

The Angela Project

Improving diagnosis and post-diagnostic support for younger people with dementia

Vasileios Stamou

Centre for Applied Dementia Studies, University of Bradford



Background

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

The Angela Project

Aim 1

Improve the accuracy of YOD diagnosis

Objectives

Develop quality indicators that:

- a) will act as a guide for clinicians
- b) meet the needs of those who receive the diagnosis during the process

Aim 2

Improve post-diagnostic services and support for YOD

Objectives

Develop guidance on best practice that:

- a) meets the needs of YPD and supporters
- b) will enable commissioners and service providers to improve post-diagnostic care and support

Who is taking part?

- Younger people with dementia
 - Primary carers of YPD
 - Other family members/supporters who are affected by the diagnosis of YOD
 - National and international clinicians and experts in YOD
 - Service providers and commissioners
- **15 key NHS sites in the North, Midlands, and South including:**
 - dedicated YOD diagnostic services
 - age-generic dementia diagnostic services
 - neurology-led diagnostic services
 - **Northern NHS Sites:** Pennine Care, Leeds and York Partnership, Northumberland, Tyne and Wear, Northumbria Healthcare, Gateshead Health, Tees, Esk & Wear Valley
 - Third sector organisations and other NHS sites taking part in some aspects

Improving post-diagnostic care

National Survey: The Improving Support & Service Use Survey (Online/paper, Focus groups)

Good practice examples, overview of service use, costs, satisfaction with care, care patterns



Follow-up Interviews with younger people with dementia and caregivers

In depth understanding of good practice examples & met needs



Interviews with Service providers and Commissioners

Barriers & facilitators to commissioning/providing good services



Guidance on Best Practice in post-diagnostic care and support for YOD

- Illustrative 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 survey (Preliminary findings)

- 198 responses so far (70% volunteered for a follow up interview)
- 45% from NHS sites, 55% from third-sector

- Age at diagnosis: 37 – 65 years old, $m = 56.5$

In paid employment

Yes – 5%

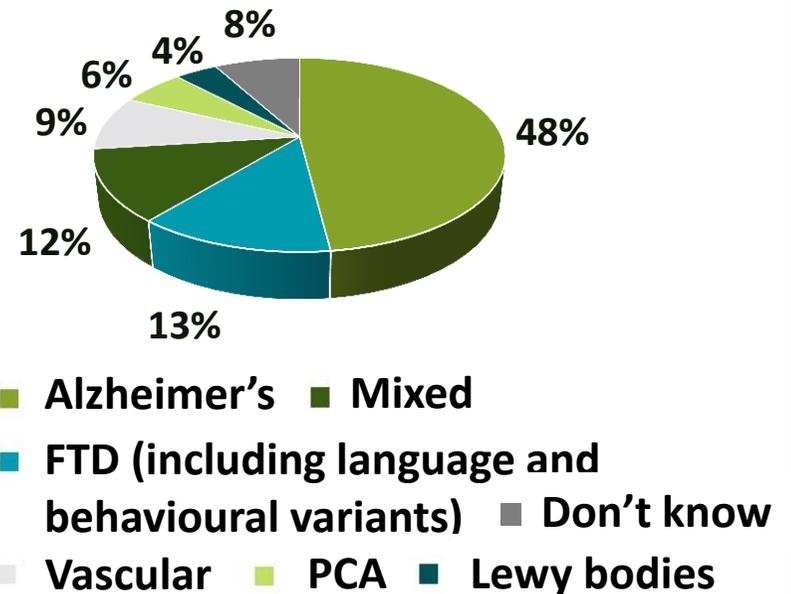
No – 95%

Living alone

Yes – 19%

No – 81%

Diagnosis



Preliminary analysis

Overall framework



- **Living well with dementia across the care pathway, after diagnosis**

Positive examples of support



- **What** was provided/achieved by the services?
- **How** were the services supportive of the needs of YPD/supporters?
- **Why** did the support feel positive and meaningful (needs met)?

Common aspects of good practice



- **Common characteristics of positive experiences of support - essential elements of good practice across the care pathway**

Service Types in Positive Experiences (Preliminary findings)

- General Practitioner
- Assessment and Diagnosis Services
- YOD specific service
- Specialist Dementia Nurse
- Dementia Specific Advice and Information Services
- Care co-ordination

- General Advice and Information Services
- Meaningful Activity and Occupation
- Self-Help
- One to one support
- Counselling
- Assistive Technology
- Supporting Independence

What was provided by the services? (Preliminary findings)



Advocacy
Referral
Advice &
Information
Future care
planning

Access/signposting to
appropriate support



Voice
Recreational
Socialising
Camaraderie
Sharing

Social opportunities



Finances
Education
Cognition
Relational Interv.
Medical Support
Transport
Safety

Targeted information/interventions

How were the services supportive? (Preliminary findings)

Approach
Attitude
Honesty
Responsiveness

Professionals

Services

Consistency
Continuity
Collaboration
Proximity
Holistic

**YPD/FM/
Supporters**

**Trustworthy, Active listening,
Instilling confidence, Reassuring**

Why the support felt positive and meaningful? (Preliminary findings)

Understanding,
Immediate help & support,
Feeling held & supported,
Relief, Protection

Being heard,
Expression
of feelings,
Communication

Active, Independence, Comfort, Fun

Hope, Motivation, Purpose,
Giving to loved ones

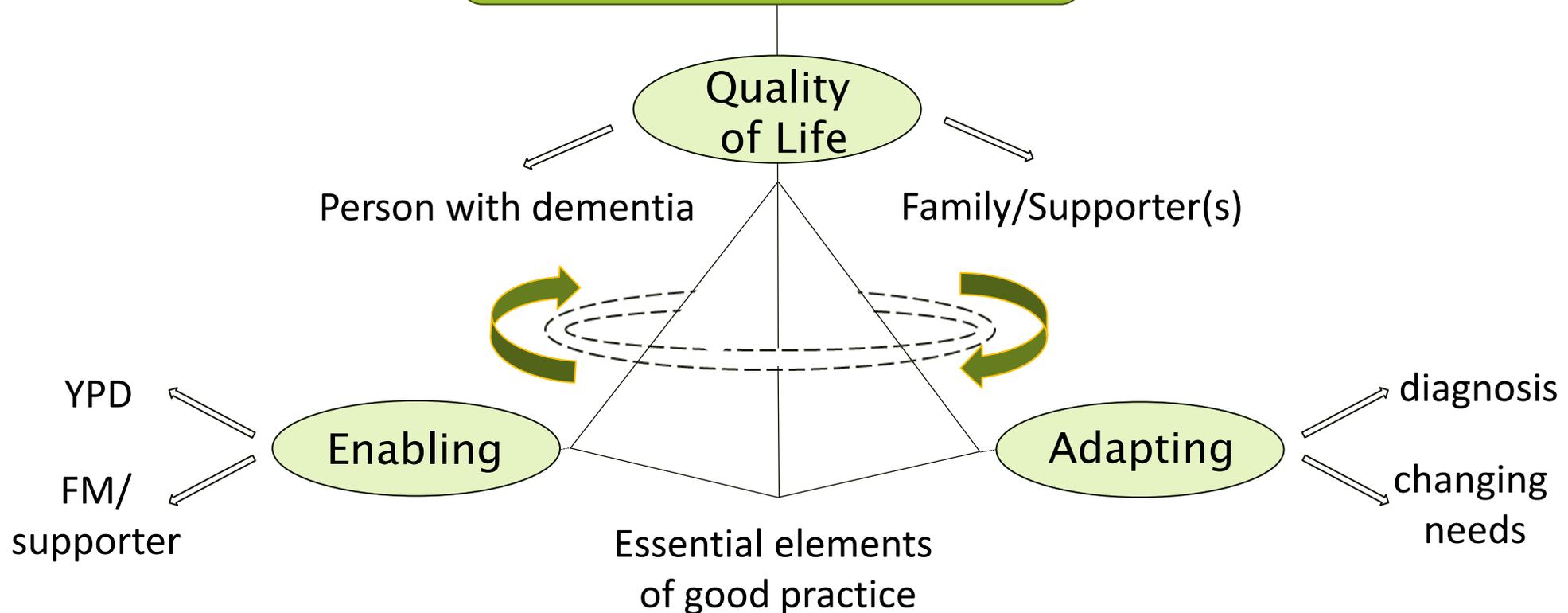
Contribution, Valued, Destigmatisation

Physical exercise,
Cognitive skills, Mood regulation



Common aspects of good practice (Preliminary findings)

A holistic approach to living well with dementia, after diagnosis



Example 1 - Hope

“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)

Example 2 – Education

“The mostly I get is from Meri Yaadain group. We usually meet every month and share experiences from the different way of life. If the carer needs education, they call specialists on dementia, or from the benefit side, or for any other kind of information needed, e.g. for adaptability equipment, falls, disability living allowance or if someone is suffering badly. It happened so many times. I learned a lot, because sometimes the symptoms in dementia patients are so different. You get to learn what you have to do in this kind of situations, and that you need to support the person with dementia whatever the situation is. So many people have appreciated that”.

(Family member)

Example 3 – Relational interventions

“We attended 7 sessions of speech, language and communication therapy together. We were amazed at how much these sessions improved our ability to communicate effectively. They improved our relationship, and there was an improvement in my husband's concentration and perceived QoL. It was very good therapy for me to be able to talk about our situation in a safe environment with someone who clearly knew a lot about FTD, was non-judgemental, kind and empathetic. We both enjoyed the sessions and bonded so well with the two therapists. It was highly person-centred”.

(Family member and YPD)

Example 4 – Family support

“Alzheimer Scotland provided access to a counsellor and a clinical psychologist for members of the immediate family who required help. Invaluable to be able to speak to an impartial person who had knowledge of the particular issues that coping with a loved one with a dementia diagnosis brings. The support given took the burden off each individual family member to cope”.

(Other family members)

Objectives on post-diagnostic support for the next 18 months

- Achieve minimum target of 200 responses to survey by Sept 2018
- Conduct 8 focus groups to address diversity
- Conduct follow-up interviews
- Conduct interviews with service providers and commissioners
- Use data to develop guidance for improving post-diagnostic support across the care pathway (according to diagnosis)

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Contact details: V.Stamou@bradford.ac.uk, tel. 01274 233 994, mob. 07876 790 462

Website: www.ucl.ac.uk/psychiatry/the-angela-project

University College London

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