

Dementia groups slam Derry's diagnosis waiting lists

Catherine McGinty

catherine.mcginty@iconicnews.ie

People in Derry, Strabane and Limavady face an anxious 15 to 16 month wait to receive a dementia diagnosis, Derry News can reveal.

Shockingly, in West Tyrone and Fermanagh the current wait is 69 months, almost six years, from initial referral to diagnosis.

There are currently 420 patients on a waiting list for a dementia diagnosis in the whole Western Health and Social Care Trust (WHST) Area.

Speaking to Derry News, Foyle MP Colum Eastwood described the waiting times as a "scandal".

The SDLP leader said: "The fact some people are waiting almost six years for a diagnosis after a referral in our Trust is a scandal.

"It is one of the worst things I have ever heard about the state of our health service.

"It is not a reflection on the doctors or nurses working to help as many people as possible, it is a damning indictment of how broken health services are and of the abysmal failure of politics to address it.

"Almost everyone knows a person or a family impacted by dementia. It's a cruel condition that has a huge impact on a loved one and their entire family and social circle."

Stressing the urgency of "catching the signs [of dementia] early", the Foyle MP said.

"It is important so someone with dementia can maintain their independence for as long as possible. These waiting times, sadly, show that these patients don't have that opportunity, even if they recognise the signs early.

"Every one of the 420 people on the Western Trust waiting list deserves the best chance at maintaining their independence and living a long, happy life.

"Their families deserve to have the longest possible time with their loved ones.

"This is an out and out disgrace and I intend to raise it at the highest levels of government."

Dr Paschal McKeown is the Charity Director at Age NI, which is responsible for services, programmes and activities to improve outcomes for older people and ensure everyone can enjoy a better later life.

Speaking to Derry News about the lengthy dementia diagnosis waiting lists, he said: "It is important people receive a dementia diagnosis as early as possible.

"This means they receive clear, timely information about their diagnosis and what it might mean for them and their family, as well as

signposts to whatever support is available."

Martin Reilly, the National Influencing Officer for Alzheimer's Society NI said tackling waiting lists and achieving faster diagnosis was "absolutely vital".

He added: "A diagnosis means someone who is worried about dementia can get the help and advice they need. Alzheimer's Society works with all the NI Trusts and has been collaborating with the WHST to provide support to people from the moment of their diagnosis and as their illness progresses.

"We know there are many people out there who are still waiting for their diagnosis and living with a great deal of worry and anxiety.

"We are keen to partner further with the Trust to provide the right level of support to people pre and post diagnosis.

"We would like to see faster diagnosis across the board, as well as a reduction in disparities across our local Trusts, where people are waiting longer in some parts of Northern Ireland than others," said Martin Reilly.

Mr Reilly explained the government needed to prioritise diagnosis now as the North faced an increase in dementia costs over the next decade.

He said: "Diagnosis is mission-critical. Northern Ireland's predicted rates are particularly high due to a range of health and demographic factors.

"More than 22,700 people in Northern Ireland are living with dementia, with over a third yet to receive a diagnosis. In addition, the number of people with dementia is predicted to nearly double to 42,000 by 2040. This has clear implications for our local Trust social care budgets."

"There are signs of hope for the future in the form of research around new drug therapies and new ways of diagnosing dementia.

"Research is key in addressing the challenge of dementia. The new disease modifying drug therapies, which have received a great deal of publicity recently, will need to have an effective diagnosis system ready once they receive regulatory approval for use in the UK."

Mr Reilly advocated starting to prepare the system and "building capacity, resources, and pathways to deliver new treatments and improve dementia diagnosis".

He said: "So, it is key central government and the Northern Ireland Assembly make dementia a priority."

"We are also working at pace to deliver new ways to diagnose dementia. A large project is already underway with Alzheimer's Society working together with Alzheimer's Research UK and the National



Foyle MP Colum Eastwood branded the length of the waiting times as "an out and out disgrace".

Institute for Health and Care Research (NIHR).

"The game-changing Blood Biomarker Challenge will revolutionise the way dementia is diagnosed.

"The project, which is being funded by a £5m award raised by players of People's Postcode Lottery, will gather the information needed to introduce a blood test for dementia into UK healthcare systems."

Dementia NI is a membership organisation which aims to empower and support people with dementia in the North "to live well" and to "drive positive change".

Speaking to Derry News, Ashleigh Davis, Dementia NI's Empowerment Lead highlighted the charity's recently established Derry Empowerment Group.

She said: "The Derry Empowerment Group, like all of Dementia NI's Empowerment Groups, is a place for people who have been diagnosed with dementia, and are in the early to middle stages of the condition.

"People come together to share experiences, provide peer support and consult with organisations to improve dementia services and policy.

"The Dementia NI Derry Empowerment Group is free of charge. I would encourage anyone with a diagnosis of dementia, in the

early or middle stages of the condition, to attend. The group meets on a monthly basis.

"We are also starting a group in Limavady this week. For more information, call 028 9693 1555 or email info@dementiani.org."

Ms Davis heads up a team of five Dementia NI facilitators throughout the North.

She explained: "When a referral comes through to Dementia NI head office, I would delegate our local Dementia NI empowerment facilitator in that area and they would arrange an initial visit with the person.

"We have a facilitator in Derry. They would explain what Dementia NI does and learn a wee bit more about the person and how their dementia is affecting them.

"Dementia NI takes the approach there is life very much to live following a diagnosis and through our empowerment groups. We would encourage people to come along and be involved in the groups, to access peer support and friendships from other people in the same boat.

"That way they will have the opportunity to become better informed about their diagnosis and will realise it is possible to live well with a dementia diagnosis.

"That is one of the most important reasons an early diagnosis is so important. It means

people get access to services like Dementia NI and they get access to appropriate resources, support and information through the Trusts' Dementia Navigator Service.

"It also gives people the opportunity to make decisions for themselves and to have the ability to plan for their own future."

Ms Davis added she would like to put a call out to offer people the opportunity to get in touch with their local Dementia NI Empowerment Group.

"I want to make people aware there is support in the Derry area and we also have a group which is currently being established in Limavady."

In a statement to Derry News, a spokesperson for the WHST explained: "The extended waiting times [for a dementia diagnosis] in the Tyrone and Fermanagh localities is due to an ongoing workforce challenge of medical staff.

"With a new Locum Consultant Psychiatrist now in post in the southern sector it is anticipated that waiting times will reduce to 26 months from April 2024.

"This is due to the Older People's Mental Health Service currently undertaking a service improvement project to review all strands of service delivery including the dementia pathway and waiting times."



Derry Dementia NI member waited almost four years for diagnosis

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catherine.mcginty@iconicnews.ie

"I went to the doctor in June 2018 and was diagnosed in April 2022."

Two months shy of four years, that is the shocking length of time Graham, a Dementia NI member from Derry, had to wait for his young-onset dementia diagnosis.

"That was from initial referral to receiving a diagnosis," Graham told Derry News.

"I first went to my GP because I was having a few issues around memory with dates and times and people," he explained.

"My doctor did a memory test, which started the ball rolling. She said I hadn't scored too well on the memory test, so she referred me to the memory clinic.

"It took a few months for that referral to come through. I then sat down and did a very similar memory test with them. They then discussed that with their colleagues and the process of diagnosis rolled out from there.

"I am told there were three brain scans, a few more memory test meetings, and a few more meetings with a specialist because of my age. With young-onset dementia, they are hesitant to diagnose and they try to fob you off with different things."

He added: "Everything is taken into consideration - your medical history, weight, height and family history. There is no family history of dementia in our family, either parents or grandparents.

"They build up a picture and then they talk to their colleagues, constantly. There is a meeting every couple of months.

"Once you are diagnosed, which has to be done by a consultant, you are referred

to your Trust's dementia navigator, and you are never seen again, by anybody. You are diagnosed and good luck, basically. 'Get your affairs in order' is what they normally tell you.

"The dementia navigator takes over and then, brilliantly, people like Dementia NI step in. Your dementia navigator, a nurse, will come out and assess you in your home. They will have a chat and see what your needs are and then signpost you to other services, like Dementia NI."

Crucially, people must get a diagnosis of dementia before they can receive medication.

"That is why it is so important to get an early diagnosis, said Graham, "because you can't get medication until you get your diagnosis and you might need to try different medications before you find the right one."

Graham said the time taken to get his dementia diagnosis caused "a major amount of stress".

"Especially because you don't really know what's going on. You are not sure if you are having a nervous breakdown. I had an idea because of my symptoms. It causes stress within the family because no-body knows what's going on. It generally makes life harder and the impact on mental health is difficult.

"It is like living in a fog. Mornings for me are very slow. It takes a while for everything to start working properly. I don't like being asked questions or being talked to in the morning. It takes a while. Everything takes longer and life is a little bit slower.

"You can't process it as quickly and that was strange. And as that went on, no-one was able to tell you what was the cause. It was just, next

appointment, next appointment, next brain scan or whatever and nobody tells you anything in the meantime because nobody wants to give you any false hope or the other way around. It is a long drawn out process.

"I was a volunteer. I did that every day during my diagnosis and I still do it. I find it a little bit harder remembering names now. I am also terrible for appointments.

"Even though I have a calendar here, with everything written on it in big bold writing, I am still turning up on the wrong day at the wrong time.

"Dementia has its challenges. It is stressful. I have not told a lot of people. Professionally, anyone I shared the diagnosis with has taken a step back. My bank won't even deal with me anymore. They deal with my wife.

"We have to do a thing called enduring power of attorney, if I get to the stage where I really don't know what's going on. However, the bank took that as activated

immediately.

"They will only deal with my wife now so things like that are strange. Handling money and information is quite hard at the minute."

Notwithstanding, Graham said he felt "relieved" when he finally got his diagnosis.

"Because I thought, 'Now we can get help'. Because, until you get the diagnosis, to be honest, no-one will touch you because, obviously, they are not sure and they don't want to jump in and start doing stuff if there is no diagnosis because there are a few other things it can be.

"It can just be a mental health issue. It can be depression. It can be lots of different things.

"So, when you get a diagnosis and meet the dementia navigator, they can signpost you to Dementia NI and one of its empowerment groups.

"Getting the diagnosis was still a shock, don't get me wrong, but it is a relief. The downside of my diagnosis was it was done by video link. I think sitting in front of somebody and giving them

their diagnosis would be better. It was myself and my wife in a room with a 70 inch video screen.

"It was basically, 'Yes, we have looked at all of your charts. You definitely have Alzheimer's. You need to get your affairs in order. Any other questions?' and that was that.

"I get fantastic support from Dementia NI. Our empowerment group has a facilitator and a volunteer to help out. It is just about meeting together and not having to explain yourself.

"There is support there. Dementia NI has lots of different activities going on. We get out and help / volunteer at different events, fundraising, doing awareness raising events, such as the recent dementia conference in the city."

Graham said people were quite surprised when they found out he had young-onset dementia.

"Everybody thinks dementia is an old person's disease," he said. "It is also about challenging the stigma, which is why it is great that Dementia NI gives us the

platform to go out and do that because we are the people with the experience of dementia."

Dementia NI members are often to be found at stands in supermarkets and community events informing people about dementia.

"We talk to people about dementia and let them know there is hope," said Graham. "You can very much live well with dementia."

Graham said he would advise people to keep pushing for a diagnosis all through the process.

"The waiting times for a dementia diagnosis need to come down, especially if there is medication that, if it is given quicker, helps. The medication I am on does not cure dementia but for some people it slows down the progression.

"I would just like to get the word out there, if you are struggling in any way at all, if your memory is starting to slip, go and talk to your doctor, because there could be something there and the more people who talk about dementia, it is not a stigma anymore."

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