

'Less common' dementias affect many people

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It is always unsatisfactory to define things using negative terms, and this is certainly true of ‘less common’ or ‘uncommon’ or ‘rare’ dementias. It is much easier to say what we mean by term ‘common dementias’, which is that Alzheimer’s disease and vascular dementia are responsible for the majority of cases. Estimates from different studies on the number and proportion of people with Alzheimer’s or other dementias vary, depending on how each study was conducted (Alzheimer’s Association, 2020). A typical estimate is that Alzheimer’s disease and vascular dementia are responsible for about 85% of all dementias (BRACE, 2021), in which case the proportion of non-Alzheimer and non-vascular dementias would be roughly about 15%. The term ‘less common dementias’ is not necessarily a scientific one, but is instead more a convenient way of banding together several diverse conditions that cause dementia, each with varying biological, anatomical and clinical pictures. There are also many causes of dementia that disappear into the medical small print, so it is difficult to say exactly how many forms of dementia there really are.

In the present issue, along with another future issue, the authors will be publishing two papers, providing a clinical review of some of the more important forms of non-Alzheimer, non-vascular dementia. We think this will be helpful for many people, as dementia and Alzheimer’s disease are easy to conflate; therefore, it is possible to overlook important aspects and features of these and other dementias. We are also trying to communicate an important message: that, although these disorders are much less common than Alzheimer’s disease, some are not as rare as is often assumed. As the number of people in the UK with dementia approaches one million (Wittenberg et al, 2019), a condition that affects even a small minority of this total will have an impact on thousands of people. It is also important to consider that the number of people affected by dementia are not solely those with the diagnosis, but also their families and loved ones, who provide most of the support and care that a patient receives. Beyond that, many other people, such as health professionals, care home and community care staff, are also involved, since dementia care is part or all of their daily work.

In these papers, ‘less common’ dementia is taken to mean non-Alzheimer, non-vascular dementia. We have chosen to discuss those that are probably most frequently encountered: Parkinsonian dementias (Parkinson’s disease dementia, dementia with Lewy bodies, so-called Parkinson’s plus disorders), Huntington’s disease, frontotemporal dementia, human immunodeficiency virus (HIV) dementia, prion diseases, and alcohol-related dementia. Between them, they account for most of the cases of non-Alzheimer, non-vascular dementia. For reasons of space, we have not included some other conditions that could justifiably have been included—for example, Down syndrome dementia or dementia following traumatic brain injury (for up to date reviews, see McGlinchey et al (2020) for Down syndrome and LoBue et al (2019) for traumatic brain injury). We have also not included many of the forms of dementia that can arise from a range of neurological

diseases, such as multiple sclerosis or antibody-mediated encephalitis (see Graham 2021 for an account of neurological dementias).

One feature of the less common dementias is that they are more prominent causes of dementia among relatively young patients. Alzheimer's disease and vascular dementia are still probably the most common causes of dementia among people under the age of 65 years, but other possible causes are also frequently found (Ray and Dening, 2021). However, less common dementias can be seen at any age.

For patients with suspected dementia, providing a timely diagnosis that is as accurate as possible is important. It enables clinicians to provide patients and their families with appropriate information and help them to access effective care and support. Diagnosis is also a helpful indicator of the expected progression and prognosis of the dementia, aiding those affected to adjust their expectations and make plans for their future. Accurate diagnosis also provides hope that distinct illnesses can be better characterised and understood, which may mean that less common dementias are diagnosed more frequently in the future. Better diagnosis offers, too, the prospect of future treatments that may slow the course of the underlying disease. However, it remains the case that most of the less common dementias are progressive and have no effective disease-modifying treatments. For the present, nursing practice will focus on communication with patients and families, dealing with practical, soluble problems, and providing nursing support and care from time of diagnosis to the end of life.

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