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

Summary

This document is a summary of the full young onset dementia framework for ICBs developed by Dementia UK and the Young Dementia Network, with input from an Advisory Group of experts.

The framework aims to help ICBs address the unique needs of people with young onset dementia (where symptoms develop before the age of 65) across all stages of the condition by providing:

- standards for care pathways and structures
- guidance on implementation
- learning from others through good practice examples

This summary document contains a shortened version of the standards and implementation guidance. For more detailed information on implementing the framework and examples of good practice, please refer to the **full version of the document**.

Framework recommendations

The framework recommends 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 for the framework

Implementing this framework will improve outcomes for all stages of dementia:

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.

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.

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.

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.

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.

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 biannually, or when needed

Living

Person is living with dementia

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

1 year: medication is reviewed when optimal dose is reached, then on a biannual 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

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.

This summary contains condensed versions of the implementation guidance. For more detailed guidance and examples of learning from others, › **please refer to the full document**.

Overarching standards for ICBs

Goals	Explanation	Target for delivery
A young onset dementia strategy	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. Where a dementia strategy is in place, young onset dementia should be explicitly included.	Agreed and in place within a year.
A young onset dementia care pathway	All ICBs should establish a young onset dementia pathway which includes: • 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.

Further to these overarching standards, all ICBs should ensure:

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.

Click here › to see the Diagnosing section of the full document.

Implementation guidance

Initial investigation

To support the initial stage of investigations, GPs should receive training on young onset dementia to improve their awareness and knowledge of the condition to ensure:

- lower referral thresholds for younger people with suspected cognitive impairment
- greater awareness of symptoms and engagement with the person and their family
- thorough investigation of symptoms, including baseline tests, physical examinations, daily living assessments and brief cognitive assessments.
- accurate exclusion of treatable illnesses or reversible causes of cognitive impairment
- written explanations of diagnosis and implications are provided to the person and their family
- awareness of the young onset dementia clinical lead for the ICB
- accurate recording and reporting of dementia diagnoses, including subtypes

Specialist diagnostic services

Specialist diagnostic services should ensure:

- a designated expert young onset dementia lead
- provision of pre-assessment counselling and pre-diagnosis support
- clinicians in memory clinics, neurology, or other diagnostic services are knowledgeable about young onset dementia and its impact on the person and families
- clinicians have access to specialist advice, comprehensive assessments, investigations and necessary personnel for diagnosis and ongoing support

Key elements of a diagnostic assessment

- access to a specialist with expertise in the diagnosis of young onset and rarer dementias
- thorough history taking and 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
- electroencephalography (EEG), cerebrospinal fluid (CSF) analysis, genetic testing where appropriate

See the **main framework document** for guidance on communicating the diagnosis and learning from others relating to this section.

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.

Click here ➜ to see the Supporting section of the full document.

Implementation guidance

Who is a key worker?

A key worker may be a clinical or non-clinical trained professional with expertise in young onset dementia. Sometimes referred to as a Dementia Specialist Practitioner, Dementia Navigator or Case Manager, the key worker's responsibility is to provide support and continuity of care from the point of diagnosis. They do this by acting as a liaison between clinical services and the person's community, and as a coordinator of services, organisations and people. 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.

The exact nature of who fulfils this role and where it is hosted may vary depending on local provision but may include a dementia specialist admiral nurse, primary care, voluntary sector partners, local mental health teams or memory and neurology services.

Introduction of the key worker into the person's post diagnostic care

- Contact with the key worker should occur within two weeks of specialist diagnosis and:
  - give clear information about next steps
  - provide emotional support to the person and family
  - connect the person and family to peer support
  - ensure the person and/or family know how they can contact their key worker
- In the follow-up meetings the key worker should initiate discussions about advanced care and end of life planning, with plans to revisit discussions in 12 months if appropriate. They should also develop a tailored care plan and complete the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) document
- If the person with dementia opts out of ongoing support, the family should still be offered access to support
- The family should be made aware of other support, including out of hours support, such as the Dementia UK Helpline, or, in case of emergencies, Adult Social Care Services

Delivering regular multi discipline wraparound care

Following diagnosis, a shared care plan should be agreed and regularly reviewed by a GP, or an alternative specialist dementia practitioner with input from a GP. The plan should include linking the person and family with local support services.

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

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

Outcomes

Living

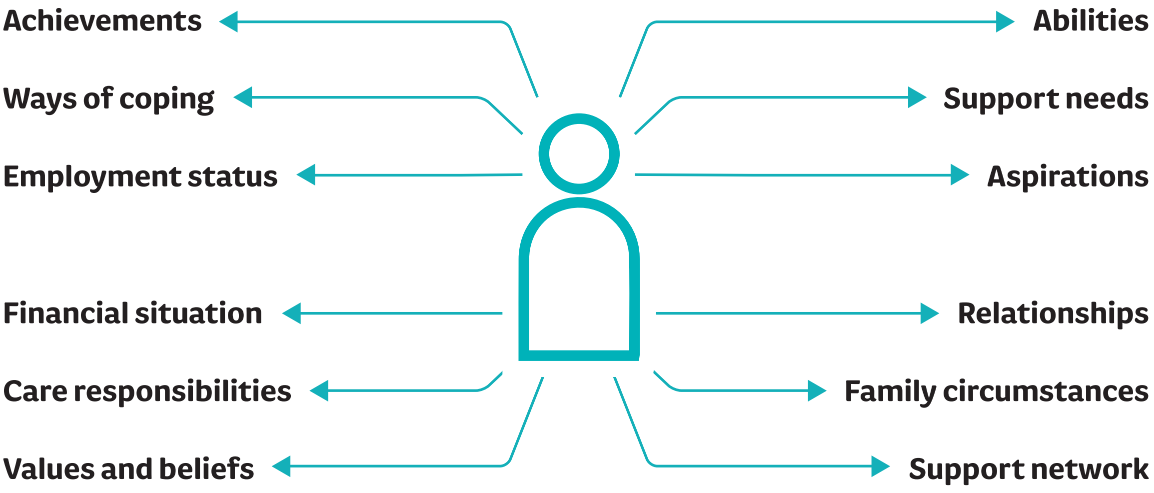
A well coordinated and comprehensive range of support, advice and signposting that enables the person with young onset dementia and their family to adapt to and plan for dementia progression whilst continuing to participate in family, social and community life.

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.	Acccessible 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 p6).	N/A	Within a year of adopting a young onset dementia strategy.

Click here › **to see the Living section of the full document**.

Implementation guidance

Key worker should form a well-rounded understanding of the person:



Joint reviews with the care team

- A multidisciplinary team consisting of a key worker, primary care provider, Admiral Nurse, social services and voluntary organisations should work closely to provide a comprehensive, joined-up service under a coordinated and aligned care plan
- The person and their family should have ongoing access to the services outlined in the ‘Supporting’ section
- The clinical team should review the person’s response to medication once the dose is optimised. The key worker should liaise with the clinical team if a review of medication is needed

Ongoing support

- After initial contact, the key worker should arrange follow-up visits at six and 12 weeks, and then at least twice a year, with additional support available as needed
- During follow-ups, the key worker should help the person and their family assess changing needs and goals, and explore solutions
- As soon as appropriate, the key worker should provide support for advance care planning
- The key worker should also act as a liaison, facilitating access to specialist advice, services and support. If care needs increase, they should assist in arranging short- and long-term care. When appropriate, they should support advance care planning. Throughout, the key worker should offer advice and emotional support

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
Care pathway		
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.	Near the end of life stage.	Targets to be outlined in ICB young onset dementia strategy.
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.	Information to be provided when the end of life pathway is initiated.	Within a year of adopting a young onset dementia pathway and in line with ICB targets.
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.	Reviewed regularly during the end of life stage.	Targets for provision to be outlined in ICB young onset dementia strategy.
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.	Throughout the end of life stage.	Within a year of establishing a young onset care pathway.
Post-bereavement support The key worker should maintain contact and provide advice to bereaved families, guiding them to post-bereavement support and counselling.	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.

Click here to see the Towards end of life section of the full document.

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 should liaise 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
- Where possible, the person should be supported to stay in their home if this is what they and their family want
- The person and their family should have access to age-appropriate long-term residential care within a reasonable distance of home
- 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. The importance of bereavement support tailored to multiple age groups is of increased importance with young onset dementia, where people are more likely to leave behind younger and older family members.

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.

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**.

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.

To support with evaluation, the › **main framework document** provides a list of suggested evaluation criteria, both quantitative and qualitative, that may help to demonstrate successful implementation across the four stages of the dementia pathway.

References

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Dementia UK
Helping families face dementia

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

Young Dementia Network

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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