key points

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Although the risk of developing dementia increases with age, onset can be as early as the third or fourth decade of life. It is estimated that there are 42,325 people diagnosed with young onset dementia in the UK, representing approximately 5% of the 850,000 people living with dementia. Genetic influences play a more important role in younger than in older people with dementia, so young onset dementia may cluster in families.

Diagnosing young onset dementia is challenging. The range of possible presenting features is broad, encompassing behavioural, cognitive, psychiatric and neurological domains, and symptoms are often subtle initially. Frequently the complaints are misattributed to stress or depression, and the patient is falsely reassured that they are too young to have dementia.

Epidemiological studies conducted in the UK have found that the most common causes of young onset dementia are early onset forms of adult neurodegenerative conditions and alcohol. Vascular dementia is the second most common cause of young onset dementia after Alzheimer's disease. Conventional vascular risk factors may be absent and diagnosis relies on imaging evidence of cerebrovascular disease.

Priority should be given to diagnosing treatable causes for cognitive complaints which include depression, hydrocephalus, hypothyroidism, alcohol and drugs including prescribed medication e.g. opioids. Obtaining a detailed history remains the most important part of the workup and usually requires corroboration by a third party. Undertaking a basic neurological examination is also important.

Those with suspected young onset dementia should be referred to a neurology-led cognitive disorders clinic where available as the differential diagnosis is considerably broader than in older adults and requires specialist investigation.

A multidisciplinary approach is essential. Most patients will require a comprehensive social needs assessment. Where a genetic cause for the dementia syndrome is suspected, questions about the implications for other family members should be referred to a clinical genetics service.