



Supporting
implementation of
the NICE guideline for
people with young
onset dementia



This resource explains the unique needs of people with young onset dementia that require a tailored approach to support and care. It outlines the additional challenges younger people with dementia face throughout the dementia pathway in the absence of a tailored approach, and the consequences of this on people and their families as well as for the health and social care system.

The table (page 8) provides guidance on how to address the challenges and meet the unique needs of people of working age living with dementia and provides signposting to supporting resources.

Introduction

Young onset dementia (dementia with onset before 65 years) has significant differences from late onset dementia, with higher prevalence of rarer types, greater heritability and a much wider range of causes^{1 2}. This means that specialist expertise is essential to ensure adequate assessment, investigation and support after diagnosis.

The difference in life stage at the point of diagnosis also means specialist support is essential. People living with young onset dementia are likely to still be working, have significant financial responsibilities and have children or parents to care for. Specialist young onset dementia services have been shown to have improved outcomes^{3 4} and are recommended⁵.

Despite the distinctive needs of younger people with dementia, access to local specialist services is limited⁶ and most people with suspected young onset dementia will be seen in all-age memory services, where specialist knowledge is lacking due to the rarity of cases seen and support and services are generic for all ages.

Evidence shows that the needs of younger people with dementia are not being met by this age-generic approach and they are facing additional challenges across the pathway. This includes taking longer to get an accurate and specific diagnosis, lack of availability of young onset specific information including advice and support to stay independent, and lack of age-appropriate activity to stay fit, mentally well and to maintain identity.

These unmet needs can have a devastating impact on the individual from unnecessary multiple assessments and increased rates of depression⁷, lower quality of life⁸, and increased financial and care burden experienced by caregivers and family members who themselves may struggle with deteriorating health^{9 10}. These personal, social and potentially reversible economic costs could be reduced by the provision of appropriate, proactive support earlier in the pathway^{4 8 9 10 11}.

It takes on average **4.4 years** for a person aged under 65 to receive a dementia diagnosis

The diagnosis rate of young onset dementia in England may be **just 45%**

42% of people with young onset dementia receive no services whatsoever in the first six weeks following diagnosis

Diagnosis

Younger people with dementia face long waiting times for diagnosis and there is limited access to the complex investigations that are often necessary.



Analysis has shown people with young onset dementia can wait four years¹² for diagnosis, and the diagnosis rate of young onset dementia in England may be just 45%, compared to 68% for over 65s. During this time there may be repeated medical assessments, which could be avoided if GPs had greater knowledge of the ‘red flag’ symptoms characteristic of young onset dementia, which often overlap with symptoms of common psychiatric disorders such as depression^{13 14}, and if there were clear local pathways into care⁷.

Delays to diagnosis also result in a long period of coping with unexplained symptoms and no support, for both the person with dementia and their family, during which time health may deteriorate and further needs may develop. Collectively, evidence suggests that upskilling clinicians in diagnosis¹⁵ and improving awareness of symptoms of young onset dementia would help to improve accurate diagnosis¹⁶, reduce delays¹² and allow access to correct treatment and support after diagnosis^{17 18}.

With higher prevalence of rarer types and a much wider range of causes^{1 2}, a clinically rigorous and systematic approach is necessary

to avoid misdiagnosis or under-diagnosis in younger people¹³. This includes access to NICE recommended specialist investigations (imaging, neuropsychology, molecular biomarkers, genetic testing) that can ensure a high-quality diagnostic service. Making an accurate and timely diagnosis provides family members with insight and understanding into the often complex behavioural and cognitive symptoms which manifest in young onset dementia^{19, 20} and is associated with improving autonomy and wellbeing for younger people with dementia and reduced carer burden¹⁷. However, studies have evaluated the quality of the diagnostic work-up for younger people and identified that an acceptable diagnosis was performed in only 24% of cases. Use of supplementary investigations such as cerebrospinal fluid and neuropsychology were rarely applied²¹. Equally, a comprehensive diagnostic pathway brings with it the ability to rule out a diagnosis of young onset dementia for those with other disorders.

Importantly, studies which directly examine lived experience^{22 23} show that people aged under 65 with dementia highlight diagnosis and improved recognition of symptoms as their highest priorities for service improvement.

Support

Evidence suggests that support for people with young onset dementia is often poor ⁴. Evaluations have found that:

42%

of people with young onset dementia receive no services whatsoever in the first six weeks following diagnosis

39%

of people with young onset dementia reported seeing no health professional within the previous three months

62%

of people with young onset dementia had no key worker

70%

of people with young onset dementia had no care plan

46%

of people with young onset dementia had not attended any dementia related activities in the previous three months ⁴

71%

of family carers have not attended a carer support group ⁴

Support

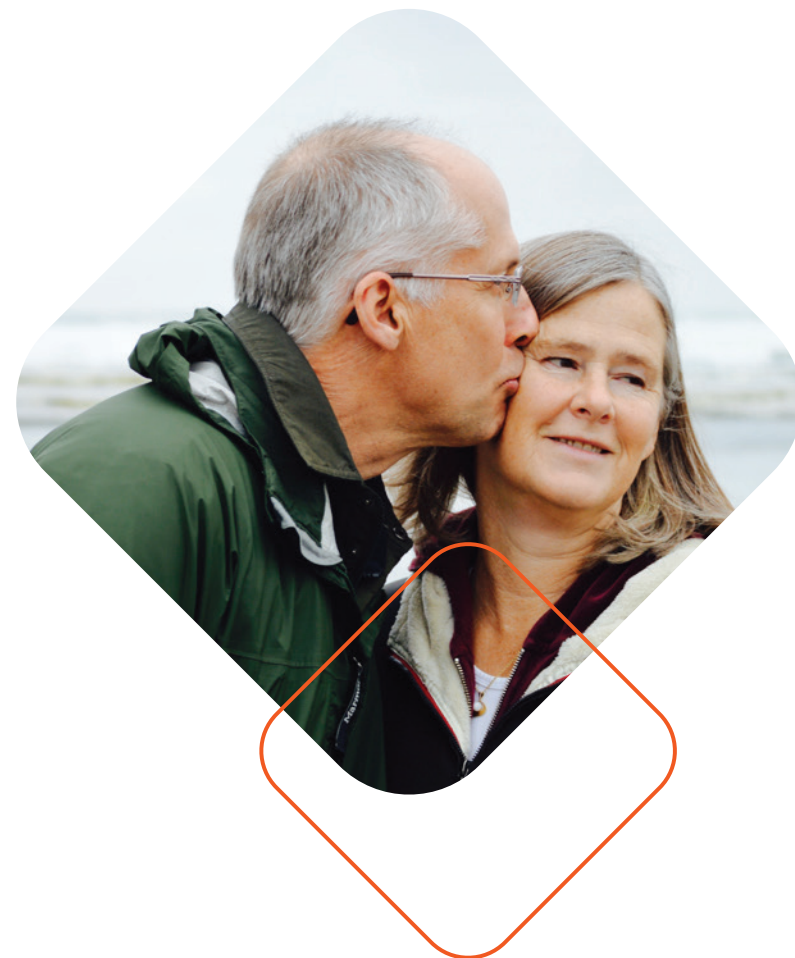
Younger people with dementia are likely to face a lack of age-appropriate support and are often unable to access the psychological and practical support they need to come to terms with the diagnosis and to live well.

A diagnosis of dementia is always devastating but the younger the person is when they receive a diagnosis, the greater their expectations will have been of future years being fully active and independent, and pursuing ambitions that rely on these abilities. They may still be in work. They may be supporting children or elderly parents. The impact on a partner can be particularly devastating also, as they too would have expected many more years with their partner in good health. They may also have to reduce hours or give up work in order to provide care. The psychological impact on both the person with dementia and their family members can be compounded by financial hardship due to loss of earnings from having to leave work or reduce hours.

A lack of age-appropriate activities can increase social isolation, apathy and a decline in health, all of which can compound existing health

needs. Evidence shows that to be considered helpful to people with young onset dementia, services need to provide age-appropriate activities aimed at younger people, be responsive as needs change, be integrated by having a tailored care pathway and there should be consistency across time eg seeing the same professional, knowing who to contact ^{4 21} and having a dedicated key worker ²⁴. Staff should have awareness, knowledge, competence and flexibility of approach ¹⁹.

The economic and social costs of care from family members / supporters are valued at over 20 times the cost of support from formal services ⁴, economic costs from loss to the workforce are considerable ²⁵ and there are high levels of physical and psychological complaints for family members ^{15 25}. The economic and human cost can be reduced by ensuring services provide specialist advice and information on young onset dementia, provide age-appropriate activities to help people remain independent and maintain physical and mental health, help maintain a sense of connection with wider society, and enable family members to retain aspects of life beyond caring ^{21 26}.



The NICE dementia guideline sets out best practice for diagnosing and managing dementia and aims to improve care by making recommendations to support people living with dementia. Younger people with dementia and their families have unique needs and face different challenges. Additional guidance is therefore necessary to address these challenges and to support design and delivery of services.



Involving people living with dementia in decisions about their care



Diagnosis



Care coordination



Interventions to promote cognition, independence and wellbeing



Supporting carers





Involving people living with dementia in decisions about their care

Recommendation in NICE guideline

1.1.4 Provide people living with dementia and their family members or carers with information that is relevant to their circumstances and the stage of their condition

Additional guidance for supporting people with young onset dementia and their families

Provide or facilitate access to information about young onset dementia and rare forms of dementia and how to communicate the diagnosis to children, family, employers and friends.

Provide or facilitate access to specialist advice and support about young onset specific needs eg employment, mortgage, financial obligations and future financial planning.

Provide information and advice about social recreational and age-appropriate meaningful activities and peer support.



Resource: Information leaflet for anyone newly diagnosed with young onset dementia created by the Young Dementia Network.

Further resources:

- ➔ Dementia UK
- ➔ Young Dementia Network
- ➔ Alzheimer's Research UK
- ➔ Rare Dementia Support



Diagnosis

Recommendation in NICE guideline

1.2.1 Taking a history from the person with suspected dementia and from someone who knows the person well

1.2.4 Do not rule out dementia solely because the person has a normal score on a cognitive instrument

1.2.6 Refer the person to a specialist dementia diagnostic service

NICE dementia quality standard:

People with suspected dementia are referred to a specialist dementia diagnostic service if reversible causes of cognitive decline have been investigated

Additional guidance for supporting people with young onset dementia and their families

GP aware of young onset dementia.

GP knowledgeable about young onset dementia and the variety of symptoms which can present, which may differ from those with later onset dementia.

GP has a low threshold for referral if there are 'red flags.'

Referral is made to the locally agreed young onset referral care pathway.

Pre-assessment counselling is routinely provided to establish informed consent, find out what someone wants to know about their diagnosis, who else they would like to be present when it is given, and if there is someone else they would like to be informed.



Resource: Decision-making guide for GPs created by the Young Dementia Network.



Resource: Young onset dementia pathway created by the Young Dementia Network.



Diagnosis

Recommendation in NICE guideline

1.2.9 Diagnose a dementia subtype

Additional guidance for supporting people with young onset dementia and their families

Clinicians based in memory clinic or specialist services / departments where diagnosis takes place are knowledgeable and skilled regarding young onset dementia and the impact the diagnosis can have on the person diagnosed and their family.

There are designated young onset dementia leads in each memory clinic / diagnostic department.



Resource: MSNAP standards for memory services, ninth edition

Type 1 standard: no. 20, 101

Type 2: 102, 115, 132, 142

Type 3: 14, 77

Diagnostic services have access to appropriate investigations for diagnosing and subtyping rare dementia, including FDG-PET or perfusion SPECT, cerebrospinal fluid biomarkers and amyloid PET imaging, as the presence or absence of amyloid pathology can increase diagnostic certainty in atypical young onset dementia.

Genetic counselling and testing for familial dementia is available.

Comprehensive assessment is performed by a commissioned multi-disciplinary team of key professionals including neurology, psychiatry, nursing, psychology, occupational therapy and neuroradiology including access to allied services as appropriate eg occupational therapy, speech and language therapy, social worker, physiotherapy and dieticians as necessary.

1.2.33 After a person is diagnosed with dementia, ensure they and their family members or carers (as appropriate) have access to a memory service or equivalent hospital - or primary-care-based multidisciplinary dementia service

Diagnosis is delivered with recognition that the person diagnosed with young onset dementia and their family may still be in work, have dependent young children or other care responsibilities, so may have different questions and responses to the diagnosis.



Care coordination

Recommendation in NICE guideline

1.3.2 Named care coordination professionals

NICE dementia quality standard:

People with dementia have a single named practitioner to coordinate their care.

Additional guidance for supporting people with young onset dementia and their families

Care coordination professionals should engage with individuals and their family / friends to understand their needs. This includes discussing life, achievements, abilities and aspirations pre and post diagnosis, gaining understanding of employment status, financial status, care responsibilities and family situation, and meeting family members and support circle to understand their perspective and circumstances.

Care coordination professionals should tailor a plan with the individual and their family which is appropriate for their stage in life, including:

- ◆ Providing or facilitating access to information about young onset dementia and rare forms of dementia and how to communicate the diagnosis to children, family, employers and friends

- ◆ Providing or facilitating access to specialist advice and support about young onset specific needs eg employment, mortgage and financial obligations and future financial planning
- ◆ Providing advice and emotional support to family members and others closely involved in care



Resource: Young onset dementia: guidance for dementia support roles who may not usually support younger people with dementia, created by the Young Dementia Network.



Resource: Young onset dementia pathway, created by the Young Dementia Network.

1.3.6 Services should be accessible to as many people living with dementia as possible, including: people who have other responsibilities (such as work, children, or being a carer themselves)

Age-appropriate meaningful activities, such as cognitive stimulation therapy and activities based on the interests of local people with young onset dementia.



Interventions to promote cognition, independence and wellbeing

Recommendation in NICE guideline

1.4.1 Offer a range of activities to promote wellbeing that are tailored to the person's preferences

NICE dementia quality standard:

People with dementia are supported to choose from a range of activities to promote wellbeing that are tailored to their preferences.

Additional guidance for supporting people with young onset dementia and their families

Age-appropriate meaningful activities, such as cognitive stimulation therapy and activities based on the interests of local people with young onset dementia.



Supporting family members / carers

1.11 Support for carers

NICE dementia quality standard:

Carers of people with dementia are offered education and skills training.

Key worker meets with family members and support circle to understand their perspective and circumstances.

Key worker provides advice and emotional support to family members and others closely involved in care.

Key worker engages with individual and their family / friends to understand their needs.

Key worker tailors a plan with the individual and their family which is appropriate for their stage in life.



Resource: Young onset dementia: guidance for dementia support roles who may not usually support younger people with dementia, created by the Young Dementia Network.



References

1. Sampson, E. L., Warren, J. D., & Rossor, M. N. (2004). Young onset dementia. *Postgraduate Medical Journal*, 80(941), 125-139.
2. Kelley, B. J., Boeve, B. F., & Josephs, K. A. (2009). Rapidly progressive young-onset dementia. *Cognitive and Behavioral Neurology*, 22(1), 22-27.
3. Loi SM, Goh AMY, Mocellin R, Malpas CB, Parker S, Eratne D, Farrand S, Kelso W, Evans A, Walterfang M, Velakoulis D (2020). Time to diagnosis in younger-onset dementia and the impact of a specialist diagnostic service. *Int Psychogeriatr*. Aug 28;1-9.
4. Stamou V, La Fontaine J, Gage H, Jones B, Williams P, O'Malley M, Parkes J, Carter J, Oyeboode J (2021). Services for people with young onset dementia: The 'Angela' project national UK survey of service use and satisfaction *Int J Geriatr Psychiatry* 36 (3):411-422
5. Royal College of Psychiatrists. Young-onset dementia in mental health services. Recommendations for service provision. (2018) <https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr217.pdf>
6. Rodda, J., & Carter, J. E. (2016). A survey of UK services for younger people living with dementia. *International Journal of Geriatric Psychiatry*, 951-959.
7. Williams, T. Dearden, A., Cameron, I (2001). From pillar to post – a study of younger people with dementia. *Psych. Bull*, 25, 384-387
8. Bakker C, de Vugt ME, van Vliet D, et al. (2014). Unmet needs and health-related quality of life in young-onset dementia. *Am J Geriatr Psychiatry*;22(11):1121-1130.
9. Tor Atle Rosness, Marit Mjørud & Knut Engedal (2011) Quality of life and depression in carers of patients with early onset dementia, *Aging & Mental Health*, 15:3, 299-306
10. Hvidsten L, Engedal K, Selbæk G, Wyller TB, Šaltytė Benth J, Kersten H (2020) Quality of life of family carers of persons with young-onset dementia: A Nordic two-year observational multicenter study. *Aging Mental Health* 24(9):1394-1401
11. Drummond Roach, P., Drummond, N., & Keady, J. (2016). 'Nobody would say that it is Alzheimer's or dementia at this age': Family adjustment following a diagnosis of early-onset dementia. *Journal of ageing studies*, 36, 26-32.
12. van Vliet, D. et al. (2013). Time to diagnosis in young onset dementia as compared with late-onset dementia. *Psychological Medicine*, 43(2), 423-432
13. O'Malley, M., Stamou, V., Parkes, J., La Fontaine, J., Oyeboode, J. Carter (2019). Young-onset dementia: scoping review of key pointers to diagnostic accuracy. *BJPsych open*, 4;5(3):e48. doi: 10.1192/bjpo.2019.36.
14. Woolley JD, Khan BK, Murthy NK, Miller BL, Rankin KP. The diagnostic challenge of psychiatric symptoms in neurodegenerative disease; rates of and risk factors for prior psychiatric diagnosis in patients with early neurodegenerative disease. *J Clin Psych*. 2011;72(2):126-33
15. O'Malley, M., Parkes, J., Campbell, J., Stamou, V., La Fontaine, J., Oyeboode, J. Carter, J (2020). International consensus on quality indicators for comprehensive assessment of dementia in young adults using a modified e-Delphi approach *Int J Geriatr Psychiatry* 35 (11) 1309-1321
16. Johannessen, A. and Moller, A (2011) "Experiences of persons with early onset dementia in everyday life: a qualitative study. *Dementia* 12, 4, 410-424"
17. Stamou, V., La Fontaine, J., O'Malley, M., Jones, B., Gage, H., Parkes, J., Carter J., Oyeboode, J (2020). The nature of positive post-diagnostic support as experienced by people with young onset dementia. *Aging & Mental Health* doi:10.1080/13607863.2020.1727854
18. Van Vliet, D., de Vugt, M.E., Bakker, C., Koopmans. R. T.C., Verhey, F.R. (2011). Caregivers' perspectives on the pre-diagnostic period in early onset dementia: a long and winding road *Int Psychogeriatr* Nov;23(9):1393-404.



References

19. Ducharme F, Kergoat M-J, Antoine P, Pasquier F, Coulombe R. (2013). The unique experience of spouses in early-onset dementia. *Am J Alzheimers Dis Other Dement* 28 (6) 634-641
20. Salem LC, Andersen BB, Nielsen TR, Stokholm J, Jørgensen MB, Waldemar G. (2014) Inadequate diagnostic evaluation in young patients registered with a diagnosis of dementia: a nationwide register-based study. *Dement Geriatr Cogn Dis*. 4:31-44. 2
21. Stamou, V, La Fontaine, J, O'Malley, M, Jones, B, Parkes, J, Carter, J, Oyebode, J. Helpful post-diagnostic services for young onset dementia: Findings and recommendations from The Angela Project. *Health Soc Care Community*. 2021; 00: 1-12. <https://doi.org/10.1111/hsc.13383>
22. Armari E., Jarmolowicz A., Panegyres PK. (2013). The Needs of Patients with Early Onset Dementia. *Am J Alzheimers Dis Other Dementia*, 28 (1), 42-6
23. O'Malley, M., Parkes, J., Campbell, J., Stamou, V., La Fontaine, J., Oyebode, J. Carter, J (2020) Receiving a diagnosis of young onset dementia: evidence-based statements to inform best practice. *Dementia* doi. [org/10.1177.1471301220969269](https://doi.org/10.1177.1471301220969269)
24. Hussey, J., Hayo, H. (2019). Young dementia: The specialist keyworker role. *Journal of Dementia Care*, 27(3), 25-27.
25. Kandiah, Nagaendran et al. Cost Related to Dementia in the Young (2016). *J. of Alzheimer's Disease*, 49: (2): 277-285
26. Joany K. Millenaar, Marjolein E. de Vugt, Christian Bakker, Deliane van Vliet, Yolande A.L. Pijnenburg, Raymond T.C.M. Koopmans, Frans R.J. Verhey (2016). The Impact of Young onset dementia on Informal Caregivers Compared with Late Onset Dementia: Results from the NeedYD Study, *The American Journal of Geriatric Psychiatry*, :24 (6): 467-474

This resource was created by members of the Young Dementia Network. The Network is hosted by Dementia UK and is a collaboration between people affected by and working in the field of young onset dementia. It campaigns to bring about improvements for people living with young onset dementia now and in the future.

You may find the following Young Dementia Network resources useful. They are available to download or hard copies can be requested via the **Resources** section of our website.

- ⇒ Diagnosis experience checklists - for people who may have young onset dementia and their family members and healthcare professionals
- ⇒ GP surgery leaflet to raise awareness of young onset dementia created by the Young Dementia Network
- ⇒ Good practice in young onset dementia – results from The Angela Project, a study on young onset dementia
- ⇒ Eight key needs of people with young onset dementia and family members – videos created as part of The Angela Project
- ⇒ Young onset dementia ID cards – cards that can be used when out and about when people may need help and support created by the Young Dementia Network

Web: youngdementianetwork.org

Email: youngdementianetwork@dementiauk.org

