DEMENTIA DIAGNOSIS POSITION STATEMENT

Background
Not everyone with dementia has a diagnosis – as of August 2018, the dementia diagnosis rate for people aged 65 and over in England was estimated to be 68% [1]. A diagnosis of dementia is often difficult, because there is no test that is 100% definitive, and changes to function can be subtle and take time to develop. Symptoms can also overlap with other common medical conditions, such as depression, making a dementia diagnosis even more challenging. There is also limited public awareness of the diseases that cause dementia, and stigma about seeking medical advice.

Dementia diagnosis rates
Due to the variation in progression of the disease and the evolution of symptoms it is unrealistic to expect that everyone with dementia will have a diagnosis. It is also important that people are not misdiagnosed with dementia. For this reason, we do not expect diagnosis to reach 100%.

Our position on timely diagnosis
Alzheimer’s Research UK acknowledges that not everyone will want a diagnosis and supports an individual’s right to make this decision. However, we believe that timely diagnosis is important and can be beneficial. There are several reasons for this:

- If someone is diagnosed with dementia, there may be prescribed drugs or other treatments that can help with the symptoms or improve quality of life, some of which are more effective if given early (such as acetylcholinesterase inhibitors [2]). There are also other forms of support available to help an individual to live with dementia (such as behaviour therapy [3] and cognitive stimulation [4]).
- If a person is diagnosed, then both GPs and social services have an obligation to provide not only the person with dementia, but also their carer(s) with an assessment of their needs. This is vital to ensure the carers of people with dementia are supported and are able to discuss options with a professional who can help navigate the system during such a difficult time in their lives.
- We need to understand how many people have dementia, and the size and composition of this population, so that services can be planned accordingly.
- Timely and accurate diagnosis is also vital for research into new treatments. It gives people the opportunity to participate in research should they wish, through initiatives such as Join Dementia Research. Early diagnosis is important to identify patients who could take part in clinical trials at a stage where they are more likely to benefit from potential new treatments. As well as helping research to progress faster, those people who volunteer for research can find it a positive experience.
- People may be able to make decisions about their future care while they still have capacity to do so. This can include consideration of early retirement, financial planning, safety and security issues, and tying up legal matters such as Lasting Power of Attorney (LPA).
- There is evidence to suggest that while a diagnosis of dementia can be a shock, it can also be positive as it can help people and their families to make sense of their symptoms, as well as helping to increase understanding about the condition [5].

In order to achieve timely diagnosis, we need to ensure that GPs and clinicians are well trained and educated about the condition and know when to appropriately refer for a diagnostic assessment. Diagnosis must be supported by appropriate post-diagnostic facilities and services. This should include:
• Development of appropriate care pathways that facilitate ongoing support and equality of access for both the person with dementia and their carers.
• Services are developed in conjunction with people with dementia and local communities.
• Appropriate workforce development and training across primary, secondary and tertiary health and care.
• Opportunities to get involved in research. This can be empowering to people, as it can help them to understand what is happening to them and provides a positive focus.

We also need to ensure that the general public are educated about symptoms and are encouraged to seek advice. Investment in research must be increased, to allow improvements to be made to the accuracy and speed of diagnosis, allowing people to get the right diagnosis, at the time they want it.

Population screening
The issue of screening for dementia has been the subject of debate within the academic community and policy circles [6][7]. Given that dementia is a syndrome, with a range of pathologies and symptoms, the diagnosis of dementia is not simple. Evidence from research shows that there is currently no definitive way, be that neuroimaging, biomarker or questionnaire-based classification, to diagnose Alzheimer’s or other dementias.

The National Screening Committee has a series of criteria used to assess whether a screening programme should be introduced to the UK. The criteria encompass understanding of the epidemiology of the condition, evidence and validation of the screening test and the availability of a suitable treatment to support the diagnosis. In January 2015, the National Screening Committee concluded that currently there is insufficient evidence to support such a programme [8]. Key areas which failed to meet the criteria include the limited understanding of the epidemiology of the condition, issues with evidence, accuracy and validity of tests and the lack of effective treatments and interventions.

Our position on population screening
At the moment, screening the general population for dementia is not recommended for several reasons. First, there is no simple and accurate way to identify people with early dementia. Also, there is not yet enough evidence to suggest that screening people who do not have concerns about their memory is beneficial.

While screening is not currently appropriate, we do believe an early and accurate diagnosis for people who are experiencing symptoms of dementia is important for allowing people to access support and treatments.

References

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