WaMH in PC Wales Mental Health in Primary Care

WALES MENTAL HEALTH IN PRIMARY CARE

MANAGING DEMENTIA IN PRIMARY CARE TRAINING RESOURCE

DEMENTIA RESOURCE BOOK - INFORMATION & SIGNPOSTING

Acknowledgements:

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RCGP WALES
Royal College of General Practitioners

the creative work place

GIG CYMRU NHS WALES
Iechyd Cyhoeddus Cymru
Public Health Wales

CARDIFF UNIVERSITY
PRIFYSGOL CAERDYDD

Leading the fight against dementia
Alzheimer's Society

This book contains a range of resources to support the dementia training package

CONTENTS

BACKGROUND NOTES ON THE DVD

These notes contain additional information about each section of the DVD and are a useful resource for all practice staff.

DVD SECTION 2 – About Dementia

Professor Tony Bayer - IPCPH, School of Medicine,
Cardiff University & Director Memory Team,
Cardiff and Vale University Health Board

DEMENTIA IS…

- A progressive and largely irreversible clinical syndrome
- Characterised by global deterioration in intellectual function, behaviour and personality (in the presence of normal consciousness)
- Cognitive deficits sufficiently severe to interfere with day-to-day functioning

Young onset dementia – formerly known as 'pre-senile dementia', refers to patients who develop dementia before the age of 65 years

Late-onset dementia – previously known as 'senile dementia', refers to patients who develop dementia after the age of 65 years

DEMENTIA AFFECTS…

- Estimated 45,000 people with dementia in Wales
- Numbers predicted to double in the next 30 years
- 1 in 3 people alive today will die with dementia
- Two thirds live in private households, the rest in care homes
- Incidence increases with age; most are aged over 75 years
- Young onset dementia (<65) is relatively rare
- Average GP practice with 10,000 patients will have ~50 people with dementia (more if high % of care homes)
  Only ~40% of predicted are on QoF GP dementia registers

RISK FACTORS FOR DEMENTIA

Non Modifiable risk factors

- Age (advancing age is the most important risk factor doubling numbers every 5 years after age 55)
- Learning disabilities – in Down's syndrome, dementia develops 30-40 years earlier than normally
- Gender – higher risk in women than in men
- Genetic factors – but familial dementia is uncommon

Modifiable risk factors

- Alcohol consumption
- Smoking
- Obesity and type 2 diabetes
- Lack of exercise
- Hypertension
- Hypercholesterolaemia
- Early education and mental stimulation

MAJOR CAUSES OF DEMENTIA

Alzheimer's disease (AD) (50 – 60%) – typically presents with poor recent memory, disorientation, language breakdown, poor judgement, lack of insight

Vascular dementia (VAD) (20-30%) – often associated with stroke disease and AD; typically characterised by slow thinking, difficultly planning and poor memory retrieval

Dementia with Lewy bodies (DLB)/Parkinson's Dementia (PDD) (10 – 20%) – typically fluctuating cognition, visual hallucinations and Parkinsonism

Frontotemporal dementia (FTD) (5%) – presents with early behaviour, personality and language impairment; usually present as young onset dementia

Alcoholic dementia (5%) – under recognised; poor memory and lack of concern

DISTINGUISHING NORMAL AGEING FROM EARLY DEMENTIA

	NORMAL AGEING	**EARLY DEMENTIA**
Memory	Occasional lapses	Loss of memory of recent events
Orientation	Full in time, space and person	Variable disorientation in time and place
Judgement & Problem Solving	Solves everyday problems	Some difficulty with complex problems
Outside home	Independent functioning	Engaged in some activities but not independently; may appear 'normal'
At home	Activities and interests maintained	More difficult tasks and hobbies abandoned
Personal care	Fully capable	Needs some prompting

Based on the Clinical Dementia Rating (CDR): Hughes et al (1982)

MILD COGNITIVE IMPAIRMENT (MCI)

- Mild cognitive impairment (MCI) is syndrome of cognitive impairment greater than expected for an individual's age and education level and **without** experiencing considerable changes in usual activities of everyday life
- Intermediate between a cognitively normal elderly person and someone with clear dementia
- Typically amnestic type (memory is affected), but also non-amnestic (memory is not affected)
- Possibility of developing dementia (mostly Alzheimer disease) in an individual with MCI (10-15% per year) is 5 to 10 times greater when compared to cognitively healthy individuals (1-2% per year), so reassessment in 6-12 months is appropriate

WHEN TO SUSPECT DEMENTIA

- When family members report memory impairment but the patient denies it
- When the patient is questioned, he/she looks at the carer for an answer – the 'head-turning sign'
- Conversation is repetitive, or instructions are forgotten
- Appointments are muddled, or prescriptions not collected regularly
- Evidence of self-neglect
- Recent change in behaviour or personality

WHY IS DEMENTIA DIAGNOSIS IMPORTANT?

Timely diagnosis can lead to…

- Better quality of life for both the person with dementia, and carer/families
- The right support for carers/families, at the right time
- Reduction in the risk of misdiagnosis and inappropriate management
- Delaying a move to a care home, enabling people to remain in their own home, for longer
- Ensuring people have access to services and medication, enabling them to live well, for longer
- Planning for future care/support needs, including end of life care

SCREENING FOR DEMENTIA?

Not recommended for general population (but case finding may be justified)

May be a case for screening in high-risk groups, i.e.

- Down's syndrome and other learning disabilities
- Parkinson's disease
- After a stroke

BACKGROUND NOTES

SECTION 3 – Timely Diagnosis

Dr Alison Neisser, Locum GP

RATIONALE FOR EARLY INTERVENTIONS

- Patients have choices
- Carers have choices
- Exclude treatable conditions
- Mitigate rate of decline
- End of life planning

PATIENTS HAVE CHOICES

Receiving an early diagnosis of dementia will enable patients to:

- Plan for the future
- Maximize quality of life
- Access and benefit from treatments
- Demystify and de-stigmatise the condition
- Gain access to information, resources and support
- Explain to friends, family and colleagues what has changed

ON A PRACTICAL LEVEL

- Check on eligibility for any state support
- Find out about services that are available in their area
- Patients may wish to review their financial situation. This might include arranging for bills to be paid by direct debit and arranging a lasting power of attorney
- If still in employment, then think about reducing hours or changing work patterns (or maybe take early retirement)

- GPs should advise patients who are driving to inform the DVLA about their condition. The DVLA will decide if the patient can carry on driving after contact with the patient and GP or specialist. Rarely, a driving assessment may be required.
- Patients who continue to drive must tell their insurance company that they have dementia. Not telling the insurance company will mean that their insurance may not be valid and they will not be covered if they have an accident.

'THINGS TO DO'

Before dementia compromises enjoyment and participation:

- Make regular use of simple memory aids and encourage regular routines
- Change light bulbs – brighter is better
- Consider if a move nearer to relatives and support would be helpful
- Keep socially active
- Change the kitchen cupboard doors to glass so you can see what is in them
- Get rid of patterned carpets, de-clutter etc.
- Optimise general health & well-being: exercise, stop smoking, optimise eyesight & hearing, review medication

BACKGROUND NOTES

SECTION 4 – Memory Clinics

Professor Tony Bayer - IPCPH, School of Medicine,
Cardiff University & Director Memory Team,
Cardiff and Vale University Health Board

WHEN REFERRING TO MEMORY CLINIC

- Do a brief cognitive assessment
- Explain to patient the potential benefit of referral
- Consider whether primary diagnosis is depression or delirium and treat appropriately. Could alcohol or drugs be contributory?
- Undertake routine blood screening (FBC, U&E, LFT, HbA1c/glucose, TFT, B12 & folate)
- Consider ordering CT scan, so that result available in clinic
- Encourage patient to attend clinic with close relative/friend
- Provide clinic with carer contact details and information about patient's first language (so interpreter can be arranged if needed)

WHAT TYPICALLY HAPPENS IN MEMORY CLINIC

- Comprehensive history from patient and informant, detailed cognitive assessment and appropriate investigations, leading to diagnosis
- Discussion with patient and informant about nature of problems and cause and provision of written information
- Initiation of any appropriate anti-dementia drugs
- Advice (e.g. Power of Attorney, driving, benefits, memory aids etc.) and referral for support (e.g. Alzheimer's Society, cognitive stimulation, carer support, etc.)
- Explanation about future follow up arrangements

BACKGROUND NOTES

SECTION 5 – REDUCING THE RISK OF DEMENTIA

Phill Chick
Mental Health Development Lead for Wales,
Public Health Wales

REDUCING THE RISK – WHY BOTHER?

- Current treatment options for dementias have limited effectiveness.
- Whilst more effective treatments for dementias are sought, prevention approaches provide primary care with a low cost, low risk intervention.
- Dementia prevention is a major public health issue. With an increasing prevalence of dementia, the need to prevent or slow down the onset of dementias is vital to avoid the individual, familial, social and economic consequences of the condition.
- Dementia prevention advice is complimentary to current primary health care well-being advice.
- The level of concern about the risk of dementia may tip people into making recommended lifestyle changes.

TO WHOM SHOULD THE ADVICE BE DIRECTED?

- Evidence suggests that taking action in middle age 40-60 is most effective. However, as much of the advice is largely supportive of general well-being, potentially the whole adult practice population can be targeted.
- Evidence suggests that there are genetic risks for some dementias. Therefore those people with a familial history of dementia could be prioritised for preventative advice and treatment.

WHAT ADVICE SHOULD BE GIVEN?

The predominant advice for dementia prevention concerns lifestyle.

The messages are consistent with physical health lifestyle advice:

- Stay physically active
- Stay mentally active
- Moderate alcohol use
- Don’t smoke
- Eat healthily
- Maintain social contacts
- Improve sleep quality
- Manage stress
- Avoid head injuries
- Maintain a healthy body mass index

WHICH INTERVENTIONS ARE INDICATED?

- Identify and treat hypertension
- Identify and treat depression
- Avoid excessive alcohol use and stop smoking
- Identify and treat diabetes (but avoid low blood sugars)
- Ensure good, balanced diet

BACKGROUND NOTES

SECTION 6 – Living with Dementia

Sue Phelps

Director of Alzheimer's Society in Wales

WHAT DO PEOPLE NEED AT THE POINT OF DIAGNOSIS

- Focus on what can be done, rather than what can't
- Provide good information to take away
- Allow people time to come to terms with the diagnosis

LIVING WITH DEMENTIA

- People want to be able to live as well as possible
- They want people to understand their condition
- They want support for their needs
- They want to be as independent as possible for as long as possible
- Don't assume that support should always come from their carer

EARLY DIAGNOSIS

Diagnosis unlocks the door to:

- Support
- Information
- Medical treatment
- Choice
- Taking control of decisions that affect lives

BACKGROUND NOTES

Advance Care Planning in Dementia and End of Life Care

Dr Helen Herbert, GP Aberaeron

ADVANCE CARE PLANNING IN DEMENTIA

It is important to recognise that Advance Care Planning is necessary to do at an early stage in the patient's illness, to enable them to make choices at a stage when they still have capacity. Where these are not in place, a best interests decision is made.

PREFERRED PRIORITIES

This is an opportunity for patients to include wishes and preferences for their care. It is not legally binding, but can help decision making in the future at a time when they may have limited or no capacity.

ADVANCE REFUSALS

This is a document completed by a competent individual, stating treatments and interventions they would not want to receive in specific circumstances in the future when they may not be competent to make this decision. An example of this may be resuscitation. However, it is extremely important that the specific circumstances are defined. This is a legal document.

LASTING POWER OF ATTORNEY

This is a legal document whereby the decision making for an incompetent has been handed over to a specific individual. There are two types; one for health decisions, and another for financial.

BEST INTEREST DECISIONS

Made when the patient lacks capacity to make a decision, and there is no welfare Lasting Power of Attorney.

May need to involve an Independent Mental Capacity Advocate (IMCA).

CARE PLANS

- Discuss with patient as appropriate
- Discuss with family and carers
- Review appropriateness of medication
- Plan treat goals and ceilings
- Consider "Do Not Attempt Cardiopulmonary Resuscitation (NACPR)"
- Consider "just in case box"

RECOGNISED TRIGGERS FOR PATIENTS WHO MAY BE ENTERING THE LAST YEAR OF LIFE WITH ADVANCED DEMENTIA

Look for two or more clinical indicators of advanced progressive illness:

- Progressive deterioration in physical function despite optimal therapy
- Speech problems with increasing difficulty communicating and/or progressive dysphagia
- Recurrent febrile episodes or infections; aspiration pneumonia; breathless or respiratory failure
- Unable to dress, walk or eat without help; unable to communicate meaningfully
- Needing assistance with feeding/maintaining nutrition
- Urinary and faecal incontinence

END OF LIFE CARE IN DEMENTIA

- Plan Care
- Discuss with patients as appropriate
- Discuss with family
- Discuss with carers
- Review appropriateness of medication
- Plan treatment goals

END OF LIFE CARE IN DEMENTIA

Symptom Control

Pain and symptom control should be achieved in line with good clinical practice at the end of life for all patients. However, there are some specific issues in patients with advanced dementia that need to be considered.

- Agitation, aggression and hallucinations; non-pharmacological methods should be considered first and any physical cause i.e. pain and infection, excluded. Where sedation thought necessary, consider trazodone or advice from secondary care.
- Low mood, lability of mood and sexual disinhibition; these are common, and where physical causes have been excluded, consider an SSRI. Where there is treatment failure, seek advice from secondary care.

Environment

- Changes in environment can exacerbate disorientation and agitation, and where possible these should be minimised.
- It is important to identify ceilings of care, such as resuscitation, to try and minimise exacerbating distress and changes in care setting at the end of life.

Covert Medication

- May be used when capacity is lost after a risk benefit analysis
- A best interest decision can be made after discussion with family / carers, and should be documented.
- Transdermal analgesic patches should be used with caution and avoided in the opiate naïve.

The next section of the resource book contains a wide range of information relevant to dementia care

READ CODES

Patients with diagnosed dementia

Suggested READ codes /Terms that could be used to indicate a diagnosis of dementia.

- E00. Senile and presenile organic psychotic conditions
- Eu00% [X]Dementia in Alzheimer's disease
- Eu01.% Vascular Dementia
- Eu02z Unspecified Dementia
- Eu02. [X]Dementia in other diseases classified elsewhere
- E02y1 Drug-induced dementia
- Eu107 [X]Alcoholic dementia NOS
- E012. Other alcoholic dementia
- Eu041 [X]Delirium superimposed on dementia
- F110. Alzheimer's disease
- F112. Senile degeneration of brain
- F116. Lewy body disease
- dy... CENTRAL ACETYLCHOLINESTERASE INHIBITOR
- d4... ANTIPSYCHOTIC DRUGS
- dB1.. MEMANTINE HYDROCHLORIDE

For a full list of the READ codes relating to the following please refer to the Public Health Wales Quality Improvement Toolkits, located in the "Additional Resources section" of this book.

Terms

- Patients with diagnosed dementia with a record of attending a memory assessment service
- Patients with diagnosed dementia who have been reviewed in the previous 15 months
- Patients with diagnosed dementia with a medication review recorded within the last 15 months
- Patients with diagnosed dementia with a named carer recorded
- Patients presenting with memory loss symptoms / mild cognitive decline
- Patients presenting with memory loss symptoms / mild cognitive decline who have a record of having had further investigations
- Patients presenting with memory loss symptoms / mild cognitive decline who have had a review of current medication
- Patients presenting with memory loss symptoms / mild cognitive decline where a cognitive assessment is recorded
- Patients where a cognitive assessment is recorded and offered a referral to memory assessment services

WEBSITES, LINKS & ONLINE RESOURCES

Alzheimer's Society

Alzheimer's Society is a membership organisation, which works to improve the quality of life of people affected by dementia in England, Wales and Northern Ireland.
http://www.alzheimers.org.uk

Helping you to assess cognition – A practical toolkit for clinicians. Available at:
http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1661

Resources for health care professionals, including top 10 tips for nursing and care staff supporting people affected by dementia. Available at: http://www.alzheimers.org.uk/healthprofessionals

The Dementia Guide a guide for people who have recently been told they have dementia or their close friends and family. Available at:
http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1881

A bilingual information pack, entitled, "Byw yn dda gyda dementia ar ôl diagnosis/Living well with dementia after diagnosis", for people in Wales newly diagnosed with dementia. Available at:
http://www.alzheimers.org.uk/livingwellwithdementia

A downloadable guide entitled 'Be Headstrong' which contains tips to help reduce the risk of developing dementia. Available at:
http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1303

Alzheimer's Society factsheets cover a wide range of dementia related topics. Available at:
http://www.alzheimers.org.uk/factsheets

BCU HB

Palliative Care in Advanced Dementia – Leaflet for Professionals. Available at: www.wamhinpc.org.uk (dementia tab)

BMJ Learning

CPD course for GPs, GP trainees and Practice Nurses regarding the management of dementia in primary care – in association with Alzheimer's Society. Available at:
http://learning.bmj.com/learning/module-intro/dementia-primary-care.html?moduleId=10032231&searchTerm=%E2%80%9Cdementia%E2%80%9D&page=1&locale=en_GB

Book Prescription Wales Scheme (Welsh Government)

Includes books on dementia which are available to borrow. Available at:
http://www.nhsdirect.wales.nhs.uk/pdfs/WG%2016567%20A4%20Booklist%20WEB.pdf

Carer's Trust

Carer's Trust works to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.
http://www.carers.org/

Dying Matters

"Time to talk?" - starting end of life care conversations with people affected by dementia. Available at: http://dyingmatters.org/sites/default/files/user/Leaflet%2011_WEB.pdf

Mental Capacity Act

http://www.wales.nhs.uk/sites3/page.cfm?orgid=744&pid=34346

Palliative Care Matters

Palliative Care in Wales is part of the Palliative Care Matters network of sites. It is aimed at health care professionals working in the palliative care field.
http://wales.pallcare.info/

Public Health Wales.

Dementia Management in Primary Care – Quality Improvement Toolkit **(PHW Toolkit 1)**

Recognition, Assessment and Referral of Suspected Dementia in Primary Care – Quality Improvement Toolkit **(PHW Toolkit 2)**

End of Life Care Review Case Review Audit **(PHW Toolkit 3)**

All of the above are available at:
http://www.wales.nhs.uk/sitesplus/888/page/59780 (Click on 'Other Clinical Audit Topics - internet)
http://howis.wales.nhs.uk/sitesplus/888/page/49448 (intranet)
www.wamhinpc.org.uk (dementia tab)

Royal College of General Practitioners

The RCGP is the professional membership body for family doctors in the UK and overseas. We are committed to improving patient care, clinical standards and GP training.
http://www.rcgp.org.uk/

Supporting Carers: An action guide for general practitioners and their teams. Available at: http://www.rcgp.org.uk/clinical-and-research/clinical-resources/~/media/Files/CIRC/Carers/Carers-Action-Guide.ashx

Factsheet: "Dementia; diagnosis and early intervention in primary Care". Available at: www.wamhinpc.org.uk (dementia tab)

Factsheet: "Care of people with dementia in primary care". Available at: www.wamhinpc.org.uk (dementia tab)

Welsh Government

National Dementia Vision for Wales. Available at: http://wales.gov.uk/docs/dhss/publications/110302dementiaen.pdf

USEFUL TELEPHONE NUMBERS

Age Cymru
Tel: 0800 1696565
www.agecymru.org.uk

Alzheimer's Society
Tel: 02920 480593
www.alzheimers.org.uk

CAB Adviceline Wales
Tel: 08444 77 20 20
www.adviceguide.org.uk

Carers Trust
Tel: 0845 450 0350
www.carers.org/

Community Advice and Listening Line (C.A.L.L.) – Mental Health Helpline for Wales
Tel: 0800 132737
Text – 81066
www.callhelpline.org.uk

Older People's Commissioner for Wales
Tel: 08442 640 670
www.olderpeoplewales.com

Parkinson's UK Wales
Tel: 0303 3033 100
http://www.parkinsons.org.uk/content/wales

Wales Dementia Helpline
Tel: 0808 8082235
Text – 81066
www.dementiahelpline.org.uk

PLEASE ADD CONTACT DETAILS FOR LOCAL RESOURCES HERE