10 Key Steps

Improving dementia care in primary care: 10 key steps for General Practice
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Introduction

This Briefing is designed to support GPs and primary health care teams to improve the recognition, diagnosis management of dementia. It promotes:

- people’s rights, and tackling stigma associated with dementia
- case finding approaches
- tools to support initial assessment
- tips for better coding and record keeping, and
- signposts to additional training and education resources.

It is supplemented by additional resources, including:

- [Improving diagnosis of dementia: 10 key steps for Commissioners and Clinical Commissioning Groups](South West Dementia Partnership, 2012)
- [Dementia Care in Primary Care Toolkit](South West Dementia Partnership, 2012)
- [Guidance and Standards for Diagnosing Dementia](South West Dementia Partnership, 2012)
- [New Models of Care for Dementia](South West Dementia Partnership, 2012)

The primary care gateway

GPs and primary health care teams are often the first port of call for people worried about their memory, and are a gateway to early diagnosis and interventions.

- [Find out more about the role of the GP and primary health care team in dementia care](www.southwestdementiapartnership.org.uk)
1. Think dementia

2. Check

3. Recognise

4. Assess

5. Refer

6. Record

7. Review

8. Case find

9. Code

10. Engage

10 Key Steps for GPs improving dementia care in primary care
1. Think dementia

- Bring dementia out of the shadows: a diagnosis of dementia still carries with it stigma and fear; people report that they fear receiving a diagnosis; people also report that they fear the consequences of becoming a carer of someone with a diagnosis.

- In the UK today it is estimated that 60 per cent of people with dementia have no formal diagnosis. Avoiding ‘naming’ memory problems and possible dementia is a key factor preventing people seeking, and being offered the treatment and support they need, early enough.

- GPs and primary health care teams are central to enabling people to have sometimes difficult conversations about memory problems, and to help people to live as well as possible with dementia.
  - Consider what messages your Practice gives to people who may be concerned about memory problems.
  - How confident are staff in dealing with memory problems?
  - What information about dementia, local support and services are available to patients within your Practice, and in what format?

- Early diagnosis and interventions can deliver better outcomes for people with dementia, and their carers/families, and save money.
2. Check

- Introduce questions about memory functioning in scheduled visits and routine health checks and investigations for people over 65 years. These might include,
  - annual checks for over-65s with long term conditions
  - annual flu clinic health questionnaires
  - adults with Downs Syndrome, over 40 years

- Be alert to those cases involving
  - falls
  - patients failing to attend appointments
  - patients failing to collect dispensed medications
  - cases where a previous initial assessment for dementia has been undertaken
  - references to confusion, depression, problems thinking, reasoning, struggling to follow conversations, forgetfulness, and other changes in mood and cognition.

- Remember that carers/families may bring their concerns to you. What should be the Practice’s response?

- With your primary health care team, consider older patients who may be vulnerable, who may be presenting with a change in mood or cognition, or whose self care is deteriorating. Could memory problems be a feature? Would it be appropriate and timely to offer a memory check?

- Check for a low threshold for assessing patients who are occupying community hospital beds for which the GP surgery provides clinical cover.

- Consider patients who are in care homes. Where dementia is established,
  - Has a diagnosis been recorded and captured on the Practice dementia register?
  - Are these patients benefitting from regular health checks, and reviews of medication?
  - Are staff in the care home able to manage behaviours that challenge, offering alternatives to prescribing antipsychotics?
  - Are there trends in emergency admissions to hospital?
3. Recognise

- Be alert to the signs and symptoms of memory problems.
- Take time to ask the right questions. These might include,
  - When speaking do you have more difficulty in finding the right word or tend to use the wrong words more than you used to?
  - Are you having trouble concentrating and/or remembering things that have happened recently?
  - Have you had any concerns about your memory in the last 6 months?
- Reassure, and actively debunk stigma associated with memory problems and dementia

Factsheets about dementia

- What is dementia? Alzheimer’s Society (2010)
- What is Creutzfeldt-Jakob disease (CJD)? Alzheimer’s Society (2010)
- What is dementia with Lewy bodies (DLB)? Alzheimer’s Society (2010)
- What is fronto-temporal dementia (including Pick's disease)? Alzheimer’s Society (2010)
- What is posterior cortical atrophy (PCA)? Alzheimer's Society (2010)

Education and training resources for GPs and primary health care teams

- Dementia Care in Primary Care Toolkit (South West Dementia Partnership, 2012)
- The dementia gateway (Social Care Institute for Excellence, 2010)
- The open dementia e-learning programme (Social Care Institute for Excellence, 2009)
4. Assess

- undertake an initial assessment to rule out other causes of confusion or memory problems
- consider who in your Primary Health Care Team could support the initial assessment process

Find out more about initial assessment and routine tests

5. Refer

- Know where to refer patients for a specialist memory assessment, where indicated.
- Signpost patients and their carers/families to local resources, information and support.

View the Map of Medicine for Dementia assessment (Map of Medicine, 2010)
View the Map of Medicine for Dementia management (Map of Medicine, 2010)
6. Record

- When a specialist memory assessment has been undertaken and a diagnosis has been made, ensure that your practice receives a clear diagnosis and records this on its dementia register.

**Quality and Outcomes Framework for GMS contract 2011/12, DEM 1**

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<thead>
<tr>
<th>No.</th>
<th>Indicator</th>
<th>Points</th>
<th>Payment stages</th>
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<tbody>
<tr>
<td>DEM1</td>
<td>The practice can produce a register of patients diagnosed with dementia</td>
<td>5</td>
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View the dementia section from the Quality and Outcomes Framework guidance for GMS contract 2011/12 (NHS Employers and British Medical Association, 2011)

View Quality and Outcomes Framework guidance for GMS contract 2011/12 (NHS Employers and British Medical Association, 2011)

Is the diagnosis rate good enough? Estimating General Practice prevalence rates

- Consider approximately how many people you would expect to be on your Practice Dementia Register. This may be subject to a number of local variables, including the demographic profile of your practice population, and the presence care homes.

- Engaging with your Practice team to estimate what your local prevalence rate might be will provide an opportunity to consider those variables affecting people presenting with memory problems, and people receiving an early diagnosis.

View the Dementia Practice Prevalence Calculator (South West Dementia Partnership, 2011)

Note: the Dementia Practice Prevalence will not predict the prevalence rate because numbers are too small to be statistically significant at Practice level. The Calculator has been provided so that Practices may start with a figure, and consider and agree:

- the factors to consider as variables that would impact the local prevalence rate;
- a rationale for arriving at the same, or a different prevalence rate;
- trajectories for improving the actual diagnosis rate, year-on-year, and how to achieve this.
7. Review

A. Mild cognitive impairment

• Ensure that your practice has in place a system for recalling patients who may have mild cognitive impairment, for review.

• When a patient is recalled for a review, capture and record any changes in his/her presentation, including diagnosis.

B. Dementia diagnosis

• Review all patients with a diagnosis of dementia at least every 15 months (QOF DEM2).

• Review carers’ needs; consider whether they need referral for a carer’s assessment;

• Signpost people to sources of advice, guidance and support in the community

• Regular health checks

  1. General physical health check including blood pressure, pulse (check for new atrial fibrillation). Those with vascular dementia are likely to be on other QOF registers too (eg hypertension, CHD, CVA/TIA) which require other specific checks like cholesterol, taking certain preventative medication etc.

  2. Medication review including cholinesterase (if shared care guideline and GP is issuing not secondary care), co-prescribing of anticholinergics (stop if possible), vascular risk reduction.

  3. Assess falls risk and consider suitable prescribing or referral if high.

  4. Assess for any triggers to behavioral problems over past 12 months and what helped resolved the problems (drug or environmental). Liaise with carer to promote preventative strategies (e.g. clean urine pot/supply of antibiotics in case of urine infection, regular aperients, analgesia available).

  5. Ensure any care preferences are documented and shared with local agencies (e.g. out of hours, ambulance provider, care home staff).
C. Prescribing of low dose antipsychotics

- Audit all prescribing of low dose antipsychotics to ensure that it falls within NICE/SCIE CG42
- Review all patients on low dose antipsychotics in order to establish,
  - the reasons for this prescription,
  - whether a diagnosis of dementia is indicated
- are they on the Practice dementia register?
- If the patient has been prescribed antipsychotics to treat behaviours that challenge, consider whether,
  - their treatment and care falls in line with NICE/SCIE CG42
  - alternatives to prescribing antipsychotics have been offered
  - and any action to be taken to bring prescribing practice into line with national guidance.

View a sample Audit Protocol for the prescribing of antipsychotics for people with dementia


View the national Call 2 Action for the reduction of prescribing of antipsychotics for people with dementia (Dementia Action Alliance and NHS Institute for Innovation and Improvement, 2011)
8. Case find

- Consider patients with co-morbid conditions where the incidence of dementia may be a factor. These include patients with
  - cardiovascular disease and stroke
  - Huntington’s Disease
  - Parkinson’s Disease
  - depression.
- Review patient records for drugs commonly prescribed including Donepezil, Rivastigmine and Galantamine.


Key questions:
- Are any further investigations required to establish whether dementia is indicated?
- If memory problems, and/or the symptoms of dementia are having an impact on these patients and their carers/families, what information and support do they need? What information or support could the general practice offer, or signpost them to?
9. Code

Differential coding can camouflage cases of dementia. Check coding practice, and audit coding to identify those codes that could be indicate a diagnosis of dementia. They will include:

- **F110** Alzheimer’s Disease
- **F111** Pick’s Disease (front temporal dementia)
- **Eu01** Vascular dementia
- **Eu02** Lewy Body Dementia
- **Eu023** Dementia in Parkinson’s disease
- **E00** Senile and presenile organic psychotic conditions, and for advanced dementia (not being referred for memory assessment)
- **Eu01** ‘Mixed Dementia’

Please consider checking any patients with the following codes:

- **1B1A** Memory loss symptom
- **1B1A0** Temporary loss of memory
- **Eu057** Mild cognitive disorder

Where probable dementia is established, ensure that these cases

- are captured on the General Practice’s dementia register (QOF DEM1),
- and are subject to regular review (QOF DEM2).

Consider the information and support needs of these patients and their carers/families. What information or support could the general practice offer, or signpost them to?
10. Engage

- Engage with, and call on the expertise of other specialists to support the diagnosis, treatment, care and review of patients with dementia, or at risk of developing dementia.
- Take opportunities to listen to, and learn from the experience of people using services, and people supporting them.
- Multidisciplinary working across specialties will accelerate and improve people’s treatment and care. General Practices can promote opportunities for shared care approaches and collaborative working with,
  - cardiovascular and stroke specialists
  - geriatricians
  - neurologists
  - social services
  - memory assessment services
  - specialist dementia services
  - dementia advisors; dementia support workers.
Appendix 1: References


South West Dementia Partnership (2012) Dementia Care in Primary Care Toolkit. www.southwestdementiapartnership.org.uk/primarycaretoolkit/


Appendix 2: Useful websites

**AgeUK**
The Age UK Group works to improve later life for everyone by providing life-enhancing services and vital support.

**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.

**ATdementia**
Supports people to consider areas of daily living where they may experience difficulties and offers advice and information on technologies and other strategies that may be helpful.

**Carers UK**
Carers UK is a charity set up to help the millions of people who care for family or friends.

**Dementia Action Alliance**
Over 40 organisations committed to transforming the quality of life of people living with dementia in the UK and the millions of people who care for them.

**Department of Health Dementia Portal**
This website follows the implementation of the National Dementia Strategy. It offers information to anyone with an interest in improving services for people with dementia.

**Horsesmouth**
Horsesmouth is a website where people with questions can ask people with relevant personal experiences for advice.

**Social Care Institute for Excellence Dementia Gateway**
A set of web based resources focused on supporting people with dementia, their carers and staff working in dementia services.