

# Early signs and diagnosis

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## Key messages

- Early signs and symptoms of dementia include memory problems, confusion and communication difficulties, problems with functioning at work, difficulty managing everyday tasks, struggling to follow a conversation, emotional problems and needing help.<sup>1,2</sup>
- Early diagnosis, together with effective services and support through the course of the illness, can enable people to live well with dementia if services are tailored to the person with dementia.<sup>8</sup>
- Research suggests that GPs do not feel confident about recognising and diagnosing dementia.<sup>4,28</sup> Additionally, care staff often do not have the knowledge and skills to recognise that a person is developing dementia.<sup>4</sup>
- Recognising dementia can be difficult for various reasons, including the fact that in the early stages the symptoms can be vague, and people often do not tell the GP they have memory problems.<sup>1</sup>
- In 2009, the Department of Health reported that only a third of people with dementia received a proper diagnosis or made contact with specialist services at any time in their illness.<sup>8</sup> This figure had risen to 44.2 per cent by 2012.<sup>10</sup>
- Most research about early signs and diagnosis of dementia, by and large, misses the views of people with dementia about their experiences in getting diagnosed and getting information.<sup>3</sup>  
Awareness about dementia is low in Black Caribbean and Irish communities,<sup>11,13,14</sup> and in most South Asian languages, there is no word for 'dementia'.<sup>11,24,25</sup>

## Introduction

This summary highlights key messages from the research on early signs and the diagnosis of dementia. It is not intended to be a comprehensive review of the literature on this topic. The material was identified through focused searching of the literature published from 2008–2012. Some material pre-dating 2008 has also been referred to in order to illustrate matters of relevance, not contained within the retrieved material.

## Status of research

Most research about early signs and diagnosis of dementia appears to be clinical and, by and large, misses the views of people with dementia about their experiences in getting diagnosed and securing information.<sup>3</sup>

There is not much clinical evidence and research on the value of medicines and non-drug treatments for people in the early stages of dementia.<sup>5</sup>

There is little clinical and general research material on early signs and symptoms of dementia.

Another gap is in the evidence on the outcomes from earlier diagnosis for people with dementia, including the effect on their overall health, cognitive (thinking, knowing and remembering) ability and quality of life.<sup>5</sup>

There is also not much research on the economic benefits of early assessment and diagnosis.<sup>5</sup>

Despite research exploring the help-seeking behaviour of people with suspected dementia and their carers in the context of health and social care,

there is a sense that not a lot of it is directly reported opinion from people themselves.

## What is the issue?

Early diagnosis and intervention leads to better outcomes for people with dementia and their families.<sup>7</sup>

If a person with dementia is not diagnosed, they and their family carer are unable to make informed plans for their future and do not have access to help, support, social and psychological treatments, and medicine.<sup>8</sup> However, people can often find it difficult to access information, support and advice even when they have been informed of the diagnosis.

## Early signs and symptoms

### Typical signs

Early signs and symptoms of dementia include memory problems, confusion and communication difficulties, problems with functioning at work, difficulty managing everyday tasks, struggling to follow a conversation, emotional problems and needing help.<sup>1,2</sup>

### Mild cognitive impairment (MCI)

Mild cognitive impairment (MCI) describes problems with thinking, knowing and remembering but these may not be severe enough to meet the criteria for a diagnosis of dementia.<sup>19</sup> People with MCI are a high-risk group for developing Alzheimer's disease,<sup>20,21</sup> but not all will develop dementia, as reported in research with large population samples where, even

after eight years follow up, dementia had not been identified or indicated.<sup>21</sup>

### The problem of under-diagnosis

In 2009, the Department of Health reported that only a third of people with dementia received a proper diagnosis or made contact with specialist services at any time in their illness.<sup>8</sup> According to Alzheimer's Society research, this figure had risen to 44.2 per cent by 2012.<sup>10</sup> Late diagnosis and contact usually means that the potential benefits from interventions may not be as effective.<sup>8</sup>

### Cost benefits of early assessment and diagnosis

Despite the limited evidence base, it does suggest that considerable future savings could be made.<sup>5</sup> Early assessment of dementia has significant cost benefits.<sup>12</sup> Similarly, early diagnosis and intervention can help to reduce long-term care costs, such as residential care, and allow access to treatment and support that improves quality of life for people with dementia and their carers.<sup>5,9,26</sup>

### Benefits of early diagnosis for the person with dementia

Support at an early stage appears to improve quality of life and reduce symptoms associated with dementia such as agitation, depression, apathy, delusions, hallucinations, and sleep impairment.<sup>15</sup> People with dementia may benefit from therapeutic support, such as structured group cognitive

stimulation programmes, which can sustain cognitive ability.<sup>27,29</sup>

### Supporting carers

Carers can experience high rates of stress and emotional strain, which affects their health and causes potential problems with providing care for their relative.<sup>16,17,18</sup> Carer support and counselling, such as regular support sessions and telephone counselling, improve carers' self-reported health and quality of life,<sup>9</sup> and can reduce the need for the person with dementia to move into a care home by 28 per cent.<sup>9</sup>

### What factors can complicate diagnosis?

Diagnosis can be complicated by a mixture of factors that may be related to individuals and their families, or extrinsic factors which are to do with services. Some of these are outlined below.

#### **Vague symptoms**

Recognising dementia can be difficult for various reasons, including the fact that in the early stages the symptoms can be vague, and people often do not seek advice from the GP about memory problems.<sup>1</sup>

#### **Pre-existing medical conditions**

Diagnosis may be made difficult where a person has other existing conditions, such as depression with dementia, or is having medicines to treat mental health problems.<sup>22</sup>

### **Feeling stigmatised**

Sometimes people do not want the label of a diagnosis of dementia<sup>22</sup> and this could be because of the stigma that goes along with it.

### **Carer experience and help-seeking**

Carers may not be sure about the importance of early symptoms,<sup>22</sup> or think of early symptoms as age-related.<sup>1</sup> Carers may also be managing additional medical conditions which distract them from noticing any early signs of dementia.<sup>22</sup> They may be deterred from help-seeking because the person with dementia is in denial of their symptoms<sup>22</sup> and resist contact with services.<sup>17,22</sup> Active help-seeking is often triggered by crises, such as a relative getting lost and not knowing where they are.<sup>22</sup>

### **Black and minority ethnic (BME) communities**

People from black and minority ethnic (BME) communities access help from specialist services much later than the majority population.<sup>23</sup> Research shows that awareness about dementia is low in black Caribbean and Irish communities,<sup>11,13,14</sup> and in most South Asian languages, there is no word for 'dementia'.<sup>11,24,25</sup> Early signs of dementia could be overlooked as individuals and their families mistake these signs for normal ageing.<sup>11,25</sup>

### **Professional barriers**

Some barriers to diagnosis are service-related and include skills and attitudes of staff as illustrated below.

### **Lack of GP skills**

GPs do not feel confident about recognising and diagnosing dementia<sup>4,28</sup> and mild dementia is especially under-recognised.<sup>5,6</sup> In the Netherlands, it was found that where GPs did recognise mild dementia, they were aware of cognitive impairments but did not follow through to a diagnosis of dementia.<sup>6</sup>

### **Care staff skills**

Care staff often do not have the knowledge and skills to recognise that a person is developing dementia, and this is one contributing factor to low levels of diagnosis.<sup>4</sup> However, home care workers who may suspect that a person has dementia are not well-placed to organise a referral for assessment. Studies are rare and they estimate that the level of dementia care training among care home staff is quite low at between 8 and 14 per cent.<sup>4</sup> A National Audit Office (NAO) report on dementia services found 36 per cent of community mental health teams considered home care workers were not properly trained about dementia.<sup>26</sup>

### **GP attitudes**

A study investigating the attitudes, awareness, and practice of GPs in England and views of local specialist services, indicated that older GPs (those who graduated before 1990) were less likely than younger colleagues to look for early signs of dementia.<sup>7</sup> Despite confidence in diagnosing and advising about dementia, they were less likely to feel that early diagnosis was beneficial, especially as there were not enough specialist services to refer people on to.<sup>7</sup>

### **Assessment**

According to NICE and SCIE dementia guidelines, a diagnosis of dementia should be made only after a comprehensive assessment, which should include: history taking; cognitive and mental state examination; physical check-up and other appropriate investigations; and a review of medication in order to identify and minimise use of drugs that may have a negative effect on cognition.<sup>27</sup>

### **Early diagnosis through memory services**

The memory clinic is the most common form of memory service, providing early diagnosis, information, initiation and monitoring of treatment, and education and training, as well as person-centred support, care and advice. But access to memory services is variable across the country.<sup>9</sup> An evaluation of the Croydon memory clinic, for instance, found that there was a 63 per cent increase in the number of new dementia cases after it opened.<sup>15</sup>

### **Implications from the research**

Early diagnosis, together with effective services and support through the course of the illness, can enable people to live well with dementia if services are tailored to the person with dementia.<sup>8</sup>

There is also a need to enhance knowledge in general practice. Professionals have been suggesting that further research is needed to develop appropriate tools for use in primary care settings.<sup>1</sup>

It is also essential that training and staff development are rooted in a proper awareness of the specific needs of people with dementia and their families. This is an area where further research would be welcome.

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