

Good Practice in Young Onset Dementia

Improving diagnosis and support for younger people with dementia

Results from The Angela Project - a study on young onset dementia



The Angela Project

The Angela Project was dedicated to Angela who was diagnosed with dementia at 51 years of age.

She had symptoms for three years before getting a confirmed diagnosis.

Many other people experience diagnostic delays like Angela.

Our aims were to improve diagnosis and post-diagnostic support for younger people living with dementia and their caregivers.

Our public and patient involvement group played a vital role and informed the design of the project over a three-year period.

What is young onset dementia?

Dementia is considered young onset when it affects people of working age, usually between 30 and 65 years old.

It is estimated there are over 42,000 people in the UK who have been diagnosed with young onset dementia.

This document summarises the findings from The Angela Project, a three-year long Alzheimer's Society funded research study.

Researchers consulted young people living with dementia and their families, international clinical experts and service providers in the largest study of young onset dementia ever carried out in the UK.

It aims to raise awareness of inequalities and provide evidence-based recommendations for good practice.



Good practice in assessment and diagnosis is lacking

- Delays in diagnosis can often be attributed to delays in accessing help, and misattribution of symptoms by the clinician.
- The impact of diagnosis is influenced by the clinician's use of language. Reactions to diagnosis can vary from feeling reassured to have an explanation for symptoms, to shock and destabilisation.*
- A clinically rigorous and systematic approach is necessary in order to avoid mis- or under-diagnosis for younger people.
- The advent of new disease-modifying treatments necessitates clinicians in the field to improve knowledge of new imaging techniques and genetics, with the goal of improving training and practice, and highlights the need for quality indicators and alignment of diagnostic procedures across clinical settings.*

* Visit www.youngdementiauk.org/angela-project for additional information.



'I would have liked to have been told more about what was happening to me and the process - I was often confused'

Person living with young onset dementia

'With young onset it's less well

recognised. The diagnostic rate takes double the time to diagnose a younger person than it does an older person.'

Service Provider 11

'Quite a few, maybe 50-60% have been seen in another memory service before, and they have had a lengthy and convoluted journey, sometimes with diagnostic difficulties. Wrong diagnosis is quite frequent really.' Service Provider 15

The Angela Project found that making an accurate diagnosis and improving the individual experience of receiving the diagnosis are essential to ensure good practice



- Over 400 clinical notes of young people diagnosed with dementia showed that current assessments fail to reach a 'necessary standard'.
- Young people living with dementia say that paying attention to the clinic environment and style of communication make a difference to the experience of receiving a diagnosis.
- International experts have agreed on key elements in the assessment and diagnosis of young onset dementia that can be implemented to improve current standards.

Key recommendations from The Angela Project to improve diagnostic accuracy

An international Delphi consensus with clinical experts in young onset dementia agreed that clinicians should...

- Start the assessment with counselling to ascertain what patient and supporters require.
- Obtain a thorough understanding of any difficulties from someone who knows the person well such as a family member.
- Acquire information about loss of sympathy / empathy towards others, disinhibited behaviour, changes in food preferences and personality.
- Ask if a first degree relative has had young onset dementia.
- Conduct thorough neuroimaging investigations. 80% agreed on MRI with a Dementia Protocol.
- Assess for Praxis and Parkinsonism.
- Provide support from diagnosis to end-of-life.*

* Visit www.youngdementiauk.org/angela-project for the full list of statements.



Key recommendations from The Angela Project to improve best practice for patient experience

A study with younger people with dementia and family supporters found 80% agreement that the assessment for dementia should...



- Use considerate language
- Offer home visits
- Allow time to ask questions
- Adopt a calm approach
- Improve the MRI experience
- Make quicker referrals
- Refer to specialists
- Use a multi-disciplinary team
- Explain assessments
- Offer improved access to clinics
- Issue results more quickly
- Reduce time to diagnosis

Post-diagnostic support for people affected by young onset dementia is lacking



- 39% had seen no health professional in the previous three months.
- 42% of those surveyed received no follow-up in the first six weeks after diagnosis.
- 60% of those diagnosed in neurology services received no follow-up in the first six weeks.
- 16% had no-one managing their ongoing care.
- Only 20% had ongoing management from young onset dementia specialists.
- Although 57% of family carers provided support for five hours or more every day, 69% of carers reported there was no service that provided care for their relative to allow them to take a break.
- In the last three months alone, most families spent the equivalent of £8372 providing family care, whereas health and social care expenditure was only £394 for the same period.

Key recommendations from The Angela Project on key needs that should be considered in care plans

Thematic analysis of 856 survey examples and 34 in-depth interviews found that...

People with young onset dementia need

- Young onset dementia-specific advice, information and support to remain independent; supported age-appropriate activity and occupation to maintain sense of identity.
- Support to maintain their physical and mental health as well as possible.

People with young onset dementia and family carers need to maintain a sense of connection with others through

- Social engagement in age-appropriate forums / activities.
- Relationships with family.
- Contributing to wider society.

Family carers need

- Specialist support to understand how to care for their relative with issues specific to young onset dementia.
- Support to retain aspects of life beyond caring, such as employment.



Key recommendations from The Angela Project for service design and development

Analysis of 20 interviews with service providers and commissioners shows commissioners and providers should...

- Adopt a specific strategy for young onset dementia built on partnership working.
- Work in partnership with people living with young onset dementia, their family members and local champions to deliver the strategy.
- Build capacity and ownership of young onset dementia services within, and between, organisations.

Sophisticated statistical analysis of 217 survey respondents indicated that post-diagnostic services should...

- Provide specialist or shared care, rather than care from a GP alone.
- Offer ongoing case management from a specialist young onset service.
- Have knowledge of who a person should contact when they need support.



The difference good practice can make to people's lives

Annie* is 63 years old and lives with her spouse, Rachel*. She was diagnosed with Alzheimer's disease three years after her first symptoms appeared at the age of 55

Annie's story

After diagnosis I started using the local young onset dementia service. It has become an absolute life-line ever since. I have taken part in all sorts of workshops and social activities like art, singing, bowls, gardening, horse riding and cycling. All specifically designed for people like me. I really enjoy it and it just feels relevant. Everyone there makes me feel accepted and respect me for who I am. I feel normal and good about myself with them. I have even succeeded at things I had never tried before.

*names have been changed and a stock image used



Rachel's story

During the first year, the consultant saw us both regularly. She suggested we find out about legal issues such as Lasting Power of Attorney and financial support to plan our future care. This was invaluable advice.

She also put us in touch with a local university to take part in research. It felt like we had a voice that counts.

After the first year, we moved to 'shared care' between the memory clinic and GP. They coordinate and liaise with all the services involved in our care and treat us as a couple that both need support and help.

They are always available and very supportive. They include and listen to both of us and we never feel rushed. They have helped us to understand young onset dementia, the challenges involved and how to adjust to life

with the diagnosis which helped us to explain the changes to our children and wider family and friends.

When Annie could not be left at home alone and I started having difficulties caring 24/7, we began to have home care for three hours a week. This meant I could have some time to myself, while knowing that Annie was in good hands.

I also have access to an Admiral Nurse who provides me with emotional and practical support and is available through a simple telephone call. Without this support, it would be very difficult for me to cope.

We are very lucky to have a team around us who we can reach out to if we feel worried or anxious. They are always there to help and that means the world to me.

For more information about The Angela Project
www.youngdementiauk.org/angela-project
Email network@youngdementiauk.org



If you would like more information about young onset dementia

Alzheimer's Society
www.alzheimers.org.uk

Dementia UK
www.dementiauk.org

YoungDementia UK
www.youngdementiauk.org

Thank you to everyone who participated in The Angela Project, especially to all the people with young onset dementia and family supporters who so generously gave up their time

