DEMENTIA CARE IN PRIMARY CARE
- AN INTERPROFESSIONAL APPROACH -
A GUIDE FOR WORKSHOP FACILITATORS
INTRODUCTION

Facilitator’s Workshop Guide

DEVELOPED BY THE PREPARED TEAM

PRIMARY CARE, EDUCATION, PATHWAYS AND RESEARCH OF DEMENTIA

THE DEPARTMENT OF GENERAL PRACTICE,

UNIVERSITY COLLEGE CORK

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About PREPARED

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

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

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WORKSHOP

Dementia in Primary Care – An Inter-Professional Approach

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INTRODUCTION

Population ageing across Europe means that the number of people 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 with dementia to remain living at home for as long as possible (1). However, empirical evidence suggests that people with dementia, experience significant difficulty accessing appropriate community care services (2-7). Cahill et al found that services offered for people 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 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 with dementia and their families and carers. 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).

Background

Population ageing across Europe means that the number of people 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 with dementia to remain living at home for as long as possible (1). However, empirical evidence suggests that people with dementia, experience significant difficulty accessing appropriate community care services (2-7). Cahill et al found that services offered for people 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).

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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 optimizes 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 organized 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 a 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 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 prioritized dementia-specific educational needs of primary care and community-based health professionals. Other excellent educational resources are available, many of which we have referenced.

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 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.

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**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

<table>
<thead>
<tr>
<th>TOPIC</th>
<th>SUGGESTED TIME ALLOCATION</th>
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<tbody>
<tr>
<td>WELCOME AND INTRODUCTION (INCLUDING VIDEO, BACKGROUND TO PREPARED PROJECT, AND INTRODUCTION OF DEMENTIAPATHWAYS.IE WEBSITE)</td>
<td>25 MINUTES</td>
</tr>
<tr>
<td>OVERVIEW OF DEMENTIA</td>
<td>40 MINUTES</td>
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<tr>
<td>BREAK</td>
<td>15 MINUTES</td>
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<tr>
<td>CASE STUDY</td>
<td>70 MINUTES</td>
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<tr>
<td>• PART 1: 10 MINS GROUPWORK, 10 MINS DISCUSSION (INCLUDING LEARNING POINTS)</td>
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<td>• PART 2: 15 MINS GROUPWORK, 10 MINS DISCUSSION (INCLUDING LEARNING POINTS)</td>
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<td>• PART 3: 15 MINS GROUPWORK, 10 MINS DISCUSSION (INCLUDING LEARNING POINTS)</td>
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<tr>
<td>DISCUSSION – ‘DEMENTIA PROJECT IDEAS’</td>
<td>25 MINUTES</td>
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<tr>
<td>• 15 MINUTES GROUPWORK</td>
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<tr>
<td>• 10 MINUTES DISCUSSION</td>
<td></td>
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<tr>
<td>SUMMARY, RESOURCES, CONTACTS, THANK YOU</td>
<td>5 MINUTES</td>
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<tr>
<td>TOTAL DURATION</td>
<td>180 MINUTES</td>
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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 with dementia and the roles of GPs and primary care health professionals.

Video clip available at dementiapathways.ie or on youtube at https://www.youtube.com/watch?v=7sAXTkQZjJw

Ask participants to introduce themselves and to share one positive aspect of their role in providing care for a person with dementia in primary care 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 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 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 (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 55,000 (15). Approximately 4,066 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 147,000 by 2041 with dementia now being one of the key health challenges of the 21st Century (16).
**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.
- 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, 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 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.
- 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.’
- 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.
Today’s workshop will include a:

- Brief overview of the PREPARED project
- Emphasise that the overall aim is to foster a deeper understanding of each others’ roles in caring for a person with dementia and to improve knowledge of dementia and promote interdisciplinary collaboration seen as critical to improving outcomes for people 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 with dementia

The PREPARED project (Primary Care Education, Pathways and Research of Dementia) is based in the Department of General Practice in University College Cork (UCC) and is a collaboration between the Department of General Practice, UCC, the Irish College of General Practitioners (ICGP) and Dublin City University (DCU). It is funded through the Irish National Dementia Strategy (HSE/Atlantic Philanthropies). PREPARED aims to support GPs and Primary Care Teams nationally in their delivery of integrated, multidisciplinary dementia care.

The aim of this workshop is to foster a deeper understanding of each others’ roles in caring for a patient with dementia and to introduce the PREPARED project to Primary Care Teams 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 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 some time to reflect on introducing a change with the potential of improving team collaboration and forming a common goal of improving outcomes for people with dementia living 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.
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 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 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 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 with dementia and family carers was 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
Dementia Pathways (www.dementiapathways.ie) is a web-based clinical education resource designed for Irish GPs and community based healthcare professionals. It has been launched as part of the PREPARED initiative (24).
The main bulk of care for people 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). An Irish survey found that the average number of hours per day spent caring as the dementia progressed rise from 7.18 hours in the early stage to 13.15 hours during the late stages (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 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 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 is a syndrome characterised by progressive cognitive impairment and is associated with impairment in functional abilities and in many cases, behavioural and psychological symptoms.

The term dementia refers to a group of syndromes characterized by a progressive decline in cognitive function. Over 200 subtypes have been defined.

The main sub-types of dementia include Alzheimer’s Disease (AD), Vascular Dementia (VaD), Dementia with Lewy Bodies (DLB), fronto-temporal dementia, and Mixed Dementias.

The diagnostic criteria for dementia is outlined on this slide. The medical terminology used on the slide will now be further explained:

APRAXIA
- the inability to carry out voluntary and purposeful movements despite the fact that muscular power, sensibility and coordination are intact. In everyday terms this might include the inability to tie shoelaces, turn a tap on, fasten buttons or switch on a radio.

APHASIA
- a difficulty or loss of ability to speak or understand spoken, written or sign language as a result of damage to the corresponding nervous center. May involve substituting a word which is linked by meaning e.g. time instead of clock, using the wrong word but one which sounds similar e.g. boat instead of coat or use a completely different word with no apparent link.

AGNOSIA
- the loss of the ability to recognise what objects are and what they are used for. May result in a person attempting to use a fork instead of a spoon or a knife instead of a pencil. With regard to people, this might involve failing to recognise who people are.

EXECUTIVE FUNCTION
- the cognitive process that organises simple ideas, behaviours and affects into complex actions, the one best action for the environmental cue and the right step for the goal. Impairments in this domain typically involve errors of planning, judgement, problem solving, impulse control and abstract reasoning.

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 with dementia, the impact on their lives may be much greater – may be still working, financial commitments, family commitments, unfulfilled ambitions etc.
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 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.
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, organizing the information, deciding what is important / not important, storing the information for later retrieval, retrieving it when useful
- Using the information to make decisions about what to do, to solve problems, to communicate.
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, organizing it, and marking it for storage

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

**RETRIEVAL:** Calling stored information to consciousness (30)
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 will live 4-8 years following diagnosis but may live up to 20 years.

**VASCULAR DEMENTIA** 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 unrecognized 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
caused by disease that primarily affects the frontal and temporal lobes of the brain.

Presentation: Affects the ability to reason and make decisions, prioritize 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).
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

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 organize. 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]

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

‘Hello Brain’, an innovative website promoting brain health was recently 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/

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 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
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
- AMTS: Abbreviated Mental Test Score
- ACE-R: Addenbrooke’s Cognitive Examination

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 favourably 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. There is also an ACE-111 app called the ACE mobile. This digital version can automatically score the completed test and generate reports. More details can be found at www.acemobile.org. The ACE-111 and the ACE mobile app are both free to download.
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.

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 investigation. The differential diagnosis needs to be considered. Treatable causes of cognitive impairment include depression, hypothyroidism, certain vitamin deficiencies and delirium.

**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 characterized by inattention, disorganized 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.

**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 haemorrhage, extra and subdural haematoma, 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 does 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.
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 behavioural symptoms

Non pharmacological interventions should be considered first for BPSD/responsive behaviours

Antipsychotic use may be justified in severe cases of disturbance and complex risk

People with dementia can be prescribed a range of medications during the course of the illness. Some are specifically for the dementia, some for underlying pathology and others for symptoms that may emerge as part of the dementia. For example, people with vascular dementia often need to take medications for underlying conditions such as stroke, high blood pressure, diabetes, high cholesterol or heart problems. Controlling these conditions and adopting a healthy lifestyle may help to delay the progression of this dementia.

People with dementia may also be prescribed a range of medications to help relieve behavioural symptoms and depression. Not every person with dementia will need these medications and there are other methods to help manage these symptoms. Some people may need medication for a short period of time. A decision to prescribe these medications should involve a full assessment of the person with dementia, their physical health and wellbeing and any other factors that might precipitate or exacerbate the behavior.
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 (AChEIs) are the first-line agents for the treatment of mild to moderate Alzheimer disease. While AChEIs 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 with dementia. AChEIs are licensed for the treatment of mild to moderate Alzheimer’s disease (except rivastigmine 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. Patients 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 patients 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 BPSD/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 person’s 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).
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 carer in discussion with regard to proposed use

BPSD is a general term used to describe a range of behavioural and psychological symptoms experienced by people with dementia. The term ‘Responsive Behaviour’ (as opposed to challenging behaviour) is now also being widely used in an attempt to shift the focus solely from pathology/disease as the root cause of all behaviours and actions to a multi-dimensional approach that seeks a broader and more comprehensive understanding of the person with dementia (40). It looks beyond the purely physical causes to the social, psychological and environmental factors which may also precipitate certain behaviours.

ANTIPSYCHOTICS

Antipsychotics are frequently prescribed for the management of BPSD/Responsive Behaviour, 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 BPSD 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 (serequol). Typical antipsychotics are known to have a severe side effect profile; therefore, atypical antipsychotics are more widely used as side effects are less.

It has become clear that people with dementia as a whole are at higher risk of potentially serious adverse effects from antipsychotic medication. Therefore, antipsychotics should not be a first-line treatment except in circumstances of extreme risk and harm. 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-pharmacologic 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.

Other medications that may be used over the course of the person’s dementia includes:
- Antipsychotics for the management of BPSD/Responsive Behaviour
- Antidepressants to treat depression
- Hypnotics for nighttime disturbance
- Anticonvulsants for the treatment of agitation and anxiety
Note. Certain behaviours are unlikely to respond to pharmacological intervention:

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

**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 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).

**ANTICONVULSANTS**
In some trials carbamazepine has been found to reduce agitation, restlessness and anxiety (44, 45), however the efficacy and tolerability of long term use of this drug is yet to be established (46).

**BENZODIAZEPINES**
Due to their significant side effects use of benzodiazepines should be avoided in the treatment of people with dementia (42). They 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).
People with dementia will need information appropriate to their stage of illness

Will need increasing levels of support as dementia progresses

People 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

**POST DIAGNOSIS**

It is known that informing and educating people with dementia about the condition can enable them and their caregivers to adjust and adapt to living with dementia (48, 49). Yet people with dementia and their families have described how even after getting a diagnosis, they felt that they were left to their own devices to source and access appropriate services, if indeed they existed.

The information given to the person with dementia should be appropriate to their stage of illness and in the early stages may include information on the following:

- the signs and symptoms of dementia
- its course and prognosis
- medications
- practical tips for dealing with memory loss
- cognitive stimulation/ rehabilitation
- sources of financial and legal advice, and advocacy
- the income supports available for those with an illness/disability and for those with caring responsibilities
- advice on driving
- local information sources, including libraries and voluntary organisations

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 with dementia and their families or be able to signpost them to the relevant information.
and supports. As available services may differ in different healthcare areas you should familiarise
yourself with local resources.

**DISEASE PROGRESSION**

As dementia advances the person with dementia and their family will require more information to
help them understand what is happening. The focus of care should be to maintain independence for
as long as possible. Support should only be provided incrementally as the person needs it. Without
education, there is a danger that carers may be inclined to ‘overcare’ thus creating excess disability
for the person with dementia. Similarly, not providing appropriate support when needed can also
create excess disability.

Services such as day care, respite care, home help and particularly home care packages can assist
family caregivers to continue providing care.

The person with dementia will also require the intervention of more than one member of the team
as issues present for example, nutrition, diet, swallow, gait, communication, safety, risk.

Assistive technology ranges from very simple tools, such as calendar clocks and touch lamps,
to high-tech solutions such as satellite navigation systems to help find someone who has gone
missing. These modifications and technologies can promote independence and autonomy, both for
the person with dementia and those around them, and can reduce the stress on carers, improving
their quality of life, and that of the person with dementia. The consent of the person with dementia
should, where possible, be sought and obtained for the use of assistive technology.

**PREVENTION/MANAGEMENT OF BPSD/RESPONSIVE BEHAVIOUR**

People with dementia may develop behavioural and psychological symptoms/Responsive
Behaviour in dementia 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 behavior 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 behavior may be attributable to factors other than
the person’s dementia, although dementia makes the person more vulnerable to negative
consequences. A change in behavior therefore should be considered as communication of 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. Non pharmacological 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 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.

**NON-PHARMACOLOGICAL INTERVENTIONS**

The following interventions have been found to have benefit for people with dementia but 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.

Participation in social activities – 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 manage behaviour that is distressing for the person with dementia and a cause of stress and strain for the caregiver.

DEMENTIA PALLIATIVE CARE

Palliative dementia care involves supporting the person 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 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 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 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 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 – generally the first point of contact – 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. Other services include Dietetic, Podiatry, Pharmacy, Community Welfare Officer, Practice nurse, Environmental Health, Audiology – and there may be others.
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.

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. 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.

Acknowledge that the participants in the room are already the experts in their own field. The focus of the case study is to understand each other’s role and how we can learn from one another to improve outcomes for the person with dementia and their family.

Refer to handouts of the case study summary if available.

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

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 low. Has stopped playing golf and going out socially.
- MMSE 24/30. Independent in ADLs. Did not require Home Help.

Consider

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?
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 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 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 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 patients and their families, therefore disclosing a diagnosis is preferable. For some people it may take longer to accept a diagnosis and it may only be achieved after several consultations with the GP. A small number are unable to confront/cope with a diagnosis and in such instances the diagnosis may be withheld. Good team communication is essential at this time.
The person 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.
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

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.
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?

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?
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 unrecognized. 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 hospitalization can speed up deterioration.
Pain – people 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 with dementia, are more likely to suffer from a range of medical conditions that can cause pain. In the early stages people 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. If a person becomes withdrawn or distressed because of pain, they may be assumed to be depressed and prescribed antidepressants. 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 good reason for their continuance they should be discontinued.

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.
What approach should the team take?

There are practical steps to take when assessing somebody with BPSD/Responsive Behaviour. 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 the 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 or undue distress.
A TEMPLATE FOR ASSESSING BPSD/RESPONSIVE BEHAVIOUR: (57)

**BPSD/RESPONSIVE BEHAVIOUR ASSESSMENT**

- Out rule delirium

- Identify target behaviour

- Identify Trigger(s)

**Physical Unmet Need**
- Pain
- Constipation

**Medication**
- Anticholinergic
- Opioid

**Environmental**
- Poor Communication
- Noise
- Under/Over Stimulation

**Psychological**
- Anxiety
- Depression

**Personality Biography**
- Personality Traits
- Previous Work Patterns/Habits
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

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**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 with dementia in the community
- Knowledge of local services and supports and when/where to refer essential

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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 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)

› 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 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 (dementiapathways.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 dementiapathways.ie
- To contact us:
  - dementiapathways@ucc.ie
- Thank you for your time today

Draw participants’ attention to the list of online resources and publications and availability of additional discipline specific materials and resources, especially those on the dementiapathways.ie website

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-111 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 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 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 having 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) but stopped going about 4 months ago 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
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THE MANAGEMENT OF BPSD IN PRIMARY CARE