

We also have an allocated Psychiatrist for "Fiona". She understands young onset dementia

Care coordinator put in place. Was able to advocate for us with social services and provide access to other services such as occupational therapy. Cut through some of the bureaucracy and helped social services to take our needs more seriously.

Physio and OT have helped with some mobility issues round the house, they spoke to mum not me and listened.

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### The Angela Project

Positive experiences of services of post-diagnostic care reported by people with young onset dementia

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Supported by:  
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 Dementia UK  
 PPI Group members  
 Advisory group members  
 Third and Independent sector  
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### Post-Diagnostic Support

#### Challenges in living with dementia at a younger age

- 'Off time'
- Uncommon
- A time of peak activity in people's lives
- A wide range of diagnoses, each with different needs

#### Major barriers to living well with Young Onset Dementia

- Complicated journeys to diagnosis
- Lack of understanding and awareness
- Lack of life-stage, diagnosis-focused and wellbeing-focused support and care
- We know what doesn't work but what does?

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### Post-diagnostic work stream of Angela project

**Aims**

1. Highlight the essential elements that constitute good practice
2. Develop guidance for improving post-diagnostic support

**Objectives**

- Gather positive examples of good services
- Gain overview of current service use, costs and satisfaction
- Gain more understanding of barriers and facilitators to commissioning

### Information we gathered



### Intended outputs and dissemination



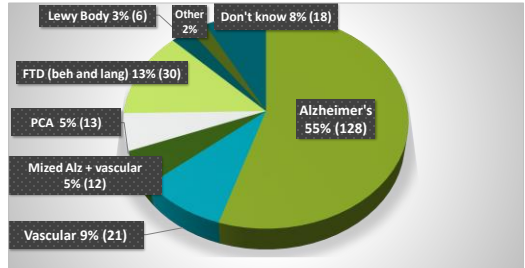
### The Improving Support & Service Use Survey

- Socio-demographic information
  - Nature of dementia
  - Service use and satisfaction (based on CSRI)
  - Positive service experiences
- Can you think of times when the help and assistance you received was helpful?
  - If yes, what was helpful, why was it helpful, who was involved, what was the name of the service?
  - Up until diagnosis, first year, up to current time
- Available via Internet, paper or 1:1

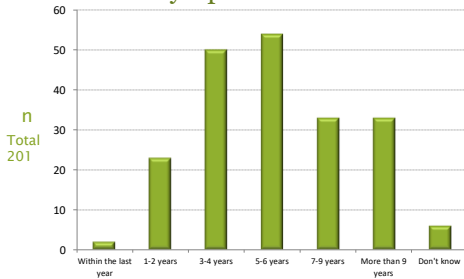
### The Improving Support & Service Use Survey

- 233 usable responses
- Age at diagnosis: 37 – 65 years old, *m* = 58
- The survey included people with:
  - ✓ with rarer types of dementia
  - ✓ were currently employed
  - ✓ who lived alone or in care homes
- 51% men and 49% women

### Diagnoses (n=233)



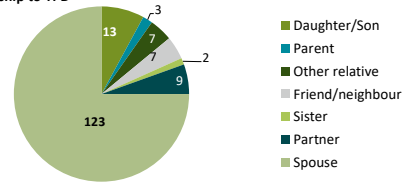
### Time since symptoms were first noticed

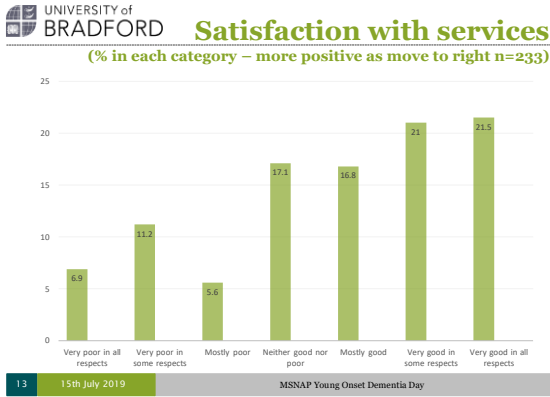


### Carers (n=164)

- Age: 19-75, *m* = 58.5
- Gender: F = 68%, M = 32%
- 60 carers in paid employment
- 126 carers living with YPD
- 15.5% had children <18 years at home
- 43% help from friends/relatives with caring

#### Relationship to YPD





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Survey analysis

- Inductive thematic analysis of 856 examples of positive support provided by 233 people

- Who provided each service/form of support → 'WHO' themes
- Objectives of each service/form of support → 'WHAT' themes
- The way services/support were delivered to be supportive of needs → 'HOW' themes
- The needs met by the services → 'WHY' themes

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### Positive Experiences

Who? What? How? Why?

*“Alzheimer’s Society Support Group I was given the opportunity to meet and talk with someone of my own age group to compare experiences and views. They offered me understanding support when I needed it most. Also, they were the only ones to make sure I had information specifically about young onset dementia. With their help I am beginning to feel I have a purpose in life again after years of being made to feel useless. They made me feel useful instead of a burden.” (Person living with YOD).*

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### What do services offer that is perceived as positive?

- Awareness and understanding of dementia
- Enablement through advocacy, referral on
- A voice in care, support, policy etc.
- Maintenance of mental and physical health
- Meaningful occupation or activities
- Participation in social circles and community
- Maintenance of relationships with family

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## How are positively experienced services delivered?

- They engage sensitively with the person (approachable, open, honest)
- They are accessible and responsive (proactive, timely, creative)
- They offer consistency and continuity

## Why are these services experienced as positive?

- Feel 'held and supported'
- Maintain autonomy
- Maintain identity
- Enable giving/ contribution (sense of value)
- Maintain a sense of belonging/inclusion (social well-being)
- Offer enjoyment and pleasure
- Promote growth and resilience

Example – accessible/responsive support, awareness/ understanding → feeling held and supported

During this period, we moved to 'shared care' between Memory Clinic and GP. Both are excellent and see us when we have concerns. It is important to feel you have a 'team' around you who you can reach out to if you feel worried or anxious. 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.

Person with young onset dementia and family member

Example – sensitive engagement, a voice → maintenance of autonomy, sense of value

Physio and OT have helped with some mobility issues round the house, they spoke to mum not me and listened. They also emailed mum (she can't use the phone) at times instead of phoning me, so they adapted method of communication. Also helps her maintain independence. [ . . . ] Mum still has capacity and the ability to make decisions. It's only respectful to speak to mum about her care and not me when she is in the room. Feeling valued and respected is not only her right, but makes her happy, which makes me happy. Communication: mum can still communicate by email, so if services can do that it helps her feel in control and means I don't have to wait for phone calls.

Daughter of person living with young onset dementia

**Example – maintenance of cognitive health**  
 → enjoyment/pleasure, resilience, autonomy

We attended 7 sessions of speech, language and communication therapy together. [...] Although my husband is still able to express himself fairly clearly we were amazed at how much these sessions improved our ability to communicate effectively, we learnt (and practised) strategies to improve word finding, turn taking, repairing breakdown in conversation, topic management and dealing with frustration caused by misunderstanding. We learnt to recognise where problems might arise, and how to prevent them or reduce their effect. We really could communicate better afterwards, it improved our relationship, and there was a measurable improvement in my husband's perceived QoL. It was also helpful because we both enjoyed the sessions [...]

Wife of person living with young onset dementia

**Example – responsive and consistent care, meaningful occupation and participation** → social well-being

Wife of person living with young onset dementia

The biggest, best and huge thing that has happened to us has been the involvement of what started out as a companion for my husband when he was still at home and I had retired. We still did not really want to be involved in support groups and our CPN put us in touch with a chap [...]. Roy started by just going for walks with my husband but these gradually morphed from a few hours to complete days. This gave us a break from each other and, for my husband some decent male company. When he retired most of his friends 'forgot' him, which I know he found incredibly upsetting. Roy became his best friend and, 7 years later, still is.

**What needs does positive support meet?**



Need to be met (Why)	Activity (What)	Delivery (How)	Professional (Who) and when	Impact for person (Outcome)	Timeframe and review (start and finish date)
To feel held and supported	Outpatient review	One to one	Consultant Psychiatrist, 3 monthly	Being cared for, monitored, check of my health, source of person centred clinical specialist advice	Indefinite
To maintain identity (previously a head teacher)	Forget-me-nots / Envoy / Ambassador	Meetings, conferences, reading, advising, consulting	Clinical psychologists, students, monthly and as required	Enjoyment Connectedness Identity Contributing	6 monthly review with Consultant Psych
To continue to contribute	Inter-generational support from psychology students, volunteers for above	Formal and informal meetings	Pool of students /volunteers with supervisors, 1-2 times per month	Helping young people: enrich their placement, offer guidance, experience, friendship	Annual review

## Preliminary idea for guidance

**Theme and sub-theme heading, e.g. Empowerment: Having a Voice**

**An example from the survey – 'John'**

**Benefits to John of having a voice**

**Other themes illustrated by this experience and their benefits to John**

**How else might younger people with dementia be enabled to have a voice**

**Benefits to the services**

**How can commissioners and service providers enable this to happen**

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## Conclusions from Angela positive real-life examples

- The picture is not all bad – 59.3% in our sample rated care as at least 'mostly good'
- 233 people provided 856 examples of positive support
- Our analysis suggests experiences are rated positively when they lead to the person with young onset dementia:
  - feeling held & supported
  - maintaining autonomy & identity
  - being enabled to contribute
  - having a sense of belonging,
  - having enjoyment & pleasure
  - experiencing growth & resilience
- Our survey has suggested what needs to be provided and how, to help people with young onset dementia achieve these results

## Our next steps

- Complete our analysis
- A knowledge exchange event to share guidance – Nov 2019
- Leaflets for good practice
- Journal articles

Project finishes early December 2019

### Taking the field forward

- Produce useful 'tools' based on our findings (e.g. audit checklists for providers/commissioners to assess their provision. Guidance for clinicians to use with people with YOD and families to establish needs and a care plan.
- Pilot, roll-out and evaluate the 'tools'

## Some thoughts to take away

- What sort of young onset dementia pathway do you have locally?
- How do you establish the WHY behind provision for younger people with dementia?
- Does your service fulfill the HOW and WHAT aspects of Good Practice?
- Do you need further information or connections re young onset dementia?
- See <https://www.youngdementiauk.org>

## Thank you for listening!

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[www.ucl.ac.uk/psychiatry/the-angela-project](http://www.ucl.ac.uk/psychiatry/the-angela-project)

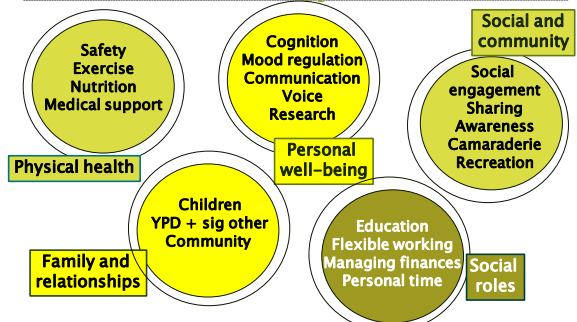
## MSNAP young onset dementia related standards

- 1.1.4 a specific pathway for young onset dementia, people with learning disabilities and people with rarer types of dementia
- 2.3.5 a named lead within the team for people with young onset dementia
- 3.5.13 access to in-depth assessment of occupational functioning and neuropsychological assessment as required (e.g. for young onset dementia...)
- 6.5.2 can refer on to specialist services for rare or young onset dementia and/or complex care needs (e.g. regional/tertiary neurology/neuropsychiatry services)
- 6.7.2 signposts younger people with dementia to structured activities such as work, education and volunteering.

## 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

## What did YPD or supporter perceive as being provided by the services? Support with ....





### Services after diagnosis for 233 people with young onset dementia

Number of services in first 6 weeks after diagnosis	N	Service in which assessed and diagnosed			
		Neurology	Memory clinic	Older people's mental health service	Specialist young onset service
0	84	61.4% (35)	37.3% (28)	38.2% (13)	22.2% (8)
1	70	19.3% (11)	36% (27)	50% (17)	41.7% (15)
2+	48	19.3% (11)	26.7% (20)	11.7% (4)	36.1% (13)

### Some service indicators

Who manages care?	Nobody	GP alone	GP/shared care	Neurology alone	OPMH alone	Specialist YOD service alone
	16% (36)	19% (43)	9% (20)	7% (15)	11% (24)	20% (45) Other 40 (18%)
% know who to contact if have questions	42%	53.5%	70%	80%	71%	98%
% who see same professional each time?	5.7%	37%	41%	14%	30%	47%
% with a key worker?	14%	17%	53%	13%	41%	76%