There are currently over 800,000 people in the UK with a form of dementia. Over 17,000 of these are under the age of 65. The true figure may be up to three times higher as many people with young onset dementia do not seek help in the early stages of the disease (Alzheimer’s Society 2014).

Ian Grant, a dentist in Swindon, was diagnosed with dementia at 59 and had to give up work at his practice.
00:01:22 We ended up seeing a neurologist at the local hospital, which was not one of my best experiences. And um, to be honest then, we then spent a year, over a year, trying to find out exactly what was going on.

Maria Parsons Director, Oxford Ageing Research Group

00:01:46 Very much up until now, people have come to their doctors and that’s been the last thing probably on the list, dementia. So they are regularly being diagnosed with depression or mental health problems, you know, and sent away. And certainly the people that I’ve worked with on the whole have sometimes gone up to two years without getting a formal diagnosis and it’s been heartbreaking.

Narrator

00:02:10 Maria believes that because there are relatively few people with early onset dementia, even after diagnosis, services can be lacking.

Maria Parsons

00:02:20 The problem is that often people get a lot of help at the beginning and then they’re left to fend for themselves without really being plugged into local services.

Narrator

00:02:30 At the Forget-Me-Not Centre in Swindon, they exclusively support people under 65 with early onset dementia. Funded by Avon and Wiltshire Partnership NHS Trust, people are referred through their GP or older mental health services.

Forget-Me-Not member: What time we going?

Forget-Me-Not member: Probably about 11 o’clock.

Forget-Me-Not member: Lynda’s just phoned and said she’s just leaving, she’ll be about half an hour.
Lynda Hughes  Occupational Therapist, Wiltshire Health Trust
00:02:54  The understanding in society is it's a disease of old age, so if you're diagnosed in your early 50's or early 60's or even earlier, that's quite devastating, your expectations of life are different, you're in the full thrust of your adult life, you've often got dependent children, you know, you expect to go on working, you're looking forward to retirement, the financial implications are absolutely enormous.

Ian Grant
00:03:23  I was suddenly faced with all the angst and the worry and the worry of where we were going, what was happening, you know.

Narrator
00:03:32  Ian was referred to the centre, and like all clients can receive counselling and support if he needs it.

Lynda Hughes
You don't look like you've got an illness, you look perfectly normal and therefore people expect you to be able to function, and you know that's very hard for people to contend with. And you can't sit in a dark room, and do nothing, you have to engage with life, and that means engaging in the real world which is really tough.

Ian Grant

It's just a bit confusing, you know, finding the places I wanted to go to.

Lynda Hughes

It's hard isn't it?

Ian Grant

It is, quite. And the other thing...

Lynda Hughes

You can't necessarily tell people how to live a better life. For a while you have to do it with them. So for example if somebody is really scared and living at home and hasn't gone out for ages because they've had a terrible experience in the shop and they can't get the bus anymore. Then actually, they can find their way to the shop, but you have to do it with them. Every single thing needs to be broken down into very small tasks, and practiced a lot. So that's a big message for services, I think, because it's not about sitting in a clinic room, you can only help people and show them the way by doing it with them for a while.

Woman

Good, press that one down, that's it. Thank you very much.

Man

Is that enough?

Narrator:
With rehabilitation in mind, individuals are encouraged to take on simple tasks, like making a picnic for their regular sailing trip.

Ian Grant

You want a bit of danger in everything really. Nobody wants to be cocooned really, and if we can make it so that - some of us are fitter than others, then we can help each other you know.

Man

Step down

Woman

That’s it, Terry, well done.

Narrator

Sandy Reed found out she had dementia at age 58.

Sandy Reed

They said to me oh yes, there’s something wrong. And after that I was just sent home, there was no follow on straightaway or anything. You know to be told you’ve got something and then left, it’s horrible. And it got to the stage where I’d just sit in the house and draw the curtains. And I think the depression set in then and Lynda came along and said would you like to start at Forget-Me-Not and I thought, I’ll give it a try, but I won’t stay.

Sailing Group

Uh-oh!

Sailing Woman

We’re trying to look professional, you know!

Lynda Hughes
It's such an invisible illness, and people are so shamed about describing their difficulties, that to be in an environment where they can do, not just ordinary things, but great and amazing things, is transformational actually. And it enables people to take the lead, to take responsibility where they can, they can learn each week to do a little bit extra so you know - how lovely to go home and have something to talk about actually.

Sailing woman

Come on

Sailing woman

There you go

Sandy Reed

It was a challenge to me because of the water. But I thought, come on girl, if the rest of them can do it, you show them you can do it.

Sandy Reed

I'm dead, I'm dead.

Sailing man

You're alright.

Sandy Reed

So I got in there, and it was really good, really good.

Sandy Reed

Look, I've got hold of my string!

Sailing man

[laughs]

Sandy Reed

I try anything, I'm afraid. I'm a bit of a risky person.

Maria Parsons
People with dementia who are under 65 are often really quite physically fit. So being able to go somewhere in which you have a physical regime, you know you enjoy activities, you get involved with other people, peer support is absolutely crucial. You know, being in touch with other people who share the same diagnosis can make such a deal of difference because you don’t feel marginalised anymore, and you certainly feel included.

Ian Grant

Excellent, excellent. That was quite energetic, the paddling, I think you’ve heard everybody laughing all the time. So it’s a great day, you know. And my wife knows where I am, but she can do what the hell she likes.

Maria Parsons

There may be some doors opening in terms of social care personal budgets, obviously the younger person with dementia would have to be eligible for that budget, which means they would have to have critical care needs, possibly living by themselves and having other severe needs. But the possibility is there and I would have thought that this group is very very well set up for taking advantage of the social care personal budgets.

Lynda Hughes

Although we are specialist mental health actually this model is a very very worthy model and a model that ought to be embedded in practice across the UK, I think, in dementia care. Fundamentally people are not in any care service unless they’re offered opportunities to do what they want to do and supported to do what they want to do. They don’t want things taken away from them, they want to be empowered to do whatever it is, and to take the risks that make life worth living.
It’s a different life but it’s a good life, it’s a good life that we’ve got at the moment at the club. In fact it’s quite wonderful. Best carers in the world.

Title: Key learning points

It can be difficult to diagnose dementia when people are younger

Even after diagnosis it can be difficult to get the support that people with early onset dementia need

Some new services are being developed to support younger people with dementia; peer support is often helpful and helps people feel included

People with early onset dementia are often physically fit and may choose to take risks that make their life worth living

END