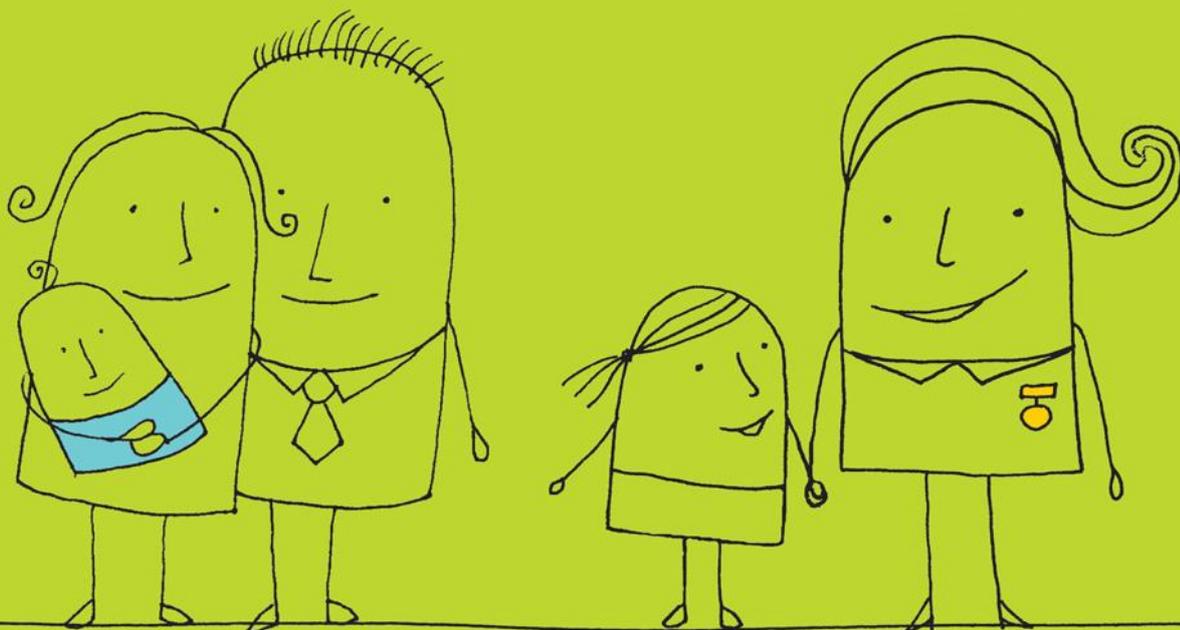


Early onset dementia

The experience of living with early onset dementia – people with the condition and family members tell their story.



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1. Introduction

1.1 Overview

In 2016/2017, the Patient and Client Council (PCC) commenced a project exploring the care experience of people living with dementia.

The first phase of the project, a scoping exercise, highlighted areas of good practice and some of the challenges of caring and supporting people with dementia. In the course of this work it became apparent that people with early onset dementia had unique challenges that were not always recognised or addressed.

[A full version of the scoping exercise is available at:

http://www.patientclientcouncil.hscni.net/uploads/research/Dementia_Scoping_Paper_FINAL.pdf]

The second phase of the project, presented in this report, identifies the issues experienced by people with early onset dementia and their carers. It used patient case studies and, from the findings, it makes recommendations to improve the experience of this discrete group of patients.

1.2 Context

Dementia is recognised as a global health issue. The World Health Organisation has identified it as a public health priority and recognised the toll this illness has, not only on the people who have it, but also their families and caregivers.¹ In 2012, it was estimated that 35.6 million people in the world had dementia. This figure is expected to double by 2030 and more than triple by 2050.¹

While dementia is often seen as a disease of old age, about 5% of people with dementia are classed as having early onset dementia i.e. diagnosed under the age of 65.²

1.2.1 What is early onset dementia?

People with dementia whose symptoms started before they were 65 are often described as 'younger people with dementia' or as having early onset dementia. The age of 65 is used because it is the age at which people traditionally retired. Other terms used for dementia that started before age 65 include 'early onset dementia' and 'working age dementia'.²

Early onset dementia is caused by broadly similar diseases to dementia in older people ('late onset dementia'), but there are some important differences. A younger person is much more likely to have a rarer form of dementia and early onset dementia is also more likely to cause problems with movement, walking, co-ordination or balance.² In addition, dementia may be the only serious condition that a younger person has compared to older people who may be living with several co-morbidities.²

Early onset dementia is also more likely than late onset dementia to be hereditary and as such the diagnosis may have implications for birth relatives (sisters, brothers children) of the person affected.² Younger people with dementia often experience a higher level of mood and behavioural problems. In addition, it can be difficult to distinguish dementia from depression in the initial stages of early onset dementia. This is the case particularly in frontotemporal dementia (FTD), which may present with apathy, irritability, dietary changes and deteriorating self-care. The prevalence rates of the dementia subtypes also differ in younger people. For example, FTD will affect 12% of young people who are diagnosed with some form of dementia while FTD will affect 2% of older people diagnosed with dementia.⁷ Two thirds of older people diagnosed with some form of dementia will have Alzheimer's disease, but only a third of younger people who are diagnosed will have this type of dementia.⁷

1.2.2 The Context in Northern Ireland

In Northern Ireland it is estimated that there are about 23,000 people with dementia in 2017; fewer than 1,000 of whom have early onset dementia. It is expected that the

total number of people with dementia will, however, continue to rise and reach around 60,000 by 2051.³

The Department of Health, Social Services and Public Safety published a dementia strategy in November 2011 entitled 'Improving Dementia Services in Northern Ireland – A Regional Strategy'.³ The overall aim of the strategy was to reduce the risk or delay the onset of dementia in the Northern Ireland population while also raising dementia awareness. The strategy stressed the importance of an early and accurate diagnosis and stated that delaying the onset of dementia by five years could halve its prevalence. It also raised the issue of proper and effective medication use, particularly the appropriate use of antipsychotics which can have negative side effects.³

The strategy also made specific reference to younger people with dementia. It stresses that dementia is a particularly difficult diagnosis for younger people to receive as they will often be in employment, have a family to support and have financial commitments. It was also acknowledged that many of the services available for older people with dementia were inappropriate for people with early onset dementia, and recommended that a specific care pathway was needed for younger people.³

1.2.3 Literature review

The experience of younger people with dementia in Northern Ireland has been explored previously by McErlean in 2001 who found that because people with early onset dementia didn't fit neatly into the 'mental health' or 'older people's' categories they were likely to be missed. McErlean concluded that there was a need for more appropriate, flexible services, tailored to meet the needs of these individuals.⁴ Haase (2005) examined the lives of younger people with dementia in the Republic of Ireland.⁶ He discovered that the majority (59%) of younger people with dementia are living with their partner, whilst about 15% live with a son or daughter or other relative. A small proportion (8%), all of whom are in the early stages of dementia, live on their own. Only 15% of younger people with dementia were in a residential home.

Haase noted that there is a strong preference by younger people with dementia and their caregivers to maintain arrangements to be able to live in their own homes for as long as possible. It is also important to note that such arrangements are the most cost-effective for society as a whole. However, caring for younger people with dementia in their own home crucially depends on the availability of flexible care arrangements to facilitate this.⁶

Previous work has also focused on a number of issues specific to younger people with dementia that are different from those who develop dementia over 65. An Australian paper in 2007 reviewed existing literature and sought out the opinions of younger people with dementia. The authors concluded that:

‘There are unique and complex issues faced by younger people with dementia and their family members... compared to older people, these people experience far more difficulty in accessing services appropriate to their needs.’⁷

Three recent UK studies have also highlighted the need for specific services for those with early onset dementia⁸⁻¹⁰. These studies found that despite national guidelines being in place in the UK, there are still many variations in the services provided across the country. They noted a clear gap between policy documents and actual on-the-ground services, with the majority of dementia care focused upon the need of older patients. As a consequence, many younger people affected by dementia and their families do not receive the specialist assessment, diagnosis and intervention that they need.

The difficulties of diagnosing younger people with dementia have been discussed in a number of studies. While these investigations emphasise the need for early intervention, in practice, the challenge of being able to diagnose a person under 65 with dementia may lead to delays in treatment. While authors argue that the diagnosis of younger people is essentially the same as for those over 65, achieving a diagnosis with younger people may be complicated by the need to eliminate other possible conditions and risks.^{11,12}

Being diagnosed with dementia can be distressing not only for the patient, but also for all members of the family. A recent study published in 2016 examined how the children of people with early onset dementia reacted on learning that their mother or father has dementia. The paper highlighted the emotional toll of caring, keeping the family together, grief and loss, and psychological distress.¹³

The needs of family caregivers have also been examined. In one study, the author concluded that many early onset dementia caregivers had unmet support needs. These were mainly around information and psychological support to help them cope with changes in their marital, family and professional lives.¹⁴ A study which compared caring for a person with early onset dementia with caring for someone with late onset dementia, found that the former was more difficult because of the behavioural problems experienced and with coming to terms with the diagnosis.¹⁵

2. What we did

The PCC 2017/18 Business Plan includes the following objective:

The Patient and Client Council will seek to understand what the HSC issues are for young people and their carers living with dementia

The Patient and Client Council will follow up on its 2016/17 scoping exercise to understand what the health and social care issues are for young people and their carers living with dementia. This will be done in partnership with Dementia NI.

As highlighted in the introduction (Section1), one of the key findings from the scoping exercise conducted by the PCC in 2016/17 was the unique challenges faced by those with early onset dementia. Therefore, it was decided that during 2017/18 the PCC would undertake further engagement to explore the issues experienced by people living with early onset dementia.

The approach used to gather information from younger people with dementia and their carers was one-to-one interviews. This enabled people to talk in-depth about their dementia journey and to tell their story.

A sample was obtained by working with voluntary groups caring for people with dementia, namely Dementia NI and Alzheimer's Society. Dementia navigators in each Trust were also contacted in the hope that they could signpost us to possible interviewees. A call for participants also went out through the PCC Membership scheme.

3. What people told us

A total of 19 people were interviewed. The study involved people from across Northern Ireland. Seven participants were individuals who had a diagnosis of early onset dementia and 12 participants were carers of those with early onset dementia. Ten interviews have been written up as case studies and are presented in Section 3.1. All interviews were analysed in order to identify common aspects of people's experience and these key themes are presented in Section 3.2.

The ten interviews presented as case studies were selected in order to provide a balance view into the lived experience of both people with early onset dementia (N=5) and carers' (N=5). We also selected case studies in order to reflect the experience of individuals from both urban and rural locations. As might be expected, the extent to which individuals were able to engage in interviews differed across the participants. As a result more detailed interviews were chosen to be presented as case studies.

3.1 Case studies

CASE STUDY 1

Female (57) - Alzheimer's

I was just diagnosed with Alzheimer's relatively recently. I had been attending for tests and seeing the Consultant and there were a few early diagnoses. I think the first one was mild cognitive impairment. The process of diagnosis was pretty good I didn't feel at any time I was being left or being abandoned; it was just taking time to go through the process. When I was diagnosed with Alzheimer's about 10 months ago I was put on medication and I expect I will have regular reviews going forward.

Even though I knew that I probably had dementia, when I heard the diagnosis it was quite a slap in the face, it was quite a shock and in another way it was a relief to know what was going on and it meant at that stage the medication could be started.

After I was diagnosed I was contacted by a Dementia Navigator and she came out and explained things and put me in contact with someone from Dementia NI so that I could go to different support groups with them and that's been a lifeline. Going to the Dementia NI groups was the start of getting to see that there is actually life after the diagnosis and to meet other people who are in a similar situation.

I had to stop working. I probably would have stopped work just over a year even before diagnosis because I was finding that I wasn't coping, I was making mistakes. I worked as an interpreter and I was having enough problems speaking without having to try and change languages around in my head. That has been a major life change for me. I loved my job, every day was so different and I got to meet so many different people but it wasn't fair on the clients and it was putting more pressure on me which I think was making my condition appear worse.

I'm still allowed to drive which is brilliant, I had to contact the DVLANI to let them know the diagnosis and I then had to do a test with Disability Action, even though the Consultant had said I was okay to drive but I knew that was a matter of formality. I

find that I can't go into the like of a big supermarket by myself anymore as I panic. The noise in an environment like that becomes overwhelming and would affect my thinking; my head would be quite scrambled up in processing stuff. Whereas I can go into the local butcher's and fruit shop and bakery, shops where I'm being served more or less one to one. I find that no problem. The Church has been brilliant and family and friends have been fantastic. My family and friends would obviously be aware of my condition, so it means if I am having an off day they will be able to pick that up. I would have momentary lapses, for a split second I just wouldn't know where I was but as quick as that happened I'm back out of it again. People who know me have gotten to know and they will ask if I am okay.

Recently a speaker had attended our Dementia NI empowerment group to inform us about the Dementia Companion role. From the discussion I understood that the Dementia Companion service would be available to anyone going into hospital and that a banner and leaflets advertising the service would be positioned within the A&E department so that anyone coming in as an emergency could access information and request a Dementia Companion. I found this very reassuring because on my last visit to A&E I felt the staff dismissed my statement that I have dementia which had panicked me. I was very interested to hear of the role of the Dementia Companion as I felt that should I be in hospital again this service would mean that all staff would be aware of my diagnosis.

However, I have taken part in some publicity activity for the Dementia Champion service and now I am not as reassured. I agreed to have my picture taken for a leaflet about the service but when I arrived at the hospital I was taken to the care of the elderly ward and my photograph was taken with a backdrop of old film stars and a CD with music from the 1940s on show. It made me question why they wanted a younger face on the leaflet when the information behind me was still referring to dementia as an older person's problem when this is not the case. On the day I was getting my photograph taken I asked where the Dementia Companion service would be available within the hospital and I was told it would only be available in two care of the elderly wards and wouldn't be available for anyone coming into A&E or being admitted to a general surgery or medical ward. I sincerely hope that if I am admitted to hospital that I wouldn't be put into a care of the elderly ward just because I have a

dementia diagnosis. As a younger person with dementia I feel this service should be more widely available through the hospital departments and particularly for people attending A&E.

I am in my mid-fifties, I don't class myself as being old yet, in my mind I'm still not old and I don't feel old, physically I feel absolutely fine. So I think awareness is needed that dementia doesn't necessarily just affect older people, it can affect anybody at any age. I think the most important lesson for me from attending the support group is finding out you that can't just stop living, this isn't the end. Okay there are days you begin to think further forward and you wonder how long do I have being as well as I currently am but you try to come out of that. I try to live for the moment really and not to think too far because none of us know what the future holds.

Carer of lady in Case Study 1

My wife started to show signs probably two to three years ago. The signs were very subtle, for example, she would have pauses in conversations, and we began to notice it more and more. We went to the doctor who referred her to mental health and they carried out an assessment. At that stage they told her she had nothing really to worry about that she had what they called mild cognitive impairment. We felt okay with the news and thought that if that's what it was we would just have to deal with it.

Approximately a year later my wife had a review. She struggled more with the test this time. I had noticed a deterioration in her ability over that period of time. She was forgetting words, as well as experiencing absences and she was doing things in the kitchen, for example, putting the gas ring on but not actually putting the pot on top of the ring. At that stage she was diagnosed with Primary Progressive Aphasia (PPA) and we were told that if it would proceed that it would be some form of dementia. Needless to say there was another review and her test results deteriorated further. We saw a different doctor that time and she just said to us "there is no easy way to say this, but with everything we know now, it is Alzheimer's", that was how the diagnosis was delivered to us.

It wasn't a shock because we knew something was wrong. I suppose it was a case of thinking, now that we knew what it was, we had to learn how to cope and deal with it. Although it was a label that was put on my wife, we felt that the diagnosis would enable her to access services and help us get support. It also meant that we could tell people to help them understand that she had a problem. I tried to look upon it as positively as I possibly could for the purposes of helping my wife to cope with it.

Once we got the diagnosis I contacted the Alzheimer's Society and had a chat with them. I went on a training course for informal carers with Alzheimer's which I found extremely helpful. In that group there were probably about 10 people who were very much in the same boat as me. They were carers and we were able to share experiences of how we were able to cope with different situations. We were then contacted by a dementia navigator and she is helping us to access support. I go out with other carers to meet them for coffee or things like that and I find that very useful. My wife is a member now of Dementia NI which meets every fortnight. She loves it, she absolutely loves it.

The decision makers really need to seriously examine the overall costs of services. They have got to look at the cost of training and supporting informal carers taking into account what they do to keep people suffering from dementia out of nursing homes, out of other care. At the end of the day, if you take away the support for carers people will end up being more dependent on the state and more dependent on health and social care services. I think it is very short sighted to cut funding and I reckon it will cost more money in the long-term. It's cheaper to give something back to the carers because they're not doing it because they are being paid, they do it because they love the person and they want to do it. I think they should actually be looking at increasing the funding for dementia because the numbers of people with dementia are increasing.

In terms of our own personal circumstances I think we have got the support that we need at the moment. I don't want to be bombarded with support that we don't actually need because I think it's a waste of resources. I think the level of support we have is balanced against my wife's needs at the moment and once her condition

deteriorates and we know it will, then hopefully that support will exponentially increase.

I am medically retired which means that I am around to keep an eye on my wife and to sort of subtly supervise. I try not to tell her what to do, more to help her out if she is having difficulty doing something. I just try to be as caring and loving as I can about it, and not to cause any undue stress. At the end of the day if she wants to do something, I let her do it. I don't want her to feel like she is a burden or she is unable to do something she wants but I do want her to be honest with me if she isn't coping.

My wife would have got lost sometimes when she was out walking her dog but we have lived in this area for a long time so she is very familiar with her surroundings and everybody knows her so I know she will be okay if she was out by herself. She still gets lost and on occasion she's goes out without her phone and that can be worrying. There was one day the phone was here, the car was here, and she wasn't here and I had to go and look for her. Eventually she came home but that's rare occurrence for us.

My wife still drives at the moment and she is waiting on an assessment from the DVLANI but her driving actually is incredible. Her brain seems to work fine in that environment. The consultant told us that in her opinion my wife could still drive at this moment in time, that's great because it gives her a bit of freedom. We have grandchildren and she goes over to look after them. I don't need to be with her and the kids keep her on her toes.

My wife's mother and grandmother both had dementia. Her mother had it from she was 60 and she died at 81, she had it for 21 years. She didn't get any treatment for it, she just sort of left it, but her mother died in 2005 so we know things have moved on since then. We try to be positive about the whole situation, I do think if some people weren't as strong or weren't able to get support then it could result in you becoming depressed.

CASE STUDY 2

Male 59 - Frontotemporal dementia

I was around fifty-two years of age when things started to go wrong with me. I was an outgoing kind of a guy and lived life to the full and then suddenly I couldn't be bothered going out, I didn't want to socialise, didn't want to mix. I got myself more and more into a shell. At the time I didn't know what was happening but it was depression coming on and I didn't know what depression was, I didn't realise the low moods. A change of character, losing my confidence, that all came into it. My marriage had just broken up and I thought that was part of it too because it had a deep effect on me. I thought that was probably the issue.

I decided one day to go down to my GP to discuss what was going on and I had a good conversation with her. She started the ball rolling on getting me my diagnosis, I went through the scans, the electrodes, the memory clinics you name it. Then I had an appointment with the Consultant, I had a good experience with the Consultant not like some people that I know. My sister came with me to the Consultant appointment and I was told then that I was diagnosed with frontal lobe dementia.

I didn't know what frontal lobe dementia was because I never heard tell of it, nor did I know what dementia was. After getting my diagnosis I felt like I had to find out all about it and I did and that really put me into a really dark, dark place.

In terms of the support that's out there, there's nothing for us. In the first support group I went to people were away in the latter stages of dementia and it wasn't for me, I thought to myself "that is not what you need". So that is why I got together with other people and helped set up Dementia NI for people like me who have a voice of our own, to be able to tell people how it is, how we live with dementia, because there was nothing like that out there. Being part of Dementia NI slowly but surely built my confidence up again, but I had to take that battle on. If it wasn't for Dementia NI and the support that those guys give the likes of me I don't think I'd have a purpose in life. Some days I feel like life isn't worth living.

I've had frontal lobe dementia now for six and a half years and it is hard work. It's getting harder all the time for me because of the struggles that I have on a daily basis. People don't realise that for me to think things out its ten times harder than for someone without any problems so therefore when it comes evening time I'm not fit to do anything more and mentally I'm exhausted, but people don't understand that. That's one of the stigmas that we deal with. We deal with the stigma every day, and that hurts me. People say to you, "you look ok, there's nothing wrong with you, you're getting on with it and sure you're alright" and I keep thinking "what do you have to look like to have dementia?"

I have to live with my condition every day and it is very lonely. I could be in the middle of a thousand people but I'm still lonely. I know how I am going to end up and thinking about that takes me to a lonely place. I've nobody to talk to about that. The underlying things are the big problem, the lack of confidence, the low moods, feeling insecure about things, the frustration. I have to deal with all of that too. It is not just about memory. That is what I need support to help me with, some reassurance.

There should be a service that we can talk to somebody that's trained and understands dementia. There's no point in having a person who doesn't understand what the person is going through in the first place. I do talks on dementia all over Northern Ireland and the first thing I tell people is that the person with dementia is the expert because we are the people living with it. What we are telling people is what we are living through. There is nobody to tell that to within health and social care services, there is nobody to turn to.

I'm lucky I have my family around me but what about the man or the woman or the young person that hasn't got any of that? How do they deal with it? Within my role in Dementia NI I talk to people in that situation and they feel hopeless and lost. That shouldn't be. Dementia is not taken seriously. If someone has cancer it's taken seriously, everything switches into motion right away. It's only a matter of lifting the phone. But there's nothing for people with dementia.

I'm in a different situation because my family is in full support of me. But I still feel left out. I want to fight this and I want to be as independent as I can for as long as I can. I

know I need support and I know that I need help but the support and help is not out there for me. It's only my family, and that puts a lot of pressure on them to be dealing with that every day to be seeing me deteriorating. Most of the carers are left to their own devices and mine are no different. There should be a respite period set up for people or at least it should be on offer, but that support is not there.

There's no cure for dementia, I've got a terminal illness, I don't know when but it's going to kill me and it's going to kill everybody that has got it. For people with cancer probably about 70% of them are going to live, and yet there is still more support for people living with cancer. How is that the situation? There's something wrong here somewhere.

Since I was diagnosed with dementia I had a heart attack and was in the hospital. A nurse on the ward came to take some notes and she was asking me question after question and I was starting to get confused. I told her I had dementia and that if she gave me time I would be able to answer her questions. In the end she gave up and she got up and she left me because she couldn't handle the situation. That is part of what is wrong with the current situation. There should have been somebody there that was fit to handle that situation that had the right training. That nurse wasn't trained to handle somebody with dementia and she was out of her depth so she left me.

I think that younger people with dementia aren't taken seriously because most people still think of people with dementia as old people with walking sticks or in wheelchairs living in care homes. That is still the stigma behind dementia.

CASE STUDY 3

Female 55 - Alzheimer's/Posterior Cortical Atrophy

It has been eight years or so since I've been diagnosed. I first noticed issues when I was at work I actually thought I was going mad. One example was when I went to the toilet and I lost my way back, a colleague thought I was joking when I asked him if he could take me back to my office. I used to write a lot of reports for assessments but I started to notice I couldn't get the words together and couldn't formulate sentences. It was as if the text was jumping all over the page. I had lots of tears in work.

I went down to the GP and was told that it was menopause but I knew in myself that wasn't right. I just got to a stage where it was too much for me and I walked out of work one day. I got into the back of the car, lay down and cried. I couldn't stop crying. It got so bad I went up to one of our spare rooms and stayed there for nearly a year. During this time I was still going to see doctors. My oldest daughter started to accompany me and she started to tell the doctors that they needed to send me to a psychiatrist because mentally I was just torn apart. I was thinking of suicide big time.

I suppose the only rewarding thing was that the doctor sent me to see a Psychiatrist who listened to me and realised it just wasn't mental health, that there was really something happening. She first diagnosed me with fibromyalgia and then I was sent for three big scans. The final scan was able to show that I had Alzheimer's. When the Psychiatrist told me my diagnosis she explained that she was also going to ask my husband to come into the room so she could also explain to him. She also told me that she would have to transfer me over to elderly services.

I can't even explain how I felt but at the same time I was thinking at least something is being recognised. Myself and my husband came home and told our family it was an awfully emotional time but at the same time I was relieved that I was not going mad.

I went back again to meet the Consultant in elderly services and he was lovely. He was a very gentle person and made me feel so at ease. I had a bigger scan and was told I had Posterior Cortical Atrophy (PCA) as well and that clearly made sense because of some of the issues I was experiencing - my balance, going through doors, the moving text. I couldn't read any more. I am now partially sighted I'm not blind as yet although sometimes my vision does disappear. I also get very disorientated. I used to go walking a lot with the dog but when I walked up the street and turned around to go home the street looked different because I was looking at it from a different angle and I would get totally lost.

I can remember things because I keep a diary, sometimes I do forget to write in it but most of the years I've had a diary and I go over it and over it and over it to remind myself. At the moment I am using my iPad to record but it is tedious because I'm slow at it, although when my sight goes I am able to do it by audio.

My own GP was absolutely humiliated when he heard the diagnosis he couldn't apologise enough but then I do understand that somebody coming in at 47 you wouldn't think automatically of dementia. I really thought myself at that time that I was having a mental breakdown.

After being given the diagnosis of Alzheimer's and Posterior Cortical Atrophy I started to research online I shouldn't have done that. I was very depressed and I did try to end my life. I also went online to look at information about assisted suicide in Switzerland and I signed myself up for it. At the stage after my suicide attempt I was given a community psychiatric nurse who was a lovely person. She also helped get my husband training so he really does know me inside out now. I think that helps most of all.

For me there's nothing for young people with dementia at all. The only thing that I got involved with is the Alzheimer's Society and Dementia NI because there are a lot of younger people using their services. My Consultant has said to me that he feels I may be able to talk until near the end as I am quite intellectual and I do believe that working with the Alzheimer's Society and Dementia NI has kept my brain intact.

I have been diagnosed with Parkinsonism, so I have a shake and I have developed fibrosis of the lungs. That's when it hit me hardest as I just see all this deterioration happening and I'm still aware of it. I had stopped going to the Alzheimer's Society and I had stopped going to Dementia NI, probably feeling sorry for myself. I do try to look at the positive side though. I have portable oxygen, so that can help me get around.

I do try to be as independent as possible still, I can't multi task because it just takes too much out of me, but I still do my ironing, my washing and potter around. I used to have Age NI out before I was diagnosed with the respiratory condition. It was a good service as it enabled me to get out and do things like grocery shopping. I'm hoping in the new year to maybe pick that up again. Age NI were giving me three hours twice a week and it gave my husband some respite.

The Alzheimer's Society have other activities such as a choir but I can't do as much now because it tires me. By 1pm most days I wouldn't be fit to do anything else, whereas it used to be I was doing something in the morning and in the afternoon. I have to accept that there are good days and there are bad days and I try to look at the good side of things.

Carer of lady in Case Study 3

I started noticing things weren't quite right with my wife when she was doing the dishes and she was putting things in the wrong place. She'd maybe put a cup in the fridge or put things away where they normally wouldn't go. She would also have trouble knowing what date it was or she could drift a bit in conversation and get lost with what she was saying, those types of things. As it went on I think she started to realise herself.

My wife loved her work. She's a very kind and giving woman but I noticed when she was coming home from work she wasn't happy, it wasn't the same. She went to see a really good Psychiatrist who diagnosed that my wife was depressed but she also felt there was something else underlying. The Psychiatrist told us to leave things with her until she did some research and that she would send my wife for some scans of

her brain to find out what was actually going on. The first scan came back but it didn't show anything which was disappointing. The Psychiatrist then had my wife referred for a PET (positron emission tomography) scan it showed that there were at least two parts of her brain that were affected - the left temporal lobe and the front temporal lobe. I think the hardest part, was that after the diagnosis the Psychiatrist told us that she couldn't treat my wife anymore and that she had to be transferred to the old age, geriatrics team. But it turned out that Consultant was lovely and he put my wife's mind at ease.

I was very shocked at the diagnosis my wife was only in her mid-forties, but the Psychiatrist says "there's no getting away from this, the scan has shown that your wife has definitely got Alzheimer's." I have learned that it has to be more accepted that people at any age can get this disease. My wife is highly educated and can speak for herself so when we tell people that she has Alzheimer's they sort of dismiss it in a sense. Even in the hospital we have had nurses say "she's too young to have it".

I get support from the CPN nurse who also supports my wife. If I ring her up and tell her I am finding it tough she could sometimes organise something to get me out of the house, like getting a massage. Dealing with the illness is difficult. For instance my wife's mother died over a decade ago but when she was living she always came over for Christmas dinner. Now every Christmas she tells me her mum is coming. There was a situation a few years ago where I had to remind her that her mum had died and it was like going through the funeral all over again because she didn't realise. There are days my wife will be perfect and there's days she is a shell of herself and that's what Alzheimer's is really like I'm losing her day to day she's drifting away day by day.

CASE STUDY 4

Male 54 – Frontotemporal dementia

Things were starting to get a bit funny and different things were happening. So I went to the GP who referred me for a brain scan first and then referred me to the memory lady. I did a test with the memory lady and I didn't do so well in the test so I was referred on to the Consultant. When I had my appointment with the Consultant I think I did a test with him as well which I didn't do well in. He was then just talking generally and then the next thing he just told me I had frontotemporal dementia. He stood up and he shook my hand and told me to put my affairs in order. He told me he had no leaflets to give me but that he would post one out to me. That was it. He opened the door and away we went. I just didn't know where I was or what to do. I was just in shock, I don't think I've come to terms with it even yet.

The community psychiatric nurse who comes to see me is really good. She used to see me weekly but that has changed to fortnightly now but I can ring her anytime, there's no problem that way. I used to be seen by mental health services for some issues I was having but when I was diagnosed with dementia I was discharged from that team. I felt very let down about that as I felt they had been a great support to me, I had felt very secure within mental health services. Not to take away from my current community psychiatric nurse but it seems to me that under elderly care there is nothing for me, support wise for my mental health.

I got in touch with Dementia NI. I've been there now three or four times and it's good. There's a man and a woman there as well both of them are older than I am but we have more or less had the same experiences. It is good to talk to them just to see how other people are managing. I felt so alone as well and it was good to go to the group, I go a lot out of just hearing from others who had dementia and seeing that their lives are not over.

As regards hospital wise though I just feel very let down. There doesn't seem to be any place for a younger man with dementia. I was up at the hospital for a check-up appointment the other day and I saw the Consultant's deputy. He did a memory test

with me but I could barely understand what he said. I had been hoping to do better in that test but I couldn't even understand what he was asking me sometimes. Again I just felt he was very bland, he didn't seem that interested in the whole thing. Maybe that's my impression, maybe I'm wrong, but it's just the way it came across. I mean I understand I have dementia, there's nothing anybody can really do for me that way but support wise it seems very lacking. Even just the lack of information provided when I was diagnosed, I was just adrift after getting the news and I got quite badly depressed as well. It comes and goes a wee bit the depression now as well.

Coming to terms with a dementia diagnosis properly is very difficult. I think having a professional to meet you after receiving your initial diagnosis would be good. It would be nicer if there was somebody trained, like a nurse, just to take people aside and even make you tea or coffee and just to talk through things with you and make sure you understood.

Carer of man in Case Study 4

I knew things were wrong as I noticed my husband's memory getting worse and worse and worse. He was seeing mental health services at the time and one day one of the nurses phoned to discuss the fact that they also thought there were some problems with my husband's memory. I explained all the issues I had noticed and the nurse advised that they would get him referred for an MRI scan he had already had a CT scan done.

The day my husband was called to the appointment with the Consultant I went with him. The Consultant went through a lot of details asking questions about family history my husband's mental health history and I had also brought a list of all the medication my husband was on. After he had gone through all the details he basically just got up and said "Yeah, you have dementia". He told my husband he had no booklets at the minute and that he would get his secretary to post information out. He shook our hands, told us to get power of attorney sorted, to get our affairs in order, to inform the DVLA and our insurance company. That was it. We walked out through the door and I knew I couldn't cry because I had to be strong for my husband. When we got home my husband went straight on to the computer, I

couldn't get him off it. He sat that night, the whole night on the computer researching dementia and frontal lobe dementia.

Then there was the medication. My husband had serious side effects on the first set of medication he was given, I thought he was going mad. He was hallucinating, he was jumping up in the middle of the night...he thought that there were bomb explosions, that there was people in the room. I had to ring the community psychiatric nurse on call as I felt he was going to commit suicide, he was totally away with it. The doctor on call phoned me back after consulting with my husband's nurse, who is excellent, and just told me to stop the tablet and that they would prescribe a new one. We waited a few weeks before a new medication was issued.

I broke down in front of the community psychiatric nurse just last week I told her that I feel as if the whole situation is on my shoulders. My daughter has also taken it very bad. One of her first questions to me was "will daddy ever remember my graduation? Will he be able to walk me down the aisle?" Our children have never got speaking to anybody to explain to them what way dementia works whether he can lead a normal life, the only reassurance they have been given is from me.

CASE STUDY 5

Male 62

I'm not sure if it was four or five years ago that I started noticing issues. I had three sisters with the same kind of dementia as me and I knew I was showing some of the symptoms but you just don't believe it at the time. I decided to go and see the GP and things happened quite quickly, my GP asked me if I would go and get a scan and I agreed. I got the scans and I just tried to put it out of my head. When I got sent for by the Consultant my son came up with me. The Consultant I met was actually the Consultant who had dealt with my sisters. She brought me into a wee room and talked to me all about it, it was like somebody hitting me with a brick.

I waited until I got home and I brought my sons in and sat them down and told them about the dementia. They were shocked, like I was, I'm still in shock. But then I was sort of glad in a way because things for me happened dead quick. You know with the getting the appointments and with people coming out to see me and getting things sorted. It just all seemed to come at once which was a help. I am still scared after seeing what my sisters went through, it's a terrible thing. I have seen all the stages from the start to the end and it scares me. I don't talk about it too often.

My sons stay with me every night and I'm glad of it because I do some silly things, like go out and get lost. You don't know you're doing these things. I went out to get the paper to the corner shop and ended up out at IKEA. Don't ask me how I ended up there it is whatever goes on in your mind. You just do the stupidest things. Even making a cup of tea is like multitasking it's like someone telling you to make a dinner and you just can't, or else you do something stupid like put the teapot in the fridge. My kids used to be in stitches because I would be putting the teapot in the fridge and the milk in the oven but they understand.

Some nights you get really down. I have phoned Lifeline before because all those suicidal thoughts come into your head. I wouldn't do anything because of my kids but that is the terrible things that dementia does to you. What goes through your mind is terrible. I don't think I would have come forward only for my sisters but unless you

get help you'll end up in a bad place or you'll end up killing yourself or something. So you're better getting help right away.

I think the thing that is still needed is to make people more aware of dementia. I know that there are people sitting the way I was, that won't go to their doctor. Even I should have been to see the doctor quicker and that is with me knowing about dementia because of my sisters. So more advertising and things are needed. People need to understand that they might not even have dementia, it might be something else, you don't know what they're going to tell you but you need to get help.

CASE STUDY 6

Female carer – Husband has frontotemporal dementia

At the beginning I wasn't sure what was wrong with my husband. I just knew that my husband's personality was changing. I could see changes in his behaviour; I could see patterns developing. I could see him becoming very fixated on sequences, time became very important to him; it was almost as if routine was ruling his life.

It was bizarre and it was strange, and I couldn't put my finger on it. I didn't really know what it was. At that time my husband worked night shifts, he kept telling me the night shifts were killing him. So I thought at the beginning that it might be stress related, I advised him to go to his GP to discuss it.

His GP then told him it was stress and put him off work for a short period of time. My husband returned to work after that but it didn't get better, he was increasingly becoming worse. So I then asked him to go back to the doctor again.

This time the doctors decided that he was depressed and they put him on medication. At that stage I began to think, maybe he is a bit depressed. But there were other issues, for example, if I were to say I would be home at six o'clock, if I wasn't home by five past six I would have noticed that my husband would have called me three times in a row and text me. You could sense he was getting more frantic as if something was going to happen to me.

This went on for a few months and then we noticed that he started doing things, saying things that were inappropriate, like he was disinhibited. So the next time I went into the GP with him, and said I wanted to them to get to the bottom of it as we had been going through this for about a year now and we were getting nowhere we were going around in a circle. However, again we were told it was likely depression or stress and there was nothing really happening or done.

Around that time my daughter through her work was at an event organised by Dementia NI. She brought home leaflets and one was about frontal temporal lobe

dementia. She brought it home to me and she said “That is dad! Tell me one box that he doesn’t tick”. I looked through the leaflet and all of a sudden the penny dropped and I knew that was what my husband had and that I needed to talk to his GPs.

I brought the leaflet with me to the next appointment. I told the GP that I had my husband had frontal temporal lobe dementia and pointed out the similarities with all of the symptoms. The GP’s response was that the condition was very rare and that it was unlikely that my husband had the condition. I wasn’t taken seriously and that annoyed me. The GP did refer my husband to a Psychiatrist due to his apparent depression but it was within a team that specialised in drug and alcohol problems. My husband attended three appointments but it was clear to me that he wasn’t receiving the right intervention.

After we left the third appointment, I phoned my husband’s social worker, who was the only person I felt that was actually listening to me and she agreed to help us find the right support. So behind the scenes she was trying to find out who the right person would be for us to see and she identified a Consultant within the old age team. We eventually got an appointment through the assistance of the social worker.

When the Consultant saw my husband he asked him different questions and gave him different tests than the other Psychiatrists had been doing. After the assessment he asked to speak to me alone. He told me that he agreed with me that my husband may have a form of dementia and that it would need to be explored further so he referred us to the specialist. We received that appointment within six weeks and that was the first time I felt we were on the proper journey to get the answers my husband and my family needed.

From the point we were first trying to find out what was going on with my husband until now has been a period of about two years in total but the staff involved in the process in the last six months have been very professional and on the ball. My husband is now being seen by two experts, a Psychiatrist who is treating the behavioural symptoms and the Neurologist who is treating the condition. Now whenever I feel something has changed with my husband, the team understand and are able to explain how the issue is linked to his condition. When I require anything I

know where to go. I know who to ring if there is an emergency, I would know what to do in a crisis. I can only thank them for that now, but I didn't have any of that support at the beginning.

We've had the confirmation in writing that my husband has got frontal temporal dementia. I feel really let down by the GPs, I blame them to a point but in addition I think the systems are wrong. GPs could not have accessed the tests that my husband needed. It was only when we were referred to the old age team that the Consultant could red flag the test and get it done as a priority.

I do feel that there should be more training at general practice level and even within the whole family of primary care because there are other professionals who would have been seeing my husband at times not just the GPs that could have helped support us to get a diagnosis. I think within primary care more training is needed for professionals so that they can recognise the signs and symptoms of early onset dementia. I also think that healthcare staff should explore all options before they dismiss the possibility of early onset dementia.

There are inadequate and inappropriate support services in place for people like my husband. I need a friend or somebody to call for my husband who knows what his interests are and can take him out for a few hours to do something that he enjoys. I think that would help to keep him active and keep him motivated and that's not happening. Medically they are looking after him but not socially. I think services are very fragmented and needs to be a much more joined up approach. That's what I would like to see.

I suppose for me the thing that I am most dissatisfied with was that I felt I wasn't listened to. I felt that when I went to the health professionals in spite of me being involved in the world of health, I felt that nobody was listening to me and as a result it took so much longer to get my husband diagnosed and to get him the treatment he needed.

CASE STUDY 7

Female Carer

My husband was knocked down in December 2000 and my mother always said he was never the same after the accident. We knew something was wrong, but because my own father suffered from depression and mental health we put it down to stress and anxiety. That's how my husband's condition manifested itself, low moods, stressed and not able to cope. His memory didn't go but his logic had gone.

The GP prescribed him anti-depressants which my husband refused to take. He was off work on sickness during November 2007 and eventually he was called for a medical assessment and was retired on medical grounds in April 2008. He would have been 60 years old then. After that he spent his days just sitting in front of the TV. He would have done the school run for our daughter and helped out with grandchildren but that was it.

As a family we knew something just wasn't right but we didn't know what it was. We were getting more and more concerned but we didn't know what to do. My eldest daughter asked my husband to go to see the doctor but he refused because he said he thought he would be put into a home. Like us, he knew there was something wrong, but he didn't know what.

In the summer of 2014 my husband and I went on holiday alone together for the first time since we had our family. One afternoon my husband wanted to go for a walk and although I was concerned I told him just to take a short walk and to come straight back. He ended up not coming back for hours as he got lost and the Spanish police had to bring him back. At that point I told him he had to go back to see the doctor.

When we came home he went to see the GP who did blood tests which came back clear. Then one night my husband could not remember where he had parked the car and he thought it had been stolen. This time I went with my husband to the GP. The GP asked my husband to come back the next week to see him on his own. At that

appointment the GP did a cognitive assessment with my husband and based on his results he referred him to a Neurologist.

On the day my husband went to see the Neurologist he really was not good, he was in absolute bits and all over the place so the Neurologist only asked him four questions. During the appointment the Consultant turned to me and asked me whether I knew that my husband had Alzheimer's and I told him I didn't. The Neurologist that day was absolutely brilliant; straight away he advised me about issues such as power of attorney, getting our wills changed and he advised me to speak to the Alzheimer's Society.

Life has just sort of trundled on. Alzheimer's is a slow gradual decline affected mostly by memory, but my husband's logic had gone. He also developed a tremor on his left hand side, so he was sent for tests and it came back that he had Lewy Bodies dementia (LBD) and Parkinson's disease. That explained an awful lot to me because with LBD he will you'll have times when he is very lucid and times where he's not in this world.

We used the service from the Alzheimer's Society since the diagnosis but I'd had no social worker until one day when I got in a bad way and I rang up the emergency helpline and told them I needed help. I don't know why those things weren't put in place for us from the start but I am really happy with my social worker now. She would encourage me to ask for help and has suggested carers to come in at night. My husband now has an allocated place in a day centre three days a week. We also have someone to come in and sit with him for a couple of hours twice a week. He also goes to the Day Hospice for people with dementia through NI Hospice and to a befriending group which is run by the Alzheimer's Society week about. At the Day Hospice they organised sessions with professionals such as an Occupational Therapist and a Dietician. I feel like they look after the whole person, physically and emotionally as well. They do holistic therapies, crafts, and a lot of singing. We've a volunteer who comes in from Age NI, he maybe only comes in to talk, even for me just to sit and talk. I'm content with what I'm getting at the moment. The family help out as well, my youngest daughter will sometimes take him for a cup of coffee to give me a break at the weekends. In the very beginning, I remember saying to myself that

if it continued the way it was going I wouldn't be able to manage but it's really changing now.

We need more information and more awareness. We need to get away from this view that only older people have dementia. My husband doesn't look his age and we had a young family. When my husband was first diagnosed my youngest daughter found it very hard to cope with because she said, "people don't understand mummy, it is their grandad or their granny it is not their daddy". Dementia is on the increase I think we need to get the message out and also we need more research as well to hopefully get a cure for this at some stage.

3.2 Key themes emerging from the interviews

3.2.1 Journey to diagnosis – knowing something was wrong

The participants we spoke to talked about noticing something was wrong often years before they actually received a diagnosis. Seven participants reported that when they told their GP their symptoms, the GP was quick to conduct initial tests and to refer them for scans/examinations to determine the diagnosis. The other 12 participants described a prolonged journey to obtaining a diagnosis which often took a number of years. One participant (a carer) described how it had taken as long as 10 years to get a diagnosis. The delay in a diagnosis of dementia was usually due to GPs exploring other options that could explain the symptoms that the patient/carers was describing. Common diagnoses were stress, depression or hormonal problems. Delays in referral to services that were not dementia-specific inevitably meant waiting longer.

Fourteen participants, both people with dementia and their carers, did not consider a diagnosis of dementia due to the age of the person in question. Three individuals believed they had some form of mental illness but also felt that there was something else underlying their symptoms. Five out of the seven participants with dementia reflected on how they were in denial that there was anything wrong and would not go to the doctor. Nine carers described how they were the ones encouraging their loved one to see a GP or who were pushing for answers.

3.2.2 Impact of diagnosis

The participants commonly referred to a sense of shock once they had been given their diagnosis even though in all cases they had a clear understanding that something was wrong. However, individuals also spoke of a sense of relief because there was now some explanation for the symptoms they were experiencing.

Fourteen people felt that their doctors had broken the news to them as best they could. Once the diagnosis was given, however, twelve participants spoke of being

left abandoned with no information provided and no opportunity to discuss the impact of their diagnosis with a health professional.

All the participants acknowledged that the diagnosis of dementia affected them greatly. One participant described “I knew at that point my world had changed”. Others spoke of going into a “dark place”, especially after having researched their condition on the internet. Four of those with dementia spoke of feeling suicidal, a feeling that for some participants recurs frequently. They described how they felt their lives were over and felt that suicide was the only option available. One participant explained how they wanted to save their family having to take on what they saw as the burden of caring.

3.2.3 Life after diagnosis

Those individuals who have dementia described their awareness of their decline and their frustration that they could see themselves deteriorate from day to day and week to week. However, four participants spoke about how they had made the conscious decision to try to deal with whatever lay ahead positively. This latter position was mostly expressed by carers who felt that they needed to support the person for whom they were caring. Participants spoke about trying to continue to participate in activities that they enjoyed and also going to support groups such as Dementia NI and Alzheimer’s Society where they could meet other people with dementia who shared their experience.

One key issue experienced by participants with dementia in this study was that they were no longer able to work due to the impact of their condition. Participants described how the demands of their jobs proved too much and people either decided to leave work voluntarily or were pensioned off. Individuals described how employers had tried to support them by reducing their workload or giving them more straightforward tasks. However, with loss of memory and concentration, continuing to work proved impossible. This was reported as a great loss by six of the participants with dementia. Four carers had also given up their job or now worked part-time.

People also spoke about no longer being able to pursue everyday activities such as driving, reading or going out on their own. In particular, people with dementia reflected on the ability to drive as having a massive impact on maintaining independence and those who could no longer drive felt that not having access to a car restricted their independence.

Carers described the constant worry and the psychological stress of monitoring/supervising the person with dementia and feeling that they had to do this in order to ensure no harm came to them. Carers were also concerned about what would happen next and how they saw the person they cared for gradually change. They felt that they were losing the person they knew. Carers also had to deal with the manifestations of the disease, such as hallucinations and incidents of aggression but also felt that however hard it got they wanted to be able to care for their loved one at home. Nine participants also highlighted that there was not appropriate support available for the children of individuals with early onset dementia who were also trying to deal with the diagnosis and understand the impact.

3.2.4 Current services

Seven participants felt that they were getting the level of support they currently needed, both from health and social care and from the groups they attended. Five participants with dementia mentioned the high level of support that they received from Dementia NI. This was particularly relevant to those living in the Belfast area.

However, in general people living outside Belfast did not feel that they were particularly well supported, even when they had input from a Community Psychiatric Nurse. Eight participants described how they were told their diagnosis and felt then were left to cope, not only having to dealing with the news themselves but having to break it to their families. Some family members found it hard to deal with and their mental health suffered as a result.

Five carers talked about having to find out everything themselves as they had been given no information and were not signposted to any support services after diagnosis. Respite was also discussed a number of times; carers found that these

services were very hard to access unless you could plan well in advance, which was not always possible. Three participants reported having access to services that enabled the family carer to have some free time for a least one afternoon or evening per week.

Two carers also raised practical issues, such as making provision for people with dementia when they lost some mobility and could no longer use stairs. Carers were concerned about the costs of these adaptations and worried about money.

3.2.5 The need for a specialised service for early onset dementia

When asked what would improve the services, participants identified a number of aspects. Five identified the need for a more comprehensive service and used cancer services as a comparison. These participants had the perception that when someone receives a cancer diagnosis, access to services and support is streamlined and they felt there was a need for an equivalent service for those with early onset dementia. Particular features that were discussed were: help and support in dealing with the diagnosis; help with form filling to access any benefits that might be available; and improved long term support.

3.2.6 The need for age appropriate activities for individuals with early onset dementia

A major issue for young people with dementia was having activities that were suitable for their age. Nine participants noted that many groups and activities were aimed at older people with dementia. In contrast, they were keen to participate with people their own age in order to share experiences as they felt they would have more in common with them and their dementia journey.

3.2.7 Continued education and awareness raising around dementia

Four participants discussed the need for education and awareness training for health and social care staff, particularly GPs. They emphasised the need for GPs to have a good understanding of early onset dementia so they at least consider the possibility of this diagnosis when a younger person presented with symptoms. Six participants

who had recent experience of using hospital services also felt the general hospitals workforce needed better training. They recounted times when such professionals had doubted their diagnosis or where they had been treated by professionals who had lacked the skills to engage with someone with dementia.

3.2.8 Apparent disparity between urban versus rural service provision

It should also be noted in this study that there appeared to be a disparity between help available to people in urban areas and those living in rural areas. Inevitably in rural areas, distances are greater (thus can be harder to get to a support group). Therefore, it can be more difficult to provide a range of support that people can access in an urban area. Participants living in rural areas who received support from a Community Psychiatric Nurse reported that they benefited from this interaction. However, they did not feel that this support was frequent enough. Participants from rural areas also highlighted that they would like improved opportunities to socialise within groups where the interests of their own age group were reflected.

4. Conclusion and recommendations

Being diagnosed with dementia is hard at any age. For younger people who still have financial commitments and/or children who are not yet adults, it can be even more distressing. While people who are affected need time to come to terms with a diagnosis of dementia, they need to have access to and be aware of services that are available to them. In some cases there may be practical interventions that can help people stay at home, including the provision of equipment. However, for most people it is a question of being able to access appropriate informational and emotional support.

The experiences shared by participants in this study emphasise the need for a specific service and a defined care pathway for younger people with dementia. This will ensure that they are not automatically incorporated into older people's services. This reinforces the NI Strategy for Dementia and the Dementia Learning and Development, both of which identify a need for such a service.

Delays in diagnosis as recounted by participants also echo earlier research highlighting that doctors may not think of dementia when the person in front of them is a younger individual. It is clear that those interviewed for this study felt that there needed to be greater awareness, that being young does not preclude you from developing dementia and that GPs in particular need to at least consider that option when certain symptoms are displayed. Plans and strategies for educating and raising awareness among health service staff and the public are a necessity, particularly for those diagnosed with early onset dementia. Greater awareness could lead to an earlier diagnosis, which in turn means that people with dementia and their carers can get support and treatment they need at an earlier stage in their dementia journey.

The lack of age-specific services or activities for younger people makes having the disease more lonely and isolating both for the carer and the person with dementia. The needs and interests of someone in their 50s will inevitably be different from those in their seventies and eighties. There was a clear sense from participants in

this project that there a need for greater access to appropriate support services for both the person diagnosed with early onset dementia and their family members.

The following update was provided by the PHA regarding the current context in Northern Ireland: “Over the next five years the planned focus for dementia services is to develop a new memory pathway which will shift some of the assessment/diagnosis and ongoing support towards a more primary care facing approach carried out by a multidisciplinary team supporting GPs. A draft pathway is waiting for the endorsement of a Health Minister. While it is recognised that a more primary care approach will require a large training component for staff it is hoped that such a model would improve the GP experience described by some participants in this project.

Progress has also been made over the past three years through the successful delivery of an extensive number of projects delivered through the Dementia Together NI Project, an example being the Dementia Learning and Development Framework referenced earlier in this report. Other achievements have been the development of 11 information booklets covering a range of topics that are available on NI Direct and also have been widely distributed to GP surgeries and across the wider HSC system. Hopefully developments such as this will lead to improved experiences for people diagnosed with dementia and their families. Other outcomes from the Dementia Together NI project include the development of the Dementia Navigator roles and the Still Me media campaign the most recent of which included a younger lady living with dementia.

Other developments in dementia services has been the investment in the training of dementia champions, the introduction of dementia companions and delirium trainers in some of the acute hospitals. It is recognised that much more needs to be done in this area and the need for funding for a focused piece of work in this area has been raised with the Department of Health.”

While the PCC is encouraged by the developments mentioned above there are a number of actions which we would propose based on the contributions of the participants in this study. These include:

1. The need for improved awareness of the signs and symptoms of early onset dementia among the wider health and social care workforce in order to ensure timely diagnosis of the condition and appropriate care.
2. Access to a patient portal for all people diagnosed with dementia. As part of the 'Health and Wellbeing 2026: Delivering Together' action plan a new patient portal is being developed. This will allow people living with dementia and their carers to have secure on-line access to their own health and care information. A delivery date is set for the summer of 2018. The PCC welcomes this development and recommends that access is rolled out widely as personalised health and care information would help address some of the issues highlighted by individuals in this study.
3. The necessity for streamlined processes to support people with early onset dementia and their carers to access immediate and appropriate support following diagnosis, including varied approaches such as befriending services targeted at people with early onset dementia and support for the young children who are impacted by diagnosis of early onset dementia within the family. Access to these services needs to be consistent across Northern Ireland with particular thought given as to how to ensure equity of access for those living in rural areas.
4. The need for dedicated attention to be given as to how to best address the significant negative impact on mental well-being resulting from a diagnosis of early onset dementia.

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