



Framework for a young onset dementia pathway for integrated care boards (ICBs)





Dementia UK is the specialist dementia nursing charity that is there for the whole family. Our nurses, known as Admiral Nurses, provide life-changing advice on all aspects of dementia. Dementia UK is a centre of expertise for young onset dementia, which includes increasing access to specialist and age-appropriate support and influencing health and social care policy improvements.

➔ dementiauk.org



The Young Dementia Network, hosted by Dementia UK, is an influencing community of over 6,000 members, including people with lived experience of dementia and professionals working in the field. Working collaboratively, the Network seeks to improve lives through campaigning, informing and involving people affected by the condition and increasing knowledge and expertise in professionals.

➔ youngdementianetwork.org

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Executive summary

This framework, developed by Dementia UK and the Young Dementia Network working with an Advisory Group of experts in young onset dementia, outlines best practices and standards for a young onset dementia pathway.

The framework aims to help integrated care boards (ICBs) in England address the unique needs of people with young onset dementia (where symptoms develop before the age of 65), who often face specific challenges including changes in family roles and relationships, employment issues and loss of social identity. The framework includes clear guidance on implementation and learning from others to outline best practice and how the standards can be met.

Key principles underpinning this framework

- **a comprehensive, integrated and collaborative pathway**
- **a person- and family-led approach**
- **timely, adaptive and coordinated care which challenges existing health inequalities**
- **cost-effective, ringfenced and sustainable funding**
- **high-quality research, statistics and evidence**

We recommend that all ICBs have:

- a **strategy** for young onset dementia
- a **care pathway** for young onset dementia
- a **named lead** for young onset dementia in the integrated care system (ICS)

The framework also supports ICBs to improve:

- reporting and assessing the prevalence of young onset dementia, including subtypes
- diagnosis, including rates, timeliness and accuracy
- lived experience involvement in the design and delivery of services
- funding allocation ringfenced for young onset dementia
- leadership, including a clinical and commissioner network for young onset dementia to ensure oversight



Outcomes of a young onset dementia framework



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Diagnosing

Equitable access to timely and accurate diagnosis through collaboration and multidisciplinary working. GPs to be aware of young onset dementia and appropriate local referral routes to specialist diagnostic services.



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Supporting

Personalised, age-appropriate care plans providing information, advice and support, with key workers assigned immediately after diagnosis. Ongoing reviews enabling continuity and adaptation and advance care planning are prioritised.



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Living

Comprehensive services, regular medication reviews and access to age-appropriate local respite and long-term care, ensuring the person and their family are supported in adapting to the progression of dementia whilst continuing to live their lives as fully as possible.



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Towards end of life

Early advance care planning, 24/7 access to end of life support and tailored palliative care, ensuring ongoing support for families after bereavement.

This comprehensive framework is designed to meet the unique needs of people with young onset dementia and their families across all stages of the condition.

It is at the local level that change can be progressed right now. ICBs have a crucial role to play by leading efforts to meet the needs of those residing in their area who are living with, or supporting a person with, young onset dementia.

We look forward to working with you to achieve this.

Forewords

“ My mum and dad first visited the GP in 2007 to discuss their concerns about the changes in Dad’s behaviour and abilities. But because Dad was young at 57 years of age, physically fit and didn’t fit the ‘traditional’ presentation of someone with dementia, our attempts to get doctors to listen to us – even as the changes in his behaviour and abilities became more pronounced – fell on deaf ears.

Dad was eventually given a diagnosis of mild cognitive impairment in 2015, and in 2016, was finally diagnosed with young onset Alzheimer’s disease. It had literally taken years, with appointments with the GP, psychiatrists, neurologists, the memory clinic, mental health nurses and more. None of these appointments gave us the clarity we sought or the help we needed.

Just one year later, we lost Dad to pneumonia associated with young onset Alzheimer’s disease.

Sadly, the route to diagnosis for people living with young onset dementia has got worse, not better, since Dad died. Families like ours are still left to cope on their own, fighting the system at every turn whilst living with a condition that affects every aspect of a person’s physical and psychological health.

Many people living with young onset dementia are still working, paying mortgages and bringing up children. They are essentially in the prime of their lives. And for these people and those who love them, dementia is devastating. The very least that we can give these families is a roadmap to finding the support and care they so desperately need.

Emma Crozier, Young Dementia Network Steering Group member and former carer for her father



“The very least that we can give these families is a roadmap to finding the support and care they so desperately need.”

“ My mum was diagnosed with young onset dementia when she was 55. Getting a diagnosis was a long, drawn-out process taking four and a half years. Post-diagnosis, we received little to no support, right up until she died at the age of 65.

A few months after my mum died, I was diagnosed with young onset dementia at the age of 46. I have been living with the diagnosis for approaching five years. Nothing had changed in the 10-year period between my mum being diagnosed and my own diagnosis. It still took years, and post-diagnostic care was just as poor.

Getting a young onset dementia diagnosis and post-diagnosis care was, and still is, a postcode lottery. As a member of the Advisory Group for the young onset dementia pathway, I have listened to so many experiences like mine. This framework has been drafted with these people in mind.

We believe that things can change, which is why we have undertaken this work. It is practical and realistic in its delivery and will mean a better quality of life for people living with young onset dementia. We hope that ICBs will put this young onset dementia pathway into practice, improving diagnosis rates and times, increasing post-diagnostic support, and relieving some of the anxieties and frustration families face.

Michael Booth, Young Dementia Network Steering Group member and member of the Advisory Group. Michael cared for his mother with young onset dementia and lives with the condition himself



“We hope that ICBs will put this young onset dementia pathway into practice, improving diagnosis rates and times, increasing post-diagnostic support, and relieving some of the anxieties and frustration families face.”

Introduction

Around one million people in the UK currently live with dementia. People with young onset dementia make up a distinct and often hidden population within this number. They have specific concerns and needs which go largely unmet, such as barriers to diagnosis, changes in family roles and relationships, employment worries and loss of social identity.

This framework is a collaboration between Dementia UK and the Young Dementia Network which sets out best practice for ICBs in England to meet this population's needs.

An Advisory Group of experts guided the creation of the framework. This group included national and local expertise from lived experience, primary care, neurology, psychiatry, commissioning, service planning, research and specialist voluntary sector provision.

This framework draws on existing research and resources, including The Angela Project – the largest study of young onset dementia carried out in the UK – and the Young Dementia Network's evidence-based young onset dementia pathway .

About young onset dementia

Dementia is a progressive and terminal condition that involves a degeneration of the brain. It causes ongoing decline in a person's ability to think, reason, communicate and remember. A person's personality, behaviour and mood can also be affected. However, everyone's experience of dementia is unique, and the progression of the condition varies.

Dementia is described as 'young onset' when symptoms develop before the age of 65, usually between 30 and 65 years of age.

As dementia is frequently and incorrectly thought of as a condition of old age, the early symptoms of young onset dementia are often unrecognised, and instead attributed to other causes including depression, stress, menopause, physical health problems and relationship issues. This can lead to it taking an average of over four years to get an accurate diagnosis and access to appropriate support. This delay can significantly impact the life of the person with dementia and their whole family, including children.

Young onset and older age dementia – the key differences



People with young onset dementia are more likely to have a rarer form of dementia than older people.



Dementia affecting the frontal and temporal lobes of the brain is more common in younger people. Early symptoms may include changes in behaviour, language, social functions, mood, concentration, decision-making and visual and spatial awareness.



In the early stages, young onset dementia often presents with different symptoms from the memory loss typically associated with the condition.



Genetic forms of dementia are more common in people under the age of 65, and it is thought that genetic mutations account for around 12% of all cases of young onset dementia.

Younger people with dementia are also more likely to:

- experience employment issues
- have significant financial commitments such as a mortgage
- have a younger and more dependent family
- have additional caring responsibility for parents
- report significantly higher psychological and physical distress

Sub-types within young onset dementia

The most common forms of young onset dementia include:

- **Alzheimer's disease**
- **vascular dementia**
- **frontotemporal dementia**
- **dementia with Lewy bodies**
- **posterior cortical atrophy**
- **other rarer types of dementia**

Around 20% of younger people with dementia have a 'rarer' form of the condition. Examples include conditions that can lead to dementia including Parkinson's, Huntington's disease and Korsakoff's syndrome (most commonly associated with alcohol abuse).

Key statistics



The population of people affected by young onset dementia is growing

60,000 people are estimated to be living with young onset dementia in England.¹

Only 55% of these people have a formal diagnosis of dementia; around 27,000 are undiagnosed.²

By 2040 it is predicted that this population will grow to 85,500, as the overall population of people living with dementia increases to 1.4 million.³



Diagnosis is significantly harder to obtain for those with young onset dementia

It takes an average of 4.4 years for younger people to get a diagnosis, compared to 2.2 years for over-65s.⁴

30-50% of young onset dementia cases are misdiagnosed due to GPs misattributing symptoms to other conditions.⁵

Only around half (53%) of memory services have a lead for young onset dementia.⁶

For the majority of people, it takes five consultations before an accurate diagnosis is made.⁷



People cannot access the care they need

42% of people with young onset dementia receive no support from services in the first six weeks after diagnosis.⁸

The undiagnosed rate is 45% for young onset dementia, meaning that a large cohort of people will be unable to access care and services that a diagnosis would provide.

Why does young onset dementia need a unique pathway?

The current health and social care system does not systematically plan for the specific needs of people with young onset dementia. Instead, young onset dementia usually sits within Older Age Mental Health Services, but this is not a good fit for health systems or for the person with dementia and their family. There are no mandated expectations or targets in terms of provision and standards, and typically no funding dedicated to young onset dementia.

Furthermore, the national dementia diagnosis rate and other key targets do not include under-65-year-olds, making quality provision, practice and reporting on young onset dementia less of a priority. Addressing this is critical to ensuring earlier recognition, timely and accurate diagnosis and appropriate support.

In some areas, memory services, which are responsible for specialist assessments and diagnostic testing, do not accept people under the age of 65. Commonly used diagnostic tests often focus on memory issues, which are less likely to affect people with young onset dementia. Misdiagnosis is common.

Even when a person with young onset dementia is correctly diagnosed, they often experience challenges when trying to access support. Too often, post-diagnostic support is either unavailable or designed for older people and unsuitable for younger people and their families, causing additional stress.

People with young onset dementia may be in work and/or have dependants. Consequently, they and their family members often have specific needs which are currently not being consistently met.

People affected by young onset dementia need:

- specialist information
- helpline access
- employment support
- counselling
- age-appropriate advice and activities to maintain independence
- peer support groups
- carer support
- resources for children and family members

A young onset dementia framework for ICBs

Our ambition for young onset dementia

We want GPs and other health and social care professionals to:

- have an increased understanding of young onset dementia
- recognise the symptoms of dementia in younger people
- refer to memory and neurological services for a timely and accurate diagnosis

Following a diagnosis, we want to see:

- tailored dementia information and specialist support in place for the individual and their family
- people supported to adapt and live as fully as possible
- age-appropriate services and support available to serve the needs of those with young onset dementia

Underpinning principles

Developed in collaboration with people with lived and professional expertise, the following principles underpin this framework:

- a comprehensive, integrated and collaborative pathway, with no gaps, working across health and social care and the voluntary sector
- a person- and family-led approach which ensures continuity of relationships, and values and embeds lived experience
- timely, adaptive and coordinated care regardless of geography and/or demographics, which challenges existing health inequalities
- cost-effective, ringfenced and sustainable funding
- high-quality research, statistics and evidence for evaluation, benchmarking and effective delivery

Young onset dementia pathway

Diagnosing

Person goes to their GP

Within 12 weeks of presentation to GP: pre-diagnostic tests are completed; if other causes of symptoms are ruled out referral is made to specialist

Within 6 weeks of referral: initial assessment is completed

Within 18 weeks of referral: person is given diagnosis, including subtype

Supporting

Person now has a dementia diagnosis

Within 2 weeks: contact made by key worker; both person and family offered support

Within 6 weeks: create and initiate bespoke care plan

Follow-up at 6 weeks

Within 12 weeks: signposting to relevant services for the individual and family

Within 12 weeks: ongoing support is initiated by Children's and Young People's Mental Health Services if the person has dependants

Follow-up at 12 weeks

12 weeks: discussions about advanced care and end of life planning if appropriate; with follow up reviews twice a year

Twice a year: Care reviews with key worker bi annually, or when needed

Living

Person is living with dementia

Key worker continues to work closely the person, their family and wider health and social teams to ensure comprehensive support

1 year: medication is reviewed when optimal dose is reached, then on a bi-annual basis

If the person or family requests a medication review, this is completed in 4 weeks

Age-appropriate services and respite care are available

End of life

Person with dementia is reaching end of life

Access is available to 24/7 support and advance care planning/coordinated approach

Local respite and palliative care are available and accessible, with needs regularly reviewed

Key worker continues contact at home or in hospice; health and social care professionals work with family to utilise

ReSPECT documents

Following bereavement: key worker maintains contact, guides family to counselling and support

Overarching standards for ICBs

Goals	Explanation	Target for delivery
A young onset dementia strategy	<p>All ICBs should have a young onset dementia strategy in place. As part of establishing the strategy, the ICB should seek to establish existing provisions and conduct a population assessment.</p> <p>Where a dementia strategy is in place, young onset dementia should be explicitly included.</p>	Agreed and in place within a year.
A young onset dementia care pathway	<p>All ICBs should establish a young onset dementia pathway which includes:</p> <ul style="list-style-type: none"> • a clear referral route for specialist diagnosis • immediate post-diagnostic support and coordinated care plans • supported transitions between primary care, assessment services and post-diagnostic and end of life services 	Once a young onset dementia strategy is in place, and a review of existing provision and population assessment has been completed, a care pathway should be established within a year.
A young onset dementia named lead	All ICBs should identify a named lead with oversight of young onset dementia, alongside a designated clinical lead.	Agreed and in place within the first year of establishing a young onset dementia strategy.

The tables in this section lay out overarching standards that all ICBs should aim for across dementia care. The following sections of this document contain recommendations for implementing these standards across each stage of the dementia journey: diagnosing, supporting, living and end of life. Recommendations are summarised in a table at the start of each section, along with target times for delivery from the point of which the ICB establishes or renews a strategy for young onset dementia.

A young onset dementia framework for ICBs

Goals	Explanation	Target for delivery
Improved reporting	The prevalence of young onset dementia, including subtype, should be assessed and reported within local needs assessments to enable planning and delivery that meets local health needs.	In line with annual Joint Strategic Needs Assessment processes. Comprehensive prevalence and types of young onset dementia to be included in local data dashboards, within six months of establishing reporting.
Improved diagnosis	The ICB should work to improve timeliness, accuracy and rate of diagnosis with appropriate benchmarks in place.	Measured and reported annually to the ICB.
Inclusion of lived experience	The ICB should actively support the involvement of those affected by young onset dementia and their families in the design and review of services through the establishment of a young onset dementia user forum.	Quarterly meetings of young onset dementia user forums, organised by the ICB.
A young onset dementia clinical and commissioner network	The ICB should establish a young onset dementia clinical and commissioner network to coordinate care, assess provision, embed relationships between clinical and social care and upskill professionals.	Set up within the first year of having a young onset dementia strategy in place, with quarterly meetings of the network ongoing.
Improved funding	The ICB should allocate ringfenced funding for young onset dementia.	To be agreed within annual budget cycles.



Outcomes



Diagnosing

Equitable access for the person and their family to a timely and accurate diagnosis, enabled by primary care and diagnostic services working in collaboration.

Goal and description

Individual pathway

Target for delivery

Care pathway

Initial investigation

After initial GP consultation for dementia symptoms under the age of 65, tests for other possible causes should be completed within three months, and referral to specialist services initiated.

Within 12 weeks of the person initiating contact with the GP, investigations should be complete, and referral made.

Within a year.
Strategy to include training to ensure GPs' awareness of symptoms.

Referral to specialist

Specialist diagnostic services should see individuals promptly within six weeks of GP referral. Ensure local memory services do not exclude those under the age of 65.

Within six weeks of referral, person should be seen by specialist. Within 18 weeks, diagnosis is made.

Within a year.

Reporting

Diagnostic reporting

Coding of diagnosis/dementia subtype and age should be accurately and consistently communicated, recorded and reported.

N/A

Established within six months of the care pathway implementation.
Measured through an annual audit of GP patient and diagnostic service records.

Leadership

Multidisciplinary oversight

A multidisciplinary team should be in place consisting of:

- a clinical lead for young onset dementia
- at least two other professionals, such as an Admiral Nurse with specialist knowledge of dementia
- access to a range of other professionals covering a range of disciplines where necessary

Cases reviewed according to need, on an ongoing basis.

Established within six months of implementation of care pathway. GPs and primary care professionals are made aware of the team and how to contact them for support when people with suspected young onset dementia make contact and throughout diagnosis.

Implementation guidance

Diagnosis and referral within primary care

The following process can be put in place to help GPs become more aware of young onset dementia and appropriate local referral routes to specialist diagnostic services; and more knowledgeable about young onset dementia and the variety of symptoms it can present, which may differ from those in people with later onset dementia.

- GPs receive training on young onset dementia and have a lower threshold for referral of younger people suspected to have cognitive impairment
- Where young onset dementia symptoms are suspected, GPs listen to the person and family members and make a thorough assessment of symptoms including baseline investigations, physical examination, assessment of activities of daily living and a brief cognitive assessment
- GPs exclude any potentially treatable illnesses or reversible causes of cognitive impairment
- GPs ensure they are aware of the young onset dementia lead in the diagnostic services for their area
- Information is provided in writing to the individual, including reason for referral, expectation/possible outcome and implications for other areas of life
- Primary care coding of dementia type is accurately recorded and reported once diagnosis is confirmed

A collaborative diagnostic process via specialist services

1. Specialist diagnostic services should ensure:

- There is a designated expert young onset dementia lead
- Pre-assessment counselling and pre-diagnosis support are routinely provided
- Clinicians based in memory clinics, neurology or other diagnostic services are knowledgeable and skilled regarding young onset dementia and the impact the diagnosis can have on the person diagnosed, their children and wider family
- Clinicians based in diagnostic services have access to the full range of in-depth assessments, investigations and personnel necessary to make

A young onset dementia framework for ICBs

a diagnosis; and provide ongoing support as required for young onset dementia and/or complex presentations

- Comprehensive assessment is performed by a multidisciplinary team of professionals with specialist advice taken when interpreting investigations and scans

2. Key elements of a diagnostic assessment

- Access to a specialist with expertise in the diagnosis of young onset and rarer dementias to improve standards of assessment and diagnostic accuracy
- Thorough history-taking
- Speaking to someone who knows the person well, for example a family member
- Neurological examination
- Blood screening for rarer causes
- Neuroimaging
- Advanced cognitive assessment/neuropsychology
- Consider electroencephalography (EEG), cerebrospinal fluid (CSF) analysis, genetic testing



3. How to communicate the diagnosis

- The diagnosis should be given in a quiet, private setting, and delivered sensitively, verbally and in writing, with enough time available for questions
- There should be recognition that the person with young onset dementia may still be working, have dependants including children, and have other responsibilities. The person and their family should be signposted to relevant personalised support and advice including around employment and managing the impact on dependants
- Depending on the person's wishes, they should receive full feedback of the results of their assessment and diagnosis
- Following diagnosis, there should be a prompt follow-up to ensure the person and their family have access to post-diagnostic support
- Where a diagnosis is provided in a national or regional centre, there should be a clear transition plan which links the person and family back into their local services
- Following diagnosis, the individual and wider family should be able to access post-diagnostic support by being linked with a key worker. This is outlined in greater detail in the following section, 'Supporting' (p24)



Learning from others

On collaboration: joint working between neurology and psychiatry

There is a monthly joint clinic between psychiatry-led Leeds Young People with Dementia Service and the Leeds Neurology Cognitive Service. Working together on patient assessments achieves accurate, timely diagnoses and facilitates access to imaging and neuropsychology and appropriate referrals to the genetic clinic. The shared care reviews then help assign optimum pathways and support where there are diagnostic challenges such as dementia and another pre-existing condition.

This collaborative approach to diagnosis and treatment benefits from the real-time expertise of the psychiatrist, neurologist and psychologist, thereby reducing delays, especially where there are difficulties in diagnosing and in interpreting biomarkers and genetics. It also helps with symptom management and access to post-diagnostic support. This joint working increases confidence levels and knowledge, increases learning and professional development and helps integrate the services.

Dr Rumana Chowdhury, Consultant Neurologist, Leeds Teaching Hospitals NHS Trust, and Dr Zumer Jawaid, Consultant Psychiatrist, St Mary's Hospital Leeds, Leeds and York Partnership NHS Foundation Trust

On accurate coding and improving diagnosis rates

Wokingham Memory Service, having confirmed a diagnosis of a type of young onset dementia, clearly advises GPs, using a template letter, of the diagnostic code to use. The letter states the diagnosis, the ICD10 code and corresponding SNOMED code. This guides the primary care staff inputting the detail and maintains consistency and accuracy when coding, which means the patients are added correctly to the Quality Outcomes Framework (QOF) register.

Then annually, Berkshire NHS Trust shares a list of NHS numbers of all people diagnosed with young onset dementia within each local GP practice to check for and resolve missing data.

It is now everyday practice and means that each person has their correct diagnosis recorded which informs appropriate care.

Dr Jacqui Hussey, Consultant Old Age Psychiatrist, Deputy chair for Young People with Dementia, Wokingham Older People's Mental Health Service, Berkshire NHS Trust

Outcomes



Supporting

Immediate and continuing access to personalised and age-appropriate information, advice and support for the person with young onset dementia and their family, enabling them to adapt to the diagnosis.

Goal

Individual pathway

Target for delivery

Care pathway

Introduction of a key worker

The person with young onset dementia and their family should be introduced to a key worker at the time of diagnosis and a follow-up appointment should be initiated.

Contact made within two weeks of specialist diagnosis, with first follow-up within six weeks of first meeting.

Within a year of pathway establishment.

Individual care planning

The key worker, the person with dementia and their family should work together to create a bespoke care plan guided by the person’s needs and choices. Discussions on advance care and end of life planning should be initiated sensitively early after diagnosis in line with the person and family’s choice.

Initiation of the care plan occurs at the first contact with key worker, and if it is declined, is reoffered within six weeks. End of life care planning is offered within 12 weeks of diagnosis; revisit within a year as needed.

Within a year of pathway establishment.

Care reviews

Care reviews with the key worker should be scheduled regularly to offer access to information, advice and support. The frequency of reviews should respond to the needs and choices of the person and their family.

Contact to review is made six weeks following diagnosis, then at 12 weeks, and again at six months. After these initial contacts, contact is made at least twice a year.

Within a year of pathway establishment.

Clinical and commissioner network

Integrated support from local services

The key worker should contact local Children and Young People’s Mental Health Teams. These teams should understand the impact on children and young people of having a parent or family member with young onset dementia and engage wider support, including from schools and community groups.

Children and families are connected to support within 12 weeks of specialist diagnosis.

Ongoing, with regular multi-disciplinary meetings to ensure coordinated wraparound care.

Implementation guidance

Who is a key worker?

In the framework recommendations, we regularly refer to a ‘key worker’. By this we mean a trained professional with expertise in young onset dementia, sometimes referred to as a Dementia Specialist Practitioner, a Dementia Navigator or Case Manager. The exact nature of who fulfils this role will vary depending on the service provision available in each locality, but may include an Admiral Nurse.

The key worker may be clinical or non-clinical but should enable the person with young onset dementia to understand their condition and actively engage in their care plan and journey. There should also be a ‘step up’ approach that ensures the key worker has access to a dementia specialist, such as an Admiral Nurse, to support in cases of complexity.

Equipped with specialist knowledge of young onset dementia, an understanding of rarer forms of dementia, and knowledge of local and national young onset dementia service provision, the key worker’s responsibility is to provide support and continuity of care from the point of diagnosis. They act as a liaison between clinical services and the person’s community and as a coordinator of services, organisations and people, helping to connect the person with young onset dementia and their family members to local groups, networks and support services.

Key workers can be hosted in, or provided by, a variety of settings depending on local infrastructure and funding arrangements, such as primary care, voluntary sector partners, local mental health teams, memory assessment services or neurology services.

Introduction of the key worker into the person’s post-diagnostic care

- Contact with a key worker should occur within two weeks of the specialist assessment and diagnosis, or at a mutually appropriate point for the person and their family
- Clear information should be provided about the next steps and how the key worker can be contacted
- The key worker should provide information and practical and emotional support, and connect the person and their family to others affected by young onset dementia for mutual support

- Discussions about advance care and end of life planning should be prompted within 12 weeks of diagnosis. In cases where this timescale is not appropriate, it should be revisited within a year. The key worker should also develop a regularly reviewed plan tailored to meet the person and their family's needs and wishes. This should include the **Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)** document (which is a minimum standard), a care plan and an advance statement if they wish
- If the person with dementia opts out of receiving support, their family should still be offered access to support
- Outside key worker working hours, it is important that the person and their family have access to support via a helpline such as the Dementia UK Helpline, or, in case of emergencies, Adult Social Care Services

Delivering regular multi-disciplined wraparound care reviews

Following diagnosis, a shared care plan should be agreed and regularly reviewed by a GP, or other specialist dementia practitioner with input from a GP. The care plan should ensure that the person and their family are linked into local support services. This is especially important when a diagnosis is given in a regional or national centre.

As part of ongoing wraparound care, the person and their family should have access to:

- dementia specialist Admiral Nurses
- pharmacological therapies
- clinical psychologists
- cognitive stimulation therapy (CST)
- speech and language therapists
- cognitive rehabilitation and counselling
- occupational therapists
- relationship/family-led support
- peer support
- social/recreational interests and age-appropriate activities

Providing structured appropriate activities, programmes and interventions

- The person should be signposted to structured activities such as vocational rehabilitation, employment support and workplace adjustments
- People who have participated in group CST should have access to an age-appropriate maintenance CST programme
- An audit should be carried out of the diagnoses of people who are offered and participating in psychosocial interventions and support groups in order to monitor uptake, outcomes and appropriateness of the support provision



Learning from others

On tailored and personalised care inclusive of the person and their family



Dementia Oxfordshire is a service provided by Age UK Oxfordshire that supports people with young onset and late onset dementia. The Young Onset Dementia Team includes three Young Onset Dementia Advisers (YODAs) and an Admiral Nurse. It encourages early referrals post-diagnosis for effective support, prioritising fast and early contact.

Each person with young onset dementia and their family is allocated a named YODA who makes contact within two weeks to arrange an initial assessment. The next steps are informed by the person's response to the diagnosis and the introduction of the YODA.

Home visits, other venues or video calls are offered, according to the person and their family's preference. Support is offered with issues such as work-related concerns, symptoms and changes in behaviour, and is tailored to the person and their family.

The YODA regularly contacts the person and their family, involving other professionals as needed. Reviews occur every six months, but contact frequency is individually tailored, with families able to reach out at any time.

A range of support is offered:

- individual support for the person with dementia
- support for family members/carers
- joint support for both
- group support for both

YODAs can refer people with complex needs to the Admiral Nurse for advice or direct support, including joint home visits. The service offers continuous support until end of life or transition to residential care, with some families receiving support for up to six months after.

Fran Mada, Admiral Nurse at Dementia Oxfordshire

Outcomes



Living

A well coordinated and comprehensive range of support, advice and signposting that enables the person with young onset dementia and their family to adapt to and plan for dementia progression whilst continuing to participate in family, social and community life.

Goal and description

Individual pathway

Target for delivery

Care pathway

Ongoing wraparound care

Key workers should work closely and collaboratively with clinicians, Social Services and third sector organisations to provide a personalised and comprehensive service.

Accessible when needed, with age-appropriate services, able to meet changing needs.

Ongoing, with regular multidisciplinary meetings to ensure coordinated wraparound care.

Medication reviews

Medication reviews should occur regularly according to local protocol and be conducted by a specialist clinician within a memory service or neurology team. If the person or their family are concerned about prescribed medication, they can contact their key worker to request additional or more regular review.

Following the optimal medication dose being found, review at least twice a year, according to local protocol. Where requested, a review should occur within four weeks.

Within a year of adopting a young onset dementia strategy.

Access to care support

The person and their family should have access to local respite and long-term care, either residential or at home, based on their wishes.

As required.

Targets for appropriate care set in the young onset dementia strategy.

Strategy

Training for acute settings

Both general and mental health acute settings should recognise and care for people with young onset dementia, providing wards compliant with John's Campaign for family support.

N/A

Ongoing training is available. Where possible a specialist dementia nurse, such as an Admiral Nurse, is available in acute settings.

Clinical and commissioning network

Professional networks are established

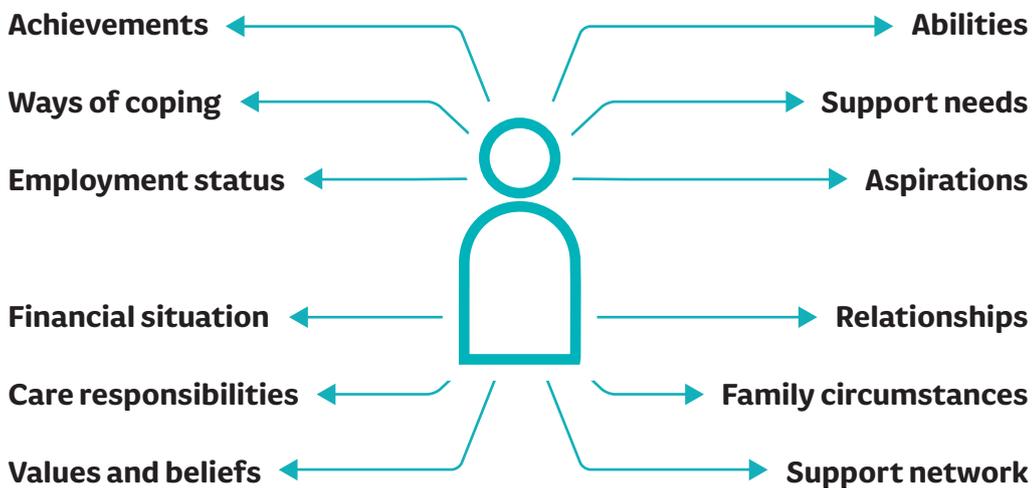
Trusts should be aware of the clinical and commissioning network (as outlined in the 'Overarching standards' section on p16).

N/A

Within a year of adopting a young onset dementia strategy.

Implementation guidance

The key worker should form a well-rounded understanding of the person, including:



Regular contact and joint reviews with a core team

- The key worker, primary care provider, clinicians, dementia specialist nurse, such as an Admiral Nurse, Social Services and voluntary organisations should work closely together to provide a comprehensive, joined-up service for the person and their family, ensuring care plans are coordinated and aligned
- The key worker and clinical team should be able to access specialist dementia nurses, occupational therapy, clinical psychology, speech and language therapists and social workers for additional specialist support as required
- The clinical team should review response to medication, usually when the dose is optimised (typically at two to four months). The key worker should liaise with the clinical team if a medication review is requested by the person or family
- The key worker and broader multidisciplinary team should work with the person and their family members to assess their changing needs and tailor care accordingly

Collaboration with the person with young onset dementia and their family to tailor and review a plan which is appropriate for their stage in life

- Following first contact, ongoing contact with a key worker should be arranged for six weeks, then 12 weeks and then six months. After these initial contacts, contact should be made at least twice a year. However, the individual and their family should be informed that they can request more regular contact if they wish
- Through regular review, the key worker should support the person and their family to continue to outline their needs, goals and aspirations, and routes to achieving these
- As required, the key worker should continue to act as a liaison point for the person and their family, providing and facilitating access to specialist advice, information and support about young onset dementia-specific needs such as how to manage or leave employment, financial management, future planning and end of life issues
- As soon as appropriate, the key worker should provide support for advance care planning
- Throughout the key worker's ongoing contact with the person, it is important that they continue to provide advice and emotional support to family members and others closely involved in the person's care
- The key worker should also continue to work with the person and their family to facilitate access to community services and opportunities, both dementia-specific and otherwise, as well as age-appropriate and meaningful activities, which can be accessed around the person and their family's work-life balance and caring needs. This helps the person and their family to maintain their identity, remain engaged in their community, and retain and develop relationships and social connectedness
- Where care needs arise and intensify, the key worker should facilitate access to age-appropriate and local short- and long-term care based in the person's own home or in residential care, depending on the needs and wishes of the person and their family

Learning from others

On age-appropriate and person-led care

“ When a person with young onset dementia (pre- or post-diagnosis) is referred to Dementia Forward, a dementia charity working in York and North Yorkshire, they are put in touch with a named Dementia Support Advisor (DSA) who will offer a home visit to provide bespoke advice and information.

The DSA has specific training in young onset dementia and can answer questions and help the person identify the support they need. This may include forward planning, signposting to appropriate legal and financial advice, emotional and practical support, and guidance on activities they may be interested in pursuing.

These activities may include our ground-breaking Time Out Together service: a weekly outward-bound group, where people can make friends, keep active and enjoy peer support, while carers benefit from respite time. We also hold regular events across the county to encourage social connection.

Along with our direct support, Dementia Forward is working to improve services for people with dementia by providing training and education to businesses, community groups and care services, and working in partnership, where possible, to improve provision. We are also developing relationships with community groups and businesses to increase and improve opportunities for people to work, volunteer or take part in activities in their local area.

In 2022, Dementia Forward launched national Young Onset Dementia Awareness Day, which now takes place every year on 24th October

**Karen Thomas, Head of Young Onset Services,
Dementia Forward, North Yorkshire**

➔ dementiaforward.org.uk



Outcomes

Towards end of life



Advance care planning is considered early and reviewed regularly, enabling end of life care to be tailored to meet the needs and wishes of the person with young onset dementia with dignity and respect. Family members are supported throughout this final life stage and bereavement support is available.

Goal and description	Individual pathway	Target for delivery
<p>Care pathway</p> <p>Advance care planning A well planned and coordinated approach should be adopted in the final stage of a person's life which takes into account their needs and wishes, including those expressed in the advance care plan.</p>	Near the end of life stage.	Targets to be outlined in ICB young onset dementia strategy.
<p>End of life support Once a person is identified as approaching the end of their life, they and their family should be able to access support 24 hours a day, seven days a week.</p>	Information to be provided when the end of life pathway is initiated.	Within a year of adopting a young onset pathway and in line with ICB targets.
<p>Respite and palliative care Tailored and appropriate respite, palliative and end of life care should be available for the person and their family as locally as possible.</p>	Reviewed regularly during the end of life stage.	Targets for provision to be outlined in ICB young onset dementia strategy.
<p>Continued support The key worker maintains contact with the person and their family, whether they are cared for at home or in residential, hospital or hospice care.</p>	Throughout the end of life stage.	Within a year of establishing young onset care pathway.
<p>Post-bereavement support The key worker should maintain contact and provide advice to bereaved families, guiding them to post-bereavement support and counselling.</p>	Post-bereavement.	Within a year of establishing a young onset dementia pathway.

Strategy

Ensure that health and social care professionals utilise the ReSPECT document and process for people with young onset dementia.	N/A	Professional training outlined in young onset dementia strategy.
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Implementation guidance

End of life reviews

Regular reviews should be adopted as the person moves towards the end of their life and support is needed. This should include:

- The key worker supporting the coordination of care between health and social care practitioners within and across different services and organisations
- The key worker maintaining contact with the person and their family within their setting, whether that is at home, in residential care, in hospital or in a hospice. The key worker liaises with the family and care or residential team

Settings for end of life care

- Acute settings should offer dementia-inclusive wards which comply with John's Campaign so a family member can be with the person during their admission and stay
- The person and their family should have access to age-appropriate long-term residential care within a reasonable distance of home
- Where possible, the person should be supported to stay in their home if this is what they and family want
- The person and their family should have access to age-appropriate palliative, hospice and end of life care

Bereavement support

Family members, including children, parents and carers, should have access to signposted and easily accessible bereavement support.

Learning from others

On local, tailored palliative care which adapts to meet the needs of the person with young onset dementia and their family at every stage



As a person with young onset dementia moves towards the end of life stage, the Admiral Nurse tailors support and care accordingly. For instance, as their physical condition worsens and they become less agile, the nurse may advise that they move downstairs within the home to make care more comfortable.

As the person approaches this stage a referral can be made to the local hospice service. The Admiral Nurse liaises with the hospice nursing team to carry out joint visits to ensure that the person's end of life symptoms are well managed and that family members, including children, are supported in the best, most tailored way possible.

Through long-term involvement, the Admiral Nurse offers personalised support to the person with dementia and their family and supports care coordination.

Following the death of the person with dementia, the Admiral Nurse pays the family several further home visits to offer more support and signpost to appropriate post-bereavement services.

Fiona Chaabane, Clinical Nurse Specialist in Younger Onset Dementia and Huntington's Disease and Consultant Admiral Nurse, Wessex Neurological Centre, Southampton General Hospital

Evaluating the impact of implementing a young onset dementia pathway

We recommend that ICBs design and embed an evaluation plan as part of implementing a young onset dementia pathway.

ICBs will have existing processes to evaluate their work; however, they may wish to consider the following points when designing and conducting evaluation.

Co-production in evaluation

It is valuable to include people with lived experience in choosing outcome measures during the design and delivery of evaluation.

The Dementia Engagement and Empowerment Project (DEEP) has produced guidance on accessible communication with people living with dementia: guidance.dementivoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf

Suggested metrics for measuring impact

To gain the greatest understanding of impact, evaluation of a framework should incorporate outcome measures that are inclusive of people with young onset dementia, their families and carers, as well as health and social care professionals.



Diagnosing

- diagnosis rate for people under 65 including their type of dementia
- time taken to receive an accurate diagnosis
- number of primary care appointments before referral to specialists
- number of consultations with specialists before accurate diagnosis
- extent to which the person with young onset dementia and their family feel supported and informed throughout the process



Supporting

- wellbeing and quality of life measures
- reported level of self-efficacy
- care plan review frequency and satisfaction levels
- extent to which the person with dementia and their family feel supported and informed throughout the process
- number of crisis/emergency hospital admissions related to dementia



Living

- reported level of social connectedness to others
- reported level of confidence in health and social care professionals
- reported level of fulfilment



End of life

- a measure related to feedback from the person with dementia and family carers
- a measure related to observation of the person with dementia
- advance care planning satisfaction and understanding
- reported level of satisfaction from family members regarding end of life care

Further resources for evaluation

As the person's dementia advances, it may be necessary to look for alternative ways to enable them to express feedback. An example of this can be found via the EMBED-Care study, which collected data in a variety of settings, such as people's own homes and residential cares, or in hospitals.

➤ onlinelibrary.wiley.com/doi/10.1002/gps.5251

An example of co-produced evaluation can be found here:

➤ academic.oup.com/ageing/article/49/4/664/5739151

Further information on co-production can be found at

➤ scie.org.uk/co-production/what-how/

Sharing learnings

To share any learnings from your evaluation please get in touch with Dementia UK and the Young Dementia Network at

➤ youngdementianetwork@dementiauk.org



Further reading, acknowledgements and references

The cost of inaction

On local health and care systems

Dementia is the leading cause of death in the UK⁹ with inadequate care structures exacerbating the considerable economic impact of the condition on local health and care systems. The combined cost of healthcare, social care and unpaid care along with quality of life and the economic losses of dementia totalled an estimated £42bn in the UK in 2024, projected to rise to £90bn by 2040.¹⁰ The impact of young onset dementia is a disproportionately high yet underreported and hidden cost within this.

Per person, the average annual cost of dementia is £28,700 for mild, £42,900 for moderate, and £80,500 for severe dementia. Unpaid care constitutes 50% of the estimated cost, impacting on the economic productivity of local populations.¹¹

After unpaid care, the second largest cost associated with dementia is social care. For those classed as having severe dementia, this cost is three times higher than for those with mild dementia.

Young onset dementia often incurs higher costs compared to older age dementia due to increased complexity; current convoluted pathways to diagnosis; a lack of specialist pathways; and specialist residential care needs.

People with young onset dementia and their families who lack appropriate post-diagnostic support and respite will find it harder to be economically productive for as long as possible and are likely to experience more crises and higher emergency service use. Emergency hospital admissions for people with dementia rose by 35% in the decade up to 2019.¹²

Further reading, acknowledgements and references

Poorly designed or non-existent young onset dementia services also affect local health and social care staff. Staff report ‘moral distress’, believing systems force them to make unethical decisions such as referring people to services they know are inappropriate. Systemic and structural inefficiencies are also particularly acute in young onset dementia, a condition perceived by staff to have greater complexity.

Conversely, specialist young onset dementia services perform better than their non-specialist counterparts on quality indicators. This includes support provision in the period following diagnosis; service continuity; and key workers.

On families

The financial costs of dementia are largely borne by individuals and their families in local populations, beyond just unpaid care. They make up 63% of the total cost of dementia.¹³ As with the overall cost of dementia, these costs increase with severity, from £9,700 annually for mild cases to £32,300 for severe cases.¹⁴ Young onset dementia can have a faster progression and complexity than dementia in older age, and is likely to incur higher care costs.

Unpaid carers often find themselves struggling to manage work, family responsibilities, caring responsibilities and their own health. As young onset dementia affects families of working age, additional challenges – such as providing ‘sandwich care’ for both the person with dementia and other dependants – may lead to physical and mental health problems.¹⁵ Family members may also find themselves reducing work hours or leaving their jobs, whilst managing mortgages, household debts and education costs. This can lead to financial hardship, with some struggling to pay bills and save for retirement.

Roles such as parenting or financial provision change, causing stress and carer burnout. Relational challenges, family conflicts, employment and financial issues and diagnostic hurdles also often lead to higher rates of relationship breakdown and divorce. Children of parents with young onset dementia often face psychological impacts and educational challenges, such as tiredness, concentration issues and bullying, affecting their long-term educational and career prospects.

By 2040, there will be a 43% increase in the number of people reliant on unpaid care for dementia.¹⁶ There is a desperate need for comprehensive post-diagnostic support for the entire family.

National policy context

This framework should not be taken in isolation, and draws from, complements, and fills a gap within guidance such as the NHS RightCare scenario, NICE quality standards and dementia strategy toolkits such as the Dementia 100 toolkit.

Exclusion from national datasets

An estimated 70,800 people in the UK, including 60,000 in England, live with young onset dementia. This is expected to rise to at least 85,500 by 2040.¹⁷ However, there is currently no national framework for tailored support, and national diagnosis rates and targets exclude those aged under 65. Enhanced diagnosis data collection at a local level is therefore vital to improve healthcare planning.

NHS 10-year plan for England

The NHS 10-year plan aims to build a health service fit for the future, designed to meet the changing needs of our population. To achieve this, healthcare systems must deliver coordinated and person-centred support for people affected by dementia, including meeting the unique needs of people living with young onset dementia and their families.

Personalisation agenda

The NHS's decade-long 'personalisation agenda' emphasises person-led care, user involvement, choice and information access. A dedicated pathway for young onset dementia aligns with this, addressing unique challenges like atypical symptoms, dependants and financial obligations.

Integration

The Health and Care Act's integration of health and social care through ICSs enables cost-effective service reorganisation, benefiting individuals with young onset dementia and the broader system.

NHS operating framework

The framework empowers ICSs to implement national policies and ensures accountability. Collaboration with Social Services, primary care networks and third-sector organisations can enhance support for young onset dementia.

Health inequalities

Diagnostic and support services for young onset dementia vary significantly by region. Memory services often lack specialised expertise and some may exclude those under 65.

Emerging treatments

New treatments under trial require timely diagnosis, yet early diagnosis remains a challenge for people with young onset dementia. Rapid identification is critical as therapies evolve.

Useful links

- Young onset dementia resources via Dementia UK
 ▶ dementiauk.org/young-onset-dementia
- Publications related to The Angela Project
 ▶ youngdementianetwork.org/the-angela-project
- The Young Dementia Network resources
 ▶ youngdementianetwork.org/resources
- Young onset dementia pathway – recommendations from the Young Dementia Network Steering Group
 ▶ youngdementianetwork.org/resources/young-onset-pathway
- Supporting implementation of the NICE guideline for people with young onset dementia – Young Dementia Network
 ▶ youngdementianetwork.org/resources/supporting-implementation-of-the-nice-guideline-for-young-onset-dementia
- Dementia 100: Pathway assessment tool
 ▶ rcpsych.ac.uk/improving-care/nccmh/service-design-and-development/dementia-100-pathway-assessment-tool
- NICE resources on dementia
 ▶ nice.org.uk/guidance/conditions-and-diseases/mental-health-behavioural-and-neurodevelopmental-conditions/dementia
- Memory Services National Accreditation Programme (MSNAP) Standards for Memory Services
 ▶ rcpsych.ac.uk/improving-care/ccqi/quality-networks-accreditation/memory-services-national-accreditation-programme-msnap/msnap-standards
- The Dementia Care Pathway – National Collaborating Centre for Mental Health
 ▶ rcpsych.ac.uk/docs/default-source/improving-care/nccmh/dementia/nccmh-dementia-care-pathway-full-implementation-guidance.pdf
- Young onset dementia in mental health services – Royal College of Psychiatrists
 ▶ rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr217.pdf

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The framework for a young onset dementia pathway for Integrated Care Boards was created by Dementia UK and the Young Dementia Network.

To share any learnings from your evaluation please get in touch with Dementia UK and the Young Dementia Network at

✉ youngdementianetwork@dementiauk.org

For more information on young onset dementia, you can visit:

✉ youngdementianetwork.org/resources/resources-for-commissioners

✉ dementiauk.org/information-and-support/young-onset-dementia

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