



Association of Directors of Adult Social Services (ADASS)

Submission to All Party Parliamentary Group inquiry into how to improve dementia diagnosis rates in the UK.

The Association of Directors of Adult Social Services (ADASS) represents Directors of Adult Social Services in Local Authorities in England. As well as having statutory responsibilities for the commissioning and provision of social care, ADASS members often also share a number of responsibilities for the commissioning and provision of housing, leisure, library, culture, arts and community services within their Councils.

ADASS welcomes the opportunity to contribute evidence to the All Party Parliamentary Group inquiry into how to improve dementia diagnosis rates in the UK. This inquiry is considered significant in continuing to focus and raise the profile of dementia diagnosis and ADASS will continue to seek to engage positively with this important initiative.

ADASS's overall approach

Our approach is based on the social model of disability. This sees disability not as something solely to do with an individual, but as something caused by the interaction between the individual and wider society and the environment. The individual with a disability is as much disabled by society as by any innate physical condition.

This is important in the case of dementia, since it is a disability with no medical "cure". However, there is much that can be done to assist the person with dementia to manage the condition and to work both with that person and with wider society to make it possible to live well.

Such an approach avoids the argument that early diagnosis is pointless since "nothing can be done". ADASS would argue that, even if primary and secondary care NHS services may have little to offer at an early stage of the condition (and some would argue that in fact the NHS can offer useful treatment), an early diagnosis can pave the way for important support.

Much of the debate about early diagnosis seems to be about the benefit to the health and social care system, especially whether any downstream savings might equal or exceed the costs of achieving the early diagnosis. Whilst this is important, ADASS would argue that it is still more important to frame the benefits as for the person with dementia and their carer.

This is because, aside from this inherently being the right approach, it is important that the public understand the potential benefits of early diagnosis, benefits which outweigh any perceived risks from the diagnosis. If people understand this, they are more likely to seek help and a diagnosis, and this will drive diagnosis rates up as least as much as education and incentives for NHS clinicians.

1. Why is early diagnosis important for service users and carers?

ADASS believes that early diagnosis has the following potential benefits.

- It gives the person with dementia the ability to plan ahead and to manage any future impact as the disease progresses. Obvious examples are finances and advance directives.
- It enables appropriate expectations to be set. For example, an employer can recognize that the employee has a disability and make reasonable adjustments.
- It enables the person with dementia to plan to mitigate the effects of dementia, for example through practical measures to address the loss of short term memory, whether in the home, or travelling, or shopping, or at work.
- It gives the person with dementia potential access to information about the condition, and this information in turn gives the person more control.
- It enables the person with dementia to seek and use peer support if so chosen, for example dementia cafes.
- It enables those close to the person with dementia, including informal carers, the chance to understand the condition and therefore to set expectations accordingly, and to devise management strategies. It helps to avoid these close people blaming the person with dementia for things which can't be helped.
- It enables the person with dementia to make his/her views known and voice heard, maximizing the time that the person can make a contribution in this way.
- It helps the person with dementia to maintain and prolong choice and control of his/her life for as long as possible, through advanced planning, or through being clear with others what aspects of life are important to maintain.

The social care response for someone with an early diagnosis will often not be an offer of "services", since by definition many people with such an early diagnosis will not meet the Fair Access to Care eligibility criteria. The offer is more likely to be essentially a "roadmap" of what can be expected now that a diagnosis has been reached, what is

likely to happen and (just as important) what will not usually happen, where the person can find information and support, and how the person can live as well as possible for as long as possible with the condition. It is important that the support is to enable the person to continue to pursue what is important and life enhancing, with all the variety of interests and relationships which this entails, rather than steering people immediately towards segregated services aimed solely at people with dementia. There may come a time when such segregated services are more needed, but not too soon.

2. Why is early diagnosis important for the wider health and social care system?

ADASS would argue that in many ways dementia should be seen as a long term condition. For other long term conditions it has long been recognized that there is benefit in early identification, risk stratification, and plans to manage the condition with minimal recourse to hospital admissions. The same logic should apply to dementia.

At present, the majority of diagnoses are arrived at in acute hospitals, following the admission of the person with dementia with a cluster of signs and symptoms. Having the diagnosis at this stage means that many people with dementia are admitted unnecessarily to hospital, are managed poorly while they are there, and stay far longer in hospital than they need to.

Lack of early diagnosis also leads to other costs for the system, for example:

- Poor medicines management where the person with dementia is not able to comply fully with the prescribed medicines plan
- Growing social isolation, which in turn is one of the key triggers for admissions to care homes
- Vulnerability to exploitation and abuse
- Greater difficulties for staff in care homes or home care agencies in responding appropriately to the needs and behaviours of their customers
- Crises occurring with no plan in place for managing them, which in turn can lead to the person needing a more intense intervention or more expensive service than would otherwise be required.

3. What are the barriers to early diagnosis and how might they be overcome?

ADASS believes that the key barriers are:

- Stigma around dementia, which means that people are fearful of receiving a diagnosis. Public awareness campaigns can help to counter act the stigma, but they need to set out clearly what the facts are and what can usually be expected
- Professional “nihilism” which sees a diagnosis as useless since there are no cures or services to which the diagnosing GP can refer people. To counter this, there needs to be a clear offer to everyone with a new diagnosis, an offer understood by the clinician who may make the diagnosis or refer for one. The offer needs to be framed to make the benefits clear.
- Anxiety for the person with dementia about the loss of control which a diagnosis may bring, with the classic example being a driving licence. To counter this, clear facts need to be part of the awareness campaign and roadmap following diagnosis, and any support commissioned locally needs to maximize choice and control.
- Costs of memory clinics and other elements of the diagnosis pathway, which need to be understood as offset many times over by downstream savings in the system.

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