



Young Onset Dementia

Experiences of Support

January 2023



What we did

Our aim was to find out about people's experiences of living with young onset dementia. We asked about the dementia support they had received and what their experiences were.

We developed a survey and put this online from 25 October 2022 to 2 January 2023. This was publicised via our newsletter and on social media. We also contacted 27 GP surgeries, who have patients with the condition, and 42 voluntary and community groups directly. Buckinghamshire Council Dementia Strategy Group also promoted the project. We collected feedback from those living with young onset dementia, their relatives, carers and friends.

Key findings

- + Two people told us they received no information when first diagnosed.
- + Most people told us, that when they received the diagnosis, it was difficult or very difficult to get information about the support that might be available.
- + We asked the people who had been given information on diagnosis about what they'd received. Less than half were given any specific information about young onset dementia and their type of dementia
- + Less than half said they had been told about making a will or power of attorney
- + Most people had not received information about: employment rights; benefits; pension advice; peer or family support groups; how to keep fit and mentally stimulated; or where to find age appropriate activities.

We asked more about the information people received at the time of diagnosis.

- + Just over half said that the information they received was age-appropriate 'to an extent'. Only one told us it was personal to the individual living with young onset dementia.

- + Only one said the information and support was received quickly enough.
- Many people found it difficult to access the support they wanted later on.
- + Half wanted someone to contact them regularly to see how they were getting on.
 - + Few attended any peer support groups.
 - + Most knew no other individuals / families living with young onset dementia.
 - + A few family members thought the person with young onset dementia would have benefitted from socialising with their peers.

Our recommendations

We recommend that Buckinghamshire Council works with dementia services to provide targeted, and local, young onset dementia support. This could include:

- providing information, which may differ from that required by older people with dementia, in a timely, personal and age appropriate way
- ad-hoc one-to-one support for issues faced by those with young onset dementia.
- a named contact regularly reaching out to individuals to see where any further help and information might be needed
- connecting peers (either those with young onset dementia themselves or their support network) to create mini support networks.

We recommend that Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board (BOB ICB):

- encourages general practice to consistently code patient records with (young onset) dementia on the EMIS system so that those who may need more support because of this diagnosis can be identified
- ensures that, on diagnosis, Memory Clinics give those with young onset dementia (and their support network) information about tailored support
- encourages general practices and primary care networks (PCNs) to work together to connect those with a young onset dementia diagnosis and their support network across a locality.

What the project was about

Background

People are said to have young onset dementia (YOD) where symptoms first occurred before they reached 65 years of age.

According to The Alzheimer's Society, approximately 900,000 people in the UK live with dementia. Of these, it is estimated that 7.5% (70,800) live with young onset dementia. This figure is based on a report ("[Prevalence of all cause young onset dementia and time lived with dementia: analysis of primary care records](#)"). This was published in September 2022 in the Journal of Dementia Care. They found that only 441,909 people in the Recorded Dataset in England for the end of September 2020 had any coding to show a formal dementia diagnosis. Only 3.4% of these were under 65 years of age. However, their research calculated that a further 4.1% (all now 65 years or older) had also received a diagnosis prior to their 65th birthday. So, in total, 7.5% (33,454) of those coded were actually diagnosed under 65 years of age.

"The estimated prevalence figure for young onset dementia, where diagnosis was between age 30–64, is 92 per 100,000 of the general population" (Dementia UK)

In October 2022, it was estimated that there were around 8,000 people in Buckinghamshire living with dementia. The NHS GP EMIS figures show that 111 people in Bucks under 65 years of age have a dementia diagnosis. Using the figures above, we might suppose that there are a further 132 (4.1%) of people with young onset dementia but who are now above 65 years of age. This would suggest that there may be at least 240 people with young onset dementia in Bucks.

It is important that people get an early diagnosis and support to manage their condition and expectations. This is particularly important as a recent report suggested that the suicide risk in patients with young onset dementia, within 3 months of diagnosis, was 6.69 times higher than in patients without dementia ([Risk of Suicide After Dementia Diagnosis](#)).

“While services that are tailored to older people may be able to provide safe and effective care to younger people with dementia, people living with YOD, not surprisingly, often express a preference to have bespoke services.” (www.nhs.uk)

On 1 April 2022, Buckinghamshire Council recommissioned the Alzheimer’s Society to provide dementia support in Bucks. This service is called Dementia Connect. People can phone a national number and seek support. A dementia advisor can refer the person to a local advisor if they feel someone would benefit from local support. In the 6 months since the service was commissioned, local dementia advisors had only spoken to one person with dementia under the age of 65.

In autumn 2022, the Council were working with various groups to collect feedback on dementia support. They aimed to present papers to the Transformation Board by January 2023. Few people with young onset dementia had given their views to the Council by October 2022.

Both Oxfordshire and Berkshire West (the other counties in BOB ICB) have specific provision for young onset dementia in addition to more general dementia support. Details of these can be found in Appendix 4.

Our Aims

We wanted to know what good dementia support looks like for those living with young onset dementia and where support might be improved in Bucks. The project looked to:

- enable those living with young-onset dementia to feed their views into the commissioners of dementia support in the county
- provide Buckinghamshire Council with the experience of a group of people living with dementia but from whom they hear little
- give further insight into the issues which are particular to those living with a condition that many perceive to only be associated with old age.

Who talked to us

Full details about who talked to us can be found in Appendix 2. Twenty five people started our survey. However, only 15 of these told us they were registered with a general practice in Buckinghamshire or lived in Buckinghamshire. This report is about these 15

people's experiences. They all identified themselves as White British. We also found the following:

- 66% identified as a woman and 33% as a man
- 20% live with young onset dementia and 80% told us they live with, or were relatives/friends of, someone with young onset dementia
- The median age was 54.

What we heard

Two respondents, living with young onset dementia, told us they didn't know when they received a diagnosis or didn't answer the question. The thirteen other respondents said the young onset dementia diagnosis had been received less than five years ago. We were able to have more detailed conversations with four survey respondents.

Initial Information about support

"1.1.4 Provide people living with dementia and their family members or carers with information that is relevant to their circumstances and the stage of their condition." (National Institute for Health and Care Excellence – NICE)

Nine people told us, that when they received the diagnosis, it was difficult or very difficult to get information about the support that might be available.

"When we were given my husband's diagnosis we found it hard to get information about the particular dementia as it is rare."

"I was difficult to get information about support for someone who was only 59. We were given lots of booklets with phone numbers and website links. We also wanted to know more about what would happen next ... and there is no clear-cut answer; everyone is different. Much of the research I had to do myself. We got nothing from the GP."

“The dementia specialists are based at the JR [John Radcliffe hospital] in Oxford so all support seems to also be based in Oxford. It is also hard to know what support you need at the time”

“I didn’t get any information.”

One person said they found it neither easy nor difficult to find information. One person told us they had found it easy to get information at the diagnosis stage.

“Alzheimer’s society, Dementia UK, Mind and Rare Dementia Support are great for information and support, they will reassure and supply useful information in literature and support groups at a time when you are desperate for help and counselling. Being put in contact with an Admiral Nurse at the earliest opportunity is essential.”

However, they did qualify this by saying:

“Due to mixed and misdiagnosis, all information had to be self-found...”

Information source

Nine respondents told us where they first looked for information about living with young onset dementia when they received the diagnosis. The three most popular answers were Dementia UK, The Alzheimer’s Society and an NHS Memory Clinic.

People could tick as many options as they liked. All answers can be seen in Table 1.

Provider / Organisation	Total
Alzheimer’s Society / Dementia Connect Service	4
Dementia UK	5
Rare Dementia Support	2
NHS Memory Clinic	4
The GP	3
Young Dementia Network	2
I didn’t get any information or support when first diagnosed	1
Other	4

Table 1 - Where did you go first to get information about living with young onset dementia?

The 'Other' providers mentioned were Dementia Adventure, Citizens Advice, family, and the Internet. One person told us they got information from most of the sources we suggested because they went looking for it. However:

"I wasn't given any other than what I found out myself"

One person told us they had not heard of the Dementia Connect Service. Instead, they had contacted Dementia UK and spoken to an Admiral nurse. However, they were disappointed that they couldn't actually meet one as the service is not available in Bucks. However, they also said the national helpline just gives out

"the same information that I get anywhere else."

What information was provided

Seven people told us about what information they (or the person with young onset dementia) were given. The full results can be seen in Appendix 3. People could tick as many options as they liked. The top answers were:

- Information about young onset dementia and the type of dementia
- Making a will and lasting power of attorney
- Which benefits and grants you may be entitled to

"He talked to Citizens Advice. I don't know who told him to go there but they told him to go to the job centre. He got Employment Support Allowance (ESA)"

Getting financial advice, how to access counselling and advice on driving were all mentioned once. No one told us they had received any information about employment rights, pension advice, or where family could seek support.

"Sometimes I'd really love to talk to people who are I my position."

Neither did anyone tell us they had received any information about peer support groups, how to keep fit and mentally stimulated or where to find age appropriate activities.

When asked how the information was provided to them at diagnosis stage, via leaflets was the most popular answer. Four people told us this was provided in conversation with the GP or in a phone call with a dementia advisor from the Alzheimer's Society. The full results can be seen in Appendix 3. People could tick as many options as they liked.

Was the initial information and support age appropriate, personal and timely?

Four people told us that the information and support they received, at the time of diagnosis, was appropriate to the age of the person with young onset dementia.

“Being a care giver, I am aware of dementia and the effects it has, and I am lucky enough to know where to go to find information.”

However, this was not the case for everyone.

“Age UK sent us the same links as they would send to a person who was 80. We were trying to get information such as financial support for a young person, not an old one.”

However, only one believed this information and support was personal to that individual.

“It was good to find about the rules about driving with dementia as he drove for a living...”

Only one of the respondents felt they received the information and support quickly enough.

Some told us they were not told of the consequences of not having a power of attorney.

“They told us about getting a lasting power of attorney organised, but no one explained why or how and so we didn't...”

“Very important to get power of attorney as the process of Court of Protection is very stressful and takes a very long time; 10 months and still waiting.”

Several told us they were unaware of local support groups or people who could help with their particular situation.

“... no one pointed us in the direction of any dementia organisations or even Carers Bucks when he was diagnosed. I only found about the latter 2 years after his diagnosis and that was via my sister... We should have been given more information at the beginning about how we could get in touch with people who could help us and had a similar experience to us. If I'd have had that information earlier, I could have been more proactive, and we might have been in a different position today. We had 1.5 years between appointments at the Whiteleaf Centre and meanwhile I'd be crying down the phone to my sister saying I don't know what to do.”

Many felt that they should have been given information about financial planning and benefits early on.

“It took nearly 6 months to get the benefits he was entitled to and by that time our savings had gone”

Two people told us that, because it had taken so long to get a diagnosis of dementia, any information about employment support would have been too late.

“He'd been fired before he got his diagnosis.”

Useful additional information

We asked if respondents didn't feel they got enough information when receiving the diagnosis, what additional support and information would they have wanted.

Two people told us one named person, who contacted them on a regular basis, would be very useful.

“Someone to visit periodically to find out how you're coping and if you're getting all the help you're entitled to. It's all very well giving out leaflets etc. telling you what to do but I didn't feel I had the energy to sort it out as I was still in shock from the diagnosis my husband had been given.”

Of the people we interviewed, none knew of any other family in Bucks living with young onset dementia. One of them suggested that if there was one point of contact, they might be able to link families together to provide informal peer support.

"I missed having the one person, the one point of contact, I could go to for support any time we needed help. Instead, I'd ring and have to explain the whole story only to be passed onto someone else and have to start all over again, every time I had to phone for something relating to dad and his condition. That one person would see families and be able to bring those with similar conditions and circumstances together say over a 10-15 mile radius. We could build lived knowledge within the county. People who work with dementia have studied it but those who live with it at home have massive, if specific, experience and knowledge too. It shouldn't be the case that I feel that we are the only ones in the area with these issues."

Two people wished they had been given more information about support groups.

"More about support groups for him and me. He was embarrassed about his condition so when he was let go from his job he just moped around all day at home whilst I was at work. He couldn't drive anymore and didn't see anyone. Because we don't know anyone else with young onset we didn't know what was out there."

One person mentioned the value of being better informed about financial matters especially when often, people when first diagnosed, are still working and paying mortgages.

"Finances are a great concern; early assistance with information would also have helped."

Two people told us any information would have been better than receiving none.

"Anything, mostly help with where a safe place to live, when you're only 53"

Two people also commented on the medical intervention they thought should be in place.

"I would have expected for her to receive follow up consultations to monitor the progression of the disease."

"An early correct diagnosis would have helped."

Conclusion

The average time taken to get a dementia diagnosis for someone over 65 is 2.2 years ([Dementia UK](#)). Often, due to different issues presenting themselves (instead of or as well as memory loss), a diagnosis for young onset dementia takes an average of 4.4 years. On average, a person will see between 2 and 5 consultants before receiving this diagnosis. People also told us that the diagnosis of the type of dementia can also change over time. It is understandable that people feel frustrated that getting a firm diagnosis takes so long.

Several respondents felt isolated and on their own without peers to support them. While they did not want continuous help, they were looking for someone to contact who understood the support issues they faced when looking after someone with young onset dementia.

Support and information later on

Nine people told us where they went later on, after diagnosis, for information and support. Three people said the Alzheimer's Society and another three said they looked online. One talked to the nurses at their surgery. One person said they took a course in understanding the principles of dementia and found the Rare Dementia Support service helpful. Positive comments about this subsequent support included:

"Rare Dementia Support are the best people to contact for young onset dementia; everything they say correlates with what is on the NICE website."

"The Alzheimer's Society are excellent. The phone operators are very good counsellors. I was very low once and they spent 1.5 hours on the phone with me. They then made a follow up call. If you're concerned about things, speak to them. They have a wealth of knowledge."

"Admiral Nurses are very compassionate and knowledgeable; extremely important to be put in contact at earliest opportunity."

However, people also left some negative comments. Having received no/little information at the diagnosis stage, three people were unaware of any organisations that might help.

"[We turned to] family as we didn't know there was anywhere else."

"Friends told us we should get power of attorney and have given us a list of things we should do but we need more help."

"I only looked at the Dementia UK website, and asked for help, yesterday once I knew about your survey and checked out the Healthwatch website. The admiral nurse was really helpful and gave me lots of links to websites that might be able to help me."

However, not everyone found information they were given personal or helpful.

"I rang Alzheimer's UK and Age UK, but they just gave out numbers for me to contact which I already had."

Peer Support

Only one respondent told us that the person with young onset dementia met with any other people their age living with similar symptoms, to share. They said they met up online and in person with their peers. We asked about the advantages and disadvantages of being able to talk to others who have young onset dementia.

"Understanding that you are not the only person trying to deal with a terrible situation. Being able to offer advice can also help all parties."

Of the other eight who told us the person with dementia did not attend any peer support groups, four said they would like the opportunity to attend one. Of these, three said they would attend a group if it was in person, and one said they preferred an online group.

One told us they didn't want to meet with their peers. Three others told us they didn't know whether their relative would want to attend a peer support group or not. One relative explained this was because the person with young onset dementia does not accept the diagnosis. Another told us that by the time of diagnosis, their loved one was no longer physically active.

"[They have] now lost mental capacity. It is difficult to know what [they] can understand."

They now attend a dementia group where everyone else is much older.

"It's possible that he'd like to spend time instead with people his own age, but he can't communicate that, and the option isn't there."

"Someone we know suggested a local dementia group she takes her mother to. But he doesn't want to go to a group for old people; he's 64, not in his 80's.... He's lost all independence... His dementia might not be so bad if he'd been more stimulated."

NICE Guideline NG97 recommends that those with dementia are offered "a range of activities to promote wellbeing that are tailored to the person's preferences".

What works well

There was one positive comment about what works well within dementia support services in Bucks for those with young onset dementia and their families / support circle.

"I researched Bucks and was impressed that they employed Dementia Mapping. One of the reasons why my wife is now in a care home in Bucks."

There were four negative comments about there being no / little support, for the family / carer network, or not being able to access it.

"Carers Bucks have a lot of good information, but it took a long time for me to find them. I can't attend their groups though as I work. He's not good in the evenings anymore; I can't go out. I don't know if it's his condition."

"Not sure, as we can't find anyone else to relate to"

What could be improved

We asked what could be improved within dementia support services in Bucks for those with young onset dementia and their families / support circle. The comments included:

- provide one consistent point of contact

- more information being given at diagnosis

“Publicise what support is out there; we only found the bits we know from friends.”

- better support early on

“Currently my husband refuses to allow any other person in to help”

- check people understand what they should do and why
- put people in contact with their peers, whether they are someone living with young onset dementia, or they support someone with the condition.

“Put people in contact with dementia support groups so people our age can talk to others in the same position. It's too late for him as his speech is so poor now but perhaps if there had been a group of young onset dementia people like him meeting, he would have gone along too knowing they all had the same problem. Now he's gone into his shell, its' too late. Although it's not too late for me but I can't leave him in the evenings and work in the daytime. I worry about financial stuff and him. It would be good to talk to people my age living through the same problems. I attend a stoma support group but nothing for dementia.”

“there doesn't seem to be any support local to us. If there is we certainly haven't been told about it or given any information.... I have only ever been given information about a support group in Oxford which is not practical for the patient. Also support group for the carers.”

Any other comments?

We have summarised these by theme.

Memory Clinic / GP

We did receive comments about the time it took people with young onset dementia to get a diagnosis and about how the actual appointment was arranged.

“Missed opportunities during early stages resulted in traumatic events of loved one being sectioned.”

“It also takes too long to get a Memory Clinic appointment; 16 months for dad.”

“The Memory Clinic phoned my dad to make an appointment, instead of myself or [X]. He told them he had nothing wrong with his memory and hung up. It took another 3 months to get another appointment.”

Hospital – Staffing – levels and training

One person told us that, despite a note on their records, the person with young onset dementia in Stoke Mandeville hospital, in May 2021, was not acknowledged as having dementia, and treated appropriately, because of their age.

“He was given a red tray at mealtimes but still no one helped him eat.”

Cost of Dementia Care

Two people told us about the financial strain of looking after someone with dementia.

“It would have been too difficult to manage if I hadn’t retired. We fell into the financial band where no social care support was funded. We’d have to pay for everything. All our reserves would have dwindled away but at the crucial point she was sectioned.”

“I can’t claim carers allowance because I work part-time.... I’ll have to give up work when he needs more care. He gets benefits at the moment, but they will disappear when he passes away. I’ll have given up work and will then have to live on savings until I get my pension in 9 years’ time or get another job. But who will employ me with my disabilities, and at my age; I’m already 57. People don’t understand how it affects younger people.”

Acknowledgements

We thank all the people who talked to us and / or completed our survey.

Disclaimer

Please note this report summarises what we heard and what we saw. It does not necessarily reflect the experiences of all service users.

Appendix 1

More about our approach

Who we included

We set up the survey to hear from people who were registered with a Buckinghamshire GP surgery or lived in Buckinghamshire. Anyone not registered in this way, or who did not live in Buckinghamshire, was excluded.

In this report we have summarised the free text feedback offered by people according to the categories used across the Healthwatch network. These summaries should be regarded as an indication of how often a theme was mentioned rather than an exact count. Some feedback offered views on more than one theme so the number of results can be more than the number of responses. People may have made a similar comment in response to different questions. The numbers for each theme reported under each question should not be added together. People could do the survey more than once so the total number of responses may be more than the number of individuals who responded.

Where suggested by the data, we looked to see if there were any differences in the answers between some groups. We focused on statistically significant findings in the main body of the report. Our statistical findings are in Appendix 4.

Who we will share our findings with

We will share our findings with the Care Quality Commission and Healthwatch England, the independent national champion for people who use health and social care services. We also share all our reports with the Buckinghamshire Council Health and Wellbeing Board and the Health and Adult Social Care Select Committee.

We will also share our findings with:

- the Buckinghamshire Oxfordshire and Berkshire West Integrated Care Board (BOB ICB).

How we follow up on our recommendations

We will request a formal response to our recommendations from:

- The BOB ICB PCN Lead (on behalf of all the PCNs).
- Buckinghamshire Council.

We will follow-up each formal response to confirm what changes have been made.

Appendix 2

Who did we hear from?

What age group are you in?

Age Group	Total
18 – 25 years	1
46 – 55 years	3
56 – 65 years	4
66 – 75 years	1
Total	9

Are you a:

Gender	Total
A man	3
A woman	6
Total	9

Is your gender identity the same as your sex recorded at birth?

Gender Identity	Total
Yes	8
Total	8

What is your sexual orientation?

Sexual Orientation	Total
Heterosexual / Straight	9
Total	9

How would you describe your marital or partnership status?

Marital or Partnership Status	Total
Cohabiting	1
Divorced / Dissolved civil partnership	1
Married	7
Total	9

What is your religion or belief?

Religion / Belief	Total
Christian	6
No religion	2
Total	8

How would you describe your ethnic group?

Ethnic Group	Total
White: British / English / Northern Irish / Scottish / Welsh	9
Total	9

What is your postcode?

Postcode	Total
HP6 5	1
HP13 7	1
HP19	1
LU7	1
MK17	1
SL2 4	1
SL9	1
Total	7

Do you consider yourself to be a carer?

Are you a carer?	Total
No	2
Yes	7
Total	9

Do you have a disability?

Do you have a disability?	Total
No	7
Yes	2
Total	9

Which of the following disabilities apply to you?

Which disabilities?	Total
Physical or mobility impairment	1
Long term condition	2

Do you have a long-term health condition?

Do you have a long-term health condition?	Total
No	6
Yes	3
Total	9

Which of the following long-term conditions?

Which long-term health conditions?	Total
Asthma, COPD or respiratory condition	1
Cardiovascular condition (including stroke)	1
Other	2

Appendix 3

What did people tell us?

What information were you (or the person living with young onset dementia) given?

Please tick all that apply.

Information	Total
Information about young onset and the type of dementia	3
Advice about your employment rights	0
Where to go for pension advice	0
Where to go for day-to-day financial advice	0
Which grants and benefits you may be entitled to	2
Making a will and a lasting power of attorney	3
Government advice on driving with dementia	1
How to keep yourself fit, healthy and mentally stimulated	0
How to find age-appropriate activities, matching your interests, in your area	0
Where to access support from a young onset dementia peer group	0
Where to access counselling	1
Where your family / supporters can get help for themselves	0
Other	1

How was this information / support provided? Please tick all that apply.

Method	Total
Leaflets	4
In a conversation with a GP	2
In a conversation at the Memory Clinic	1
In a phone call with a dementia advisor from the Alzheimer's Society / Dementia Connect	2
In a face-to-face conversation with a dementia advisor from the Alzheimer's Society / Dementia Connect	0
A website link e.g. Google	1
Other	3

Appendix 4

Support for Young Onset Dementia outside Bucks

Oxfordshire has just over two full time equivalent young onset dementia advisors. They are based in the Cognitive Disorder Unit at the John Radcliffe hospital where dementia diagnosis takes place. They are in touch with people, if required, from diagnosis to end of life. On diagnosis, clients have 6-8 sessions of 1-2-1 support; time to process the diagnosis away from the family. The emphasis is on living positively with dementia but preparing their life for the changes that young onset dementia brings. They look at the individual's values and what they can do rather than concentrate on what they can't do. They encourage people to keep doing hobbies, and to get a personal assistant or family member to support them when they need this assistance.

They support over 300 people regularly. About 120 clients have young onset dementia and another 180 are family members. They contact each client every 6 months for a review, but the client can phone in between. They also run four different types of support group with each meeting once a month. Most clients only attend 1-2-1 support; going to groups only when their condition worsens. About 25 people with young onset dementia now attend a new 8 week cognitive stimulation group.

People in Berkshire West can access the services of Younger People with Dementia (Berkshire) CIO (YPD). Each week, they run a range of daytime activities for those living with young onset dementia. They also have educational courses for family members, four different carer support groups and link to Admiral Nurses.

If you require this report in an alternative format, please contact us.

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