

dementia pathways

For Primary Care in Ireland



DEMENTIA CARE IN GENERAL PRACTICE

GP FACILITATOR'S WORKSHOP GUIDE

GP Faciliator's Workshop Guide

DEVELOPED BY THE **PREPARED** TEAM
PRIMARY CARE, EDUCATION, PATHWAYS AND RESEARCH OF DEMENTIA

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> Background

Dementia is a topic of increasing global concern because of increasing dementia prevalence rates, the significant societal impact on patients and on family-carers and because of the rapidly rising costs to healthcare systems.

The resultant need for an urgent response to the growing impact of dementia has been recognised internationally. Here in Ireland, the Government launched the Irish National Dementia Strategy (INDS) in 2014, which highlights the pivotal role played by GPs in the timely diagnosis and management of persons with dementia. However, GPs are challenged by certain aspects of dementia care, including how and when to make the diagnosis, accessing information on local services and supports for persons with dementia, and the management of the behavioural and psychological symptoms of dementia (BPSD).

Dementia specific education and training has been advocated to enable GPs to respond effectively and to deliver integrated dementia care to their patients. Reviews of the effects of dementia educational interventions in primary care have found that educational outreach, involving interactive small group workshops, audit and continuing education have the greatest direct effect on patient outcomes.

The PREPARED project (Primary Care Education, Pathways and Research of Dementia) is based in the Department of General Practice in University College Cork (UCC) 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).

Forming a core part of the PREPARED project, practice-based GP dementia workshops have been developed that involve interactive discussion of case-based clinical scenarios. The workshop design has been informed from multiple sources. Drawing from adult learning theory, the workshop themes were developed following interviews with GPs about their educational needs around dementia care. In order to ensure that the subject matter of our workshops is meaningful and relevant for GPs, we interviewed GPs to ascertain their views on their own dementia care learning needs. In addition, we sought the perspectives of people with dementia and family carers of people with dementia to explore their views on key things that they felt GPs need to know and do in order to ensure optimal dementia care. An analysis of these interviews concluded that GPs' areas of prioritized educational need were (a) post-diagnosis dementia care and (b) the management of BPSD.

> About this guide

This guide is designed to assist GP workshop facilitators in the preparation, facilitation and evaluation of effective dementia workshops. The guide contains workshop materials, including PowerPoint® presentation slide images with supporting facilitator notes and detailed referenced explanatory notes.

Workshop No. 1, entitled 'Confirming the timely diagnosis of Dementia and post-diagnosis care' consists of an introduction to the PREPARED project followed by a case-based discussion. This clinical case-scenario involves an exploration of the relative merits of making a timely diagnosis of dementia and a website resource, dementiathroughways.ie, that a GP may use post-diagnosis to guide patients and family-carers.

Workshop No. 2, entitled 'The management of the behavioural and psychological symptoms of dementia in primary care' also consists of a relevant general practice-based clinical case-scenario.

This guide is primarily designed to be used by GP workshop facilitators as a resource for two, 1 - 1.5 hr long workshops.

The guide follows the core principles of adult education. Individuals learn best when the educational process is practice-relevant, interactive

and when the existing expertise and experience of the learner is recognized and used as a resource within the training. Whenever possible, and where time permits, the facilitator is encouraged to foster group discussion of GPs 'real world' dementia care experiences, in particular of the core workshop themes of timely diagnosis & post-diagnosis care and of the management of BPSD.

Materials are designed for onsite delivery to a group of GPs in a practice setting but could also be adapted for delivery to a larger group of GPs in a CME workshop setting or through webinar conferencing. In order to be delivered virtually, the facilitator would need to modify the interactive elements of each workshop to fit the virtual environment.

This case highlights the importance of the assessment of BPSD, explores non-pharmacological management options and offers advice on appropriate prescribing.

This guide is not a comprehensive general practice dementia curriculum. Rather, the content of the training materials is based on the prioritized dementia-specific educational needs of GPs. Other excellent resources are available, many of which we have referenced.

Icon glossary



KEY POINTS

THESE ARE THE ESSENTIAL SUMMARY POINTS, TO BE DISCUSSED, WITH EACH POWERPOINT SLIDE



BACKGROUND

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



REFERENCES

THESE REFERENCE LISTS SUPPORT THE FACTS WITHIN THE BACKGROUND INFORMATION



GROUP DISCUSSION

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

Final Preparation: Suggested Equipment and Material

For the Workshop Facilitator:

- › PowerPoint® slides - USB stick and back up paper copy
- › Laptop and/or projector
- › Copy of facilitator workshop guide
- › Attendance register

For Workshop Participants:

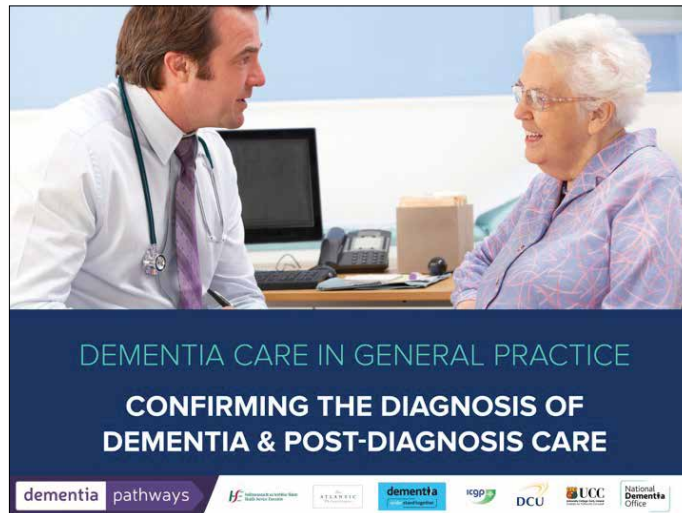
- › Workshop evaluation questionnaires
- › Copies of resources - e.g. ICGP QIP Dementia Management, A Pocket Positive Guide to Dementia
- › Handouts of the PowerPoint® slides

WORKSHOP 1

CONFIRMING THE DIAGNOSIS OF DEMENTIA AND POST-DIAGNOSIS CARE

TOPIC	SUGGESTED PROPORTION OF WORKSHOP TIME
PREPARED INTRODUCTION	10%
CASE-BASED DISCUSSION	60%
WWW.DEMENTIAPATHWAYS.IE	25%
EVALUATION QUESTIONNAIRE	5%





- › Introductions and thanks to attendees.
- › Highlight importance of dementia care – increasing prevalence, societal impact and cost.
- › General Practice is central in dementia care – but there are challenges faced by General Practice – hence the need to support GPs.



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

THE IMPORTANCE OF DEMENTIA CARE:

Prevalence:

In line with its ageing population, the prevalence of dementia in Ireland is rising, necessitating planning for future care provision. In 2009, there were an estimated 41,700 people living with some form of dementia in Ireland and this figure is expected to rise to 147,000 by 2041 [1]. Ireland is predicted to have the largest growth in the older population of all European countries in the coming decades resulting in this expected increase in dementia prevalence [2]. This growth in numbers is mirrored by international estimates with numbers worldwide expected to double over the next twenty years [3].

Societal impact:

This increase in numbers will inevitably impact on families of people with dementia (PwD) and on the healthcare resources of the nation too. There is a significant social cost to dementia care, as the majority of PwD live at home, cared for by family members.

Costs:

From an economic perspective, dementia is a costly condition. Calculations suggest that the current cost of dementia care in Ireland is €1.69 billion per annum [1], while a World Alzheimer Report has estimated the worldwide cost of dementia to be in the region of US\$604 billion per annum, accounting for 1% of the world's gross domestic product [4].

There is an increasing focus on dementia care in primary care – internationally in dementia strategies/guidelines/policy and in the Irish National Dementia Strategy published in 2014 [5].

Patients/Family carers greatly value GP care [6]. GPs play a central role in dementia care.

But there are real challenges for GPs in dementia care. As GPs we are challenged by dementia care – diagnosis, post-diagnostic care, complexity of the care pathway, BPSD, time, concern regarding harm [7, 8].

Today's Discussion

Introduce the PREPARED project

Discuss a clinical case, focusing on the value of confirming the diagnosis of dementia and the merits of pro-active post-diagnosis care

Demonstrate www.dementiaphways.ie



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Today's workshop will include a;

- › Brief overview of our PREPARED project
- › Description of what GPs, PwD and family-carers feel GPs need to know and do in delivering optimal dementia care
- › Case-based discussion focusing on dementia care in General Practice – in particular on timely diagnosis and post-diagnosis care
- › Demonstration of www.dementiaphways.ie

Why practice based workshops?

We looked at the literature on how best to deliver dementia education.

The most effective educational activities are those that include peer-facilitated workshops (GP to GP), case-based discussion, problem-solving and audit.

This reflects how we effect change in other areas of chronic disease management in primary care.

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Brief outline of PREPARED – A national general practice dementia initiative.

Collaboration between;

- › The Department of General Practice, UCC
- › ICGP &
- › DCU

Funded by Atlantic Philanthropy & the HSE, arising from a commitment in the recently published Irish National Dementia Strategy [5] to support General Practice and Primary Care in the delivery of integrated dementia care.

Brief description of how the workshops were designed.

We designed our workshops following;

- › A comprehensive review of the literature on improving dementia care in general practice.
- › A review of national and international guidelines on best-practice dementia care.
- › Interviews with GPs, people with dementia and family-carers to identify what they feel GPs need to know and do in order to better care for their patients with dementia.



The workshops have been carefully designed to order to meet the educational needs of GPs in dementia care.

WHY PRACTICE-BASED WORKSHOPS?

We looked at the literature on how best to deliver dementia education. The most effective educational activities are those that include peer-facilitated workshops (GP to GP), case-based-discussion, problem-solving and audit [9]. This reflects how we effect change in other areas of chronic disease management in primary care [10].

THE CONTENT OF THE WORKSHOPS:

We looked at the literature, peer-reviewed [7] and grey [11] in order to identify GPs educational needs in dementia care. Furthermore we reviewed national and international guidelines on the management of patients with dementia in primary care [12-14].

We also performed our own research, by interviewing GPs in order to identify their dementia-specific educational needs [15]. We felt it was also important to get the views of people with mild cognitive impairment & dementia and family-carers of about what they felt GPs should know and do in order to care for their patients with dementia.

Findings from interviews were analysed, resulting in 6 areas to include in our educational programme for GPs, namely,

1. Post-Diagnosis Care – Services & Supports
2. Management of Behavioural & Psychological Symptoms of Dementia (BPSD)
3. Counseling & Support for Family-Carers
4. Education about Dementia
5. Diagnosis
6. Medication Management

In particular, the 2 prioritised areas that were considered to be the most important were,

1. Post-diagnosis care – in particular, guidance and access to dementia specific services and supports.
2. The management of the behavioural and psychological symptoms of dementia (BPSD).

Our workshops focus on these two areas.

A Clinical Case: James

74 yr-old farmer, married, 2 sons

Wife attends GP and is concerned regarding James' memory

At review;

- Quietly conversive
- MMSE 26/30
- Bloods taken
- Decision to observe for now

dementia pathways



- › Case-based discussion.
- › James' wife, who is herself frail, has concerns about her husband James' memory.
- › At attendance, James' MMSE is falsely reassuring.



74 yr old farmer – Has 2 sons, one of whom works with him on the farm and 2 daughters. *Therefore James has land & property – prompts consideration of legal aspects of care, will, enduring power of attorney.*

Wife, Mary, attends for advice – She has rheumatoid arthritis and is concerned for James and unsure what the future holds. *She may be physically frail – prompts reflection on carer support and carer burden. Highlights need for education/information/signposting.*

James attends for a check-up.

Quietly conversive - Depression may masquerade as dementia and is probably the most common differential diagnosis that should be considered [16]. Depression and dementia may co-exist and depression may precede dementia. If strongly suspected, a trial of antidepressants may be indicated, with reassessment of the individual's capabilities and cognitive function 6-8 weeks later [16].

MMSE 26/30 - James feels his memory isn't as sharp as it used to be, but he denies any problems with activities of daily living (ADLs), such as working, dressing or driving. He consents to a memory test, and the GP performs the MMSE.

The ADL query highlights the need for a GP to consider issues beyond James' memory alone, and helps a clinician to distinguish between possible MCI (mild cognitive impairment) and dementia.

Mini-mental state examination scores are used to indicate the severity of Alzheimer's disease: mild, scores 21-26; moderate, scores 10-20; moderately severe, scores 10-14; severe, scores less than 10 [16].

The MMSE is the most commonly used tool in General Practice. It measures orientation, immediate memory, attention and calculation, recall, various aspects of language and visuospatial skills. However, scores may be difficult to interpret and it shows age, cultural and educational bias [12]. Consider alternatives, as per page 4 of ICGP QRG [12]. For instance, the GPCOG takes no longer than five minutes to administer and comprises two components: a six item cognitive assessment with the patient and an informant questionnaire (if the cognitive assessment score is equivocal: 5-8 inclusive). Scores >8 are deemed to represent cognitive impairment and <5 intact cognition. Sensitivity 82-85%; specificity 83-86% [12]

Bloods taken – GP checks bloods for TFT, FBC, Bioprofile, Glc, Fer – which come back as 'normal'.

Decision to observe for now, as James and his wife are currently coping – the GP decides that as James is not overly concerned, denies problems with ADLs and the MMSE is reassuring, that he'll observe the situation, for now

Three months later...

Phone-call from Mary, about James

Increasingly withdrawn, loss of interest in playing cards, snappy, episode getting lost

Invited to come in for cognitive screening

Clinically suspicious of dementia

Referral made to local geriatrician

dementia pathways



- › James' wife is increasingly concerned regarding James' memory and also his mood, behaviour and conversation.
- › On review GP is clinically suspicious of a diagnosis of dementia (MMSE now 21) and refers to a local geriatrician.



So, this GP has clinical concerns about an evolving dementia and appropriately refers to a local specialist for confirmation of the diagnosis. This management is reasonable, though as the case history unfolds, perhaps there are more things that the GP could do at this juncture e.g. coding, involvement of the Alzheimer Society, local services & supports and perhaps any available, relevant primary care team colleagues.

Cognitive Screening Tools

What cognitive screening tool do you use?

<http://dementiaphways.ie/clinical-resources/diagnosis-of-dementia-in-primary-care>

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- › Facilitated group discussion about what cognitive screening tools GPs are currently using
- › Where possible, consider demonstrating the GPCOG, using the www.dementiaphways.ie website



- › acknowledge that screening tools have potential bias
- › discuss GP-relevant alternatives to the MMSE
- › introduce the www.dementiaphways.ie website as a clinical resource



COGNITIVE ASSESSMENT

(taken from the ICGP dementia quick reference guide)

Cognitive function testing adds further evidence to the clinical assessment and investigations. There are a number of validated cognitive screening tools used in general practice. A patient's performance may be affected by educational ability, language, hearing and culture. Results of testing should be included in referrals to secondary care.

Over 50% of GPs use the MMSE because of availability and professional habit. A brief overview of commonly used screening tools is given in the table below.

Three well-conducted systematic reviews of cognitive screening tests in primary care have compared the properties of screening tools in use. They concurred that the best three tools for use in primary care were the *GPCOG, the **Mini-Cog and the ***MIS [17-19]. They were found to be practical, feasible, have wide applicability and were psychometrically robust.

COGNITIVE SCREENING TOOLS IN PRIMARY CARE MINI-MENTAL STATE EXAMINATION (MMSE)

Developed by Folstein, it is the most commonly used tool in General Practice. The MMSE measures orientation, immediate memory, attention and calculation, recall, various aspects of language and visuo-spatial skills. However, scores may be difficult to interpret and it shows age, cultural and educational bias. Scored out of 30, a score of < 24 suggests dementia. It may take up to 20 minutes to complete and so may be less practical for primary care. There are copyright restrictions on the use of the MMSE. The MMSE can be purchased from PAR, Inc. by calling (813) 968-3003.

***GENERAL PRACTITIONER ASSESSMENT OF COGNITION (GPCOG)**

This is a 6-item cognitive screening tool, specifically designed for use in primary care. Taking 5 minutes to complete, it appears to perform well within the primary care setting and is psychometrically robust and free of educational bias. It includes time orientation, a clock drawing task, report of a recent event and a word recall task.

****MINI-COGNITIVE ASSESSMENT INSTRUMENT (MINI-COG)**

A brief screening tool designed for primary care use, it assesses 2 aspects of cognition – short-term recall and clock drawing. It takes 3-5 minutes to complete

and performs comparably to the GPCOG, also being free of educational bias.

*****MEMORY IMPAIRMENT SCREEN (MIS)**

This is a 4-item assessment test that takes approximately 4 minutes to complete. The MIS is especially appropriate for use with ethnic minorities, as it does not show educational or language bias.

ABBREVIATED MENTAL TEST SCORE (MTS)

This is a well-established 10-item screen that samples various cognitive domains. There are only verbal items. Orientation, long-term memory, recognition and short-term memory are assessed.

SIX ITEM COGNITIVE IMPAIRMENT TOOL (6CIT)

Designed for primary care use, this takes approximately 5 minutes to complete. All items are verbally based. Orientation, short-term memory and attention/concentration are assessed.

A number of these cognitive screening tools may be accessed @ <http://dementiapathways.ie/clinical-resources/diagnosis-of-dementia-in-primary-care>



Confirming the diagnosis

- Fall and hospital admission
- Confirmed diagnosis of dementia
- Commenced Aricept 5mg nocte
- Wife, Mary, attends for advice
- She's been searching for information

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- › The case-history has progressed to James receiving a confirmed diagnosis of dementia, as the workshop focus now moves towards post-diagnosis care.



EXPLANATION AND RATIONALE FOR EACH POINT:

INCREASINGLY WITHDRAWN AND RECENT FALL

Wife recounts that James become withdrawn and has memory lapses & she has noticed repetitive questioning.

He does not have any challenging behaviour and is sleeping well.

'Withdrawn' – highlights behaviour change as one diagnostic criteria [12].

'Fall' highlights gait disturbance as an epi-phenomenon of dementia [20].

CONFIRMED DIAGNOSIS OF DEMENTIA

Diagnosis made by gerontologist following a recent hospital admission as a result of a fall., following recent hospital admission with fall. Gerontology follow-up 6/12. GP had been planning to review and hadn't yet initiated supports or coded for dementia, as James is a rare attender. *Prompts reflection on need for pro-active GP care in the interim.*

COMMENCED ARICEPT

James' GP received letter stating cognitive impairment and newly commenced on donepezil (Aricept) at a starting dose of 5mg. *Medication management commenced - prompts consideration of non-medication management.*

WIFE, MARY, ATTENDS FOR ADVICE

Mary has been searching for information on dementia as she's unsure of what lies ahead. She doesn't know what help she can access.

Prompts consideration of need to support family-carer and consider how to guide/direct families to services and supports. Family members value GP advice and frequently approach GPs as their primary source of information and support [6].

Potential benefits of confirming a diagnosis of dementia

- Facilitate planning for the future – medical, legal, financial
- Psychological benefit to person with dementia and/or family
- Maximise opportunity for patient to plan their own care
- Person's right to know
- Maximise treatment possibilities (Cholinesterase inhibitors/Memantine)
- Facilitate access to patient services and supports
- Value of coding for dementia in patient records

dementia pathways



- › Discussion around the benefits and drawbacks of diagnosis disclosure
- › Raising the value of coding for dementia



POTENTIAL BENEFITS IN CONFIRMING A DIAGNOSIS OF DEMENTIA INCLUDE [21]

- › Facilitate of planning for the future
- › Psychological benefit to person with dementia and/or family
- › Maximise opportunity for patient to plan their own care
- › Person's right to know
- › Maximise treatment possibilities
- › Facilitate access to services and supports
- › Address risks to patients, including driving, financial, self-care

ARGUMENTS AGAINST EARLY DIAGNOSTIC DISCLOSURE [21]

- › Risk of causing emotional distress and anxiety.
- › Inability of person with dementia to understand and/or retain the diagnosis
- › No perceived benefits, or perceived costs outweigh perceived benefits
- › Persons right 'not to know'
- › Lack of robust evidence of improvements to well-being from strategies aimed at earlier diagnosis
- › Potential risk of 'over-diagnosis'
- › Poor access to necessary specialists and/or support services
- › Lack of cure or effective treatments
- › Stigma associated with the diagnosis of dementia

VALUE OF CODING FOR DEMENTIA [22-24]

- › Proactive care - avoid crisis
- › Coordination of care – within general practice and to/from inpatient hospital care [24]
 - 25% of over 70s in hospital have dementia, less than a third of these were identified as having dementia on admission to the hospital.
- › Identify family carers who need support
- › Planning care – social supports, will, EPA, driving, risk minimisation (vascular/Parkinsons)
- › Patient identification – on GP review, GP out of hours services
- › Planning dementia service provision and funding
- › Clinical audit

Confirming the Diagnosis: Diagnostic Criteria

According to the *Diagnostic and Statistical Manual of Mental Disorders IV (DSM-IV)* dementia is a syndrome that may be caused or characterised by multiple cognitive deficits which may include memory impairment and at least one of the following;

- Aphasia
- Apraxia
- Agnosia
- Disturbance in executive functioning

Social or occupational function is also impaired

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- › Background information is given here to support the facilitator in any potential discussion around diagnostic criteria
- › In accordance with internationally used guidelines [13], where available, referral to a specialist services is therefore preferable for confirmation of the diagnosis, exclusion of other pathologies, subtyping of the dementia and tailoring of treatments to the specific dementia subtype [25]



DEFINING DEMENTIA

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 [12].

There may be memory loss usually related to short-term memory, communication difficulties, changes in personality or mood and problems with spatial awareness. The ability to perform activities of daily living independently may arise, with instances such as forgetting the names of common objects, times and places, missed appointments and issues around drug adherence.

DIAGNOSTIC CRITERIA

Dementia, according to the *Diagnostic and Statistical Manual of Mental Disorders IV (DSM-IV)* [26], is a syndrome that may be caused or characterized by:

Multiple cognitive deficits, which include memory impairment and at least one of the following: aphasia, apraxia, agnosia or disturbance in executive functioning. Social or occupational function is also impaired [27].

APRAXIA

is the term used to describe 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 [28].

APHASIA

is the term used to describe a difficulty or loss of the ability to speak or understand spoken, written or sign language as a result of damage to the corresponding nervous centre. This can become apparent in a number of ways. It might 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. When accompanied by echolalia (the involuntary repetition of words or phrases spoken by another person) and the constant repetition of a word or phrase, the result can be a form of speech which is difficult for others to understand or a kind of jargon [29].

AGNOSIA

is the term used to describe the loss of the ability to recognise what objects are and what they are used for. For example, a person with agnosia might attempt to use a fork instead of a spoon, a shoe instead of a cup or a knife instead of a pencil etc. With regard to people, this might involve failing to recognise who people are [29].

EXECUTIVE FUNCTION may be defined as the cognitive process that organizes simple ideas, behaviors, 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 [27].

James' post-diagnosis care:
Management options

?

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- › Facilitated discussion of the various management options of a patient with newly diagnosed dementia.
- › Discussion should explore non-drug approaches, information provision, voluntary & non-voluntary agencies, multidisciplinary (PCT) support and counselling for family carers [16].



CONSIDER OPENING QUESTIONS:

'AS A GP, HOW WOULD YOU HELP JAMES?'

Encourage discussion of non-medication management. Start with open-ended discussion before focus on services & supports.

'WHAT ADVICE WOULD YOU OFFER TO MARY?'

Highlights consideration of family-carer's needs.

Following initial discussion, if appropriate consider follow-up questions;

'WHAT LOCAL SERVICES AND SUPPORTS ARE YOU AWARE OF, THAT SUPPORT PATIENTS WITH DEMENTIA AND THEIR FAMILIES?'

Encourages discussion of care options that are available locally and stimulates discussion within the group. Highlights complexity of care pathways and the need for clear dementia care pathway for GPs to support patients and families.

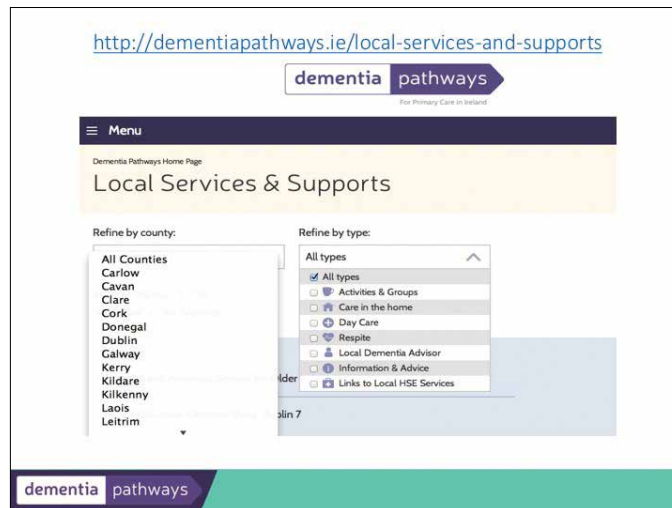
If appropriate, consider asking;

'WOULD YOU CONSIDER REFERRING TO A MEMBER OF THE PRIMARY CARE TEAM? WHY/WHY NOT?'

Prompt discussion of the role of various healthcare professionals and access to integrated multidisciplinary care.

DISCUSSION PROMPTS:

- › **ASSESS JAMES NEEDS** - response to diagnosis, understanding of diagnosis, wish to attend for review, depression, mobility, ADLs, driving, legal (will/EPA, advanced care directive), family support
- › **ASSESS MARY'S NEEDS** – stress, depression, understanding of dementia, frailty, family support
- › **DEMENTIA SERVICES/SUPPORTS** – Alzheimers Society of Ireland (ASI), Private Home care Agencies, The Carers' Association, Citizen's Information Service, Legal Aid Board, Free Legal Advice Centres (FLAC), Department of Social Protection
- › **DEMENTIA EDUCATION** – ASI, Dementia Services Information & Development Centre (DSIDC)
- › **OTHER MEMBERS OF THE PRIMARY CARE TEAM^[16]:**
 - Public Health Nurse** - e.g. access to home-help, meals on wheels, day-care centre, access to respite care
 - Physiotherapy** - e.g. falls risk assessment, mobility assessment, mobility aids
 - Occupational Therapist** - e.g. assessment of the home, aids and appliances, assistive technologies
 - Speech & Language Therapist** – e.g. communication advice, swallow assessment
 - Social Worker** – e.g. rights, entitlements
 - Community Psychologist** – e.g. counselling, support family carer
 - Community Pharmacist** – e.g. medication management, dispensing
- › **MEDICATION MANAGEMENT**
 - titrate up dose of donepezil after a month to 10mg – if patient tolerates, watching for side-effects of nausea, vomiting, anorexia, diarrhoea [12].
- › **ENCOURAGE BRAIN HEALTH STRATEGIES**
- › **ADDRESS RISK FACTORS**
 - vascular, smoking, alcohol, depression, inactivity/exercise.



Introduce dementiaphways.ie [30] and demonstrate how GPs may use it for;

- › Signposting dementia services & supports
- › Accessing clinical information about dementia care.



SIGN-POSTING TO DEMENTIA SERVICES & SUPPORTS;

- › Raise GPs' awareness of dementiaphways.ie
- › Raise GPs' awareness of local services & supports
- › Promote post-diagnosis referral to services & supports
- › Encourage building-upon and populating the dementiaphway.ie resource, locally

ACCESSING CLINICAL INFORMATION ABOUT DEMENTIA CARE;

- › Promote using dementiaphways.ie for accessing clinical information on dementia care e.g cognitive screening tools, BPSD algorithm, cholinesterase inhibitors etc.

Summary

- There are potential benefits in confirming a diagnosis of dementia
- GPs and patients have prioritized and highlighted the importance of post-diagnosis care
- There is value in coding for dementia in patient's medical records

dementia pathways



Summarise the main take-home messages;

1. THAT THERE ARE POTENTIAL BENEFITS IN CONFIRMING A DIAGNOSIS OF DEMENTIA

- › Psychological benefit to person with dementia and/or family
- › Maximise opportunity for patient to plan their own care
- › Person's right to know
- › Maximise treatment possibilities (Cholinesterase inhibitors/Memantine)
- › Facilitate access to patient services and supports
- › Coding for dementia on IT systems to promote pro-active care

2. THAT GPs AND PATIENTS HAVE PRIORITISED AND HIGHLIGHTED THE IMPORTANCE OF POST-DIAGNOSIS CARE

- › We have developed a resource to help GPs to offer guidance to patients and to families, namely, dementiapathways.ie

3. THERE IS A VALUE IN CODING FOR DEMENTIA IN PATIENTS' MEDICAL RECORDS





- › Proactive care - Avoid crisis
- › Coordination of care – within general practice and to/from inpatient hospital care [24]– 25% of over 70s in hospital have dementia, less than a third of these were identified as having dementia on admission to the hospital.
- › Identify family carers who need support
- › Planning care – social supports, will, EPA, driving, risk minimisation (vascular/parkinsons)
- › Patient identification – on GP review, GP out of hours services
- › Planning dementia service provision and funding
- › Patient review and audit

Resources

www.dementiaphways.ie

Dementia Care – Audit Tool

Contact: dementiaphways@ucc.ie



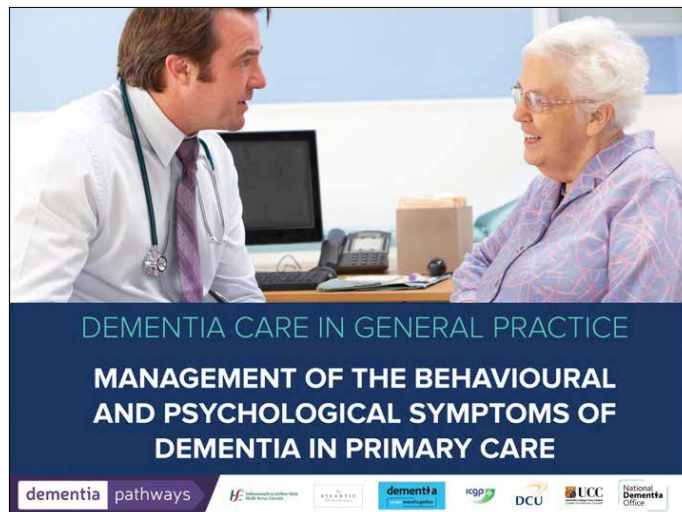
- › Reminder regarding the dementiaphways.ie website as a clinical resource and service directory
- › Discuss the options for coding and clinical audit, using the iPCRN software tools for generating dementia registers (available on Helix Practice Manager, Socrates, HealthOne and CompleteGP systems), and that audit completion will meet the ICGP professional competence audit requirements.
- › If appropriate, use this opportunity for participants to complete attendance and/or evaluation and feedback paperwork.

WORKSHOP 2

THE MANAGEMENT OF BPSD IN PRIMARY CARE

TOPIC	SUGGESTED PROPORTION OF WORKSHOP TIME
PREPARED INTRODUCTION	5%
CASE-BASED DISCUSSION	60%
DEMENTIAPATHWAYS.IE WEBSITE	15%
AUDIT DISCUSSION	15%
EVALUATION QUESTIONNAIRE	5%





- › Introductions and thanks to attendees
- › Thanks for attending
- › Brief overview of the PREPARED project.
- › The reason for choosing BPSD as a workshop topic



PREPARED

Brief outline of PREPARED – A national general practice dementia initiative. Collaboration between; The Department of General Practice, UCC ICGP & DCU Funded by Atlantic Philanthropy & the HSE, arising from a commitment in the recently published Irish National Dementia Strategy [5] to support General Practice and Primary Care in the delivery of integrated dementia care. Brief description of how the workshops were designed.

We designed our workshops following;

- › A comprehensive review of the literature on improving dementia care in general practice.
- › A review of national and international guidelines on best-practice dementia care.
- › Interviews with GPs, people with dementia and family-carers to identify what they feel
- › GPs need to know and do in order to better care for their patients with dementia.

WHY BPSD?

We explored the dementia educational needs of GPs through face-to-face interviews with GPs and family-carers of patients with dementia.

In particular, the 2 areas that were considered to be the most important by GPs and by family-carers were;

1. Post-diagnosis care – in particular, guidance and access to dementia-specific services & supports.
2. The management of the behavioural and psychological symptoms of dementia (BPSD).

These areas were identified as the main themes for our 2 practice-based workshops. We held semi-structured, face-to-face interviews with 14 GPs and 12 family-carers of patients with dementia [15]. The 2 areas that were considered to be the most important were;

1. Post-diagnosis care – in particular, guidance and access to dementia-specific services and supports.
2. The management of the behavioural and psychological symptoms of dementia (BPSD).

From this we identified these areas as the main themes for our 2 practice-based workshops. In order to address the other key themes that were identified as well as broader issues in dementia care, we are also developing educational material, through our website [30], e-learning with the ICGP [31], our ICGP dementia reference guide [12] and 12-week blended learning dementia module for GPs which is being developed in UCC.

Today's Discussion

- A framework for the assessment of behavioural and psychological symptoms of dementia (BPSD)
- The risks of antipsychotics
 - How to monitor your prescribing
 - How to withdraw antipsychotics
- Alternative management options available

dementia pathways



- › Behavioural symptoms such as aggression, agitation, wandering and psychological symptoms such as anxiety and depression are challenging symptoms to treat.
- › GPs are aware of the risks of prescribing antipsychotics in patients with dementia, but they are often prescribed as GPs may feel their management options are limited.
- › This topic is approached using a clinical case to explain the risks of antipsychotics, available alternative management strategies and includes some practical tips on antipsychotic monitoring and withdrawal.



Explain what BPSD is by giving examples of behavioural and psychological symptoms. Most of the GPs may have had experience of dealing with patients with BPSD over the years but they may be unfamiliar with the label of BPSD.

Explain the dangers of antipsychotics in persons with dementia (PwD) without being overly critical of these prescriptions.

From the outset reassure the audience that this talk will be practical, relevant and realistic.

WHAT IS BPSD?

The International Psychogeriatric Association categorises BPSD into two groups of symptoms:

1. Behavioural symptoms: aggression, screaming, restlessness, agitation, wandering, hoarding
2. Psychological symptoms: anxiety, depressive mood, hallucinations and delusions

The majority of people with dementia will experience BPSD at some time, particularly in the middle and later stages [32]. BPSD is a major contributor to caregiver stress and depression, even more significant than cognitive decline [33].

BPSD is a major reason for PwD being admitted to long-term care [34, 35]. Unfortunately, there is a lack of clear guidelines on how best to manage BPSD from a primary care perspective.

Non-pharmacological solutions are recommended first-line but frequently there are inadequate resources in the community to implement these non-pharmacological solutions.

A Clinical Case: Alice

- Alice an 84 yr-old widow, Alzheimer's type dementia, living in a local nursing home
- Aggressive when being washed; hitting out
- Appears distressed; pacing, hand wringing, needs constant reassurance
- Sleeps poorly & wanders into other rooms at night

dementia pathways



“You receive a call from the local nursing home to review Alice who is a long-term resident with advanced Alzheimer’s type dementia.

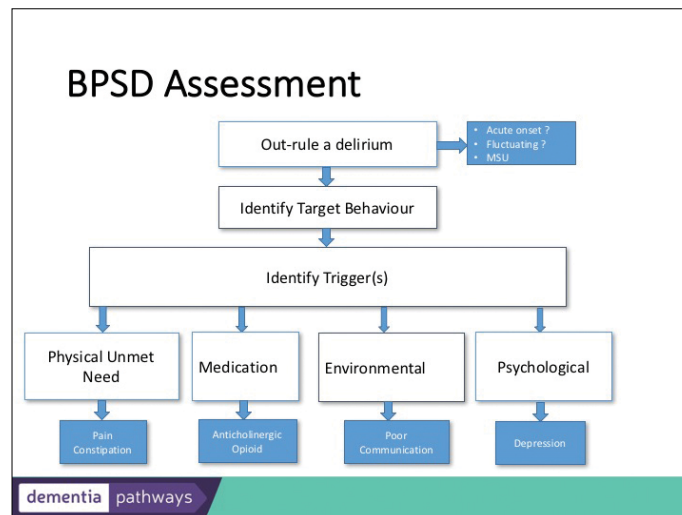
Over the past few weeks staff have found it increasingly difficult to manage her. They describe her as being ‘aggressive’. On further exploring the history you establish that...

She does become aggressive but only when being washed – note importance of establishing what the issue is

- › The rest of the time she is agitated, not aggressive
- › She is also sleeping poorly and wandering at night
- › She has past history of osteoarthritis
- › There are behavioural symptoms here that are often seen in dementia; agitation, wandering, restlessness



- › The reason for introducing the case this way is to highlight the fact that correctly identifying the target behaviour is arguably the most important aspect of managing a patient with BPSD. BPSD is not a diagnosis in itself [36] and so it does not have a blanket ‘one-size-fits all’ treatment. It is important to first identify what symptom and then target that symptoms with the appropriate treatment.
- › The description of the patient distressed/pacing/hand wringing etc fits with accepted definitions of agitation in dementia and serves to highlight what agitation is (and what it is not) [37].
- › Poor sleep and wandering are common symptoms seen in dementia and are very difficult to treat.



- › There are practical steps that you can use when assessing any patient with BPSD
- › The first step is always to establish whether this is a possible delirium – a difficult task.
- › Where possible an MSU should be obtained, which may be difficult in this patient as she is incontinent and wears a pad.
- › The next step is to clarify what is the behaviour you are trying to treat, because the appropriate management of BPSD depends on what symptom you are treating –e.g. the treatment of agitation is very different from the treatment of wandering. If we do not know what exactly is the target behaviour that we are treating then we cannot initiate an effective management plan.
- › Consider behavior as a communication of need. Identifying what ‘need’ they are trying to communicate is the key to assessing and ultimately managing BPSD.
- › Pain, for example, is one of the most common causes of BPSD.
- › Medication review is essential – review and discontinue contributing medications, where possible



1. OUTRULE A DELIRIUM

The first step when assessing a patient with BPSD is to exclude a possible delirium [38]. A delirium can contribute to or mimic BPSD. Despite the fact that dementia is an independent risk factor for delirium, delirium superimposed on dementia is an underdiagnosed illness [39]. Identifying delirium superimposed on delirium can be difficult. The following points should be looked for in the history [40]:

- › acute or subacute onset of symptoms;
- › altered consciousness (e.g. hypervigilant, drowsy)
- › reduced attention,
- › fluctuations in symptoms;
- › visual hallucinations accompanied by agitation;
- › altered psychomotor activity and occasionally asterixis.

While we do not want to lecture here on how to assess delirium but we need to highlight the importance of assessing for it and where possible never treating BPSD without getting an MSU.

2. IDENTIFY TARGET BEHAVIOUR

Take the time to correctly identify what behavior you are attempting to treat. Time spent doing this initially may save you time in the longer term. Does the behavior even require intervention?

3. IDENTIFY TRIGGERS

It is important to communicate to the audience the concept that the behaviour is often a form of communication [41]. PwD may be unable to communicate their needs and so they may react to situations with behaviour that is disturbing to others. Identifying what 'need' they are trying to communicate is the key to assessing and ultimately managing BPSD.

(i) Pain

We know that in people with dementia self-report alone is not sufficient to assess pain [42]. The Abbey Pain Scale [43],

The Pain Assessment in Advanced Dementia Scale (PAINAD) and Pain Assessment Checklist for seniors with Limited Ability to Communicate (PACSLAC) are all pain assessment tools that can be used to assess pain in PwD. One of these pain assessment checklists can be given to nursing home staff to enable more accurate assessment of underlying pain.

A placebo controlled RCT looked at the effect of regular paracetamol on nursing home residents with dementia and found that participants spent more time in social interaction, engaged with media, talking to themselves, engaged in work-like activity, and experiencing unattended distress when they received paracetamol than they did when they received placebo [44].

(ii) Environment

Ask staff/carers to consider whether there has been any recent changes to the environment e.g. room change. Ask staff to consider environmental contributors to BPSD, e.g. noise, no wandering space, cold, staff communication, inactivity.

(iii) Depression

Depression is particularly difficult to assess in a PwD. A screening tool named the Cornell Scale for Depression in Dementia (CSDD) was specifically designed to assess depression in PwD. The Geriatric Depression scale can also be used, though it is not dementia-specific like the CSDD, although it is significantly shorter than the CSDD. Both tools may be accessed on www.dementiapathways.ie

(iv) Medication

Medications that can contribute to BPSD include, anticholinergics, opioids, corticosteroids and first generation anti-histamines. If possible these medications should be stopped. Benzodiazepines and antipsychotics can also cause a paradoxical increase in agitation and should be used with caution. Also ask about any new medication as the PwD may be experiencing side effects of any new medications.

The Case Continued...

Alice's Medication List:

- Detrusitol 4mg OD
- Donepezil (Aricept) 5mg OD
- Movicol 2 sachets OD
- Quetiapine 50mg nocte – commenced 6/12 ago

Any thoughts on this list?
Any inappropriate medication?
Any medication you might like to start here?

dementia pathways



- › Some medications can worsen cognition and contribute significantly to BPSD [12]
- › PwD should not be on an anticholinergic for the following reasons:
 - The anticholinergic is working against any potential benefits of the donepezil (an Acetyl Cholinesterase Inhibitor)
 - Anticholinergics can, in themselves, worsen confusion
- › We know from previous slide that she is incontinent so it has no clinical role
- › Where possible this slide should be opened to the floor to encourage debate and discussion – all opinions are relevant



- › List has been carefully selected to focus debate on relevant issues



NEGATIVES ON THIS MEDICATION LIST:

1. **Detrusitol** (an anticholinergic) needs to be stopped urgently because:
 - a) Detrusitol is an anticholinergic and could be contributing to the patient's symptoms. Even in healthy older adults the use of anticholinergics are potentially inappropriate but in PwD their use is particularly inappropriate as these individuals are more prone to developing medication-induced cognitive impairment [45] (1).
 - b) Detrusitol is also working against any potential benefits of the Donepezil. Anticholinergics and acetylcholinesterase inhibitors (AChEIs) have opposing mechanisms of action and are, therefore, working against each other. Donepezil is an AChEI (acetylcholinesterase inhibitor), it works by enhancing the concentration of acetylcholine (a cholinergic neurotransmitter). Anticholinergics, like detrusitol, have the opposite effect - they decrease the amount of cholinergic neurotransmitters (like acetylcholine). An anticholinergic medication can, therefore, counteract the beneficial effects of AChEIs.

In summary, in general terms anticholinergics should be avoided in the elderly, in particular they should be avoided in PwD and should not be prescribed when a patient is on an AChEI.

2. **Donepezil** (AChEI) is not at maximum dose, consider increasing
3. **Quetiapine** is an antipsychotic. Should be used with caution in PwD. It is not licensed for the treatment of BPSD. Significant adverse effects may occur. We should consider withdrawing this medication. We have noted that it was commenced 6/12 ago to highlight two factors:
 - a) It was not prescribed for a pre-existing medical condition (e.g schizophrenia)
 - b) If it was going to be effective we would know by now. Generally all antipsychotics should be attempted to be withdrawn after a 6 week to 3 month period in PwD.

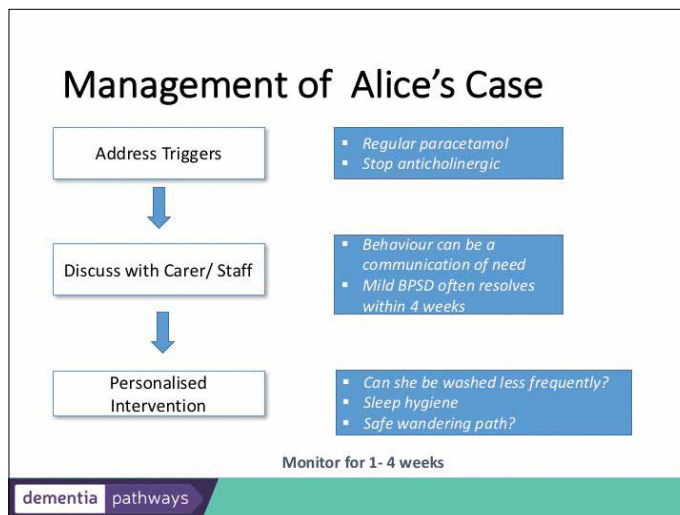
POSITIVES OF THIS MEDICATION LIST:

1. **Movicol** is listed to communicate that constipation is unlikely to be a cause (although of course still possible).
2. Limited number of medications in a patient of this age with (polypharmacy) here.

What medication to start?

- › Consider regular analgesia





- › The initial management should not be pharmacological, except in extreme circumstances where there is psychosis or severe aggression
- › First step is to address any identifiable triggers: e.g. pain, removal of any offending medication that may be causing side-effects/delirium.
- › In some cases basic education of staff may be necessary; a brief explanation to staff on how challenging behavior in dementia is often an attempt by the PwD to communicate an unmet need such as pain, hunger, thirst, cold, over- or under-stimulation.
- › For example in this case it would be worthwhile explaining why PwD often become agitated when nursing home staff attend to personal hygiene i.e. to a PwD washing/undressing. This could be viewed as a violation of personal space or as a perceived threat.
- › Sleep hygiene: There is good evidence for the use of a non-pharmacological approach of carer sleep hygiene education, daily walking and increased daylight exposure [46, 47].
- › Consider whether the nursing should a safe wandering path for Alice



1. Addressing Triggers

Rationale for this discussed extensively on previous slides.

2. Staff/ Carer Discussion

Most mild BPSD behaviours, that are not due to a medical cause, will self-resolve in 4 weeks without pharmacological intervention so if the symptoms are mild a period of 'watchful waiting' is always appropriate [48]. However, if the symptoms are more severe and involve physical aggression, these symptoms are often persistent. If symptoms are severe and persistent or there is evidence of psychosis you may consider consultation with your local psychogeriatrician/geriatrician for advice on management.

3. Personalised Interventions

The approach needs to be personalised. The limited benefits of generic interventions can largely be attributed to the diverse aetiology of BPSD. A therapy or intervention may be effective in one set of circumstances and not in another. Therefore, case-specific interventions that are tailored to individual situations are recommended.

Examples of personalised non-pharmacological interventions:

The following interventions have a role in certain situations.

a) Music Therapy

A study where PwD were played a pre-recorded selection of songs that they used to enjoy in their youth found that it decreased levels of agitation [49], however, audiotapes containing a family member's voice were even more effective than the songs in reducing agitation. Similarly engaging in a twice weekly 30-minute group music session for six weeks was found to significantly decrease levels of agitation in nursing home residents with dementia when compared to the control group [50].

b) Conversations

As little as 30-seconds has proven to be effective [48]

Advise carer/staff to use personal care as an opportunity for positive social interaction

c) Reminiscence Based Therapy

Ask the patient's family to develop a life story-book

d) Validation Therapy

Although the evidence base for validation techniques are weak [51], it remains one of the few ways of responding to high expressed emotion in the moment of agitation. Validation therapy involves not challenging the reality of the PwD. For example, if a PwD is agitated, believing they are late for school, you should not argue the point or expect the PwD to have insight into why this reality could not be true. Little will be gained by arguing the inaccuracies of their beliefs, saying something like, "No you don't go to school, you're 85 now" may only serve to distress the patient further. Instead you should acknowledge and empathise with the feelings the patient is experiencing; "oh, I hate being late for things too, where did you go to school?". This way you can steer the conversation away from their source of agitation and perhaps get them to do something else without them realising they are actually being redirected.

5. Exercise Therapy

Potential role in the management of depression

6. Aromatherapy

There is some modest evidence to support the use of lavender aromatherapy oils to decrease agitation [52, 53].

Wandering

Wandering is a difficult behaviour to manage as it can potentially raise serious safety concerns such as falls, subsequent injury, absconding and becoming lost. However, independent but safe wandering can potentially be therapeutic in that it reportedly improves sense of wellbeing and agency, stimulates appetite, relieves boredom, improves mood as well as encouraging feelings of empowerment and control. Within a safe environment wandering could, therefore, be beneficial; the aim should be to provide a safe level of wandering without a risk of injury by wandering away from the premise [54]. Well-designed studies are limited [55] but environmental interventions in the form of subjective barriers, such as the use of camouflage techniques to reduce exiting behaviour, grid patterns on doors, are often used to reduce wandering in PwD

The use of psychotropic medication to reduce wandering is ethically inappropriate and will also likely be ineffective [56, 57]. Where wandering is the result of depression, anxiety, pain, constipation or infection, these underlying triggers, if present, should be identified and actively managed with pharmacological treatment as necessary as outlined above.

Pharmacological Options available in BPSD



dementia pathways



- › If the patient does not respond to your personalised, non-pharmacological treatment plan then it may be time to consider the pharmacological options available.
There may come a time when medication management is appropriate.



- Note the following behaviours that are unlikely to respond to pharmacological intervention [56]:
- › Wandering
 - › Shadowing
 - › Repetitive verbalisation/ questioning
 - › Hiding and Hoarding
 - › Rejection or refusal of care
 - › Inappropriate undressing

Alice continued...

Two weeks later you review Alice on your rounds
Her agitation has increased in frequency

What do you do next?

dementia pathways



- › Agitation is increasing despite attempts to target triggers and implement non-pharmacological solutions
- › What options are available?
- › Patient should be reassessed to outrule a delirium.
- › Expectation is that the group would begin to consider pharmacological options



Encourage group participation and debate at this point. Incorrect assumptions or points about the differing medications can be discussed as the case continues.

All points made may be relevant and helpful for framing the rest of the workshop.

We should only consider pharmacologic treatment for BPSD behaviour that is dangerous, distressing, disturbing, damaging to social relationships and persistent, and only if the behaviour has not responded to comprehensive non-pharmacologic treatment plan, including removal of offending drugs [58].

Treatment needs to be targeted at specific problems - no blanket 'one size fits all' treatment.

Is there a role for any medications in managing BPSD?

Antipsychotics	<i>usually risk>benefit</i>
SSRIs	<i>potential role in agitation</i>
Memantine	<i>little evidence for use in BPSD</i>
AChEI	<i>evidence does not support use to rx BPSD</i>
Trazadone	<i>potential role but limited evidence</i>
Benzodiazapines	<i>not recommended</i>
Antiepileptics	<i>no evidence to support use</i>

dementia pathways



- › All of these pharmacological treatments have a potential, albeit often limited, role in BPSD.
- › The evidence for these treatments is modest
- › The choice of medication depends on which symptom you are treating. Target the treatment to the symptom.
- › Antipsychotics have a role where there is a significant risk of harm to self or others but there are serious potential side effects (will be discussed in more depth in future slides)
- › SSRIs have been shown to be effective in treating agitation in PwD but there is less evidence to support the role of SSRIs in the treatment of depression in PwD.
- › There is very little evidence to support the use of Cholinesterase Inhibitors or Memantine in BPSD but if that patient was on a sub-therapeutic dose it would be reasonable to maximize the dose and observe for side effects (SE).
- › Trazadone may have a role in managing sleep disturbance but again it has significant SEs, namely falls.
- › Due to their significant SE profile including their propensity to worsen cognition and cause falls then benzodiazapines are not recommended.
- › Currently there is no evidence to support the use of antiepileptic medications in BPSD.



CHOLINESTERASE INHIBITORS (ACHEIS)

Donepezil (Aricept), Rivastigmine (Exelon), Galantamine (Reminyl)

There are studies that show cholinesterase inhibitors have a modest benefit in BPSD [59, 60], however, the definitive study (CALM-AD trial) found that over a 12 week period, Donepezil was no more effective than placebo at managing agitation in people with Alzheimers disease [61]. AChEIs may have a role in the management of anxiety but the evidence is weak. In general, if someone experiences BPSD and is already on a sub-therapeutic dose of an AChEI then it is reasonable to maximise the dose and monitor for side effects, however, it is not recommended to commence an AChEI just for the purposes of managing BPSD.

Side Effects of AChEIs

Be aware that the side effects of AChEIs could potentially contribute to BPSD as the most common side effects are nausea and gastrointestinal (GI) upset. These side effects are often dose related and may improve over time, or with dose reduction. The GI symptoms can occasionally be overcome by use of a topical Rivastigmine patch.

Less common side-effects include heart arrhythmias, increased dreaming and nightmares.

Due to the potential to cause heart arrhythmias, prior to commencing a AChEIs we a baseline ECG should be performed – sometimes patients are on a beta-blocker or other agents that slows the heart rate and the addition of a AChEI in individuals with conduction block could precipitate heart block or lead to syncope.

2. SELECTIVE SEROTONIN RE-UPTAKE INHIBITORS (SSRIs)

Citalopram, Sertraline

SSRIs in Agitation in a PwD

A Cochrane review in 2011 found some evidence to support the role for antidepressants in the treatment of agitation in dementia but commented on the dearth of studies in this area [62]. This Cochrane review on the role of antidepressants in the management of agitation in PwD found that the SSRIs sertraline and citalopram were associated with a reduction in symptoms of agitation when compared to placebo in two studies. Both SSRIs and trazodone were tolerated reasonably well when compared to placebo, typical antipsychotics and atypical antipsychotics.

Subsequently in 2014 Cit-AD, a large, well-powered 9 week multi-centred placebo-controlled double-blind RCT, looked at the effectiveness of citalopram in managing agitation in people with dementia. Cit-AD found that 40% of patients on citalopram had a moderate or marked improvement from baseline compared to 26% on placebo, a clinically meaningful reduction in agitation comparable to that seen with antipsychotics [63]. In that RCT the addition of citalopram 30mg significantly reduced agitation and caregiver distress, however, the citalopram group did see worsening of cognition and QT interval prolongation. It is difficult to interpret the practical implications of this worsening of cognition as it has not been found in other studies of SSRIs or in a recent meta-analysis that looked at the role of SSRIs in the management of depression which included one study with citalopram [64]. The authors of the CitAD study concluded that although citalopram does effectively reduce agitation in this patient group, the cognitive and cardiac adverse effects of citalopram may limit its practical application. However, the dose used in that RCT was 30 mg/d dose and the current prescribing information recommends a maximum daily dose of 20 mg of citalopram for patients over 60 years of age because of substantially higher exposures, decreased clearance, and prolonged cardiac repolarization potential. The RCT did not have enough people in the 20mg group to assess the efficacy of that dose. Of note a subsequent study looking at response time found that treatment with citalopram for agitation in AD needs to be at least 9 weeks in duration to allow sufficient time for full response [65].

Therefore, in carefully selected patients there is strong evidence to support the role of citalopram to treat agitation in PwD, however, clinicians should be aware of a possible risk of worsening of cognition and QT prolongation.

Also the treatment should be continued for nine weeks to allow sufficient time for 'late responders'.

SSRIs in Depression in PwD

SSRIs have traditionally been the first-line pharmacological treatment of depression in PwD, however, all the major trials and meta-analyses published to date, (except for one trial - DIADS), have found that SSRIs were no better than placebo in reducing symptoms of depression in PwD [66].

A Cochrane review in 2002 looking at the use of antidepressants for the management of depression found that the evidence to support the use of antidepressants was weak, however, this analysis was based on a number of studies of small sample size and the authors commented on the paucity of research in this area [67].

The one trial that did find a positive effect for SSRIs in the management of depression in PwD was the DIADS trial [68] published the following year. The DIADS trial was a randomised, placebo-controlled, parallel, 12 week trial that found sertraline to be superior to placebo at reducing depression at 12 weeks of treatment, however, this was a relatively small study with 44 participants.

A meta-analysis in 2012 analysed five different studies on the effect of SSRIs on depression in PwD and found that current evidence does not support the efficacy of SSRI treatment for symptoms of comorbid depression in AD [64].

The most recent, and definitive trial, in this area was HTA-SADD, a large randomised controlled trial in 2011 on the treatment of depression in dementia which found that there was no effect of mirtazapine or sertraline compared with placebo [69]. This multi-centred, parallel-group, double-blind, placebo-controlled, randomised trial was the largest study to date of SSRI treatment for depression in dementia and had 13 and 39 week follow-up. This RCT found that neither sertraline nor mirtazapine reduced severity of clinically significant depression over 39 weeks compared with placebo in people with dementia. In addition, adverse events were more common with antidepressants than with placebo [70]. The HTA-SADD study concluded that it is possible that depression in dementia might be different in terms of neurobiology than depression occurring in those without dementia.

It does seem that based on current evidence it appears that SSRIs are ineffective at managing depression in PwD, however, we should note that the vast majority of these trials focused on sertraline. In real-world clinical practice, however, psychogeriatricians and geriatricians do use SSRIs to treat depression in PwD.

Side Effects of SSRIs

Consider following side-effects: headache, nausea, diarrhoea, sweating, insomnia.

Be aware of the potential to cause hyponatremia – it usually develops within the first weeks of treatment, and QT prolongation.

Titrate doses slowly while monitoring therapeutic and adverse effects, and effects on existing illnesses. The highest tolerated allowed dose should be used (e.g in citalopram the recommended maximum dose for the elderly is 20 mg daily). It is not appropriate to continue an ineffective low dose of an antidepressant. Consider trial an antidepressant for 4–6 weeks at the optimum dose before changing. If there is no benefit after six weeks, it should be slowly tapered and stopped. However, when using citalopram to treat agitation there has been evidence that some ‘late responders’ can take up to 9 weeks before they develop a full response.

3. MEMANTINE

There is little evidence to support the use of memantine in the management of BPSD.

Memantine in aggression/agitation

Previous studies and pooled analysis of studies did indicate that there was significant benefit for memantine versus placebo in treating agitation, delusions, hallucinations in PwD [71]. The problem with these studies is that the trials were initially designed with the purpose of testing cognition so the populations recruited did not necessarily have problematic agitation or high levels of neuropsychiatric symptoms.

A relatively recent trial published in 2012 [72] specifically looked at the efficacy of Memantine in treating agitation in PwD. This was a well-run double-blind randomised-controlled trial which was ran in the UK over a 3 year period with 153 PwD. This trial found that memantine is no better than placebo. Similarly a 2015 trial also did not find an improvement with Memantine [73].

Overall, there isn't strong evidence to support the use of memantine to manage aggression/agitation in PwD is poor.

Side effects of memantine include;

Headaches dizziness, constipation, confusion, decreased renal function.

Additionally while memantine is generally well-tolerated, some persons with dementia, particularly those with Lewy body pathology, may be susceptible to developing adverse effects which include increased aggression, new delusions, hallucinations or agitation [74, 75]. So close observation for worsening of symptoms is required if prescribing memantine.

Example of a memantine titration schedule:

The maximum daily dose is 20 mg per day. In order to reduce the risk of undesirable effects, the maintenance dose is achieved by upward titration of 5 mg per week over the first 3 weeks as follows:

- › Week 1 (day 1-7): 5mg OD (1/2 a 10mg tablet)
- › Week 2 (day 8-14): 10mg daily
- › Week 3 (day 15-21): 15mg daily
- › Week 4 on: 20mg daily

4. TRAZADONE**Trazadone in Sleep Disturbance in a PwD**

A Cochrane review on pharmacotherapies for sleep disorders in dementia found that trazodone 50 mg administered at night for two weeks significantly improved total nocturnal sleep time [76].

Trazadone in Anxiety in a PwD

Trazadone [77] may have some potential benefit in the management of anxiety in PwD but further trials are needed.

Trazadone in Agitation in a PwD

The evidence for the use of trazadone to manage agitation in dementia is weak, A Cochrane review looking at the role of trazadone in the management of agitation in PwD found insufficient evidence to support its use [78]. Similarly a Cochrane review in 2011 that looked at the role of various antidepressants in the management of agitation in PwD found only weak evidence to support its use [62].

Side-effects include:

Drowsiness, orthostatic hypotension – could result in falls

Potential use: If a patient had sleep disturbance in addition to depression/anxiety then trazodone may be a viable option but be aware of side effects, in particular the risk of falls.

5. BENZODIAZEPINES

The AGS-Beers criteria includes benzodiazepines in the potentially inappropriate medications class and recommends avoiding their use in older adults, especially for the treatment of insomnia, agitation or delirium. They are also included in the potentially inappropriate medications and classes to avoid in older adults in particular those with cognitive impairment and dementia as they can worsen cognition [79].

A systematic review on the role of benzodiazepine in the management of BPSD found that available data, although limited, does not support the routine use of benzodiazepines for the treatment of BPSD [80].

Due to their significant side effects benzodiazepines are not recommended for use in PwD, however, one possible use of benzodiazepines would be short term use in an agitated patient while waiting for an SSRI to take effect [81].

6. VALPROATE

A Cochrane review in 2009 confirmed that valproate preparations are ineffective in treating agitation in people with dementia. Additionally, valproate therapy is associated with an unacceptable rate of adverse effects [82].

7. GABAPENTIN

There are no meta-analyses or RCTs looking at Gabapentin in the management of BPSD. There is currently no evidence to support its use in the management of BPSD.

Alice continued...

Management Plan
 Increase Donepezil (Aricept) to 10mg OD
 If poor response planned to introduce citalopram
 plan not documented clearly

Colleague asked to review Alice the next week
 Increased quetiapine from 50mg OD to 50mg BD
 Alice subsequently has a fall
 Possibly a result of worsening orthostatic hypotension
 Resulted in a hip # with superimposed delirium

dementia pathways



- › The use of quetiapine is inappropriate and may have precipitated her fall



The dose increase in quetiapine is inappropriate and the choice of quetiapine as a pharmacologically agent is inappropriate. Quetiapine has no proven efficacy in the management of BPSD and specifically has an increased risk of orthostatic hypotension when compared to other anti-psychotics.

Limited role for quetiapine in BPSD

Although initially there was also some evidence to support the use of quetiapine in the management of aggressive behaviour in dementia [83], there is now consistent evidence from randomised controlled trials in people with Alzheimer's disease and Parkinson's disease dementia that quetiapine is ineffective in treating psychosis, aggression or agitation [84, 85]. Additionally quetiapine can have a sedative effect, can cause orthostatic hypotension and can also have a more detrimental effect on cognition than other antipsychotics [86]. On the positive side, quetiapine has the lowest mortality risk [87], however, the medication itself has not been shown to have efficacy in the management of BPSD.

Antipsychotics in Dementia

Risks of antipsychotics in dementia

- Death
- Stroke
- Falls
- Drowsiness
- Aspiration pneumonia

Avoid in Dementia with Lewy Body

dementia
pathways



While they are sometimes prescribed, and may have a short-term role, we should be aware of all the possible side-effects when prescribing antipsychotics to PwD who have BPSD.

Potential serious side-effects of antipsychotics in PwD include;

- › Increasing the risk of death (~ x 2) and stroke (~ x 3).
- › Increasing the risk of falls and drowsiness- resulting in increased injuries such as hip fractures.
- › Affecting swallow, resulting in an aspiration pneumonia.

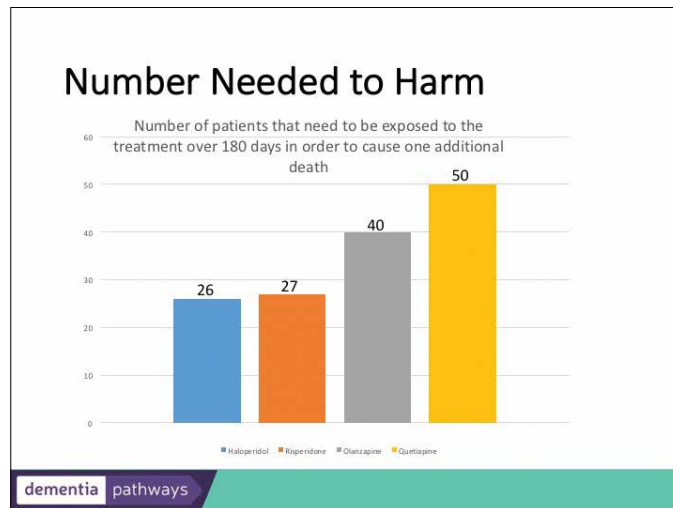


Antipsychotics are frequently associated with adverse effects, including increased risk of falls and drowsiness, hip fractures, pneumonia, parkinsonism, akathisia, tardive dyskinesa, social withdrawal, accelerated cognitive decline, QT prolongation, stroke, and sensitivity reactions [88, 87]. Several studies have shown an association between treatment with antipsychotic drugs and increased morbidity and mortality in PwD [89, 90, 86]. Additionally antipsychotics have been shown to have only limited efficacy in managing BPSD [89]. Given that antipsychotics are only minimally better than placebo for managing BPSD and they have serious adverse effects, antipsychotics are not recommended in BPSD unless there is a serious risk of harm to the patient or to others (<http://www.nice.org.uk/guidance/CG42>)

Could this be dementia with Lewy Bodies or Parkinsons Disease Dementia?

Key features of dementia with Lewy Bodies: long term (>6 months) history of vivid visual hallucinations or parkinsonism or fluctuating cognition.

If yes – do not prescribe an antipsychotic, as prescribing antipsychotics to people with this condition can result in life-threatening adverse effects. Prescribing a typical antipsychotic can cause sedation, rigidity, postural instability, falls, increased confusion, and neuroleptic malignant syndrome, with an associated two- to threefold increase in mortality [91]. Atypical antipsychotics can cause similar adverse effects and increase the risk of stroke.



- › Explain the graph briefly - During a 180-day period, starting haloperidol therapy for a patient with dementia was associated with 1 additional death for every 26 patients receiving treatment
- › We are not recommending any antipsychotic in particular here. We are demonstrating that all antipsychotics have an increased mortality risk in dementia.
- › Of note mortality risk is substantially increased for haloperidol and decreased for olanzapine when compared with risperidone.
- › Although quetiapine has a lower mortality risk recent studies have advised against prescribing of quetiapine as it has not been shown to be effective in the management of BPSD.
- › **The overall benefit of antipsychotics in BPSD is small and is limited by their side-effects [84, 92]**
- › Risperidone is the only licensed antipsychotic in people with dementia
 - › Starting dose of Risperidone is 0.25 – 0.5 mg/day
 - › Max dose 2mg daily



The number needed to harm (NNH) is a useful metric for clinicians to understand a treatment's potential for harm, expressing the number of patients who have to receive treatment for a particular harmful outcome to occur with the intervention.

This graph is based on a study by Maust et al [87]:

Risperidone is the only licensed antipsychotic in people with dementia. Its license is for the short-term treatment (up to 6 weeks) of persistent aggression in patients with moderate to severe Alzheimer's dementia unresponsive to non-pharmacological approaches and when there is a risk of harm to self or others. Starting dose of Risperidone is 0.25 – 0.5 mg/day. This dosage can be individually adjusted by increments of 0.25 mg twice daily, not more frequently than every other day, if needed. The lowest effective dose of risperidone for managing aggression is 1mg/day [86]. Some patients, however, may benefit from doses up to 1 mg twice daily but 2mg daily is the maximum dose. Watch out for extrapyramidal effects.

Effectiveness of Anti-Psychotics in BPSD

The definitive CATIE-AD study [85] was a placebo-controlled, double-blind, randomized clinical trial that compared three antipsychotics (quetiapine, risperidone, olanzapine) to each other and to placebo. This study included patients in non-nursing home settings and followed these patients over a nine-month period. This study found that there were no significant differences among treatments with regard to the time to the discontinuation of treatment for any reason: olanzapine (median, 8.1 weeks), quetiapine (median, 5.3 weeks), risperidone (median, 7.4 weeks), and placebo (median, 8.0 weeks) ($P = 0.52$). In other words, the participants who took placebo benefited just as much as those who took any of the three antipsychotic medications. This study also found that those taking olanzapine and risperidone were less likely to cite lack of benefit as a reason to discontinue use. However, those taking any of the three antipsychotic medications were more likely to discontinue use because of intolerable side effects than those taking placebo. The conclusion of the study was that the overall benefit of these medications is offset by intolerability to associated side effects.

Lack of Effectiveness for Quetiapine in particular

A comprehensive systematic review found that aripiprazole, olanzapine, and risperidone all had a statistically significant effect on the management of BPSD but quetiapine did not [93]. There is now consistent evidence from randomised controlled trials in people with Alzheimer's disease and Parkinson's disease dementia that quetiapine is ineffective in treating psychosis, aggression or agitation [84].

See slide 10 for the evidence on why to avoid prescribing of quetiapine in BPSD.



Monitoring Antipsychotic Prescribing

There is a role for antipsychotics in carefully selected patients with regular review

A Repeat Prescribing Tool for Antipsychotics in Primary Care

dementia pathways



- › The use of antipsychotics should be reserved for use in severe aggression or agitation where there is a risk to self or others. In certain carefully selected patients antipsychotics can be helpful, but they should be carefully monitored at all times.
- › When we do prescribe antipsychotics it is important that we have a review process in place to monitor prescribing
- › Antipsychotics can be successfully withdrawn in people with dementia
- › Discuss at this point an example of an antipsychotic monitoring tool for General Practice. The monitoring tool is available at dementiapathways.ie



Review antipsychotics prescribed regularly

- › Ask staff/carers to review regularly (weekly) initially for any adverse effects
- › Extra-pyramidal side effects can emerge with days with impact on gait & swallowing difficulties
- › Clinician review should occur 1-2 weeks after starting antipsychotic agent
- › PwD should have a trial of 6-12 weeks of the antipsychotic, then taper down and stop if no relapse in symptoms
- › Don't continue the antipsychotic if it is clinically ineffective

Some patients do need long-term antipsychotic medication but by having a **repeat prescribing tool** in place you can effectively monitor your antipsychotic prescribing.

Antipsychotics can be successfully withdrawn in people with dementia:

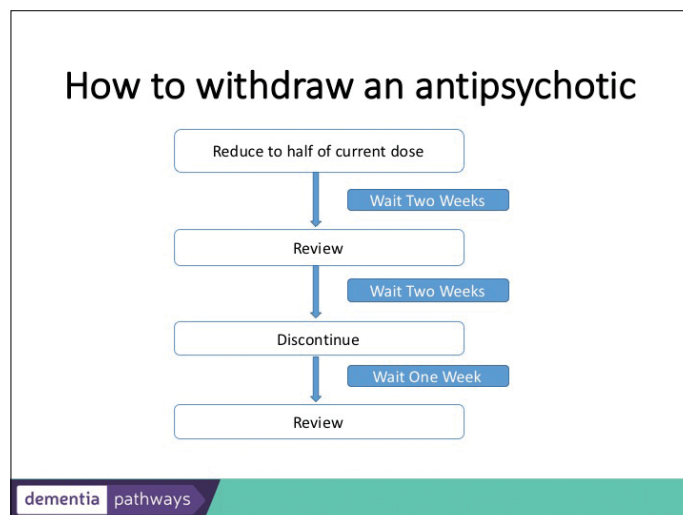
- › 70% of people have no worsening of symptoms when antipsychotics are discontinued and for those patients that do have worsening behaviour most of them are effectively managed with watchful waiting [48].
- › But in the minority that you cannot successfully withdraw the medication, a reduction in dose is still important, as the negative effects, particular the mortality risk, are dose related [92].

On starting an antipsychotic a plan should be put in place for when the antipsychotic will be stopped.

Patients should be reviewed regularly.

Document the therapeutic response and signs of possible adverse events including mobility, falls, sedation, low blood pressure, chest infection, and anticholinergic side effects [94].

Consider reducing or stopping medication if appropriate after 3 months, at the latest.



- › Withdrawing antipsychotics is relatively straightforward and generally very effective [95].
- › If attempting to implement this in practice in a nursing home setting, it is advisable to;
 - First, discontinue the antipsychotic in those patients that are considered the least likely to need it, in order to give the nursing home staff confidence in the process.
 - Any discontinuation date should usually be planned for a Monday so that if behavioural symptoms reappear these can be assessed during the working week.
- › If symptoms reappear then it may be necessary to restart the antipsychotic but a trial of 'watchful waiting' often results in resolution of the symptoms without restarting the antipsychotic
- › Even if you can't fully withdraw the antipsychotic agent, then a reduction in dose is still important as the negative effects, particular the mortality risk, is dose related [92].



If someone is on a low dose then the antipsychotic can be discontinued immediately. Higher doses need to be stopped more slowly.

SUGGESTED DAILY LOW DOSE

Aripiprazole

Less than 5mg can be stopped immediately

Olanzapine

2.5mg or less can be stopped immediately

Quetiapine

25mg or less can be stopped immediately

Risperidone

0.5mg or less can be stopped immediately

Haloperidol

0.5mg or less can be stopped immediately

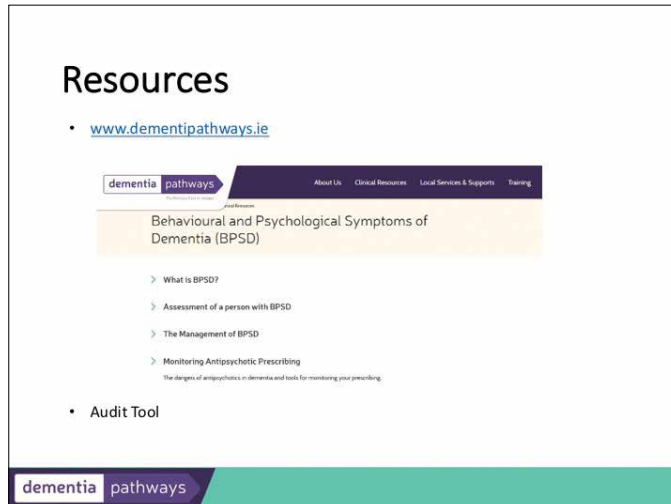
Amisulpiride

25mg or less can be stopped immediately

In some cases it may be necessary to withdraw the antipsychotic more slowly, particularly if symptoms reappear. If a PwD is on a higher dose then these, then the antipsychotic will need to be tapered over a one-month period.

Example dose-reduction regimens are given in Table 1, below.

Drug	Total daily dose	Step 1	Step 2	Step 3
Risperidone	Up to 500 micrograms	Stop		
	Up to 1mg	Halve dose	Stop	
	Over 1mg	Halve dose	Halve dose	Stop
Quetiapine	25mg	Stop		
	Up to 50mg	Halve dose	Stop	
	Over 50mg	Halve dose	Halve dose	Stop
Haloperidol	Up to 500 micrograms	Stop		
	Up to 1mg	Halve dose	Stop	
	Over 1mg	Halve dose	Halve dose	Stop



The screenshot shows the 'dementia pathways' website. The main heading is 'Resources' with a link to www.dementipathways.ie. Below this is a navigation menu with 'About Us', 'Clinical Resources', 'Local Services & Supports', and 'Training'. The main content area is titled 'Behavioural and Psychological Symptoms of Dementia (BPSD)' and lists several resources:

- > What is BPSD?
- > Assessment of a person with BPSD
- > The Management of BPSD
- > Monitoring Antipsychotic Prescribing
The dangers of antipsychotics in dementia and tools for monitoring your prescribing

At the bottom, there is a link to 'Audit Tool'.



Introduce dementipathways.ie and demonstrate how GPs may use it for;

- › Sign-posting dementia services & supports
- › Accessing clinical information about dementia care.

Introduce the audit tool

- › Practices can avail of these tools through their practice computer software systems – including the Socrates, Practice Manager, Helix Health One, and Complete GP software systems.
- › Undertaking a practice-based audit may improve the management of patients with dementia who are on an antipsychotic agent.



BACKGROUND TO AUDIT TOOL

Antipsychotic Prescribing in People with Dementia Audit

Step 1.

Identify all patients coded with dementia that are on an antipsychotic.

Step 2.

Review this list

- › If on antipsychotic for pre-existing condition prior to dementia diagnosis then do not change
- › Any antipsychotic prescriptions for management of BPSD where the dose could be reduced?
- › Any antipsychotic prescriptions for management of BPSD where the dose could be withdrawn?
- › 3. Consider dose reduction/withdrawal - Use withdrawal schedule to withdraw/ reduce dose of antipsychotics prescribed

Step 3.

Consider dose reduction/withdrawal - Use withdrawal schedule to withdraw/ reduce dose of antipsychotics prescribed

Step 4.

Generate list of PwD who are now on an antipsychotic – this completes the audit cycle.

In addition you can continue to use the antipsychotic monitoring tool to monitor patients that remain on antipsychotics



Summary

Be clear about the behaviour you are trying to treat

Does this behaviour have a meaning? Sleuth it out

If prescribing antipsychotics then monitor them

Antipsychotics can be successfully withdrawn in people with dementia – try it

dementia pathways



- › Before intervening be sure you have an accurate description of the behaviour
- › Be realistic: success is measured by decreases in intensity, frequency and duration of behaviours, rarely extinguishment

Thank You

Contact the team on:

dementiaphways@ucc.ie



- › Discuss the options for clinical audit, using the iPCRNI/ICGP software tools for generating dementia registers (available on Helix Practice Manager, Socrates, HealthOne and CompleteGP practice management systems), and that audit completion will meet the ICGP professional competence audit requirements.
- › The dementiaphways.ie website is accessible to all.
- › If appropriate, use this opportunity for participants to complete attendance and/or evaluation and feedback paperwork.



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