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Dementia in Younger Ages Mapping Ideal Care (DYNAMIC)

Universities of Bradford and York



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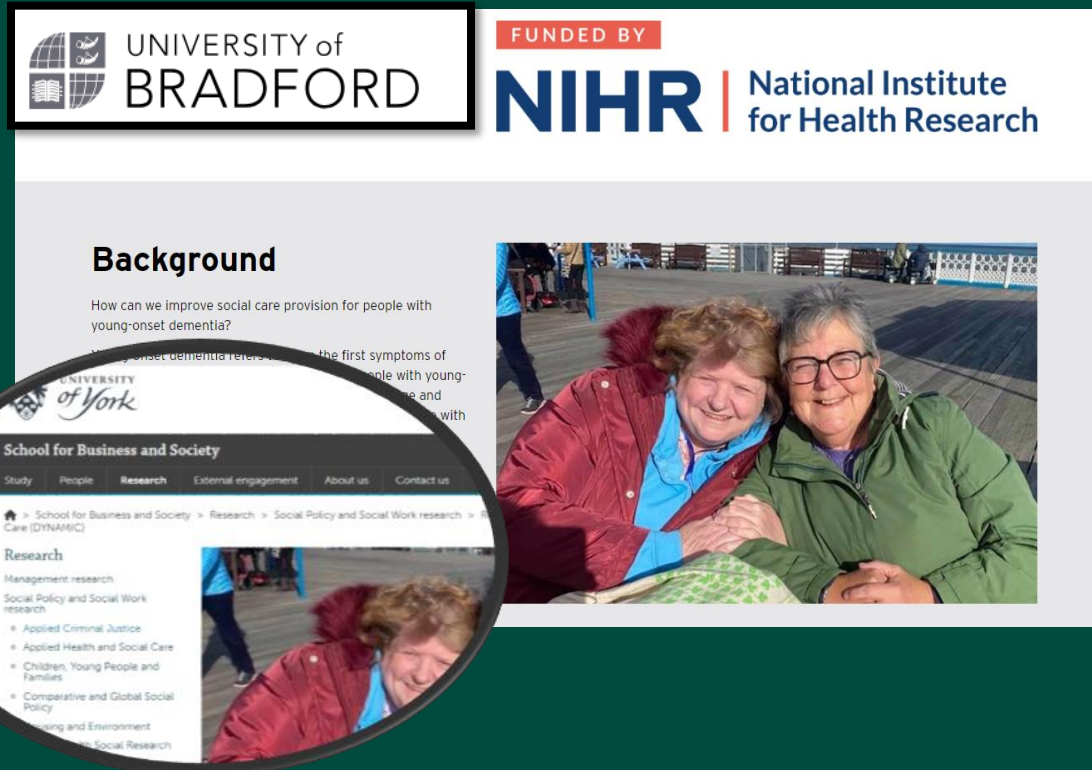
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In partnership with:



A study of social care for people with young onset dementia and their family supporters



- Collaboration between Universities of Bradford and York
- Began April 2023, ends Oct 2025 (work in progress!)

Today:

- Introduce the project
- Progress and our approach to analysis (with examples)



Health warning:

- This research is not finished!
- All findings presented here are preliminary and subject to change
- We are due to report in October 2025
- Full findings will be made available on the study websites next year (see links below)
- For more information contact Helen Young
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Study websites:

<https://www.bradford.ac.uk/dementia/research/current-projects/dynamic/>

<https://www.york.ac.uk/business-society/research/spsw/dynamic/>



Young onset dementia: Dementia where symptoms begin under 65 years of age



Some similarities with dementia in older age



AND some differences:

Where does young onset dementia 'fit'?

- Not the focus of older people's services
- Adult social care for people of working age may not have dementia on the radar

Different disease characteristics:

- Less about memory loss

Different time of life:

- Still working?
- Children still living at home?
- Different societal expectations?



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Building on the Angela Project

What was The Angela Project?

The Angela Project was a three-year research study carried out in 2016-late 2019 by the universities of Bradford, Northampton, Surrey and UCL, funded by the Alzheimer's Society, and in partnership with Dementia UK and YoungDementia UK.

It was the largest study of young onset dementia ever carried out in the UK and was designed to look at how diagnosis and post-diagnostic support for people living with young onset dementia can be improved.

The study 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.

Largest research study ever into young onset dementia services



Building on the Angela Project

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Largest research study ever into young onset dementia services



Angela findings indicated that:

- Social care pivotal in the well-being of people with young onset dementia and their families
- But almost 1/3 people had no regular appointments with any social or health care professional
- More than 2/3 had no care plan

**Improving social care could improve the experience of living with young onset dementia...
...but how?**



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The DYNAMIC project aims to:



Understand the social care needs, experiences and preferences
of people living with young onset dementia and their families



Establish levels of awareness, knowledge and practice among
professionals regarding social care



Produce recommendations and resources to improve social care
for people with young onset dementia and family members



The DYNAMIC Project

WP1

Qualitative interviews

- People with young onset dementia
- Supporters

WP2

National survey

- Professionals

Synthesis of
findings
using
convergence
analysis

WP3

Prioritisation
with
stakeholders

Review
existing
knowledge
and practice

Co-produce
guidance
and
resources



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Work package 1

In-depth interviews with people with young onset dementia and their main supporters

25 interviews completed:

A flexible approach:

- 8 dyadic (person with dementia and supporter together)
- 17 individual (14 supporter alone, 3 person with dementia alone)

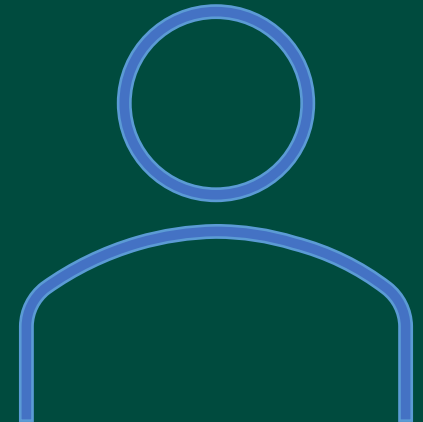
Choice of mode:

- 13 in-person
- 8 online
- 4 telephone

33 participants in total

11 people with young
onset dementia

22 supporters



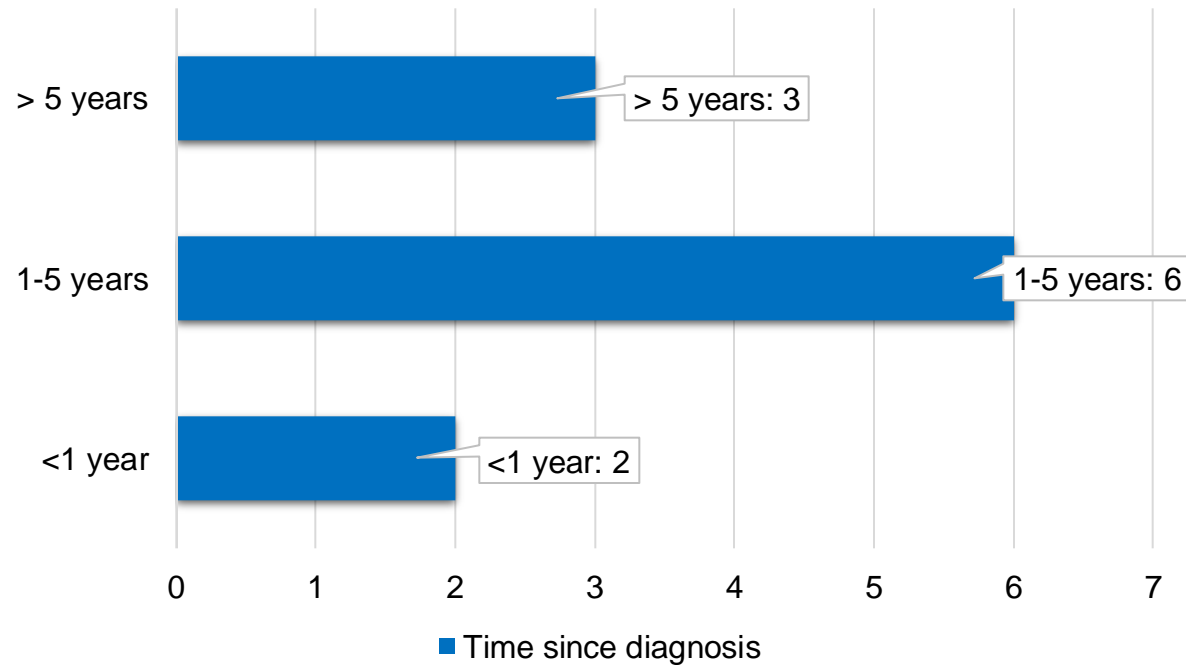


Sample characteristics (total N=33)

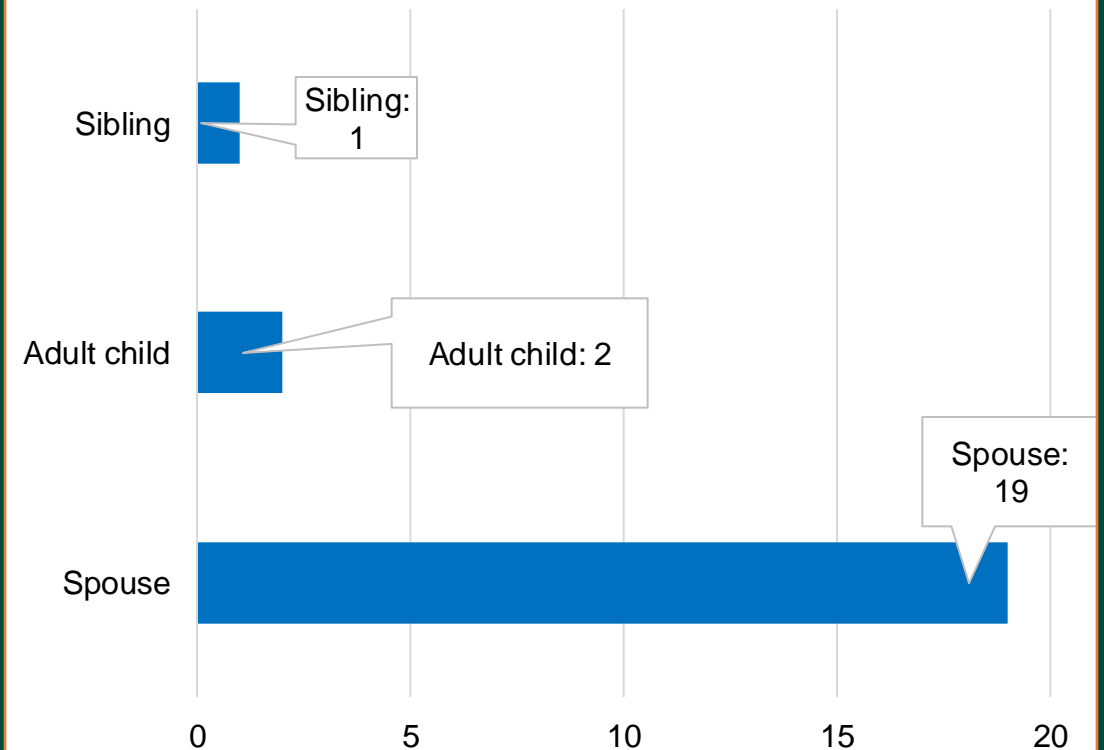
	Gender	Age	Ethnicity	Location
Participants with dementia (n=11)	3 women 8 men	Under 60 n=5 60 or over n=6	2 Asian/white other	7 urban 4 rural or semi-rural
Supporters (n=22)	14 women 8 men	Under 60 n=13 60 or over n=9	2 Black/Asian (plus 1 supporting Asian person)	13 urban 9 rural or semi-rural
Combined (N=33)	17 women 16 men	Under 60 n=18 60 or over n=15	4 BAME participants (plus 1 W/B supporter of BAME person)	20 urban 13 rural or semi-rural



Person with dementia's time since diagnosis

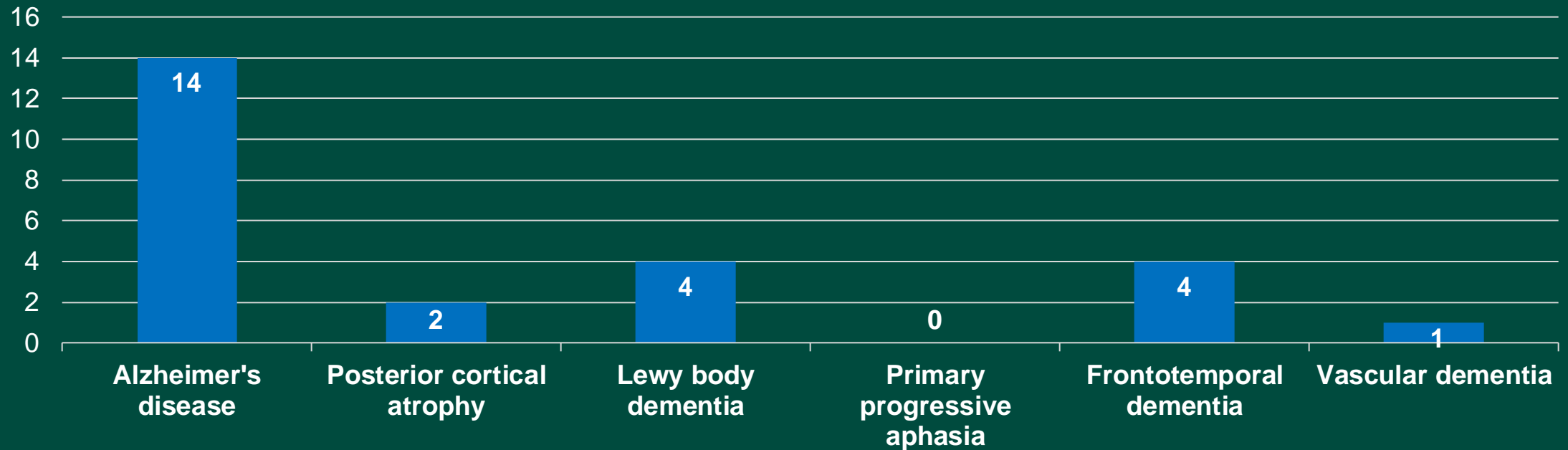


Supporter's relationship to person with dementia



Types of dementia represented (whole sample)

Type of young onset dementia





Characteristics: Family and living arrangements

Living alone: 3 participants with dementia living alone, 1 supporter of a person living alone

Children in household: 20 participants (people with dementia and/or supporters) currently have dependent children

Often juggling work: 14 supporters in employment (some had retired because of caring)

Sandwich generation: common to be caring for partner, children and own parents

Approach to analysis:

- Thematic
- Focusing on accounts of experience
- Using a Framework approach
- Wider team and Advisory Group feeding in through meetings where extracts are discussed, and framework headings refined

	A	B	C	
1	Participant ID	Employment	Person-centredness	Age-appropri
	NT10S HY 14th Dec 2023. Interview with husband of 58 year old wife with FTD			
2				
	NT06D HY 7TH DEC 2023. Interview with person with dementia and carer			
3				
	INT04S HY 5th Dec 2023. Interview with husband of person with advanced dementia			
4				
	INT03S HY 29th Nov 2023 Interview with wife of person with dementia			

Framework Headings

- Headings are just labels for drawers.
- They help us organise information



Sheet 6. Examples of Good Practice

Employment

Person-centredness

Age-appropriate support

Support for carer

Sheet 3: Types of social care received

Live in care and value of this

Homecare and value of this

Day services/respite and value of this

Sitting services/befriending and value of this

Peer-support (for the person or carer) and value of this

Social work (and assessments) and value of this



Sheet 2: Needs or challenges

Early signs and how they were managed (including any support that would have helped)

Current challenges and what support does/would help



Analytic Headings

From
discussion
with team

Not just
children
in the
home



Sheet 4 Headings: Young Onset Themes

Lack of age-appropriate respite/day care

Financial issues linked to not working

Atypical presentation that delays diagnosis

Impact on children

Importance of opportunities for reciprocity (giving as well as receiving help) for the person

Peer-support (in its widest sense: 'who you are is wider than your dementia')

Value of peer-contact for family/carers

Social inclusion and identity

Employment issues

Family transitions





... [our daughter] was more comfortable moving away actually because it meant that she didn't have to see [her mum] so often in the state that she was in and that's not a criticism of [daughter] in any way but it's understandable that she just couldn't, she struggled because I know [son], our son, really was struggling to see their mother in such a state in a different way from what they were used to and wanted to...

They [sons] are both really good with their mum. They do toileting with their mother. I thought, well, I'm not sure I would have done that with my mum, but they've been absolutely brilliant.

Husband of person with young onset dementia



Husband of different person with young onset dementia



Analytic Headings

Sheet 4 Headings: Young Onset Themes

Lack of age-appropriate respite/day care

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From
discussion
with
Advisory
Group





Peer-support (in its widest sense):

Person with dementia: "...even though they [people in his bowling group] don't know I've got it, it's been very good. And I find that groups like that will help you anyway because they're friendly. Whether you tell them or not you got dementia, it doesn't make any difference the way they actually treat you..."

Researcher: "Yeah. So at no stage you felt the need to let them know about your dementia?"

Person with dementia: "Not really. Sometimes I say something, oh, I did that, and that's the reason why I did it because I felt it needed saying. But I don't normally mention it."

- This excerpt demonstrates the importance of groups and activities for everyone (not necessarily dementia specific)
- Ties in with social inclusion and identity

Who you are is wider
than your dementia

Advisory group member with young
onset dementia in analysis session

Sheet 5 heading. Gaps and improvement needed

Help to navigate, make decisions about and access services
(includes using Personal Budgets)

Personal assistance (what I really need is another partner!)

Boundary issues between services/areas

Communication/continuity



Person with dementia: “Well, there was people there [at a young onset dementia event] that were also like me that were young onset. And one of the big guys there was a musician. And he did a lot of talking, and I went to him afterwards and spoke to him, and that was interesting. ... But they haven't followed it up at all. They've never written to us... ...It's just gone flat on it. ...We haven't heard anything. Yeah.”

Supporter: “...since then. So whether there's not been anything planned or anything else.”

Person with dementia: “I think we're a bit far away from them.”





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Work package 2

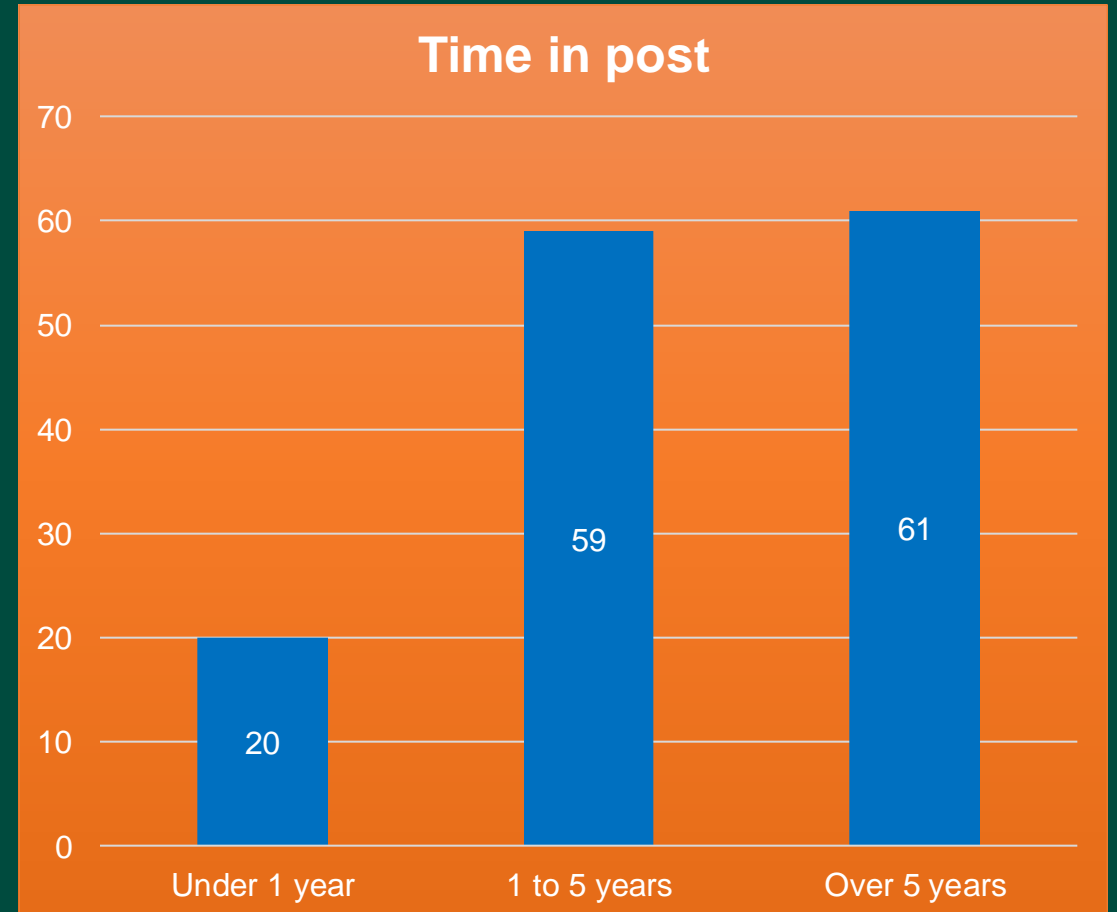
Survey of staff involved in planning and provision of social care



An experienced, mainly female sample (n=140)

- 28 questions
- Closed 31/5/24
- 140 eligible responses

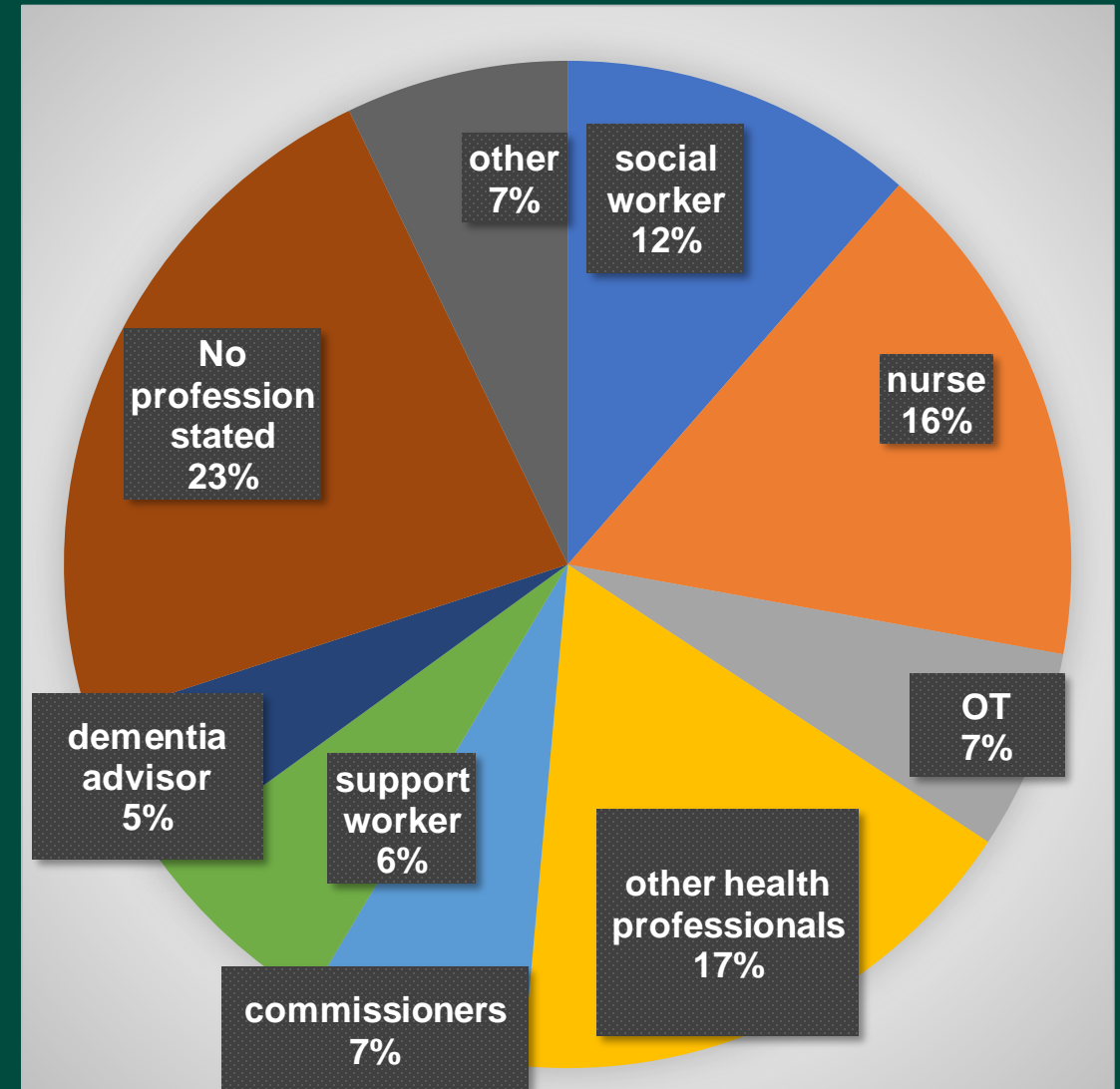
87% female
69% aged 41-60 years
16% from minority ethnicities





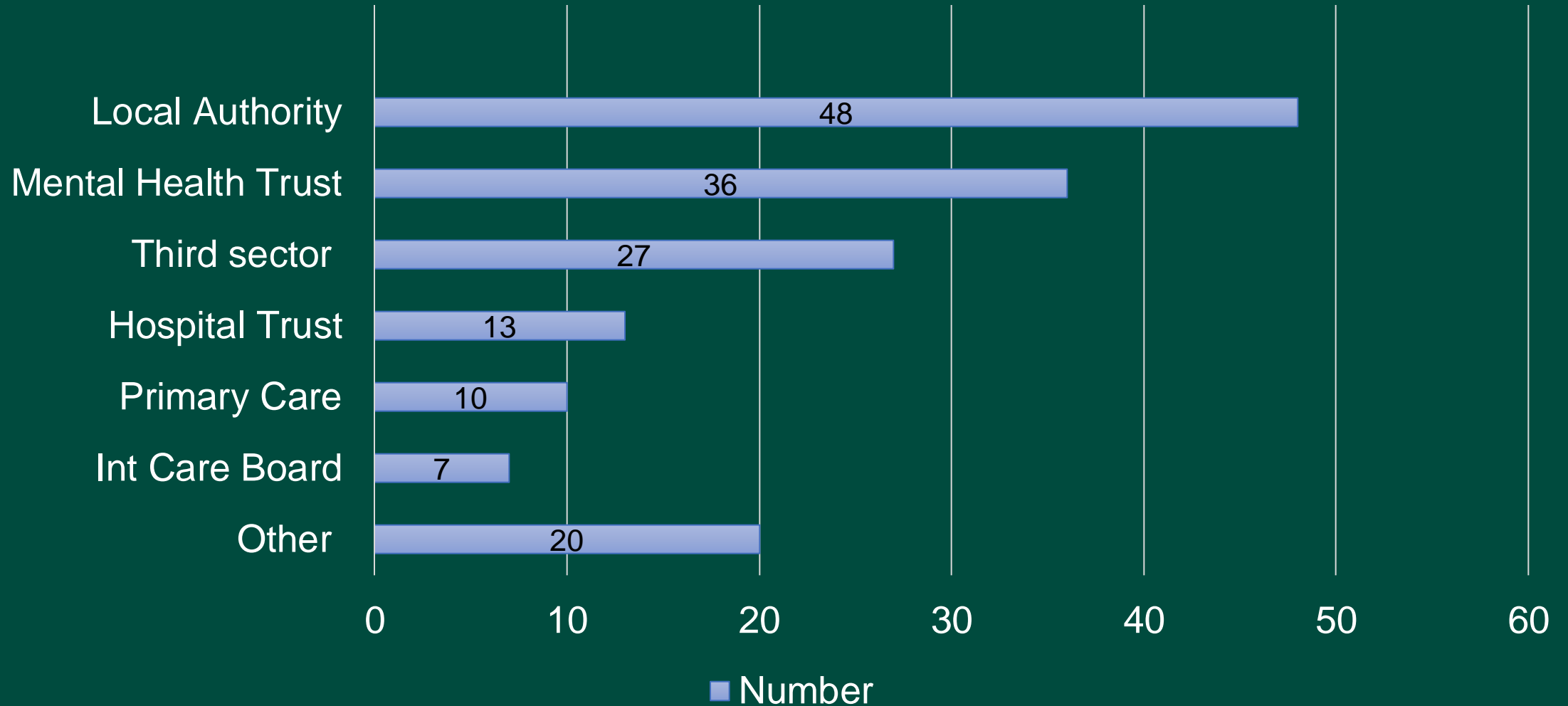
Profession of respondents:

- A wide range of professionals responded
- Many in senior roles (leadership and management)



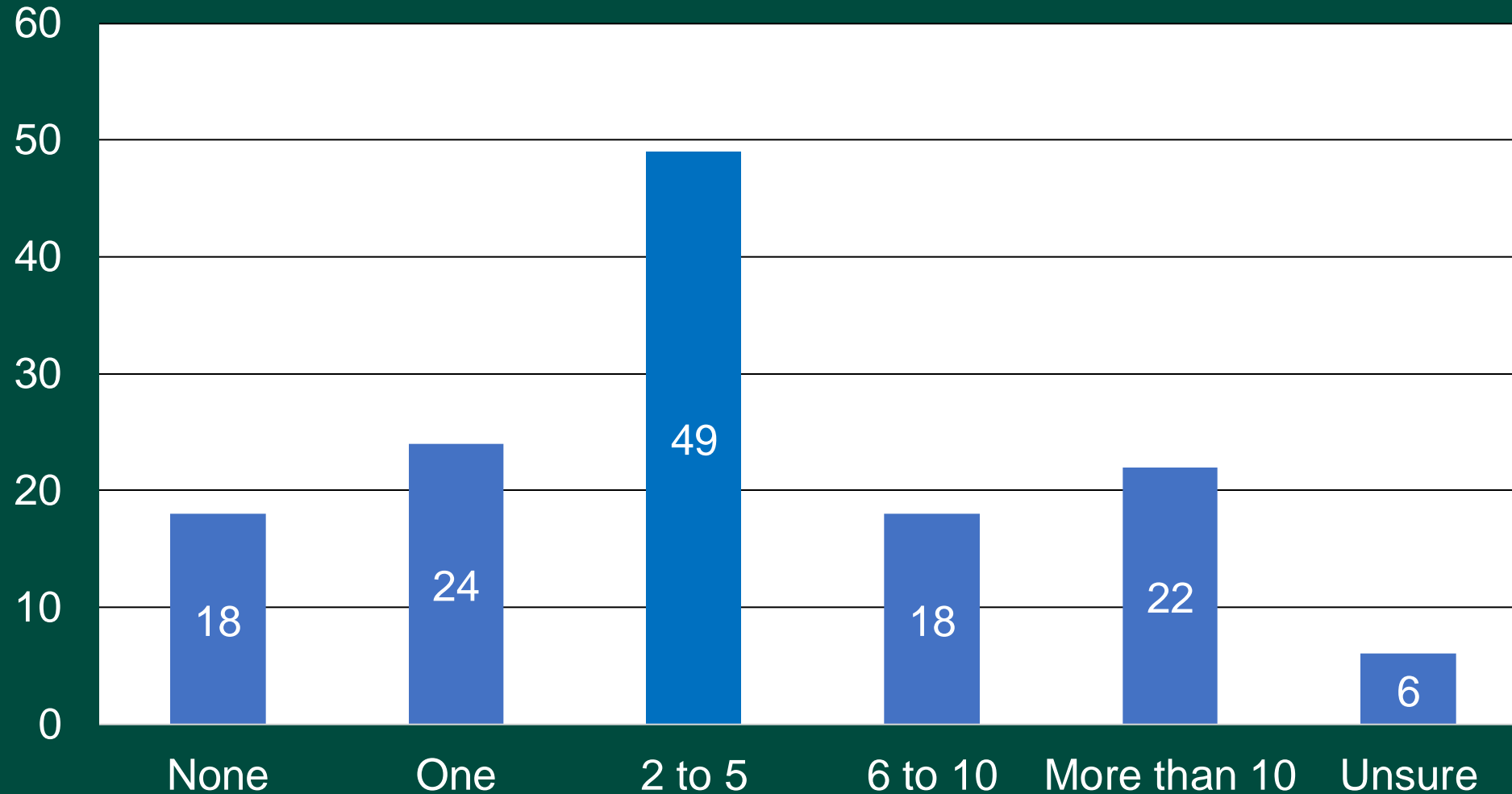


Respondents by sector





Number of people with young onset dementia
seen over previous 3 months (N=137)





Conducting social care for people with young-onset dementia or their families

55% undertake or have oversight of social care assessments, carer assessments or social prescriptions

53% devise care plans/ provide social care, for example, related to finances, employment, children/family issues or other issues



Referrals to social care

74% refer for social care assessments

75% refer for carer assessments

55% refer for social prescription

70% refer for other reasons

Examples of 'other reasons' for referral to social care:

GP screening

Financial support and or advice and guidance through charities such as Age UK, Dementia UK, Alzheimer's UK.

Groups and social activities

support organisations - Carers support , alzheimers society, young dementia network, private clubs

social inclusion activities

Not always referring but signposting to carers groups and cafes and for OT assessment or therapy

specialist younger onset day service

Voluntary sector support and support groups and Carers Centre
Equipment
Benefit advice

Alzheimer's society



Situations that trigger social care referrals

Transitions - concerns for safety - carer well-being:

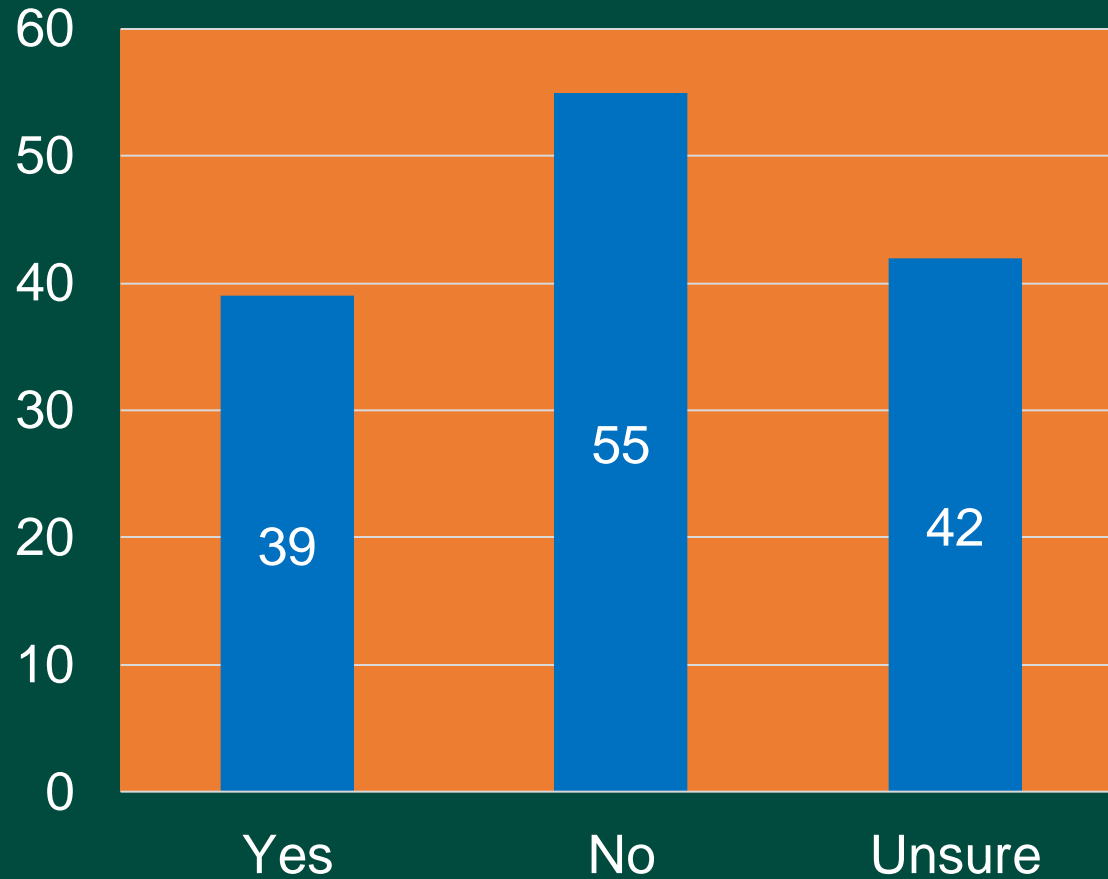
When employment is no longer an option for the person with YOD.
When the Carer cannot leave the spouse alone to go to work.
When finances are stretched and funding private support is no longer an option.
When Deprivation of Liberty is needed to keep the person with YOD safe e.g. the use of trackers.

Behaviour which puts family or members of the community at risk, safeguarding resulting from financial abuse, behaviours resulting in self injury or self harm, obtaining food and drink without the means to pay.

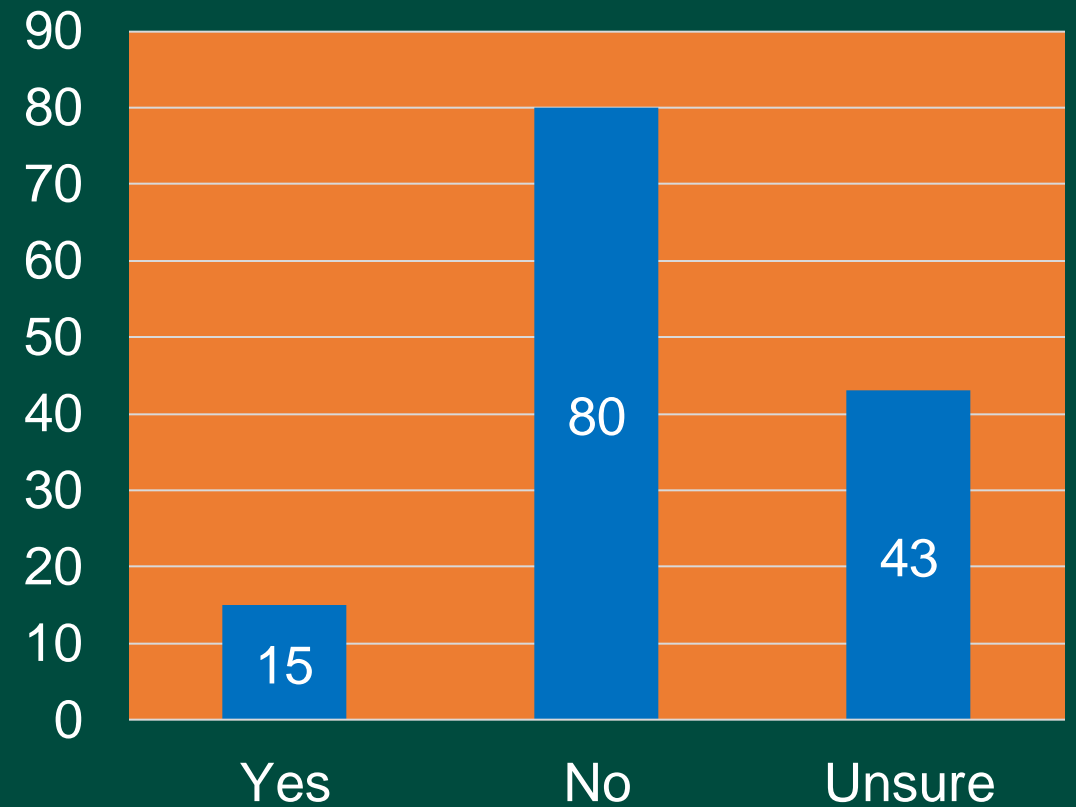


Care pathway and guidance?

YOD care pathway?



Written guidance for work
with YOD?





85 respondents gave examples of good practice

1. We have sought animal therapy for a person who loved animals.
2. Many of our outreach clients like to go on long walks.
3. We had a cookery group with clients and carers that created a cookery book.
4. Art therapy - created artwork for our patio.
5. Clients contributed to our newsletter and welcome part.
6. We have had input from Leeds Museums, holding a day that celebrated 1982.
7. We have reached out to BME services to learn, create friendship and remove barriers.
8. We have regular client meetings to which clients contribute ideas.

Sometimes using care agencies that are more experienced in working with adults with learning disabilities or acquired brain injuries is more appropriate than traditional domiciliary care agencies. The use of a Personal assistant through a direct payment too is useful.

Use of personal budget to fund diesel and campsite fees in order that a couple could continue motor home travel. The husband needed no other care as his wife did it all but travelling not only for holidays but to dementia conferences maintained his self worth, his confidence, his general wellbeing



115 suggestions for improvement

General: “More things available and peer support for YOD”

Specific

“Self-directed support is an excellent funding model however there are very limited numbers of social care providers who can provide the specialist care package to individuals who require this.”

“Flexible, non-traditional input e.g provision of a 'PA' to support with managing paperwork or going out socially or supporting people at work.”

“Care co-ordinator to deal with the needs of the whole family, support needed on who, how, when and where support can be accessed ESPECIALLY financially, when people have a mortgage to pay and children to bring up.”

Comprehensive: “Improving access to social care for individuals with young-onset dementia involves several key strategies - [7-point plan] - By implementing these strategies, social care systems can better support individuals with young-onset dementia and improve their quality of life.’



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Work package 3

Identifying improvement priorities and co-producing resources

Data synthesis



From interviews: Gaps and improvement needed

Help to navigate, make decisions about and access services (includes using Personal Budgets)

Personal assistance (what I really need is another partner!)

Boundary issues between services/areas

Communication/continuity



From survey – improvements needed

Self directed support – informed social care providers - provide the specialist care package

Provision of a 'PA' to support with managing paperwork or going out socially or supporting people at work

Care co-ordinator for needs of the whole family, support needed on who, how, when, and where support can be accessed ESPECIALLY financially, when people have a mortgage and children



Co-production of recommendations and resources to improve social care planning and provision

Synthesis of WP 1 and 2 findings

Convergence analysis

Identify 2-3 priorities for improvement.

Stakeholder consensus workshop

Establish existing knowledge and best practice

Scoping reviews and interviews with key social care staff

Co-produce recommendations and resources

Small working groups guided by the evidence base and best practice examples





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Questions?



And thank you!

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