



Living Well with Young Onset Dementia

What research tells us younger people with dementia, and their families/supporters need

How primary care (and others) can assist

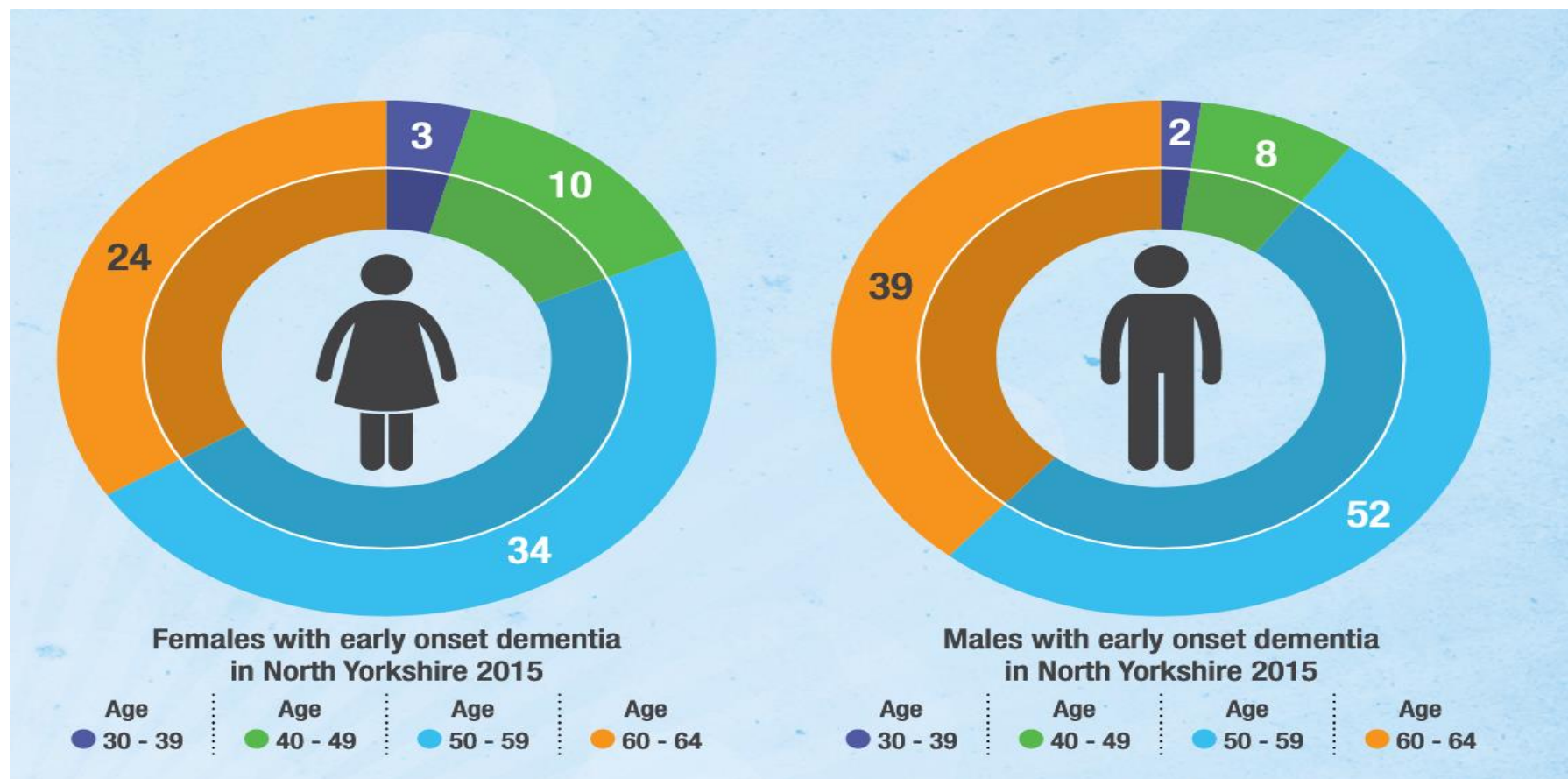
Jan Oyebode, Professor of Dementia Care
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Young Onset Dementia: an area of health inequality

- **Over 42,000** younger people with dementia in the UK - expected to increase by 20% over the next 40 years, only 40% diagnosed
- Young onset dementia includes **rarer types** that present in various ways – leads to significant delays in diagnosis which have a negative effect
- Younger people have **different needs** due to life stage and family life stage – but many services are not used to meeting younger people's needs
- Younger people and their families **require needs- and age-specific services and support** after diagnosis

Numbers in West Yorkshire and Harrogate?

North Yorkshire Health and Well-being Board: Bring Me Sunshine
 Dementia Strategy, estimate: 173



[UCL Home](#) / [Psychiatry](#) / [The Angela Project](#)

Welcome to The Angela Project

The Angela Project is dedicated to Angela who was recently diagnosed with dementia at 51 years of age. She had symptoms for 3 years before getting a confirmed diagnosis. Many other people experience delays like Angela.

Our Aim is to improve diagnosis and post-diagnostic support for younger people living with dementia and their caregivers



Improving post-diagnostic support

Improving Support & Service Use Survey –
positive examples, service use, satisfaction and costs



Follow-up Interviews – needs-based understanding
younger people with dementia and family members



Interviews with service providers and commissioners –
facilitators and barriers



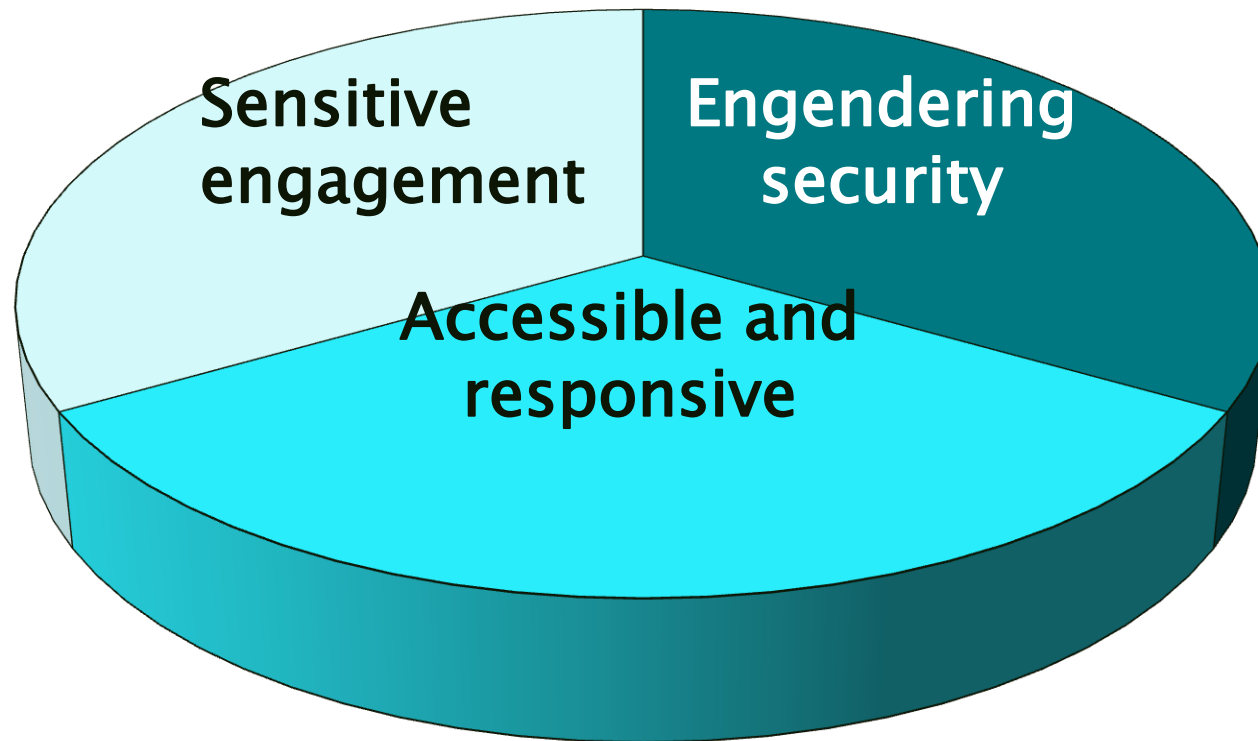
Guidance on Best Practice for Care & Support
Examples of good services across the care pathway & needs met
Essential elements that constitute good practice across the pathway
Barriers and facilitators to be considered



The Improving Support & Service Use Survey

- 291 responses and 856 examples of positive support
- Age at diagnosis: 37 – 65 years old, $m = 56.5$
- The survey included people with:
 - ✓ with rarer types of dementia
 - ✓ were currently employed
 - ✓ who lived alone or in care homes
- Roughly equal numbers of men and women

How were the services supportive?



Sensitive engagement: approach, attitude, active listening, honesty

My GP has been very helpful, he gives me time to explain myself as I get very mixed up when I try and talk, words get confused and I waffle, I tend to write things down in advance and read them to him before we discuss why I have gone in detail; he seems to understand this is how I need to work now.

Accessible and responsive: Holistic, timely, close, collaborative, cost-effective

During this period we moved to 'shared care' between Memory Clinic and GP. Both are excellent and see us when we have concerns. [. . .] They liaise and co-ordinate in terms of our joint care and very much treat us as a couple who both need support and help. [. . .] They have both helped us to adjust to and understand the condition at every stage. It was helpful for both of us and the wider circle of family and friends as we are able to explain things to them.

Engendering security: consistency, continuity, giving confidence

GP – Giving me time to talk over my memory problems. I can see him when I need to. Helpful for me. Just someone to talk to and listen.

GP will see mum immediately, has same GP for continuity of care. Will see mum every 2 months unless something comes up in-between.

What needs does positive support meet?

To feel held and supported thro' understanding that instils security

It met my/our needs:

To feel empowered thro' positive outlook and retaining autonomy

To live well with the diagnosis thro' maintaining health and thro' enjoyment and pleasure

To feel 'togetherness' in key relationships thro' continuing to give and thro' camaraderie

Being held and supported

“The GP has been helpful throughout. As a carer, I approached her myself initially and she was supportive in encouraging Linda to make an appointment. Linda found her very friendly and interested, and she made clear we could always book an appointment when needed.”

“Our GP has continued to be helpful, and it reassuring to know she is always there and has got to know Linda a little.”

“The GP has continued to provide helpful support, for example referring Linda to a neurologist recently when she developed muscle spasms.”

Empowerment

As I was a GP myself, I was treated as a fellow professional which I appreciated. I understand the medical terms and am also very much aware of dementia. MRI showed white patches not Alzheimer's! Great relief but future uncertainty. It was useful for me and my husband. GP referred me on my request. Both psychiatrist and psychologist excellent, professional and supportive.

GP issued medical exemption charge for prescriptions and shortened process of collection, this means Px goes to pharmacy automatically to be dispensed and only requires one collection per month.

Living Well

Mixing with people - helping with walks organised by GP surgery, going for coffee afterwards. Mixing with people. Gives me purpose. It's stimulating for the brain.

Conclusions from Angela positive real-life examples

- Primary care is the essential starting point of the young onset dementia care pathway
- Where staff engage sensitively, are responsive and give continuity, services are experienced as positive
- GPs can be central in enabling people with Young Onset Dementia to feel **held and supported**
- GPs can be **empowering** through giving information and enabling independence
- Primary care services can help people with young onset dementia to **live well** by attending to physical health and offering social opportunity

Some thoughts to take away

- Does your practice have any patients with young onset dementia or possible young onset dementia?
- Does your service fulfill the HOW and WHAT aspects of Good Practice?
- What sort of young onset dementia pathway do you have locally?
- Do you need further information or connections re young onset dementia?
- See <https://www.youngdementiauk.org>

Acknowledgements

**Centre for Applied Dementia Studies,
University of Bradford**



Vasileios Stamou, Research Assistant

Jenny La Fontaine, Research Fellow

Jan Oyeboode, Professor of Dementia Care

University of Northampton



Mary O'Malley, Research Assistant

Jacqueline Parkes, Prof. of Applied Mental Health

University College London

Janet Carter, Chief Investigator



University of Surrey



Bridget Jones, Research Fellow

Heather Gage, Prof. of Health Economics

Funded by:



The Alzheimer's Society

Supported by:

Young Dementia UK



Dementia UK



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What patients and their family members tell us about their experience of being diagnosed



'My GP was really thorough and listened to me and my wife explain our concerns. He sent me for tests to exclude a brain tumour, but eventually I was sent to my local memory clinic where I was diagnosed with Alzheimer's disease at 55.'

...

'I wish our GP had asked how I found living with my husband. I would have said that I've lived with him for over 40 years and now the whole experience of being with him is completely different.'

...

'Ten years before being diagnosed I began to worry, as friends were finding it increasingly difficult to be with him. Two years before, I was noticing lack of empathy and his understanding of daily chores. If only he had been diagnosed sooner we could have accessed the support we so desperately needed.'

...

'My dad was a financial adviser and then he couldn't count the change in his pocket. He was treated for depression for six months before we saw a memory specialist.'



Young Dementia
Network

The Young Dementia Network is a community of people living with young onset dementia, their family and friends, and professionals who work in dementia and social care. We are working together to improve services for all people affected by young onset dementia.

The Young Dementia Network is guided by a collaborative group and managed by YoungDementia UK.

To find out more about the people and organisations involved, and to join, visit

www.youngdementiauk.org/young-dementia-network

11/2017

Diagnosing dementia in younger people

A decision-making guide for GPs

Endorsed by



Royal College of
General Practitioners

This diagnostic guide is designed to support GPs to identify the most common signs and symptoms of young onset and rarer forms of dementia.

It aims to help GPs identify 'red flags' which suggest referral to specialist diagnostic services may be required.



Young Dementia
Network

Why we created this guide

- Over 42,000 people are living with young onset dementia in the UK.¹
- It takes on average 4.4 years for younger people to be diagnosed², twice as long as older people, delaying access to treatment and support.
- Many younger people are misdiagnosed with depression, anxiety, stress, marital issues, menopause or personality disorder.

Picking up the critical signs of these diagnoses is not always easy, and at times is based on your, or your patients' gut feeling that something is amiss. Family and friends may play an invaluable role in helping you to understand the full range of symptoms your patient might be experiencing.

To find out more information about young onset dementia

www.youngdementiauk.org
mail@youngdementiauk.org

References

- 1 Dementia UK, 2nd edition 2014, Alzheimer's Society
- 2 NeedYD Study, 2010, C Bakker et al
- 3 Alzheimer's Society website

