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NIHR

National Institute for
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Resources to raise social workers' awareness of young onset dementia



15th October 2025

DYNAMIC Awareness webinar for Young Dementia Network



Development of resources to raise social care staff awareness of young onset dementia

- Context of social care provision
- The DYNAMIC project
- The focus on awareness of social care staff
- Developing the resources
- The resources

Context



What is social care?

Social care is support that helps people live independently and stay safe and well

- Personal support for activities of daily living
- Support to stay active and engaged
- Establishes and builds connections, enables contribution and maintains function.

[Adult Social Care: Key facts And figures | The King's Fund](https://www.kingsfund.org.uk)
[\(kingsfund.org.uk\)](https://www.kingsfund.org.uk)



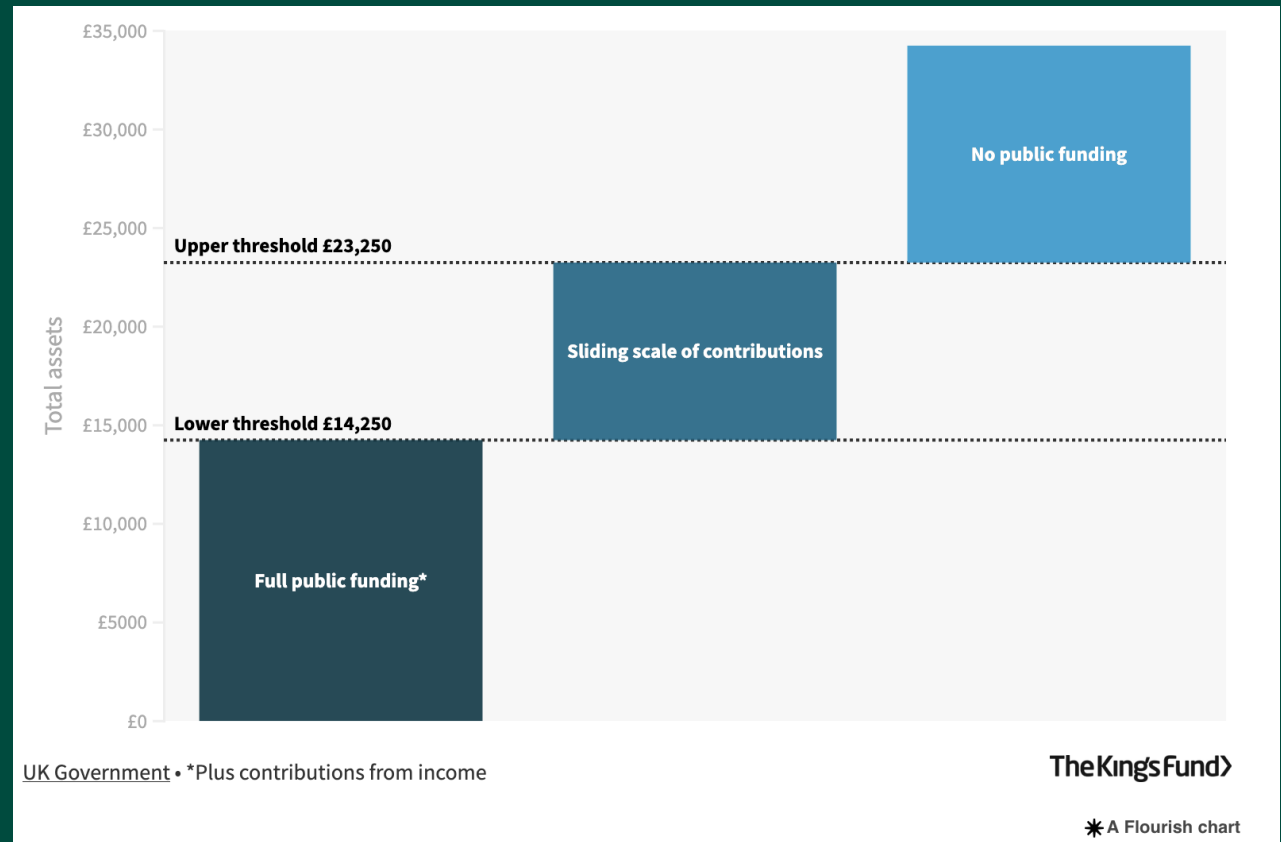
Social care is highly relevant in young onset dementia: Eight key needs of people with young onset dementia (from the Angela project)

People with young onset dementia need	1. Young onset specific information, advice and support to stay independent
	2. Age-appropriate support to stay fit, active and mentally well
	3. Age-appropriate activity and occupation to maintain identity
Family supporters need	4. Specialist support to know how to care for issues specific to young onset dementia
	5. Support to retain life beyond caring, such as employment
Both need	6. To feel connected with each other
	7. To feel connected with friends or others who understand challenges of living with young onset dementia
	8. To have opportunities to contribute to wider society

But social care is not free

Only those with the highest needs and the lowest financial assets receive state support.

Otherwise, people have to fund themselves and may rely on self-help.





The DYNAMIC project

Social care for people with young onset dementia and their family supporters: Current practice and resources for improvement.

The DYNAMIC study is funded by the National Institute for Health and Care Research Programme through grant NIHR204266. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care



DYNAMIC project aims



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



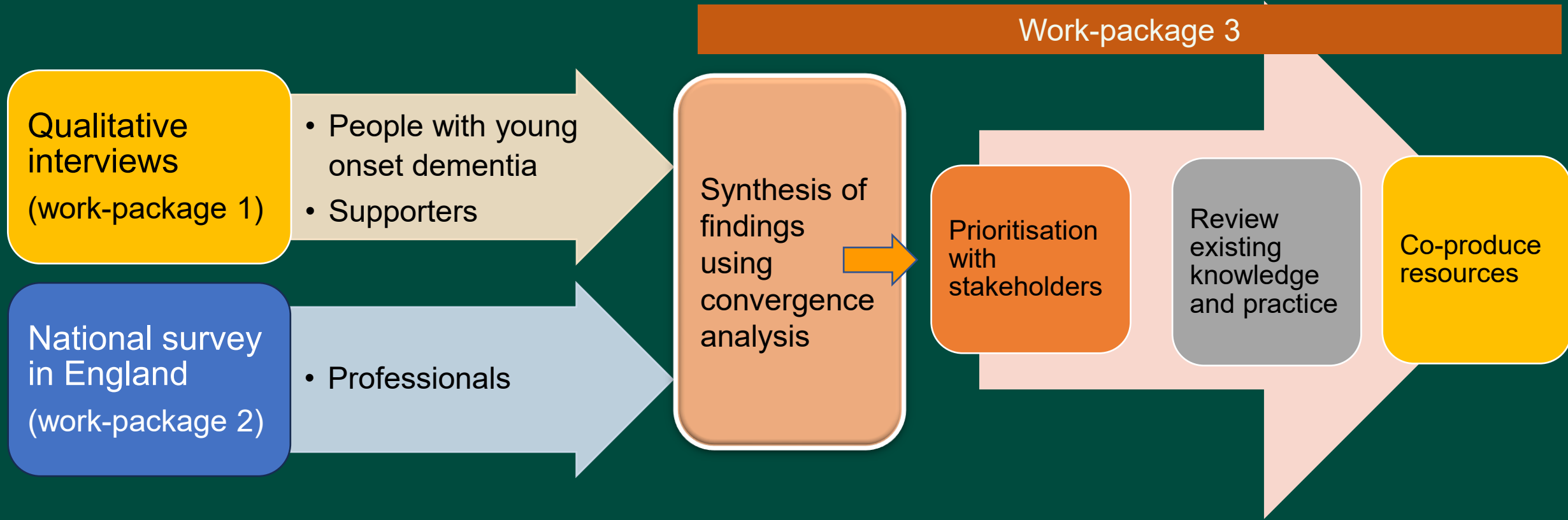
Establish levels of awareness, knowledge and practice among professionals regarding social care



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



DYNAMIC project overview



April 23 ----- Nov 24 ----- Oct 25

15th October 2025

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The focus on awareness of social care staff



Awareness as a key theme



30 stakeholders confirmed this as one of the two areas to focus on for the rest of the project at a workshop in September '24

Convergence analysis identified better awareness of young onset dementia by social care staff as 1 of 6 key areas for improving social care

People with young onset dementia and family members told us social care staff's lack of awareness of YOD was a major concern

Many social care professionals told us they lacked knowledge and confidence to work well with people with YOD



tide (together in dementia everyday), 2022

Surveyed 91 current or former carers of people living with YOD and found lack of knowledge in health and social care staff was a common theme

“Health and social care agencies need to train staff on needs of those diagnosed with young onset dementia to realise that they have to reconfigure their services to be age appropriate.”



The awareness priority for improvement

Our goal is to raise awareness of social care staff around social care needs of people with young onset dementia and their families

- Develop a resource or set of recommendations to improve knowledge and awareness of young onset dementia in social care staff

N.B. Within this area we are considering the needs of the South Asian population as well as the wider population.



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Co-producing the resources



The process of producing the resources



3. Given steps 1 and 2, what can WE do to contribute further – co-production



2. What examples are there of good practice in this area? – interviews with 13 professionals with knowledge of the field



1. What is already known about raising knowledge and awareness of health or social care staff about dementia? – review of publications

What is already known – a review of publications

- Only 3 in 10 care staff in England undertake dementia training (2018)
- No research on improving knowledge and awareness of Young Onset Dementia in social care professionals
- Research on dementia training for social care staff in the community is neglected
- Research on dementia training more generally suggests ways of delivering effective training (see the Alzheimer's Society Report, 2024)
- Social care staff who receive regular training (not dementia specific) have lower turnover than those who do not.
- Learning and development are one of the top three retention factors.





What professionals with expertise said about awareness training

- Training on dementia/young onset dementia is not mandatory
- There is little time and money so training tends to be superficial/online
- Commissioners can demand organisations to provide training and check it is provided
- Material on young onset dementia could be brought into mandatory training, such as on risk and culturally informed care
- Professionals gave examples of how they had raised awareness in training sessions
- Training may work best when practice-focused and timely e.g. related to a particular client or family



Professionals also stressed other ways of gaining awareness

- Experienced knowledgeable colleagues – in same team/organisation or external
- Individual induction, supervision and monitoring
- Shadowing and visits to services
- Reflective discussion, such as a monthly YOD meeting
- Co-production projects
- Learning via ‘mini-teaching’ and case-related consultation
- Piggy-backing, e.g. during Dementia Awareness Week.



Experiential learning on the job

"...And it comes through experience, I think you know my social worker who's left, I think she never, she wasn't always a young onset. You know it needed a service, she opted [in] and then learnt from the experience, a bit like mine. You know you learn through experience isn't it."



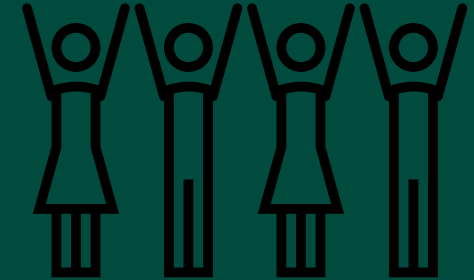
Providing person-centred, and culturally informed care

"...for me it's about that family network. And some of the cultures around family and supporting family. [. . .] So I think it's just that cultural awareness, that the workforce needs to be mindful and how that can interplay and impact the person with dementia's experience of receiving care, the caregivers' experience of giving care, but also how you work with the family to sort of help them [. . .] to develop a care plan that kind of meets the needs of everyone in that sense. So, we're thinking about the safety of the person at the middle but we're also trying to maintain those values."



Co-production of the awareness resources

- Diverse co-production group of 5 members
 - Two online meetings in July and September
 - Consultation at several other key points
 - Huge background support from DementiaUK
-
- Meeting 1 – who to target, how, what key messages





Co-production meeting 1

Who to target

- All staff involved in social care (in local authorities and third sector)?
- A specific group e.g.:
 - social workers
 - commissioners
 - other?

What format to use to reach the target audience

- Video
- Online webinar
- Module
- Compendium of good examples

What key messages do the target group need to know?

Needed to be realistic - we had about 3 months and roughly £3000

Outcome: target social workers, via a short animation with back-up information



Steps in co-production of the animation

- Identify parameters
- Identify an animator
- Agree key messages
- Set key messages into a script
- Give ideas for the animation
- Feedback on the storyboard
- Give views on the voice-over





Further information around awareness



A short booklet with information on key aspects of social care in young onset dementia including:

- Work, employment and retirement
- Meaningful occupation
- Peer support
- Support to remain safe and independent
- Support for children and young people
- Financial and legal issues
- Planning for the future
- The opportunity to influence and change things for the better



Further information on DYNAMIC

Resources and publications will be available here:

<https://www.youngdementianetwork.org/research-evidence/dynamic/>

Raising social care workers' awareness of young onset dementia

Resources to raise awareness among social care staff about the social care needs of people with young onset dementia and their families.

Resource for social care workers

Download the DYNAMIC project's resource for social workers to raise awareness of young onset dementia.

Financial impact of young onset dementia

Resources to help manage the financial impact of living with young onset dementia.

Summary findings of the DYNAMIC project

Download an infographic showing summary findings of the DYNAMIC project.

Quinn, C. et al. (2025). Professionals' Views on Social Care Planning and Provision for People With Young-Onset Dementia and Their Families in England: Findings From the DYNAMIC Study. *International journal of geriatric psychiatry*, 40(9), e70155.