Early Interventions in Dementia
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Early Interventions in Dementia

Introduction

The purpose of this paper is to stimulate development of early diagnosis and intervention services for people with dementia in primary care. The National Dementia Strategy identified early diagnosis and intervention as a key objective which involves; a rapid competent and sensitive assessment; an accurate diagnosis; and following diagnosis timely treatment and support. Dementia has a serious impact on people’s lives, not only for the person with dementia but also for their carers, families and friends. Research over the past 10 years has consistently shown that the majority of people with early dementia are undiagnosed in primary care practices.\(^1\) It is well understood that brief interview and screening techniques which can be easily utilized in primary care can detect the presence of dementia with an acceptable level of precision and accuracy. Despite this, the use of such screening tools in primary care is low and many people with dementia *never* get an accurate diagnosis. This means that the person with dementia and their families often remain distressed and unable to effectively plan for their future, gain access to the services and interventions that they need, and may languish in uncertainty without proper support. Achieving future improvements in diagnosis, treatment and support will require concerted efforts to improve public and professional awareness and understanding of dementia as well as considerable efforts to rapidly improve and build on existing services and examples of good practice. Here in the West Midlands work continues on the 9\(^{th}\) Darzi Clinical pathway – Dementia.\(^2\) This paper intends to contribute to the strategic quality framework within which primary care services can make a significant contribution to the delivery of world class dementia services for the future.
Funding

This evidence review was developed by the Centre for Ageing and Mental Health at Staffordshire University under contract to the Care Services Improvement Partnership (West Midlands). A small steering group from the Centre for Ageing and Mental Health, funding agency and invited experts contributed to the design and development of the review.

The Nature and Epidemiology of Dementia

Dementia refers to a syndrome in which there is a progressive decline in memory and other cognitive domains such as language, visuo spatial, or executive functions which are of an intensity where social or occupational functioning becomes increasingly difficult. Dementia has multiple causes. The two most common forms of dementia are Alzheimer’s disease and Vascular Dementia (cerebrovascular ischemia). Some individuals may have both of these forms of the disease. Only a very small number of cases of mild to moderate dementia are fully reversible and these are in the cases of hypothyroidism and Vitamin B12 Deficiency.

Age is the strongest risk factor for Alzheimer’s disease. Aside from age having a first degree relative with a history of Alzheimer’s disease and the apolipoprotein E-e4 (APOE-e4) genotype is also a risk factor. Another important risk factor for both Alzheimer’s disease and vascular dementia is the presence of cardiovascular disease, particularly hypertension. Rarer types of dementia also exist such as Lewy Body dementia, Parkinson’s disease related dementia and fronto-temporal dementia. Whatever the sub type of dementia its impact on those with the disease and their families can be devastating. No section of society remains unaffected by dementia – it can occur regardless of gender, class, or ethnicity. People with learning disabilities are at particular risk of developing the disease, and dementia can also affect younger people including those still at work.
In the United Kingdom key data indicates that:\(^3\)

- There are 700,000 people with dementia
- By 2037 this number will double to 1.4 Million
- Dementia cost’s the UK about £17 billion per year
- By 2037 this cost will rise to £50 billion\(^4\)
- At least 15,000 people under the age of 65 have the disease
- Dementia affects both men and women and its incidence and prevalence increases exponentially with age.
- For families, it can lead to anxiety, depression, financial difficulties, relationship breakdown and increased time spent caring for the sufferer.
- The level of UK diagnosis and treatment of people with dementia is low especially when compared to other European countries (the UK is in the bottom third).\(^5\)
- Much more can be done to improve rates of screening, diagnosis, treatments and support for those with dementia including support and practical assistance for carers and families\(^6\)

**Methods**

The methods used to collect and select the evidence for this paper were:

- A search of electronic databases; CINAHL, MEDLINE, Cochrane Database, Bandolier.
- A search of *E-bry* – a full text on-line library of textbooks
- A hand search of library books and printed journals
- Identification of related key policy and discussion documents published over the last 15 years.
Nine themes were used to guide the search these are set out below;

<table>
<thead>
<tr>
<th>Search Strategy for Early Interventions in Dementia – Key Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Theme</strong></td>
</tr>
<tr>
<td>---</td>
</tr>
</tbody>
</table>
| Epidemiology of Dementia | U.K Text Books published in last 20 years  
The National Dementia Strategy and associated documents.  
The Consensus Statement - accessible at: [www.olderpeoplesmentalhealth.csip.org.uk/if](http://www.olderpeoplesmentalhealth.csip.org.uk/if) |
| Screening for Dementia | RCT  
Outcome Studies  
Journal Articles |
| Undiagnosed Dementia | Systematic Reviews  
Prevalence Studies from Community or Primary Care  
(pref U.K) |
| Screening Tests | Systematic Reviews  
Cohorts  
Community or Primary Care  
(pref U.K) |
| Drug Treatments | RCT’s  
Systematic Reviews  
(mild to moderate dementia)  
Peer Reviewed Journal Studies |
| **Psychosocial Interventions** | RCT’s and Journal Studies  
Systematic Reviews  
(mild to moderate dementia)  
Journal Papers  
Texts (evidence based) |
|-------------------------------|----------------------------------------------------------|
| **Carer perspectives**        | Systematic Reviews  
RCT’s  
Journal papers  
_N.B Especially Outcomes_ |
| **Future Planning**           | Systematic Reviews  
RCT’s  
Journal papers  
_N.B Especially Outcomes_  
(mild to moderate dementia) |
| **Risks/Ethical/Legal Aspects** | Westlaw (An electronic law database)  
Systematic Reviews (Harm from screening or treatment)  
RCT’s  
Journal papers  
_N.B Especially Outcomes_  
(mild to moderate dementia)  
Psychological/Social Risks |
Inclusion and Exclusion criteria

- The Search focused on papers published between 1989 and 2009
- Only papers in English were included
- Only data and papers related to mild and moderate dementia were included
- Wherever possible only papers, tests and data relating to subjects over the age of 60 were included

Search sequence

The search was conducted in the following sequence; (1) Bandolier (2) Cochrane Library (3) Medline (at Pubmed) (4) PsycINFO (5) Cinahl (6) Google Scholar (7) Google. (8) Specific Sites: Dept of Health Web Site/Age Concern/Alzheimer’s Society/ President’s Council on Bioethics

Key Documents

The search identified more than 250 papers which appeared suitable for consideration/inclusion but some of the items identified were of particular significance in providing both context and content for the review, these items were:


The NICE-SCIE Dementia Guideline on supporting people with dementia and their carers in health and social care was produced in 2007 and is due for revision in 2010. It provides a comprehensive evidence based review on supporting people with dementia and provides a very useful source for direction in identifying evidence based practice in dementia care.
During the writing of this review a number of other documents proved particularly helpful in providing background information, these were:


All of the above documents are available via download from the identified organization’s web sites. Finally an excellent evidence based text on early psychosocial interventions in dementia has recently been published by Jessica Kingsley Publishers:


This text provides a useful way to develop evidence based knowledge and practice in early psychosocial interventions in dementia.

**Good Practice for Early Interventions in Dementia**

An overarching principle of current thinking in dementia care is non-discrimination. Age discrimination is the most common form of discrimination reported by people over the age of 55 years. The future success of the National Dementia Strategy will to a large degree depend on the reduction of discrimination toward older people not only by the public but also by health professionals, including those working in primary care:

*People with dementia should not be excluded from any service because of their diagnosis, age (whether designated too young or too old) or coexisting learning disabilities.*
A second important principle concerns the importance of ensuring that people with dementia are fully involved in making important decisions and in providing valid consent in all aspects of their investigation, diagnosis and treatment. This means:

- Informing the person of options
- Checking understanding
- Safeguarding against coercion and undue influence
- Ensuring the continuation of consent over time

Should a person lack the capacity to consent then the law as set out in the Mental Capacity Act (2005) must be followed. The code of practice for this act can be found at [http://www.justice.gov.uk/guidance/mca-code-of-practice.htm](http://www.justice.gov.uk/guidance/mca-code-of-practice.htm)

A third important principal relates to proper support for carers of people with dementia. They are entitled to an assessment of needs as set out in the Carers and Disabled Children Act 2000 and the Carers (Equal Opportunities) Act 2004. It is the responsibility of health and social care managers to ensure that these rights are recognized. It is also good practice to ensure that where carers are experiencing psychological problems relating to their caring role that they are offered psychological therapy from a suitably qualified specialist practitioner.

Being under investigation for, and receiving a diagnosis of dementia can be one of the most difficult and traumatic experiences in a person’s life. It is crucial therefore that the ethical principles of autonomy, nonmaleficence, beneficence and justice guide the health professional’s actions at all times. One expression of some of these ethical principles concerns the person’s rights and wishes concerning the disclosure of the diagnosis. It is good practice to for the person who is being assessed for the possibility that they have dementia to be asked if they wish to know the diagnosis and with whom this information can be shared.
Prevention of Dementia in Primary Care

At the present time there is no systematic public health strategy for the prevention of dementia in England. The National Dementia Strategy only relates to prevention indirectly and is mostly concerned with improved awareness of the disease, its early identification and achieving a higher quality of dementia care. Clearly the long term aim would be to achieve a significant reduction in the numbers of people with dementia through primary prevention activities. It may be the case that at the time of writing a cure for dementia syndrome may be many years into the future, but prevention activities now may significantly affect the time of onset of the disease. In the vast majority of cases dementia is a disease of later life so by delaying its onset by just a few years may significantly reduce the numbers of people who develop it. For example if the onset of dementia could be delayed by just 5 years, its prevalence would half.11

Any successful long term prevention strategy would require detailed knowledge of the risk factors for dementia; fortunately these have been reasonably well identified in the research literature. The risk factors fall into two broad groups; those that are not modifiable (e.g. age) and those that are modifiable (e.g. alcohol consumption). Non modifiable risk factors for dementia are

- Age
- Learning Disabilities
- Gender
- Genotype

Modifiable Risk Factors for Dementia

Modifiable risk factors for dementia provide us with the opportunity to significantly lower the future incidence of Dementia. Health professionals in primary care have a vital role to play in risk reduction for dementia in the following areas:
Alcohol Consumption

Excessive alcohol consumption is a well known risk factor for dementia. Moderate rates of alcohol consumption are associated with lower rates of cardiovascular disease, cerebrovascular disease and dementia than are abstinence or heavy consumption.

Smoking Reduction and Cessation

Smoking is a risk factor for dementia (both Alzheimer’s and vascular types). Smoking is known to be a risk factor for both cardiovascular and cerebrovascular disease.

Obesity

Studies have suggested that obesity (raised body mass index) in mid life is linked to increased likelihood of dementia in later life (particularly Alzheimer’s disease). We also know that obesity is a risk factor for type 2 Diabetes which in turn is a risk factor for cerebrovascular disease and the subsequent development of dementia.

Hypertension

Hypertension is a well established risk factor for cardiovascular and cerebrovascular disease and the increased likelihood of subsequent dementia. Hypertension in mid life is associated with increased risk of Alzheimer’s disease and vascular dementia in later life.

Hypercholesterolaemia

High cholesterol levels have been reported in the research as being a risk factor for dementia. Raised cholesterol is a known risk factor for cerebrovascular accidents which in turn are associated with increased risk for vascular dementia.

Head Injury

Studies demonstrate that head injury sufficient to cause loss of consciousness approximately doubles the risk of dementia.
Low Folate and Raised Homocysteine levels

Low folate intake and low folate levels have been associated with increased risk of cardiovascular and cerebrovascular disease and dementia.\textsuperscript{24}

Depression

It is known that rates of depression in those with dementia are raised; depression can be an early manifestation of dementia.\textsuperscript{25} A Meta analysis study found that people with a history of depressive illness doubled their risk of future dementia.\textsuperscript{26} The MIRAGE study\textsuperscript{27} found that depressive illness occurring as much as 25 years before the onset of cognitive impairment increase the risk of dementia.

Exercise

There is some evidence that regular exercise (at least twice a week and of 20-30 minutes duration and which causes breathlessness and sweating) in mid life can reduce the likelihood of dementia in later life by about one half.\textsuperscript{28}
Mental Stimulation and Education

It is possible that low educational attainment is associated with increased risk for dementia. This has led to speculation about whether cognitive stimulation may be a protective factor. One study found that a group of people engaging in common mentally stimulating activities did subsequently have a decreased likelihood of developing dementia. There is also evidence from randomised trials that cognitive stimulation can have positive benefits which last for up to two years. Another study found that engaging in cognitively challenging pastimes and hobbies may protect against dementia. Activities followed up by this study over a median period of more than 5 years included; reading; board games; playing a musical instrument and dancing. The benefits of such activities demonstrated decreased risk for both Alzheimer’s disease and for vascular dementia. This is clearly a very interesting area of research and more work needs to be done before definite conclusions can be drawn. In the meantime there would appear to be many good reasons why encouraging people to engage in cognitively stimulating activities is good practice in primary care.

Given the above evidence positive health promotion in general practice and in primary care as a whole has an important role to play in the long term prevention of dementia. It provides added impetus to health promotion activities in the areas of the moderation of alcohol consumption; smoking cessation programmes; weight control; reducing hypertension; lowering cholesterol; avoidance of head injury (wearing proper head protection in at risk activities, wearing seat belts, and risk reduction). It would be helpful for such health promotion activities to explicitly include information about the reduced risk of dementia as a potential benefit.

Early identification and Mild Cognitive Impairment

There is growing evidence in population studies of ageing which include the study of cognitive ability over time that impairment in the cognitive domain is observable years before a diagnosis of dementia is made. The kinds of
changes seen are very similar to those found in ‘normal ageing’ and are suggestive that there is a ‘slow drift’ into the pre clinical phase of dementia.

It is unlikely that such slow and gradual changes could be detected in the general practice consultation. ‘Mild Cognitive Impairment’ refers to a state in which people subjectively experiences symptoms (usually memory loss) and has measurable cognitive deficits but does not experience these to the extent that they interfere to a significant degree with their everyday lives. Tests of episodic memory and imaging techniques can be used but no single test at this point in time can accurately identify individuals who will go on to develop Alzheimer’s disease or another form of dementia.\textsuperscript{34} It has been suggested that the use of neuroimaging techniques and neuropsychological testing for detecting and measuring the very early signs of Alzheimer’s disease are “outpacing the therapeutic options available” the implication being that the usefulness of such early pre-clinical diagnosis is uncertain.\textsuperscript{35} For other types of dementia the pattern may be different. Vascular dementia typically presents problems with attention and executive functioning, whereas language problems frequently occur in fronto-temporal dementia. In dementia with lewy bodies psychosis and motor disturbances typically occur.
The NICE guidelines suggest that where language problems do occur referral to speech and language therapists for assessment and assistance would be appropriate.\textsuperscript{36}

Screening for Dementia

General population screening for dementia is not supported by the research evidence.\textsuperscript{37} Evidence suggests that for Alzheimer’s disease the relatively stable pre-clinical phase of the disease eventually moves into a much more rapid decline in functioning which typically lasts between 2 -5 years. During this phase of the disease memory for facts and general knowledge as well as the way past experiences affect current performance becomes problematic.\textsuperscript{38} There is some evidence to suggest that by recognising dementia at an early stage and commencing active therapy at an early point then subsequent need for nursing home care can be delayed\textsuperscript{39} Clearly by recognising dementia early and actively intervening there is the potential to help allay anxieties over memory, mood and behaviour problems, and also the opportunity to begin to plan out future resource needs. It has been pointed out however that public awareness and professional understanding of dementia is such that much work remains to be done to improve the current situation.\textsuperscript{40}

The national dementia strategy has set out an ambitious plan to assist in the early diagnosis of dementia which includes work to develop resources, and training and working practices.\textsuperscript{41} One danger here is that imperative to move towards early intervention and treatment will outpace the development work needed to ensure that resources, people and systems are in place to support early intervention and treatment.\textsuperscript{42} In terms of cognitive rehabilitation it would appear that where the person with Alzheimer’s disease has personal awareness of changes in their own cognitive functioning then better treatment outcomes result.\textsuperscript{43}
The National Dementia Strategy has as key objective 2 that:

...All people with dementia to have access to a pathway of care that delivers: a rapid and competent specialist assessment; an accurate diagnosis sensitively communicated to the person with dementia and their carers; and treatment, care and support provided as needed following diagnosis. The system needs to have the capacity to see all new cases of dementia in the area.\(^\text{44}\)

The emphasis here is on specialist assessment. Contrary to the authors expectation it appears that only about one-third of people with dementia ever receive a formal diagnosis.\(^\text{45}\) It is self evident that effective therapy, intervention and support depend on an accurate diagnosis being made.\(^\text{46}\) About one half to two thirds of general practitioners do not tell the person with dementia their diagnosis\(^\text{47}\) This reticence in disclosure is also reflected in other reports.\(^\text{48, 49}\) In recognising this problem it is proposed that primary care play an important ‘gatekeeper’ role in referring people on for specialist diagnosis, rather that taking on the complex burden of diagnosis themselves. The research evidences clearly shows that many GP’s are reluctant to directly involve themselves in diagnosis for a wide range of reasons:

- So called ‘therapeutic nihilism’ based on the idea that a diagnosis is irrelevant because nothing can be done to help the person with dementia.

- Risk averse beliefs particularly around the issue of making the wrong diagnosis which will lead to false positives (people being diagnosed and then possible treated for a condition that they do not in fact have) and false negatives (people who actually do have dementia but where that diagnosis has been excluded which leads to appropriate care and treatment not being given.)

- Wanting to protect the patient and their family from the likely distress and anguish that a diagnosis of dementia would bring about. The logic here is that in the view of some GPs it may be better to live on with a reasonably normal life for as long as possible rather than face the future in the knowledge of the diagnosis of dementia.
• Worries about not being competent to make an accurate diagnosis. Diagnosing dementia is one thing but it is necessary to identify the exact sub-type (or combination of sub-types) in order to implement the appropriate interventions.\textsuperscript{50} Worries about competence may be particularly relevant where the diagnosis is suspected in a young person.

• Fears about the availability of resources

It is also the case that many other conditions apart from dementia can present in primary care with cognitive impairment as a principle clinical feature. The most commonly presented conditions that may at first sight look like a probable case of dementia are:

• Delirium
• Depression
• Side effects of medication
• Substance misuse
• Hypothyroidism
• Intracerebral infections
• Space occupying lesions

It is important therefore that a full and careful assessment be carried out which will include any additional tests and investigations before a preliminary diagnosis of dementia can be made.

For the purposes of this paper a clinical diagnosis of dementia is made when:

\textit{Acquired cognitive deficits in more than one domain, representing a decline from a previously higher level of functioning, interfere with social and/or occupational functioning. Other features, including behavioural changes and symptoms such as depression, delusions and hallucinations, are commonly present...it is usually progressive and can in some circumstances be reversible (for example when due to space occupying lesion or infective or metabolic process).}\textsuperscript{51}
Before going on to look at screening tests for suspected dementia we will briefly examine the likely prevalence of undiagnosed dementia in the community.

**Prevalence of Undiagnosed Dementia in the Community**

It is likely to be the case that a person experiencing the very early signs of dementia may ‘explain away’ the symptoms as a temporary lapse, tiredness or just part of growing old. As the disorder progresses a person make ‘cover up’ what they experiencing from others frequently by rationalising that “it will soon go away.” Those around the person with the early signs of dementia may also engage in similar processes and quite understandably want life to go on as normal. This means that it may be some considerable time before a person or their family seek out a consultation with a doctor. Evidence suggests that in some cases it may be as long as three years before the problem comes to the attention of the family doctor. Given the likelihood that the GP will not in the majority of cases refer on for a specialist assessment it may be many more months (if at all) before such an assessment takes place. One consequence of this is that things will come to a crisis and the much needed care, treatment and support will arrive too late in the progress of the disease.

So just how much undiagnosed dementia may be out there in the community? In a study of dementia across nine countries it was found that a “…large proportion of people with dementia do not receive any diagnosis, let alone an early diagnosis, and so have no chance of access to treatment and care.” In two studies conducted in North America the prevalence of undiagnosed dementia in primary care patients was for one study 1.8% and for the second study 5.7 % In one other non-us study the prevalence rate was found to be 3.2% and 12%. Assuming one could extrapolate from these studies to the U.K population, this would mean that for every thousand patients over the age of 65 on the books of a General Practice there would be somewhere between 18 and 57 people with undiagnosed dementia. The average list size for a General practice in England in 2005 was 6,250 patients. If we assume that such a ‘typical’ practice would have about 25% of its list over the age of 65 then there is likely to be somewhere between 27 and 85 patients with undiagnosed dementia on the practices list.
Clearly it would be a mistake to read too much into such ‘rough and ready’ figures but they do give some idea of the likely numbers of people with undiagnosed dementia in a typical practice. There are about 8,000 general practices in England so there are likely to be between 144,000 and 456,000 people with undiagnosed dementia in England.

**Screening Tests for Dementia**

The NICE Guidelines on Dementia identify a range of screening tests that can be used to assist in cases of suspected dementia. The most frequently used test is the Mini Mental State Examination (MMSE). There are a number of alternatives:

- The 6-Item Cognitive Impairment Test (6-CIT)
- The General Practitioner Assessment of Cognition (GPCOG)
- The 7-Minute Screen

Each of these tests can be administered in just a few minutes and could greatly assist the hard pressed General Practitioner in screening for suspected dementia.

These tests are not without problems and the interpretation of the scores needs to take account of things such as the educational level of the person taking the test, prior level of functioning and attainment, language, possible sensory impairments, or the presence of other psychiatric disorders (particularly Depression and Delirium) or neurological conditions.

The use of such screening tests are part of the examination of attention and concentration, orientation, short and long term memory, praxis, language and executive function. A formal diagnosis should only be made after a comprehensive specialist assessment but the General Practitioner could screen for referral to such a service by identifying the patients history, a physical examination and other appropriate investigations. A review of medication that may be adversely affecting cognitive functioning would also be very appropriate.

The Nice guidelines on dementia recommend that on presentation (usually within general practice) that a basic dementia screen should include:
• Routine haematology

• Biochemistry tests – electrolytes, calcium, glucose, and renal and liver function

• Thyroid function test

• Serum vitamin B12 and folate levels.

The routine use of testing for syphilis serology or HIV should not be necessary except where the general practitioner believes that the patient’s history indicates that they are risk or the overall clinical picture suggests that such tests are indicated. If the General Practitioner suspects that delirium is a possibility then a mid stream urine test should be carried out. A chest X-ray or electrocardiogram should only be necessary if the overall clinical presentation indicates that they are needed. Cerebrospinal fluid examination should not be performed as a routine investigation for dementia. So a preliminary diagnosis of dementia should only be made on the basis of a full assessment which would include the following elements:

**History**

A detailed history should be taken from the person and as they may not be able to give accurate answers to provide a full history then a history from a close relative or friend could also be obtained. Typically the history would include; the presenting complaint; a review of the past medical and psychiatric history; current and past medication; drug and alcohol use; family medical and psychiatric history; changes in personality and or behaviour; and changes in the ability to carry out everyday tasks and activities. One very useful tool to assist in this process is the Informant questionnaire on Cognitive Decline in the Elderly (IQCODE).\(^{58}\) A useful tool to assist in the assessment of activities of daily living is the Bristol Activities of Daily Living Scale (BADL).\(^{59}\)
Physical Examination

A physical examination can assist in the detection of a range of disorders that might cause cognitive impairment. The physical examination should include a basic neurological examination.

Mental State Examination

A mental state examination is very important. It will help to identify any other psychiatric disorder that may cause cognitive impairment. Of particular relevance here is the possible presence of depression. The examining physician should also note any other non-cognitive psychiatric symptoms such as delusions, hallucinations, and misidentifications that might impact on diagnosis and subsequent management.\(^{60, 61}\)

Cognitive Testing

A range of easy to use standardised screening tests that can be used in the initial cognitive testing for dementia exist:

- The Mini Mental State Examination (MMSE) is the most widely used test and consists of just 30 items and it takes about 5 minutes to complete.
- The Newcastle Mental Test Score
- The 7 Minute Screen\(^ {62}\)
- The Clock Draw Test\(^ {63}\), which is very useful for assessing praxis and executive function.
- The General Practitioner Assessment of Cognition (GPCOG)\(^ {64}\) which also includes a brief informant rating.
- The 6-Item Cognitive Impairment Test (6-CIT)\(^ {65}\)

The use of short tests such as these will establish a baseline against which future performance can be measured.
For example; cognitive decline over time, and improvements following medication review or treatment for delirium or depression. The use of these tests also means performance can be quantified and communicated to others (e.g. specialists). The literature reports some potential difficulties with these kinds of tests (particularly the MMSE):

- With educational level and sensitivity to depression.\(^{66}\)
- Variance in terms of reliability where standardised instructions and testing procedures are not followed correctly.
- Where the person has language or sensory impairment.
- Where the person has a particularly high or low premorbid ability
- Where English is not the persons first language.

If the person’s first language is not English then the tests are usually available in a range of other languages and an interpreter could be used. On the basis of the above screening activities the GP would then in the case of suspected dementia refer to the local memory service or clinic.
Diagnosis of Sub Types

The diagnosis of a specific sub-type of dementia should be made healthcare professionals with expertise in differential diagnosis using the international standardised criteria set out below:

<table>
<thead>
<tr>
<th>Type of dementia</th>
<th>Diagnostic criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer’s disease</td>
<td>Preferred criteria: NINCDS/ADRDA. Alternatives include ICD-10 and DSM-IV</td>
</tr>
<tr>
<td>Vascular dementia</td>
<td>Preferred criteria: NINDS-AIREN. Alternatives include ICD-10 and DSM-IV</td>
</tr>
<tr>
<td>Dementia with Lewy bodies</td>
<td>International Consensus criteria for dementia with Lewy bodies</td>
</tr>
<tr>
<td>Frontotemporal dementia</td>
<td>LUND-Manchester criteria, NINDS criteria for fronto-temporal dementia</td>
</tr>
</tbody>
</table>

DSM-IV, Diagnostical and Statistical Manual of Mental Disorders, fourth edition; ICD-10, International Classification of Diseases, 10\textsuperscript{th} revision; NINDS/ADRA, National Institute of Neurological and Communicative Diseases and Strokes/Alzheimer’s Disease and Related Disorders association; NINDS-AIREN, Neuroepidemiology Branch of the National Institute of Neurological Disorders and Stroke –Association Internationale pour la Recherche et l'Enseignement en Neurosciences.

Table Source: NICE Clinical Guideline No 42: Issue date Nov 2006 p.25

The NICE guidelines indicate that structural imaging should be used in assessment for dementia to exclude other possible cerebral pathologies and to assist in the diagnosis of particular a sub-type of dementia. The preferred modality is by Magnetic Resonance Imaging (MRI) which can assist in early
diagnosis and in detecting sub cortical vascular changes. The NICE guidelines indicate that Computed Tomography (CT) could also be used.

Electroencephalography (EEG) should not be used as a routine investigation for people who may have dementia, but can be used if a diagnosis of delirium, frontotemporal dementia or Creutzfeldt-Jakob disease is suspected. An EEG may also be required where there is an associated seizure disorder. Cerebrospinal fluid examination should only be used if Creutzfeldt-Jakob disease or another form of rapidly progressive dementia is suspected.

Brain biopsy should only be considered for diagnostic purposes in the few patients whose dementia is thought to be due to a potentially reversible condition that cannot be diagnosed in any other way. When the dementia is of a mixed type (most typically Alzheimer’s disease and Vascular dementia) then the case should be managed according to the condition which is thought to be the predominant cause.

**Breaking Bad News**

It is typically the case that in the past a diagnosis of a dementia will have been made after a protracted period of uncertainty on the part of the patient and their family and after several visits to a variety of health professionals. As previously stated it may also be the case that the patient may never have actually been told their diagnosis. Experiencing this process may have been extremely traumatic and the patient and their families may have gone through a whole range of disturbing emotions. As a health professional we can often forget or lose sight of what the patient and their family may have been through. For these reasons it is imperative that all health professionals involved in the care of the patient are sensitive to the patient and can show empathy and understanding at all points in the diagnostic process.

Given the high numbers of patients who never receive a diagnosis of dementia it is very likely that many health professionals also find the process of reaching a diagnosis difficult and potentially upsetting. Breaking bad news can be difficult but there is a wealth of research evidence about how it can be done sensitively and effectively:
If in the early stages of contact with services a dementia is suspected then the lead health professional can ask the patient (in private) if they would like to be told their diagnosis, and who else the diagnosis might be shared with.\textsuperscript{68 69}

The literature clearly demonstrates that in the early stages of dementia people would prefer to know their diagnosis,\textsuperscript{70} and evidence suggests that having a diagnosis can have positive benefits:\textsuperscript{71}:

- It ends a long period of uncertainty
- Helps to increase understanding of the problem and put the patients experiences into context
- It can give access to a range of supports
- It provides an opportunity for questions and for dispelling incorrect thinking about the disease
- It can facilitate planning and help identify future goals.

Health professionals often dislike breaking and explaining bad news. There is a range of possible reasons for this:\textsuperscript{72}:

- Feelings of incompetence in the area of interpersonal skills
- Worry about getting blamed
- Fears about the patients possible reactions
- Doubts about not having been able to “cure” the patient
- Wishing to protect the patient from distress
- Not considering oneself very good at expressing empathy
- Worries about being about to contain the patients distress
- Feelings of inadequacy and embarrassment
- Believing that one does not have enough time
- Feeling helpless in the face of the patient’s uncertain future
A Ten Stage Model for Breaking Bad News

Peter Kaye, a Consultant in Palliative care who has extensive experience in breaking bad news and has written extensively on this subject proposes a ten step approach to breaking bad news:73

1. **Preparation** - Gather relevant facts; find out if the patient would like others to be present; ensure privacy.

2. **What does the patient know?** – Invite the patient to give a narrative of events as they see them.

3. **Is more information wanted?** – Ask the patient if they would like you to explain a bit more and provide further information.

4. **Give a warning shot** – At some point as the conversation unfolds use a statement such as “Now that we have got a more complete picture of what is going on, things do not look to good…” At this point allow space for the patient to respond.

5. **Allow denial** – Denial is a defence mechanism that can allow the patient time to assimilate what is being said to them, and is useful in enabling the patient to control the amount of information that they can cope with.

6. **Explain (if requested)** – Given the shock (for some) of disclosure the precise details of what is being conveyed may not be remembered, but it is very likely that the patient will remember the manner in which you disclosed the diagnosis and explained things.

7. **Listen** – Invite the patient to express any concerns they may have and allow time for the patient to express how they feel.

8. **Encourage expression of emotion** – This is likely to be what the patient remembers most about your manner and approach.

9. **Summary and plan** – Summarise concerns, plan the next steps and foster hope.
10 **Offer availability** — More explanation may be needed, and the patient may need support in adjusting to the news.

Kaye makes the point that in breaking bad news one should treat these key points as PRINCIPLES rather than as a mechanical prescription about how to act. Kaye also makes the important point that "a patient has a right but not a duty, to hear bad news, which is why negotiation is needed." It is for this reason that it would be appropriate to negotiate early in the pathway of investigation if the patient would like to know or if anyone else should be told the results and the diagnosis. The patients answer to these questions could be recorded prominently in the medical record.

In summary informing someone that they have dementia can sometimes be very badly handled in terms of information given and follow-up offered. When disclosure is badly managed it can leave the patient (and their families) disturbed, upset and confused. It is also clear from the literature that the process of disclosure does not end with the telling of the diagnosis, the patient (and their family) will continue to need support from primary care services. Following the disclosure of diagnosis of dementia the patient may well exhibit grief and feelings of loss, it is therefore that follow up support is not only available but is pro-active. As stated earlier there is evidence that many patients with dementia never receive a diagnosis, but that other family members and carers may well be told. The Mental Capacity Act requires every health care practitioner to have a presumption of competence in relation to their patients. Unless there is clear evidence that the patient may not be competent to receive the diagnosis then the patient does indeed have the right to know. The code of practice for the Mental Capacity Act provides detailed guidance about how information can be offered in a way that is sensitive to and respectful of the patient who may be cognitively impaired. The sharing of a diagnosis with negative implications for the future is often cited by physicians as one of the most difficult aspects of their work, and they may require support with this.
It would seem self evident that access to accurate information about local support for people who are newly diagnosed with dementia should be easily available from primary and secondary care, social care and in appropriate community settings.  

There is evidence that such information is most appreciated where people with dementia and their carers have been involved in putting the information together. The kinds of concerns expressed by patients and carers are often different from those anticipated by the health professionals involved. For example:

- There may be financial worries requiring referral to financial advice agencies.
- Following diagnosis Depression is not uncommon and help in accessing appropriate support may be needed
- Information may be needed that is appropriate for the children in families where someone has dementia. It is often the case that children in such families may be (or will at some future point be) assisting in providing care.
- People with dementia who belong to minority communities may require specialist support, information and advice. This is particularly true where English is not their first language.

Interventions in Dementia

In treating dementia three key approaches can be identified. The first are those interventions that aim to maintain function; the second are those interventions that are primarily directed at managing challenging behaviours; the third are those interventions whose primary aim is to reduce co-morbid emotional disorders. By managing these different interventions well the patient can be assisted in maintaining the highest level of functioning for as long as possible. An examination of the available literature suggests that there are a vast number of interventions that might be effective in dementia. In many cases these
interventions are of an interpersonal nature and rigorous testing via Random Controlled Trials are rarely (if ever) possible. It is also clear that everyday interactions with other people, having a functioning circle of support and simple cognitive stimulation through human contact are all important in maintaining an acceptable level of functioning.

Many of the interventions that are described below need to be delivered consistently and to high standard. This makes it imperative that those utilising the interventions are properly trained and have adequate time to deliver the intervention. Carers and family members will play a vital part in delivering therapeutic interactions so it is important that they receive adequate support and training and are involved in the total package of care at all stages.

There is some evidence that those supporting the person with dementia may if not given proper encouragement and support tend to take over and perform activities that with the right support the person could do for themselves. It is therefore crucial that carers, family members and friends all be consistent in creating opportunities for the person with dementia to maintain an appropriately active life for as long as possible. Clearly this would also involve judgements about the right level of challenge and stimulation for the person concerned. The key here would be to heed one of the key principles of the Mental Capacity Act and begin all interactions and activities with a presumption of capacity.

Maintaining autonomy and Independence

In order to maintain independence the following approaches appear to be supported by at least some evidence that they are part of good practice:

- **Regular interpersonal communication** – this includes using language and sentence construction which matches the persons existing levels of comprehension, their current levels of sensory impairment (if any) and their cultural preferences. People with dementia should have their eyesight and hearing regularly checked. Common sense also tells us that trying out different combinations of words and sentences to elicit the appropriate response may make the difference between being understood and the person doing/choosing for themselves and having to take over and do something for the person. There is some evidence that the use of
things such as memory books can help to facilitate communication. Referral to speech and language therapists may also be appropriate.
- **Activities of Daily Living Skills Training** – there is some (but not extensive) evidence that training in the activities of daily living can promote independence and help maintain the person at a maximal level of functioning.\(^9^1\)

- **Use of Assistive Technology and Adaptive Aids** – In essence this means the use of available equipment, products or systems that can be utilised to maintain or increase the functional capabilities of the person with dementia. Examples might include spectacles, hearing aids, cutlery, frames, hoists, automated chairs and beds, alarms, movement sensors, visual prompts, signs and home alterations.\(^9^2\) Memory aids such as calendars, diaries, memory books, message boards and electronic aids may all be useful.\(^9^3\) Using a Combination of memory aids, assistive/adaptive technologies, and memory training exercises has been found to be effective.\(^9^4\)

- **Telecare** – In recent years electronic technology has increasingly been used to deliver care ‘remotely’ and support older people in their own homes.\(^9^5\)\(^9^6\) Telecare involves such things as electronic reminder systems, video conference visiting, and remotely controlled security sensors. There is some evidence that the use of such devices can improve personal safety, support independence and reduce the likelihood of a person with dementia requiring institutionalised care.\(^9^7\)

- **The promotion of exercise** – Increasingly research is demonstrating that exercise is important as a means of maintaining mobility and independence in older people.\(^9^8\) Exercise programmes will typically involve such things as, walking, gait training, muscle group strengthening, and balance improvement.\(^9^9\) These programmes can be delivered in both group and individual formats and can be centred on recreational activities such as pet care, gardening and rambling. It should be emphasised that engaging in exercise can also be an opportunity for mental stimulation, talking to other people and increasing social support. Exercise can also be part of a continence programme.\(^1^0^0\) It seems self evident that engaging in regular exercise may improve physical resilience and reduce the likelihood of falls.
One potential barrier to the implementation of such programmes is that they may involve undue risk, but with careful risk assessment and risk management the risks involved should not pose to much of a barrier that it prevents older people with dementia from participation in such activities.

- **Community based rehabilitation services** – Access to rehabilitation has been highly problematic for people with dementia.\(^\text{101}\) The literature clearly shows that people with dementia can make positive progress if they are afforded access to rehabilitation services.\(^\text{102}\) For example access to rehabilitation can assist with improving and maintaining cognitive skills, maintaining mobility and promoting independence.\(^\text{103} \text{ 104}\)

In practice people with dementia will benefit most from combinations of therapies, whilst at the same time work with carers and environmental modifications are also taking place.\(^\text{105}\) Given that physical health problems may also be present it is also important that psychiatric services work closely with the appropriate medical specialists to ensure that any such problems are also managed and treated. In summary promoting independence in people who have dementia requires that the person be encouraged and assisted to maintain the performance of roles and activities to the maximum degree that is commensurate with their abilities. Service providers, carers, family and friends need to support this as much as possible otherwise the person with dementia quickly be part of a “vicious circle” where low expectation and effort on the part of others leads to low performance by the person with dementia, which in turn further lowers the expectations of others. In such a scenario the person with dementia may quickly become dependent, leading to restricted role performance and loss of hope.

**Maintaining Cognitive Functioning**

The maintenance of cognitive functioning is a key component of early intervention for dementia. Two main approaches can be identified in the literature. The first approach is *pharmacological* and the second is *everything else*. This paper will not review the pharmacological approaches in any depth as
the subject is complex, rapidly developing and could easily warrant a paper on its own.

A good starting point for those readers who are particularly interested in the use of pharmacological interventions which aim to maintain and/or improve cognitive functioning is the Dementia: A NICE-SCIE Guideline on supporting people with dementia and their cares in health and social care. This document can be seen (and downloaded) at http://www.nice.org.uk/guidance/cg42

In gathering evidence for this paper it quickly became clear that a great number of non-pharmacological approaches are being used. This perhaps reflects the pragmatism and commitment of health professionals, carers, families and friends to assist the person with dementia. For many of the interventions there is some degree of consensus by carers and experts that they have some benefit. However, many of the interventions identified have not been systematically assessed in sufficient depth to warrant a scientific ‘seal of approval.’ Many of the interventions identified are primarily social in that they often involve group based recreational type activity activities the aim of which is to provide stimulation and facilitate interaction and enjoyment. Next are a range of interventions whose primary aim is cognitive training. These interventions are delivered in both group and individual settings and often involve practice and repetition in order to stimulate particular aspects of cognitive processing. A third type of intervention are individualised cognitive rehabilitation approaches where the person with dementia, the caring team (including carers and friends) work with the person to develop highly individualised personal targets and then utilize a variety of materials, educational strategies and personal interactions to achieve them. In reality these three conceptual categories are overlapping approaches and are often being delivered at the same time in the form of a care package. A common theme in many of the interventions is reminiscence. It should be stressed however that current thinking is that reminiscence activities should not be used indiscriminately and should always be tailored to individual need. Put simply we should not assume that all old people with dementia want to talk about the past or be constantly reminded as to time, place and person.
In order to maintain **cognitive functioning** the following approaches appear to be supported by at least some evidence for effectiveness:

- Reality Orientation
- Life Review
- Reminiscence
- Validation Therapy
- Creative Arts Therapy
- Animal Based Therapies

It may be the case that even if the improvements gained by these approaches are not particularly significant for some people they can make a very significant contribution to the overall quality of life of the person by creating structure and purpose, by promoting social interaction, mobility and enjoyment. Such approaches can also (pragmatically) provide some respite for the carer. There is also some (anecdotal) evidence that providing clear structures and routines in this way can build hope.

**Responding to challenging behaviour**

In seeking out evidence for ways to manage and reduce challenging behaviour in people with dementia outcomes generally relate to reducing its **frequency**, its **intensity** and its **duration**. Challenging behaviour occurs in the context of a particular **environment** and to reduce its frequency, duration and intensity may simply be a matter of:

- Adding something to it
- Taking something away from it
- Or modifying it in some other way

Once an environmental cause has been ‘ruled out’ as not significant then one can look at the **behaviour** itself. Challenging behaviour usually comes in three different forms:

- **Under behaving** – the person does too little of something
- **Over behaving** – the person does too much of something
- The person **does (X) instead of (Y)**
The management approach here is to modify the behaviour by either increasing the person capabilities (skills, strategies, plans, comprehension) or by using some form of behaviour modification technique.

In the recent past challenging behaviour has often been labelled as “attention seeking” implying that the behaviour is “acted out” to attract attention and is in some way intentionally designed to annoy and irritate. This view of challenging behaviour has been replaced by a much more dynamic and flexible model where the behaviour is seen as the persons attempt to communicate something which is important to them; that the behaviour is functional and understandable when seen through their eyes and their model of the world. By approaching the challenge from this perspective the behaviour can often be very effectively addressed by identifying the need and (where feasible) responding positively to it.

In dementia it may also be the case that the behaviour is the result of changes in the brain and it’s functioning. In this case the underlying physical cause of the behaviour needs to be understood and modified in some way, often through the use of drugs. Another common cause of challenging behaviour is the presence of pain. Given that a person with dementia may have great difficulty in communicating this verbally to others, it is important that this possibility is investigated and managed appropriately. We also need to recognise that the cause of challenging behaviour may be the result of what others are doing. It is quite easy to imagine a scenario where a stressed carer staff member is actually causing and increasing the frequency, duration and intensity of the challenging behaviour through their actions. If this is the case then it is easy to see the relevance of support, education and training for carers (whether staff or relatives) in managing challenging behaviour. In summary managing challenging behaviour requires us to look further than the person exhibiting it to understand and effectively manage it. As with cognitive functioning, the most effective interventions in challenging behaviour would appear to be those that look at and deal with it in an individualised and particular way. It is not the case that “one size fits all.” The examination of current practice suggests that non-drug based approaches should be the first approach in responding to challenging behaviour. Empirical evidence would suggest however that this is often not the case and that pharmacological interventions are often the first port of call.
Using psycho-social means to manage challenge behaviour requires consistency, patience, skill, empathy, tolerance and understanding. It also requires sufficient numbers of people who are trained in these approaches, being available to the person in need.

Earlier this paper talked about the delay which often occurs between suspecting that someone might have dementia and first referral to a specialist. It is often challenging behaviour that precipitates this referral. The family and relatives have coped perhaps for months or years with a family member with ‘memory problems’ as time goes on the behaviour of the person begins to deteriorate and the family members become stressed, anxious and arrives at the point where they cannot go on. Family loyalty is often such that family members might feel that seeking outside help is an admission of ‘failure’ or in some way a betrayal of the person. This is, in some cases supported or at least not discouraged by staff in primary care. It is very important to emphasise that ‘early referral’ to specialists is to be encouraged in primary care, before such crises occur.

In order to manage **challenging behaviour** the following approaches appear to be supported by at least some evidence for effectiveness:

- Behavioural management (strongest evidence)
- Provision of structured activities
- Environmental modifications
- Relaxation
- Social contact
- Managing sleep patterns
- Pain management
- Training for carers and staff
- Regular hearing/eyesight checks and provision of aids
- Removal of restraints
- Environmental design to facilitate safe wandering
- Physical exercise

The use of such measures most often occur in combination and need to be tailored to the specific type of challenging behavior, which vary widely in nature – the most frequent being; aggression, disinhibition, wandering, agitation, screaming and shouting, hoarding and sleep disturbance.
The Carers Perspective

Receiving a diagnosis of dementia can be one of the most traumatic and devastating things that can happen to a person, but the family members of those diagnosed will also need careful support and help. For the primary carer (often the partner or spouse) a diagnosis of dementia in someone who is so central to their lives can be overwhelming and catastrophic. After the diagnosis has been explained the needs of the carer and the support needed by them should not be overlooked. The family of those recently diagnosed with dementia can go through all of the emotions often associated with bereavement and loss. Anger, bargaining, denial, realisation and acceptance are all likely to be part of the powerful emotional turmoil that the diagnosis of dementia can bring. Such feelings might at one end of the spectrum be transient and fleeting with a determination to face the future positively with steely pragmatism. At the other end of the spectrum the diagnosis may lead to long term grieving and feelings of hopelessness and loss. The feelings of loss experienced in the process of caring for someone with dementia can be multiple, including loss of:

- a companion, soul mate, lover, and friend
- a father, mother, grandfather, grandmother
- income and financial security
- being in control of ones own life
- dreams, hopes, aspirations, and opportunities

At the same time as experiencing such ideas and emotions there will also be a need for readjustment and adaption to a quite different future from the one that may previously have been anticipated. In addition to this there will be the need to attend to the care needs of the person with dementia, whilst at the same time trying to maintain employment and deal with the stresses and potential recrimination within the family group.

The key person in this will often be the person identified (either through choice or necessity) as the primary care giver. It is this person that the literature identifies as the most vulnerable and in need of support. It is not uncommon for that person to feel abandoned and unsupported not only by services but also by family and friends. Depression, exhaustion and despair can quickly follow.
If not adequately addressed this in turn can lead to an unwillingness to go on, divorce, major family schisms and ultimately suicide. It seems self evident, that the needs of carers must be recognized and responded to. The literature identifies the key kinds of support that carers may need as:

- information about dementia itself
- information about treatment options
- emotional support
- financial and legal advice (including entitlements)
- other kinds of practical assistance
- respite
- attention to their own health needs (both physical and mental)
- training and education
- signposting to services (statutory and non statutory)
- spiritual assistance (religious or secular)
- to be a key player in care planning and decision making
- to be treated with dignity and respect.

Evidence suggests that a well supported and resourced carer is a major factor in the long term well being of the person they are caring for. A well supported and involved carer who feels valued and is given practical help will enable the person with dementia to lead as full and happy a life as possible in the most difficult of circumstances. A useful resource for information about caring can be found at the Directgov website:


The current picture is that there is a mixed economy of carer support and provision with health service, local authority, voluntary, and faith groups all contributing to provision in one form or another. High quality evidence regarding interventions aimed at carers is at best scant, perhaps reflecting limited resources and the previously low priority given to funding significant high quality research in this area. This is clearly an issue that needs to be urgently and systematically addressed.
In order to assist and support carers the following approaches appear to be supported by some evidence for effectiveness:

- education about dementia
- supportive counselling
- psychotherapy
- rapid support in crisis
- support from other carers (particularly social contact and events which provide some degree of respite)
- faith based spiritual assistance

In terms of outcomes, interventions such as these can contribute to psychological well being, the maintenance of hope, reducing carer burden, increased social functioning, maintenance of physical health, increased knowledge and skills and access to employment, education and leisure. Trying to summarize the research in this area is extremely difficult given the range of interventions, the variable modes of delivery, the small scale nature of many studies, and the fact that carers are often engaged in multiple support strategies and networks at the same time. This said the overall picture is that such interventions can be effective, but more and better quality research is needed. The picture is perhaps best summed up by Brodaty et al\textsuperscript{110} whose meta-analysis of consisted of 30 controlled trials and found that the outcomes were variable but that there was some positive effect resulting from the interventions. In another study by Fear\textsuperscript{111} it was noted that there may be significant gender differences between men and women. It suggests that men may more be solution focused in their caring style whilst women are more emotion-focused in their caring style. This might suggest that support for carers might be better developed along gender lines.

**The Risks of Early Detection**

The National dementia strategy clearly places high priority on the early detection, diagnosis and treatment of dementia. This is a welcome development but it is one where there are most certainly associated risks. An excellent overview of the kinds of risks involved is provided by Iliffe and Manthorpe\textsuperscript{112} where in summarising the work of themselves and others the following risks are identified:
Risks to the Individual

- The risk of false positives with resultant congestion of services
- The associated ‘missing’ of treatable conditions such as depression
- False positives may lead to distress and lower confidence in GP judgements
- Cognitive tests do not necessarily reflect actual levels of functioning
- Early adoption of pharmacological interventions have associated risks
- A diagnosis of dementia is stigmatizing and can result in normal behaviour being seen as part of the illness, and in people becoming over-protective
- The diagnosis may prematurely put the person onto the “care escalator”
- Fears of others finding out, withdrawal, and hyper-vigilance for evidence of cognitive failure
- Low self esteem and feelings of helplessness
- Potential loss or diminution of role – particularly those roles most cherished by the person (such as father, mother, husband, wife)
- Possible threats to driving, and insurance cover
- Inappropriate abrogation of control of resources (property, money, possessions)

Risks to families and social networks

- Early diagnosis may prematurely change family dynamics with unknown consequences
- Early diagnosis may label family members as ‘carers’ prematurely
- It may unduly increasing the families exposure to stress
- The expectation that family members will take up new roles
- The giving up of employment too soon
Risks to services

- Frustration by health practitioners making a diagnosis in the absence of sufficient local resources
- Health practitioners lack of education and skills in diagnosing and managing dementia
- Service planners may not develop their capacity in provision for dementia
- By shifting the focus to dementia other (more prevalent) conditions, which are currently more treatable (such as depression) than dementia will be neglected particularly in terms of resource allocation
- Increased workloads across all disciplines
- Increased pressure on voluntary organisations to provide without increased resources

Having identified some of the potential risks to individuals, families and support networks and services, it is clear that the implementation of an early intervention strategy is not as straightforward as it might at first seem. For example in implementing a strategy which will lead to increased activity and demand we will need to ensure that additional resources are in place to meet it. If this does not happen then demand will quickly outstrip services ability to respond. Clearly the provision of adequate resource will be crucial to the success of the new dementia strategy. It is also the case that if we do not manage to successfully challenge and change the culture in primary care and positively value older people who may have dementia then the project will falter and fail. It is not simply a case of giving those in primary care the tools and processes and assuming that is enough, values and attitudes will need to change. Sharing the diagnosis itself is one thing but dealing with the potential effects of such disclosure will not be without consequences. We need to think about this now and ensure that risks such as those identified above are effectively assessed and managed.
Conclusions

The purpose of this paper was to stimulate development of early diagnosis and intervention services for people with dementia in primary care. The National Dementia Strategy has now been published and clearly identifies early diagnosis and intervention as a priority. Key objectives of the strategy are that rapid competent and sensitive assessment; accurate diagnosis; and timely treatment and support are essential to its success. As a consequence of the future demographics of the ageing population it is anticipated that rising numbers of people with dementia will make it one of the major challenges in health and social care over the next few decades. We know that many people with dementia do not receive a diagnosis and even when they do, subsequent care often does not meet the expectations of either people living with dementia or of their families. There is an extensive research literature on early diagnosis and intervention and it is broadly supportive. However much of the published research is small scale (often single case based) and it is extremely difficult to separate out the effects of interventions and treatments when people are receiving multiple interventions at one and the same time, and are also exposed (rightly) to wider social support. This said there does exist considerable consensus about what works and what does not, providing it is recognised that interventions need to be specifically tailored to the needs and life-styles of the person concerned. Implementing the strategy of early diagnosis and intervention is not without risk to the person diagnosed, their families and to services. These risks can be managed with the provision of adequate additional resource combined with careful planning, and preparatory training and education for health professionals. Major attitudinal barriers exist not only in the wider culture but also in health and social care, and a key indicator of the likely success of the strategy will be the extent to which it changes existing attitudes and values towards older people in general, and toward dementia in particular.
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