The challenges of diagnosing Alzheimer disease
Anna Dowrick – Alzheimer’s Society

‘I knew that something was wrong. Things at home weren’t quite right. I was losing things and stopped being able to recognise things. One day I didn’t recognise a glass. I felt depressed and demoralised, took on too much at work and got sacked.’

‘At first, the symptoms were put down to depression, but when I was told “You’ve got Alzheimer's disease”, I cried with relief. After 18 months of trying to remember if I’d read the paper, I finally realised what was really happening.’

[Person with dementia]

The impact and significance of dementia is unique - and yet we still have some way to go until society understands the realities of the condition and the complexities of how dementia affects each individual differently. As many as one in three people over the age of 65 will die with dementia, it costs the economy £23 billion and remains shrouded in stigma which demotivates people to come forward for assessment - contributing to less than half of people who are living with the symptoms receiving a formal diagnosis.

General practitioners have a crucial role to play in diagnosing and managing dementia. Perhaps in no other field of medicine is the responsibility so incumbent on GPs to ensure people who need further investigation are getting a direct referral and, following that, post-diagnosis support that enables them to feel as in control as far as possible. Alzheimer’s Society recognises the many demands placed on GPs and the difficulties of raising concerns about a patient’s memory in a 10 minute consultation. But the lived experience of people with dementia, their families and carers articulates just how important getting a timely diagnosis of dementia is. A diagnosis enables access to treatments and support and acts as a catalyst for discussions about how to live with dementia including Power of Attorney, maintaining health, driving and Advanced Care Planning. It enables support for a family carer to be properly addressed.

‘Even today I wonder what would have happened if he hadn’t taken himself to the doctors. It would have been several months before I would have thought of booking him an appointment. Going to see the doctor early meant we got so much more quality time together as he was on the right medication.’

[Carer of a person with dementia]

A survey of 382 GPs in England, Wales and Northern Ireland conducted by the. Alzheimer’s Society found that 53 per cent of clinicians cited a lack of support services as a barrier to diagnosis, despite 88 per cent of GPs agreeing that there are benefits to an early diagnosis of dementia [Worried about your memory? GP survey].

There is pressure on memory clinic capacity in many areas and commonly inadequate social care services. But a lack of support services shouldn’t be a reason to deny a person the time to plan for the future and access to treatments. Indeed patients diagnosed with dementia make the case to commissioners that there is a real and present need for more dementia services in the UK. Additionally, there are universal services such as Alzheimer’s Society’s fact sheets, the National Dementia Helpline and Talking Point (an online support and discussion forum for anyone affected by dementia) that can be signposted to. Those areas who have in place local support, such as Dementia Advisors, demonstrate the way forward in equipping people to live well with dementia.

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The dementia Directed Enhanced Service (DES)

The introduction of the dementia DES in 2012 was designed to help deal with the historically low levels of dementia diagnosis rates by building in financial levers to the GP contract. The DES promotes a case finding approach based on a great deal of what we know about comorbidities of dementia, namely that those with vascular risk factors are at much greater risk – in some cases estimated to be over 50 per cent – of dementia.

The DES comes as part of a package of changes designed to improve the lives of people with dementia - and is in part responsible for raising diagnosis rates in England from 45 per cent of the 670,000 people living with dementia in 2012 to 48 per cent today. It has sparked debate among practitioners and policy makers, with concerns that incentivising could lead to over diagnosis. Additionally, questions about the patient benefit of early diagnosis of dementia have been raised by doctors concerned about their duty of care.

The debate around diagnosis is underpinned on some sides by a sense of fatalism – that because there are only limited measures we can take, we should do nothing. There are of course no silver bullet treatments for dementia and the four licensed treatments for Alzheimer’s do not modify the disease, but can lessen the symptoms for a while in some people. Does this add up to a reason to shy away from an initiative to diagnose more people? Would you suggest non diagnosis for other diseases on this basis? By equipping clinicians with the training and tools needed to understand those most at risk of developing dementia, and putting them in the driving seat of any clinical assessment, we protect individuals against inappropriate interventions.

The DES has also erroneously been labelled as population screening by some. Population screening for dementia does not exist in the UK and there are no plans to introduce it. It is misleading to suggest that the current approach is tantamount to a diagnosis being ‘forced’ on people and absolute respect must be given to anyone not wishing to know. However, we must be mindful of the availability of online tests, the success of awareness campaigns and the interest in dementia means that the public are much more informed and willing to talk about dementia and the symptoms of memory loss.

Resources for GPs

Alzheimer's Society's Dementia Guide – developed with the Royal College of General Practitioners - offers advice to help people come to terms with their diagnosis and plan ahead and enable them to live well with the condition. The guide has been developed to give GPs and psychiatrists the opportunity to provide people with dementia and carers with know-how and guidance at the point of diagnosis. To order copies of the guide please visit alzheimers.org.uk/dementiaguide or phone 0300 303 5933.