

# Young Onset Dementia Engagement Report

Experiences of diagnosis and support services across South  
London

November 2019

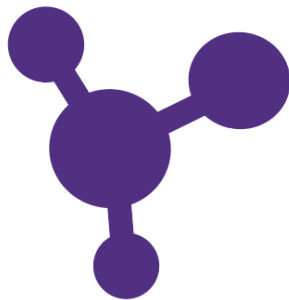
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# About

The Health Innovation Network is the Academic Health Science Network (AHSN) for south London, one of 15 AHSNs across England. As the only bodies that connect NHS and academic organisations, local authorities, the third sector and industry, we are catalysts that create the right conditions to facilitate change across whole health and social care economies, with a clear focus on improving outcomes for patients.

This means we are uniquely placed to identify and spread health innovation at pace and scale; driving the adoption and spread of innovative ideas and technologies across large populations.



## Section 1

# Background

The South London Mental Health and Community Partnership (SLP) has convened a south London working group to gather information on the existing young onset dementia diagnosis pathways and available support across south London, with the view to learn and make improvements to the diagnosis experience and access to support services.

This group was formed in recognition that the SLP, a partnership of the three mental health trusts, is in a potentially unique position to implement positive changes in the young onset dementia pathway.

### Membership of the group includes:

- Oxleas NHS Foundation trust
- South West London and St Georges NHS Mental Health Trust
- South London and Maudsley NHS Foundation Trust
- St Georges NHS Foundation Trust
- Kings College Hospital NHS Foundation Trust
- London Dementia Clinical Network
- Lewisham CCG
- South West London Health and Care Partnership
- Health Innovation Network (HIN) AHSN

During October and November 2019, the HIN undertook engagement on behalf of the working group, with people diagnosed with young onset dementia and their carers to understand their current lived experience of diagnosis and the support they receive.

## Section 2

# Executive Summary

This young onset dementia engagement report provides an overview of the experience of people with young onset dementia and their carers from diagnosis to post-diagnostic support.

The Health Innovation Network (HIN) engaged with 3 young onset dementia support groups in south London during October and November 2019. Our findings present a mixed picture of experience of good practice and some clear indications of changes that are required to improve the lives of people with young onset dementia and their carers in south London.

All participants highly valued their young onset dementia support group, the fact that there are only 3 known existing support groups in south London indicates that more needs to be done to ensure all people with young onset dementia and their carers can benefit from this support.

The following is a summary of findings of the engagement a full list of recommendations can be found in **section 8**.

- There is a need to offer psychological support to the children of young people with dementia and adult family carers
- Access to speech therapy is a highly valued very scarce resource
- The financial and employment impact on families of working age is a source of great concern, providing access to financial advice and employment support should be prioritised.
- Clear communication pathways need to be set up between hospitals, GPs and support services (e.g. Alzheimer's society)
- Support services that are integral to the diagnosis process are highly valued
- GPs should receive more guidance on 'signs and symptoms' of young onset dementia through the patient presentation /families' stories (recognising the complexity of diagnosis of this disease)
- Young onset dementia support groups are highly valued and more needs to be done to ensure equitable access across south London
- People with young onset dementia, their children and carers are isolated. Consideration should be given to a digital response that enables peer to peer support 24/7

## Section 3

# Demographics

People with dementia whose symptoms started before they were 65 are often described as 'younger people with dementia' or as having young-onset dementia. The age of 65 is used because it is the age at which people traditionally retired. However, this is an artificial cut-off point without any biological significance.

The symptoms of dementia are not determined by a person's age, but younger people often have different needs, and require some different support. (Alzheimer's Society <https://www.alzheimers.org.uk/about-dementia/types-dementia/younger-people-with-dementia> )

The exact number of people under 65 with a diagnosis of dementia is not known in south London. Earlier in 2019 the South London Partnership (Oxleas, South London and Maudsley and South West London NHS trusts) reviewed the data on each trust's clinical record system for the period April 2016- March 2019 to establish the known recorded dementia diagnosis of this age group.

- 300 patients were identified with a diagnosis of dementia
- The ages range varied between 31 years to 64 years
- The dementia diagnosis increased significantly between the ages of 50 and 60 years.

It is recognised that these 300 patients are an underestimation of the number of people living with dementia in south London, e.g. it does not necessarily capture all patients diagnosed in acute NHS settings (Neurology). The working group are continuing to refine how to capture this information.

## Section 4

# Methodology

The HIN approached the South London CCG Commissioners and the London Dementia Clinical Network to identify any existing young onset dementia forums/support groups. Only 3 young onset dementia groups were identified, 1 was already known through the working group, 1 was identified by the HIN and one was sourced through a commissioner. The 3 groups based in Twickenham, Wandsworth and Blackheath were all approached, and all agreed to participate in the engagement project. A total of 21 people (11 people diagnosed with young onset dementia and 10 carers) participated in either a 1:1 interview or a focus group. See table 1 for breakdown by setting.

**Table 1: Engagement by Setting**

Engagement by Setting	Method	People with dementia	Carers
St George's Young Onset Dementia Support Group, St George's Hospital, SW17	1:1 interview	0	8
Age Exchange Blackheath Young Onset Dementia Group, SE3	1:1 interview	4	2
Alzheimer's Society Young Onset Dementia Group, Age UK wellbeing centre, Twickenham TW1	Focus Group	7	0

## Section 5

# Approach

A HIN Senior Project Manager, experienced in qualitative research with people with dementia carried out 1:1 interviews and facilitated the focus group, supported by a project support officer. Interviews and the focus group were based on six 'Measuring Dementia Outcomes' questions (see Table 2), developed by the Health Innovation Network in 2017 to obtain meaningful feedback from people with dementia on how services meet their needs to inform service improvement.

The HIN used the six questions below (table 2) as a base to explore people’s experiences of diagnosis, available support and services.

Consent was obtained for interviews and the focus group to be recorded and transcribed verbatim. Thematic analysis was undertaken to identify commonalities within the data.

**Table 2: Interview and Focus Group Questions**

Question	Yes	No	Sometimes	Comment
1. On diagnosis, did you feel supported and understood?				
2. Do you know how to get involved in research trials?				
3. Are you involved in decisions about things that are important to you?				
4. Do you know how to get help to get what you need?				
5. Do you know about local services or activities so you can choose what would be best for you?				
6. Do you feel the service helps you?				

## Section 6

# Findings

People’s experiences were similar across all three groups and are presented together by question theme. **Tables 3** and **4** show responses to the questions split by people with dementia and carers. It is important to note that although respondents answered ‘yes’ to some questions, the reality of young onset dementia means accessing services or help is not straightforward and this is unpacked and discussed in more detail below.

**Table 3: responses from people with young onset dementia**

Questions	Yes	No	Sometimes
On diagnosis, did you feel supported and understood?	3	5	3
Do you know how to get involved in research trials?	4	4	
Are you involved in decisions about things that are important to you?	5	1	1
Do you know how to get help to get what you need?	4		1
Do you know about local services or activities so you can choose what would be best for you?	6	1	1
Do you feel the service helps you?	11		

**Table 4: responses from carers of people young onset dementia**

Carers of people with Young Onset Dementia	Yes	No	Sometimes
On diagnosis, did you feel supported and understood?	2		7
Do you know how to get involved in research trials?	6	2	1
Are you involved in decisions about things that are important to you?	6	1	2
Do you know how to get help to get what you need?	5	3	1
Do you know about local services or activities so you can choose what would be best for you?	4		3
Do you feel the service helps you?	9		

## 6.1. Diagnosis

Five respondents (2 carers) stated they felt supported and understood during their diagnosis of young onset dementia. When asked how they were supported, respondents shared that they had access to a support worker during the diagnosis or immediately after, and or had timely contact with The Alzheimer’s Society or similar post-diagnosis. Diagnosis where a support worker wasn’t present was often referred to as ‘clinical’ and lacking emotional support.

Six participants said there was a delay between diagnosis and being referred to, or contacted by the Alzheimer’s Society or similar, ranging from one week up to six months, impacting on their emotional wellbeing and how well they felt supported. When they did access this support, it was valued by most people with participants appreciating the signposting to Young Onset Dementia Groups. Two people shared they travel some distance to the Young Onset Dementia groups, citing there was no Alzheimer’s Society presence in Lambeth or Young Onset Dementia support Kingston.



Eight respondents had experienced a delay in diagnosis, explained by three people with young onset dementia having co-morbidities or rare forms of dementia, resulting in lengthy exploration and testing before diagnosis. Five participants felt delays in diagnosis were due to their younger age and GPs not listening to them or taking their symptoms seriously, either as the person with dementia or as a carer. One person shared the delay was themselves not attributing behaviour changes to dementia. One respondent highlighted the risk of inaccuracy in assessment based on the questions used, highlighting relevance to a young person with dementia versus an older person.

Theme	Quotes from people with young onset dementia and carers
<b>A clinical delivery</b>	<p>“It was a very clinical delivery, in terms of after my brain scan and tests. I was then confronted with ‘you have dementia’ and that was it”. - <b>Person with young onset dementia</b></p> <p>“I went to my doctor, just me on my own...‘you have dementia’ and that’s all they said. I then went back to my spouse and told them. It was just ridiculous that the doctor told me I had dementia without my spouse coming with me”. – <b>Person with young onset dementia</b></p> <p>“Usually there is someone sitting in the room, but we didn’t have that. There was no advice to point us in any direction. The dementia nurse said, ‘oh yeah...they have 3 years to go, so after 3 years they won’t remember anything”. It is like reinforcing they had dementia rather than trying to support”. - <b>Carer</b></p>
<b>Delays in diagnosis</b>	<p>“It’s only recently they have been diagnosed after a good 5 years of having problems. It has been, not a rough ride, but it is just so hard to work out what it isn’t.....”. - <b>Carer</b></p> <p>“They [person with young onset dementia] would answer the questions and get 18/20. It took over a year to 18 months to get a diagnosis. They are heavily involved in politics and so to ask them who the prime minister is... And they worked in statistics so asking them to count back from 100 ... those sorts of questions have always been, and still are part of their life.....”. - <b>Carer</b></p> <p>“Their GP gave them a diagnosis of depression. That was around 3 or 4 years before their official diagnosis. It was a case of, ‘you have depression, just take some tablets and you will be fine’. We changed GP and they said, ‘I am sorry, but I don’t think this is depression and I am going to refer you to St George’s’. We got the referral to St George’s and in a matter of months, weeks in fact, we had a proper diagnosis. So, from their [GPs] referral to here, it was a short period of time”. - <b>Carer</b></p>
<b>Families not being listened to</b>	<p>“It took too long to diagnose. I blame it on my doctor. My doctor blamed forgetfulness on age. I felt silly keep taking them [person with young onset dementia] back, but they were getting worse. I said we live with the person and would notice things. In the end I didn’t leave until we had been referred”. - <b>Carer</b></p> <p>“I did keep saying that my spouses mum had appeared to have the same thing, but I don’t think anybody was really listening about that, but of course it was exactly the same symptoms, dropping words at the beginning, sentence structure...”. - <b>Carer</b></p>

"I knew...there were so many things that they [person with young onset dementia] would get completely wrong, or knives and forks in the wrong place, but at no point did anyone recognise this towards the diagnosis. It wasn't a perfect diagnosis, but it may have been better to have more support in what I was saying in the early stages. To have that dismissed by the GP and keep going through the same process again..." - **Carer**

**Dementia not considered (family)**

"Well I think we had a good diagnosis. Our problem was with the lateness. We didn't understand what was going on. Me working in the city for long hours, it was my children telling me the symptoms. Once we got the diagnosis the support has been good". - **Carer**

**Support during and post-diagnosis (positive feedback)**

"I had a scan and it was quite quick really. The best thing for me, at that time was somebody who was working with them. As soon as you got your diagnosis, they were there. After diagnosis we had a cup of tea and they signposted me to different things". – **Person with young onset dementia**

It was someone from the Alzheimer's Society who signposted me to any support. Somehow my doctor or someone contacted them, and they got in contact with me, and told me about this group". – **Person with young onset dementia**

"Monthly consultation meetings – my support worker from there was extremely helpful for practical things". – **Person with young onset dementia**

"I changed my doctor (GP) and they were the best doctor I could have had. The doctor sent me to get tested and it was positive". – **Person with young onset dementia**

"We had a private diagnosis. My spouse was successful in business, so we weren't part of the system. We saw the NHS consultant privately and they said, 'you need to switch [to the NHS]' so when we came to St George's we felt supported, more than I had privately, because then joined a support group, then a dementia nurse was introduced and that kind of thing". - **Carer**

"I mean, perhaps I'm sounding too positive, but the experience that we've had has been good, but we have had to put a lot of effort in as well – time to do the research etc". – **Carer**

**Support post diagnosis – negative feedback**

"At the time of diagnosis my spouse was pretty stable. We were told there was a dementia nurse, and 24-hour crisis line. When they [person with young onset dementia] had psychotic episode a month later, I rang everybody, and nobody would help me. Nobody would even answer the call. We ended up in A&E and they said they would call the police to have them sectioned. My spouse ended up in Hospital for 12 and half weeks..." - **Carer**

"No, there was no support. I knew there was a time frame so I researched everything I could find about the type of dementia he had and there wasn't very much. I had to do everything myself as there was nobody there to support a young person". - **Carer**

"I think we got lost in the system a bit (following diagnosis). For about 6 months we weren't told about the Alzheimer's Society. I don't understand why GPs can't flag it up

when they do a diagnosis". – **Carer**

"After diagnosis, I would have liked somebody to have taken us to one side, not in a clinical way, but take us to one side and say, 'you've had this diagnosis, how can I help you to move forward and deal with things?'. I would have liked somebody to say, 'you have young children, so they are going to need support as well. You are young, still have a mortgage...you need to sort out your finances'. – **Carer**

### Sharing of information between services

"We are lucky we have a Parkinson's nurse who is working with the GP and two consultants. They are great. If we did not have them, then we are completely fragmented". - **Carer**

"We went to the memory clinic, and then when we came to the Hospital to do tests, ...of course nothing was on any screen at all that had been done at the memory clinic. So, this is the whole thing – we had to explain everything all over again and that happened over the year of tests at Memory Clinic .....saying that the last time we saw ... they [clinician] didn't even have the letter with my spouses diagnosis on their screen that was sent to us six weeks ago. So, I had to give them what they had said about it! I could only do this because I have 5 years' worth of hospital letters and appointments. When they first thought it was epilepsy, again nothing was on the screen – luckily, I have the paperwork". - **Carer**

"They [person with young onset dementia] didn't get a proper diagnosis. It was like, you have a few memory problems. The word wasn't mentioned. No one told the GP. There was no official diagnosis for at least six years" - **Carer**

## 6.2. Involvement in clinical trials

Eleven out of 21 people knew how to get involved in research, four of these people were involved with a clinical trial. Information about clinical research was shared by GPs, hospital Consultants and the Young Onset Dementia Groups. There were mixed feelings about clinical research in terms of wanting to help future generations and feeling they should be involved to help others but concerned their condition may worsen. Two people were interested in being involved and put their name forward, but had not heard anything since, implying an expectation that if you are registered you would be involved.

## 6.3. Involvement in decisions

Overall people with young onset dementia and their carers felt involved in decisions about their care, particularly those who were in earlier stages of the condition, and this was echoed by the facilitators at the Twickenham and Blackheath groups. Carers took responsibility for decision making if needed but felt the decisions they made were in collaboration with their partner. Two people with dementia who attended without their carer shared that the condition had affected their ability to be involved at the same level as before

### Quotes from people with dementia, a carer and a Group Facilitator

"You are all able and responsible to make decisions without a shadow of a doubt. You are absolutely still able to and quite confident to be responsible". - **Facilitator, Young Onset Dementia Support Group**

"It is 24/7 with my spouse and I think I am a full-time carer. I am involved with everything because they are dependent on me. I do talk to them [spouse] and they don't feel like they aren't involved". - **Carer**

"It's hard as sometimes my family don't understand what it is like to have dementia. They don't understand what I mean". – **Person with young onset dementia**

"I have a child who helps me quite a bit. I feel my social life is affected a bit". – **Person with young onset dementia**

## 6.4. Sourcing help if needed

The Young Onset Group was the main source of information to get help and support for most respondents. Outside of the groups it was generally felt that there is limited information and help available. Five carers shared they had actively researched information about their partner's condition and support available as there had been none available at the time of diagnosis.

Diagnosis when younger, still working, with financial responsibilities and or with dependent children was cited to be a very different experience to that of a person diagnosed at an older age. It was stated that support with housing, finances and respite and domiciliary care often doesn't apply to younger people as often people are in employment and above the threshold for means tested services. Nearly all people interviewed had now stopped working due to their diagnosis, or reduced hours or stopped working to provide care, which has impacted on present and future financial security.

The psychological effect on dependant children was highlighted by four people, citing no services or resources to help them understand and manage a parent's diagnosis and impact on family life. Carers knew about the Alzheimer's Society CRISP (Carers Information and Support) programme and some had accessed it, others were on a waiting list. Two carers had accessed private counselling services but found them insufficient in duration or understanding about young onset dementia and how it impacts on people's lives.

In relation to health services, most people were satisfied with the hospital-based teams who managed their care post-diagnosis, trusting their Neurologist and appreciating the support offered by the nurse consultant. Three respondents cited difficulties accessing and communicating with health services for routine appointments. Two respondents and a facilitator highlighted delays and barriers in accessing speech therapy, a need that was supported by members involved in the focus group at Twickenham.

### Theme

### Quotes from people with young onset dementia and carers

#### Knowing about and accessing help

"We take care of ourselves now, so that doesn't necessarily apply to us. In terms of a carer – I do most things. I haven't applied yet, but I find the system incredibly long winded. What needs to happen is a bullet point thing, just for each stage you can get this, this is what you should do and who reply to. Not a 40-page form that says at the end you aren't going to get anything". - **Carer**

"I got social services involved early on to be told I wasn't entitled to anything because I am so young and I was fit and healthy, so as a carer, I wasn't entitled to anything like that". - **Carer**

"It's a combination of being told by various health professionals, but also my own research I have done myself". - **Carer**

"Social services were hopeless. I went for a carers assessment and had a student do the assessment and I didn't even get the report afterwards". - **Carer**

"This group here is the tip of the iceberg. There are a lot of people who do not come out and say, 'I have dementia'. It is a social stigma having the dementia, and on top of it, having young onset, is a double stigma. People are embarrassed, so they basically become isolated". - **Carer**

"People ask you questions but you can't answer if you don't have the information in the first place". – **Person with young onset dementia**

## Housing

"We lived in a town house and my spouse couldn't navigate the stairs. We had to rent privately, paying £1900 month, but my spouse had lost their job, we had our children still living at home. I was using credit cards to pay for things. We were on the list for sheltered housing, but to cut a long story short, kept getting turned down as I wasn't 60. One of the other things with sheltered housing is that our children effectively became homeless. They were a big part of my support system – we are now living in a block of flats with people who are around 80. ...." - **Carer**

## Respite Care

"I've had trouble finding respite care. My spouse and another have to travel to Essex for young onset dementia respite care. There is only one other in Tottenham. This is something I have to pay for myself. More day centres would be useful where they do not have to stay and is local". - **Carer**

"As far as social services are concerned, no [to respite care] because all that is means tested and all that. When you are on a tight budget, even though things are means tested, you think I haven't got the money to pay for respite. It is £1700 a week or something. It is a big hit". - **Carer**

## Financial Support

"If we needed to get a live-in carer and there are care homes near us that we would have to pay for, but nevertheless they are there. However, it is expensive, and you do wonder how the hell you are going to be able to afford it without help". - **Carer**

"We don't get anything as over the threshold. We are living on half the earnings that we used to earn". - **Carer**

"You will find it all comes down to money. There is no point going through any social system at all as we aren't entitled to anything, apart from dependency allowance which is £5k and that's it. We still have dependent children and both working up until January last year. There is nothing else. It has taken me 9 months to get care in place for my spouse as they can no longer be left alone, but none of that is through the social system". - **Carer**

"Somebody is 48, they have dependants, credit card, mortgages. There is massive financial implications". - **Carer**

## Psychological support

"There needs to be help with counselling. I have been through everything and there is nothing. There was somebody a few months ago, she was on the floor in absolute pieces. We are trying to be pragmatic, but all in the same boat which is devastation. I have been to see a counsellor and psychiatrist – one session each – and neither of them could help. How do you help somebody to grieve when they [person with dementia] are still physically present?". - **Carer**

"I'm the one close to having a major breakdown and it is not just me, it is my children. My child is unwell. They think they has MS or something and has a neurologist. My other child drinks too much, but won't admit they have a problem. You know...this is what it has done to us" –**Carer**

"I'm finding it difficult to cope. They advertised a course where they would help talk through difficult situations. It was full and they said they would get back to me. I think that would be useful. Do they wait to the point where it is too late and then come back and say now, we will help you as you've done something stupid". - **Carer**

"Some spouses have a pretty hard time when partners become violent. I think that has been brought out at some of the care meetings and we have had help to deal from people here (young onset dementia support group) to help us deal with those situations". - **Carer**

"People have children, teenage or younger ....and they get bullied at school. All these things make it a different game from elderly dementia, but people do not understand that". - **Carer**

"My child just bottled everything up. They cut themselves off from their friends. I tried everywhere to get help, but there was just nothing. In the end, I ended up booking a course through Jigsaw, the bereavement counselling service for children, but this was further down the line. I think if I could have found something right at the very beginning, so they could have gotten everything out and not internalised it, it might have helped them better". - **Carer**

## Experience of health services post diagnosis

"There are lots of professionals writing letters to those who have been referred, but the services just aren't joined up". - **Carer**

"I asked the consultant if we could speak 1:1 as it is not nice for my spouse to hear me say they went wandering etc. Therefore, I don't tell the truth to the consultant as it is not nice for they [spouse] to hear". - **Carer**

"My spouse is meant to have a review every 6 months with the GP. The person allocated is never there to answer the phone, or when I go in and ask for appointment, I'm told they will ring me, and they never do. I would rather they do nothing than say they will do it. I could strangle them, for the energy I've wasted for nothing...it's really annoying". - **Carer**

## Speech therapy

"In this borough you used to get support as part of the illness. I need help as I can't get my words out. There is now a thing in the borough, but only if you can't swallow you can access speech therapy. This is very important for all of us". – **Person with young onset**

## dementia

“When we got our diagnosis, speech therapy was mentioned, but we never ever got offered it until [Group facilitator] was in touch with a speech therapist who was doing a programme. We went on that programme, but by that time it is too late, their [person with young onset dementia] speech had almost gone. Whereas, I think if we were offered it at diagnosis...that is one of the first things you really need to have”. - **Carer**

“Emotional support is important, but it is also physical support; like speech and language therapy. If you had cancer, they will do anything for you. They talk about it a lot in Government but don't do anything about it”. - **Facilitator of Young Onset Dementia Support Group**

## 6.5. Local services and activities

For most respondents, the Young Onset Group is the only service/activity accessed. Four out of 11 people with young onset dementia had attended additional activities tailored towards young onset dementia and found these enjoyable, all stated the sessions had a waiting list and were time limited. All respondents cited the importance of being able to socialise with people of similar age, with consensus that mainstream dementia services were inappropriate due the age difference and activity style. Being able to meet without your partner attending was important to those who had the opportunity, citing independence and ability to talk freely with others in a similar situation. One group met weekly, others were less so, with a request from participants for increased frequency and more age and activity appropriate services to be made available. Two people with dementia and three carers highlighted the importance of staying physically active yet found it difficult to find appropriate activities or organisations to support them to do so.

Theme	Quotes from people with young onset dementia and carers
<b>Mainstream dementia services</b>	<p>“There are for older people. We tried everything. But there was nobody.... like I would phone up local authority and I would ask them what services they had [for young onset dementia] and well...there was nothing. There was just nothing”. - <b>Carer</b></p> <p>“We have not set foot in them as this is the only group around their [person with young onset dementia] age. They attended an art group once but didn't feel comfortable. If they didn't have this group they [person with young onset dementia] wouldn't be going anywhere – this is the only time I see them smile, they have made friends and feel good about”. - <b>Carer</b></p> <p>“The services aren't catering for the ages we are all at. There is memory café and although they are all lovely, the people are talking about rationing and bringing in stuff from the 40s”. – <b>Person with young onset dementia</b></p> <p>“We know about them [Dementia services] but none of them are best for us – all services are tailored for the elderly. Inclusive activities are good – walking football, sporting memories. At the moment such activities are totally lacking, almost zero” - <b>Carer</b></p>

"There are issues around young onset dementia and that they are physically fit and don't want to be sitting down. My spouse still runs a mile and half every day, they box, they go to the gym. Obviously, someone is with him. It is a very different thing (young onset dementia) and everybody merges and mashes it together [with elderly dementia] and yet it is completely different". - **Carer**

"I'm trying to hold down a job. All the things for carers are in the day-time as they think all carers are old" - **Carer**

## Young onset dementia support groups

"As a carer I didn't realise it was going to be this hard, but this group has made it easier for me. We are not alone (here) definitely not". - **Carer**

"It's nice when people come up to you and say can we talk. Not many people do that. Sometimes other people don't understand what it is like so coming here is important" – **Person with young onset dementia**

"I love the group; I would like it to be every week if possible" – **Person with young onset dementia**

"The group fills a void. It would be nice if it was more frequent" – **Person with young onset dementia**

"I don't think of my spouse as a carer. They are my spouse. I still go out with my friends and come to things like this and they [spouse] should do their own thing." - **Carer**

"Full of praise for this group and my spouse loves coming". - **Carer**

"They [person with young onset dementia] love coming here. They are becoming isolated as normal conversations become difficult. We've had friends for 40 years and we have stopped being invited to things since my spouses' diagnosis. They [young onset dementia peer support group] did a memory disco and my spouse loves music from the 60s and they really loved it". - **Carer**

"I think the opportunity to talk [without carers] and be more independent is needed". – **Person with young onset dementia**

## Other young onset dementia activities

"I have been told about Sydenham Gardens, but you can only go once for the six weeks then it's over". – **Person with young onset dementia**

"About three weeks ago the memory clinic hosted a garden party and said they were going to do it more often, but I've heard nothing from them." – **Person with young onset dementia**

"Kew Gardens November walk, we are on the list for that. There is a health walk, but I asked whether they [person with young onset dementia] could do that as they are physically fit, but they are restricted to certain boroughs so we can't do that". - **Carer**

## Mainstream activities

"My spouse liked going to the gym, but it got expensive as I had to go with them. It is a problem because you still have all your bills to pay and you still have a mortgage to pay and if you want to stay fit, and you like going to the gym and it is a sociable thing, these companies need to step up their game....I am sure they can work out some sort of programme". – **Carer**



## Section 7

# Conclusion

This engagement report with people who have young onset dementia and their carers highlights opportunities for improvements related to the diagnosis experience and the immediate and subsequent support offered to the individual and families.

Delays leading up to diagnosis are commonplace. In some situations, this will be necessary due to the complexity of indications in order to eliminate health conditions with similar symptomology. The findings identify missed opportunities to consider dementia as a possible diagnosis, for example listening to patients and their families concerns and identification of behaviour change, or when patient's present with existing conditions that may overshadow behaviour change associated with dementia.

Receiving a diagnosis of dementia is a clinical experience, yet critically it is the availability of immediate emotional support that can result in the experience being interpreted as 'good' or 'bad' by patients and their families. Having access to a support worker at the time of diagnosis was felt by participants as crucial; having information about support available and a name and number to call reassured participants that they were not alone. The importance of this was highlighted by those who did not have this experience, with no contact from the Alzheimer's Society or similar, or in some cases no contact with their GP, led to feelings of abandonment and 'lost to the system'. Any time lag in being told about support impacted on feelings of isolation, highlighted by several participants receiving a call from the Alzheimer's Society, or similar, 1 – 2 weeks post-diagnosis but feeling this was too long a delay. In other words, what may be an acceptable response to the system, isn't necessarily acceptable or what is needed by patients and their families.

All participants felt that the impact of having a young onset dementia diagnosis is very different to developing dementia at an older age and its socio-economic impact is not understood by either health or social care. At the time of diagnosis, people are usually in full time employment, managing mortgages and can have dependent children at home. People may be financially secure at the time of diagnosis, but security can quickly deteriorate when people stop working or reduce their hours. Many participants were above the threshold for accessing support, but very much struggling financially and in need of information and guidance as to how to manage their finances.

Carers frequently mentioned the emotional impact of the life changes associated with young onset dementia, becoming a carer, stopping work and looking after children if they had a family. Outside of the CRISP programme, which is infrequent and therefore not available potentially at the time of need, psychological support for carers and the wider family was found to be non-existent or lacking in understanding. Services or interventions for children were mentioned specifically as an area for improvement. Carers also requested increased availability of local young onset day and respite care, referencing two homes in Essex and Tottenham only.

Overall there is satisfaction with care and support offered by hospital-based teams. There was noted frustration with a lack of joined up information sharing across services (GP and hospital) and some people had experienced unsatisfactory service in booking appointments and accessing the Dementia nurses. Access to speech therapy was specifically mentioned by 8 participants, in terms of access and availability. It was felt that dementia related speech therapy was overlooked with reference to other long-term conditions and that it was something you had to fight for. Encouragingly several participants had been told about involvement in research and some of these were involved in trials.

There was unanimous agreement of a lack of services for people with young onset dementia. Mainstream dementia services are viewed as inappropriate due to the generational difference in group members and activities, and often seen as too sedentary for a physically fit younger person. The three groups involved in this engagement work were the only three regular groups the HIN identified in south London. These groups are described as a lifeline for people attending, both in terms accessing social/peer support and information about other services and wider support. Although some participants were aware of and/or accessed young onset activities in their locality and enjoyed them, these were time limited or one-off events. For several participants, the groups were their sole social activity that week or fortnight and there was consensus across all participants for groups to be more frequent.

## Section 8

# Recommendations

Engagement with people with young onset dementia and their carers has identified the complexities associated with reaching a diagnosis and subsequent support received. It has highlighted valued interventions alongside gaps in service provision, information and support.

Based on the findings, the HIN recommends:

- A south London approach be adopted to implement and improve the experience of people with young onset dementia and their families and carers
- GPs should be supported to recognise signs and symptoms of dementia in younger people, with a greater emphasis on listening to patients and their families, in combination with clinical assessments and testing.
- Diagnosis support should include the presence of a support worker at the time of diagnosis or very shortly after diagnosis
- Timely, clear communication needs to be prioritised between the hospital, GP and Alzheimer's Society to ensure people are not 'lost' in the system and receive the right support at the right time.
- The availability of speech therapy for people with young onset dementia is a priority
- Children and 'family' carers would benefit from greater access to psychological support.
- Consideration should be given to the use of digital technology to support young people/'family' carers to facilitate peer to peer conversations.
- Wider availability of age appropriate support groups and activities for people with young onset dementia to participate in, with a stronger focus on maintaining physical health and activity would be highly valued. Ideally regular events, rather than one off or time limited
- Financial advice and employment support should be provided to people with young onset dementia and their 'families'.

- Provision of young onset dementia specific day / respite care services within South London should be available.
- The support groups who participated in this engagement work to receive a formal update on changes to improve their lived experience of young onset dementia, (planned or in progress) in summer 2020.

## Section 9

# Acknowledgements

The HIN would like to thank the all the members of the Young Onset dementia support groups that contributed their lived experiences to this report

- St George's Young Onset Dementia Group,
- The Alzheimer's Society Young Onset Dementia Group Twickenham
- Age Exchange Young Onset Dementia Group Blackheath.

## Section 10

# References

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