls under the responsibility and governance of the National Dementia Office.

## Prevalence of dementia across different settings in Ireland

Estimated 55,000 people living with dementia in Ireland (HSE, 2016)

- **Majority live in the community** - (63%) with between 6,000 – 10,000 living alone
- Research suggests up to 25% of all acute hospital patients may have dementia (Cahill et al, 2012)
- Approximately 456 people with dementia in Psychiatric care
- 34% of people with dementia in long term care (Connolly et al, 2014)

dementia pathways



- › Majority of people diagnosed with dementia live in the community
- › Informal family carers provide the bulk of care
- › Full range of health and social care required over time to delay deterioration, maintain health and enhance coping – knowing who to involve and when is essential
- › Absence of appropriate supports when needed can result in excess disability for the person living with dementia, caregiver strain and premature movement to residential care settings



The main bulk of care for people living with dementia is provided in their own homes, in the community, mostly free of charge by adult children and spouses, many of whom are frail and older themselves (25). A recent Irish study on spousal caregivers of people living with dementia found 79% of participants were providing 81% – 100% of the care required for an average of five years with almost 50% of carers reporting they spend all their waking time looking after their spouse (26). In the absence of the required level of community care supports, families find they are placed under greater demands and strains trying to provide around the clock care, seeking to prevent their relatives living with dementia being placed in long-term care prematurely (8). Caring for somebody with dementia places much greater strain on family members compared to other caring roles (27, 28). Caregiver burnout therefore presents a significant and immediate threat to the balance of care for people with dementia (26).

Over time, the symptoms of dementia will require a full range of health and social care interventions to delay deterioration, maintain health and wellbeing and enhance coping. This typically requires the intervention of more than one discipline, however there is a lack of consistency with regard to the number of fully functioning primary care teams in Ireland.

Primary care teams have the potential to improve the quality of care for people living with dementia and their families. For this to happen the roles and responsibilities of team members need to be clearly defined – knowing who to involve and when. This also applies to accessing professionals and services (voluntary and statutory) outside the group of individuals working in a single team – knowing who to involve and when. Good communication is also essential for effective team working but it can be difficult, especially with status differences and where some members report to different authorities. Where teams manage communication well, it makes a positive difference.

## Dementia

The WHO (2019) describe dementia as a syndrome, usually of a chronic or progressive nature, in which there is deterioration in memory, thinking, behaviour and the ability to perform everyday activities.

Sometimes described as an umbrella term or a collective term referring to the wide range of conditions/diseases affecting the brain

dementia
pathways



- › Dementia definition - a syndrome caused or characterised by multiple cognitive deficits
- › Cognitive deficits cause significant impairment in social or occupational functioning and represent a significant decline from an individual's previous level of functioning.



Dementia is a syndrome characterised by progressive cognitive impairment and is associated with impairment in functional abilities and in many cases, behavioural and psychological symptoms.

Dementia is regularly described as a 'syndrome', and other times as 'an umbrella term' or 'a collective term' depicting the many causes/subtypes of the condition. Over 400 subtypes have been defined however most are quite rare. The main sub-types of dementia include Alzheimer's Disease (AD), Vascular Dementia (VaD), Dementia with Lewy Bodies (DLB), fronto-temporal dementia (FTD), and Mixed Dementias.

According to the DSM- IV dementia is a syndrome, caused or characterised by multiple cognitive deficits which may include memory impairment (impaired ability to learn new information or to recall previously learned information) and one or more of the following;

- aphasia (language disturbance)
- apraxia (impaired ability to carry out motor activities despite intact motor function)
- agnosia (failure to recognise or identify objects despite intact sensory function)
- disturbance in executive functioning (i.e., planning, organizing, sequencing, abstracting)

The new Diagnostic and Statistical Manual of Mental Disorders (DSM- V) replaces the term dementia with 'Major Neurological disorder' and 'Mild Neurological disorder'.

Dementia is one of the major causes of disability and dependency among older people worldwide. Where dementia affects people under the age of 65 years it is referred to as 'young onset' or 'early onset' dementia. Although younger people experience similar symptoms to older people living with dementia, the impact on their lives may be much greater – may be still working, financial commitments, family commitments, unfulfilled ambitions etc.

## More than a syndrome?

**D=P+B+H+NI+SR**

**Dementia Process**  
**P=Personality**  
**B=Biography**  
**H=Physical health**  
**NI=Neurological impairment**  
**SR=Social relationships**

dementia pathways



- › Dementia cannot be understood solely in terms of neurological impairment
- › Multiplicity of factors involved which affect the individuals experience of dementia including neurological impairment, physical health, the person's personal biography and personality, and the social environment within which they live



Each person's experience of dementia is unique and the progression of the condition varies. Some symptoms are more likely to occur with certain types of dementia. However, there are many other factors that influences how an individual experiences dementia. Professor Tom Kitwood from Bradford University argued that people's experience of dementia not only arises from the bio-medical phenomena such as their degree of neurological impairment and their physical health but also from social and psychological factors such as their personal biography and day to day interactions with the physical and social environment which can have a negative or positive impact (29).

A person-centred care approach seeks to maximise wellbeing by focusing not only on the neurological impairment but on other dimensions that affect quality of life.

### Common Types of Dementia

DEMENTIA TYPE	PREVALENCE	COMMON SYMPTOMS
Alzheimer's Disease	50-60%	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, visuospatial perception and mood changes.
Vascular & Mixed Dementia (Alzheimer's & Vascular)	25%	Vascular dementia exhibits a more stepwise decline May find gait abnormalities, signs of vascular disease and focal neurological signs
Dementia with Lewy Bodies	10-15%	Fluctuating cognition Visual Hallucinations Signs of Parkinsonism
Frontotemporal Dementia	2-4%	Generally develops at a younger age (around 60). Changes in behaviour such as disinhibition, loss of social awareness and loss of insight are much more common than memory problems.
Parkinson's Dementia	2-5%	Symptoms are similar to Lewy Body dementia but unlike LBD movement problems precede cognitive symptoms by years

dementia pathways



- › There are multiple types of dementia
- › Often present with very similar symptoms making it difficult to distinguish between them
- › Some types have more distinct presentations



**ALZHEIMER'S DISEASE**

Is a chronic progressive, degenerative brain disease characterized by the presence of intraneuronal tangles and extra neuronal plaques which contain an amyloid core.

**Presentation:** Short term memory loss is the classic early symptom followed over time by problems with attention, orientation, language, comprehension, visuospatial perception and mood changes. It is the most common type of dementia.

**Course:** Generally, (though not exclusively) diagnosed in people over the age of 65. On average a person with Alzheimer's disease will live 4-8 years following diagnosis but may live up to 20 years.

**VASCULAR DEMENTIA (VaD)**

results from damage to the brain from a blood clot or a hemorrhage cutting off the brain's blood supply due to a stroke or succession of strokes.

**Presentation:** Symptoms can vary widely depending on the severity and location of the blood vessel damage. Symptoms will be most obvious after a major stroke, however the majority of cases of vascular dementia present with more insidious decline (largely indistinguishable from Alzheimer's disease) in the context of chronic vascular risk factors. Cognitively, impaired attention and frontal features predominate. Memory loss may or may not be a significant symptom depending on the specific brain areas where blood flow is reduced. Impairments in visuospatial and perceptual abilities may also be prominent. Fluctuations in performance and night time confusion are very common. Emotional lability, gait disturbance and incontinence may also present.

**Course:** Dementia that results from many small strokes usually progresses more gradually than that due to a few large strokes. However, symptoms may worsen suddenly and then plateau (until the next vascular event) in what is often described as a stepwise progression. Management of vascular risk factors can improve prognosis but about 6 in 10 people die within 5 years after symptoms begin, often due to a stroke or heart attack.

**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 brain changes also often coexist with Lewy bodies. In some cases, a person may have brain changes linked to all three conditions.

**DEMENTIA WITH LEWY BODIES (DLB)**

Is one of the more common forms of progressive dementia. It is associated with abnormal deposits of a protein called alpha-synuclein in the brain, which is also found in Parkinson's dementia and Alzheimer's disease.

**Presentation:** Many people with DLB experience movement symptoms similar to those seen in Parkinson's disease (postural instability, rigid muscles, shuffling walk and trouble initiating movement) although symptoms such as difficulty sleeping, loss of smell, and visual hallucinations often precede movement and other problems by as long as 10 years. Many have REM sleep disorder characterised by vivid dreams which may be acted out sometimes resulting in injuring the bed partner. These symptoms can result in DLB going unrecognised or misdiagnosed as a psychiatric disorder until its later stages. Later in the course of DLB, signs and symptoms are similar to AD and may include memory loss, poor judgment, and confusion. Fluctuating cognitive function is a relatively specific feature of Lewy body dementia i.e. periods of being alert and orientated alternating with periods of confusion and being unresponsive to questions. Excessive drowsiness is common.

**Course:** Age of onset is typically after age 60. Average duration is 5-7 years but there is substantial variability with some people affected living up to 20 years after diagnosis.

**FRONTOTEMPORAL DEMENTIA (FTD)**

Caused by disease that primarily affects the frontal and temporal lobes of the brain.

**Presentation:** Affects the ability to reason and make decisions, prioritise and multitask, act appropriately, and in some cases control movement. Behavioural and personality changes typically present first while memory remains relatively intact for longer.

**Course:** People generally develop symptoms at a younger age (at about age 60). Some people decline rapidly over 2 to 3 years, while others show only minimal changes for many years. People can live with frontotemporal disorders for 2 to 10 years, sometimes longer.

**PARKINSON'S DISEASE DEMENTIA**

A chronic and progressive degenerative disorder of the central nervous system. As the disease progresses a high number of those affected will experience mild cognitive impairment with estimates varying (between 50-80%) as to the proportion that will go on to develop dementia.

**Presentation:** Symptoms are similar to Lewy Body dementia but unlike DLB movement problems precede cognitive symptoms by years. Compared to Alzheimer's disease people who have Parkinson's dementia tend to have greater impairment of attention, orientation in and negotiation of the environment. They are also less flexible in their way of thinking and may have visual hallucinations (usually less frequent and more benign than in DLB) and false fixed ideas. In Parkinson disease dementia, postural instability and gait abnormalities are more common, motor decline is more rapid, and falls are more frequent than in Parkinson disease without dementia.

**Course:** Age of onset is typically after age 70 (but may be younger). People with Parkinson's dementia have a worse prognosis than those with Parkinson's disease who do not have dementia (30-32).

## Less Common Dementias

- Normal Pressure Hydrocephalus
- Corticobasal Degeneration (CBD)
- Progressive Supranuclear Palsy (PSP).
- Huntington’s Disease (HD)
- Creutzfeldt-Jakob Disease (CJD)
- Korsakoff’s Syndrome
- HIV-associated Neurocognitive Disorder

dementia
pathways



- › There are many less common types of Dementia
- › Supports the need for a comprehensive assessment



NB: It is sufficient to point out that there are many less common types of dementia. The information provided below is for the facilitator’s benefit should questions arise.

**NORMAL PRESSURE HYDROCEPHALUS (NPH)** is a brain disorder in which excess cerebrospinal fluid accumulates in the brain’s ventricles. Called "normal pressure" because despite the excess fluid, cerebrospinal fluid pressure as measured during a spinal tap is often normal. As ventricles enlarge with fluid they can disrupt and damage nearby tissue. If symptoms and an MRI strongly suggest NPH, a large-volume spinal tap may be used to identify those who may benefit from a shunt.

**Presentation:** The following symptoms are considered hallmarks of NPH: difficulty walking (wide based gait and as if feet glued to ground); overall slowing of thought processes (apathy, impaired planning and decision making, reduced concentration, changes in personality and behavior). Loss of bladder control is common.

**Course:** NPH primarily affects people in their 60s and 70s. Symptoms usually worsen if left untreated but shunting does not help everyone with NPH.

**CORTICOBASAL DEGENERATION (CBD)** is a rare neurological disease. The cortex, or outer layer of the brain, is severely affected, especially the fronto-parietal regions. Other, deeper brain regions are also affected, including parts of the basal ganglia, hence the name "corticobasal" degeneration.

**Presentation:** Symptoms are similar to those found in Parkinson’s disease. Initial symptoms may first appear on one side of the body (unilateral), but eventually affect both sides as the disease progresses. An individual with corticobasal degeneration eventually becomes unable to walk. There is no treatment available to slow progression. Drugs used to treat Parkinson disease-type symptoms do not produce any significant or sustained improvement. Occupational, physical, and speech therapy can help in managing disability.

**Course:** Typically occurs between the ages of 45-70. Corticobasal degeneration progresses gradually over 6-8 years.

**PROGRESSIVE SUPRANUCLEAR PALSY (PSP)** is a relatively rare brain disorder that damages the upper brain stem, including the substantia nigra (a movement control center in the midbrain). This region also is affected in Parkinson's disease, which may explain an overlap in motor symptoms shared by these disorders.

**Presentation:** Characterised by progressive lack of coordination, stiffness of the neck and trunk, difficulties with eye movement, slow movements, cognitive dysfunction, and difficulty walking that can result in falls. A person with this type of dementia may suddenly laugh or cry very easily (known as pseudobulbar affect). Speech usually becomes slurred, and swallowing solid foods or liquids becomes difficult. There is currently no effective treatment for PSP. In some patients the slowness, stiffness, and balance problems of PSP may respond to anti-Parkinsonian agents, but the effect is usually temporary. Formal physical therapy is of no proven benefit in PSP, but certain exercises can be done to keep the joints limber.

**Course:** The dementia is classically subcortical. Many people become incapacitated within about 5 years and die within about 10 years.

**HUNTINGTON'S DISEASE (HD)** is a genetic neurodegenerative condition (defective gene on chromosome four) that leads to progressive physical, cognitive and emotional symptoms.

**Presentation:** The hallmark symptom of Huntington's disease is uncontrolled movement of the arms, legs, head, face and upper body. The neuropsychological picture is one of subcortical dementia, with decline in thinking and reasoning skills, including memory, concentration, judgment and ability to plan and organise. Leads to alterations in mood, especially depression, anxiety, and uncharacteristic anger and irritability. A common symptom is obsessive-compulsive behavior, leading a person to repeat the same question or activity. There is no treatment that can stop or reverse the course of HD, treatment is aimed at relieving symptoms.

**Course:** Peak age of presentation is in the 40s but can occur years earlier or many years later (even up to age 80).

**CREUTZFELDT-JAKOB DISEASE (CJD)** is a rare degenerative fatal brain disorder believed to be caused by infectious proteins called prions that become misfolded.

**Presentation:** In the early stages of disease, people may have failing memory, behavioral changes, lack of coordination and visual disturbances. As the illness progresses, mental deterioration becomes pronounced and involuntary movements, blindness, weakness of extremities, and coma may occur. There is no treatment that can cure or control CJD. Current treatment is aimed at alleviating symptoms and making the person as comfortable as possible.

**Course:** Typically, onset of symptoms occurs about age 60, and about 90 percent of individuals die within 1 year.

**KORSAKOFF'S SYNDROME** is a brain disorder caused by extensive thiamine deficiency. Often, but not always, preceded by an episode of Wernicke encephalopathy, which is a life threatening, acute brain reaction to severe lack of thiamine. Thiamine (vitamin B-1) helps brain cells produce energy from sugar. When levels fall too low, brain cells cannot generate enough energy to function properly. It is most commonly precipitated by over-consumption of alcohol causing damage to the thalamus and hypothalamus. Other causes include anorexia, overly-stringent dieting, fasting, or weight-loss surgery; uncontrolled vomiting; AIDS; kidney dialysis; chronic infection; or cancer that has spread throughout the body.

**Presentation:** Its main symptoms are anterograde amnesia (inability to form new memories and to learn new information or tasks) and retrograde amnesia (severe loss of existing memories), confabulation (invented memories, which are then taken as true due to gaps in memory), meagre content in conversation, lack of insight and apathy. Treatment involves replacement of thiamine, other vitamins and magnesium and providing proper nutrition and hydration. Stopping alcohol use may prevent further nerve and brain damage.

**Course:** Some research suggests that those who recover from an episode may have a normal life expectancy if they abstain from alcohol.

**HIV ASSOCIATED NEUROCOGNITIVE DISORDER (HAND):** Difficulties with memory, thinking and reasoning are common with HIV, but they are usually mild and dementia is much rarer (prevalence rate 7-27%) Dementia occurs primarily in persons with more advanced HIV infection and may be caused by the virus directly damaging the brain or may also be the result of a weakened immune system enabling infections and cancers to attack the brain.

**Presentation:** Symptoms include a gradual decline in cognitive function, including trouble with concentration, memory, and attention. Persons with HIV Associated Neurocognitive Disorder also show progressive slowing of motor function, loss of dexterity and coordination and behavioral changes.

**Course:** People with HIV infection and untreated dementia have a worse prognosis (average life expectancy of 6 months) than those without dementia. Treatment with a combination of antiretroviral drugs often prevents cognitive impairments worsening and, for many people, can reverse the cognitive damage caused by HIV. Rehabilitation programmes may also help people with HAND to re-learn skills (30-32).

## Risk Factors

**Non Changeable:**

- Increasing Age
- Family history
- People with Down Syndrome

**Changeable:**

- Hypertension
- Smoking
- Atherosclerosis
- Diabetes
- Obesity
- General lifestyle (diet, alcohol, physical & cognitive inactivity)
- Depression

(Alzheimer's Association, 2014)

dementia pathways



- › Estimated that up to half the cases of Alzheimer's disease worldwide may be the result of seven key modifiable risk factors.
- › A healthy lifestyle can help reduce the risk of Alzheimer's disease and other dementias



Risk reduction involves:

- › Being physical active
- › Eating a healthy well-balanced diet e.g. Mediterranean diet
- › Keeping weight, blood pressure, cholesterol and blood sugars within the recommended range
- › Staying socially connected
- › Staying cognitively active i.e. challenging the brain by learning something new -musical instrument, a new language, card game etc.
- › Managing stress – think young and think positive

'Hello Brain', an innovative website promoting brain health launched in Trinity College Dublin as part of a new EU Commission initiative to increase the societal impact of brain research. The 'Hello Brain' website provides practical tips on how to keep your brain healthy using a range of entertaining videos and online resources, including the Hello Brain Health App which can be downloaded for free. [www.hellobrain.eu/](http://www.hellobrain.eu/)

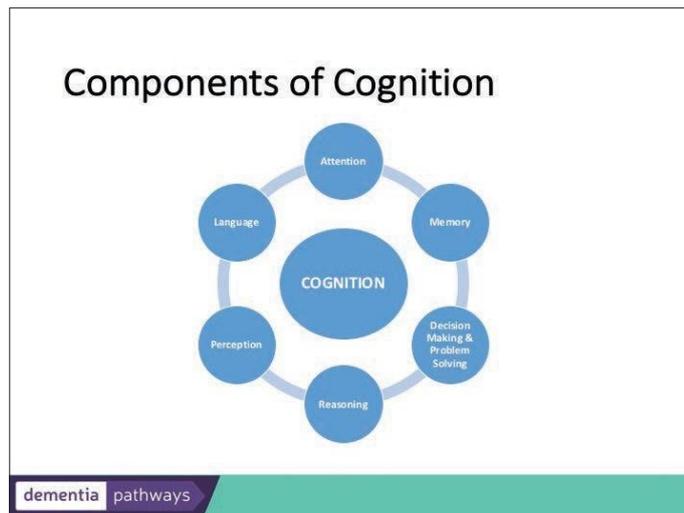
The key messages of the 'Hello Brain' campaign are:

- › Cognitive decline is not inevitable
- › The brain is plastic and can change even in later life (now known the brain is more flexible than once thought and even the injured brain has the ability to respond with new cells or a rewiring to compensate for damage)
- › Cognitive reserve offers protection against decline (now thought that our brains can hold some reserve to ward off the impacts of damage over time).
- › Risk and protective factors have been identified therefore it is possible and important to be proactive about brain health

WHO Global action plan on the public health response to dementia 2017 – 2025 aims to improve the lives of people living with dementia, their carers and families, while decreasing the impact of dementia on communities and countries. The action plan highlights the need for healthcare professionals to improve their knowledge and practices with regard to proactively managing the changeable risk factors of dementia. The WHO (2019) issued a guidance document on Risk Reduction of Cognitive Decline and Dementia providing evidence-based recommendations on lifestyle, behaviours, and interventions to delay or prevent cognitive decline and dementia in the general population. This document is available for download using the following link:

[https://www.who.int/mental\\_health/neurology/dementia/guidelines\\_risk\\_reduction/en/](https://www.who.int/mental_health/neurology/dementia/guidelines_risk_reduction/en/)

The National Dementia Office (2020) also developed a guidance document for healthcare professionals on risk reduction of dementia based on the WHO's recommendations and the best available evidence, working with a national team of experts. This document is available for download on [www.dementiapathways.ie](http://www.dementiapathways.ie)



Cognition refers to all of the mental activities involved in receiving information, comprehending it, storing it, retrieving it, and using it – memory is just one component of cognition



Cognition involves:

- › Sensory and perceptual processes that enable us to receive information from the world (e.g. vision, hearing, smell, taste, touch)
- › All of the mental processes involved in attending to the information, recognising it as something meaningful, making sense of the information, relating it to what is already known, organising the information, deciding what is important / not important, storing the information for later retrieval, and retrieving it when useful
- › Using the information to make decisions about what to do, to solve problems, to communicate.

## How Memory Works

Memory is the process in which information is **encoded, stored, and retrieved**. Memory is just one component of cognition.



dementia pathways



- › We tend to think our memory works like a filing cabinet.
- › We experience an event, generate a memory and then file it away for later use.
- › However, the basic mechanisms behind memory are much more dynamic



Memory is the term given to the structures and processes involved in the storage and subsequent retrieval of information. Some of the physiology and neurology involved in these processes is highly complex and technical (and some of it still not completely understood).

**ENCODING:** Processing information, organising it, and marking it for storage

**STORAGE:** Short term memories can become long term memories through the process of consolidation (the process of stabilising a memory trace after the initial acquisition)

**RETRIEVAL:** Calling stored information to consciousness (30).

## Cognitive Assessment Tools

- MMSE: Mini Mental State Examination
- MOCA: Montreal Cognitive Assessment
- SLUMS: Saint Louis University Mental Status Exam
- GPCOG: General Practitioner Assessment of Cognition
- AMST: Abbreviated Mental Score Test
- ACE-R: Addenbrooke's Cognitive Examination

dementia pathways



- › Cognitive functioning tests are tools developed to help evaluate cognitive function
- › Poor performance is merely indicative of a problem with cognitive functioning that will need further assessment/examination before a diagnosis is reached
- › Many different tools are currently in use and choice of tool varies considerably with the MMSE most commonly used - results should be interpreted based on normative values for a person's age and education
- › All screening tools have strengths and limitations



NB: It is sufficient to outline the key points above with regard to cognitive assessment tools. The information provided below is to support the facilitator should further questions arise.

### MMSE: MINI MENTAL STATE EXAMINATION

The Folstein MMSE is a brief, quantitative measure of cognitive status in adults, and should not, by itself, be used as a diagnostic tool to identify dementia. It can be used to screen for cognitive impairment, to estimate the severity of cognitive impairment at a given point in time and to follow the course of cognitive changes in an individual over time. The Folstein MMSE is a global cognitive evaluation tool. It consists of a variety of questions that explores a person's sense of time and space (orientation), their retention (memory) attention to detail, ability to calculate, language skills and constructional praxia. It takes approximately 10 minutes to complete and has a maximum score of 30. Suggested cutoff is 24 but results should be interpreted based on normative values for a person's age and education e.g. the lower limit of normal for an elderly person with only a few years of education is radically different to that of a young, highly educated professional (33). It should be noted that there is educational and cultural bias and the use of the tool is copyright restricted.

### GPCOG: GENERAL PRACTITIONER ASSESSMENT OF COGNITION

The GPCOG screening tool for the assessment of cognitive impairment has been especially designed by a group of Australian experts for use in primary care settings. The GPCOG has been found to perform at least as well as the MMSE but takes less time to administer (34). It has two sections: a patient examination (GPCOG-patient, 4 minutes) with a maximum score of nine and an informant interview (GPCOG-informant, 2 minutes) with a maximum score of 6.

### AMTS: ABBREVIATED MENTAL TEST SCORE

The AMTS was introduced by Hodkinson in 1972 to quickly assess cognition. It takes around five minutes and is widely used, particularly in general hospital settings. Maximum score is 10. A score of less than 7 or 8 suggests cognitive impairment.

### MOCA: MONTREAL COGNITIVE ASSESSMENT TEST

The MOCA is more sensitive than the MMSE for milder forms of early cognitive impairment (35). It was created by Ziad Nasreddine in 1996 in Montreal, Quebec. Assessing many of the same areas as the MMSE, the MoCA is a little more in depth and includes tasks such as a clock-drawing test and a trail test (connecting the dots). Time to administer the MoCA is approximately 10 -15 minutes. The total possible score is 30 points; suggested cut-off point on the MoCA is 26. As with the MMSE it should be interpreted based on normative values for a person's age and education.

### SLUMS: SAINT LOUIS UNIVERSITY MENTAL STATUS EXAM

SLUMS is a 30-point test designed to measure ability in the domains of orientation, executive function, memory and attention. It was developed at the Division of Geriatric Medicine Saint Louis University. Unlike the MMSE it is not proprietary and is free to download. Takes approximately 7-10 minutes to complete. Compares favorably with the MOCA and shown to be superior to the MMSE in the detection of early dementia (36). The maximum score is 30 points and as with other tests should be interpreted based on normative values for a person's age and education.

### ACE: ADDENBROOKE'S COGNITIVE EXAMINATION

The original ACE was developed in the 1990s in Cambridge University in an attempt to bridge the gap between the brief testing tools and more elaborate scales. It is shown to be more sensitive to early AD and to differentiate AD from frontotemporal dementia. It has also been shown to be useful in the separation of organic brain disease from psychiatric states and in the detection of cognitive dysfunction associated with the parkinsonian syndromes of PSP, CBD and MSA (30). The ACE-III replaced the previous ACE and ACE-R versions in November 2012 and includes the five subdomains of Attention, Fluency, Language, Memory and Visuospatial ability. It provides a cognitive score out of a maximum of 100. ACE-III has also been made available as an I-pad based app, which is available cost-free via iTunes and at [acemobileorg@gmail.com](mailto:acemobileorg@gmail.com). The automated scoring and the clear instructions are designed to reduce errors in administration and scoring (Newman et al, 2018).

## Diagnosis

Individual history Collateral history Cognitive assessment Functional assessment • ADLs • IADLs	Physical Examination Blood screen Urinalysis Review of medication CT scan brain, MRI Chest x-ray ECG
--	---

dementia
pathways



- › Timely diagnosis of dementia has been recognised as key in the improvement of dementia service provision
- › The accurate diagnosis of dementia is a challenge for both GPs and specialists
- › Depression and delirium should be considered as part of the differential diagnosis
- › Delirium and dementia often co-exist and can be difficult to distinguish



- › The GP is generally the first point of contact for somebody with memory problems, although in the primary care setting any healthcare professional may come into contact with individuals who have underlying cognitive impairment, at which point a referral should be made to the GP.
- › There is no simple test for the diagnosis of dementia; diagnosis is made on clinical assessment and supported by completion of cognitive screening tools and further investigations. The differential diagnosis needs to be considered. Treatable causes of cognitive impairment include depression, hypothyroidism, certain vitamin deficiencies and delirium. Delirium and dementia often co-exist creating additional challenges in diagnosis.

**DELIRIUM:** A transient usually reversible acute confused state is a common and potentially life-threatening condition in older adults. It develops over a short period (hours to days) and is characterised by inattention, disorganised thinking, altered level of consciousness (confused, drowsy, lethargy, stupor) and perceptual disturbances (37). Delirium is typically an indicator of a physical pathology. In such cases a search for an acute medical cause is required, such as infection (e.g. UTI or respiratory infection), constipation, electrolyte disturbance, liver or renal disease. Age and the presence of dementia are probably the highest risk factors for developing delirium. Adverse outcomes in older adults include longer hospitalisations, functional and mental decline, higher costs and mortality rates. The residual effects of a delirium can last for weeks and months; therefore, it is important that primary care teams know if a person has had delirium while hospitalised.

**Delirium has three subtypes.**

**Hypoactive Delirium** is easy to miss – easily misdiagnosed as Depression – dull, drowsy, apathetic, lethargic and difficult to arouse. (Also referred to as ‘Quiet Delirium’)

**Hyperactive Delirium** difficult to miss but often labelled as ‘confused’ / ‘agitated’. Agitation, delusions and disorientation are prominent. (Also referred to as ‘Excited Delirium’)

**Mixed Delirium** – combination of hypoactive and hyperactive delirium. Alternating between agitation and lethargy over minutes/hours.

The 4AT is the nationally recommended screening tool for delirium (National Clinical Programme for Older People and National Dementia Office). In the acute care setting staff can follow the algorithm for the 'Early Identification and Initial Management of Delirium in the Emergency Department /Acute Medical Assessment Unit' available at:

<http://www.iaem.ie/wp-content/uploads/2013/08/Delirium-ED-AMAU-Pathway-July2016-Final-Print-copy.pdf>

To date, there is not a nationally endorsed tool for delirium screening in residential care settings. The 4AT can be used however a person with advanced dementia may "fail" the screen. In residential settings staff have a greater opportunity to know their residents which supports the prompt identification of any acute change from baseline or altered behaviours. The RADAR screening tool (Recognising Acute Delirium as Part of Your Routine) supports timely identification of acute change from baseline by prompting care staff to observe for signs of delirium on medication rounds (Voyer et al, 2015).

Additional information on RADAR available at :-

<https://bmcnurs.biomedcentral.com/articles/10.1186/s12912-015-0070-1>

**Responding to Delirium: -**

- › Identify and treat cause(s)
- › Maintain a safe environment
- › Reduce noise, re-orientate, reassure, use effective communication and regular review
- › If patient is agitated or distressed always try non-pharmacologic measures first – use medication only if absolutely necessary i.e. risk of harm, interruption of vital medical care. The current evidence for the role of antipsychotics in treating delirium is weak – these are mainly used for psychotic symptoms in delirium (hallucinations and delusions) and severe distress or risk of harm.
- › Educate patient and family/care partner on delirium and prognosis – enlist their help to promote calmness and familiarity.

**HISTORY:** Specific attention should be paid to mode of onset, course of progression, pattern of cognitive impairment and presence of non-cognitive symptoms such as behavioural disturbance, hallucinations and delusions- focusing on the key diagnostic criteria of dementia – short term memory loss, aphasia, apraxia, agnosia, and loss of executive function. A collateral history from a relative or carer is essential as a person with dementia may not be able to give a fully accurate history. It is important to be careful when evaluating the history e.g. a 'sudden onset' may mean a sudden realisation of the condition by relatives or others such as when a spouse who took care of the person dies or they come to medical attention because of another problem. A very fast progression is seen in some secondary dementias e.g. Korsakoff syndrome and in conditions such as CJD (38).

**PHYSICAL EXAMINATION:** The focus of the physical examination should be on cardiovascular disease e.g. signs of CVA, neurological signs e.g. Parkinsonism, sensory loss, and the exclusion of any possible reversible causes of cognitive decline or delirium.

**BLOOD TESTS:** Full Blood Count (FBC), Erythrocyte Sedimentation Rate (ESR), Urea & Electrolytes (U&E), Thyroid Function Test (TFTs), Liver Function Test (LFTs), Glucose, Lipids, Calcium, Folic Acid, Ferritin & Vitamin B12 (to detect co-morbid conditions and to exclude reversible causes).

**CT SCAN:** (to exclude intracranial lesions, cerebral infarction and hemorrhage, extra and subdural hematoma, normal pressure hydrocephalus). MRI Scan (a sensitive indicator of cerebrovascular disease).

**MEDICATION REVIEW:** Many older people are prescribed multiple medications which greatly increases the risk of drug interaction and adverse reactions that can negatively impact cognitive and physical status (herbal medications included). Additionally, in vulnerable patients, some medications are more commonly associated with confusion including benzodiazepines, opiates, tricyclic antidepressants, anti-parkinsonian drugs, corticosteroids, certain cardiac drugs and anticonvulsants. Attention should also be paid to the person's ability to manage their medication. Cognitive impairment can result in the person taking prescribed drugs erratically e.g. uncharacteristic variations in INR in a person normally taking stable doses of warfarin. As dementia progresses difficulty managing medication becomes more prominent.

**GENERAL MEDICAL INVESTIGATIONS:** Urinalysis. Chest X-Ray if clinically indicated. ECG (Cholinesterase inhibitors may induce sinus bradycardia and aggravate pre-existing sinus node disease and AV block).

**SPECIALIST INPUT & MEMORY CLINICS:** Referral to specialist services is beneficial in patients where dementia is not clinically obvious; for confirmation of the diagnosis; exclusion of other pathologies; subtyping of the dementia and tailoring of treatments to the specific dementia subtype. The decision on whether to refer for a specialist opinion to Old Age Psychiatry, Gerontology, Neurology or a dedicated Memory Clinic is dependent upon resources available locally.

## Treatment: Pharmacological

Medication management in dementia usually focuses on the following:

- Drugs for Alzheimer's Disease
- Treatment of underlying pathology e.g. vascular dementia – hypertension, raised cholesterol, cardiac problems, diabetes
- Management of NCS D & Responsive behaviours

dementia pathways



- › Currently no disease-modifying drugs available for the treatment of dementia
- › Available drugs may provide some benefit in terms of improvements in cognition, ADLs and NCS D
- › Non pharmacological interventions must be considered as first line response to NCS D
- › Antipsychotic use may be justified **only** in severe cases of significant distress and complex risk



People with dementia can be prescribed a range of medications during the course of the illness. Some are specifically prescribed for dementia, some for underlying pathology and others are sometimes prescribed to target non-cognitive symptoms of dementia (NCS D). For example, people with vascular dementia often need to take medications to treat underlying conditions such as, high blood pressure, diabetes, high cholesterol or heart problems. Controlling these conditions and adopting a healthy lifestyle may help delay the progression of dementia.

People with dementia may also be prescribed a range of medications to alleviate distress and reduce risks associated with NCS D and responsive behaviours. Not every person with dementia will need these medications as there are evidenced based non-pharmacological interventions available which are recommended as first line response to NCS D, depending on level of distress and risk (58). A decision to prescribe these medications should involve a comprehensive assessment, taking into consideration the individual's physical and mental health status, their biography, collateral history, caregiver factors, environmental factors and any other factors that might precipitate or exacerbate the NCS D. Depression can also be a relatively common concomitant of dementia, although often difficult to distinguish against a background of other NCS D such as apathy, and possible physical issues such as hypodelirium and pain. Following a comprehensive assessment, the GP may initiate a trial of antidepressant medications or refer to Psychiatry of Old Age for assessment who may also prescribe a trial of antidepressant medications.

### Treatment: Pharmacological

**Donepezil** (Aricept) Initially 5mgs daily for 4-6 weeks titrating to 10mgs daily if tolerated.

**Rivastigmine Tablets**(Exelon) Initially 1.5mgs twice daily titrating upwards in increments of 2 weeks to 6mgs twice daily if tolerated.

**Rivastigmine Patch** (Exelon)Initially 4.6mgs/24hrs for 4-6 weeks titrating to 9.5mgs/24hrs if tolerated.

**Galantamine Tablets** (Reminyl) Initially 4mgs BD titrating in increments of 4mgs BD every 4 weeks to 24mgs daily if tolerated

**Galantamine XL Tablets**(Reminyl) initially 8mgs daily titrating in increments of 8mgs daily every 4 weeks to 24mgs daily if tolerated

**Memantine** (Ebixa) Initially 5mgs daily for one week titrating by 5mgs weekly to maintenance dose of 20mgs daily if tolerated

dementia pathways



- › Currently only 4 drug treatments available
- › None of these drugs can stop or reverse the course of the disease.
- › Acetylcholinesterase inhibitors (AChEIs) may temporarily improve or stabilise cognition, ADL's, and NCSd, and may slow progression



In Alzheimer's disease there are multiple neurotransmitter abnormalities but most prominent are cholinergic with reduced activity of choline acetyltransferase. Acetylcholinesterase inhibitors act by increasing cholinergic transmission via inhibition of the breakdown of acetylcholine. In terms of the management of cognitive symptoms and maintenance of function, acetyl cholinesterase inhibitors (AChEI's) are first-line agents for the treatment of mild to moderate Alzheimer disease (67). While AChEI's are associated with mild improvements in cognitive function, behaviour, and activities of daily living, the clinical relevance of these effects however is unclear and the duration of improvements variable amongst people living with dementia. AChEIs are licensed for the treatment of mild to moderate Alzheimer's disease (except Rivastigmine which is licensed for AD and Parkinson's disease dementia) but are also used for treatment of Lewy body dementia and Parkinson's disease dementia. It is unclear whether AChEIs are of benefit in vascular dementia however many people have both Alzheimer's and cerebrovascular disease. People presenting with mixed dementia should be managed according to the condition that is thought to be the predominant cause of their dementia.

Memantine is recommended for the management of moderate and severe Alzheimer's disease and for those who are intolerant of or have a contraindication to AChEIs. It is an NMDA (N-methyl-D-aspartate) receptor antagonist, which means it blocks a chemical messenger called glutamate, which is released in excessive amounts in people with Alzheimer's disease, causing brain cells to be damaged further. It may be used alone or in combination with cholinesterase inhibitors.

The most common adverse effects of AChEIs are gastrointestinal, involving nausea, vomiting, diarrhoea and abdominal pains. These effects occur most commonly on initiation and up-titration of the dosage and are usually transient. Adverse effects may be reduced or avoided by increasing the dose slowly or by taking the medicine after food. Patients who do not tolerate one AChEI may tolerate another. Be aware that the side effects of AChEIs could potentially contribute to the emergence of NCSd and Responsive Behaviour. Memantine is generally well tolerated although common undesirable effects are dizziness, headache, constipation, drowsiness and hypertension. However, although Memantine is well tolerated, some people living with dementia, particularly those with Lewy body pathology, may be susceptible to developing adverse effects including increased aggression, delusions, hallucinations or agitation so close observation is required (39).

## Treatment: Pharmacological

Other medications that may be used over the course of the person's dementia includes:

- Antipsychotics for the management of NCS/Responsive Behaviour
- Antidepressants to treat depression
- Hypnotics for sleep disturbance

dementia pathways



- › Antipsychotics should not be a first line treatment (except in psychosis and severe cases with risk of harm)
- › Growing impetus to reduce their use because of limited positive effect and risk of adverse effects in people with dementia
- › Should include the person with dementia (where possible) and their care partner in discussion with regard to proposed use



The clinical features of dementia are usually considered in two groups, cognitive symptoms and non-cognitive symptoms. Whilst most people consider cognitive symptoms such as poor memory, disorientation, confusion etc. as being the main features of dementia it is now recognised that non-cognitive symptoms such as apathy, agitation, aggression etc. are often the most distressing for the person living with dementia and their families/caregivers. Previous education programmes used the term BPSD 'behavioural and psychological symptoms' to describe behaviours such as agitation etc., however, this programme is using the current preferred terminology of NCS 'Non-Cognitive Symptoms in Dementia'.

### ANTIPSYCHOTICS

Antipsychotics are frequently prescribed for the management of NCS and responsive behaviours, however, the main licensed use for antipsychotics is for the treatment of schizophrenia or bipolar disorder where there is a psychosis (41). A review of the evidence shows that antipsychotics have a limited positive effect in the management of NCS and may cause considerable harm (41).

This first generation of antipsychotic medication, developed in the 1950s, is now generally known as the 'typical' antipsychotics. This is to differentiate them from the 'atypical' antipsychotics, which became available from the 1990s. Examples of typical antipsychotics include chlorpromazine (Largactil), Haloperidol (Serenace) and Trifluoperazine (Stelazine); examples of atypical antipsychotics include Risperidone (Risperdal), Olanzapine (Zyprexa) and Quetiapine (Serequel). Typical antipsychotics are known to have a severe side effect profile; therefore, atypical antipsychotics are more widely used as side effects are less.

Significant concern exists surrounding the increased risk of serious side effects for people living with dementia prescribed these drugs. Serious side effects include a 3-time increased risk of stroke and 1.7 times increased risk of mortality when compared to placebo (60). Other side effects include; increased risk of drowsiness, falls, hip fractures, pneumonia, reduced motor function, Parkinsonism, tardive dyskinesia, accelerated cognitive decline and QT prolongation (61). Given that response to these drugs

when used for the treatment of NCSO is modest at best (61) serious concerns exist around their use. The National Restraint Policy (2017) includes chemical restraint in their overall definition of restraint and provides procedures and guidelines in relation to restraint use. The National Standards for Residential Care Settings for Older People in Ireland (63) also provides guidance on chemical restraint procedures and stipulates that the potential benefits must outweigh the possible negative effects on the person. Research suggests an over-reliance of psychotropic drugs in Ireland for the management of NCSO and responsive behaviours. It is felt that many healthcare staff simply are not aware of the associated risks and lack of benefit of these medications (64).

Note: Certain behaviours are unlikely to respond to pharmacological intervention:

- › Wander walking
- › Shadowing
- › Repetitive vocalisation/questioning
- › Hiding and hoarding
- › Rejection or refusal of care Inappropriate undressing

Given the risk of potential serious side effects and limited evidence on response, antipsychotics should not be a first-line treatment except in circumstances of extreme risk and harm (59). Non pharmacological interventions (discussed later) are the recommended first line treatment followed by a period of 'watchful waiting' – some behaviours will resolve without treatment (42). Medication should only be considered for behavior that is dangerous, distressing, disturbing, damaging to social relationships and persistent, and only where behavior has not responded to comprehensive non-pharmacological treatment. If a risk/benefit assessment favors the use of an antipsychotic once initiated, the drug's continuation should be reviewed regularly and following review reduction or cessation of the medication should be actively considered. Risperidone is the only licensed antipsychotic medication for use in people diagnosed with dementia and its license indicates its use for no longer than six weeks, without review or specialist referral. The recently published National Clinical Guideline on 'Appropriate prescribing of psychotropic medication for non-cognitive symptoms in people with dementia' supports an initial period of watchful waiting depending on level of risk and distress, in keeping with research outcomes and international best practice guidelines (59).

### ANTIDEPRESSANTS

Antidepressants should be considered if there is evidence of depression or anxiety. Tricyclics should be avoided as antimuscarinic (anticholinergic) activity may lead to a worsening of cognitive impairment. Selective Serotonin Re-uptake Inhibitors (SSRIs) have traditionally been the first line pharmacological treatment of depression in people living with dementia. A Cochrane review on pharmacotherapies for sleep disorders in dementia found Trazodone (antidepressant with anxiolytic and hypnotic properties) when administered at night for two weeks significantly improved nocturnal sleep time (43).

### HYPNOTICS

Hypnotics may be of limited benefit, especially for night-time disturbance. However, increasing tolerance and adverse effects including over sedation, confusion, agitation and risks of falls needs to be considered (43).

### BENZODIAZEPINES

Due to their significant side effects, use of benzodiazepines should be avoided in the treatment of people living with dementia (42). Usage is **strictly** limited to **short term** use for severe anxiety episodes in exceptional circumstances (59). These drugs are also included in the potentially inappropriate medications and classes to avoid in older adults particularly those presenting with insomnia, agitation or delirium. Side effects include worsening cognition, hypotension, dizziness, weakness and falls. In some patients may contribute to increased aggression and depression – the so called ‘paradoxical effect’ (47).

### ANTICONVULSANTS

Anticonvulsant medication is indicated for the treatment of seizures, bipolar disorder, or as an adjunctive therapy for pain, but is **NOT** recommended as a treatment for non-cognitive symptoms in a person living with dementia.

## Post Diagnostic Support

<p><b>Post Diagnosis:</b></p> <ul style="list-style-type: none"> <li>• Information about dementia</li> <li>• Advice regarding medications</li> <li>• Practical strategies to offset cognitive difficulties, help build resilience</li> <li>• Lifestyle advice – diet, exercise, cognitive stimulation</li> <li>• Planning ahead and legal advice</li> <li>• Link with local clubs, groups – staying socially connected</li> <li>• Family support</li> </ul>	<p><b>Later:</b></p> <ul style="list-style-type: none"> <li>• Information about progression and advice on changing needs</li> <li>• Information about communicating</li> <li>• Advice on Assistive Technologies</li> <li>• Assessment of need for home help, day care, respite care</li> <li>• Safety advice and assessment re aids, environmental adaptations</li> <li>• Mobility assessment – falls prevention, aids</li> <li>• Nutritional advice, swallow assessment</li> <li>• Support to make decisions</li> <li>• Information on understanding, preventing, and responding to NCSD and Responsive Behaviours</li> <li>• Carer education and support</li> </ul>
---	---

**dementia pathways**



- › People living with dementia and their carer’s will need information appropriate to their stage of illness
- › Will need increasing levels of support as dementia progresses
- › People living with dementia will need the intervention of different members of the team to address increasing complex need
- › Also need to find early opportunities to discuss forward planning i.e. legal issues, driving, wishes around care, end of life care preferences etc.



### POST DIAGNOSIS

Receiving a diagnosis of dementia is life changing for the individual and their care partner. Post diagnostic support (PDS) and post diagnostic psychoeducation programmes are increasingly recognised as an essential element in the care infrastructure for people living with dementia and their care partners. It is not only the provision of these supports that are important, the timing is also critical. The information provided needs to be the right information, given at the right time and in the right way for each individual. Managing the emotional and psychological impact of the disease can be very distressing but, with the right supports, relevant coping strategies can be developed that help reduce anxiety and improve quality of life (65). Dementia Services Information and Development Centre (DSIDC) were commissioned by the National Dementia Office to develop and produce a guidance document to support the establishment and ongoing facilitation of dementia post-diagnostic psychoeducation programmes for people living with dementia and their care partners. The completed document entitled ‘The Next Steps: Dementia Post-Diagnostic Support Guidance’ (66) is available to download at

<https://dementiapathways.ie/filecache/a8a/602/1136-the-next-steps-dementia-post-diagnostic-support-guidance-2019-.pdf>

The information given to the person living with dementia and families/carers should be appropriate to the stage of illness. The information required in the early stage of dementia information may include:

- › The signs and symptoms of dementia
- › Course of illness and prognosis
- › Medications
- › Practical tips on enhancing memory

- › Therapeutic interventions for example Cognitive stimulation and cognitive rehabilitation
- › Psychosocial interventions for example music therapy and physical therapy
- › Staying socially connected and peer support
- › Sources of financial and legal advice, and advocacy
- › Income supports available for those living with dementia and their carers
- › Advice on assistive technologies
- › Advice on driving
- › Local & National information resources, including libraries, websites for e.g. [www.understandtogether.ie](http://www.understandtogether.ie), and voluntary organisations
- › Local Supports e.g. voluntary groups, Alzheimer’s Cafes, day care, befriending services & Social Prescribing

The importance of continued intervention should not be underestimated as many people experience an ongoing need for information, support and advice as they try to adjust to the diagnosis (50). Members of the primary care team should be able to meet the information needs of people living with dementia and their families or be able to signpost them to the relevant information required. Where available, a referral to a Dementia Adviser will ensure the provision of highly responsive and individualised information and signposting throughout the trajectory of the illness. Further information on the National Dementia Adviser Service is available at <https://alzheimer.ie/service/dementia-adviser/>

As available services and supports may differ across healthcare areas encourage participants to familiarise themselves with local resources. The service finder on [www.understandtogether.ie](http://www.understandtogether.ie) is a useful information resource which healthcare professionals can share with the person living with dementia and their care partners. In relation to assistive technology, Memory Technology Resource Rooms (MTRR), a free service, is available nationally to allow families and carers see and try out various devices that promote independence, safety and quality of life before purchasing same. There are currently 26 MTRR services available nationally. Additional information on assistive technology and MTRR services is available at <https://dementiaphways.ie/services-and-support/memory-technology-resource-rooms> and <https://www.understandtogether.ie/training-resources/helpful-resources/memory-assistive-technologies/>

### PREVENTION/MANAGEMENT OF NCSO/RESPONSIVE BEHAVIOUR

People living with dementia may develop non-cognitive symptoms (NCSO) and responsive behaviours such as agitation, aggression, wandering, shouting, repeated questioning, sleep disturbance, depression and psychosis (41). They can occur at any stage of the illness but particularly in the middle and late stages. It is important to identify the NCSO and investigate any underlying cause:

- › Health - physical illness and delirium
- › Psychological – anxiety, depression
- › Personal Biography – life history, personal traits and habits
- › Environment – physical and social
- › Neurological Impairment – impact of dementia

It is important also to understand that the NCSO may be attributable to factors other than the person’s dementia, although dementia makes the person more vulnerable to negative consequences. Any change in behavior therefore should be considered an attempt by the person living with dementia to communicate a need – what is the person trying to tell us? For example, a change in routine may adversely affect the person or too much noise e.g. too many people visiting the house together, talking loudly and faster than the person can cope with. It is important therefore to monitor what is going on in and around the person before deciding what action is required. Psychosocial

interventions should be the first line treatment (except in the presence of psychosis or severe aggression with risk of harm). In the example above family members and friends should try to work out when is the best time to visit, and modify conversation so that the person with dementia does not feel overwhelmed or left out. An apparently simple solution but important as the situation could potentially worsen and lead to the use of antipsychotic medication if the trigger for the behavior is not identified. Again, another reason why family caregiver education is so important together with knowledgeable assessment when required. Additional information and guidance on NCSO is available on the Dementia pathways webpage using the link: <https://dementiaphways.ie/resources-for-practice/non-cognitive-symptoms-of-dementia>

## PSYCHOSOCIAL INTERVENTIONS

Overall, there is limited evidence on the benefit of various psychosocial interventions, with many studies being small and quasi-experimental. A recently launched guidance document from the National Dementia Office (58) entitled “Guidance for Healthcare Professionals on non-pharmacological interventions for Non-cognitive Symptoms of Dementia” provides detailed evidence and guidance on the indications, choices and use of non-pharmacological interventions for NCSO. Participants can download a copy of this guidance document via the following link: <https://dementiaphways.ie/resources-for-practice/non-cognitive-symptoms-of-dementia/assessment-of-a-person-with-non-cognitive-symptoms-of-dementia-ncs>

Empathise the importance of ensuring whatever intervention is selected must be person-centred, i.e. personalised tailored interventions and solutions to meet the individual needs of the person living with dementia, taking into consideration their biography, personality, residual cognitive and functional abilities, strengths, goals, and preferences. As previously stated, psychosocial interventions should be first line response to NCSO except in the presence of psychosis or severe aggression with risk of harm to self and/or others (67). In general, the list of psychosocial interventions is endless depending on the imagination and willingness of family and care staff to think outside the box when developing person-centred responsive care plans based on the assessment outcome.

The following four areas encompass a variety of psychosocial interventions; however, participants may be aware of others.

- › Cognitive = Reminiscence, Cognitive stimulation therapy, Cognitive rehabilitation, Memory training, Validation therapy, Simulation therapy, Montessori-Based Dementia Programming, Tovertafel table.
- › Sensory = Snoezelen, Multisensory stimulation therapy, Aromatherapy, Music therapy, Light therapy, Expressive physical touch, Massage, Progressive relaxation therapy.
- › Specific/Targeted = Difficulty sleeping - Night lights; daily exercise; caffeine restrictions etc..., Walking about (wandering), Safe pathway; redirection; visual cues etc....
- › Other = Pet/animal assisted therapy e.g. Peata, Doll therapy, Art Therapy, Drama Therapy, Physical therapy, Exercises – chair, walking, ‘Sonas’, community based social events e.g. Alzheimer Café, social clubs, markets, fete, Social Prescribing, Men’s Sheds, retirement groups, etc.

The following interventions have been found to have benefit for people living with dementia but again, need to be tailored to the individual:

- › **Exercise** – person should be encouraged to exercise (within their limits). Walking, swimming or chair-based exercises can be physically and mentally beneficial
- › **Social Engagement** – friends, clubs, men’s sheds, day care, art classes. Social stimulation can improve mood and prevent boredom, which has been found to contribute to emergence of responsive behaviour.
- › **Capability Model** – Based on Person Centred Care and Montessori principles reorienting care away from disability and toward capability (physical /emotional). Putting in place strategies to support maintained skills (51).

- › **Music Therapy** – A study where people with dementia were played a pre-recorded selection of songs that they used to enjoy when younger found that it decreased levels of agitation. Audiotapes containing a family member’s voice were even more effective than the songs in reducing agitation.
- › **Reminiscence Based Therapy** – conversations that explore the life and history of the person and creation of a ‘Life Story Book’ or ‘This is Me’ profile. Some evidence to suggest that reminiscence improves mood and wellbeing (52).
- › **Sleep Hygiene** – daily walking and increased daylight exposure, short naps to prevent over tiredness avoiding long naps, limit caffeine.
- › **Validation** – Although the evidence base is weak, validation remains one of the few ways of responding to high expressed emotion in the moment of agitation. It involves not challenging the reality of the person with dementia. For example, e. if a person with dementia is agitated, believing they are late for school, do not argue the point or expect the person to have insight into why this reality could not be true i.e. they couldn’t be going to school because they are 85 years old now. This will only add to the person’s distress. Instead, acknowledge and empathise with the feelings the person is expressing e.g. “Oh I hate being late for school too, didn’t you go to school to St Joseph’s”. In this way the conversation is steering away from their source of agitation and perhaps get them to do something else without them realising they are actually being redirected.
- › **Aromatherapy** – there is modest evidence to support the use of lavender aromatherapy oils to decrease agitation.

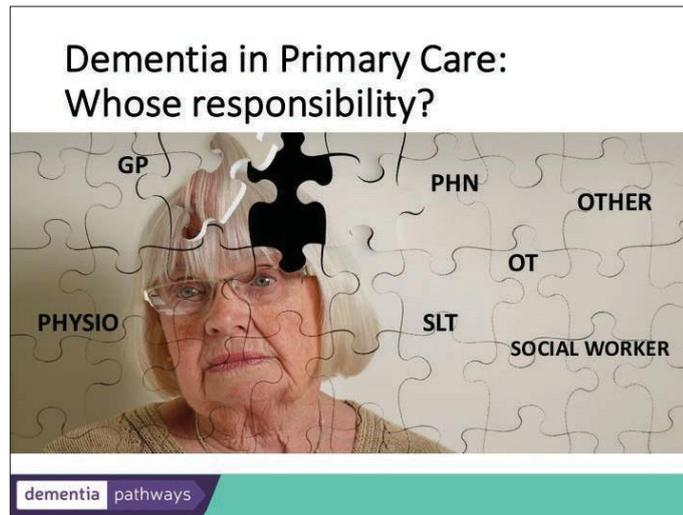
Supporting the individual and educating caregivers regarding how best to use these interventions can help prevent or respond to a NCSO which is distressing for the person living with dementia and a cause of stress and strain for the caregiver.

### DEMENTIA PALLIATIVE CARE

Palliative dementia care involves supporting the person living with dementia and their family to address and relieve the pain, distress and discomfort associated with advancing dementia and inviting them to participate in making decisions about future care needs. Providing this care and comfort presents services with a significant challenge as each person’s journey through dementia is unique with huge variability in the length of the final phase, difficulties in communication and a lack of awareness about the terminal nature of dementia. It is recommended that palliative care principles are introduced in the person’s care early on, ideally soon after diagnosis when the person can meaningfully engage in discussions about their future care.

As part of The Irish Hospice Foundation's Changing Minds programme, a suite of seven guidance documents were developed to support healthcare staff working with people with dementia from all care settings in addressing specific aspects of dementia palliative care. Each guidance document is accompanied by a factsheet, all of which are available to download via the following link

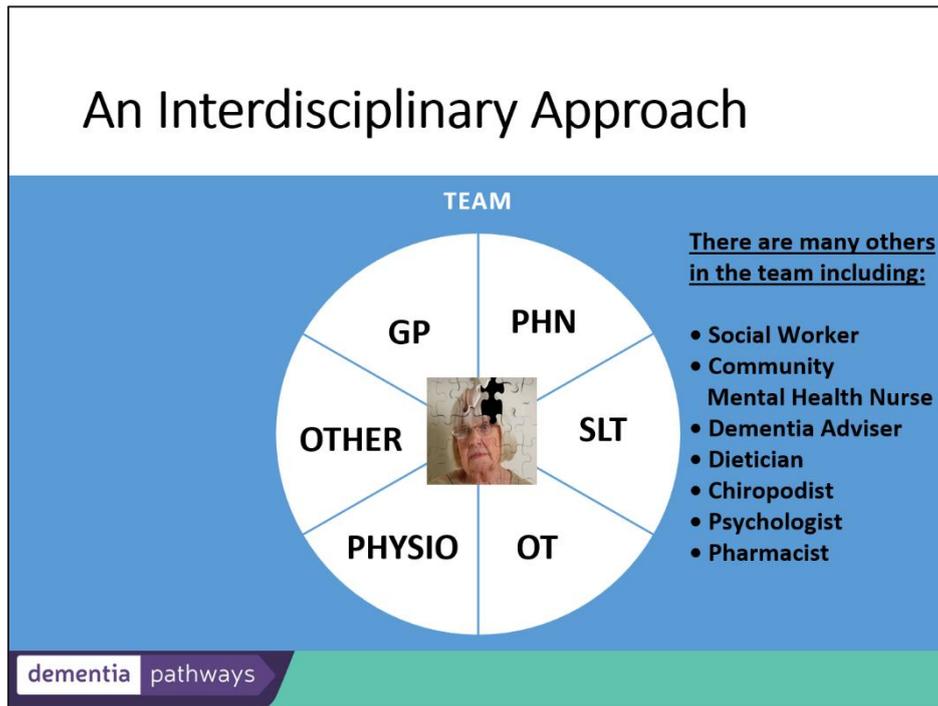
<http://hospicefoundation.ie/healthcare-programmes/dementia-palliative-care/guidance-documents-dementia/>



- › Open the discussion on the range of primary care healthcare staff who may be working with people living with dementia
- › Acknowledge that primary care teams are not uniform throughout the country



- › Ask individual team members to think about their role in supporting individuals living with dementia (and their families?)
- › How do the range of disciplines involved in individual cases communicate with each other?



- › The importance of an interdisciplinary approach for community and primary care dementia services



- › Consider how team members can increase collaboration in order to improve outcomes for people living with dementia
- Consider where disciplines overlap so that duplication is avoided
- › Consider how other professionals or agencies not on your team can contribute and how to access them
- › How can we ensure that the care is person centred?



*'A functioning primary care team is where a patient receives a better standard of care from interacting with a team than they would receive from dealing with individual health professionals. In essence teamwork leads to the sum being greater than the parts leading to improved quality of service for the patient' (ICGP Definition of a Functioning Primary Care Team)*

- › General Practitioner – assessment and diagnosis, information, treatment
- › Public Health Nurse – information and advice, assessment, access to home-help, meals on wheels, day-care centre, access to respite care
- › Physiotherapy - falls risk assessment, mobility assessment, mobility aids
- › Occupational Therapist – information, assessment and goal setting, practical strategies, assessment of the home, aids and appliances, assistive technologies
- › Speech and Language Therapist – communication advice, swallow assessment, assessment of speech/aphasia
- › Social Worker – rights, entitlements, advocacy, counselling
- › Community Psychologist – counselling, support family carer

Some of the above may not be part of your team so it's important to consider how the network of other available services in the community can contribute to the care of the person living with dementia. Other services include; Mental Health Services, Dementia Adviser, Dietetic, Podiatry, Pharmacy, Community Welfare Officer, Practice nurse, Environmental Health, Audiology – and there may be others.

A leaflet explaining Health & Social Care roles for people living with dementia and their families is available using the link: [https://www.understandtogether.ie/Training-resources/Helpful-Resources/Understand-Together-Resources/Leaflets/Leaflet-A4-Role-of-HSCP-in-Dementia-201901-FINAL\\_.pdf](https://www.understandtogether.ie/Training-resources/Helpful-Resources/Understand-Together-Resources/Leaflets/Leaflet-A4-Role-of-HSCP-in-Dementia-201901-FINAL_.pdf)



- › Part 1 of the case study is following a diagnosis of dementia (0–6 months)
- › Participants to consider their individual role in the care and management of Tom and how care can be enhanced by a team approach
- › Emphasise that dementia is a chronic, progressive disease and that input of expertise and interventions will be required by different professions at different stages, depending on the needs of the person living with dementia, their family and care partner.



This case study is presented in 3 parts in order to highlight the chronic and progressive nature of dementia and that intervention by different disciplines will be required at different times as the disease progresses and care needs change. There is a danger of creating overlap or lost opportunities for early intervention if professionals operate individually rather than taking a team-based approach. Furthermore, poor communication within the team can lead to fragmented and disjointed care where an overall goal or plan of care is not identified or pursued.

The focus of the exercise is to investigate what is important for Tom and his family which will determine the post diagnostic support(s) required and which member(s) of the interprofessional team is best placed to provide this support. The case study exercise will help participants understand each other's role and how they can learn from one another to improve outcomes for the person living with dementia and their family. Acknowledge that all participants in the room are already experts in their own field.

Refer to handouts of the case study summary if available.



Ask the group(s) to consider the questions in relation to the case study.

## SLIDE 22

## Case Study: Tom

- 76 year old retired carpenter (medical card holder)
- Diagnosed with Vascular Dementia 2 months ago in memory clinic
- History of Type 2 Diabetes, hypertension, hypercholesterolemia, osteoarthritis
- Independent in ADLs, driving, managing finances
- MMSE 25/30, ACE-111 72/100
- Lives with 71 year old wife
- 2 daughters living nearby
- On routine visit GP advised re medication, diet, exercise, power of attorney
- PHN called and gave numbers for Alzheimer's Society and local Dementia Day Care Centre

dementia pathways

## SLIDE 23

## continued six months later...

- Tom's daughter worried about home situation and enquiring about follow up appointment.
- Seen by GP – nil acute issues. Referred Tom to PHN.
- PHN called. Family not coping well with diagnosis.
- Wife taking on a lot of Tom's responsibilities. Constantly correcting him.
- Tom's confidence and motivation is low. He has stopped playing golf and going out socially.
- MMSE 24/30. Independent in ADL's. Did not require Home Help.

dementia pathways

## SLIDE 24

## Consider

- How might Tom be feeling?
- How might his wife be feeling?
- Consider how disciplines within the interprofessional health care team can help Tom and his family
- What would the likely outcome be if no action is taken?

dementia pathways

## Case Study Part 1: Learning Points

- People with dementia and their families will require post diagnostic support
- Carer education is an essential part of post diagnostic support
- Team members need to equip themselves with knowledge of dementia & available services in order to support the person
- Need to know who to refer to (within and outside the team) as needs change
- Knowledge of each others' roles will prevent overlap and duplication
- Early intervention can help limit the need for crisis intervention at a later stage

dementia pathways



- › People with dementia and their families will require post diagnostic support
- › Every team member does not need to be directly involved at this stage, although case discussion within the team can help direct an appropriate response
- › Appropriate intervention at the time of diagnosis can help the person living with dementia adapt and cope with a diagnosis of dementia
- › Important to note that 'over caring' is as much responsible for creating excess disability as the lack of appropriate supports when needed.



Coming to terms with a diagnosis of dementia may take a long time both for the person living with dementia and their family. The person might experience a range of emotions, including shock, anger, fear, or even relief at having their symptoms explained. Many people living with dementia and their families report not having access to sufficient information following a diagnosis. This may be the case however in many cases other factors are involved including:

- › person too shocked to take in the information – may need prolonged support from team member, support group, referral for counselling.
- › too much information given at once – information should be appropriate to the stage of the disease.
- › information given in a way the person did not understand – recommended that people receive written and verbal information at a level the person understands.
- › denial – not conveying the diagnosis and the use of euphemism adds to uncertainty for people living with dementia and their families, therefore disclosing a diagnosis is preferable. Disclosure of the diagnosis of dementia to the person living with dementia and their preferred other is an intrinsic part of the diagnostic process. This ensures 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. Some people may take longer to accept the diagnosis and acceptance may only be achieved after several consultations with the GP.

The person living with dementia needs to be allowed express their feelings and have them validated. It may be necessary for the nurse in Tom's case to restate some of the information he has already received with regard to the diagnosis and advice on lifestyle and other issues (general information that all healthcare professionals should possess). What Tom needs at this stage is reassurance. He has lost his confidence and needs encouragement to get back to normal living. He is in the early stages of dementia and still independent, there should be no reason he cannot go back to playing golf (consider enlisting a friend if experiencing difficulties) and getting out and about. Referral to the local Alzheimer's day care centre in Tom's case was premature and distressing for him as the people attending were at a more advanced stage. Furthermore, there should not be any reason for his wife to assume all the household responsibilities unless there is a particular difficulty e.g. forgetting to pay bills in which case perhaps this could be navigated together. Remember that 'over caring' may be as responsible for creating excess disability as the lack of appropriate supports when needed. Practical advice on managing memory deficits might prove helpful at this stage and if the healthcare professional does not feel competent to deliver this information, he/she should have knowledge of local services so that an appropriate referral can be made.



- › Part 2 of the case study and Tom's dementia has progressed
- › Participants to consider their individual role in the care and management of Tom and how care can be enhanced by a team approach

## SLIDE 27

## Tom 4 years later...

- PHN visits Tom at home following discharge from hospital - admitted for a fall (second in 3 months) and delirium secondary to a UTI
- Gait unsteady since discharge, less confident
- Appetite poor, sleeping a lot – staying in bed late or dozing in the chair
- Noted he was still on Quetiapine 25mgs following discharge from hospital
- Complaining of aches and pains

dementia pathways

## SLIDE 28

## Continued...

- More mixed up than usual and can get confused at night
- Generally more forgetful and easily distracted – losing things, not turning off the tap
- Less particular about appearance, argues about shaving and showering
- Conversation less fluent, frustrated at times
- Stopped attending day care 4 months ago and since then doing little in the way of social occupation.

dementia pathways

## Consider

- What action should the PHN take?
- What other member(s) of the primary care team should be involved? **How?**
- What other member(s) of the team could be involved? **How?**
- How might roles overlap and how could this be avoided?
- After this intervention, what follow up will be required for Tom and his family?
- By whom?

dementia pathways



- › Ask the group(s) to consider the questions relating to the case study.



- › Participants should consider the questions on the slide utilising existing expertise and experience

- › Allow sufficient time for discussion but if any of the following issues have not been addressed, consider prompts such as:

Residual effects of delirium – what is the impact on individual and the carer – what might be needed?

Second fall in four months – what action is required?

Tom is losing things, forgetting to turn off taps – what might help?

What about the night time confusion?

Why did he stop going to day care – can he go back or is there another alternative?

Tom is getting frustrated trying to communicate – what would help?

Is Tom in pain- how will this be assessed?

Does he still need to be on the antipsychotic Quetiapine?

What about the carer?

### Case Study Part 2: Learning Points

- As dementia progresses, needs change and become more complex
- Overtime, person will require a full range of health and social care interventions
- Aim is to delay deterioration, maintain health and wellbeing and enhance coping
- For this to happen roles and responsibilities of team members need to be clearly defined

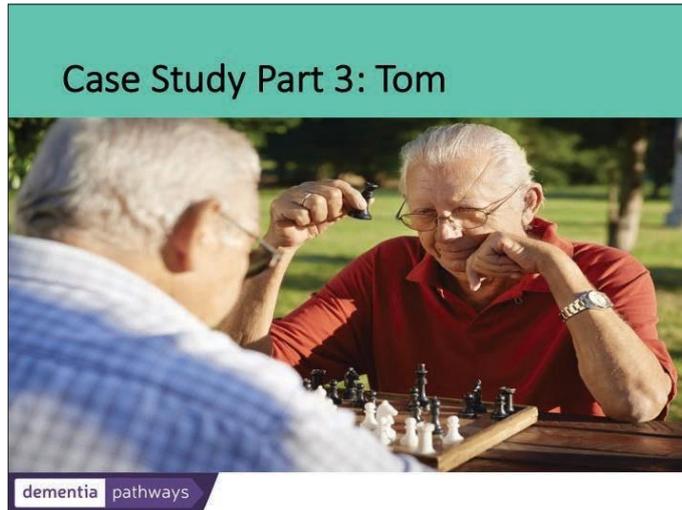
dementia pathways



- › As dementia progresses, the person’s needs change and can become complex.
- › Over time a fuller range of health and social care interventions are required, with the aim of delaying deterioration, maintaining health and wellbeing and enhancing coping.
- › Consider who can contribute to Tom’s care and in what ways, e.g.
  - › GP: physical assessment, medication review
  - › PHN: assessment, advice ADLs, referral for supports e.g. home help, voluntary organisations,
  - › OT: functional assessment, aids and appliances, assistive technology, advice on social occupation, compensation strategies, education
  - › SLT: assessment, communication plan, carer education
  - › Physiotherapist: gait and balance assessment, falls prevention
  - › Social Worker: family facilitation, emotional support/counselling, legal issues, crisis intervention
  - › Other? How?



- › **Vascular dementia** – generally progresses in a stepwise fashion (sudden worsening followed by periods of stability) often as a result of mini strokes that go unrecognised. As a remarkable degree of insight is sometimes maintained for a long time in VaD, the person often reacts to the awareness of deficit by extreme anxiety and depression (53). Evening or nocturnal confusion is a feature.
- › **Delirium** - As discussed previously delirium is typically an indicator of a physical pathology and even after treatment of the underlying cause in this case UTI, residual effects may persist. Educating the carer about those effects is important. Once the delirium has fully resolved the person may well return to their baseline, although an episode of delirium and hospitalisation can speed up deterioration.



- › **Pain** – people living with dementia are at increased risk of experiencing pain because they are at increased risk of other things that can cause pain, such as falls, accidents and injuries. Also, older people in general, including those living with dementia, are more likely to experience a range of medical conditions that can cause pain. In the early stages people living with dementia are able to communicate pain but as dementia progresses this becomes more difficult so it is important to watch for non-verbal signs such as, agitation or resistance to care. If a person becomes withdrawn or distressed because of pain, they may be assumed to be depressed and prescribed antidepressants. Observational pain assessment tools can help e.g. Abbey Pain Scale and The Pain Assessment in Advanced Dementia Scale (PAINAD).
- › **Falls** - vascular dementia causes changes in gait and postural stability which increases the risk of falls. While falls are a major health problem in their own right for older people living with dementia, it must be remembered that the older person living with dementia who is experiencing falls will also often have a number of other co-existing health problems. Consideration needs to be given to the complex interplay of these co-existing health problems, and also identify opportunities where an intervention may be beneficial across a number of co-existing health problems (54).
- › **Antipsychotics** - often prescribed to treat delirium in hospitalised patients but are not always discontinued on discharge. Unless there is a strong rationale for their continuance they should be discontinued. For additional information encourage participants to download the DoH, National clinical guideline on the 'Appropriate prescribing of psychotropic medication for non-cognitive symptoms in people with dementia available at: <https://www.gov.ie/en/collection/c9fa9a-national-clinical-guidelines/#appropriate-prescribing-of-psychotropic-medication-for-non-cognitive-symptoms-in-people-with-dementia>
- › **Carers** - Research evidence shows that there is a lack of information at all stages of the caring journey (55). Timely information, advice and guidance can help carers make effective decisions about care and support and develop effective coping strategies. Dementia Advisers, where available, provide a locally based, individualised, information, signposting and emotional support service to people who are concerned about their cognitive health and/or dementia and for their families and friends at all stages of the journey. Carer Development Officers, where available, also provide support, education and guidance to people living with dementia and their carers. The challenge at present is that neither services are provided nationally, therefore the importance of participants being aware of the local resources and supports available.

## And later again...

- Getting up and dressed in the middle of the night (now sleeping downstairs)
- Can be verbally aggressive, but has also lashed out once or twice
- Thinks the neighbours are coming in and stealing things
- Up and down – crying one minute, laughing the next
- Restless and pacing some days
- Wife exhausted

dementia pathways



› What approach should the team take?



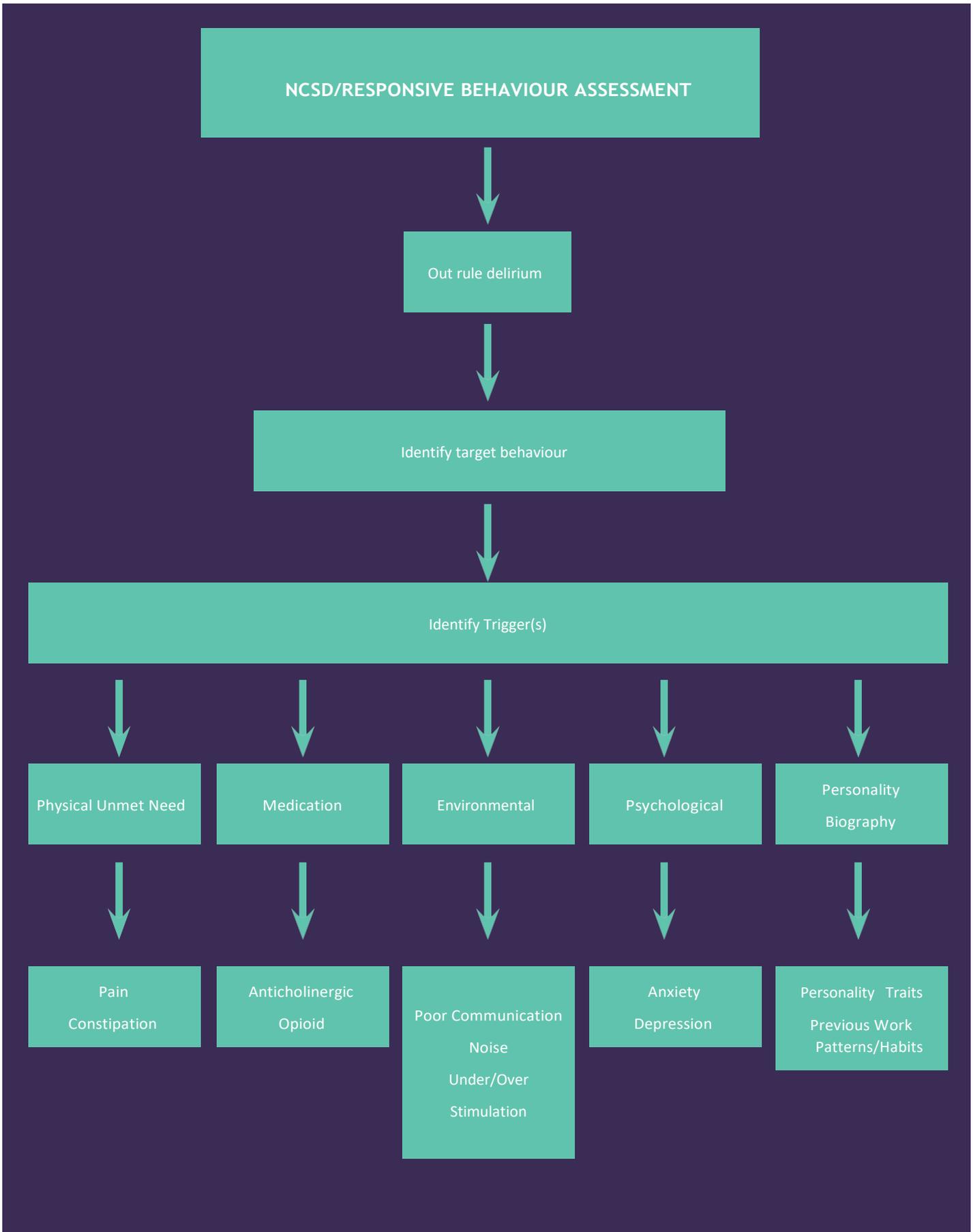
There are practical steps to take when assessing somebody with NCS/Responsive Behaviour (see template for assessment below). The first step is always to rule out delirium which requires treatment of the underlying cause.

The next step is to clarify what behavior you wish to address. Does the behavior even need intervention? For instance, in vascular dementia lability and explosive emotional outbursts, episodes of noisy weeping or laughing may occur on minor provocation, often without accompanying subjective distress or elation (56). Occasionally a person with Vascular dementia will strongly believe things that are not true (delusions) or see things that are not really there (hallucinations). Unless they are distressing the person or interfering with their quality of life, they may not require treatment with medication but carer education is essential.

### IDENTIFY TRIGGERS.

It is important to convey the concept that behaviour is often a form of communication. The person may be unable to communicate a need and so may react to situations with behaviour that is disturbing to others. Identifying the need that the person is trying to communicate will dictate the approach/treatment. Non-pharmacological interventions should always be the first line treatment except in situations where there is immediate risk of harm to self and/or others or undue distress.

A TEMPLATE FOR ASSESSING NCSD/RESPONSIVE BEHAVIOUR: (57)



## Consider

What approach should the team take now?  
What ongoing and future care needs should be discussed?

Discussion with the family could include:

- What supports are needed for Tom to continue living at home?
- Are there any safety issues?
- Has nursing home care been considered?
- Issues around acute care admission and treatment?
- Palliative care wishes?

dementia pathways



**Ask the group(s) to consider the questions relating to the case study.**



**Participants should consider the questions on the slide utilising existing expertise and experience**

Allow sufficient time for discussion but if any of the following issues have not been addressed, consider prompts such as:

- › Wife exhausted – evidence of significant carer stress
- › What are the immediate risks to both Tom & Wife?
- › Is there a need for emergency respite?
- › Is there a need for an urgent case conference to explore future care options?
- › Are there any additional home supports for e.g. home help hours available?
- › Tom sleeping downstairs – could assistive technology be used to enhance safety?
- › Are there finances to buy in private care at this time?
- › What are Tom's wishes - Has he an Advanced Healthcare Directive?

SLIDE 34

### Case Study Part 3: Learning Points

- Tom’s dementia has advanced
- Important to intervene quickly as issues arise to prevent carer burden
- Carer education important – what is normal progression and how to respond
- NCSO/Responsive behaviour should be seen as a form of communication
- Assessment of possible triggers should be undertaken before any intervention
- Family will need support to discuss care options as Tom’s dementia progresses

dementia pathways



Ongoing and future care needs will need to be assessed. Discussion with the family should include:

- › What support is needed for Tom to continue living at home?
- › Are there any safety issues?
- › Has nursing home care been considered?
- › Issues around acute care admission and treatment?
- › End of life care wishes and palliative care

SLIDE 35

### Final Summary

- Dementia is a chronic and progressive condition
- Over time, symptoms will require a full range of health and social care interventions
- Typically requires more than one discipline to address
- Necessary to understand others’ professions and one’s own role with regard to dementia care
- Better interdisciplinary collaboration seen as critical to improving outcomes for people living with dementia in the community
- Knowledge of local services and supports and when/where to refer essential

dementia pathways



- › Restate the aim of the programme which is to enhance skills and knowledge, promote a better understanding of each other’s roles and encourage collaborative care of clients living with dementia.

## Project Ideas

Take 15 minutes to discuss how as a team you can increase collaboration that will lead to better outcomes for people with dementia

For example:

- Case discussion at primary care meeting
- Choose a case to follow (full PCT involvement)
- Improve referral pathway
- Improve communication pathway
- List resources available locally (type of service, how to access)
- Look at national initiatives (see handouts)

dementia pathways



- › Ask the group(s) to discuss a change that they could implement– could revisit challenges highlighted at the start of the workshop to inform this discussion
- › Acknowledge concerns about resources
- › Emphasise that even small changes to practice such as improved team communication processes can improve team efficiency, leading to improved outcomes for the person living with dementia and improved satisfaction for the team



- › If applicable, acknowledge concerns around time and resources to undertake a project, and emphasis that even small changes to practice such as improved team communication processes can improve team efficiency and lead to improved outcomes for the person with dementia.
- › Consider projects that might help improve interprofessional practice, and projects where GPs and general practice staff, community pharmacists, HSE health care professionals and voluntary sector agencies could work together on shared initiatives.
- › Raise the option for GPs and for other PCT members to look at clinical audit projects. For GPs that might be interested, there are practice-based data tools and clinical audit guides available on dementia audits (dementiaphways.ie, and on the ICGP website)

## Resources, Contact us, and Thanks!

- List of useful websites and resources (see handouts)
- More clinical and educational information on [dementiaphathways.ie](http://dementiaphathways.ie)
- To contact us:  
National Dementia Office [dementia.office@hse.ie](mailto:dementia.office@hse.ie)
- Thank you for your time today

dementia pathways



- › Draw participants' attention to the list of online resources and publications and availability of additional discipline specific materials and resources, especially those on [www.dementiaphathways.ie](http://www.dementiaphathways.ie)
- › If applicable, refer to any handouts and resources given to attendees
- › If applicable, ask for attendees to complete feedback evaluation forms
- › Thank all attendees for their participation

## CASE STUDY TOM

### Part One

Tom is a 76-year-old retired carpenter (medical card holder), diagnosed with Vascular dementia 2 months ago in the local memory clinic. He has a history of Type 2 diabetes, hypertension, hypercholesterolemia, osteoarthritis.

- › Independent in ADLs, driving, managing finances
- › MMSE 25/30, ACE-III 72/100
- › Lives with 71-year-old wife, and has 2 daughters living nearby
- › On routine visit GP advised re medication, diet, exercise, power of attorney
- › PHN called and gave numbers for Alzheimer's Society and local Dementia Day Care Centre

### Six months later:

Tom's daughter rang the memory clinic enquiring about a follow up appointment. Advised to return to GP or PHN. Tom was seen by the GP – nil acute issues, and Tom was referred to the PHN.

PHN called and met Tom, his wife Mary and daughter Marie. Daughter Marie worried about her mother who was finding it hard to cope with the diagnosis, and had taken over managing his medications and paying the bills. Wife Mary doesn't drive but now doesn't want Tom driving on his own, although he has had no problems thus far. Constantly correcting him and checking up on him. Daughter feels all this is having a negative impact on Tom. He has stopped playing golf – was having trouble keeping the score, going out less socially. Embarrassed if he forgets people's names or can't follow conversation. Tom's wife encouraged him to visit local Alzheimer's Day Care Centre, but he was very upset afterwards and didn't return. Appears quieter with less motivation to do things. MMSE 24/30. Independent in ADLs. Did not require Home Help.



- › How might the client be feeling?
- › How might his wife be feeling?
- › Consider how disciplines within the interprofessional health care team can help Tom and his family
- › What would the likely outcome be if no action is taken?

## CASE STUDY TOM

### Part Two

#### Four years later:

- › PHN visits Tom at home following discharge from hospital - admitted for a fall (second in 3 months) and delirium secondary to a UTI
- › Wife reported that his mobility had deteriorated especially since hospital admission, unsteady and less confident
- › Appetite poor, sleeping a lot – staying in bed late or dozing in the chair
- › Noted he was still on Quetiapine 25mgs following discharge from hospital  
Complaining of aches and pains
- › Appears more easily distracted – leaves taps on and doors open
- › More mixed up than usual and can get confused at night which is a new development
- › Less particular about appearance, argues about shaving and showering
- › Conversation less fluent, clearly frustrated at times.
- › Everything going fairly smoothly up to 4 months ago when he stopped attending day care (had started attending 2 days a week, 18 months previously) and since then doing little in the way of social occupation.
- › His wife seemed tired and upset.



- › What action should the PHN take?
- › What other member(s) of the primary care team should be involved? How?
- › What other member(s) of the team could be involved? How?
- › How might roles overlap and how could this be avoided?
- › After this intervention, what follow up will be required for Tom and his family?
- › By whom?

## CASE STUDY TOM

### Part Three

#### 7 years later...

Tom is often getting up and dressed in the middle of the night (now sleeping downstairs)

He can be verbally aggressive, but has also lashed out once or twice

- › Tom thinks the neighbours are coming in and stealing things
- › He's up and down – crying one minute, laughing the next
- › Restless and pacing some days
- › Tom's wife, Mary, is exhausted



- › What approach should the team take?
- › What ongoing and future care needs should be discussed?
- › Discussion with the family could include:
  - › What support is needed for Tom to continue living at home?
  - › Are there any safety issues?
  - › Has nursing home care been considered?
  - › Issues around acute care admission and treatment?
  - › Palliative Care wishes



## References & Resources

1. Department of Health. The Irish National Dementia Strategy. 2014.
2. Hopper L, Joyce, R., Bieber, A., Broda, A., Irving, K., Verhey, F., Experiences of providing formal home and community dementia care in Ireland: advocating for a holistic systemic approach. *Age and Ageing*. 2016;45(Supplement 2).
3. O' Shea E, Monaghan, C., Keogh, F. Resource allocation on the boundary of care for people with dementia in Ireland. *Age and Ageing*. 2016;45(Supplement 2).
4. Argyle E, Downs, M. and Tasker, J. Continuing to Care for People with Dementia: Irish Family Carers' Experience of their Relative's Transition to a Nursing Home. Bradford Dementia Group, Bradford, The Alzheimer Society of Ireland, Dublin and St Luke's Home, Cork: 2010.
5. Begley E. I know what it is but how bad does it get?": Insights into the Lived Experiences and Services Needs of People with Early-State Dementia. Trinity College Dublin: 2009.
6. Hastings R. An Exploration into Family Caregivers' Experiences of Caring for a Person with Dementia. 2009.
7. Alzheimer Society of Ireland. Early-onset dementia the needs of younger people with dementia in Ireland. Dublin: 2005.
8. Cahill S, O'Shea E, Pierce M. Creating Excellence in Dementia Care: A Research Review for Ireland's National Dementia Strategy. 2012.
9. Irving K, Piasek P, Kilcullen S, Coen A-M, and Manning M. National Educational Needs Analysis Report. Elevator, 2014.
10. World Health Organisation. Framework for Action on Interprofessional Education and Collaborative Practice. Geneva, Switzerland: 2010.
11. Reeves S, Goldman, J., Sawatzky-Girling, B., Burton, A. Knowledge transfer and exchange in inter-professional education: Synthesizing the evidence to foster evidence-based decision-making. Vancouver, Canada: Canadian Interprofessional Health Collaborative, 2008.
12. Barr H, Freeth D, Hammick M, Koppel I, Reeves S. Evaluations of interprofessional education: A United Kingdom review for health and social care.: Centre for the Advancement of Interprofessional Education in Primary Health and Community Care: 2000.
13. Mickan S, Hoffman SJ, Nasmith L. Collaborative practice in a global health context: Common themes from developed and developing countries. *Journal of interprofessional care*. 2010;24(5):492-502.
14. Alzheimer's Research UK. One in three people born in 2015 will develop dementia, new analysis shows 2015. Available from: <https://medicalxpress.com/news/2015-09-people-born-dementia-analysis.html>
15. Pierce M, Cahill, S and O'Shea, E.,. Prevalence and Projections of Dementia in Ireland 2011-2046. Trinity College Dublin and National University College Galway: 2014.
16. Mesterton J, Wimo A, By A, Langworth S, Winblad B, Jonsson L. Cross sectional observational study on the societal costs of Alzheimer's disease. *Current Alzheimer research*. 2010;7(4):358-67.
17. World Health Organisation. Everybody's business: strengthening health systems to improve health outcomes: WHO's framework for action. WHO Document Production Services, Geneva, Switzerland: 2007.
18. Zwarenstein M, Reeves S, Perrier L. Effectiveness of pre-licensure interprofessional education and post-licensure collaborative interventions. *Journal of interprofessional care*. 2005;19 Suppl 1:148-65.
19. Lumague M, Morgan A, Mak D, Hanna M, Kwong J, Cameron C, et al. Interprofessional education: the student perspective. *Journal of interprofessional care*. 2006;20(3):246-53.
20. Hammick M, Olkers, L and Campion-Smith, C. Learning in Interprofessional Teams. Dundee, UK: Association for Medical Education in Europe (AMEE): 2010.
21. Centre for the Advancement of Interprofessional Education. Interprofessional Education: a definition 2002. Available from: <https://www.caipe.org/>
22. Oeseburg B, Hilberts R, Luten TA, van Etten AV, Slaets JP, Roodbol PF. Interprofessional education in primary care for the elderly: a pilot study. *BMC Medical Education*. 2013;13(1):161.
23. Dementia Pathways. Available from: [www.dementiapathways.ie](http://www.dementiapathways.ie)
24. O' Shea E, Murphy, E. Genio Dementia Programme: Year 1 Evaluation. Irish Centre for Social Gerontology. NUI Galway: 2014.
25. Brennan, S., Lawlor, B., Pertl, M., O'Sullivan, M., Begley, E., and O'Connell, C. De-Stress: A study to assess the health & wellbeing of spousal carers of people with dementia in Ireland. Dublin, Alzheimer's Society of Ireland:2017.
26. Pinquart M, Sorensen S. Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: a meta-analysis. *The journals of gerontology Series B, Psychological sciences and social sciences*. 2003;58(2): P112-28.
27. Bertrand RM, Fredman L, Saczynski J. Are all caregivers created equal? Stress in caregivers to adults with and without dementia. *Journal of aging and health*. 2006;18(4):534-51.
28. Kitwood T. Dementia Reconsidered: The Person Comes First. Buckingham: Open University Press: 1997.
29. Hodges J. Cognitive Assessment for Clinicians: Oxford University Press: 2007.

30. Pryse-Phillips W, Wahlund, L. Other dementias. In G. Wilcock, R. Bucks & K. Rockwood. *Diagnosis and the management of dementia: A manual for memory disorder teams*: Oxford University Press; 1999.
31. European Communities. *Rare forms of Dementia*. 2005.
32. Arevalo-Rodriguez I, Smailagic N, Roqué i Figuls M, Ciapponi A, Sanchez-Perez E, Giannakou A, et al. Mini-Mental State Examination (MMSE) for the detection of Alzheimer's disease and other dementias in people with mild cognitive impairment (MCI). *Cochrane Database of Systematic Reviews*. 2015(3).
33. Brodaty H, Pond D, Kemp NM, Luscombe G, Harding L, Berman K, et al. The GPCOG: a new screening test for dementia designed for general practice. *Journal of the American Geriatrics Society*. 2002;50(3):530-4.
34. Trzepacz PT, Hochstetler H, Wang S, Walker B, Saykin AJ. Relationship between the Montreal Cognitive Assessment and Mini-mental State Examination for assessment of mild cognitive impairment in older adults. *BMC Geriatrics*. 2015; 15:107.
35. Tariq SH, Tumosa N, Chibnall JT, Perry MH, 3rd, Morley JE. Comparison of the Saint Louis University mental status examination and the mini-mental state examination for detecting dementia and mild neurocognitive disorder--a pilot study. *The American journal of Geriatric Psychiatry: official journal of the American Association for Geriatric Psychiatry*. 2006;14(11):900-10.
36. McCabe JJ, Kennelly SP. Acute care of older patients in the emergency department: strategies to improve patient outcomes. *Open Access Emergency Medicine: OAEM*. 2015; 7:45-54.
37. Wilcock G, Bucks, R., Rockwood, K. *Diagnosis and management of dementia: a manual for memory disorder teams*: Oxford University Press; 1999.
38. Foley TDS, Greg Prof.; ICGP Quality in Practice Committee. *Dementia: Diagnosis and Management in General Practice. Quick Reference Guide*. Irish College of General Practitioners: 2014.
39. Alzheimer Society Europe. *What are responsive behaviours* 2011. Available from: <http://u-first.ca/understanding-dementia/what-are-responsive-behaviours/>.
40. Department of Health. *The use of antipsychotic medication for people with dementia: Time for action*. 2009.
41. Alzheimer's Society. *Optimising treatment and care for people with behavioural and psychological symptoms of dementia*: 2011.
42. McCleery J, Cohen DA, Sharpley AL. Pharmacotherapies for sleep disturbances in Alzheimer's disease. *The Cochrane database of systematic reviews*. 2014(3):Cd009178.
43. Tariot PN, Erb R, Leibovici A, Podgorski CA, Cox C, Asnis J, et al. Carbamazepine treatment of agitation in nursing home patients with dementia: a preliminary study. *Journal of the American Geriatrics Society*. 1994;42(11):1160-6.
44. Stoppe G, Brandt CA, Staedt JH. Behavioural problems associated with dementia: the role of newer antipsychotics. *Drugs & aging*: 1999;14(1):41-54.
45. Kozman MN, Wattis J, Curran S. Pharmacological management of behavioural and psychological disturbance in dementia. *Human psychopharmacology*. 2006;21(1):1-12.
46. Foley T, Swanwick GP, Committee. IQiP. *Dementia: Diagnosis and Management in General Practice*. Irish College of General Practitioners: 2014.
47. Connell CM, Boise L, Stuckey JC, Holmes SB, Hudson ML. Attitudes toward the diagnosis and disclosure of dementia among family caregivers and primary care physicians. *The Gerontologist*. 2004;44(4):500-7.
48. Derksen E, Vernooij-Dassen M, Gillissen F, Olde Rikkert M, Scheltens P. Impact of diagnostic disclosure in dementia on patients and carers: qualitative case series analysis. *Aging & Mental Health*. 2006;10(5):525-31.
49. La Fontaine J, Buckell, A., Knibbs, T and Palfrey, M. *Early and Timely intervention in Dementia: Pre assessment counselling*. Briefing Paper for Faculty for Psychology of Older People and Dementia Action Alliance: 2013.
50. Moyle W, Venturato L, Cooke M, Murfield J, Griffiths S, Hughes J, et al. Evaluating the capabilities model of dementia care: a non-randomized controlled trial exploring resident quality of life and care staff attitudes and experiences. *International psychogeriatrics*. 2016;28(7):1091-100.
51. Okumura Y, Tanimukai S, Asada T. Effects of short-term reminiscence therapy on elderly with dementia: A comparison with everyday conversation approaches. *Psychogeriatrics*. 2008;8(3):124-33.
52. Kar N. Behavioral and psychological symptoms of dementia and their management. *Indian Journal of Psychiatry*. 2009;51(Suppl1): S77-S86.
53. Hill K. *Look beyond dementia diagnosis to stop falls* Australian Ageing Agenda 2016. Available from: <https://www.australianageingagenda.com.au/contributors/opinion/look-beyond-dementia-diagnosis-to-stop-falls/>.
54. Carers Trust. *A Road Less Rocky: Supporting Carers of People with Dementia*. 2013.
55. Lishman W. *Organic Psychiatry: The Psychological Consequences of Cerebral Disorder* Blackwell Scientific Publications; 1987.
56. Foley T, Jennings, A. *Dementia Care in General Practice: Facilitator's Workshop Guide*. Primary Care Education, Pathways and Research of Dementia (PREPARED): University College Cork: 2016.

58. McGowan, B., Gibb, M., Cullen, K., Craig, C. Non-Cognitive Symptoms of Dementia (NCSD): Guidance on Non-pharmacological Interventions for Healthcare and Social Care Practitioners. Tullamore: National Dementia Office: 2019 Available at <http://dementiathways.ie/permacache/fdd/cf3/a82/78c5c1dbdb7312e20fd87ee90c660c48.pdf>
59. Department of Health. Appropriate prescribing of psychotropic medication for non-cognitive symptoms in people with dementia. (NCEC National Clinical Guideline No 21). 2019. Available at: <https://www.gov.ie/en/collection/ac0046-appropriate-prescribing-of-psychotropic-medication-for-non-cognitive/>
60. Schneider, L.S., Dagerman, K.S., and Insel, P. Risk of death with atypical antipsychotic drug treatment for dementia: meta-analysis of randomized placebo-controlled trials. *JAMA*. 2005; 19; 294(15):1934-1943.
61. Schneider, L.S., Dagerman, K.S., and Insel, P. Efficacy and adverse effects of atypical antipsychotics for dementia: meta-analysis of randomized, placebo-controlled trials. *American Journal of Geriatric Psychiatry*. 2006;14(3):191-210.
62. Banerjee, S. The use of antipsychotic medication for people with dementia: Time for action. Department of Health. London: 2009
63. Health Information and Quality Authority National Standards for Residential Care Settings for Older People in Ireland: 2016. Available at: <https://www.hiqa.ie/sites/default/files/2017-01/National-Standards-for-Older-People.pdf>
64. Walsh, K.A., Sinnott, C., Fleming, A., McSharry, J., Byrne, S., Browne, J., and Timmons, S. Exploring Antipsychotic Prescribing Behaviours for Nursing Home Residents with Dementia: A Qualitative Study. *Journal of the American Medical Directors Association*. 2018. 19(11): 948-958.
65. O'Shea, E., Cahill, S., and Pierce, M. Developing and implementing dementia policy in Ireland. Centre for Economic and Social Research on Dementia. Galway: 2017.
66. Gibb, M., O'Caheny, D., Craig, C., and Begley, E. The Next Steps: Dementia post-diagnostic support guidance. National Dementia Office. Tullamore: 2019.
67. NICE. Clinical Guideline (NG97): Dementia: assessment, management and support for people living with dementia and their carers. London: National Institute for Clinical Excellence: 2018. Available at: <https://www.nice.org.uk/guidance/ng97>
68. Newman, C., A., Zajicek, J., Hodges, J., Vuillermoz, E., Dickenson, J., Kelly, D. S., Brown, S. & Noad, R.S. (2018) Improving the quality of cognitive screening assessments: ACEmobile, an iPad-based version of the Addenbrooke's cognitive examination-III. *Diagnosis, Assessment & Disease Monitoring: Alzheimer's & Dementia*; 2018. p. 182–187.
69. Understand Together Service Finder: <https://www.understandtogether.ie/get-support/service-finder/>





# dementia pathways

For Health & Social Care Professionals

