

Wigan Later Life and Memory Service (LLAMS): Improving Young Onset Dementia (YOD) Services

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INTRODUCTION

Approximately 5% of people diagnosed with dementia are under-65; this is known as young onset dementia (YOD). Being given a diagnosis of dementia at this age may have more impact on the person because of issues such as work, finances and family responsibilities (Alzheimers UK, 2015).

Typically, dementia services are designed for older people and there has been concern about the standard and consistency of YOD services across the country (YoungDementia UK, 2016; Rodda and Carter, 2016).

In Wigan, we estimate that 130 people are living with YOD. They are offered the same diagnostic and post-diagnostic support as people with late onset dementia, which raised the question of whether the service is meeting their needs.

AIMS & OBJECTIVES

To evaluate how Wigan LLAMS provides services for people who have been diagnosed with YOD and their families.

Objectives– to find out

- Who is living with YOD in Wigan?
- Does LLAMS meet their needs?
- Are there any gaps in services? How can we do things better?
- How does LLAMS fit with other services in Wigan?

DESIGN AND PROGRESS



WHAT? 50-70 questionnaires
WHO? Current and past service users
WHY? To get an overview of people's experiences
WAITING FOR RESPONSES



WHAT? 10 interviews
WHO? People with YOD and/or their family.
WHY? To better understand people's experiences
2 INTERVIEWS COMPLETED



WHAT? 2 focus groups
WHO? LLAMS staff
WHY? To hear staff views on the service
2 FOCUS GROUS COMPLETED & ANALYSED

RESULTS SO FAR

The focus groups with LLAMS community staff identified three main ways that they support people with YOD and what is important at each stage.

MAKING THE DIAGNOSIS

GETTING THE DIAGNOSIS RIGHT

GIVING THE DIAGNOSIS

COPING WITH THE IMPACT OF THE DIAGNOSIS

LIVING WITH THE DIAGNOSIS

FINDING THE RIGHT SUPPORT FOR THE INDIVIDUAL

Across the LLAMS pathway, there were common themes that influenced how staff are able to support people with YOD

- People's needs can be more complex and require more input
- People are seen as being 'too young to have dementia'
- There is a small population and only infrequent cases of YOD
- The availability of support networks and relationships

"You do have to assess that, because the majority of the time that's what it is, anxiety, depression... but it's always there at the back of your mind you can't dismiss the fact that it may be a dementia and you do have to do a lot more unpicking with someone younger with a dementia"
Nurse, Memory Service

"They did come to the post-diagnostic groups, which they did get a lot out of, but when I spoke to them, their concern was they felt that they were too young to go those groups"
Nurse, Memory Service

"Their partners and their families are younger so they're working and doing things... and so they're just being left at home, but if they're older they've got their partner to take them to groups"
Support worker, Community Mental Health Team

"We might only have two or three in the service at any one time and our groups are only really beneficial for people in the early stages of the condition, so if we're keeping somebody for a year in order to wait to have a viable number for groups, it may no longer be of use to them, things have moved on hugely in a year in for this population"
Occupational Therapist, Memory Service

"It's really difficult because they don't want to be seen in a walking group with older people that are maybe walking a lot slower, maybe have more physical health problems, more mobility problems but there isn't a great deal out there tailor made for that 1:1 support for someone with young onset"
Nurse, Community Mental Health Team

"It wasn't very clear what were his problems, although they certainly seemed significant, and he was treated for months for depression when actually his wife was adamant from the beginning, and it became patently obvious as things progressed, that this was far more than a depression"
Occupational Therapist, Memory Service

"We've had people through the service that reported "If I get a diagnosis of dementia, I will end my life" and that's really difficult to manage as a clinician... Because there is more impact, you find that there's more depression and anxiety in this younger onset range that is part of the condition isn't it?"
Nurse, Memory Service

"What we found difficult was tailoring a care plan to meet her specific needs... if she saw a reflection in a mirror, she didn't recognise herself and she would go to smash the mirror. So to take her out in public places was extremely difficult"
Support Worker, Memory Service

"His wife wanted the diagnosis quickly, but because of the age you don't want to just do that; give a diagnosis and it's the wrong diagnosis. You want to make sure everything's done before we do that, because as you say it affects everything doesn't it?"
Nurse, Memory Service

Staff felt that the service is good at making and giving people their diagnosis, but after discharge from LLAMS there was a lack of appropriate support in the local area.

In part, this was influenced by the role of the memory service which is not commissioned to provide long term support after diagnosis. Staff were concerned about how people could be supported during "the middle bit" when people had been diagnosed, but did not have symptoms or risks that would require input from the community mental health team.



"It's appropriate [for making] a diagnosis. It's sort of the after, the treatment, the things that we've already discussed that isn't particularly age-appropriate..."
Occupational Therapist, Memory Service

"I think that's sometimes where we have gaps. Because they come through memory service and we provide all this support, they don't then have the risks and needs that warrant CMHT so we discharge them..."
Nurse, Memory Service

Staff felt that people would benefit from access to peer support, meaningful activities and regular contact with a professional that they trust.

It was also felt that there was a lack of understanding of YOD in the wider community, including other professionals e.g. benefit assessments. Staff were unsure how these could be provided, but identified that LLAMS was not necessarily the best service to meet all of these needs. It was recognised that there is an important need for joint working with other agencies, particularly when supporting people with complex needs.

The ongoing questionnaires and interviews with service users and/or people who support them will be used to identify how they view the accessibility and acceptability of the service LLAMS provides, and how they feel that services in Wigan can be improved.

REFERENCES

- Alzheimer's Society. (2015) *What is Young-onset Dementia?* London: Alzheimer's Society.
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