

Diagnosis and support for people with young onset dementia and their families

Recommendations from the Young Dementia Network Steering Group

Summary

This document brings together the experience and expertise of people affected by young onset dementia (YOD) and the people who work with and support them. It highlights that the impact of dementia can be very different depending on your stage of life and that because of this, services must be tailored to meet those needs. Currently, this is rarely the case and this means that a younger person can take twice as long to be diagnosed than an older person. Once they receive this diagnosis they are often left with no appropriate support and no one with the specialist knowledge to guide them through the journey ahead.

From first contact with a GP to end of life care, that journey can be very different for a younger person. They are likely to be in work, have a financial responsibilities and dependent children. They may have a rarer form of dementia which means they are part of an even smaller minority. A dementia diagnosis is always devastating. But for a younger person, that diagnosis means that life changes beyond recognition.

Together we have identified a series of recommendations which are designed to meet those different needs. These recommendations will guide policy makers, commissioners and practitioners in designing and delivering services. Most importantly, we hope they will empower younger people with dementia and their families to demand the services to meet their needs.

Recommendations for policy makers and commissioners

- Commissioned services must be designed to address the specific needs of younger people with dementia and their families. This means that providers must be able to demonstrate how their service is adapted for younger people. In particular, offering or signposting to age-appropriate activities and support to maintain physical, cognitive and mental health and social engagement for people at all stages of YOD; and specialist support for families
- Dedicate commissioning to developing and supporting existing services to allow sustained clinical experience and development of continuity and co-ordination across different service providers. Ongoing care needs to be specialist or shared, not from GP alone
- Appoint a dementia lead in the Clinical Commissioning Group to link with a multi-agency partnership responsible for identifying needs and improving services for younger people with dementia
- Adopt a specific strategy for young onset dementia and implement a joined-up care pathway across primary care and specialist services, including social care

Recommendations in detail

- Positive contact with my GP which reduces the time taken to receive the correct diagnosis
 - GPs to have an awareness of young onset dementia and the variety of symptoms with which it can present including atypical ones. This could improve recognition by GPs of key symptoms that may indicate a referral to specialist services is required
 - Clear referral routes from the GP to specialist diagnostic services
- A clear and collaborative diagnostic process which is young onset specific
 - Ensure a defined local care pathway for younger people with possible cognitive impairment with special attention to transitions between primary care and assessment services; and assessment services and post-diagnostic support services
 - Provide access to a specialist with expertise in the diagnosis of young onset and rare dementia, to improve standards of assessment and diagnostic accuracy
- Specialist support and information which meets our changing needs
 - A Key worker who has specialist knowledge, training and experience of young onset dementia and its impact on the person with the diagnosis and their family, as well as knowledge of local and national service provision
- Living with young onset dementia
 - For the Keyworker, clinicians, social services and charitable organisations to work closely together to provide a comprehensive service for the person with young onset and their families
 - Access to age-appropriate and meaningful activities which enable younger people and their families to remain engaged in their communities, retain and develop relationships and social connectedness. Age-appropriate means that the content, location and timings of activities are designed to be beneficial and accessible for younger people
 - Advice which enables the person to plan for common issues such as: how to manage or leave employment, how to manage financially, future planning and for the end of life
 - Access to age-appropriate and local short term and long-term care, based in their own home or in residential care depending on the person's wishes and needs

Recommendations by role

We recommend GPs should

- a) Be aware of young onset dementia and have a low threshold for referral of younger people suspected of cognitive impairment
- b) Be aware of referral routes to specialist services
- c) Be aware of the young onset dementia specialist lead for their area
- d) When the person has received a diagnosis, develop, agree and regularly review a shared care plan which ensures that they are linked into local support services. This is especially important when a diagnosis was given in a regional or national centre.

We recommend clinicians based in diagnostic services should

- a) Have a named young onset dementia lead
- b) Have knowledge of the varied impact of a diagnosis of young onset dementia on the person and their family

- c) Have access to the full range of assessment, investigations and personnel necessary to make a diagnosis and provide ongoing post-diagnostic support

We recommend the Key worker role should

- a) Have specialist knowledge, skills and experience of the impact on young onset dementia. This will include a knowledge and understanding of rarer forms of dementia, as well as the impact of a diagnosis at a younger age for the person diagnosed and their family
- b) Provide information, practical and emotional support for family members, as well as connect them to others for mutual support
- c) Provide continuity of support, and enable the person living with young onset dementia to understand their condition and actively engage in their care plan and journey
- d) Act as a co-ordinator of services, organisations and people, helping to connect the person living with young onset to local groups networks and support services. They will also act as a liaison between clinical services and the person's community and home
- e) May be delivered through a variety of organisations depending on local infrastructure and funding arrangements. For example (but not limited to) primary care, voluntary sector or be based within local mental health teams or neurology services.

A young onset dementia pathway

	Person with young onset dementia and their family carers	Services to support these needs
<p>Positive contact with my GP which reduces the time taken to receive the correct diagnosis</p>	<p>We have the right to an early and accurate diagnosis</p> <p>My GP listens to me and doesn't discount dementia because of my age</p> <p>I can talk to my GP about how young onset dementia could affect me, or my family</p> <p>My GP knows about the referral process for young onset dementia and it is explained to me. I'm able to record these conversations so I can refer to them later</p> <p>I'm told about the Young Dementia Network, and local young onset support services who can support me</p> <p>I can participate in counselling tailored to my age and situation, in preparation for the journey ahead</p>	<p>GP aware of young onset dementia and appropriate local referral routes</p> <ul style="list-style-type: none"> • 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' • GP listens to the person and family members to make thorough assessment of symptoms including baseline investigations, physical examination, assessment of activities of daily living and a brief cognitive assessment • GP excludes a potentially treatable illness or reversible cause of the 'dementia' <p>Referral is made to the locally agreed young onset referral care pathway</p> <p>Access to pre-assessment counselling</p> <ul style="list-style-type: none"> • Pre-diagnostic review/support and counselling <p>Also see 'Diagnosing Well' - NHS Well Pathway</p> <p>Information is provided, including</p> <ul style="list-style-type: none"> • Reason for referral • Expectation/possible outcome/consent • Implications for other areas of life

A clear collaborative and specialist diagnostic process

We have the right to an early and accurate diagnosis

We have the right to receive evidence based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live

I know who my young onset dementia lead is and am kept updated about the diagnostic process

I'm offered the same support as older people who are going through the process of being diagnosed with dementia. For example, I might need a family member or close friend to attend appointments with me

If I'm supporting someone through diagnosis, I can speak to someone who understands my concerns and can answer questions I may have about what a dementia diagnosis at this age might mean for my family/friend

Making the diagnosis in specialist services

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

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 e.g. occupational therapy, speech and language therapy, social worker, physiotherapy and dieticians as necessary

The team should have the opportunities for multidisciplinary case discussion

- 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

Key elements of diagnostic assessment

- Thorough history taking
- Speaking to someone who knows the person well
- Neurological examination
- Blood screen for rare cause
- Neuroimaging
- Advanced cognitive assessment / neuropsychology
- Consider EEG, CSF analysis, genetic testing

Feeding back diagnosis

Diagnosis is given in a confidential setting and is delivered sensitively. There should be a 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

Enough time should be allocated in order to answer these questions

Depending on the persons' wishes, they will receive full feedback of the results of their assessment and an explanation about how the diagnosis was reached as a result and should be provided with prompt follow-up

Where a diagnosis is provided in a national or regional centre, there must be a clear 'exit plan' which links the person back into their local services

Introduction to Key worker

- Key worker works in collaboration with the diagnostic team and introductions can be made at the time of diagnosis or when appropriate for individual
- Clear information is provided about next steps and how they can be contacted
- Working together with clinicians to ensure a joined-up service

Also see 'Supporting Well' - NHS Well Pathway

Specialist support and information which meets our changing needs

We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future

I'm contacted by a Key worker who, if I choose, meets with me to discuss what dementia at my age will mean for me and my family. I have the opportunity to ask about the impact on my job, mortgage and/or other financial commitments, childcare and any other concerns I might have

I have the opportunity to learn more about my type of dementia, which because of my age, is more likely to be a rarer form

If I'm supporting someone with dementia, the Key worker also supports me

If I/we have children or young people living at home, the Key worker discussed family needs and relationships and can direct us to any support we need

A regular review with the person, their family, the clinical team and others involved in their care is established

The individual and family should have access to

- Information about the diagnosis
- Evidence based treatment and support e.g. pharmacological e.g. Cholinesterase inhibitors / and or memantine, adapted cognitive stimulation therapy, cognitive rehabilitation and counselling, relationship or family-centred work
- Information and advice about social recreational and age-appropriate meaningful activities and peer support
- Allied health professionals as indicated, including clinical psychologists, speech and language therapists and occupational therapists, who can offer specialised approaches
- Admiral nurses or specialist dementia nurses who can work intensively with families who are facing a difficulty managing the effects of the diagnosis

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

- Discuss life, achievements, abilities, relationships and aspirations pre and post-diagnosis
- Discuss preferred / usual ways of coping and their potential support needs
- Gain understanding of employment status, financial situation, care responsibilities and family circumstances
- Meet family members and support circle to understand their perspective and circumstances

Also see 'Living Well' - NHS Well Pathway

Living with young onset dementia

We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it

I work with my Key worker to prepare for what lies ahead. I am supported to plan my life and what I want for my future including the end of my life

They provide information about practical issues like financial and care planning, as well as helping me to talk about my condition with my children, family and employers

I know I can contact my Key worker and they can point me in the direction of other helpful services

I want to continue my social life, relationships and activities and hobbies. My Key worker helps me to adapt so I can keep doing the activities that I am interested in

I'm introduced to new activities and social contacts/groups that are more specific to dementia when the time is right for me

Regular contact with joint reviews with a core team including Key worker and Clinical team with access to specialist nurses, occupational therapy, clinical psychology, speech and language therapists and social work support as necessary

Review response to medication

Assess needs of the younger person and their family and support family members

Signpost the younger person to age-appropriate meaningful activities including those that enable the person to maintain identity and continue to make a contribution to society

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

- Outline needs, goals and aspirations and routes to achieving these
- Facilitate access to community services and opportunities, both dementia specific and otherwise
- 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 e.g. employment, mortgage and financial obligations and future financial planning
- Provides support for advanced care planning
- Provide advice and emotional support to family members and others closely involved in care
- Link to health and social services to ensure plans are aligned

Also see 'Living Well' - NHS Well Pathway

**Towards the
end of life**

We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future

I'm supported to think about and prepare for the end of my life, including talking about what I do and don't want

The support I get is tailored to me, depending if I live alone or with my family

The family and friends of the person with dementia are given information and support to help them to prepare for the end of life

Regular reviews are adopted as the person reaches the end of their life and support is tailored to provide

- Facilitate access to short term care that gives family members a break from caring (including day and residential care)
- Acute care is provided in dementia friendly wards which comply with John's Campaign so a family member can stay with the person during their stay
- Age-appropriate long-term residential care within a reasonable distance from home
- Support to stay in the home if this is what the person wants
- Age-appropriate palliative and end of life care
- Bereavement support for families and carers

Also see 'Dying Well' - NHS Well Pathway

Evidence for our recommendations

Current research is improving but remains behind best practice. The evidence base regarding needs of younger people with dementia and the needs of their families is better developed, although gaps remain. There remain significant gaps in understanding current prevalence rates for young onset dementia in the UK, the evaluation of services and interventions and their impact and cost effectiveness. Where there is recent research evidence, we have included it. Our recommendations in some cases are based upon what people affected by dementia tells us works as well as professional expertise.

Positive contact with my GP which reduces the time taken to receive the correct diagnosis

Dementia teams have become 'ageless services' in which staff may not often see people with young onset dementia and may feel unskilled. Many younger people with cognitive impairment are referred as a result of local policy with the Clinical Commissioning Group to adult mental health services who lack expertise in diagnosis of dementia (Rodda and Carter, 2015).

UK evidence and European evidence points to delays in diagnosis for young onset dementia compared to later onset dementia i.e. 4 years compared to 2 years (van Vliet et al, 2013) and lack of a clearly defined local referral pathway is one of the primary causes of delay in diagnosis (Harris et al, 2004).

National Institute for Health and Care Excellence/Social Care Institute of Excellence (NICE/SCIE). Dementia: supporting people with dementia and their carers in health and social care. (Clinical guideline CG42) 2006. <http://guidance.nice.org.uk/CG42>. See also NICE Dementia Guidelines 2018 and NICE Dementia Quality Standards 2019

Living with Young Onset Dementia and actively shaping dementia research through PPI - The Angela Project

Keith Oliver, Dr Mary O'Malley, Prof Jacqueline Parkes, Dr Vasileios Stamou, Dr Jenny LaFontaine, Prof Jan Oyeboode & Dr Janet Carter. (*Dementia*, 2020, 19 (1): 41-48) doi.org/10.1177/1471301219876414

A clear, collaborative and specialist diagnostic process

Young onset dementia has a vast differential diagnosis. It includes not only atypical dementias but also rare sporadic and hereditary diseases. There is clear evidence that younger people are frequently misdiagnosed with functional and other psychiatric conditions and/or are under-investigated for rare cause dementia.

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Memory Services National Accreditation Programme (MSNAP) (2020) Standards for Memory Services (7th Edition)

Feeding back the diagnosis

Health professionals can be reluctant to speak openly and honestly with patients and their families about dementia, with some refraining from using the 'D' word. Although initially discussing the diagnosis may be distressing, evidence suggests most people prefer to know if they have dementia in order to access appropriate support and treatment and to plan for the future. This matter of choice is established at the pre-assessment counselling stage.

Receiving a diagnosis of young onset dementia: evidence-based statements to inform best practice O'Malley M, Parkes J, Stamou V, LaFontaine J, Oyebode J, Carter J (2020). *Dementia* - in press)

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DoH (2009) 'National Dementia Strategy', see also Dementia Challenge 2020

Benefits of a timely diagnosis. Dementia Action Alliance report for primary care

Receiving a diagnosis of young onset dementia: a scoping review of lived experiences. O'Malley M, Stamou V, LaFontaine J, Oyebode J, Carter J, Parkes J. *Aging Ment Health.* 2019 Oct 24:1 - 12. doi: 10.1080/13607863.2019.1673699

Specialist support and information which meets our changing needs

The support needs of younger people with dementia are different from those of people who are older because their diagnosis is 'off time', their symptoms are more likely to reflect rarer dementias and their life stage differs. They are more likely to be physically active, have fewer co-morbidities, be employed, have responsibilities to children/young people or elderly parents, have more financial outgoings, and have a greater loss of future. Related needs are hard to meet through 'all age' dementia services. Only about 1 in 5 younger people with dementia in the UK receive specialist YOD services yet the quality indicators suggest people with YOD are best supported by specialist teams.

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Cost related to dementia in the young and the impact of aetiological subtype on cost. Nagaendran K, Wang V, Xuling L, Nyu M, Lim L, Ng A, Hameed S & Wee HW. (2015). *J Alz Dis* 49(2), 277-285

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This document was produced by the **Young Dementia Network Steering Group**, a collaboration of people and organisations. Details of our Steering Group membership can be found at www.youngdementiauk.org/network-steering-group. The document was originally produced in 2016, revised in 2018 and revised again in 2020.

We would welcome updates, comments and feedback – network@youngdementiauk.org