

Young onset dementia: bridging the diagnosis gap

Diagnosis rates for young onset dementia languish well below those for people aged over 65. **Jacqueline Hussey** and **Leena Reddy** argue that this is unacceptable and issue a call for radical change



Dementia diagnosis rates for people over the age of 65 have reached 67%, in line with a target set by NHS England in 2013. Yet the diagnosis rate for young onset dementia (diagnosis before the age of 65) remains below 40%. Here, we will look at this diagnosis gap for young onset dementia and highlight the need not only for improved referral and diagnosis rates, but for more efficient recording of these diagnoses by GPs.

In 2014, Alzheimer's Society published updated prevalence rates predicting that there should be at least 42,325 people with young onset dementia in the UK. Information on actual numbers of people with dementia are entered by GP practices on to the Quality Outcomes Framework (QOF) dementia register, using a coding system for different dementia subtypes called Read codes (see table 1 below). The QOF helps identify the number of people with a diagnosis of dementia and the numbers whose care is reviewed each year.

In August 2018, there was a reported diagnosis rate of 67.8% for people 65 and over and an estimated 35.8% for

people under 65 (NHS Digital 2018). Clearly, the numbers living with young onset dementia are being seriously underestimated, which has important implications for access to interventions and care as well as for service planning and commissioning.

There are a number of possible factors to explain low diagnosis rates in young onset dementia. One study has shown that 80% of younger people present with non-cognitive symptoms (Kelly et al 2009). They are also likely to have one of the rarer forms of dementia, making it more difficult for GPs to identify it and more likely that they will attribute symptoms to another cause such as depression.

In the frequent absence of a co-ordinated referral or care pathway, people may find themselves having multiple consultations from different professionals and medical disciplines. One UK study of 132 people with young onset dementia identified 38 different care pathways (Williams 2001). Delays in diagnosis are the result, the average time to diagnosis being 4.5 years (Draper et al 2016, Van Vliet et al 2013).

Younger people with dementia are usually physically fitter than their older counterparts and have hobbies and interests which are likely to differ from theirs. Mainstream services designed to support older people may therefore be deemed inappropriate, leading to a lack of age-appropriate and effective post-diagnostic support. One of the problems here is that non-availability of post-diagnostic support for younger people is correlated with lower referral rates for diagnosis.

Wokingham Memory Service has kept a case register of people diagnosed with young onset dementia since 2005. It is regularly updated to provide numbers of those currently under the memory service or community older adults team, those transferring in or out of the area, those in nursing home care, those deceased and those discharged from the service caseload. In consequence, it is a fairly accurate record of people diagnosed in Wokingham,

including those who were diagnosed before 65 but are now older than this.

Wokingham team also works closely with the neurology department and the charity YPWD (Berkshire), which provides a range of age-appropriate interventions and encourages early referrals for diagnosis. Each year GPs are sent updated lists of all people with dementia on the memory clinic caseload and each letter sent to GPs about a patient has their diagnostic Read code with a reminder to enter it on to the QOF register.

Diagnosis gap

Using population and prevalence estimates by age (Alzheimer's Society 2014) it is possible to estimate the predicted number of people with young onset in the catchment of Wokingham (see table 2 below). Based on these figures, we would predict there to be 108 people with young onset dementia in Wokingham borough.

| Diagnosis | Read Code |
|---------------------------------|-----------|
| Alzheimer's disease | EU 00 |
| Young onset Alzheimer's disease | EU 000 |
| Frontotemporal dementia (FTD) | EU 02 |
| Dementia with Lewy Bodies | EU 023 |
| Vascular dementia | EU 01 |

Table 1: Examples of Read codes

| NHS Wokingham (Age Range) | Number Expected |
|---------------------------|-----------------|
| 30 - 34 | 1 |
| 35 - 39 | 1 |
| 40 - 44 | 2 |
| 45 - 49 | 4 |
| 50 - 54 | 7 |
| 55 - 59 | 13 |
| 60 - 64 | 80 |
| TOTAL | 108 |

Table 2: Predicted numbers of people with young onset dementia in Wokingham

| | Total Number | Under 65 years currently Range 49 - 64 years | Over 65 years now but young onset Range 65 - 69 years |
|-------------------------------|--------------|--|---|
| In community | 59 | 40 | 19 |
| In 24 hour care | 21 | 8 | 13 |
| Total number known to service | 80 | 48 | 32 |
| Predicted number | 108 | | |
| Number on QOF Register | 29 | | |

Table 3: Numbers of people with young onset dementia known to services in Wokingham

In fact, there are actually 80 diagnosed with young onset dementia on the Wokingham case register, 48 of whom are under the age of 65 and the other 32 who were diagnosed with dementia under the age of 65 but have grown older (see table 3 above). In contrast, there were just 29 patients on the GP QOF dementia registers for our area (data from Public Health England 2018).

Coding problems

What is striking is that even in a service where there is a care pathway for young onset dementia and five-day provision of age-appropriate aftercare through YPWD (Berkshire), there is still a large discrepancy between predicted prevalence and recorded prevalence. In other words, there appears to be a diagnosis gap.

Of course, part of this is about making the diagnosis in the first place. Rates will only improve if there is earlier recognition through better public and GP education along with clear referral and diagnostic pathways. The Young Dementia Network has produced a decision-making guide for GPs (2017) and the Royal College of Psychiatrists has published updated guidelines on young onset (2018) with this in view. Raising the importance of symptom recognition and diagnosis reporting among GPs is vital, as is incentivising them to refer by improving referral pathways and post-diagnostic support.

However, there is also a coding problem, which arises because GP Read codes only have a code for young onset Alzheimer's disease but no other subtypes of dementia. For example, there is just one code for frontotemporal dementia which does not distinguish between ages of onset.

The upshot is that someone diagnosed with Alzheimer's dementia at the age of 62 will still appear as having young onset Alzheimer's when they reach 65. In contrast, someone diagnosed with dementia with Lewy bodies or frontotemporal dementia at the age of 62 will not be recognised as having had a young onset diagnosis once they reach the age of 65. We must revise the coding of subtypes of young onset dementia if we are to accurately record numbers and understand the true diagnosis gap.

It is hard to imagine that a national diagnosis rate of less than 40% would be acceptable for any other condition. Under-reporting has major implications if we are to persuade commissioners to fund age-appropriate services for people living with young onset dementia, whose own needs and those of their families are often significant and complex.

Only by diagnosing and recording more effectively can we gain a true picture of young onset dementia and ensure that there are sufficient and properly coordinated services. Not least among the benefits will be greater social inclusion and connection for people with

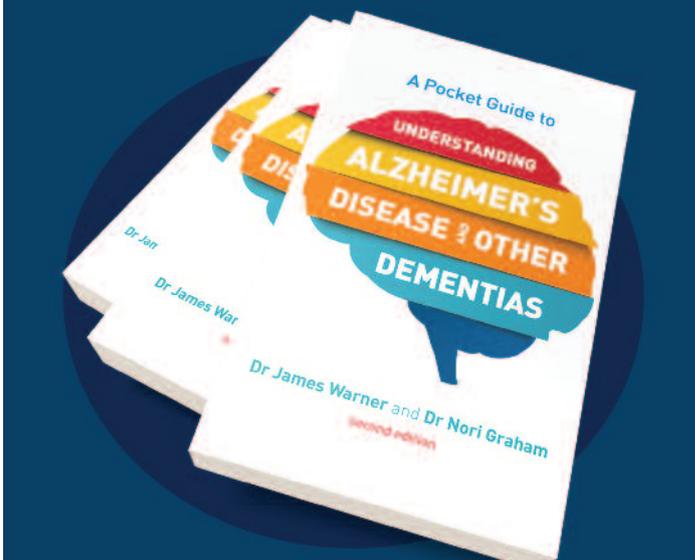
the condition by providing a network for them and their families. ■

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■ Dr Jacqueline Hussey is a consultant old age psychiatrist at Berkshire Healthcare NHS Trust, clinical director for the charity YPWD (Berkshire) and steering group member of the Young Dementia Network. Dr Leena Reddy is a higher trainee in old age psychiatry, Oxford Deanery.



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