Young-onset dementia: changing perceptions in diagnosis

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Why is diagnosis important?

We believe diagnosis should take place earlier and be more accurate.

It is the key to:

944,000 people are estimated to be living with dementia in the UK.

152m cases worldwide estimated by 2050
Perceptions around diagnosis:
1. Desire for pre-symptomatic diagnosis
2. Desire for symptomatic diagnosis
3. Willingness to undergo diagnostic tests
1. Public desire for pre-symptomatic diagnosis is higher than psychiatrists think

**Psychiatrists** underestimate the public’s desire for receiving an early diagnosis of Alzheimer’s disease.

**Psychiatrists**: do you agree the majority of the public would want to know they had Alzheimer’s disease prior to the onset of symptoms?

Source: Are we ready for new treatments? ARUK 2020

**Public**: would you want to know if you had Alzheimer’s disease before symptoms develop?

Source: Detecting and diagnosing Alzheimer’s Disease ARUK 2019
Vast majority of people would be likely to seek a formal diagnosis if they were concerned about dementia.

Psychiatrists are less certain about communicating a diagnosis of early Alzheimer’s disease to patients.
3. Public desire for diagnosis and testing is high, even in the absence of a disease modifying treatment

87% of people say they would take a test

<table>
<thead>
<tr>
<th>Option</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Take the test regardless of the effectiveness of treatments available</td>
<td>50%</td>
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<tr>
<td>Take the test, but only if I could be offered an effective treatment</td>
<td>20%</td>
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<td>Take the test, but only if I could be offered an effective prevention</td>
<td>17%</td>
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<tr>
<td>Not take the test. I would not want to know if I was in the very early stages of Alzheimer’s/dementia</td>
<td>11%</td>
</tr>
<tr>
<td>Don’t know</td>
<td>3%</td>
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Source: Dementia Attitudes Monitor (wave 2) 2021
Perceptions around new dementia treatments:
1. Willingness to participate in research for new treatments
2. What people want from new treatments
3. Appetite for risk in a new treatment
In 2021, 69% of UK adults said they would consider getting involved in medical research, mainly driven by a belief that research is ‘the only answer to dementia’.

In the same year, the Memory Assessment Services Spotlight revealed only 24% of patients were asked about medical research during their memory assessment service appointment.

Source: Dementia Attitudes Monitor (wave 2) 2021
Based on a public survey with over 5800 responses:

• Key finding: the most important outcomes for the public are not those included in the Clinical Dementia Rating Scale (CDR):
  • memory, orientation, problem solving, community affairs, home and hobbies, personal care
• Views were not dependent on whether people had a diagnosis of dementia.
• The direct lived experience of people with memory problems is critical to finding sensitive outcome measures.

Most important outcomes for public

• Reading & writing
• Driving
• Interactions with friends and family
• Supporting or caring for others
• Meaningful conversations

Project explored the risks that an individual would be willing to accept for the benefit of delaying progression of disease.

Key findings

- More than half of respondents were willing to accept very high risks.
- Living with memory problems or having lived experienced of dementia as a carer did not change risk tolerance.
- More tolerance to moderate side effects if younger, male, higher’ educational attainment or living alone.
- Generally greater tolerance for side effects than found in previous studies than for other chronic diseases
Useful links


